

**Physiotherapy or Self-Selected Exercise
in Multiple Sclerosis:
A Comparative Evaluation of
Community-based Interventions**

By

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LIST OF ABBREVIATIONS

AMCA	Amended Motor Club Assessment.
GNDS	Guy’s Neurological Disability Scale.
HAQ	Health Assessment Questionnaire.
NRS	Numerical Rating Scale
MAS	Modified Ashworth Scale
MRC	Medical Research Council (strength scale)
PT	Physiotherapy
OT	Occupational therapy
ADL	Activities of Daily Living
BtxA	Botulinum Toxin A
ICF	International Classification of Function
WHO	World Health Organisation
MRI	Magnetic Resonance Imaging
NICE	National Institute for Clinical Excellence
NSF	National Service Framework
IPA	Interpretative Phenomenological Analysis

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ABSTRACT

Multiple Sclerosis is a major cause of neurological disability in the population of the UK with an incidence of 2,500 new cases diagnosed each year. The estimated number of people affected with MS in the UK is currently believed to be 85,000. (MS Trust 2006). The disease affects those in the prime of their lives as well as those more advanced in years. The reality of living with a progressive neurological condition requires self-management strategies as well as professional involvement. One method of encouraging self-management is the use of exercise to ameliorate some of the problems presented by MS and thus to encourage independence.

This study was developed to compare the effects of a home-based physiotherapy exercise programme against readily accessible self-selected exercise opportunities. It was conducted entirely in the community with a convenience sample of 40 subjects recruited from the caseload of the Rehabilitation Medicine Service in Lincolnshire, 39 people eventually completed the study. The participants were of mixed MS presentations but were capable of fulfilling the exercise requirements of the study.

The study was in two parts, a pre exercise phase and an exercise phase. Assessments were carried out at three stages during the study at week 1, week 12 and week 36. A baseline assessment taken at study onset, focused on physical function using the Amended Motor Club Assessment, (AMCA), as the primary outcome variable. The Health Assessment Questionnaire, (HAQ), and Timed Walk were also used to assess function. Muscle tone and muscle strength, were assessed using the Modified Ashworth Scale, (MAS), and the Medical Research Council, (MRC), strength scale. Psychological state was gauged using the MSQOL 54 and a Numerical Rating Scale. Symptom presentation was assessed using the Guys Neurological Disability Scale, (GNDS). The participants were given a journal at week 1 and this remained with the participant until week 36. It was returned to the researcher after the final assessment. Indications of psychological state and exercise experiences were extracted from the journals where unfettered comments regarding the regimes and any other MS or personal issues were recorded. The first and second assessments were carried out by the investigator. The third assessment was completed by one of the two independent physiotherapy assessors.

Phase one of the study, the pre exercise phase, extended over 12 weeks during which time educational material plus the MS Trust booklet, “Tips to Living with MS” was distributed. This time also provided a washout period negating the effects of previous exercise involvement.

In phase two the participants joined their respective exercise groups. Group 1 participants received the home physiotherapy programme consisting of a three-part exercise regime administered over eight weeks. The regimes included exercises in lying, sitting and standing with a strengthening element using red, medium strength, Theraband. The group 2 participants selected their own activity regime providing it was compatible with their exercise capabilities. The activities selected included progressive walking, gym attendances, swimming, Pilates, yoga and motorcise, a motorised cycling routine. The exercise phase lasted for 24 weeks. Total study involvement lasted for 36 weeks.

The results from the pre exercise phase indicated that there were no improvements in physical or psychological function except a perceived improvement in symptom presentation as shown by a significant improvement in the GNDS score. This could be attributable to the nature of the information offered and the previous extensive knowledge already in the possession of the participants.

Exercise positively influenced the AMCA, the primary outcome variable in both groups but the benefit of one approach over the other was not conclusively demonstrated. Physiotherapy appeared to produce significantly better results than self-selection in the HAQ, the NRS, lower limb tone, and lower limb strength. Both groups improved significantly on upper limb tone, upper limb strength. The Timed Walk did not improve in either group. Neither group showed improvement after exercise on the GNDS. The MSQOL 54 was affected but significant differences were only seen in one domain in each of the two groups. Supporting evidence from analysis of the participants’ journals indicated the desire for exercise and showed subjectively how those in this study benefited from it. These results did not offer definitive proof as to the most beneficial regime but they provided compelling evidence to support the

relevance of exercise to those with MS to maintain physical and psychological wellbeing.

A follow-up questionnaire was issued to each participant 26 weeks after study completion to assess whether they had continued to exercise. Of the 39 people who completed the study, 34 responded to the follow-up questionnaire. Of these 34 people, 33 were still engaging in some type of exercise indicating that the changes necessary to embed the new behaviour had been successfully achieved.

Chapter 1

An introduction to Multiple Sclerosis, fundamental concepts of rehabilitation, physiotherapy and exercise

1.1. Introduction

This pilot study compared physiotherapeutic home-based exercise with self-selected exercise choices for people with Multiple Sclerosis, (MS). Its primary intention was to show whether a home-based physiotherapy exercise regime provided better functional gains when compared to self-selected exercise choices carried out in the community. The data was collected using; 1. MS specific scales where available. 2. Neurological scales when appropriate. 3. A specially designed journal completed by each participant throughout study involvement. 4. A follow-up questionnaire completed six months after study involvement was over.

Exercise has been acknowledged as a method of self-management that can significantly impact on function and psychological wellbeing for those with MS (MS Trust 2006. Freeman 2006. Ennis et al 2006. Liu et al 2003. The Cochrane Review of exercise randomised controlled trials in MS (RCT's) 2004 conducted by Reitberg et al). The research to date is predominantly in-patient/out-patient based. Motl et al, (2005), noted that despite its importance little is known about activity levels among people with MS and that there may be significant barriers to exercise uptake in the MS population compared to unaffected people. The potential for exercise to serve as a therapeutic intervention in the community exists, yet deficits in resources and service provision present substantive barriers to its implementation (Freeman and Thompson 2000).

1.1.1. Thesis structure

The chapters of this thesis adhere to the following format. Chapter 1 outlines the pathology of MS and the problems that can result. It introduces the general concept of rehabilitation and highlights some of the issues associated with the provision of neurological rehabilitation. It discusses the underlying principles of physiotherapy and exercise, the theory of behavioural change and the stages of change (transtheoretical) model as applied to exercise plus some of the psychological aspects that impact on

exercise uptake. Chapter 2 presents exercise and physiotherapy in relation to MS and identifies barriers both physical and psychological that influence exercise uptake in MS. The relevant literature is included and the research questions are identified. Chapter 3 describes the study methodology and includes an explanation of the chosen assessment scales and the exercise regimes used. Chapter 4 presents the results gathered from the assessment scales. Chapter 5 considers the subjective impact of the pre exercise and exercise phases of the study. This information was taken from the participants' journals, recorded as the semi-structured questionnaire results. An Interpretative Phenomenological Analysis of the transcripts will also be included plus the information gathered by the follow-up questionnaire. Chapter 6 discusses the findings described in Chapters 4 and 5 in relation to current research and knowledge. Chapter 7 offers conclusions and further recommendations.

1.2. Multiple Sclerosis

There now follows a resume of the pathology of Multiple Sclerosis and its clinical presentations.

Multiple Sclerosis, (MS), is a disease of the Central Nervous System, (CNS), in which the myelin sheath surrounding the nerve suffers a series of assaults over time and is eventually destroyed (Schapiro 1998). As a consequence of these attacks scarring (sclerosis) occurs and the ability of the nerve to conduct electrical impulses is severely impeded (Sheean 1998). This results in disturbances in both motor and sensory function throughout the nerve's course (MS Trust 2005). MS is more common in women than men with the risk being 1.5 to 2.0 times higher (Bashir and Whitaker 2002). This differentiation is more pronounced before the age of 40. Women also often present with symptoms earlier in life than men (Bashir and Whitaker 2002). Life expectancy was believed to be reduced in MS but Weinschenker et al (1989), demonstrated in their study that the median survival time was now greater than 40 years with 88% of people surviving 40 years post disease onset.

The condition is indiscriminate in its dissemination throughout the population in respect of age or physical fitness. "It is the most common cause of neurological disability in young adults" Barnes (2004). There have been reports of clusters of MS in differing

locations around the globe that suggests a regional preponderance or climatic influences (Kesslering 1997. Kurtzke 1997). This information is still speculative however the sum of the accumulated data does indicate a latitude effect, ie MS prevalence increases with distance from the equator with a higher risk in the temperate latitudes (Bashir and Whittaker 2002. Bahra and Cikurel 1999).

1.2.1. Pathology of MS

The immune response has been credited with much of the destructive process inflicted on the myelin sheaths causing the demyelination and plaque formation characteristic of MS (Schapiro 1998. Bornstein and Appel 1961. Esiri and Gay 1997). The lesions occur anywhere within the CNS where myelin is present. There is no record of any such damage to the peripheral nerves. This is attributed to fundamental differences in the protein content of peripheral nerves when compared to that of the CNS. Consequently this not subject to the same type of attack (Schapiro 1998. Wilkinson 1999). MS typically runs a course of exacerbation and remission although there are also primary and secondary types that present differently.

1.2.1.1. Primary progressive MS

Primary progressive MS presents in a chronic form at onset (MS Trust 2005) and can be quite aggressive in its progression. The person may experience a steady and often quite rapid decline into disability after diagnosis (Matthews 1991). This type does not provide periods of remission (Lublin and Reingold 1996).

1.2.1.2. Relapsing /remitting MS

Relapsing/Remitting MS is characterised by clearly defined patterns of acute attacks followed by remissions during which there is no further disease progression (Lublin and Reingold 1996). Following each attack the person may notice some degree of functional loss or residual neurological signs that were not present previously (MS Trust 2005). It is generally accepted that roughly 66% of people will have this type of MS at disease onset with a further 15% having the primary progressive type with acute episodes (Barnes 2004). The remainder will have the chronically progressive course from disease onset (Weinschenker et al 1989. Mathews et al 1985).

1.2.1.3. Secondary progressive MS

Secondary progressive MS often begins as the relapse/remission type that evolves into the secondary presentation after some years of disease activity (Barnes 2004).

Secondary progressive MS is synonymous with a slow deterioration of ability concomitant with the progression of the disease process (MS Trust 2005).

Weinschenker et al (1989) demonstrated that 41% of individuals with relapsing/remitting MS had changed to this type after 10 years, 57% after 15 years and 65% after 25 years.

1.2.2. Clinical presentation of MS

This section outlines the most commonly reported symptoms of MS and some of the resulting difficulties. The proliferation and location of plaque formation will determine the extent of any problems displayed and plaques can occur anywhere within the CNS (Wilkinson 1999). Post mortem examinations have revealed extensive areas of damage while in life the person displayed only minor difficulties (Lassman 1999). Conversely, a plaque located in a primary motor or sensory region can cause major problems that appear to be more extensive than the plaque size would demand (Lassman 1999. Barnes 2004. Mathews 1991). The problems detailed in this section are not arranged in any order of severity or priority.

1.2.2.1. Motor problems

Motor dysfunction usually presents as loss of walking speed or fluency of the walking pattern (Matthews 1991. Barnes 2004). The person may also experience dragging or heaviness of one of the lower limbs or a staggering, wide-based gait known as ataxia (Bahra and Cikurel 1999). In the more extreme examples it represents a total loss of walking ability. This may return as the inflammatory process within the CNS gradually subsides. On physical examination there may be signs of spasticity, muscle weakness or spasms (Wilkinson 1999).

Ataxia is a symptom that is commonly associated with demyelination in the cerebellar pathways but can also be due to loss of sensation, “..more specifically a sensorimotor feedback deficit” Matthews (1999). The cerebellum is the body’s main balance and co-ordination center so any lesion in this area could be potentially disabling depending on

the distribution and frequency of the lesions. It follows therefore that balance and co-ordination of movement will be affected due to interference of innervation of these motor tracts. These difficulties need not be related to loss of strength.

1.2.2.2. Sensory disturbance

It is common for individuals to experience sensory symptoms at the onset of MS or early on in a relapse (Matthews 1999. Bashir and Whittaker 2002). Individuals will also often describe sensations of burning, tingling and numbness in the hands and/or feet (Schapiro 1998). This manifestation can spread to involve the whole limb as the relapse progresses. There may be a loss of perineal sensation although control of micturition and defecation can remain normal (Schapiro 1998).

Sensation is not only limited to the transmission of external stimuli to the brain. It also provides information on the position of the limbs and trunk in relation to the environment allowing smooth co-ordinated movement to take place (Wilkinson 1999). Therefore sensory disturbance can have a significant impact on motor function.

1.2.2.3. Pain

Pain is a distressing symptom of MS that is often related to the effects of disability or disease progression (Moulin et al 1988. Stenager et al 1991) and is experienced by up to 80% of people with MS at some stage (Archibald et al 1994). The pain resulting from disease progression is often neurogenic in origin and is associated with the damaged nerve pathways. This is frequently described as burning, stabbing, shooting and/or tingling (MS Trust 2005). This type of pain is commonly noted as a trigeminal neuralgia, an acute pain following the course of the trigeminal nerve along the lateral aspect of the face. It has been noted that trigeminal neuralgia occurs 300 times more frequently in people with MS than in the general population (Thompson 1996). Pain can also manifest as headaches and spasms in muscles supplied by the affected sites in the CNS (MS Trust 2006). Neurogenic pain relievers can sometimes be effective in these cases. The effects of pain can be felt anywhere in the body and people may describe a deep-seated ache from which they can find no relief. This pain presentation is more musculo-skeletal in origin due to immobility or stresses on limbs due to the use

of eg, walking aids. Exercise can be beneficial in reducing the effects of this type of pain (Merton 1994).

1.2.2.4. Fatigue

Fatigue is mentioned here as a symptom of MS. However it is recognised that it impacts significantly on all aspects of life especially the ability to exercise consequently it will be discussed in greater detail in Chapter 2 as a physical impediment to exercise.

Possibly the most common fatigue presentation is “Lassitude”, an over whelming tiredness or lack of energy. This can be managed pharmacologically with amantadine or pemoline but with limited success (Copperman et al 1994).

“Neural fatigue” or short-circuiting fatigue has been described in MS as a specific physiological deficit (Enoka and Stuart 1992). Unfortunately, there has been little in the way of effective management identified in the research that has been conducted into its causes (Hubsy and Sears 1992. Schapiro 1998). Fatigue is reported to worsen during periods of heat, over-exertion, illness or infection and stress and it may also contribute to an increase in other symptoms giving a false impression of disease advancement (Freal et al 1984).

In their study conducted in 1996 Djaldetti et al attempted to quantify fatigue in MS people. They compared fatigue in MS to that experienced by those with Chronic Fatigue Syndrome (CFS). They included 30 people with mild to moderate MS symptoms and four with CFS. There were 13 controls with no neurological deficits. The study emphasised the symptom of fatigue as a physical manifestation rather than a psychological one based on their demonstration of pyramidal tract affectation in MS.

1.2.2.5. Spasticity

“Spasticity is a motor disorder characterised by a velocity dependent increase in the tonic stretch reflexes, (muscle tone) with exaggerated tendon jerks resulting from hyperexcitability of the stretch reflex ” (Lance 1980) with an accompanying denervation hypersensitivity (Young and Delwade 1981). These changes increase the

motor segment's reaction to sensory input causing an increase in excitability (Sheean 1998). It is variable in its presentation and in some cases can be successfully recruited to facilitate function (Kesselring and Thompson 1997. Ko Ko 1999). In extreme instances when tonal changes are such that useful recruitment is impossible, the affected limb will become rigid and virtually impossible to move passively or actively resulting in immobility and possible pressure areas (MS Trust 2005).

Spasticity tends to adopt an extensor pattern in the lower limbs and a flexor pattern in the upper limbs (Sheean 1998). However this pattern may change as the damage to the CNS becomes more extensive. If the spasticity remains uncontrolled the muscles affected will shorten and eventually a fixed contracture of the limb will result (Jarrett 2004). In long-standing MS this can be a common feature due in part to poor spasticity management in the earlier stages of the disease and may require surgical intervention (Ko Ko and Ward 1997).

1.2.2.6.Tremor

Tremor is a result of the inco-ordination of neuronal firing in reciprocal muscle groups producing an oscillating movement of the part (Sheean 1998). The tremor can be gross in which large oscillations are produced or fine in nature where a slight shaking is observed (Schapiro 1998). Tremor can affect any part of the body and can be extremely disabling both physically and psychologically (MS Trust 2005). Classically the tremor's amplitude increases during targeted movements as observed during the finger to nose test (Feys et al 2003). It is thought to present in 85% of people with MS at some stage during the disease progression (Bauer 1978). This is one of the more difficult symptoms of MS to treat effectively (Clanet and Brassat 2000).

1.2.2.7. Bladder and bowel dysfunction

The most common features of bladder dysfunction are urgency, frequency and incontinence (Betts et al 1993) although some people experience problems with hesitancy and retention (Clanet and Brassat 2000). The commonest symptom affecting the bowel is constipation (Sullivan and Ebers 1983). This is due in part to damage inflicted on the nerves supplying the bowel causing the bowel action to become sluggish (MS Trust 2005). It has been noted by Wiesel et al (2001) that this problem is

more prevalent in those with MS than in the general population. The frequency of excretory difficulties increases with age, disease duration and the degree of disability (MS Trust 2005). Bladder and bowel problems are often experienced simultaneously and in an effort to control the bladder people will sometimes reduce their fluid intake without realising the detrimental affects this will have on the function of the bowel (Schapiro 1998).

1.2.2.8. Visual disturbances

Visual disturbance can present as the first indicator of the disease and it is often identified by assessment of the optic nerve with inflammation being visible on retinal examination (Wilkinson 1999). There may be a blurring of vision, double vision, a cling-film effect over the eye or black spots in the field of vision (Bashir and Whitaker 2002). Some people report pain behind the eye and an inability to focus (Mathews 1999).

1.2.2.9. Dysphagia and dysarthria

Difficulty swallowing fluids or solids may be a feature of MS (Hartelius et al 2000). This can be transient in the early stages of the disease or present as a more permanent and disabling feature in the later stages. Most dysarthric, (speech), difficulties present as a slurring of speech (MS Trust 2005). In its most severe form this can make a persons speech unintelligible but there is evidence to show that therapy can be beneficial for some people (Hartelius et al 1997). Tremor may also interfere with a persons speech patterns by interrupting breath control or volume.

1.2.2.10. Sexual dysfunction

Sexual dysfunction may be caused by neurological changes or associated difficulties with spasticity, bladder or bowel problems, pain or fatigue (Hulter and Lundberg 1995). A clearly defined relationship between bladder and bowel dysfunction and sexual difficulties has been identified (Cartlidge 1972). It has been noted by Lilius et al (1976) that most people with MS report changes to their sexual function that impinged on enjoyment and satisfaction and the NICE guidelines (2003) acknowledged this aspect of MS deficit as a significant factor affecting QoL.

1.2.2.11. Cognitive deficit

Cognitive deficit often presents as problems with, “.. recent and remote memory accompanied by varying degrees of affectation in conceptual reasoning, judgement, planning and insight” (Bashir and Whitaker 2002). These deficits can make management of the disease and implementation of appropriate care difficult in extremely affected individuals unless an accepting attitude is adopted (Langdon and Thompson 1996). Neuropsychological assessment and support may aid with diagnosis of specific areas of deficit and advance strategies for coping with the resulting problems (MS Trust 2005). At some time, however minor the signs, a degree of cognitive deficit will be evident in most people with MS (Matthews 1999).

1.2.3. Current treatments for MS

This section will describe a selection of the currently available treatments for MS.

1.2.3.1. Drug therapies

The most commonly used drug interventions will be outlined in this next section. Treatments can be divided into those that directly affect the disease process and those aimed at alleviating the consequences of MS.

Disease modifying drugs

It is assumed that the aetiology and pathogenesis of the disease is autoimmune in nature therefore efforts to modify the disease process have concentrated on the development of immune related therapies (Giovannoni and Hartung 1996). These include, Glatiramer Acetate (Copaxone), Interferon Beta 1a, (Avonex), and Interferon Beta 1a (Rebif) as well as Interferon Beta 1b, (Betaferon). Their action is believed to reduce the occurrence of relapses and thus slow down the progression of disability (Jacobs et al 1996). These are administered by intramuscular injection. Also available are an intravenous immunoglobulin therapy and immunosuppressants like Azathioprin and Methotrexate (Bashir and Whitaker 2002). The use of these immunological therapies is at the discretion of the neurologist after consultation with the person regarding possible side effects.

Steroids

Relapses of the disease are often treated with steroids usually Methylprednisolone (MS Trust 2005). The drug is administered intravenously over a five-day period and often followed up orally over two/three weeks of decreasing doses (NICE 2003). There has been no long-term benefit shown from the use of steroids (Rose et al 1970) and extensive interventions exceeding three in any one year are discouraged (NICE 2003).

Bladder/bowel problems

Oxybutinin and other anticholinergic drugs are often prescribed for bladder problems (Andersson 2004). Sometimes it may be necessary to empty the bladder using either intermittent catheterisation or to consider the use of an indwelling catheter (Winder 2002). It is often the role of the specialist nurse to provide advice and training in this area. Bowel action tends to slow resulting in constipation. This can be successfully countered in many cases with laxatives, increasing fluid intake and a dietary change (DasGupta and Fowler 2003).

Antispasticity drugs

Drugs used for the control of spasticity include baclofen, tizanidine and gabapentin and these can be administered with diazepam in some cases if required (Sheehan 1998. Bakheit 2001). It is often beneficial to combine drug treatments with physiotherapy to maximise the benefits that result from reductions in muscle tone and to capitalise on previously inhibited movement patterns (MS Trust 2005).

Often individuals will present with focal spasticity affecting dominant muscle groups in one or more limbs. Recently the use of Botulinum Toxin A, (BtxA), has gained prominence in the treatment of these focal problems (Dunne et al 1995. Simpson et al 1996. Barnes 2004). BtxA is administered by intramuscular injection into the spastic muscles. It can be easily targeted to specific problem areas and its effect is localised to the injected muscle (Sheehan 1998). After three to four months the paralytic action of the toxin on the neuromuscular junction will fade and the problem may re-emerge (Moore 1995). BtxA is recognised as one of the most useful advances in focal spasticity management in recent years (Barnes 2004).

1.2.3.2. Physiotherapy/Occupational therapy

As most people take antispasticity medication at some time, physiotherapy (PT), can be an important adjunct to these drug interventions (Albany 1997). The therapist needs to be aware of the consequences of the drug's effects and how best to capitalise on any functional changes that occur (White and Dressendorfer 2004). The treatment will involve stretching affected muscle groups and teaching inhibiting positions to alleviate the spasms and prevent muscle shortening that can lead to permanent joint contractures (Taylor 2000. Bakheit 2001). Exercise can then be introduced as a self-management strategy. This is most relevant post Botulinum toxin treatment as research has shown that the effects of BtxA are prolonged by physical activity (Koman et al 1993. Albany 1997). The involvement of an occupational therapist, (OT), to capitalise on regained function is often recommended (NICE 2003. MS Trust 2005). Ideally the OT and PT work as part of a team either hospital or community based. The two professions have many complimentary skills that can be combined to produce significant functional gains for the individual (MS Trust 2006). Specific OT skills include promotion of Activities of Daily Living, (ADL), wheelchair prescription, home assessments and liaising with other agencies to facilitate study and work opportunities.

1.2.3.3. Alternative therapies

Alternative therapies are gaining popularity among those with MS as self-management strategies and a combination of approaches can be beneficial when dealing with MS symptoms (MS Trust 2006. Schapiro 1998). Some of the more popular therapies are now described.

Yoga

Yoga is an ancient system of meditation, breathing and postures that are used to develop balance within the body and harmony within the mind (Oken et al 2004). The positions adopted are practiced in conjunction with breathing and relaxation to facilitate a total mind/body co-ordination. This is a suitable regime for many people with MS to adopt (Oken et al 2004). It has the ability through gentle progressions to re-educate balance and movement patterns that have been compromised as a result of demyelination. It can also assist the person to adapt to their current ability through

meditation. Many people with MS select yoga as a life long regime for maintaining function and well-being (MS Trust 2006).

Pilates

Pilates involves a series of movements and “holds” which are performed slowly and rhythmically to enhance muscle strength and core stability (Lange et al 2000). There have been many anecdotal reports from people with MS who have derived benefit from performing such repetitive activities (MS Trust 2006). This system has the benefit of being able to be performed successfully at home or in a group situation thus providing social interaction as with yoga.

Aromatherapy

Aromatherapy massage can prove extremely beneficial to individuals who suffer from painful limbs and spasm by relieving pain and lowering tone (Wang et al 1999), although to date there are no scientific studies supporting its use, (MS Trust 2005). It is often available in local health centers and sometimes from MS society run centers as an adjunct to conventional interventions.

Reflexology

This therapy is based on Chinese medicine and uses the various body zones represented on the sole of the foot. These zones are treated with the application of pressure and are believed to affect the distal body systems corresponding to the foot “map”. It can provide temporary relief for many symptoms of MS in particular constipation and the circulatory problems often associated with immobility and pain (Siev-Ner et al 2003).

Homeopathy

Herbal remedies do have a role to play in the management of MS. Many people use Oil of Evening Primrose on a regular basis as well as vitamin and mineral additives (MS Trust 2006). Used sparingly these additives can replace missing trace elements to a person’s diet and many derive tangible benefits from their use (Cusherat et al 2000). There are as yet no clinical trials investigating the efficacy of homeopathy in MS although there are case reports of improvements in symptoms (Johnson 1990).

1.3. Rehabilitation: An overview of its use as a therapeutic intervention

This section presents an overview of rehabilitation, its origins and its use as a therapeutic medium.

Rehabilitation has existed in some form since Roman times. In Europe in the 18th century it gained notoriety in the field of balneotherapy, (medicinal bathing eg spas) and orthopaedics with this interest progressing into the 19th century to combine the use of physical medicine, exercise and movement, with the existing therapeutic spa treatments (Fialka-Moser 1999). In the 20th century in the United States physical medicine appears to have evolved as a direct response to the casualties sustained during the First World War (Strickland 1947). It could be hypothesised that rehabilitation developed as a result of the preponderance of impairments resulting from military conflict (Eldar and Jelic 2003) and military rehabilitation facilities continue to be a necessity today.

In its infancy rehabilitation was restricted to people where an improvement in their physical condition could be predicted (Strickland 1947). In other cases its application was restricted even further to include only those who could expect a return to gainful employment (Aldes 1967). For others it meant having something done to them, for example therapy conducted by a qualified therapist (Wade 1992). Modern day rehabilitation embraces a more holistic philosophy and invites the personal involvement of the participant (Kesselring and Beer 2005). This usually embraces problem solving and education relevant to the person's social context with the aim of reducing the effects of impairment due to injury or disease (Wade and De Jong 2000). Research has demonstrated that this sharing of responsibility can and does facilitate significant gains in future disease/injury management by enhancing the ability to cope with long-term illness or physical deficit (Uhrin 2000. Halper and Holland 1998). It is now accepted that rehabilitation must be a dynamic process that enables therapists to adopt a diverse approach to the re-education of a variety of disorders (Edwards et al 2004). Therapeutic autonomy has allowed for the development of specialist physiotherapeutic treatment regimes some of which will be considered later in this chapter.

Kesselring and Beer (2005), have offered this definition of rehabilitation, “--an active process of education and enablement which is focused on the appropriate management of disability and minimising limitation of handicap with the goal of achieving full recovery”. Education and self-management have also been identified as key components by Thompson (2005), and are recognised as being significant predictors of rehabilitative success. In other words, the knowledge base of the individual plays an important role in the ability to cope with and manage the disease or deficit and the person must be central to the process by their involvement in realistic goal setting and outcome measurement.

Outcomes are a necessary part of rehabilitation and the rehabilitation process must be focused, patient centered and goal orientated (Macdonell and Dewey 2001. Kesselring and Beer 2005). Thompson (2005) noted that although the principles of a Multidisciplinary Team (MDT) assessment were admirable, the evidence base for such a process was weak. One reason for this may be that the end point for the professional may differ from the aspirations of the participant (Bloom et al 2006). Guidance will be required to prevent unrealistic expectations that could result in failure. This may deter the person from any future participation in activity or health promoting behaviours. In the case of MS, functional gains may be small (Ashburn and DeSouza 1988) yet these gains need to be recognised and applauded as this can prolong function and re-enforce the person’s self-efficacy concept in the face of their disability.

It is acknowledged that “.. if an individual limits physical activity, the capacity to perform physical acts becomes diminished” Sutherland and Anderson (2001). Within the confines of neurological disability, the role of rehabilitation is to utilise all available resources to minimise the effects of deterioration by preventing deformity, limiting the effects of disability and promoting social inclusion (Edwards et al 2004). Unfortunately this desirable state is not a nationwide phenomenon and it is clear that a major deficit exists in the provision of such rehabilitation strategies to most facets of the disability spectrum (Chamberlain 1992). It is the contention of Tallis (2003), that government targets and budget cuts have made “rehabilitation provision” a more challenging prospect. We as therapists have the responsibility to seek out and apply high quality effective interventions that meet the needs of the person in spite of rather than as a result of these changes.

1.3.1. The International Classification of Function, (ICF), definitions as guidelines in rehabilitation

The ICF has provided a standard classification for use by rehabilitation services worldwide. Its purpose was to provide a universal language as a frame of reference for “the consequences of health conditions” (ICIDH-2 1997). In 2001 the World Health Organisation, (WHO), executed a major revision of the 1997 document to highlight the importance of activity and participation in relation to the impairment, previously defined as “disability”. In the 1997 version impairment was based on comparisons with healthy individuals with consideration being given to loss of body function. The term impairment now concerns deviations from generally accepted population standards in the biomedical status of the body and its function. These deviations can be either temporary or permanent

In the ICF classifications Activity refers to the execution of a task or action by an individual and is related to the nature and extent of a person’s abilities and may be limited in type, quality and duration. The classification allows for activities to be carried out with varying degrees of ease or difficulty and embraces an extensive selection of actions both simple and complex. This is known as Activity Limitation.

Participation is the extent to which the person engages with life in relation to their impairments and activity restrictions. It is characterised by the outcome of the relationship between, “--a persons’ health condition and in particular the impairments or limitations of activities he or she has” and on “-- features of the context that represent the circumstances in which the person lives and conducts his or her life.” (ICIDH 1997).

The important additions to this classification have been the considerations given to social, cultural, economic and psychological factors as determinants of a person’s role within the family and society as a whole, (WHO 1999, 2001). This is a concern for those dealing with people with neurological disabilities that impacts far beyond the initial diagnosis.

1.4. Neurological rehabilitation

Generally the provision of neurorehabilitation focuses on the involvement of a multidisciplinary team with expertise in the many facets of disability that will impact on the person's social and psychological perceptions and physical functioning (Kesselring 2004). An important aspect of this is the changing trajectory of the condition as it progresses and/or deteriorates. It has been mentioned by Dal Bello-Haas (2002) that even though the course of the disease cannot be altered appropriate rehabilitation regimes can positively impact on function and independence.

Clanet and Brassat (2000), proposed that neurorehabilitation required a four step strategy: multidisciplinary assessment, the identification of areas of functional improvement, setting of goals both long and short term and the measurement of outcomes. This should facilitate function in the real world by fostering self-esteem and quality of life, a concept that most researchers recognise as pivotal to coping with long-term disability (LaRocca et al 1996. Kaplan 1990).

To achieve these desirable goals rehabilitation activities should be targeted, achievable and produce some functional gain. It will be of little value to sit statically with a good mid-line posture if the effort involved removes any possibility of dynamic activity (Edwards et al 2004). Although it is desirable to regain "normal" postures and movement, in most cases this will not be possible with a damaged nervous system (Bobath 1990). There is usually some degree of abnormality remaining that has to be incorporated into the person's life. The CNS does have a limited capacity to recover from trauma a process known as Neuroplasticity. Studies have examined the ability of the CNS to reorganise itself after injury (Aizawa et al 1991. Nudo et al 1995) and this ability is a vital component in the successful management of neurological disorders.

There has been consideration given to appropriate methods of care delivery in neurological rehabilitation such as the work by Freeman and Thompson (2000), Compston et al (1993) and the Association for Quality in Healthcare (1998). The care continuum must include socio-economic and psychological considerations as well as the more immediate physical requirements. Ideally the involvement of the team should begin at diagnosis and follow the patient through for as long as they require such input.

Dal Bello-Haas (2002) has described this as a three-part process classified as early, middle and late. This allies to the divisions proposed by Thompson (2005), of minimal disability, moderate disability and severe disability with the addition of a diagnostic stage. Dal Bello-Haas has also proposed a therapeutic continuum that intervenes along the disability pathway to improve functional limitations. It is effectively a process of reflective practice and forward planning for neurological care using the previously described classifications of involvement. She felt this would facilitate the implementation of the care continuum with the main thrust of input from the therapist being aimed at addressing functional limitations and disabilities. This could be described as a reactive approach to care. An opposing viewpoint is offered by Kraft (1989). He proposed the possibility of “over-rehabilitating”. This approach described the initiation of treatment techniques before specific problems have emerged. This method could be considered as proactive. A proactive approach can be problematic as the inherent nature of MS dictates that functional changes cannot be predicted or pre-empted. Therefore it could be suggested that individual problem specific therapies should not be instigated on the off chance that a certain symptom/problem will arise.

To revisit Dal Bello-Haas’s subdivisions of rehabilitation, the early stage commences at diagnosis and primarily requires the provision of information and explanation. Support should be offered to the patient and significant others. The middle stage, equating to moderate disability impacts on function and will involve the interventions necessary to treat and mediate the signs and symptoms of the disease that begin to intrude into life. The late stage that of severe functional impairment requires an approach that targets the specifics of physical and psychological deficit with a view to prolonging the remaining abilities of the person. Underlying this care continuum is the concept of goal identification.

The identification and setting of achievable goals is a useful tactic to adopt in most areas of life and Thompson (2002), proposed that goal-orientated rehabilitation was beneficial in promoting successful rehabilitation strategies. In the case of work conducted on MS subjects’ evidence is accumulating to support this approach (Kesselring and Beer 2005. Ward and McIntosh 2004). Thompson also promoted the need for specialist community services to provide the expertise required to manage this client group once in-patient interventions were completed. The survey by Wade and

Green (2001) of community based services for people with MS also advocated the necessity for specialist expertise to be available plus the need for a multidisciplinary team and co-ordinated care systems in each district. Despite the growing consensus on the requirement for these services, the provision of such care systems is difficult to achieve (Freeman and Thompson 2004). These difficulties aside, it is accepted that the philosophy of rehabilitation in respect of the neurologically damaged must address all the needs of the patient not just the physical manifestations of the condition (Kesslering and Beer 2005).

1.4.1. Factors that influence neurological rehabilitation

The next section will consider some of the elements pertinent to neurological rehabilitation that have the potential to affect its outcome.

1.4.1.1. Self-efficacy

How a person sees him or her self will contribute to their ability to engage with rehabilitation and so further their recovery and Bandura's self-efficacy construct (1977), has highlighted the confidence a person feels when engaging in a specific behaviour as central to the ability to participate in that behaviour. This construct relates to the ideas described by the model of Planned Behaviour Beliefs (Ajzen 1985) an underlying theory used in this study. This model is expanded upon later in this chapter but it is mentioned here as it describes factors that can impact on the concept of self-efficacy and has a bearing on the participants' views on rehabilitation and their competencies in relation to it. The second theoretical study underpinning was based on the supposition that individuals progress through a series of changes as they alter their usual behaviours to adopt more healthy ones and this process also has the potential to influence self-efficacy (Prochaska and Marcus 1994). The stages that exert influence over the behavioural changes are Precontemplation, Contemplation, Preparation, Action and Maintenance. This process is also explained later in this chapter. The changes that the model predicts are a necessary element of successful rehabilitation.

1.4.1.2. Motivation

Motivation could be considered as the foundation stone for successful rehabilitation. Milroy and O'Neil (2000) noted that although it is a common goal of any health professional to empower their patients, generating a motivation to participate in the therapeutic process could prove problematic. Mulder and Hochstenbach (2004) have noted that, "A person's motivational state influences both the way he selects and integrates information and the type of action he selects". This indicates that there exists an intimate relationship between information and action. It could be argued that a major feature of motivation is the interaction between the person and the therapist and that the outcome will rely on behavioural changes that ally to the theory of Planned Behaviour Belief.

1.4.1.3. Health perception

How a person views their health status will be colored by the opinion of those they deem important as well as their own internal evaluation, (Levine 1987). There exists a paradox regarding health status, (Albrecht and Devlieger 1999), that will make or break any attempt to alter a set behaviour. If the disability is considered an illness then rehabilitation or exercise is unlikely to feature in daily life. If one views them self as disabled yet healthy then the tenor of the perception has the potential to change. This internal evaluation plus the external endorsement will significantly impact on rehabilitation involvement. Consequently there may be issues around health perception that need to be addressed before rehabilitation can be attempted, (Stuifbergen et al 2006). The disability paradox alluded to in this section will be discussed in more detail in Chapter 6 as a factor influencing psychological aspects of exercise uptake.

1.4.1.4. Health behaviour

Notions of self-perception in relation to health govern the eventual health behaviour that the person will present and there is a belief that regular participation in physical activity as part of a rehabilitation regime can change a person's response to illness (Stuifbergen 1997). This is achieved by minimising muscle deconditioning while maintaining optimum levels of physical functioning within the context of living with the condition (Rosenthal and Scheinberg 1990). This change in illness response could

potentially produce a positively impact on independence providing exercise participation can be regularly maintained as part of a disease management strategy.

Promoting health behaviours has been acknowledged as an important factor in the maintenance of independence and quality of life in people with chronic and/or disabling conditions (Parcel et al 1986. USDHHS 1991). Studies reporting the needs expressed by people with MS, noted that exercise was the most frequently cited strategy used to deal with problems of a physical nature (Brown and Kraft 2005. Somerset et al 2001). It would follow therefore that this is a desirable health behaviour to foster.

1.4.1.5. Goals and expectations

Goals are acknowledged as an important factor in the rehabilitation process and for rehabilitation to succeed it is necessary to agree on goals that can be realistically achieved (Thompson 2000. Kesselring and Beer 2005). Individuals need to own their rehabilitation regime and be involved in its design (Milroy and O'Neil 2000). This involvement encourages adherence by defining the person's areas of ability agreeing their goals and focusing on them.

To facilitate this it is important that individuals are aware that their condition will impose a physical loss on previous ability and that they place their current abilities in perspective. With this in mind relevant goal identification will allow for improvement to be demonstrated (Thompson 2000). Even if the original goal remains unattained, the fact that a target was set will encourage improved levels of function and a positive exercise effect (Dunn et al 1998. Weinberg and Gould 2007). This is an important aspect of neurorehabilitation and activity recommendation that will assist with issues of adherence over time.

1.4.1.6. Autonomy, adaptation and empowerment

Current opinion is leaning toward patient choice and autonomy (DoH 2006). It is desirable for people to be in possession of the facts to facilitate informed decisions (MacLaren 1996). They also need to be guided and supported when unpleasant situations arise as is common in MS. The study by Somerset et al (2001) determined the health-care preferences of people with MS. They identified distinct deficits in

information provision over a variety of aspects of care that included the desire for access to competent professionals. The study concluded that this was a necessary component of high quality service provision and could be achieved without eroding patient choice or autonomy.

The importance of professional interventions was researched by Keferi et al (2004). They investigated the extent to which rehabilitation counsellors' interventions exerted a positive or a negative paternalistic influence over their client group. Paternalism has been defined as one person in a position of authority, the doctor or therapist for example, acting for another to promote his or her welfare (Hershey 1985). This is usually conducted altruistically with the assumption of responsibility for the actions of the person concerned. Conversely there is the antipaternalistic faction who believes that this altruism violates the person's personal freedoms irrespective of circumstances (Brennan 1994). These are disparate opinions from widely divergent belief systems and cannot be indiscriminately applied to the needs of those with MS. Therefore, although paternalism per se is to be discouraged, it cannot be wholly discounted when considering the long-term management of a condition like MS.

For professionals involved in neurological rehabilitation autonomy necessitates a re-evaluation of notions of empowerment and control (Brennan 1994). To assign a prescribed level of choice would not fulfil the requirements of the majority. The therapist must be aware of the disparate nature of empowerment that impacts on autonomy and act as a conduit for the amount of control a person demands. They must also understand that practitioners do not directly empower people by their interventions. People become empowered through their own self-awareness and their utilisation of available resources (Gibson 1991).

This concept of empowerment is demonstrated in the daily practice of most therapists. There is always one person who demands complete control and every available piece of evidence to be supplied to them. Conversely, there is the other who would like all responsibility for their treatment reassigned to someone other than themselves (Brennan 1994). Seeking the middle ground is a difficult task that faces all professionals who engage with the neurologically disabled. Enabling the person to accept their condition

will foster an understanding of the condition that could promote the desired states of autonomy and empowerment. From this base the process of rehabilitation can begin.

The need for the individual to adapt to disease limitations must be acknowledged (Dimond and Jones 1983) and this adaptational process will take on different forms. These will relate to the individual's personality, their ability to cope with the disease process and the support they receive from significant others (Oliver 1996). The interaction of these factors will influence the extent of a person's adaptational ability (Burnfield 1995) and this can range from complete denial to an uneasy acceptance of the disease. The process could be seen as a journey of self-discovery that is dependant on trial and error (Stuifbergen and Rogers 1997). Many people will seek their own strategies to enable them to live with the consequences of disease and this quest facilitates an individualistic adaptational strategy that will impact on the rehabilitation process.

1.4.2. Principles of physiotherapy in neurological rehabilitation

This section will consider the principles governing physiotherapy as an intervention in neurological disability. It will also describe some of the most common therapy techniques used. As a general concept, physiotherapy interventions have proven beneficial in the treatment of musculoskeletal problems (Kerry 2002. Saunders 2003. Kochar and Dogra 2002). Neurological treatments have emerged as a specialist area of interest and consequently therapeutic modalities pertinent to this field have also emerged (Bohannon 1993. Green 1996. Kell et al 2001. Bobath 1990. Carr and Shepherd 1998). These physiotherapy techniques include the short-term use of electrotherapeutic techniques and mobilisations to speed the recovery of focal injury to the long-term involvement required to treat a neurological problem. The same inherent skills of assessment, treatment planning and implementation are applied to the management of those with neurological deficits as to those in other physiotherapy specialities.

Neurological rehabilitation revolves primarily around reacquisition of movement and function within the confines of the prevailing physical deficit (Edwards et al 2004). To

explain the underlying theories of the interventions included in this study a brief explanation of the principles of movement and posture is presented.

1.4.2.1. Movement

Voluntary movement in a therapeutic environment has been routinely described as follows (Gardiner 1975):

- **Active movement.** This is under voluntary control and it can include assisted movements in which aid is offered to perform the movement. This may involve the use of a sling to support a limb during an activity.
- **Unassisted movements.** This would require working into a range of motion without a resistance and unaided in the performance of the action.
- **Assistance with resistance.** A slight resistance is offered to the assisted movement.
- **Resisted movements.** Muscular activity working against an applied force. This would be demonstrated by the free use of weights or resisted cycling. All of these descriptors are encompassed in the term exercise and are the basis of all exercise therapies (Wells 1971).

Voluntary movements involve many components and to be effective are dependant on memory in conjunction with neuro/musculoskeletal changes within the body and environmental changes without (Kendall et al 1993). They are also dependent on an intact sensory system for their fluidity of activation. Movement can also be involuntary, for example, a reflex action or a spasm (Gardiner 1975). This is not considered to be a true movement and it cannot be used as an exercise tool. In other words it does not promote activity to minimise dysfunction, it does not prevent loss of joint or muscle integrity and it does not facilitate recovery or maximise ability.

1.4.2.2. Passive movement

Movement can also be a Passive process in which the part is moved by an external force (Galley and Forster 1987). The action can be:

- Relaxed. When the part is moved slowly and rhythmically by a second party or mechanical device through an appropriate range of motion.
- Applied Pressure. As occurs when moving spastic or shortened limbs in an effort to re-gain muscle length (Wells 1971).
- Manipulative. As in the application of grade 5 Maitland manipulative treatments (Maitland 2005). These are high velocity thrusts carried out by trained therapists that are used to realign spinal joints.

1.4.2.3. Posture

Posture has been defined as, “..the relative arrangement of the parts of the body. Good posture is that state of muscular and skeletal balance which protects the supporting structures of the body against injury or progressive deformity irrespective of the attitude (erect, lying, sitting, squatting, stooping) in which these structures are resting or working...Poor posture is a faulty relationship of the various parts of the body which produces increased strain on the supporting structures and in which there is a less efficient balance of the body over its base of support” Posture committee of the American Academy of Orthopaedic Surgeons (1947).

Loss of postural control associated with neurological damage impacts on most functional abilities (Davies 1985). As posture is the base from which all movement takes place (Galley and Foster 1987), bipeds could be considered to be at a mechanical disadvantage in a postural sense when compared to four-footed animals. Their center of gravity is closer to the ground and located within a well-balanced four-point support structure thus providing a more stable base from which movement can be initiated. The upright being is constantly required to make subtle postural adjustments to maintain their center of gravity within their two-point base of support. Balance and postures are adapted to facilitate action and provide stability (Kendall et al 1993). Without such postural competence the body would be unable to move in a balanced fashion.

Maintaining an upright posture against the effects of gravity can be taxing. The energy expenditure experienced whilst standing or sitting for prolonged periods is often underestimated when considering appropriate physical therapies for neurorehabilitation purposes. Even in lying some degree of postural readiness exists and muscular fatigue

can present when exercising in this fully supported position. Therefore before effective movement can be achieved attention must be paid to posture (Bobath 1990). As with movement this could also be described as active and passive in nature. In the passive state the body responds with minor adjustments to environmental changes to maintain itself against the effects of gravity. In the active state it will be facilitating dynamic activity by adjusting its posture in response to the required movement.

1.4.2.4. Physiotherapy and the CNS

For most therapists involved in neurorehabilitation much of their daily practice is based on their accumulated knowledge, experience and a process of ongoing learning that provides invaluable insights into the vagaries of the work. However successful interventions are governed by specific principles that rely on knowledge of the CNS and the effects of damage to it (Cohen and Hallett 2004). These interventions also depend on an appreciation of neural recovery, the CNS's involvement in movement and postural control and its ability to learn and adapt a process known as neuroplasticity.

With this in mind therapists approach the compromised CNS with a view of how it should react to various stressors. Therapies are based on a comprehensive assessment of the presenting difficulties in relation to how the CNS is currently performing and an action plan is designed to address these problems. The study by Byl et al (2003), demonstrated how this knowledge improves outcomes. They studied stroke patients six months to seven years post stroke (n=21) and showed improvement in functional ability with an eight-week programme of 1.5 hours of physiotherapy per week. They used a learning based sensorimotor retraining regime that capitalised on the adaptability of the CNS.

The concept of neuroplasticity was the focus of the Rasova et al (2005) project, (n=28), the thrust of which was to determine whether neurorehabilitation was able to influence brain function as shown on Magnetic Resonance Imaging, (MRI). The therapy involved sensorimotor learning and adaptation plus an eclectic mix of Bobath, proprioceptive neuromuscular facilitation and yoga. Positive gains were shown in fatigue levels, impairment, disability and handicap but no detectable changes were evident on MRI. This does not detract from the value of neurorehabilitation nor does it negate the theory

of neuroplasticity as the clinical outcomes in regards to fatigue, depression, impairment and disability were significant.

Ideally a full return to normal function would be the best possible outcome following a rehabilitation effort unfortunately this seldom occurs once the CNS is damaged (Davies 1990). It then becomes the role of the therapist to maximise available activity and adapt movement to encourage useful functional recovery while fostering realistic expectations. This may not be the preferred option of the patient and possible conflicts may arise between therapist and patient regarding achievable goals (Bloom et al 2006).

The relevance of physiotherapy in the rehabilitation of neurological disorders has gained prominence and it is a valuable, perhaps vital, component of the rehabilitative process (Edwards et al 2004). The development of various schools of thought on the best therapeutic approaches has paved the way for therapists to evaluate and include these new ideas in their existing knowledge base. A selection of these techniques is discussed in the next section.

1.4.3. Physiotherapeutic techniques commonly used in neurological rehabilitation

This section examines some of the more commonly used physiotherapeutic techniques that have evolved in the wake of developing rehabilitation philosophies. The inclusions are not in order of preference or popularity of application and offer an overview rather than a detailed description of each one. Research investigating comparative studies is included.

The CNS learns by repetition (Moore 1980. Cohen and Hallett 2004) and active involvement in therapy has demonstrated the recovery of function far more effectively than a passive approach. The development of neurological rehabilitation has fostered the growth of many different modalities based on this premise such as: Bobath (1985,1990), Proprioceptive Neuromuscular Facilitation, (PNF) (Kabat and Knott 1954), Motor Relearning Programmes (Carr and Shepard 1989, 1998), Hydrotherapy, Functional Electrical Stimulation and the use of a treadmill to facilitate gait.

These techniques have concentrated on maximising function after injury to the nervous system or the acquisition of a neurological disease. They are neither fool proof nor definitive in their application to certain conditions. Therapists will evaluate each technique on its appropriateness to the presenting difficulties and it is likely that no one approach will take precedence. It is this researcher's experience that an open-minded attitude using the available evidence will best advance the progress of the individual.

These treatments must be used in conjunction with appropriate drug interventions to control spasticity and pain. Uncontrolled spastic responses are extremely difficult to override without drug interventions yet when drug therapies are used in conjunction with physiotherapy significant therapeutic gains can be achieved (MS Trust 2006).

1.4.3.1. Bobath

The basic principles of movement and posture provide the foundation for the modern theory of normal movement (Bobath 1985). This has focused on the re-acquisition of previously established motor pathways to re-introduce an accepted movement pattern thus restoring normal voluntary movement. This re-acquisition is governed by reflex activity or the strength and nature of an external stimulus. A course of action or a functional activity is initiated using pre-existing, learned, well-controlled circuits within the brain (Davies 1985). The Bobath technique capitalises on these pre-learned actions.

Bertha and Karel Bobath developed the concept in the 1950's. It evolved as a result of their work with cerebral palsy children. Their view proposed that as a result of inhibited postural reflexes there was a concomitant interference in the ability to direct purposeful movement with a subsequent loss of postural control. The treatment typically involved the manual handling of the person in an effort to inhibit these abnormal responses and thus allows the normal patterns to re-emerge (Davies 1990). This was often achieved passively by positioning of the person in such a way as to inhibit the abnormal patterns.

More recently therapists have adapted their approach to encompass more dynamic interventions based on the principles identified by the Bobath technique (Bobath 1990). They actively attempt to change the postural tone of the individual by encouraging re-acquisition of movement in conjunction with the manual handling intervention

previously mentioned. This technique is carried out in a variety of positions and often requires the participation of two therapists for safety and accuracy of application.

Studies considering the efficacy of this approach are numerous and it has been suggested that the Bobath method is unsuitable for people over 75 years of age and it is difficult to justify the treatment to those over 80 (Panturin 2001). The studies differ in their methodology, application, duration of rehabilitation and use of outcome measures thus making comparisons difficult and Paci (2003) has concluded that they do not analyse the real effectiveness of the Bobath method. Nor do they support the view that this is the optimal treatment modality for stroke rehabilitation. It was not considered as a treatment option specifically for MS in these studies.

The study by Langhammer and Stanghelle (2000) compared the effects of Bobath against a motor relearning programme. The study was carried out on in-patients and was a double-blind study of two groups of 61 stroke patients. For all participants this was the first stroke with a hemiparesis. They concluded that the motor re-learning strategy was preferable to the Bobath approach because the improvement in motor function was measurably better in the short term and that the subjects had a shorter hospital stay before being deemed well enough for discharge.

This conclusion has invited a response from those who support the Bobath approach. Brock et al (2000) commented on the evolution of the Bobath concept to embrace the “systems approach to motor control” as described by Lennon (1996). They also intimated that the correct application of the Bobath approach demanded a skilled practitioner and that might not have been the case in the Langhammer and Stanghelle study.

The Bobath method has been studied in relation to rehabilitation in MS by Smedal et al, (2006) in respect of balance and gait re-education. The study only involved two people with MS and it did not offer conclusive evidence for the generalisable implementation of this treatment for MS. However both subjects demonstrated improved quality of gait, balance and functional mobility. Overall the participants described their condition as “much improved”. This researcher has also found that the technique can be successfully adapted to alter tone and promote movement in MS. However it can be a demanding

technique both on the operator and on the patient and requires skill and confidence to apply correctly for optimum results.

1.4.3.2. Proprioceptive Neuromuscular Facilitation (PNF)

“PNF is more than a technique, it is a philosophy of treatment” Adler et al (1993).

The philosophy springs from the idea that all human beings, including those with disabilities, have untapped potential (Kabat 1950 a). There are certain principles that underpin its foundation. Firstly, the treatment approach is always a positive one. In other words encouraging and building on physical and psychological abilities. Secondly it aims to achieve the highest level of function possible. Thirdly, PNF is a holistic approach that is concerned with the total human being rather than specific problem areas or segmental levels of deficit.

The application of the technique involves the use of active and passive movements and afferent input (external stimulation), to, “..bring about maximal excitation of the available anterior horn cells” Kabat (1950 b). Resistance and rotation are an integral part of the treatment that facilitates the muscles’ ability to contract and relax thus improving motor control. It promotes awareness of movement and improves strength. The use of resistance must be appropriate to the ability of the person. This requires a skilled operator which a knowledge of the deficits that are being addressed (Adler et al 1993). This aspect of its application may limit its generalisability in some rehabilitation arenas.

Studies into the effectiveness of this technique have found it to be better at increasing joint range and flexibility than other more passive stretching and mobilising methods (Sady et al 1982. Weiss et al 1986). The researcher has also found it to be a useful adjunct to the rehabilitation armoury and has used it most successfully as part of an evolving rehabilitation process.

1.4.3.3. Motor relearning programmes

The theory of “Motor Relearning Programmes” was developed in Australia by Carr and Shepherd, (1989. 1998). The programmes evolved out of personal experience combined with an extensive literature review concentrating on the study of behaviour and

movement. The system was developed primarily for use in stroke rehabilitation and focused on the re-acquisition of seven basic motor skills deemed by the authors to be necessary for daily living. The selection of these motor skills was based on the premise that we all use the same basic movements to attain functional independence. The selected skill areas were functional facial movements, upper/lower limb tasks performed in sitting or standing, standing to sitting and walking.

The motor re-learning approach embraces the concept of re-initiating patterns of movement that have previously been learned and which due to an insult to the CNS have been suppressed or erased. Positive reinforcement is given via verbal encouragement to produce functional movements that enhance independence. The basis of the technique is one of cognitive re-learning as opposed to the manual facilitation of movement as with Bobath. The motor re-learning method relies on repetition of specific skills or movements to reinforce the overall pattern. There is evidence to show that this method has comparable outcomes to the Bobath method at three months in stroke rehabilitation (Langhammer and Stanghelle 2000). However Gustavsen et al (2002) felt that these findings were inconclusive and there was no definitive decision as to the optimum approach to adopt.

The motor re-learning method was the basis for the physiotherapeutic exercise regimes used in this study. It allowed for self-guided exercise to take place while the repetitive element, vital to CNS re-education, served to strengthen sensori-motor feedback. This facilitated movement patterns and thus functional gain.

The motor re-learning approach has been used extensively in the community by the researcher and it was the most appropriate basis for the physiotherapy home regimes for the following reasons: the participants were required to comply with the regimes unaided, there was a necessity to re-acquire lost functional patterns and this method was compatible with independent exercise plus it allowed for movements to be practiced in a controlled manner with minimal risk of CNS overload. The other physiotherapeutic techniques discussed here are usually dependant on the intervention of a second party for their implementation and in some cases the provision of equipment that would not be compatible with home use.

The therapeutic techniques described have focused on conditions that present after a traumatic single/multiple event that produces a disability. The difficulty with MS is the changing nature of the condition and the disability that fluctuates between functional and non-functional presentations. It may be for this reason that studies into targeted therapeutic intervention for MS are lacking. Consequently it is this researchers contention that a diverse approach is most often adopted drawing on the evidence from successful interventions used on other neurological conditions.

1.4.4. Other useful therapeutic techniques

This sub-section will outline a selection of some other commonly used physiotherapeutic modalities.

1.4.4.1. Hydrotherapy

Hydrotherapy offers many advantages when performing physical activity. It provides a non weight-bearing environment for joint range to be increased (Peterson 2001). It can be used as a graduated resistance to promote strength and aerobic capacity. It also has relaxation properties that can assist with reducing raised tone in spastic muscles (Bates and Hanson 1996).

Caution must be exercised when using hydrotherapy in the treatment of MS as the water temperature required for therapy may be too high (94 degrees Fahrenheit) and induce fatigue (Guthrie and Nelson 1995). Peterson (2001) concluded that aquatic therapy has value for those with MS but the water temperature should, ideally, be below 85 degrees Fahrenheit. Use of a local pool or leisure facility may be appropriate as the water temperature will be lower than that in a therapeutic pool.

1.4.4.2. Functional Electrical Stimulation (FES)

This intervention typically involves electrical stimulation of the peroneal nerve for the correction of foot drop associated with hemiparesis (Bogotaj et al 1995). It is also used to promote nerve conduction in the thigh and hip muscles to facilitate knee control and pelvic alignment during walking re-education as well as the shoulder region to acquire reciprocal arm swing (MS Trust 2005). This technique is generally used as an adjunct to other therapies for example, Bobath or motor re-learning to promote movement and

independence. This method has been shown to be effective in gait rehabilitation but it can be difficult to use on a daily basis due to the technical requirements of calibration of the equipment and the time needed to apply the electrodes accurately (Bogotaj et al 1995. Hesse et al 1995 a).

The randomised trial carried out by Burrige et al (1997) examined hemiplegic people with foot drop (n=32). They compared FES against standard physiotherapy sessions and found that the FES group was able to walk significantly faster and more efficiently with the stimulator. No evidence of improvement was shown without the stimulator thus a carry-over effect was not demonstrated. Hemiparetic foot drop can occur in MS and this technique can be successfully applied to these cases.

1.4.4.3. Treadmill gait re-education

This approach to gait re-education involves the use of partial/full body weight and the mechanical aid of the treadmill to supply a walking pattern. Hesse et al (1995 b) compared this approach with Bobath in the gait re-education of seven non-ambulatory hemiparetic people using an A-B-A design. All participants received the treadmill then physiotherapy using the Bobath method then the treadmill. They concluded that the treadmill was more effective in the restoration of gait ability and speed over a shorter treatment time and that it had significant applications as a treatment option the main drawback being the cost of the equipment.

Much of the most recently published research compares physiotherapeutic interventions against the Bobath method specifically in stroke rehabilitation. There is no holy grail in neurological rehabilitation, rather a mix of techniques that demands skilful sifting. A successful intervention should meet the needs of the person, the physical presentation of the condition and the possibility of improvement where possible or maintenance where improvement cannot be achieved.

1.4.5. Provision of physiotherapy in the community

The previous section has introduced the principles of physiotherapy in relation to neurological rehabilitation and has discussed a selection of commonly used therapeutic techniques. This section considers physiotherapy and exercise provision as a

community intervention. To avoid confusion the word “community” in this study is deemed to mean treatment carried out in the home, local fitness center or swimming pool. It does not refer to exercise classes run in clinical settings, eg rehabilitation centers or physiotherapy gyms.

Although difficulties exist with the implementation and maintenance of community physiotherapy services ranging from lack of resources, travelling time and commitment from service users (Freeman and Thompson 2000) it is not impossible. A successful service has been set up in Nunavut, Canada, an area with considerable geographical and logistical problems facing service provision (Achtemichuk et al 2004). The service is primarily treating musculoskeletal conditions but there are numerous neurological referrals that have been successfully accommodated. Community-based exercise has been researched in Australia in an “at-risk” of falling group of older people (Barnett et al 2003). The study was conducted in a class situation with the addition of home regimes. It was found that the rate of falls was considerably diminished in the exercise group in comparison to the control group who received no intervention.

Community-based rehabilitation teams are an important element of the Department of Health, (DoH), proposals for long-term conditions (National Service Framework 2005). The evidence offered in this publication was the result of extensive consultations with experts in the field. Prior to its publication McMillan and Ledder (2001) produced a paper that investigated the role, function and staffing of community rehabilitation teams dealing with neurological disability. They conducted a survey of 35 teams over 25 health authorities in South East England. Stroke and multiple sclerosis were the most common referrals. It was their conclusion from the results of the survey that the teams were insufficiently resourced to provide a comprehensive service for the included client group. This conclusion reflects the findings of other researchers indicating gaps in service provision (Freeman and Thompson 2000. Williams and Bowie 1993). Despite the publication of the NSF (2005), these deficits are still to be adequately addressed.

The use of mainstream facilities and other freely available physical activity opportunities play an important role in the lives of those with neurological problems (MS Trust 2005). Access to such opportunities should be encouraged especially with

the current crisis in physiotherapy provision around the country (Bell 2006). The management of a chronic neurological condition requires the maintenance of ability over time and this is as significant as any improvements that may occur due to activity participation (Ashburn and DeSouza 1988. Freeman 2006). These elements were lacking in most community services mainly due to funding allocation, the inability to provide outcomes and discharges that met the government targets plus inconsistencies in community care provision (Freeman and Thompson 2000. Rawlins 1999).

There are studies involving entirely community-based treatment such as the Stephenson and Wiles (2000), project. They investigated the views of patients and therapists involved in a home stroke service (n=15). They highlighted the difficulties experienced by therapists due to lack of equipment and in controlling the session. The patients found that they were more comfortable at home but that they felt de-motivated to continue once the therapist had left. However the relevance of goal setting and achievement was acknowledged, as was the need to continue to move rehabilitation from the acute setting to a more community based one.

Community rehabilitation has also been examined in a case study by Husain and Kelleher (2005), for an obese spinal injured patient. Despite the many problems faced by the physiotherapy service in effectively managing this person's care they still demonstrated a positive outcome.

Home physiotherapy has found a place in the management of Parkinson's disease. Nieuwboer et al (2001) evaluated the effect of this intervention. It involved 33 patients on a six-week home exercise regime concentrating on functional activities such as walking and transfers. The physiotherapists taught conscious movement control and cueing three times a week in the home. The study showed that there were significant improvements in function leading the researchers to conclude that home physiotherapy has an important role to play in Parkinson's rehabilitation.

Unfortunately community physiotherapy services nationwide struggle to fulfil the requirements of neurological conditions and as yet there has been no examination of the supply of community services in respect of demand (Freeman and Thompson 2000). Despite the advent of the NICE guidelines for MS (2003) and the evidence supplied

by the MS Trust's scoping exercise (Freeman 2006), inequity in provision, lack of resources and skill erosion continue (Frontline 2006). Freeman and Thompson (2000) remarked that these wide variations in service provision for both outpatient and community groups are unacceptable and required urgent attention.

1.4.5.1. Evidence supporting community physiotherapy

The question of who would benefit most from home treatments deserves consideration. In 2006 the DoH initiated the Expert Patient programme in an effort to encourage a more self-managed direction when living with a long-term illness. This was to be an integral part of care provision for people in this disability group allowing for the development of a more patient centered care system. The programme involves a six-week training course to develop new skills to facilitate coping and improve quality of life. Enabling those who are able to manage their own home exercise regimes fits with this concept as not only are the rights of the person considered but their responsibilities are also highlighted.

The NSF for long-term conditions published in 2005 predated the Expert Patient document and presented many new challenges to professionals. The government withdrew from a centrally funded system to a local method of funding and service delivery. There were standards to be met that included the community support of chronic conditions revolving around person-centered care and choice. Local services were to provide community rehabilitation and outreach teams to function within the home. A significant element of such teams was that of specialist physiotherapists providing community based interventions.

Community based treatments have many benefits. They can negate the detrimental effects of uncomfortable ambulance journeys that may undo the gains made in the therapy session (Seymour and Kerr 1996). Individuals have remarked that they were better able to understand and retain information given in the home as well as appreciating the privacy that home therapy can offer (Stephenson and Wiles 2000. Wade 1992). Home provision may also remove the emotional reliance on others for transportation and assistance at outpatient appointments (Casanett and Karlavish 2001).

Home interventions are often perceived as being more relevant to peoples' lives and it has been shown that recipients benefit substantially as a result (Gladman et al 1993. Lafferty 1996). Bjorkdahl et al (2006), in their study on home exercise treatment post stroke, (n=58), found that those receiving the home intervention improved quicker than the group attending the day center. The home group had the benefit of individually tailored physiotherapy programmes focusing on activities in a familiar environment. They concluded that the home regime was as good as or better than the clinic programme. This concurs with the work by Roderick et al (2001), who added that there was scope for greater involvement of the caregivers in the person's home. This can be achieved in a task-orientated way to suit individual need by utilising familiar objects found in the home (Stephenson and Wiles 2000). Often the requirements of function differ from those involving segmental control (Lord et al 1998) and home exercise regimes can incorporate rehabilitative activity into daily tasks more effectively than those undertaken in an outpatient setting (Nieuwboer et al 2006). Assisting individuals to cope at home throughout all stages of their disease is in line with the government directives of past decades (Secretary of State for Health, The Health of the Nation 1991. NSF for long-term conditions 2005. The Expert Patient 2006).

It could be concluded that the provision of home exercise programmes is an acceptable option when attendance at a mainstream facility is not feasible (Stephenson and Wiles 2000). A programme that is monitored and amended as required should form part of the person's management strategy (Ashburn et al 1997). However, the provision of a support mechanism is vital to augment the home intervention. The relevance of maintenance interventions is also recognised as playing an important role in long-term management of neurological conditions with the emphasis being on community-based treatments (Chard 2006). Research has noted that exercise during all stages of the MS disease process is highly recommended (Cornell 1996. Poser and Ronthal 1991. Solari et al 1999. Thompson 2005. Reitberg et al 2004) and participation in a low level cost effective method of disease management should be encouraged such as can be offered by community interventions.

1.5. Exercise as a physiotherapeutic tool

The preceding sections have described the broad concepts of rehabilitation and more specific issues relating to neurorehabilitation and physiotherapy techniques that are applicable to this rehabilitative arena. This next section defines exercise and considers its use in rehabilitation. It outlines the principles of exercise and offers evidence to support its benefits.

“Exercise” and “physical activity” are generic terms clearly distinguishable from the term “exercises”. The former describes any activity that will minimise the affects of inactivity (Gardiner 1975). Exercises are specific in that they describe precisely the form the action is to take, are usually prescriptive and are specific to the needs of the situation.

Casperson et al (1985) defined exercise, fitness and physical activity for the purposes of health related research and divided the terms into three clearly distinguishable categories: Physical activity - any bodily movement produced by skeletal muscles that result in energy expenditure. Exercise - a planned, structured and repetitive bodily movement done to improve or maintain one or more components of physical fitness. Physical fitness - a set of attributes that people have or achieve that relate to the ability to perform physical activity. Exercise can be used as an appropriate physical activity to accomplish a specific goal and specific goals have been shown to have a significant impact on exercise behaviours (Weinberg and Gould 2007).

So working from the preceding premises, exercise is “..a physical activity but not all physical activity is exercise” (Casperson et al 1985). Neuro-rehabilitation subscribes to this concept and embraces the notion of task orientation proposed by Gentile (1987) that concentrated on the re-acquisition of skills to enhance independence. In the physical management of MS, all actions that facilitate independence and maintain a person’s ability are of equal value. Importantly, Petajan and White (1999) noted that exercise must activate working muscles whilst avoiding overloading which can result in nerve conduction block.

Exercise has assumed a prominent role in modern society (Weinberg and Gould 2007). The advent of the recreational jogger has raised the profile of exercise and it has adopted a conspicuous position in the health concepts of many people. Traditionally exercise has been the purview of the able bodied, carried out in high-tech environments under the supervision of fitness instructors. It has been proposed however that sedentary people can accrue significant health benefits from relatively low levels of exercise involvement (Haskell 1994). The notion that the disabled individual can also benefit from exercise is acknowledged (Lord et al 1998) although the opportunities for participation are often hampered by unfavourable circumstances (Stuijbergen 1995). These include environmental barriers and physical and psychological limitations.

These limitations support the belief that peoples' actions are greatly influenced by their perception of that action (Bandura 1977). In other words if the outcome is perceived as unattainable then the participant will disengage from the action. The concept of cumulative benefits allows for the outcome to become a reality by encouraging the bankability of exercise efforts with the production of tangible physical gain (Phillips et al 1996). Exercise can achieve this goal when it is performed at therapeutically appropriate levels. It is performed less intensively than exercise performed by an able bodied person due to the added difficulties of fatigue, muscular weakness, loss of co-ordination, spasm and/or tremor. It is vital to design an exercise programme to compliment the impairment presentation thus allowing an individual to perform an activity within their physical limitations.

The concept of cumulative benefit from short bursts of exercise is now gaining credence (Blair and Connelly 1996). If people can be convinced of this then engaging them in meaningful exercise regimes becomes more likely. An important point to remember when promoting the health benefits of exercise is that improvements in physical fitness are not necessarily the aim and people may become discouraged if they think they are expected to become fit (Wendell 1992). A positive effect on one's health and physical function is the goal and this can be achieved through moderate exercise interventions (van der Ploeg et al 2004).

The promotion of positive health effects is dependent on motivation (Milroy and O'Neil 2000) and an important motivational consideration when engaging in exercise is

the individual's pre-morbid ability (Petajan and White 1999). Those who participated in exercise for recreational purposes or competitively prior to their diagnosis may demonstrate a better ability to persevere with an exercise regime than those who have never included exercise in their daily lives. Motivation may also be a barrier to long-term exercise involvement and Kinne et al (1999), found that this was one of the predictors of exercise maintenance.

Psychosocial considerations could also impact on physical activity and decreases in health status could result (Burnfield 1995). Feelings of inadequacy, loss of one's place in the social group and diminished quality of life perception deepen as abilities are eroded over time (Charmaz 1983. Dal Bello-Haas 2002). This leads to social isolation and feelings of hopelessness. Man has an inherent need to belong to and participate in the activity of a peer or family group. Klein (1996) noted that the involvement of the family played a significant part in exercise behaviour and “.. as long as there was not an active discouragement of exercise by family members, activity levels were increased”.

This active approval of others in the performance of a new behaviour plus individual perceived control contributes towards the anticipated performance effort (Ajzen and Driver 1992). It follows that to successfully participate in exercise an individual's perceptions of the regime will greatly influence compliance. The value placed on the regime and the degree of control in its execution will reinforce this. Value and acquisition of control are two of the most important determinants of success or failure in exercise adherence as, “Perceived control predicts exercise behaviour in chronically ill populations.” Trafimow and Trafimow (1998).

Ulbrich (1999) stated in her work on exercise as self-care for those at risk of cardiovascular disease that, “ Exercise results from the relationship among type, intensity, and duration of activity.” Exercise has the potential to minimise dysfunction, prevent loss of joint or muscle integrity and it facilitates recovery by maximising ability all of which are worthwhile goals for those with MS.

1.5.1. Health benefits of exercise

Exercise is a major contributor to a person's health and psychological wellbeing (Klein 1996. Biddle 2000). Ardell (1985) defined this state as, “ a conscious and deliberate approach to an advanced state of physical and psychological/spiritual health”. Exercise can be effectively used as a calculated approach to achieving this life balance providing individuals undertaking exercise as a lifelong pursuit are convinced of its value to them and are re-assured that they can participate safely. Often this is re-enforced by defining specific areas they wish to positively change. Weinberg and Gould (2007) have indicated that this as a performance goal that operates independently of others and is personal to the person.

Exercise must not be considered in isolation and attention should be paid to other aspects of health behaviour that impact on the person as a whole (Dishman 1991). These will include diet, smoking and alcohol consumption. Klein (1996) advocates a “user friendly” approach to exercise that promotes its obvious health benefits in an attainable way. Even so success cannot be guaranteed and an inherent desire to participate must exist if the regime is to succeed.

All these potential benefits are to be set against the backdrop of quality of life as defined by the individual. The study by Jonsson et al (1996) identified a link between quality of life and physical performance that encouraged the use of exercise as a psychological as well as physical tool. Improved quality of life will encourage further exercise engagement, as will other benefits such as weight loss and improved cardiovascular capacity.

1.6. Theories of behaviour

This section will introduce the concept of behavioural change. Table 1.1 presents a selection of some of the relevant theories with a brief description of their properties. Those highlighted in bold were applied to this study and are described in detail in sections 1.7 and 1.8.

Table 1. 1. Theories of behaviour

Theory	Components	Author/Year
Planned Behaviour Beliefs	Belief based structure used to identify preconceptions that may influence exercise interventions.	Ajzen 1985. 1991.
Stages of change (transtheoretical model)	Explains intentional behaviour along a time frame involving both cognitive and active elements.	Prochaska and DiClemente 1984
Self efficacy concept	Used to explain and predict psychological changes as a result of an intervention. Depends on the individual's belief in their capacity to perform.	Bandura 1977
Social Cognitive Theory.	A model developing a self-efficacy towards the adopted behaviour. (From Bandura 1977).	
Theory of Reasoned Action	“An expectancy value model with emphasis on attitudes, subjective norms, intentions and behaviours directed to a specific focus.” (Blue 1995)	Ajzen and Fishbein 1980
Relapse Prevention Model	A model using self-regulation to deter participants from disengaging from exercise.	Marlatt and Gordon 1985
Known Determinants	The categorisation of past and present personal attributes, environments and physical ability to predict exercise uptake/adherence.	Dishman 1982. Dishman et al 1985
Behaviour Change Interventions	Use of eg, positive re-enforcement using written contracts, self monitoring, goal setting, feedback and decision making to encourage/predict behavioural change in relation to exercise.	Knapp 1988
Behaviour Modification.	Changing an undesirable behaviour. Mainly used in cognitively impaired individuals with neurological damage. Is applicable to exercise avoidance by promoting this as a desirable behaviour and re-enforcing the change with positive outcomes.	From Gardner 1971
Adaptive Change Model	Based on the Stages of Change Model. Hypothetical model using positive and negative factors to support change.	Bowles 2006

The adoption of behavioural change was the theoretical underpinning of this study and its application governed the outcomes. The literature concerning the concept of behavioural change has been applied to an alteration in health behaviours involving conditions such as cardiovascular disease, diabetes and obesity (Hilton et al 1999. Hassler et al 2000) and in the promotion of other health behaviours for those with a chronic disability (Stuifbergen 1995. Parcel et al 1986). Dishman (1991) indicated that previous attempts to improve health in medical populations had failed because not enough attention was paid to the concept of behavioural change. He advocated that greater priority should be given to this concept. Becker and Maiman (1975) also noted that successful behavioural changes were dependent on health beliefs indicating that more consideration should be given to these areas.

The change of health behaviour related to exercise for this study's participants was an important consideration. It had the potential to significantly influence physical abilities while accommodating the effects of a compromised CNS. If a person's health beliefs cannot be altered then the long-term benefits of any exercise programme cannot be guaranteed (Kerner et al 2001). Attempting to alter a set behaviour involves an internal debate that will explore the expected value of the change and the amount of effort involved to adopt it (Weinberg and Gould 2007). This amount of effort often acts as a major determinant to the success or failure of any proposed exercise programme. Also physical capabilities may not equate to the effort required to produce the desired gains and this can deter people from attempting exercise. The two models used in this study will now be described and the reasons for their selection identified.

1.7. Theory of Planned Behaviour Beliefs

The theory of Planned Behaviour Beliefs as described by Ajzen (1985) provides the framework for the investigation of attitudinal change that is applicable to exercise uptake. Rowland et al (1994) postulated that this concept predicted exercise behaviour and the study by Wankel et al (1994) also identified that the degree of intention to exercise correlated to this belief system. Research with younger adults and men has consistently upheld the significance of behavioural beliefs for seeding the intention to exercise (Courneya and Freidenreich 1999. Kerner et al 2001).

It has also proven valuable in examining exercise motivations in other disability groups (Karvinen et al 2007).

The theory involves three distinct belief structures that embrace the gamut of belief adjustment required to successfully engage in long-term exercise involvement. These will now be described.

1.7.1. Personal gains, (perceived control)

In the theory of planned behaviour the perception of personal gain is one of the three elements of the behavioural change “trifactor”. The incentive to change behaviour depends on the perceived gain that can be attained, the intention to perform the new behaviour and the amount of control the person can exercise over the behaviour. This factor has been identified as a consistently important predictor of an adult’s exercise intention (Blue 1995. Blue et al 2001). It has also been shown to predict exercise behaviour in chronically ill populations (Courneya and Freidenreich 1997. Trafimow and Trafimow 1998).

For those with MS the benefits of exercise have been well researched (Petajan and White 1999. Di Fabio et al 1997. Sutherland and Anderson 2001. Reitberg et al 2004) and as previously noted perceived control has been shown to predict exercise behaviour in chronically ill populations (Courneya et al 2003. Trafimow and Trafimow 1998). It follows therefore that if potential exercisers have a positive view of their effort in relation to outcomes then they will comply with the regime. Equally the opposite holds true. Perceived barriers to exercise either physical or psychological will also negatively impact on the outcome.

There are many factors inherent with MS that could impede exercise uptake and these all have the potential to interfere with the exercise process. To counter these difficulties the person must be convinced of the eventual benefit to them and this must relate to the amount of effort they will be required to put in. It has been noted by Norman and Connor (2005) that, “---with respect to exercise, planning is an important moderator of the intention behaviour relationship”. Therefore it could be suggested that the

involvement of the person at the inception of the exercise regime would positively affect perceived control and therefore support compliance (Blue 1995).

1.7.2. Self-belief, (behavioural beliefs)

Self-belief in the theory of planned behaviour equates to self-efficacy and has been described by Schaal Fletcher and Banasik (2001) as, “--the belief and conviction that one can successfully perform a given activity.” To facilitate exercise adherence it is necessary to appreciate the barriers perceived or real to the desired action (Sluijs et al 1993). In the case of those with MS barriers to exercise are easily identified. They include unpredictable physical ability and symptom presentation, difficult environments and lack of knowledge as to appropriate activities and activity levels (Becker and Stuifbergen 2004).

To overcome these barriers it is necessary to influence the person's perception of their exercise capability (Weinberg and Gould 2007). The perception of self-efficacy has been allied to four influencing factors. These are: past exercise performance, social modelling, social persuasion and the prevalence of physical symptoms (Bandura 1997). It is believed that past performance was the most reliable predictor of future exercise involvement (McAuley et al 1999). Unfortunately those who exhibit low or unsatisfactory exercise experiences tend to adopt an avoidance behaviour that discourages exercise uptake. These people will offer multiple excuses for not undertaking exercise (Schaal Fletcher and Banasik 2001) yet it is these people who, if they could be encouraged to revise their exercise preconceptions, have the most potential to make significant gains (Dunn et al 1998. Andersen et al 1999. Schapiro 1998).

Self-efficacy is also related to the degree of disability. Sluijs et al (1993) found that those with more disabling conditions performed better at home exercise regimes than those less affected. They also found that those who believed that their problems would eventually resolve performed better than those with a long-term condition. These findings highlighted two separate issues in this study. Firstly could the condition be affected and secondly who would benefit the most.

1.7.3. Perceptions of others, (subjective norms)

The third element of the theory of planned behaviour is the perception of others. Positive reinforcement from significant others is a noteworthy driver behind one's intentions to change a behaviour (Klein 1996. Laitakari et al 1996). For those with a disability this factor takes on special significance. They may for example be dependent on a partner or friend for transport or assistance with exercise performance. They may also require positive re-enforcement to undertake and continue with a behavioural change that they find difficult. However the research is inconclusive as to the value of this belief system in relation to exercise (Blue et al 2001). Theodorakis (1994) concluded that subjective norms did not predict exercise intention or exercise behaviour among their studied population of women.

Cognitive difficulties may also present that require the involvement of a second party to facilitate exercise participation. Laitakari et al (1996) identified cognitive skills as vital to the person's capacity and capability to carry out the behaviour independently. These factors necessitate the involvement of a supportive person to facilitate the behaviour especially in the case of those with a condition such as MS.

The Planned Behaviour Beliefs strategy was appropriate to this study because the data collection procedures involved both active and cognitive elements. The participants were required to perform an activity while subtle changes in their perception of that activity took place. The participants were also dependant to some extent on the approval of significant others to initiate and maintain the new activity. To promote exercise as a long-term action the psychological back drop to why the cohort were not initially active and how they changed their concepts regarding exercise over time were import foundation stones to prolonged exercise uptake. This model explained the process and the inherent qualities that needed consideration to follow the programme through.

In summary the behavioural change theory as described by Ajzen (1988) influenced the extent of exercise uptake in this study. The elements of behavioural change are dependent on the persons perception of how difficult or easy the new behaviour will be (perceived control), how much they stand to gain from it (behavioural beliefs) and what

others will think of them if they do make the change (subjective norms) (Ajzen and Driver 1992). It could be surmised therefore that without some degree of external endorsement the will of the participants to effect change could be compromised. Equally if the perception of gain is too low or the expectation of effort too high then the process will fail. In the meta-analysis carried out by Hagger et al (2002) significant correlations between these three factors were identified. The theory of planned behaviour and the stages of behavioural change, described in the next section, were the theoretical underpinnings for this study and after examining their principles it became clear that they were a necessary consideration governing the potential exercise outcomes. For this study there were the additional considerations of the unpredictable nature of MS and the resultant psychological responses.

1.8. The Stages of Change Model, (Transtheoretical Model of Change) in relation to exercise

This next sub-section will outline the stages of change (transtheoretical) model of behavioural change and its relevance to exercise engagement.

The three factors of perceived control behavioural beliefs and subjective norms discussed in the previous section can be considered as the basis for the application of the transtheoretical or stages of change model (Prochaska and DiClemente 1984) as applicable to exercise. It is particularly relevant to those engaging in exercise as it is not, “--an all or nothing phenomenon” Sonstroem and Morgan (1989). Rather it allows for the possibility that those who, for whatever reason, stop exercising may have the intention to re-start when circumstances allowed. This is central to the cyclical nature of the model (Prochaska et al 1992).

The prospective exerciser will progress through various preparatory stages to achieve the desired exercise state. The stages of change model details the expected processes necessary to evolve from non-participant to active engager in the new behaviour (Prochaska and Marcus 1994). The stages of change are as follows:

- Precontemplation: the time when the person is not even considering making a change.

- Contemplation: the idea is beginning to take shape.
- Preparation: the person is preparing to undertake the change and may be exercising but infrequently.
- Action: the change is initiated and exercise assumes a regular place in daily life.
- Maintenance: the change is established and enters into regular use over an extended time scale.

As people move through these stages of change there are other factors that interact with them to promote exercise uptake. These factors were identified by Laitakari et al (1996) in their study on long-term maintenance of health-related physical activity. They found that the time and effort required to impact on sedentary routines, involvement in choosing the exercise in which the person has an interest, repetition of the new activity and simplicity of performance plus the reinforcing approval of others governed adherence. It could also be surmised therefore that to facilitate the transition through the stages it was important to strengthen the person's self-efficacy regarding the behaviour (Lippke and Plotnikoff 2006).

A person may feel they adhere strongly to one task, eg a low fat diet, but feel less confident about their exercise potentials (Klein 1996). As self-efficacy is dependant on an inherent belief in ones potential (Schaal-Fletcher and Banasik 2001) it is vital that the person is well motivated to explore their exercise potential from the outset.

Sniehotta et al (2006) extended this idea and they have suggested that once the behavioural intention has been developed, ie at stage three of the health behaviour model, then attention to potential barriers, planning, initiative and monitoring will be required to facilitate long-term involvement. This is a conscious action control mechanism necessary to maintain the new behaviour.

The Stages of Change Model was applicable to this study as it served to explain how people approach the introduction and continuance of exercise. It also allowed for regression to occur. This was a necessary consideration as the unpredictable nature of MS could impede even those with the most determined outlook to their exercise engagement. This aspect of the model would be able to accommodate the setbacks

many people experience when living with this disease. It has been used extensively to describe the process of change that occurs when non-exercisers with varying clinical presentations evolve to become active and is a well-respected model used to describe the evolution of change in regards to exercise (Burbank et al 2002. Garner and Page 2005). The successful implementation of this model in other conditions indicated that it could also be appropriate for use in this study.

1.9. Potential barriers to successful exercise engagement

The use of structured theoretical paradigms to investigate the behavioural changes required to initiate and embed new exercise behaviours is a developing concept and is providing evidence to promote the use of exercise as a treatment medium in many fields (Kerner et al 2001. Conn et al 2003). To successfully integrate exercise into daily life there must be an attitudinal shift that embraces the new behaviour and accepts it as a life-long commitment. It requires a self-efficacy that feeds the belief that the activity is achievable and that there will be positives involved in its execution. The perceptions of self-efficacy are very task specific (Schaal-Fletcher and Banasik 2001), and people with low self-efficacy are likely to fail. Therefore an enhanced exercise belief will heighten the chances of success (Conn et al 2003).

As previously noted it is believed that past performance will enhance one's ability to engage in exercise and those with previous successful exercise encounters will fare better than those without (Milroy and O'Neil 2000). In this study there were six individuals who had previous exercise experiences that could be described as a set behaviour. For them the prospect of exercise was enticing. For the others it was daunting.

Low exercise self-efficacy can lead to exercise avoidance, a common state for many both with MS and in the general population (Schaal Fletcher and Banasik 2001). The challenge was to convince the non-exercisers of the accruable benefits associated with exercise and the fact that they could participate safely. This viewpoint was supported by Tate et al (1995) who found that less fit more sedentary people had more to gain and showed better levels of improvement than fitter individuals. Ali and Tribell (1994) and Lee (1993) highlighted the time needed to engage in the programme, the commitment

required and the more pragmatic difficulties of space and access to appropriate facilities as predictors of exercise uptake in older women but these are common barriers to behavioural change that affect most individuals.

This chapter has introduced MS and the concepts of neurorehabilitation and exercise. It has considered physiotherapy as a treatment modality and described some of the more commonly used techniques employed in neurological rehabilitation. The underlying theories of the study were outlined along with their application to exercise uptake. The next chapter concentrates on physiotherapy and exercise in relation to MS. It will review the available literature and present special considerations relating to MS and exercise.

Chapter Two

Physiotherapy and exercise in MS

2.1. Introduction

This chapter considers the role of physiotherapy and exercise in the management of MS. The relevant literature is included as are the special considerations pertinent to exercise engagement for those with MS.

2.2. Physiotherapy in MS

Physiotherapy has become a mainstay of MS management with the treatment of physical deficit and the re-acquisition of function to improve quality of life at its core (NICE 2003). Generally it aims to maintain or regain selective movement by ameliorating the effects of abnormal tone and contracture, improve co-ordination and balance and where applicable improve strength and endurance (Edwards et al 2004). As part of the multidisciplinary process it can be successfully implemented across the full spectrum of MS disability (Sutherland and Anderson 2001. Cochrane MS RCT Review, Reitberg et al 2004). Due to the range of physical deficits that present with MS, people also expect physiotherapists to explain symptoms and to assist with problem solving; in fact this has been recommended as a vital part of MS management (NICE 2003).

The physical aspect of the disease requires guided graded activity provision and physiotherapy typically uses a variety of starting positions to advance activity (MS Trust 2006). The selection of progressive starting positions allows for stretching of shortened muscle groups, activation of balance mechanisms and muscle activity with an eventual progression to optimal function. These starting positions mimic the normal postural attitudes adopted innumerable times during the day and usually adhere to the following format: Lying, Sitting and Standing (Gardiner 1985).

Activity performed in lying provides a fully supported starting position that will engender confidence and allow for complicated movements to be practiced as well as strengthening work using a resistance. Many diagonal and rotational patterns can be accomplished in lying that reinforce compromised movements. It is possible to

facilitate these patterns in preparation for use in a more functional position without undue stress to the CNS (Atkinson 1975).

Activity performed in sitting still provides a supportive base from which activity can proceed but it is more challenging to the CNS than lying. From sitting, re-acquisition of some useful postural control can begin with re-education of pelvic and trunk movements that form the basis for dynamic purposeful movement of the limbs (Atkinson 1975).

Activity performed in standing is the most challenging position for the CNS (Gardiner 1975). It is constantly required to make minute postural alterations to maintain the body in an upright position against the influence of gravity. It has to compensate for the effects of external forces, process sensory input and still initiate dynamic purposeful movements. Exercises in this position primarily concentrate on retraining balance and gait with the addition of functional activities.

The inclusion of rotational and diagonal patterns of movement is important in activity planning for those with MS. Without the ability to cross the mid-line most movements would be ineffectual. For example, in the act of lifting a cup to the mouth rotation is vital. From grip through elevation to the mouth without internal rotation and adduction to the mid-line the cup would finish at shoulder level, well away from the desired goal. Rarely is a purposeful movement completed without some degree of rotation, add/abduction and diagonal patterning (Carr and Shephard 1998). These patterns warrant special consideration in the physical regime of the MS person in conjunction with stretching and strengthening activities.

In an effort to minimise the affects of inactivity the individual may develop compensatory mechanisms (Davies 1990). In some cases these can be usefully incorporated into the person's future mobility patterns and this is a common phenomenon associated with MS. With this in mind the use of aids should always be considered where necessary.

It is agreed that exercise is used routinely as a physiotherapeutic intervention and that it is designed to impact on an individual's function, mobility and strength. In this

study the physiotherapy intervention was used to target the compromised activity of the CNS that had been affected by the disease processes common to MS. This application of the physiotherapeutic intervention is allied to a motor-relearning approach that involves directed re-training in areas of functional deficit. It relates to the specificity of motor learning that is based on the skill acquisition theory (Gentile 1987). As is demonstrated by the prescribed exercise regime, tasks are repeated in an effort to achieve mastery. This is most useful in re-education of gait patterns and has been shown to enable skill development and muscular control (Norris 2000).

As previously noted physiotherapy is not confined to exercise provision as far as MS management is concerned. It will also offer expertise in coping with the disease, assessment for equipment, usually in consultation with an occupational therapist and provide a link between the person and other relevant services (MS Trust). The physiotherapist will be able to assist with the presenting physical difficulties as well as the psychological impact these aspects of disease management produce. There is a necessity for self-management and ownership (Somerset et al 2003). The primary role of the therapist should be to support and enable the person.

There have been studies conducted into the effects of physiotherapy in the management of MS such as the works by Freeman et al (1997), Petajan et al (1996), White et al (2004) and Hale et al (2003) that are reviewed later in this chapter. Such studies have usually concentrated on the benefits accrued from an in-patient programme under the close supervision of the treating therapist. Sutherland and Andersen (2001) noted that there remains much scope for research into MS and exercise and that there was a paucity of literature available on exercise and health related quality of life for this condition. They also felt that there was a need for comparative studies with matched groups to evaluate exercise interventions. The review by Rietberg et al (Cochrane 2004) promoted the multiple benefits that can be accrued from physiotherapy including improved strength, aerobic capacity, and functional independence. To facilitate these gains the role of the therapist could be to, “.. assist the patient to accept, adjust to and compensate for limitations and disabilities in order to optimise levels of function for as long as possible” (Dal Bello- Haas 2002). Specialist physiotherapists are trained to provide a level of understanding and

expertise in the management of MS and ideally they work closely with other neurological specialists, voluntary agencies, local MS groups and treatment centers (MS Trust 2006). So it could be concluded that physiotherapeutic involvement must be holistic. The management of MS cannot solely be a series of therapies that the individual dips in and out of as their condition demands (Ashburn and DeSouza 1988). The therapist can assist the person to maximise their potential without compromising function through appropriate activity over an extended time span (Petajan and White 1999. Ashburn et al 1997. Freeman 2006). In the study by Solari et al (1999) the need for a cost effective physical intervention that could produce long-term functional and psychological gains was deemed desirable. They did not identify specifics in respect of the most cost effective method for providing therapy. They did note however that physical rehabilitation's positive effect on disability in both community or in/outpatient arenas should be sufficient to support continued provision of such services for people with MS.

2.3. Exercise in MS

The purpose of this section is to outline the role of exercise in the management of MS from a neurorehabilitation/physiotherapeutic standpoint.

Evidence to support the benefits of exercise to physical and psychological wellbeing in the general population is commonly available (Blair et al 1992. Collette et al 1994. Kell et al 2001). The use of exercise to assist those with a neurological disability is also well researched (Lord et al 1998. Freeman et al 1997). The White and Dressendorfer (2004) review of the MS exercise literature found that the majority of available studies advocated the use of exercise as a management strategy applied as part of a multidisciplinary approach to improve and maintain functional capacity. The Cochrane Review conducted by Reitberg et al (2004) concluded that although exercise was a necessary element of MS management, to date no definitive optimal treatment strategy had been discovered. The scoping activity conducted for the MS Society by Freeman (2006) highlighted the inherent difficulties in researching physiotherapy for MS and agreed that exercise provision and maintenance programmes were likely to “--- provide best pay-back for people with MS”. With this in mind, most clinicians would agree with Solari et al (1999) that “Physical

rehabilitation is generally accepted as useful for MS patients” and research into the effects of exercise for those with MS, although constantly accumulating requires further investigation.

Repetitious tasks have been acknowledged as the basis of the ability of the CNS to learn (Cifelli and Matthews 2002) and are routinely practised to re-educate movement pathways, increase strength and range of movement and facilitate a return to maximal function (Bobath 1990. Carr and Shepard 1998). Petajan et al (1996) have shown that aerobic exercise and strengthening programmes will improve aerobic capacity and other gains have been found in muscular force production, power, work and endurance as a result of targeted exercise interventions (Gehlsen et al 1984. Svensson et al 1994). It is also commonly accepted that effective therapy is usually delivered in a controlled rehabilitation environment with staff and equipment available to facilitate the recovery. Rehabilitation in the field of MS is acknowledged to be most successful when a multidisciplinary team, (MDT), is involved from an early stage (Clanet and Brasset 2000. Dixon and Caradoc 2005). However, the benefit of functional therapeutic activity being conducted in a more natural environment, namely the persons home, place of work or local fitness center is gaining credence (Stephenson and Wiles 2000. Cardini et al 2000).

To date the primary research focus on exercise and MS has concentrated on in/out-patient rehabilitation over a limited time span (Lord et al 1998. Svensson et al 1994). However, the work carried out by DeSouza and Worthington (1987) did focus on long-term activity programmes for people with MS and demonstrated that such interventions could minimise disability resulting from postural deformity and disuse atrophy. They also showed that it was possible to maximise function despite the deteriorating nature of the condition.

The adverse effects of diminished activity on people with MS have been ably demonstrated (De Haan et al 2000. Kent-Braun et al 1997). These effects include the atrophy of muscle fibres, increased fatigue and altered enzyme activity. At a cellular level these changes accumulate to reduce activity and functional problems are compounded by disability (Rudick et al 1992). As the damage to the CNS caused by demyelination is irreparable (Compston 1999) therapeutic methods are required to

maintain movement. Exercise has now been recognised as a safe viable therapy option to begin to address these problems (Sutherland et al 2001). It can be personalised, is non invasive, allows for empowerment and autonomy of application and most importantly it deals exclusively with symptoms and the management of complications produced by the disease process.

In conclusion it appears from the available evidence that there is much to gain from regular exercise participation although the optimum regime is as yet unclear. These benefits include improved strength, balance, co-ordination and postural control, reduced fatigue levels, improved cardiovascular responses and reductions in muscular deconditioning (Petajan and White 1999). The knock-on effects will include improved mobility, functional capacity and independence. All these gains will contribute to a better quality of life and the ability to participate in daily life. It is however the belief of Heesen et al (2006) that continued supervision is necessary to maximise these gains and avoid any detrimental effects from over exercising.

2.4. Research evidence for exercise as a management strategy in MS

This section will consider the available evidence supporting the provision of exercise for those with MS. Previous reviews most notably the Cochrane Review conducted by Reitberg et al (2004) and the White and Dressendorfer review (2004) have supported the benefits of exercise for those with MS. The Cochrane review concentrated on nine randomised controlled trials, (RCT's), these are included in this study's review later in this chapter. White and Dressendorfer reviewed the works concerning a multitude of physical consequences of MS and the impact of exercise interventions. The review “..emphasises the adjunctive therapeutic role of exercise in the co-ordinated treatment plan for persons with MS.”

As previously noted a review of the relevant literature showed a specific trend with the bulk of the work surrounding exercise in relation to MS being conducted in the controlled environments of the physiotherapy department or rehabilitation centers. The studies provided valuable insights into exercise and MS. However they had the benefit of being closely controlled and the results were in the main only pertinent to a limited time-scale and involved a limited number of test subjects (Mostert and

Kesselring 2002. Solari et al 1999. Freeman et al 1997. Lord et al 1998). Sutherland and Andersen (2001) also noted that most of the current exercise research did not include the more severely affected members of the MS community who were mobility aid dependent with higher levels of neurological disability.

The literature included here was researched using the electronic database Dialog Datastar. From this the relevant databases were accessed, ie MEDLINE, BMJ, PsycINFO, EMBASE and CINAHL. Key search words included, "Multiple Sclerosis", "Exercise", "Rehabilitation", "Physiotherapy", "Physical function", "Mobility", "Community" and "Leisure". Information was also sought from the Chartered Society of Physiotherapy data-bases, PEDro and REHABDATA, the MS Trust information line and hand searches conducted in the medical library at Lincoln County Hospital and the University of Nottingham medical library. All studies involving exercise and MS in the home, the rehabilitation arena or outpatient settings were included. This ensured that those using physiotherapy, aerobic exercise, aqua aerobic exercise, group sessions, resisted exercises, functional regimes and hydrotherapy would all be incorporated under the "exercise" umbrella. The search included all studies evaluating exercise extending over the preceding 30 years. It did not include those published in a language other than English. It also did not include physiologically based studies examining the effects of exercise on blood pressure, lung function, autonomic responses or cellular muscle responses to exercise. However it was acknowledged that these factors were integral to exercise uptake and where they formed part of a more generalised exercise study the information was included.

During literature appraisal the following points were considered. How many subjects were included, (n=--)? What was the treatment method chosen to elicit the effect? Additionally it was important to consider where the subjects were recruited from and whether they were randomly allocated, were the treatments and patient characteristics described, were the groups comparable at baseline and were the outcomes clinically significant (Crombie 1996).

2.4.1. MS exercise studies conducted in an in-patient environment

The available literature pertaining to in-patient exercise studies for those with MS will now be reviewed. A summary table is presented. The studies will be grouped and discussed according to their main research aims.

Table 2.1. Summary table of MS exercise studies conducted in an in-patient environment

Author/Year	Number/Control	Treatment/Control	Outcome.
Jones et al 1996	28/9	Physio and OT/No treatment	Improved function in ataxic people.
Greenspun et al 1987	28	Functional rehabilitation	Significant functional gains
Storr et al 2006	38/52	Physiotherapy/No treatment.	No positive gains shown in either group.
Kidd and Thompson 1997	44	Rehabilitation	Improved function maintained at home.
Romberg et al 2004	95	Circuit training and hydrotherapy.	Improved walking ability strength and aerobic capacity.
Mostert/Kesselring 2002	37/26	Rehab and static cycling/Rehab no cycling	Improved aerobic capacity fatigue and health perception.
Petajan et al 1996	54	Aerobic training	Significant gains in physical ability social functioning and mood.
Solari et al 1999	27/23	Physiotherapy/Home	Positive gains from in-patient regime poor in home regime.
Lui et al 2003	90	Goal orientated rehab. Retrospective	Evidence for treatment in moderate/severe disability group.
Fuller et al 1996	45	Physiotherapy	No carryover of benefit into the home.
Freeman et al 1999	50	Physiotherapy/rehab	Improvements maintained after discharged.
Freeman et al 1997	34/32	Rehab & physiotherapy/no treatment	Improvements in intervention group.
Bloom et al 2006	27	Goal identification	Mismatch of goals professional/client
Grasso et al 2006	230	Multidisciplinary rehabilitation with exercise	Mild/moderate MS improved more than severely affected.

2.4.1.1. In-patient studies considering the effects of exercise on physical function

Jones et al (1996) investigated the effectiveness of occupational therapy and physiotherapy for those with upper body ataxia. They included 28 people who

received in-patient occupational therapy and physiotherapy sessions lasting ½ hour over eight consecutive working days. The nine people in the control group received no intervention. It was the researchers' belief based on the study results that therapy improved function in ataxic patients where a spontaneous improvement would not have been expected. This is also a belief shared by this researcher who has often used exercise to influence ataxic movement patterns.

Greenspun et al (1987) also measured the changes in functional status of 28 people with MS in relation to comprehensive in-patient rehabilitation programmes. They found that the functional goals and the length of time needed to complete rehabilitation programmes varied considerably due to the unpredictability and range of clinical manifestations of the disease. They pointed out that this necessitated a tailoring of interventions to each individual and highlighted the inherent difficulty of setting time limits on the in-patient admission necessary to fulfil these requirements. Even so significant physical gains were noted but they concluded that additional research was needed to “..further clarify the rehabilitation response to MS.” Greenspun et al (1987). It would be reasonable to transfer this concept of a rehabilitation response into the home/community environment to investigate the potential gains that could accrue in that area.

Storr et al (2006) concentrated on functional aspects of disease limitation and included people with an Expanded Disability Status Scale, (EDSS), score of less than 9.0. indicating the entire spectrum of disability was included. They offered the intervention group (n=38), an in-patient admission to the local hospital for 35 days. The intervention involved multidisciplinary rehabilitation including 45 minutes of physiotherapy five times a week, three sessions of occupational therapy of 30 minutes duration, hydrotherapy and hippotherapy, (therapeutic riding), plus 30-60 minutes of self-directed gym work a day. The control group, (n=52), received no intervention. Assessments were carried out in the patients' homes. It was the researchers' conclusion that no positive gains in the chosen outcomes were demonstrated in the intervention group and so the intervention was deemed ineffectual. They felt that the recruitment rate was low and that they were lacking in adequate time to carry out the study.

The failure of Storr and colleagues to produce significant results could be due to a variety of failures with the control and implementation of the research process. Firstly there appeared to be no co-ordination of interventions rather a conglomeration of any intervention that had the potential to impact on function. They did not indicate whether there was any supervision in the self-directed gym sessions. If not the participants could have counteracted any benefits from the structured rehabilitation sessions through inappropriate activity. Their selection of outcome measures could also have masked any improvements that after such a focused rehabilitation effort should have been apparent. It was also unclear whether the groups were matched at base line for spread of disability level and exercise capability. There was also no mention of community follow-up that could have aided the maintenance of any physical gains by re-inforcing them in a more natural environment. The following studies by Kidd et al (1997) and Romberg et al (2004) despite initiating their programmes during an in-patient admission acknowledged the need for follow-up in the community and included it in their study procedures.

The study by Kidd et al (1997), questioned whether improvements made during an in-patient admission could be maintained post discharge. Handrails and ramps were fitted in the participants' homes where appropriate and community services introduced. They did not state whether active physiotherapy or occupational therapy treatments were initiated. The participants were reviewed three months post discharge. It was found that gains were maintained in 86% of the 44 people assessed. This concept of community support and follow-up is the mainstay of rehabilitation in the primary care setting and this study adds to the evidence confirming the value of such interventions.

Romberg et al (2004) investigated the effects of strength and aerobic training on a group of mild to moderately affected people with MS (n=95). There was no control group. The regime consisted of a three-week in-patient admission with a continuation of 23 weeks of home exercise. During the in-patient admission ten supervised strength training and aerobic sessions were carried out using modified circuit training and hydrotherapy. To continue the regime at home Theraband resistance exercises were taught. Aerobic exercise was continued using the hydrotherapy regime begun during the in-patient admission. There was an overall improvement in walking ability at

study conclusion and the belief that exercise was a safe treatment option for those with MS was upheld, as was the benefit of the home intervention. They also concluded that there was a direct relationship between exercise capacity and disease severity.

Mostert and Kesslering (2002) also included aerobic capacity as part of their investigation onto the effects of short-term exercise training along with fatigue, fitness and health perception (n=37). The study involved four weeks of in-patient rehabilitation for the intervention group that included the use of a static cycle. The control group continued with their usual rehabilitation regime with no cycling. The researchers found that there were improvements in aerobic capacity fatigue and health perception but that the results were not as conclusive as those supplied by the Petajan et al (1996) study. Mostert and Kesslering (2002) attributed this to the higher level of disability included and the shorter time scale of their study. It should also be noted that the results were confined to within group comparisons rather than between group and that this could be the reason for the less conclusive outcome compared to the Petajan et al work.

The Petajan et al study (1996) included 54 subjects who were randomly assigned to the exercise group or the non-exercise group. The exercise group underwent 15 weeks of aerobic training consisting of 3 x 40 minute sessions of arm and leg ergometry per week. It was the researchers' conclusion that significant gains in physical ability, social functioning and mood were accrued post treatment supporting the contention that exercise impacted positively on a variety of physical and psychological domains.

The oft-cited study by Solari et al (1999) was a two-center design (n=50) with hospital-based rehabilitation as the study intervention and a home regime acting as the control. The in-patient rehabilitation regime consisted of two daily exercise sessions lasting 45 minutes each. This group were also provided with an exercise regime for home once their study participation was completed. In contrast the home exercise control only received one day of instruction from the physiotherapist plus written instructions. It is clear that there was a lack of equity in contact between the groups and in the intensity of intervention. This would contribute to the overtly positive slant assigned to the in-patient results. However the researchers did remark on the

importance of investigating the efficacy and cost effectiveness of providing home programmes for people with MS.

The studies included in this section covered a variety of exercise interventions designed to impact on physical function. There were those who concentrated on a single intervention, (Petajan et al 1996. Mostert and Kesselring 2002) and others who embarked on multiple interventions, (Storr et al 2006. Romberg et al 2004). All reported measurable gains post exercise except the Storr et al study. There are several reasons for the negative outcomes reported by the Storr et al study and these have been mentioned previously. As for the other included works there could be questions raised as to the significance of the positive outcomes reported. Most of the studies were conducted over limited timescales and that could impact on the clinical significance of the results. For example, it is possible to demonstrate functional improvements after a short-term concentrated intervention such as those described by Jones et al (1996) and Mostert and Kesselring (2002) when these may be attributable to psychological factors, eg a Hawthorne type effect, or to temporary physical improvements that may plateau or even decline over time. Other limitations include lack of evidence of a carry-over effect, inequity in interventional contact between the groups of subjects and the diversity of different treatment techniques used that makes optimum interventions difficult to identify.

It is acknowledged that long-term exercise involvement is required to promote a prolonged positive exercise effect a fact that could be more pertinent to a changing condition such as MS. It is also known that benefits can be accrued through short bursts of activity and that these accumulate over time (Blair and Connolly 1996). Therefore it could be argued that short-term exercise interventions in MS do not offer a true evaluation of its potential benefits and time-scale may need to be a more prominent consideration for future studies.

2.4.1.2. In-patient exercise studies considering the effects of exercise on MS type

The study by Liu et al (2003) investigated the role of in-patient neurorehabilitation in relapsing/remitting MS (n=90). The admission involved a multidisciplinary, goal-

orientated programme. The study was a retrospective examination of assessment measures for the preceding nine years. They concluded that there was a place for this type of intervention especially in those with incomplete recovery from a relapse resulting in moderate to severe disability. This is a valuable study in that it offers retrospective evidence extending over several years showing the on-going benefit of a rehabilitation effect in a specific disease category.

Chronically affected MS patients were the focus of the Fuller et al (1996) study. The 45 people involved were assigned to either the group receiving “early” physiotherapy or that receiving a “late” intervention. The early group were admitted for a course of physiotherapy while the late group were used as a control and were offered an in-patient admission for treatment after the time scale of the study was completed. The assessment procedure was carried out in the patient’s home and it was concluded that there was no clear evidence to indicate improved mobility or mobility related activities of daily living in the home in the treatment group compared to the control group. This would indicate that there was little or no carryover of the benefits of the in-patient admission although the participants did mention a decrease in mobility related distress. This failure to demonstrate a continued benefit could be attributed to the lack of a concerted community follow-up programme.

The principles of the carry-over effect of an in-patient rehabilitation intervention to the community were considered by Freeman et al (1999). They followed up 50 people who they defined as having progressive MS for 12 months after discharge. In contrast to the Fuller et al (1996) study Freeman et al found that improvements were maintained for six months but that benefits did decline with time. They proposed an improvement in continuity of care between acute and primary care settings to maintain in-patient gains. This notion is supported by Stevenson and Thompson (1998, who advocated the involvement of a multidisciplinary team as the basis for both inpatient and community rehabilitation strategies for those with MS.

An earlier study by Freeman et al (1997) investigated the impact of in-patient rehabilitation again on those with progressive MS. It was their belief that there was little in the way of supporting evidence for the procedure. They included 66 people in this study, 34, who underwent a rehabilitation regime following a holistic pathway

and 32 controls. The rehabilitation regime included two 45-minute sessions of physiotherapy daily. Improvements were observed in 53% of the treatment group with only 23% of the control making positive gains. Freeman et al (1997) did note the importance of monitoring improvements in the long term and once again the need for community follow-up was mentioned.

This sub-section included studies investigating the effects of exercise on MS type. There were different approaches applied that were designed to impact on differing disease stages and levels of disability with the main finding being the lack of any long-term carry-over effect after an in-patient admission. Once again it is possible that the diversity of approaches with the accompanying lack of follow-up interventions impacted on the results and could have lessened their overall significance. It is also possible that in-patient interventions do not translate well into the home environment and as such any benefits that present remain within the “treatment environment”. Many people find it difficult to relate exercise carried out in a clinical setting to their every day lives. This may account for the lack of carry-over that has been reported.

2.4.1.3. Other exercise related in-patient studies

One other aspect of inpatient rehabilitation concerns the identification of goals pertinent to the inpatient admission. Bloom et al (2006) attempted to determine the rehabilitation expectation of MS patients (n=27) and treating professionals and found that there was often a mismatch of expectations regarding best outcome between the two groups. Successful rehabilitative outcomes depended on a co-ordination of effort towards a common goal and they found that the expectations of the patients were often higher than those of the professionals.

The work by Grasso et al (2005) presented an evaluation on effectiveness and prognostic factors relating to an in-patient rehabilitation admission. They analysed 230 consecutive inpatients participating in individualised goal orientated rehabilitation programmes. Included in this were twice-daily exercise sessions lasting 45 minutes each. This was conducted over six days for ten weeks. The results were encouraging with the mild to moderate MS classification demonstrating improvement on ADL assessments and mobility. The outcomes were not so positive for the severely

affected group a result the researchers felt was due to lack of compensatory ability within the CNS. They also felt that cognitive deficits could have contributed to the poorer results in this group. This study illustrates the need to differentiate between disease type and the effects of disability and shows that exercise interventions can be effective if applied judiciously. It also highlights the difficulties that present when trying to apply similar regimes across differently disabled groups.

Although not an exercise study as such the paper by Ashburn and DeSouza (1988) highlighted the importance of follow-up and maintenance in their work on the provision of physiotherapy for those with MS, a viewpoint shared by Schapiro et al (1988). Ashburn and DeSouza (1988) identified the importance of an extended time scale for involvement as a major contributory factor to the successful management of MS that should project beyond the in-patient interventions. They noted that, “Short-term rehabilitation programmes are inadequate in the care of these patients and frequently lead to an ad hoc supportive process instead of a determined plan to maintain or improve the individuals’ function. Because of the unpredictable pattern of the disease physiotherapeutic treatment is frequently only instigated when disabilities have become well established...” (Ashburn and DeSouza 1988).

In summary many of these studies produced measurable physical improvements as a direct result of their in-patient rehabilitative strategies as well as impacting positively on symptom presentation. They concentrated in the main on the less disabled individuals but the study by Lui et al (2003) did highlight the necessity of including severely affected individuals in the rehabilitative effort as benefit could also be demonstrated with this group. The Grasso et al study (2005) embraced all disability levels but they indicated that the results were less encouraging for the more severely affected subjects. This may indicate that the interventions offered were not individualised enough being unable to accommodate the deficiencies of the severely disabled. This raises the notion of a “one size fits all” approach to rehabilitation. There were also issues regarding the generally small numbers recruited to the studies, time-scale of the interventions, translation of positive exercise effects into the home and diversity of treatments that do not allow for a “gold standard” intervention to emerge. The range of outcome measures used also could introduce an element of confusion when assessing the effects accrued by the various interventions. With a

long-term condition such as MS continued interventions are a vital element of a successful care strategy and this seems to have been overlooked for the most part. Interestingly some authors do mention the lack of community follow-up and acknowledge its importance. This aspect of care could perhaps be supplied by using local therapeutic input (Stevenson and Thompson 1998. Romberg et al 2004. Freeman et al 1997. Solari et al 1999).

2.4.2. MS exercise studies conducted in an outpatient environment

The following section considers the available literature concerning outpatient exercise studies for MS. A summary table is presented. The studies will be grouped and discussed according to their research aims.

Table 2.2. Summary table of MS exercise studies conducted in an outpatient environment

Author/Year	Number/Control	Treatment/Control	Outcome
Smith et al 2006	34	Exercise	Exercise benefits outweigh temporary sensory changes
Di Fabio et al 1998	20/26	Physiotherapy Occupational therapy/no treatment.	Benefit shown of long-term treatment
O'Connell et al 2003	11	Circuit style supervised exercise plus weekly individual exercise	Significant improvement in heart rate, fitness and QoL.
Petajan and White 1999	Review	The value of exercise in MS	Improved well being strength and fatigue.
Kent-Braun 1997	9/8 (healthy controls)	Exercise for both groups	Reduces the effects of muscular deconditioning.
Surakka et al 2004	47/48	Resistance exercise and aerobic training/normal routine.	Women improved more than men.
Rasova et al 2006	112 in four groups	Neurophysio/Aerobic exercise/Neurophysio and aerobic exercise/no change in routine	Gains in impairment and aerobic capacity. Fatigue lessened. No change in non treatment group
Oken et al 2004	25/25/25	Yoga/physio/nothing	Improved fatigue levels no change in cognitive abilities.
Patti et al 2003	58/53	Intensive rehab/Home programme	Intensive group improved more significantly than home group. Inequity of contact and input.
Freeman and Allison 2004	10	Group exercise	Improvements in balance fatigue mobility

Dodd et al 2006	9	Progressive resisted exercise	Gains in strength safe method of exercise delivery
Carter and White 2003	11	Aerobic, strengthening and flexibility exercise	Significant effects on strength in some muscle groups and in fitness.
White et al 2004	8	Resistance training	Well tolerated method of increasing strength
Taylor et al 2006	9	Resistance training	Positive gains made
Armutlu et al 2001	13/13	Physiotherapy and pressure splinting/physiotherapy No splinting	Physiotherapy beneficial. Splinting made no significant difference
Lord et al 1998	10/10	Facilitation/ functional exercise.	Improvements in both groups with no significant differences.
Rodgers et al 1999	18	Aerobic training for gait using static cycle.	No improvements in gait made.
Smedal et al 2006	2	Bobath	Improved quality of gait
Kilef and Ashburn 2005	6	Aerobic training on static cycle.	Improvements in mobility and disability levels.
Sutherland et al 2001	11/11	Water aerobics/no special activity	Improved HRQOL and well being
Kirsch and Myslinski 1999	2	Individualise aerobic fitness regime	Significant functional and conditioning improvement
Svensson et al 1994	5	Low load exercise training	Strength and endurance improved in 3 of 5.
Gehlsen et al 1984	10	Hydrotherapy	Significant strength improvements decreased fatigue levels.
Petajan et al 1996	54	Aerobic training	Improved O2 capacity
Ponichtera-Mulcare et al 1997	19/3	Aerobic training/non exercising controls	Improved power output.
DeBolt et al 2004	19/17	Resistance exercise clinical setting and home/current level of activity.	Significant strength improvements.
Hale et al 2003	4	Strength exercises aerobic fitness balance in clinical setting and home.	Improvements in all assessed areas.
Wiles et al 2001	39	Physiotherapy clinical setting, home, no treatment	Little difference between clinical/home settings. Home more expensive.
Ennis et al 2006	32/30	Health promotion/No intervention	Significant gains
Tantucci et al 1996	10/10	Lung function, respiratory muscle strength and cardiorespiratory response	Exertional capacity limited due to poor training effect. Tacchypnea at rest surprising
Jones et al 1999.	17	Resist leg ex /mobility exercise/no exercise	No differences found on variables assessed.

2.4.2.1. Outpatient studies considering the effects of exercise on MS symptoms

There is evidence to confirm the provision of exercise as a positive outpatient rehabilitative strategy. Studies have covered the multifaceted nature of the disease with the study by Smith et al (2006) concentrating on symptom change as a result of a single exercise session. They included 34 people in the trial with exercise being prescribed by a physiotherapist. The outcome showed that although sensory symptoms increased temporarily other symptoms such as fatigue and physical function were unaffected. This result supports the notion that although temporary symptom change may occur during or after an exercise session, the benefits accrued through exercise participation usually override this. Unfortunately this study does not offer any insight into the possible effects of long-term symptom changes that occasionally present with extended periods of exercise.

Di Fabio and colleagues (1998) also considered outpatient rehabilitation in respect of symptom frequency, fatigue and functional status in people with MS. Of the 46 patients who took part, 20 received no treatment and 26 were placed in the intervention group. The intervention consisted of five hours of rehabilitation one day per week for one year involving both physiotherapy and occupational therapy. Their conclusions were encouraging and supported the long-term benefits of extended rehabilitative involvement in MS as described by Ashburn et al (1997), Ashburn and DeSouza (1988) and Bates and Thompson (1995). The Di Fabio et al study was a valuable addition to the knowledge base on long-term exercise involvement as it allowed for behavioural changes to develop and provided a continued assessment of the effects the intervention had on the participants. Its generalisability may be questioned due to the limited number of included subjects, (treatment n=26, control n=20).

The study conducted by O'Connell et al (2003) examined the impact of supervised aerobic training on those with mild disability as a result of relapsing/remitting MS. The study aimed to demonstrate the effects of aerobic training on heart rate, fitness levels and walking cadence. There were 11 participants who were randomly assigned to the exercise or non-exercise arm of the study. The study extended over three

months. At study conclusion it was discovered that significant gains were made in fitness and QoL by the exercise group with no differences being shown on the Multiple Sclerosis Impact Scale, (MSIS), or in gait speed. However due to the limited number of participants it is possible that although this was a well-conducted randomised control trial the results may not be considered generalisable. It was also unclear whether the subjects were matched for disability levels or previous exercise experience.

The work on exercise recommendation for those with MS by Petajan and White (1999) has provided a basis for some of the opinion on exercise and MS. They contended that exercise improved wellbeing and strength plus a reduction in fatigue levels. However this must be within the restrictions of the disease process and the limited ability of the person.

In respect of physical limitations, the Kent-Braun et al (1997) study examined the physiological restrictions of muscle function that commonly presents in MS. They found that the composition and activation of skeletal muscle fibers was detrimentally altered as a result of MS. They suggested that this provided a basis for using exercise as a method of reversing some of the functional deficit experienced by many with MS.

The effects of aerobic and strength activities on motor fatigue in MS was the focus of the Surakka et al study (2004). The participants attended for a three week supervised exercise regime that was followed by 23 weeks of home exercise. The study involved 47 people in the intervention group with 48 in the control group. The control group were required to continue with their normal routines throughout the study. The intervention groups had five supervised resistance exercise sessions and five aerobic sessions with hydrotherapy providing the aerobic element and circuit training the strengthening part. The home regime was devised and instructed by a physiotherapist during the outpatient course. Theraband was used to provide the resistance to the required exercises. It was discovered that the women in the study demonstrated a decrease in motor fatigue after the study but that the men did not. The researchers found that the chosen regime was more suited to the women than the men and that there could have been a physiological female gender advantage.

The results of the Surakka et al (2004) study could be due to differences in exercise expectation. It was possible that the exercise expectations of the men differed to that of the women and the regimes did not offer either the exercise effort or the exercise outcomes that the men anticipated. This is an important aspect of behavioural belief that must be addressed to successfully apply exercise to the neurologically impaired and illustrates its relevance to this study and to exercise prescription in general.

A comparative study was carried out by Rasova et al (2006) that considered a variety of clinical parameters. The study involved 112 MS patients who were divided into four groups. The first group underwent a neurophysiotherapy regime. The second engaged in aerobic training. The third completed a combination of the two and the fourth did not change their exercise habits. At study completion those involved in the treatment regimes showed better outcomes in the assessed areas than those who did not participate. It was found that the neurophysiotherapy group fared better on the impairment measures while those in the aerobic group demonstrated better gains in aerobic capacity. All treatment groups improved in fatigue levels.

Once again as with previous works, (Storr et al 2006. Hale et al 2003) the Rasova et al study considered multiple interventions that did not allow for an optimum exercise intervention to emerge. As it is known that exercise and rehabilitation efforts positively impact on MS the results of this study re-enforced the functional benefits gained by using rehabilitative strategies that have been shown in other works.

Exercise and yoga were compared by Oken and colleagues (2004). They considered these interventions as methods of influencing cognitive function, fatigue, mood and quality of life. The study was conducted over a six-month period involving three groups: one yoga (n= 25), one physiotherapy, (n= 25), and one control, (n=25) . The interventions involved class attendances and home practice. They concluded that there were no significant differences between the mood levels of the two intervention groups when compared to the control group who received no intervention but that fatigue had been positively affected in the intervention groups. The lack of improvement in mood could have been due to the time-scale of the study and the group allocation. For example, it could be argued that to truly influence mood, interventions must be both relevant to the participant and extensively practiced. If a

predominantly male cohort was assigned to the yoga group they could possibly have been less receptive to the techniques and as a consequence the possible benefits. This factor could support the notion of appropriateness when assigning exercise strategies as therapeutic interventions as noted by Weinberg and Gould (2007). However as this is the only study considering the impact of Yoga on MS symptoms and as Yoga is the exercise of choice for many people with MS (MS Trust 2005) it is an important work.

The effects of a short outpatient treatment programme on disability levels were the focus of the Patti et al (2003) study. They showed that disability rating scores for the intervention group, (n= 58), did improve after a consecutive six-week intensive rehabilitation programme involving therapy over six days a week. The control group, (n=53), received a home exercise regime but lacked the intense input and support of the intervention group demonstrating a disparity in contact that could negate the value of the results.

Group exercise classes are a popular way of engaging a number of people in exercise. Freeman and Allison (2004) considered this approach in their pilot study. The study was a pre-test/post-test design comprising ten people with MS. They found that group exercises demonstrated measurable improvements in mobility, balance and the physical dimensions of fatigue and wellbeing. Group exercise can be popular with participants as it serves both a psychological function as well as a physical one. However difficulties can present with venues, travelling and attendance that will impact on the eventual exercise effect and it is unclear whether these issues were addressed in this study.

The studies included in this sub-section concentrated on exercise effects on MS symptoms. Once again multiple interventions were tested against different MS problems using a variety of outcome measures accruing disparate results. The most significant of these could be those supplied by the Di Fabio et al (1998) study that conducted the intervention over one year. Unfortunately there were a limited number of subjects included in the study (n=20/26) and that may introduce a type 2 error into the outcome. The Surakka et al (2004) work also offered insights into the benefits of home regimes and by extending over six months it allowed for exercise effects to accumulate. One interesting aspect of the studies considered so far is the limited

number of participants recruited. This could raise the question of an inherent resistance to exercise that not only presents in the general population but that appears to be a feature of those with MS. This reluctance to exercise could suggest the existence of future research avenues requiring consideration to better understand the possible “non-exercise” culture of those with MS.

2.4.2.2. Outpatient studies considering the effects of exercise on strength

Studies concentrating on specific aspects of deficit are available. Dodd et al (2006) investigated the benefit of a gymnasium based progressive resistance exercise regime for those with MS. Nine people were included in the study. They used theraband to provide the resistance and found that this method of progressive strengthening was a safe and feasible option as an exercise intervention. Theraband was also used in this study to provide the strength element to the home physiotherapy regime.

Improvements in strength, aerobic capacity and flexibility were the area assessed by the Carter and White (2003) study. Exercise consisted of twice-weekly training in these areas over a 12-week period and was conducted in an outpatient setting with 11 participants who were randomly assigned to either the exercise or non-exercise group. It was concluded that strength training had significantly improved the hip and knee flexors but the results were less conclusive for other muscle groups. They also reported improvements in Physiological Cost Index, (PCI), (a measure of effort required to perform an activity), in the exercise group. These results are in concert with other works advocating the benefits of targeted strength training for MS but once again the limited sample size may raise queries as to their generalisability.

Strength and functional capacity was the focus of the White et al (2004) study. Eight people with MS were recruited. All had been engaged in light physical activity before the study began. The participants engaged in eight weeks of twice-weekly lower limb resistance training with 48-hour rest periods between sessions. The group showed improvements in knee extension and plantarflexion with reductions in fatigue levels and self reported disability. The researchers felt that under correct supervision resistance training was well tolerated as a method of increasing strength and reducing the effects of fatigue and disability.

Taylor et al (2006) also considered resistance exercise for those with MS. Nine people were eventually included in the study. They participated in a four-week familiarisation period followed by ten weeks of progressive resistance exercise. Resistance was applied using the weight machines in the gym. They worked the upper and lower body muscle groups. The weight was increased to the next level when the participants were able to complete two sets of 12 repetitions safely and competently. Significant improvements were shown in upper limb strength and lower limb endurance plus an increase in walking speed. It was concluded that this type of exercise could be a useful adjunct to exercise involvement for those with MS and as it has been used successfully in able-bodied regimes for years there is no reason to suppose it would not suit those with MS providing CNS deficiencies were accommodated.

Loss of strength is a major concern for many people with MS. The studies in this subsection provided evidence to show how this distressing deficit can be successfully addressed. The limited numbers included in the studies, (n=9, n=11, n=8, n=9) could call in to question the generalisability of the outcomes. However they were all conducted in well-controlled environments with one of them (Dodd et al 2006) including a home element to the regime. These results although involving small numbers do support the use of strength training for MS.

2.4.2.3. Outpatient studies considering the effects of exercise on balance and gait

Gait problems regularly present in MS and can be as a result of several factors ranging from fatigue, poor balance, decreased strength or in-coordination of movement patterns generally associated with ataxia. The problem of gait affectation and ataxia was considered by Armutlu and associates (2001). They investigated the efficacy of physiotherapy combined with the use of Johnstone pressure splints (Johnstone 1989) on those with ataxic presentations. Two groups of 13 patients were recruited. The control group received physiotherapy while the intervention group received physiotherapy as well as the splinting regime. The study produced evidence supporting the benefit of physiotherapy in ataxia management but the addition of the splints did not impact significantly on the intervention groups' results.

In the pilot study by Lord et al (1998) two physiotherapeutic approaches to improve gait were compared. Ten subjects were assigned to each treatment group. Group one underwent a facilitation regime involving postural control, recruitment of motor activity and segmental alignment. Group two carried out a programme of functional exercises compiled by the physiotherapist based on the components of walking and functional mobility. The regimes were conducted in a rehabilitation center. At study conclusion it was discovered that both groups improved in the target areas of impairment and disability with no significant differences observed between the two interventions. This may indicate that targeting specific movement deficits with corrective strategies could produce more favourable outcomes than explicit treatment techniques.

Rodgers et al (1999) also considered the problems associated with gait and used an aerobic training regime as their intervention. They used static cycling to improve aerobic capacity three times a week for 30 minutes per session. The programme lasted for 24 weeks. It was their view based on the results obtained, that no improvements in gait were evident. Once again this may be attributable to the lack of any targeted gait retraining a fact acknowledged by the researchers.

Finally the small study by Smedal et al (2006) applied the Bobath method of rehabilitation to two people with gait problems. The treatment involved facilitation of postural activity and selective motor control and was administered by two international Bobath instructors. Both patients demonstrated improved quality of gait post intervention. The study was well controlled and demonstrated the implementation of an established physiotherapeutic technique on MS subjects that impacted on both activity and impairment. This would be expected after such an intensive rehabilitative effort but the results are not generalisable to an MS population at large for the following reasons: 1 such intensive rehabilitative strategies are rarely achieved within the current climate of staff shortages and resource limitations, 2 two subjects does not allow for an assumption applicable to an MS population to be made.

The treatment of gait problems in MS appears to be problematic judging by the diversity of techniques considered and the variety of results offered by the studies

included here. It would seem that addressing the gait pattern with repetitive rehabilitation could improve deficits, (Lord et al 1998), whereas just concentrating on strength without such a rehabilitative focus is less effective (Rodgers et al 1999). However the evidence to support a definitive treatment strategy that could influence a generalised gait re-education programme has not been shown.

2.4.2.4. Outpatient studies considering the effects of exercise on aerobic capacity and endurance

Aerobic training was the focus of the work by Kileff and Ashburn (2005). Their study included a group of six individuals with moderate disability. There was no control group. The exercise regime involved 30 minutes of static cycling twice a week for twelve weeks. This was carried out to the patients' maximum exertional level. It was the researchers' belief that disability and mobility improved with this aerobic training strategy as defined by the outcome measures.

Aerobic capacity in relation to health related quality of life was considered by Sutherland et al (2001). The study included 11 test subjects and 11 controls with the intervention involving aqua aerobics three times a week for 10 weeks. The groups were matched for demographic variables. It was shown that HRQOL and well being improved in the test group with associated improvements in social and sexual functioning and less pain and fatigue.

A small study of two people with MS was conducted by Kirsch and Myslinski (1999) to determine the effects of a three-month aerobic fitness regime carried out in a health care environment. The results confirmed the benefits to physical function and muscular conditioning in line with the findings of other researchers.

Often individuals report a lack of muscle power associated with a decrease in physical endurance. Svensson et al (1994) conducted a small study with five participants to determine if endurance could be positively affected with the introduction of graduated training. This was a well-controlled study conducted in the clinical setting using advanced isokinetic measuring instruments. The training involved low-load exercise with rest periods to avoid muscular exhaustion. The small number of subjects makes

generalisability difficult but the researchers did report improved well-being, strength and endurance in three out of the five participants.

Strength and endurance in the upper and lower limbs in those with MS were examined by Gehlsen et al (1984) using a hydrotherapy exercise programme. They recruited ten people to a ten-week hydrotherapy programme and found significant changes in strength and reductions in fatigue levels between pre-test post-test scores at study conclusion.

The benefits of improving aerobic capacity are acknowledged. The study by Petajan et al (1996) demonstrated a 22% increase in maximal O₂ consumption with accompanying improvements in maximal power output after 15 weeks of aerobic training. This finding coincides with the work by Ponichtera-Mulcare and colleagues, (1997) who found similar improvements after a six-month training regime using a static cycle.

From the results of the preceding studies it would appear that aerobic capacity has the potential to impact on a variety of problems such as QoL, strength, fatigue levels, disability and mobility. The reader could be forgiven for concluding therefore that this was the most important consideration when prescribing exercise strategies for those with MS. The results of these studies could be unreliable as the limited number of subjects does preclude generalisability and introduces the possibility of a type 2 error occurring. Other studies have also demonstrated comparable positive effects on the areas mentioned here using different exercise approaches. This makes the recommendation of a specific regime that represents best practice for exercise in MS almost impossible. However these works have shown that aerobic training does have the potential to impact on many areas of disability (Sutherland et al 2001. Gehlsen et al 1984. Kileff and Ashburn 2005) and perhaps it should be afforded greater consideration when exercise regimes are being designed.

2.4.2.5. Outpatient exercise studies considering the effects of exercise in the home

Some studies have investigated elements of home exercise provision rather than using them as a control. DeBolt and McCubbin (2004) began their regime in a controlled

clinical environment and progressed to the home to discover the effects of resistance exercises on balance power and mobility. Their study extended for eight weeks with subjects randomly assigned into an exercise, (n= 19), and a non exercise, (n= 17), group. No between group effects were reported. The study demonstrated significant strength improvements in the target region of the lower limb concluding that the home-based section was well tolerated as a practical means of improving strength over a limited time scale.

As with the DeBolt and McCubbin (2004) study, Hale et al (2003) also included a home exercise element in their work. The regime extended over eight weeks with four subjects. The first four weeks were conducted in a clinical setting under physiotherapeutic supervision. This consisted of strength exercises, static cycling for aerobic fitness and balance exercises performed three times a week. The same regime was continued at home for the following four weeks. It was the researchers' conclusion that the regime was not only beneficial but was deemed to be enjoyable by the participants and a viable option for use in the home. There were measurable improvements in the outcome measures used supporting the subjective viewpoints offered.

Improving mobility is important to professionals and patients alike and Wiles et al (2001) investigated the differences between outpatient treatment and treatment at home in those with chronic MS. The treatment followed a three-part format involving eight weeks of physiotherapy as an outpatient, eight weeks of physiotherapy at home and eight weeks of no treatment. The stages were separated by eight-week intervals. They found little difference between the interventions but felt the home physiotherapy was more expensive due to staff travelling time.

The three preceding works are important as they included a home exercise phase within the regime and have shown that home interventions can for suitable participants produce comparable outcomes to those carried out in a clinical outpatient environment. They all reported improvements in mobility and function and DeBolt and McCubbin (2004) highlighted the importance of the home sessions. These results provide evidence to show that home regimes can produce functional gains and that a move away from the acute rehabilitative sector can work.

This next report is not an exercise study as such rather it concentrated on health promoting behaviours and education of which exercise was a part and was conducted by Ennis and colleagues (2003). The study was carried out on an outpatient basis and involved eight weekly sessions lasting three hours in a group format. Information pertinent to the various aspects of MS management was issued and included advice on exercise, fatigue management, stress management and responsible health practices. It was noted at study conclusion that health behaviours in the subjects addressed had improved and that the effects lasted for at least three months.

The study by Tantucci et al (1996) used exercise to evaluate cardio-respiratory competence in an MS sample, (n=10 subjects, 10 controls). They found that after a course in graded incremental exercise there were no additional metabolic costs to the subjects that impacted on spasticity or ataxic symptoms. They also found that the exertional capacity of the group was limited probably due to a poor training effect.

Finally, there was the study by Jones et al (1999). They conducted the exercise interventions entirely in the home. This study consisted of 17 subjects who were randomly assigned to one of three study strategies: 1 mobility exercises, 2 strength training using weighted leg exercise and 3, no intervention. The study extended over an eight- week period. It was the researchers' opinion at study conclusion that there were no appreciable differences between the groups when timed walk, muscle strength or transfer ability was re-assessed. However they did find that the strength group improved more significantly than the others when assessed on timed transfers. This may indicate that the postural and muscular demands necessary to perform these two assessed activities were different and that the outcome measures did not capture the nuances between the two different physical demands. There would be less in the way of postural control or balance appreciation needed to transfer safely from chair to chair when compared to the demands of walking. It could be argued therefore that these two outcomes were not comparable when considering exercise training and this may have impacted on the results.

To recap, the available literature focused on in/outpatient interventions conducted in controlled clinical environments mostly over short time scales with limited subjects in

many cases. As most of the studies were not declared to be pilots (where the investigative methods are being tested to determine their suitability and reliability), the issue of “effect size” could present (Crombie 1996). This would have a bearing on the significance of the results and contributes to the problem of generalisability. An important contribution of research is its relevance to others working in comparable fields. Small sample sizes can be subject to positive interventional effects that are not clinically significant yet still display characteristics that lead one to conclude that the result is highly relevant (Hicks 1999). One other consideration was the comparability of the study groups at baseline. If they differed significantly the outcomes could indicate false positives that mislead both the researchers and the readers. In some of the studies this issue was not mentioned and therefore the reader is unsure if it had been considered.

Overall there was strong support for physiotherapy as a treatment medium for those with MS with the best outcomes being assigned to the mild/moderate disease categories (Romberg et al 2004. O’Connell et al 2003). This could raise questions as to the logistics of providing such interventions to the more severely affected as well as the possibility of a bias in favour of the less affected disability levels that could conceivably offer the best results (Kesselring 2004). There may also be a genuine opinion within the research community that to expend scarce resources on the severely disabled group would in the long run produce little benefit. However the positive gains that may accrue for the severely disabled can only be assigned value by those it affects, by including the severely disabled in this exercise study it was hoped to show that they have as much to gain as those in the less affected disability groups.

From the review conducted for this study it was clear that the evidence existed to promote exercise for MS and that it was a safe and beneficial intervention. Exercise positively impacted on many aspects of disease management and has been advocated by the NICE guidelines (2003) as a desirable treatment option for MS. Yet community services were generally sporadic where they existed, mostly inadequate to the demands of the target population and their benefits have to date been inadequately researched despite that fact that many studies acknowledged the need for community follow-up. However the diversity of exercise approaches and outcome measures considered, the limited number of subjects included and the general lack of

community interventions available demonstrates the difficulties that present when investigating exercise provisions for MS and the uncertainty that surrounds best practice and optimum interventions for this most challenging condition (Freeman and Thompson 2000).

2.4.3. Evidence to support self-selected activities for MS

The benefits of exercise to the general population are well documented (Kell et al 2001) and are readily applicable to those with most physical deficits. There is a concern however when applying so called “normal” exercise regimes to those with a compromised CNS. Self-selected regimes will not be disease specific nor account for levels of disability. The exercise environment may not accommodate mobility deficits and there may be a lack of knowledgeable staff and advice for those with MS (Becker and Stuifbergen 2004). Self-directed programmes may also provide too much activity or too little. Gains can be made physically and psychologically however if these regimes are entered in to with caution (Stuifbergen 1997).

There are many difficulties inherent with the pursuit of leisure activities involving exercise and the survey by Hakim et al (2000) indicated that disability levels and cognitive impairments were significant predictors of withdrawal from such acts. Accompanying this was a predilection to increased stress among carers at this added responsibility.

The amount of physical activity that is required to produce measurable changes in exercise capacity in MS was considered by Romberg et al (2004). The activities undertaken were walking, including Nordic walking that involved walking with specially designed poles, aerobic endurance exercise, strength training and outdoor activities. Their main finding was that disability and exercise capacity were interrelated and that exercise prescription appropriate to healthy individuals was not appropriate for those with MS. This is in contradiction to the assumptions of Rosenthal and Scheinberg (1990) who proposed that generalised exercise regimes were applicable to the mildly disabled MS person. The Romberg et al (2004) study did offer information that predicted exercise capacity in relation to the person's pre-

exercise EDSS score and they felt that this score should be used to determine change and gauge a person's exercise capability when engaging in endurance work.

Self-selected exercise does have an important role to play in MS management yet problems such as the onset of fatigue muscle weakness and sometimes a temporary loss of function can result with over exertion and the introduction of additional exercise demands (Smith et al 2006). These aspects will require careful consideration (Freal et al 1984. Romberg et al 2004). Petajan and White (1997) advocated the use of physical activity for pleasure as well as a therapeutic medium but acknowledged that the need for more research into this area was required to provide definitive evidence for its application to MS in general.

2.4.4. Community studies in MS

Studies have been mentioned in Chapter 1 regarding home treatments for stroke rehabilitation and Parkinson's disease and there have been references to home regimes as part of other research studies for MS. However, other than these cursory inclusions exclusively community-based studies concentrating on MS are rare. This is despite the fact that exercise can produce beneficial effects when incorporated into the home life of someone with MS (Hale et al 2003).

The Jones et al (1999) work discussed earlier in this chapter was exclusively community based and has shown the benefit of interventions carried out in the home albeit over the short-term. However by considering outcome measures that appeared to respond differently to the interventions applied, the results may not provide evidence to support one regime over the other. In other words those in the strength group improved their time needed to transfer from chair to chair while those in the mobility group did not. The reason for this has been posited earlier but it would seem that the act of transferring would be more strength dependant than mobility dependant thus one must consider whether this was a fair comparison of ability as affected by the different interventions.

The two-center approach used by DeBolt and McCubbin (2004) has also been discussed previously and interestingly they did note that a longer time scale of three to

six months would have allowed for the development of functional gains that could then have been transferred to activities of daily living. Significantly they noted that “An important application of the study may be the application of the home-based exercise programme”, plus the inclusion of anecdotal evidence to support the intervention. The inclusion of the journal in this study was aimed at addressing this area.

2.5. Considerations for exercise participation in MS

This section outlines the elements that influence the ability of people with MS to exercise.

Individuals with MS have a relatively normal life expectancy (Broman et al 1981. Sadovnic et al 1992) therefore their physical abilities need to be maintained for many years. Exercise will require adaptation to accommodate changes in ability associated with disease progression. As a result of diminishing function exercise may have been avoided in the belief that this would hasten deterioration and the onset of fatigue (Sutherland and Andersen 2001) or worse, speed the physical decline.

Research has shown that those with MS also traditionally avoid recreational activities (Hakim et al 2000. Ng and Kent-Braun 1997. Stuifbergen 1997). The possibility of muscle fatigue and over-heating of the nervous/muscular system is a serious deterrent to activity participation (Kersten and McLellan 1996). Yet sedentary life styles will induce far more damaging long-term health problems. This includes the risk of encouraging muscle weakness, loss of joint range, poor co-ordination, functional deficits and osteoporosis (Pate et al 1995).

However before physical activity can commence certain elements must exist. These elements include time, energy, a conducive exercise environment, physical capabilities, knowledge, motivation to participate and the intention and the decision to exercise (Ulbrech 1999). The performance of exercise is a complex procedure and although the research has shown that exercise is beneficial to those with MS (Di Fabio et al 1998. Pontichtera-Mulcare 1992) undertaking a regular programme may be a daunting prospect.

2.5.1. Physical factors that effect exercise uptake in MS

This section considers the physical issues specific to MS that can interfere with exercise participation.

As the nature of the condition is generally one of deterioration over time (Lassman 1999) it is important that regular monitoring is available to prevent the performance of unsuitable exercises when the condition changes. The interference of life events in a person's routine could interrupt their activity participation. The advent of a relapse is not the only situation that could arise. It is also well known that MS responds adversely to alterations in temperature (Schapiro 1998. Matthews 1999). This must be a consideration for long-term exercise involvement. Many personal and emotional problems impact on exercise participation and interfere with one's physical ability and should be a consideration for exercise engagement in MS. One benefit of a community-based regime is an adaptability that aligns with a variety of situations to improve function (Hale et al 2003). This enhances autonomy and choice by devolving responsibility for exercise performance to the individual.

2.5.1.1. Fatigue

Fatigue has been described as one of the most disabling symptoms of MS (Schapiro 1998) and this encourages a deconditioning of muscle groups and the poor exercise response commonly seen in MS. The self-perpetuating cycle that often develops puts the individual at a severe functional disadvantage when contemplating exercise at any level. The fatigue that accompanies MS is very different from normal fatigue that can be ameliorated with rest and relaxation (Tesio et al 2006. Kent-Braun et al 1997) and presents as an exceptionally debilitating loss of energy that will impact significantly on a person's lifestyle (Brown and Kraft 2005). These effects of fatigue represent a major functional limitation and this has been reported by as many as 85% of people with MS (Zifko 2004). It is one of the most important factors affecting an individual's ability to engage in exercise and normal daily living (Copperman et al 1994). Fatigue can occur during any of the many phases of activity initiation from the formation of the idea in the brain to the actual performance of such (MacLaren et al

1989). The commonly described presentations of fatigue associated with MS have been outlined in Chapter 1.

The impact of fatigue on physical and psychological function has been reported in the literature (Stuifbergen and Rogers 1997. Krupp et al 1988). Exercise has been shown to exert a degree of control over these difficulties (Rasova et al 2006. Stuifbergen and Rogers 1997). However the possibility of an unpredictable response of the CNS to unaccustomed activity must be acknowledged. Due to its subjective nature many individuals feel that they are perceived to be purposely avoiding activity (Stuifbergen 1997). In extreme cases the simplest tasks will also be affected. Although an invisible symptom of MS, fatigue can be devastating in the extreme. It is the reason most often cited for individuals with MS leaving employment and retreating into the world of disability (Comi et al 2001).

Successfully managing the effects of fatigue is difficult. Stuifbergen and Rogers (1997) identified four distinct self-care strategies for fatigue management: firstly, energy conservation involving the reduction of energy consumption to delay the onset of fatigue. This will allow for maximisation of performance during valued activities rather than using up potential doing the mundane. Second, recharge efforts, including rest periods and diversional activities. Third, enhancing resistance to fatigue by engaging in physical activity and exercise, nutritional strategies or psychological approaches. Finally attempting to control one's temperature to allay the onset of lassitude.

These strategies are also described in the MS literature by other authors (Copperman et al 1994. Zifko 2004) and are a consideration in the daily lives of many people with MS. There still remains however some debate as to the actual nature of fatigue and research continues into this area. In their study conducted in 1996, Kersten and McLellan stated that at present, "It remains unclear whether MS fatigue is different in kind from fatigue which is experienced by healthy adults." The study, conducted in Southampton used a random sample of 55 MS patients identifying fatigue as a major disease symptom. They found that MS people and healthy adults both reported symptoms of fatigue associated with household activities and manual work. The only significant difference was the application of a hot bath. This made the MS group

worse while improving fatigue in the healthy controls. This finding is consistent with other investigations into the effects of demyelination on the CNS where the ability to compensate for extreme changes in temperature is lost. Kersten and McLellan (1996) concluded that, “..the differences in strength and work performance were caused by inactivity or disuse of muscle”.

It seems clear that those with MS do experience more severe fatigue than the healthy population, and that they perceive their health status to be worse as a result. They also feel that they lack the appropriate knowledge and skill to exercise safely (Stuifbergen and Rogers 1997). Consequently, they tend to be far less active (Packer et al 1994). It is also of interest to note that in mixed disability samples fatigue has been identified as the major barrier to exercise adherence (Kinne et al 1999). Exercise programmes impact positively on fatigue by countering the effects of debilitation and deconditioning. Exercise will maintain muscle tone thus allowing for function to be preserved (Kersten and McLellan 1996). This supports the conjecture made by Stuifbergen and Rogers (1997) and the work by Poser and Ronthal (1991) and Ponichtera-Mulcare (1992) that states that the use of physical activity as a method of reducing fatigue will impact favourably on perceived health status and quality of life.

2.5.1.2. Spasticity

Damage to the CNS will evoke a change in the ability to conduct electrical impulses in a co-ordinated functional manner (Sheean 1998). This can result in a loss of reception that presents as a flaccid or floppy response or the often more troublesome presentation of an overexcitation of the nerve pathways that produces a hypertonic response or spasticity (Barnes 2004). This hypertonic response is characterised by the degree of resistance felt when the muscle is stretched. Faster stretches produce greater resistance (Sheean 1998). This type of spasticity also exhibits an antigravity distribution with the flexors in the upper limb and the extensors in the lower limb being predominantly affected.

The hypertonic response has major clinical consequences. If the affected muscle group remains in a shortened position a contracture may develop and this can prove

most problematic when issues of comfort and hygiene present (Jarrett 2004). The spasticity will also restrict the amount of movement possible in the affected part.

Those experiencing spasticity often manage the problem with drug therapy (MS Trust 2006). However the spectre of spasticity and the discomfort it can produce is a concern to many affected people when contemplating exercise. Adequate spasticity management is vital to the success of any exercise regime as overexertion could exacerbate the problem thus discouraging future participation. Successful spasticity reduction will encourage recruitment of previously compromised muscle groups and the use of active exercise can be restarted (Albany 1997).

With this in mind the work by Brar (1991) evaluated the effect of stretching and baclofen on spasticity in MS. The study extended over 10 weeks with 30 participants receiving stretching, baclofen and a placebo with assessment being carried out in the home. Exercise was not included. It was found that stretching alone did not have a significant effect on spasticity but in combination with the drug positive gains were evident. The addition of active exercise could have proven even more beneficial.

2.5.1.3. Impact of the physical environment and access to facilities as barriers to exercise for those with MS

Individuals in the general population will access local sports facilities and physical activities to improve their physical condition, interact socially or to improve their well-being and fitness (Pate et al 1995). For those with MS, accessing mainstream health facilities can present physical barriers that act as a deterrent to participation (Freeman 2001). The problems associated with access to health facilities and the work-place have been highlighted in the disabled population by Daone and Scott (2003). Few health centers are equipped to accommodate those with mobility problems with adapted gym equipment disabled toilet facilities or parking/building access and barriers may also include transport and lack of adequate supervision or assistance with gym usage (Ragnarsson 1996. Casanett and Karlavish 2001).

Government directives have recommended that full access be available for disabled people to public buildings by the year 2004. It has also been a government aim to

provide equality of access for those with a disability in the work place. There are still many areas of deficit that preclude the use of these services by those with a disability and accessibility to fitness facilities remains poor in many areas. These societal barriers are not confined to the UK. McDonald (2002) mentions it as a significant impediment to exercise involvement in the USA. These barriers have also been identified by Rimmer et al (2005) in their study on accessibility to health clubs for those with mobility problems. They found a raft of impediments to inclusion including the building itself, information, equipment and staff knowledge and participant ability. The problems appear to be global and much still remains to be done to make the able-bodied world more inclusive.

2.5.1.4. Restrictions caused by the physical impairments of MS

Henderson and Bedini (1995) conducted a study into the experiences and meanings related to physical activity in women with mobility impairments. They discovered that physical activity was of limited value as the women in the study believed that the physical costs of the activity outweighed the benefits accrued through participation. Sennott-Miller and Miller (1987) also noted that the decision to participate in a physical activity was dependant upon the perceived degree of difficulty rather than the perceived benefits. This reinforces the belief that not only will participation be difficult but there will be little to be gained. Despite the evidence supporting exercise's potential to improve physical ability (Petajan et al 1996. Stuifbergen 1997) many people with MS still shy away from it.

There is also the converse view that disability or the effects of a chronic disease can be overcome if appropriate physical activity is adhered to. "When health is spoken of as a virtue, people who lack it are made to feel inadequate...treating health and vigour as moral virtues for everyone harms people with disabilities" Wendell (1992). This will compound the presenting difficulties by encouraging a lack of or a perceived lack of ability to perform. The perception can be successfully overcome by incorporating the "exercise" into daily function. Hidden ability can thus be exposed and recruited. Once confidence has been gained and the fear of exercise removed other more involved regimes can be introduced.

There have been other considerations relating to ability affecting exercise participation identified in the literature by Crespo (2000) and Kington and Smith (1997). These considerations include geographical location, age, and social and physical environment, and they can impact positively or negatively to influence exercise involvement. The physical limitations of MS compound these factors by hindering any consideration of general exercise participation. Widespread rural communities present unique impediments and do not generally enjoy the benefits of mainstream exercise facilities. An individual's level of disability may preclude them from travelling to access such centers where they exist (Becker and Stuifbergen 2004). Financial constraints may also conspire to make exercise participation impossible (Crespo 2000). This is especially pertinent to a rural population with low incomes as is common in Lincolnshire reinforcing the need for community interventions. It could be argued that the provision of a comprehensive community service would bridge the gap between opportunity and exercise involvement by encouraging physical activity participation.

2.5.2. Psychological factors that affect exercise uptake in MS

Psychological factors impact on all areas of life and restrictions to exercise participation have been noted in the literature pertaining to appearance, being unfit, lacking confidence and being over weight (Allender et al 2006. Dunton and Schneider 2006). The problems experienced by the able bodied that influence exercise involvement will be magnified for those with MS as their ability to change their situation is more limited.

Some of the psychological barriers to exercise uptake that affect those with MS are now considered. The aspects hindering rehabilitation outcomes in general have been discussed in Chapter 1 and they also apply to those with MS. Additional problems pertinent to MS that may impact on the ability to undertake exercise are mentioned here.

Not only do those with MS have to face the physical deficits the disease process produces but there is also the added element of cognitive affectation. This may be as a direct result of plaque location that could interfere with cognition and memory

(Matthews 1999). It may also be linked to the presentation of physical deficits engendering feelings of loss, grief and worthlessness (Smith et al 1997) whatever the underlying cause, there exists a necessity to consider this aspect in the process of exercise initiation.

To successfully engage in exercise all individuals need to embrace the notion of activity and proceed through a series of stages to enable the behaviour to become established (Conn et al 2003). The belief-based structure that is founded on behavioural attitudes is fundamental to this theory and has been described by Collette et al (1994) and Kerner and Grossman (2001). Behavioural attitudes rely on the previous relationship with the action and the value placed upon it (Bandura 1977). For those with a disability there will be subtle differences dependent on the degree of deficit. These differences will include the alteration of established beliefs alluding to other aspects of health behaviours, motivation and goal attainment as outlined in Chapter 1.

In their work on health behaviours, Stuifbergen (1992) and Gulick (1991) noted that persons with MS who performed health-promoting behaviours including exercise plus a self-assessment of their progress had fewer hospitalisations and clinic visits than those who did not perform such procedures. This outcome is supported by Orem (1995) who stated that the purpose of exercise was to achieve some improvement in health, the objective state of bodily and/or mental functioning, and the subjective perceptions of one's current condition of existence.

2.5.2.1. Education and knowledge

Research has shown that information and assistance provided by medical services is one of the most important requirements of most people with MS (Somerset et al 2001. Vickery et al 1999). Yet people with MS have often remarked that after diagnosis they were left with minimal information or support (Somerset et al 2001). There seems to be a lack of follow-up for many people with little or no assistance through disease progression (University of Southampton 1989). Despite the advent of MS Nurse Specialists and Rehabilitation Medicine Services many people are still coping alone. Some may prefer to find their own path but whatever the person's personal preference

it is generally accepted that information be offered in a timely manner and that it is appropriate to the person's need (Embrey and Lowndes 2003).

Education also involves a re-assigning of responsibility that includes an awareness of exercise as a management strategy. Understanding the condition will help the individual to appreciate what has occurred and how best to promote recovery and this can be significantly enhanced if exercise is used correctly (Bethoux et al 2001). It will also prevent the performance of inappropriate activities in an effort to speed up progress or recovery. For this to occur the individual must be interested in self-management and have a stake in the level of control they are willing to adopt. It is accepted that paternalism exists and some people need this approach when dealing with a long-term disability. However, individuals should be encouraged to function socially as well as physically with family and friends thus maintaining an acceptable quality of life (Somerset et al 2003) and this is down to the individual not the professional services involved.

An additional source of information is that offered by local support groups and the national societies, MS Trust and the MS Society. Their input should be used where appropriate.

2.5.2.2. Adaptation to MS

Studies have shown that those who have been diagnosed with a chronic disease need to be able to adapt to disease restrictions (Dimond and Jones 1983. Woods et al 1989). Adaptation will take many forms. Some people will adapt better than others but most people will benefit from advice and guidance from peers and professionals when coming to terms with the limitations of their condition.

Exercise has been shown to aid adaptation in both physical and psychological domains and thus promote wellbeing (Sutherland and Andersen 2001). The introduction of physical activity in daily life can facilitate this adaptation in two main areas. Firstly increasing fitness levels, no matter how minimal, will engender feelings of well-being and self-worth. These are as important as the physical benefits produced. Secondly activity used as a management strategy will encourage

empowerment and behavioural changes. These changes in attitude will influence the person's future ability to cope with the disease and deal with their fluctuating condition (Somerset et al 2003).

In their work on the disability paradox, Allbrecht and Devlieger (1999) proposed that, "The sociological evidence suggests that a low quality of life for persons with disabilities is based on difficult to manage impairments, lack of knowledge and resources and disabling environments." All of these factors will impede a person's ability to adapt to the disease process and so formulate coping strategies. It was not possible within the confines of this study to explore the levels of adaptation experienced by the participants. It is acknowledged though that this is an element of the disease experience that deserves consideration in a more appropriate arena.

2.5.2.3. Facilitation of independence and furtherance of quality of life

Independence is a subjective concept and is inexorably linked to quality of life (Reynolds and Prior 2003). They are dependant entirely on the perceptions of the individual and the opinions of others regarding a person's quality of life or independence are irrelevant in defining their boundaries. Even small physical improvements, deemed insignificant by an outsider's perception can positively enhance QoL perception (Ashburn and DeSouza 1988). This notion reinforces the individualistic nature of quality of life gains that can only be ascribed value by the individual concerned (Lerner and Levine 1994).

Quality of life is a major health benefit for people with MS. Health related quality of life has become a central measure in health care research and Sutherland and Anderson (2001) proposed that this should be routinely considered when investigating the effects of exercise on an MS population. They believed that it could reveal the physical, social and psychological health benefits of an exercise intervention. This aspect must be one of the primary outcomes to be considered when improvements in independence are being sought.

2.5.2.4. Self worth and stigma

MS produces changes in muscle tone causing the limbs to jerk or shake inappropriately, muscle weakness will alter posture and increase fatigue incoordinated movement patterns will produce an ataxic gait and poor control of the upper limbs (Lassman 1999). External manifestations of diminished physical ability reinforce the concept of the disabled persona. This can make “fitting in” to mainstream society difficult and sometimes embarrassing (Staples and Lincoln 1979). Individuals need time to grieve for the loss of ability caused by MS. This will be difficult especially if changes and deterioration occur rapidly and seemingly without end fuelling the spiral of loss of self and worthlessness (Dal Bello-Haas 2002).

MS may also affect bladder and to a lesser degree bowel control (Betts et al 1993). The uncertainty of unreliable excretory function can mean the difference between active participation and reclusivity (MS Trust 2005). Access to appropriate toilet facilities is frequently limited. People will often describe careful route planning to enable a car journey and the general lack of accessible facilities in many public buildings.

These environmental problems compound feelings of worthlessness and guilt at being a burden to family and friends that deter most people from venturing into local health facilities (Kennedy 1999). It has also been posited that any exercise, no matter how low key, could be refused from a fear of failure (Kinne et al 1999). This makes the task of engaging MS people in some form of exercise or physical activity a challenging prospect.

2.5.2.5. Planned behaviour beliefs

The theory of Planned Behaviour Beliefs, as described in Chapter 1, is applied to exercise participation in MS in this study. To reiterate, Conn et al (2003) noted that the intention to perform a behaviour and its actual performance was determined by the three conceptually independent constructs; attitudes towards the behaviour, subjective norms and perceived control.

It will be necessary to consider these stages associated with behavioural beliefs in relation to health promotion in exercise uptake. Many people with MS will never have participated in mainstream exercise prior to their diagnosis. This will require the introduction of a new dimension to a person's life to accommodate exercise as a regular part of their weekly routine (Stuifbergen and Becker 2001). Some people with MS also believe that exercise can only take place if one is fit and active. The concept of home exercise is foreign to most people unless it involves a work out video or a home gym. A change of perception as well as the change in attitudes towards exercise must be part of the behavioural change.

Work has been carried out that illustrates the concept of behavioural change in MS. The study by Hale et al (2003) conducted over eight weeks with four subjects embraced both the clinical setting under physiotherapy guidance and then transferred to the home. Although a home element was included they believed that it did not extend over a long enough time scale to allow for major behavioural change and long-term health benefit to accrue. However it became apparent that the subjects enjoyed all aspects of the programme and demonstrated small changes in behaviour towards physical activity. The investigators concluded that exercise programmes should be set up and monitored by a physiotherapist before they are carried out in the home or as a community activity.

In a small study by Stuifbergen (1997) the relationship between physical activity and social, mental and physical health in MS was examined. The data was collected using a self-completed questionnaire and no intervention was offered. She concluded that the MS people included in her study presented with much lower levels of activity participation than other groups with similar chronic conditions and that a larger sample was required to verify the findings. This could indicate that their behaviours had not changed to adopt exercise. It was also noted that the subjects in the study did not achieve control over an exercise programme therefore negating its value to them, also the conclusion of Trafimow and Trafimow (1998). Stuifbergen (1997) felt additional research would identify barriers and facilitators to the participation of MS persons in exercise and acknowledged that exercise carried out in short bursts throughout the day conferred substantial benefits.

2.6. Application of theory to practice in exercise provision for MS

The stages of behavioural change and the theory of planned behaviour must be applied within the context of living with MS and the abilities of a compromised CNS that will have a finite capacity to function. Stresses can be applied to the damaged systems but they must be tempered with the need for the system to adjust, process the input and respond in a fashion that is probably not that which the person expected (Ponichtera-Mulcare 1993). For example, repeated firing of the ankle dorsiflexors will in a normal system produce fatigue in the muscle after an extended period of activation. The same action performed in a damaged system will produce fatigue far more rapidly and a probable hypertonic response to the repetitive action that can be painful and difficult to quieten. A response of this type can present a barrier to adopting exercise for fear of exacerbating problematic and painful side effects.

Yet even with a damaged CNS exercise needs to increase the available muscular activity of the participant (Stuifbergen et al 2006). It has been proposed that moderate activity, eg brisk walking when carried out over a period of 30 minutes daily will produce significant health benefits such as reduced blood pressure, weight control and increased longevity (Bouchard et al 1990, 1994. Fletcher et al 1995. Pate et al 1995). It was vital therefore to explain the concept of the cumulative benefits of exercise and to promote a re-evaluation of peoples' perception of what exercise means to them. The novel concept of the cumulative advantages of exercise is supported by the conclusions of Phillips et al (1996) who noted that “---health benefits may be gained from multiple daily sessions of physical activity as well as from one continuous daily session.” The study by DeBusk et al (1990) also corroborates this assumption, as does the work by Stuifbergen (1997) who noted that one should “..achieve a delicate balance of exertion that promotes health and avoids adverse responses.”

Therefore all preconceptions about exercise must be discarded and a re-evaluation of how to exercise a damaged CNS must replace them. In this instance increasing speed or repetitions was not necessarily the best option and there is as yet, little evidence detailing the exact proportions of exercise uptake that will produce a collective beneficial outcome (Blair and Connelly 1996. Phillips et al 1996. Reitberg et al 2004). Therefore, it must be approached on an individual basis that may or may not be

generalisable to the disabled population. This makes the investigative procedure both unattractive and abstract as this may lessen the impact of such findings to the wider research community.

2.7. Rationale for this study

Research has shown how disabled people can be separated from mainstream activities for a variety of reasons, some physical, some personal, some environmental and some cultural (McDonald, 2002). The available research evidence supporting exercise interventions in MS is strong with the focus being more on improving health rather than a conventional increase in physical fitness (Freeman 2001. Stuifbergen 1997. Klein 1996). There appears therefore to be a discrepancy between the identified benefits accrued from exercise and the uptake of exercise by those with MS. The nature of the disease precludes actual physical fitness gains for the most part but there is room for health gains to materialise and for function to improve (Sutherland and Andersen 2001). This should be the main thrust of any exercise intervention undertaken by people with MS.

The relevance of this study is grounded in the requirement to evaluate an exclusively community-based physiotherapy intervention. Exercise regimes for neurological patients have been the mainstay of community physiotherapy interventions for many years. Unfortunately there is a paucity of research in this area to provide an evidence base for this well used modality (Thompson 2000). A study by Freeman and Thompson (2000) also showed that the provision of services especially physiotherapy around the country appeared to be a matter of chance engendering feelings of dissatisfaction from many people with MS. To counter this gap in research the NICE guidelines, (2003) recommend that studies be conducted into the relative costs and benefits of home based rehabilitation strategies. The NICE recommendations were in line with clinicians' recognition of the need to engage individuals with MS in exercise thus maintaining physical abilities and prolonging independence. It has been suggested that "--community physical therapy rehabilitation can reduce the physical and psychological effects of the disease." Chard (2006), yet the vagaries of the disease and disparate study methodologies make it difficult to amass supportive evidence (Kesselring 2004). Many individuals with MS cite exercise as one of the

major aspects of disease management that they can control (Ashburn et al 1997). Consequently, despite the attendant difficulties of measuring its benefits in a community setting, studies should be supported to further knowledge and validate this particular aspect of disease management.

The primary study intention therefore was to show whether a home physiotherapy regime could offer better functional outcomes when compared to self-selected activity. This was a perspective shared by Hale et al (2003) arguing for the provision of physiotherapy at home for individuals with MS.

2.8. The research questions

From the preceding literature review and the recommendations of the NICE document (2003) a gap in current knowledge regarding community physiotherapy exercise interventions for those with MS was identified. The primary research question was therefore generated.

- Would a home-based physiotherapy exercise programme provide better functional outcomes than a regime of self-selected exercise as assessed by the Amended Motor Club Assessment?

In addition to this secondary questions emerged:

- Would a home-based physiotherapy/self-selected exercise programme have an effect on quality of life?
- Would the theory of behavioural change explain the exercise uptake?
- What would be the effects of the pre exercise intervention alone?

This chapter has considered the available evidence concerning exercise provision for those with MS. It has discussed the relevance of physiotherapy to this provision and made mention of the special considerations necessary when proposing exercise as a management strategy to MS individuals. From this the primary research question was proposed with the three secondary questions developing from it. The next chapter will describe the procedures adopted to conduct the study.

Chapter Three

Methodology

This chapter will present the study design including potential study constraints, a resumé of the assessment tools used and the reasons for their selection. There then follows a description of the ethical issues relevant to the study. The method section includes study aims, inclusion and exclusion criteria, materials and additional resources and the study procedure. A description of the physical interventions for both groups is presented and the methods used for data analysis are introduced.

3.1. Introduction

Due to the multi-faceted presentation that characterises MS both quantitative and qualitative data collection methods were employed in this study. This was done to accommodate the psychological impact of MS that was inherently linked to the physical manifestations of the disease. When investigating the impact of a physical intervention such as exercise on MS, it was likely that the psychological consequences of the physical intervention would influence the exercise experience. It was also possible that the exercise beliefs of the participants would influence the outcome. By excluding the personal aspects of the interventions and the impact they could have on the participants, an opportunity to reveal the true exercise experience could potentially have been lost. The exercise experience was not confined to the possibility of functional improvement but included the possibility of effects on QoL. It was believed that these psychological effects and belief systems would in the long term influence the success or failure of the intervention. To this end the subjective observations of the participants were included to augment the quantitative data to help clarify the issues that governed exercise uptake for those participating in this study. This method of combining quantitative and qualitative data has proven insightful in other exercise studies (Dodd et al 2006. Stuifbergen et al 2006). This pilot study may need to be repeated with a larger sample to confirm or refute any results and to enhance generalisability. The two exercise approaches chosen for this study, ie physiotherapy and self-selected, encompassed most aspects of exercise that a person with MS would be likely to attempt. It was anticipated that by comparing a physiotherapy exercise regime with a self-selected exercise regime evidence would emerge to indicate

whether physiotherapy offered a better functional outcome than a random selection of commonly available exercise choices when performed in the community.

The participants were identified from the current caseloads of the researcher and the rehabilitation medicine service. Providing they fulfilled the inclusion criteria they were invited to participate. It was acknowledged that the criteria selected were generalisable and suited to individuals in the real world facing the day-to-day challenges of MS. The controlled conditions of a laboratory were impossible to reproduce in a community setting and the criteria were therefore not as stringent as those demanded by a more physiologically based study. A representative sample of people with MS currently in the community in Lincolnshire was therefore obtained encompassing a mix of abilities that fulfilled the exercise demands of the study.

3.2. Study design

This was a randomised, comparative pilot study designed to demonstrate the benefit of a home-based physiotherapy programme when compared to self-selected exercise regimes. 39 individuals with MS of varying disease type and duration between the ages of 31-65 were included in the study. The recruits were all known to the Lincolnshire Rehabilitation Medicine service. Each person's study involvement extended over 36 weeks.

3.2.1. Study design considerations

The need for those with MS to be offered the opportunity to exercise whether at home or in a more general setting was the driver behind this study with a specific emphasis being placed on the functional gains accrued through physiotherapy. There was a requirement to provide viable evidence to support exercise generally and physiotherapy specifically in the community and to shift away from the well-controlled environment of in-patient/out-patient interventions. The community-based nature of the study permitted the unpredictability of real world experiences to intrude into the investigation making the study difficult to control. This introduced the possibility of innumerable variables that could have derailed the investigation. In the case of this study these included the death of a parent, the suicide of a son, the adoption of a child and a house flood. However for therapists in the community this is

a professional truism. It was impossible to provide a purist physiotherapeutic approach to this type of research due to the unpredictable nature of MS and the barriers encountered by attempting exercise in an able-bodied environment.

The varied presentations of MS make it impractical to assign all individuals to the same physical activity/ability box. The disease spans a huge variety of difficulties ranging from very minor to totally disabling. It was not the purpose of this study to encompass the total disability spectrum that presents with MS, however it did attempt to include the levels of disability that are routinely referred for physiotherapy in the community. The study adhered to the definitions of disability as defined by the MS Trust, (see Chapter 4), and therefore included those with the potential to demonstrate physical gains by performing the exercise regimes.

It was envisaged that the comparative element combined with the quality of life aspect of the study would demonstrate the link between quantitative and qualitative elements of research thus illustrating their interdependence. As the complexities of MS necessitate a close relationship between the physical and the psychosocial elements of disease management, it was felt that the two could not be satisfactorily separated. Physical and psychological gains were therefore investigated as an interactive phenomenon in relation to exercise.

The cumulative benefit of short bursts of exercise over an extended time scale provided the rationale for the physiotherapy exercise regimes (Blair and Connelly 1996). This method offered a degree of protection for the CNS by preventing neural overloading, hypertonicity and subsequent fatigue. It was also for this reason that the self-selection group were monitored to prevent inappropriate exercise selection and time-scales for exercise participation were given. In most cases the CNS can be actively recruited to respond in a meaningful and productive manner and can recover quickly when its failings are accommodated (Taupin 2006. Kerschensteiner et al 2004). Once an understanding of this has been reached many activities become possible. It was therefore assumed that the exercise involvement of the study participants could produce noticeable benefits with short bursts of exercise during the day. This could be at a relatively low level of intensity that would allow for the deficiencies of the damaged CNS to be accommodated.

There were differences between the two exercise arms of the study. Individuals engaging in the home physiotherapy arm had a more focused, disease specific programme compared to those engaging in the self-selected, readily available activities that were used as the comparison. These activities were far more generalised in their application and lacked the condition specific element supplied by the physiotherapy programme.

The 12-week pre exercise phase provided both a wash out period from any previously attempted exercise and allowed for the implantation of the first three phases of the stages of change model to begin to take root (see Chapter 1). It was this preliminary stage that was the foundation stone for the longevity of exercise uptake. Although this was not appreciated at the time, it became evident that this adjustment period was a vital component of the study and positively influenced the outcome.

Important differences in this study compared to similar projects were therefore the direct comparison between the functional benefits of a physiotherapy programme compared to self-selected exercise, the exclusively community based setting, attention given to equity of contact throughout, the provision of information and the extended time scale that allowed for behavioural change to take place. The provision of home activity is the mainstay of physiotherapeutic intervention for chronic neurological disabilities (Ashburn and DeSouza 1988) but as yet has been only cursorily researched. This study hoped to add to this limited knowledge base.

3.3. Assessment scales

It was necessary to assess as many aspects of MS deficit that could potentially be influenced by exercise. Therefore an extensive data collection procedure was required to would allow for any changes in Activity Impairment or Participation to present. It was anticipated that this comprehensive assessment procedure would demonstrate the true effects of an exclusively community based physiotherapy exercise programme on the multi-faceted presentation of MS.

3.3.1. Assessment scales selected for the collection of activity, impairment and participation data

The scales selected for data collection are detailed in the following sub-section. They can be reviewed in their entirety in the assessment book (appendix 1), and are summarised in table 3.1. They fulfilled the requirements of the study in that they embraced the variety of deficit presented by MS, could be accurately applied in the field and were sensitive to any change brought about by the intervention.

Table 3.1 Summary table of assessment tools

Scale	Properties	Author/Year
The Amended Motor Club Assessment. (AMCA).	Measure of functional deficit in MS. Consists of upper/lower limb active range of movement and functional activities. Scores maximum of 54 on function.	DeSouza and Ashburn 1996
The Timed Walk	Included in the AMCA as a measure of walking ability over a fixed distance.	DeSouza and Ashburn 1996
Guy’s Neurological Disability Scale. (GNDS).	Assessment of impairment consisting of 12 categories with a short structured interview in each category. Graded 0-5	Sharrack and Hughes 1999
Health Assessment Questionnaire. (HAQ).	Self-assessment of 8 areas of functional ability. Graded 0-3	
Modified Ashworth Scale. (MAS).	Manual test of spasticity. Graded 0-4.	Ashworth 1964. Bohannon and Smith 1987.
Medical Research Council strength grading scale. (MRC).	Manual assessment of muscle strength Graded 0-5.	Demeurise et al 1980.
MS QoL 54	Self-assessment questionnaire. 12 domains and 2 items of QoL, health perception and daily activities. Relates to previous 4-week period.	Vickrey et al 1995.
The participants’ journal	A personal account of the participants’ study engagement. Used for 9 months with a semi-structured format.	
Numerical Rating Scale (NRS).	Included in the journal as a self-assessed QoL measure.	
Follow-up questionnaire	6-month follow-up to gauge continued exercise participation.	

3.3.1.1. Amended Motor Club Assessment

This scale was adapted from stroke rehabilitation by DeSouza and Ashburn (1996) and in its amended form is used as functional assessment for MS. The AMCA concentrates on range of movement and functional activities and differs from other scales in that it does not cover any other aspect of MS deficit. It is a pure measure of motor deficit.

The scale consists of three sections. The first assesses lower limb action in lying and standing. The second assesses upper limb action in lying and sitting. These two sections are scored 0, 1, 2, or X according to the instructions given. A maximum score of 28 for each upper limb and 14 for each lower limb was possible. This would indicate full range of movement in both positions. As it was not the intention of this study to focus on range of movement per se this section of the scale did not figure in the data collection process.

The third section assessed activities that embraced every day function including a timed 50-meter walk. It was this section that was used as the primary functional indicator used in this study. The various tasks for section three included the following activities: Supine to left side lying, Supine to right side lying, Bridging, Sitting balance, Sitting touch floor and return, Sitting to standing, Standing balance, Standing on left leg (5 seconds), Standing on right leg (5 seconds), Standing to get down to floor, Kneel standing balance (10 seconds), Kneel standing balance left leg (5 seconds), Kneel standing balance right leg (5 seconds), Get up from floor to chair, Transfer sitting on chair to lying on bed, Transfer bed to chair, 50-metre walk, Climbing 7 stairs/steps

These actions were scored as follows. X = unable. 0 = manual assist of two or more. 1 = manual assist of one. 2 = aid. 3 = no aid. Aid was described as the use of hands to push, furniture or sticks etc. Therefore a maximum score of 54 was possible. The higher the score the better the outcome.

The researcher anticipated difficulties applying items 17 and 18 to the home environment. Section 17 involved the 50-meter walk. As the assessment was to be

carried out in the home there was little chance that an uninterrupted 50-meter stretch could be found. On consultation with the scales inventors it was decided to confine the walk to 10 meters to allow for the scale to be used effectively in the home setting. The same problem presented with climbing up and down seven steps. Those included in this study did not have access to stairs for the most part and it was agreed to eliminate this section for the purposes of this study. The scales validity was not compromised provided the changes were applied consistently in each case. Therefore for those in this study a maximum score of 51 was possible.

The validity of the AMCA was tested in a study by Ashburn et al (1995) on a self-managed home exercise programme and was found to be effective in detecting changes in ability and motor function. It was felt that the scale would be appropriate for use in this study due to the similarity of intervention, namely home based exercise and its specificity to MS. Craig et al (2003) used this tool in their investigation of rehabilitation and intravenous steroid infusions and found that it was sensitive to positive changes in range of movement and motor control.

This scale was selected for the following reasons. It conformed to a familiar motor assessment procedure for a physiotherapist conversant with neurological disability. It embraced the variety of functions that would be routinely assessed and included the additional element of a timed walk that would not necessarily have been included in a home assessment.

3.3.1.2. Timed Walk

The walk was conducted over 10 meters in doors using the usual walking aid of choice. The time was recorded on a Timex stop-watch and times were rounded up to the nearest second for those above .5 and down to the nearest second for those below .5. Eg 12.78 seconds became 13 seconds and 12.45 seconds became 12 seconds.

This was essentially an element of the AMCA but the times were extracted and analysed as an additional functional measure as walking was the exercise of choice of four individuals in the self-selection group.

3.3.1.3. Guy's Neurological Disability Scale

The Guy's Neurological Disability Scale, (GNDS), was developed by Sharrack and Hughes (1999 a) and it assessed impairment in patients with MS. It consisted of 12 categories comprising a short interview and a scoring section. Each section is scored from 0 to 5 with 5 being the worst possible outcome for each section. The scoring levels denote a sliding scale of deficit within the category being assessed.

It has been judged easy to administer and score (Craig et al 2003). This researcher also found it easy to use and it demonstrated a true representation of symptoms and experienced difficulties for those in this study. 33 international experts have systematically reviewed the scale with 84% of them confirming both its face and content validity (Sharrack and Hughes 1999 b). The scale was also reviewed by a group of MS patients (n=176) who agreed the appropriateness of its content (Sharrack and Hughes 1999 b).

This scale has 12 sections that utilise a short questionnaire administered by the examiner and a scoring system in each of the 12 sections. It covered various aspects of disability common to MS. These sections were: Cognitive disability, Mood disability, Visual disability, Speech and communication, Swallowing disability, Upper limb disability, Lower limb disability, Bladder disability, Bowel disability, Sexual disability, Fatigue and Other disabilities.

The score was determined by the responses obtained to the questions asked. The lower the score the better the result. The twelve sections were scored separately with a cumulative score being used as an overall measure of impairment. They were scored 0-5 with 5 being the poorest outcome in each section. A maximum score of 60 would denote the highest level of impairment. The scoring levels are defined as follows. 0 = no deficit. 1 = problems noticeable to family or friends. 2 = problems noticeable to family or friends but not requiring help from others. 3 = requiring help from others for some normal daily affairs. 4 = needing help for all daily affairs. 5 = unable to manage. There were slight wording differences in each category relevant to the area being assessed.

This scale was chosen because it was MS specific. It included a subjective evaluation of the main aspects of MS symptomology. It was easy to administer and could be completed in 10-15 minutes.

3.3.1.4. Health Assessment Questionnaire

The Health Assessment Questionnaire, (HAQ), is a self-assessment of eight areas of ability encompassing upper and lower limb function and balance covering both aids to daily living and extended aids to daily living items. It has been an important assessment tool in the field of rheumatological disability (Felson et al 1995), but the categories are equally applicable to individuals with neurological deficits (Wade 1992). It is scored 0-3 with 0 being the best outcome. The questionnaire covers eight regions of functional activity. These were: Dressing and grooming, Rising, Eating, Walking, Hygiene, Reach, Grip and Activities. Activities involved going shopping, getting in and out of a car and household chores like vacuuming.

It was scored as follows, 0 = without any help. 1 = with some difficulty. 2 = with much difficulty. 3 = unable to do. As with the GNDS the lower score is indicative of the better outcome. A maximum score of 60 was possible indicating complete dependence. The HAQ was selected for its ease of completion and to gauge the individuals' subjective assessment of their ability in daily tasks.

3.3.1.5. Modified Ashworth Scale

The Modified Ashworth Scale (MAS), (Ashworth 1964. Bohannon and Smith 1987) is the universally accepted spasticity rating scale currently available in neurological assessment. It is dependant on the skill of the assessor in grading true spasticity subjectively when a limb is moved passively. The MAS has been validated in the assessment of muscle spasticity (Bohannon and Smith 1987) and the scale has been used extensively for this purpose (Bhakta et al 1996. Dunne et al 1995. Mustapha 2000).

Tone was assessed manually in each upper limb at the elbow into extension, the wrist into extension and the fingers into extension. Six areas were scored in total three on each upper limb. In each lower limb four areas were assessed. These were the hip

adductors, the knee flexors, the knee extensors and the ankle planta-flexors. Eight areas were scored in total. The scores were collated and one mean score was assigned to the limb. The most desirable score is 0 denoting normal tone in all areas assessed. The highest score of 4 denotes the highest degree of tonal abnormality. The MAS includes a 1+ score to increase grading sensitivity. 1+ is unrecognisable to the database and was entered as 1.5 for analysis purposes. As spasticity can be a major symptom in MS at all stages of the disease process, it was deemed necessary to include a measure of this type in the assessment process.

3.3.1.6. Medical Research Council strength grading scale

The Medical Research Council strength scale, (MRC), assesses muscle strength. It is a subjective determination of power when the limb is tested manually. The scale was devised initially for use with peripheral nerve lesions and Demeurise et al (1980) expanded the scale to allow it to fulfil the requirements of upper motor neurone assessment. There is compelling evidence to support the use of strength measures in neuromuscular diseases (Andres et al 1986. Bohannon 1989).

The MRC uses a scoring system of 0 to 5 with 0 being no power and 5 denoting normal power. The upper limb was assessed in four areas: shoulder, elbow, wrist and grip. The lower limb was assessed in three areas: hip, knee and ankle and a score assigned as with the upper limb. This produced a total of eight scores for the upper limbs and six for the lower limbs. The scores were collated and one mean score was assigned to the limb. Loss of strength is often cited as a major concern for those with MS and it can be related to other disease difficulties such as fatigue, muscular deconditioning or spasm. For this reason the MRC was included in the assessment procedure.

3.3.1.7. MS QoL 54

The MS QoL 54 (Vickrey et al 1995) is a self-assessment questionnaire that gathers information on an individual's health perceptions and daily activities. It refers to the previous four-week period. The questionnaire is used to assess the quality of life of those with MS. It comprises 52 items that are divided into 12 domains of health related quality of life plus two single items. The domains are classified as follows:

Physical health, Role limitation due to physical health, Role limitation due to emotional problems, Pain, Emotional wellbeing, Energy, Health perceptions, Social function, Cognitive function, Health distress, Overall quality of life and Sexual function. The two items were Satisfaction with sexual function and Change in health.

The MS QoL 54 is extensively utilised and has been trialled by Solari et al (1999) who found it to be more suitable for quality of life data collection than the previously used SF-36 in respect of MS individuals. As the MS QoL 54 is commonly used to assess quality of life in MS and it was deemed necessary to include some form of detailed quality of life measure it was used in the assessment procedure.

3.3.1.8. Participants' journal

Sutherland and Andersen (2001) have noted that the participants' perceptions of function and wellbeing are central outcomes of interventions such as exercise and should be viewed as valid sources of data. This data collection method was included in this study to add a qualitative strand to the other results. It was also anticipated that a link between the physical aspects of exercise engagement and their psychological consequences would emerge. It was in larger print for ease of use by the participants.

The journal allowed for the collection of subjective data over the 36 weeks of study involvement (see app 2). Each individual was documenting MS changes and evaluating the effects the addition of exercise had on their functional ability and quality of life. It was also anticipated that behavioural changes associated with health promotion and attitude to exercise would emerge in the journal entries.

General comments were recorded in the journal on a weekly basis and the participants also completed a semi-structured questionnaire and recorded the exercise regime performed, the frequency of performance and perceived affect on overall ability. They commented on the value of the pre exercise educational material, made observations regarding the exercise programmes and other remarks pertaining to their condition and its affect on their lives. There were slight differences between journal formats that were dependent on group allocation.

3.3.1.9. Numerical Rating Scale

A Numerical Rating Scale (NRS) was included as a subjective quality of life measure in the journal. The participant was asked to complete this scale a total of three times at Week 1, Week 12 and Week 36. The use of this type of scale has been well documented as a valid method of subjective QoL assessment (Hertlig and Kessler 2006).

The scale was linear in presentation requiring the participant to assign a numerical value to their quality of life perception. It was scored from 1-10 with 1 being the worst quality of life perception and 10 being the best. The participant marked the numbered line at the appropriate level. It was included as a visual aid to the participants who found it interesting to revisit their previous estimations after participating in the pre exercise and exercise programmes.

3.3.1.10. Follow-up questionnaire

To assess the impact of exercise long-term and to judge whether behavioural changes had occurred a questionnaire was designed for completion six months after study conclusion (see app 3). There were slight differences between the two forms pertinent to group allocation. The participants were unaware of this follow-up questionnaire until it arrived. The questionnaire was submitted to the ethics committee for approval as an amendment on 11th October 2004 and approval to proceed was granted. (See app 4).

3.3.2. Other assessment tools

Table 3.2. Other assessment tools

Extended Disability Status Scale. (EDSS).	Assesses aspects of functional system deficit including cerebellar, brainstem and sensory elements.	Kurtzke 1983.
Functional Independence Measure (FIM)	Assesses activities of daily living.	Hamilton et al 1987.
Functional Assessment Measure (FAM)	As above but includes swallowing speech and affective disabilities.	Hall et al 1993
Functional Limitation Profile (FLP)	12 areas of functioning are assessed using 138 questions.	Sibley et al 2006
Sickness Impact Profile. (SIP)	American version of above.	Trigg and Wood. 2003.
Rivermead Mobility Index	Mobility scale similar to the AMCA. Used predominantly in outpatient assessments.	Collen et al 1991.

Other assessment tools are suitable for use with MS. It is not the intention of this section to discuss these at length but mention will be made of some of them plus the reasons for their exclusion.

3.3.2.1. Extended Disability Status Scale

The most popular disability assessment scale has for some time been the Kurtzke Expanded Disability Status Scale (EDSS) (Kurtzke 1983). This scale covers aspects of functional system deficit including cerebellar, brainstem and sensory disturbances. It has been deemed impractical for clinical use in some cases as it could be considered insensitive to subtle changes in disability (Wade 1992). It has been suggested that this scale does not consider the patient perspective making its value in modern day neurorehabilitation limited (Hemmett et al 2004). It was discounted for use in this study for these reasons.

3.3.2.2. Functional Independence Measure (FIM) Functional Assessment Measure (FAM)

The Functional Independence Measure, (FIM), (Hamilton et al 1987), covers activities of daily living, (ADL), and is helpful in assessing burden of care and satisfaction with life. The Functional Assessment Measure, (FAM), (Hall et al 1993) was an attempt to make the FIM more comprehensive by including speech, swallowing and affective disabilities.

It was a matter of personal preference as to which ADL tool was employed and the researcher was unfamiliar with these assessment measures. The governing factor was the requirement for a comprehensive assessment procedure and the need for a self-completed subjective test that allowed for a variety of information to be gathered quickly with a focus on functional gains. For these reasons the Fim/Fam were not selected.

3.3.2.3. Functional Limitation Profile (FLP) Sickness Impact Profile. (SIP)

The Functional Limitation Profile, (FLP), is the British version of the Sickness Impact Profile, (SIP). It has been used in community surveys (Trigg and Wood 2003. Sibley et al 2006). This is an extensive scale covering 12 distinct areas of function using 138 questions. It takes up to one hour to complete. Although it is a well-regarded scale it was not suitable for this study for this reason.

3.3.2.4. Rivermead Mobility Index

The Rivermead Mobility Index, (RMI), (Collen et al 1991) has its roots in work carried out at the Rivermead Rehabilitation Unit. This mobility scale has been used mostly for outpatient assessments and is very similar in its form to the functions assessed by the AMCA. The fact that the AMCA was MS specific determined its inclusion rather than the Rivermead version.

3.4. Potential ethical issues

This section details the issues encountered that affected the granting of ethical approval and the study design. It also describes aspects that had the potential to influence the participants' involvement in the study.

Initially the study was to have adhered to an A-B-A design. All participants were to receive a home physiotherapy programme extending over three months. A three-month period of inactivity would follow with a re-initiation of the initial programme afterwards. The ethics committee did not approve the removal of the intervention. They expressed concerns over the feasibility of reacquiring ability once activity recommenced and that some people would not cease to exercise at all thus tainting the results.

It was necessary therefore, to redesign the study procedure to accommodate these concerns. The proposal was resubmitted with the revised design as detailed in this chapter. Ethical approval for the study was reconsidered on July 11th 2003 and approval was given (see appendix 5). The areas of concern were considered by the committee are now presented.

3.4.1. Psychological distress

For some individuals coming to terms with their condition and subsequent deterioration can be difficult (Reynolds and Prior 2003. Brown and Kraft 2005). The ethics committee felt that psychological distress could have been precipitated by the study. It was conceivable that some people may have become distressed if their assessment scales indicated that deteriorations were occurring or if they did not achieve expected improvements. In an effort to counter these potential problems the Neuropsychology department was available should this have occurred. This service was not required.

3.4.2. Confidentiality

To preserve confidentiality of information, only the investigator had access to the participants' identities and to the corresponding assessments and journal results. The final physical assessment was carried out by one of the two independent

physiotherapy assessors. The assessors were blind to the type of programme the individual had been following and were instructed not to offer opinions regarding the study processes or anticipated outcomes. An independent researcher had access to the journals for purposes of theme verification but had no knowledge of participant identity. No participant requested their journal to be returned and all were destroyed after data analysis was completed.

3.4.3. Withholding exercise

The ethics committee expressed concerns over withholding exercise from the participants for the first 12 weeks of the study. This was however a necessary element of the study in which a washout effect from any previous exercise was established. This period also enabled the participants to move through the first three stages of the stages of change model. As the requirements of the study had been explained it was taken that by signing the consent form the participants agreed to this restriction. Three of the regular exercisers did remark that this was a difficult undertaking.

3.4.4. Other study issues

There were two other study concerns that could have influenced the study process. These are now presented. Issues relating to researcher bias, MS problems and study logistics are discussed in Chapter 6.

3.4.4.1. Compulsory withdrawal from the study

Anyone who required hospitalisation, a significant drug regime change or a steroid infusion was withdrawn. Individuals who presented with major new symptoms were also withdrawn. These symptoms included, disturbances of vision, motor deficits, sensory disturbances, bladder or bowel problems and seizures of more than three days duration. A reoccurrence of previously experienced symptoms did not warrant withdrawal.

3.4.4.2. Voluntary withdrawal from the study

After initially consenting to participate, one person did subsequently withdraw. This was because they had practical difficulties with their hand function and felt unable to complete the journal entries. They perceived the journal to be a personal account of

their exercise and MS experiences and felt unable to ask anyone to complete it for them. Another recruit was obtained to take their place.

3.5. Method

There now follows a description of the study preparation including aims and inclusion/exclusion criteria. The study procedure is outlined and the physical interventions described.

The study involved the preparation of the following, the compilation of the assessment book, (see app1), the journal used for qualitative data collection, (see app 2), an information sheet for the participants, (see app 6), and consent forms, (see app 7), the research and preparation of the large print participant education pack (see app 8) plus the MS Trust booklet “Tips for Living with MS” (2002), GP letters, (see app 9). The education pack was compiled using information from the MS Society, the MS Trust and Schapiro (1998). The pack was designed to assist the individual to cope with MS by offering information on a variety of topics. This included some common symptoms of MS, drug therapies, exacerbations, exercise, local support groups and the local services available through the Rehabilitation Medicine Service in Lincolnshire. The follow-up questionnaire, (see app 3), was prepared once the study was underway.

The assessment scales were collated into one booklet for ease of transportation and a number corresponding to the participant was given to each one. Each person had three books so that each assessment could be carried out on a fresh sheet. This eliminated the possibility of re-visiting previous scores from earlier assessments. The participants' numbers were allocated by a random number series affixed to the consent forms. The group allocation was unknown to the investigator until after consent had been obtained to preserve randomisation.

3.5.1. Aims

The primary aim of this study was:

- To determine the whether the physiotherapy programme provided better functional gains than the self-selected exercise choices.

Secondary aims were:

- To assess quality of life changes between the groups.
- To determine whether behavioural changes had occurred at study conclusion.
- To see whether educational material alone could produce physical and psychological gains.

3.5.2. Inclusion criteria

The inclusion criteria were as follows:

- A diagnosis of MS as confirmed by a Neurologist on MRI or lumbar puncture.
- A willingness to participate in all stages of the study.
- The ability to commit to the programme and to record changes in the journal.
- To be physically able to participate in an exercise regime.
- To present with motor or fatigue symptoms which impacted adversely on daily life.
- Not scheduled to start on disease modifying drugs during the study.

3.5.3. Exclusion criteria

- Those with an unconfirmed diagnosis of MS.
- Individuals who were unable to record changes in their condition.
- Individuals who were unable to perform the required regimes.
- Individuals for whom exercise was clinically contraindicated.
- Participants who were receiving other physiotherapeutic interventions at the study outset that would impact on the results.
- Individuals scheduled to commence on disease modifying drugs during the study.

3.5.4. Materials

The study required the following materials.

- The assessment book.
- The information pack and MS Trust booklet, "Tips for living with MS" (2002).
- A 10-meter measure.

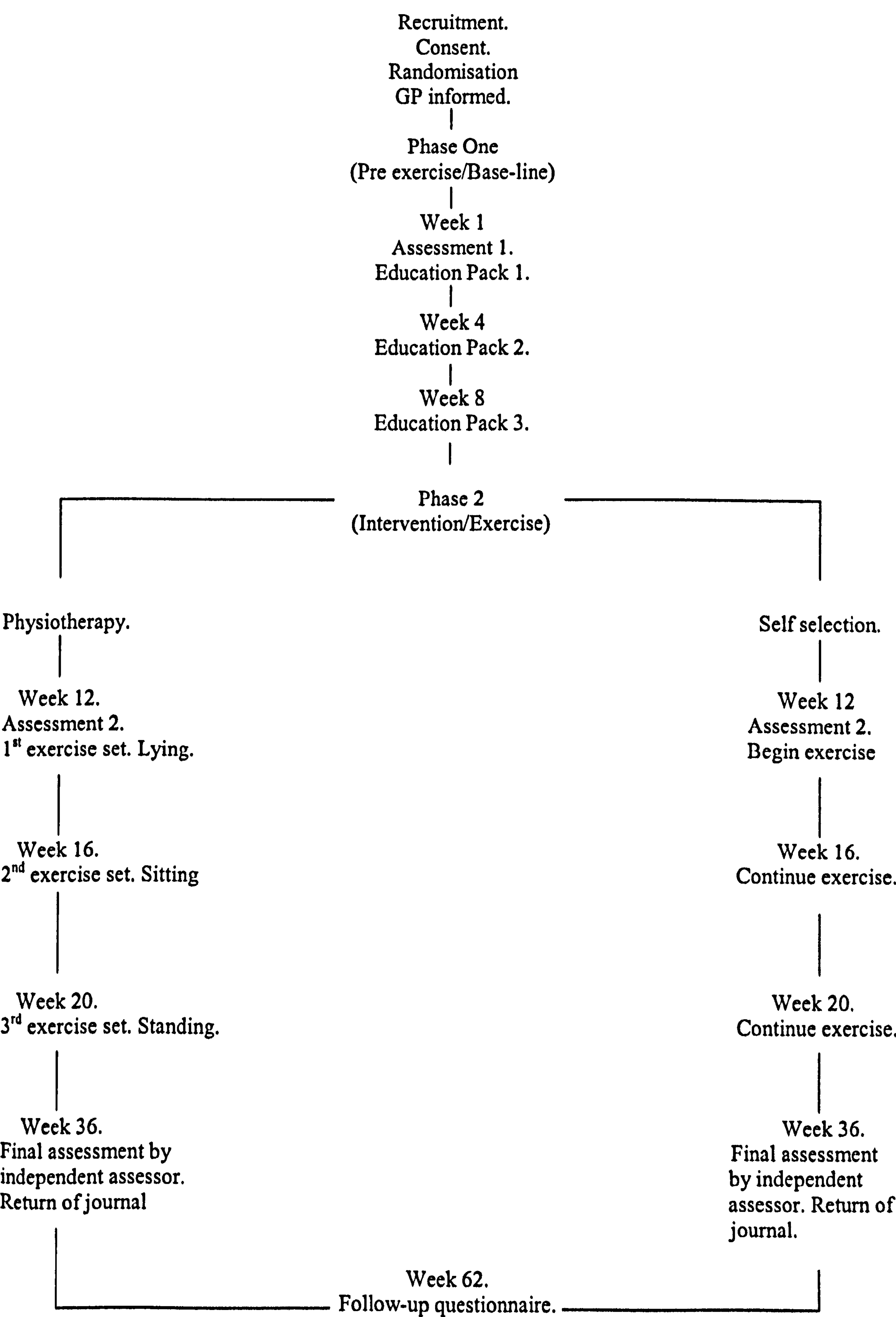
- A stopwatch.
- Exercise sheets, exercise mat, and red theraband.
- Information sheets.
- Consent forms.
- GP letters.
- Follow-up questionnaires. Return addressed envelopes.
- The journals.

3.5.5. Additional resources

- Two independent physiotherapy assessors plus funding to cover time and travelling expenses incurred.
- Independent researcher to allocate random number series on the consent forms and maintain the allocation list until recruitment had been completed. This researcher also assisted with theme identification from the journal narratives.

3.6. Study procedure

Figure 3.1. Study procedure



The study process was divided into two stages that adhered to the procedure shown in figure 3.1.

Once consent was obtained and study information supplied, individuals were randomly allocated into either the physiotherapy group (group 1) or the self-selection group (group 2). An appointment was made to complete the baseline assessment at which time the participants were issued with their journal and the first part of the educational material.

A letter outlining the study but maintaining anonymity of the participant was also issued to the appropriate GP practice, (see app 8). The opportunity was presented to the participant to discuss the study with the investigator throughout. Participants had the option to withdraw from the study at any time without prejudice should they have wished to do so.

Once the 12-week pre exercise phase was completed, the second assessment was carried out and the exercise phase began. This continued for the following 24 weeks. After the 24-week exercise stage the third assessment was conducted by one of the independent assessors. The journals and the final assessments were then returned to the investigator in a sealed envelope to preserve confidentiality.

Once study involvement was completed the follow-up questionnaire was sent out 26 weeks later.

All participants retained contact with the Rehabilitation Medicine service during the study and had access to the community outreach team at all times. If at any time the participant should have required any intervention from other professionals that would have influenced the study process or had become clinically at risk they would have been withdrawn. This did not occur.

Time was allocated at the end of the project to discuss any pertinent issues that arose as a result of study participation. Appointments were available when necessary with

the participant and the investigator. None of the participants identified any issues that required such consideration.

3.6.1. Recruitment/consent

Individuals who fulfilled the inclusion criteria were invited to participate. Due to time constraints and the evolution of a neurology service within the acute sector, the opportunity for recruitment of an original expectation of 50 subjects became impossible and the study proceeded with 40 participants who had been recruited over a six-month period. One person was forced to withdraw after an exacerbation of their condition necessitated the use of a steroid infusion. There was no time to re-recruit to fill this person's place. Therefore the study proceeded with 39 individuals.

To accommodate the variety of symptom presentations a mixed disability group of people were invited to participate. To be included the subjects had to be capable of engaging in exercise either at home or in a gym, swimming pool or class situation. After consenting to participate they were randomly allocated into one of the two exercise groups and those in group 2 were asked to consider an activity choice.

3.6.2. Randomisation

Group allocation was achieved using a random number series on the consent forms. An independent researcher allocated the consent form numbers into group 1 or group 2. The investigator was made aware of the group assignment after written consent had been obtained. As the randomisation was based on 50 subjects group allocation was unequal. Consequently 18 participants were allocated to the self-selection group and 22 to the physiotherapy group at the time recruitment ceased. One person was lost to the physiotherapy group leaving 21 participants in this group.

3.7. Physical interventions

This section describes the procedures used for the implementation of the physical interventions. The physiotherapy programme can be reviewed in appendices 10, 11 and 12. The table of self-selection exercise choices can be seen in Chapter 4. The section will first describe the physiotherapy phase.

3.7.1. Physiotherapy programme. Section one, introduction of the first set of exercises performed in lying

The home programme consisted of three parts and concentrated on the motor re-learning approach in which movements and controlled postures are repeated to reactivate compromised patterns. The exercise sheets were produced using the Physio Tools (2002) neurological package. Part one involved a total of ten exercises. These were performed in lying. Depending on the ability and preference of the participant, they were carried out either on the floor or on the bed (see app 10).

These exercises stretched and mobilised rotational patterns of movement in a fully supported position. They concentrated the participants' attention to the contraction and relaxation of selected muscle groups while attempting to prevent overflow of activity into neighbouring areas. They also begin to stabilise activity around the pelvis and hips in preparation for the more difficult exercises to follow. The participants were required to complete five repetitions of each exercise and increase to a maximum of 10 repetitions as their competence and stamina improved.

It should be remembered that although individuals with MS frequently request physiotherapy it must not take over their lives. The purpose of any regime should be to enable the participant. As such it must be easy to perform and not too time consuming yet still produce measurable gains relevant to the participant. The exercises included in the physiotherapy programme have been shown to fulfil these goals (MS Trust 2002).

3.7.2. Section two, introduction of the second set of exercises performed in sitting and the theraband strength programme

Four weeks later the second part of the programme was supplied to the participant. This consisted of two sections (see app 11). The first section was performed sitting on an armless, straight-backed chair to provide adequate support yet still stress balance mechanisms and encourage dynamic movements away from the midline. These movements are necessary for purposeful functional activity. The exercises commenced with five repetitions with the provision to increase to a maximum of 10

repetitions for each exercise. This was to ensure that the regime did not become too time consuming but would still allow for a progression of repetitions to be made.

The second section involved the use of a resistance provided by the use of theraband (Thera-Band System of Progressive Resistance, Hadamar, Germany), with the exercises being chosen from the theraband resisted exercise programme of the Physio Tools (2002) exercise package. The person remained sitting in the chair as previously. Theraband is an elasticated length of band of varying strengths designed to act as a resistance to muscle activity. The resistance was augmented gradually by increasing the repetitions performed.

Theraband is supplied in a series of resistances. They are colour coded for ease of use. The most frequently used bands are red, a medium strength band, green, a heavy strength resistance band, and black an extra strong resistance band. The band is supplied on a roll and can be cut to the required length for inclusion in an exercise programme.

For the purposes of this study the red band was used as none of the participants had normal muscle power as determined by the MRC grading scale. It fulfilled the needs of the group yet still allowed for strength gains to materialise. Strength improvements that had been made during the study would necessitate the introduction of the next resistance, the green band, to progress the home regime further.

3.7.3. Section three, introduction of the third set of exercises performed in standing

Four weeks later the third part of the programme was initiated. This consisted of ten exercises that were carried out in standing using a fixed support, eg, a kitchen work surface, if required. This was to provide an element of safety and to encourage more activity into the restricted movement patterns (see app 12). These exercises concentrated on the elements required for walking smoothly and effortlessly. Their aim was to re-educate lost fluidity of gait and to practice moving around and away from the center of gravity. Once again the participants began with five repetitions of each exercise and increased at their own pace to a maximum of 10.

The participants were required to perform all of the exercises provided during the eight week set up period. They were then invited to design their own regime using these exercises or, if preferred, to continue to perform all the prescribed exercises. It was envisaged that this would encourage empowerment and commitment to the programme.

The participants were required to exercise for a minimum of 20 minutes throughout the day, though not necessarily in one session, over five days initially, a total of one hour 40 minutes of activity per week. It was anticipated that familiarity would encourage extended exercise sessions. The participants were then required to continue performing their chosen regime for the following 16 weeks.

3.7.4. Self-selection exercise choices

There now follows a list of the exercise choices made by the self-selection group. These have been deemed beneficial for people with MS (Multiple Sclerosis Trust Information 2002):

- Walking an increasing daily distance. To be determined by the participant.
- Swimming.
- Yoga or Pilates, either in a class or using a home video.
- Low resistance gym work. Options included static cycling, home gym equipment and the participation at a local health center facility.
- A programme of their own choosing, providing this was not detrimental to their level of disability. Eg use of a static bike.

After completion of the second assessment the self-selection group were required to begin their chosen regime. Each participant was visited on two further occasions as with the physiotherapy group. They were asked to continue with their selected activities for a minimum of 20 minutes in any one day. The total exercise time per person was a minimum of 1 hour 40 minutes per week as with group 1, to be completed as convenient. The participants were encouraged to increase the time spent exercising as time and health permitted over the following 16 weeks of unsupervised activity.

3.8. Data analysis

Two different data analysis methods were employed to accommodate the two distinct data sets amassed. The paired t test, (two-tailed), and an unpaired t test, (two-tailed) were used show significant mean changes of the quantitative data gathered using the assessment scales. A two-way ANOVA calculation was used to determine between group differences. These results can be reviewed in Chapter 4. The qualitative data contained in the journals was explored using Interpretative Phenomenological Analysis. These results plus the quantitative information from the semi-structured questionnaire contained in the journal are presented in Chapter 5.

3.8.1. Quantitative data analysis

This study was a two condition design ie one group participated in a home physiotherapy programme while the other group engaged in a self-selected exercise regime. The subjects were matched in that they were all adults, all had MS, they were not taking steroids and all followed the study through to completion in their respective groups.

The primary outcome variable was the AMCA, a measure of change in physical function. The secondary outcomes were identified using the WHO (2001) definitions of Activity, Impairment and Participation. The scoring system for each scale can be reviewed in this chapter. The data input and analysis methods were the same for the pre exercise and exercise arms of the study. The individual elements of each scale for each of the participants were totalled giving each person an overall score per scale. These individual results were then combined to produce a group mean per assessment scale for each stage of the study.

All quantitative data was processed using the Statistical Package for Social Services programme number 11.0. To confirm normal distribution of the data spread the distributions were verified using the one-sample Kolmogorov-Smirnov test. All data were normally distributed for each scale at all study stages. Although 0.05 was the significance level applied in this study it was acknowledged that when comparing multiple means a type 1 error could occur. Consequently apparently significant results

could have occurred by chance. It was accepted therefore that those results with probabilities greater than 0.01 be treated with caution.

The paired t test, (two-tailed), was used to assess significance of the mean changes within groups for the following reasons: the hypothesis was one-tailed, there was only one independent variable ie, educational material in phase one of the study and exercise in phase two. An unpaired t test, (two-tailed), was similarly employed to show means changes between the groups. A two-way ANOVA calculation was used on the pre and post exercise AMCA results to examine between group effects.

3.8.2. Qualitative data analysis

The journals were transcribed onto computer and organised by group and study phase using Nvivo version 2.0. They were then printed out for ease of review. Interpretative Phenomenological Analysis, (IPA), was employed to add a context-based element to the study applicable to the experiences of this cohort. The template described by Smith and Osborn (2006) was used to develop the themes. This system produced the dominant themes that were common to the participants.

This chapter has described the method used to carry out the study. It has shown the stages of preparation, itemised the selected assessment scales and detailed the exercise procedures. An introduction to the data analysis processes was also included.

The next chapter will present the quantitative data obtained from the pre exercise and post exercise phases of the study. It will begin with an outline of demographic information for the cohort and describe the information obtained from the assessment scales. Chapter 5 gives a detailed account of theme identification and development from the participants narratives contained in the journals plus the results of the semi-structured questionnaire.

Chapter Four

Results of the quantitative data

4.1. Introduction

The first section of this chapter presents demographic data for the sample. This will include information on mobility, the participants' estimation of their disease state for the preceding three months, marital status, work status, MS category, time since diagnosis, disability category plus the major problems identified by the participants.

The second section describes the results from the pre exercise phase in which educational material was provided but no activity was undertaken. This section will present pre and post results for the assessment scales and show any changes that resulted.

Section three describes the results from the two exercise interventions and these will be presented separately.

4.2. Section One. Demographics and clinical details (whole sample)

A convenience sample of 40 individuals was recruited from the current caseload of the Rehabilitation Medicine Service in Lincolnshire. One person withdrew after three months due to an exacerbation of their condition necessitating treatment with a steroid infusion. This intervention was one of the exclusion criteria for this study. A second person withdrew due to progressive difficulties with writing. An additional person was recruited bringing the final number to 39 participants. Of these 21 people were randomly allocated to physiotherapy and 18 people to self-selection.

4.2.1. Age and sex

The age range for the group as a whole was 31 years to 65 years. The mean age was 50.82 (SD 11.4). Of the sample of 39 people 29, (77%) were female. This is consistent with the higher incidence of females with MS in the general population, (ratio of 1.5-2 to 1 Bashir and Whitaker, 2002).

4.2.2. Mobility at study onset

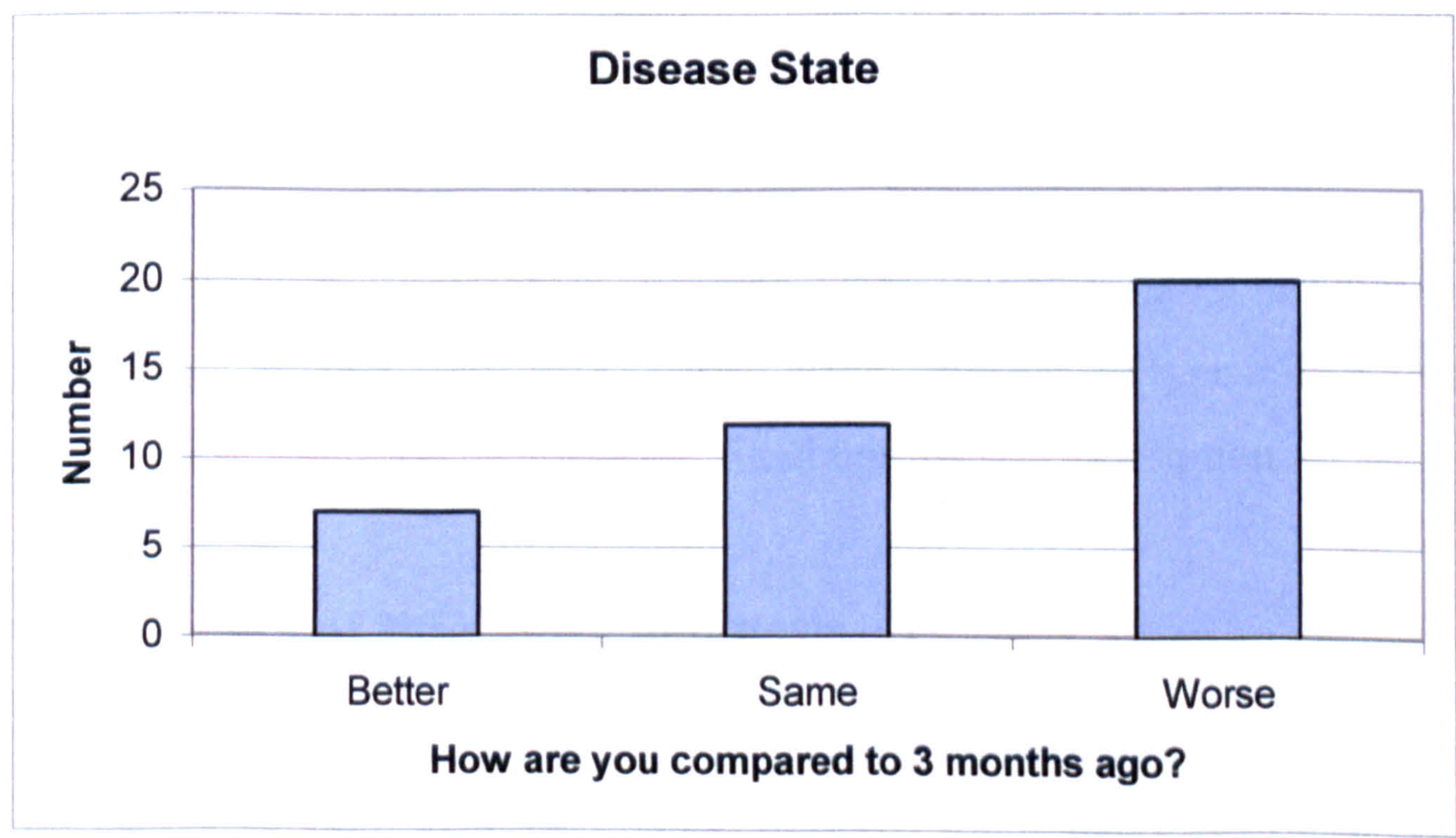
Three of the participants were full-time wheel-chair users with the ability to mobilise for a few steps around the home with an aid. This was not classed as a functional ability as they were unable to use their walking aid outside and required intermittent wheelchair assistance. The rest of the sample could mobilise with or without an aid or with the assistance of one person for 30 yards or more. All participants were able to transfer from chair/bed/car etc safely. There were 23 (58%), participants who used some form of walking aid outside, either one stick or a pair of crutches. One person used a four-wheeled walking aid. There were 13 (28%), participants who did not require walking aids in their daily activity. Of the 39 participants who completed the study 30 (75%), lived in bungalows and one person who had a house required a stair lift.

At the time of recruitment to the study, 50% of the participants, (20 people), were driving with only one of the 20 requiring a hand-controlled adapted vehicle.

4.2.3. State of MS as perceived by the participants over the preceding three months pre study involvement

The participants were asked to indicate their perception of their MS state for the preceding three months. The whole sample is included.

Figure 4.1. The disease state as indicated by the participants



Of the 39 people included in the study seven, (18 %) declared themselves to be better than three months ago, twelve people, (30 %), felt they were the same and 20 people, (52%), felt they were worse.

4.2.4. Marital status

Of the 39 participants in the study 37 (95%), were married or had long-term partners and 34 (87%), of the participants had children. The age ranges of the children were 2 years to 29 years with the mean age being 20 years.

4.2.5. Work status

Of the 39 participants in the study, six, (15 %), were working full-time, 10, (26%), were working part-time, 20, (51%), were unable to work due to the problems caused by MS and three, (8%), were of retirement age and had consequently retired from employment.

4.2.6. MS categorisation

There was a predominance of the secondary progressive type of MS in this study with 51% (20) of the participants in this category. There were 8% (3), of the participants with the primary progressive type and 41% (16) with the relapsing/remitting type. The person's neurologist defined these classifications.

These findings are in line with the commonly accepted distribution of disease type found in the MS population at large. There has been some thought given recently to a fourth category that of Benign MS (MS Trust, 2006). This type is characterised by very infrequent relapses with good interim recovery and minimal residual symptoms. It has been estimated that 20% of people exhibit this benign type of MS, (MS Trust 2006). None of the study participants fitted this disease description.

4.2.7. Length of time since diagnosis

Of the 39 participants 20%, (n= 8), were recently diagnosed in the 0 to 5 year range, 30%, (n=12), in the 6 to 10 year range, 16%, (n= 6), in the 11 to 15 year range, 18%,

(n= 7), in the 16 to 20 year range and 16%, (n= 6), were over 20 years since diagnosis. This information was available to the researcher in the participant’s physiotherapy notes.

4.2.8. Disability status

The MS Trust broadly defined the severity of disability as follows: Mild disability: having minimal effect on daily life. Moderate disability: having transitory symptoms/long term persistent symptoms effecting daily life. Severe disability: persistently debilitated. These definitions were applied to this study.

Of the 39 participants 13, (33 %) were deemed to have a mild disability. 23 people, (59%), were in the moderately disabled category and three people, (8%), were deemed to be in the severely disabled category.

4.2.9. Problems identified at study outset

Using the results of the GNDS it was possible to determine the problem areas that predominated for the group as a whole. Table 4.1. shows the self-reported problems in order of prevalence after the first assessment.

Table 4.1. Problems identified by the participants in order of prevalence

	Walking Balance	Fatigue	Bladder	Bowel	Memory	Spasticity	Sensation	Pain
No.	39	37	37	25	23	17	12	10
%	100%	95%	95%	64%	58%	43%	30%	26%

4.2.10. Demographics: Between-group comparisons

Table 4.2 shows the between group demographic comparisons after randomisation.

Table 4.2. Demographics: Between-group comparisons

Area assessed	Number in Physiotherapy (n= 21)	Number in Self-selection (n=18)
Demographics	Women 17 Men 4	Women 12 Men 6
Mobility	No aid 6 Aid 13 Mostly W/C 2	No aid 7 Aid 10 Mostly W/C 1
Work status F/T= full time P/T = part time	Working F/T 3 P/T 7 Retired/MS 10 Retired 1	Working F/T 3 P/T 3 Retired/MS 10 Retired 2
MS Type.	Primary progressive 1 Relapse/Remit 11 Secondary progressive 9	Primary progressive 2 Relapse/Remit 9 Secondary progressive 7
Time since diagnosis	< 5 years 4 5-10 years. 8 11- 15 years 3 16- 20 years 3 More than 20 yrs 3	< 5 years 4 5-10 years 4 11-15 years 3 16-20 4 More than 20 yrs. 3
Disability status at randomisation	Mild 6 Moderate 13 Severe 2	Mild 7 Moderate 10 Severe 1

4.2.11. Between-group comparisons of the AMCA scores pre exercise

The main purpose of this study was to illustrate functional changes after the two exercise interventions had been completed and to show whether one exercise approach provided better outcomes than the other. To this end the Amended Motor Club Assessment (AMCA), was used as the primary outcome variable for the reasons described in Chapter 3. The mean values for the AMCA did not differ significantly between the two groups at the start of the study. The pre exercise mean score for the physiotherapy group was 37.1 (sd= 8.41) and 38.8 (sd=8.54) for the self-selection group. An unpaired t test, (two-tailed) confirmed that there were no significant differences between the groups (t= 0.621. df= 37. p= 0.54. sd= 2.72).

4.3. Section two. Results from the assessment scales for the pre exercise phase of the study

This section will report on the results of the two-tailed t test comparisons of measures pre and post education that comprised the pre exercise phase of the study.

4.3.1. Results of the data collected from the whole sample

The words “High” and “Low” in the following tables denote the direction in which the mean was required to deviate to demonstrate improvement. “*” denotes scores that demonstrated significance at or below the 0.05 level. A paired t test, (two tailed) was used for analysis purposes.

4.3.1.1. Results of the assessment scales for the whole sample

Table 4.3. Pre/post results all scales pre exercise phase (whole sample)

TEST	AMCA High	GNDS Low	HAQ Low	NRS High	Walk Low	MAS Upper Limb Low	MAS Lower Limb Low	MRC Upper Limb High	MRC Lower Limb High
Paired t test 2-tailed.									
P Value	0.500	*0.017	0.097	0.706	0.698	0.099	0.519	0.636	0.049
t	0.681	2.493	1.704	0.381	0.391	1.690	0.652	0.474	2.030
Pre intervention mean	38.28	18.64	18.94	5.89	21.70	.546	1.07	4.19	3.80
Post intervention mean	37.87	16.92	17.30	5.79	22.24	.666	1.12	4.15	3.66
Standard deviation	3.76	4.30	6.01	1.68	8.41	.441	.508	.506	.420

AMCA	GNDS	HAQ	NRS	MAS	MRC
Amended Motor Club Assessment	Guys Neurological Disability Status Scale	Health Assessment Questionnaire	Numerical Rating Scale	Modified Ashworth Scale	Medical Research Council

The only scale that demonstrated a positive change after the pre exercise intervention was the GNDS, (see table 4.3.). The implications of this finding will be discussed in Chapter 6.

4.3.1.2. Pre/post results MSQoL 54 (whole sample)

Table 4.4. Pre/post results MSQoL 54 pre exercise phase (whole sample)

TEST	Domain 1 Physical health High	Domain 2 Limitation due to physical health High	Domain 3 High Limitation due to emotional health	Domain 4 Low Pain	Domain 5 High. Emotional well being	Domain 6 High Energy
Paired t test 2-tailed						
P value	0.215	0.653	0.697	0.946	0.365	0.452
t	1.335	0.498	0.450	0.077	1.020	0.833
Pre education mean	1.519	1.235	1.596	2.463	4.154	3.848
Post education mean	1.575	1.220	1.583	2.480	4.234	3.394
Standard deviation	.132	.060	.051	.375	.175	1.21

TEST	Domain 7 Health perceptions Low	Domain 8 Social function Low	Domain 9 Cognitive function High	Domain 10 Health distress High	Domain 11 Overall quality of life High	Domain 12 Sexual function Low
Paired t test 2 tailed						
P value	0.954	*0.021	0.147	0.065	0.414	0.051
t	0.061	6.714	1.944	2.854	1.316	3.167
Pre education mean	3.158	2.506	4.705	4.125	5.760	2.042
Post education mean	3.138	2.350	4.840	4.372	5.635	1.885
Standard deviation	.729	.040	.138	.173	.134	.099

The words “High” and “Low” in the table denotes the direction in which the means were required to deviate to demonstrate improvement. The “*” indicates scores that demonstrated significance at or below the 0.05 level

Due to the phrasing of the questions within specific domains some responses required a lowering of the mean, (“Low”), while others required a higher mean, (“High”), to

indicate improvement. The “High” domains were numbers 1, 2, 3, 5, 6, 9,10 and 11. Domains 4, 7, 8 and 12 plus the two items were “Low”. These are illustrated in table 4.4. The only domain showing significance ($p<0.05$) using a paired t test (two tailed) was domain 8, social function. No other domains showed change after t testing at this stage of the study.

4.3.1.3. Pre/post results MSQoL 54 items (whole sample)

Table 4.5. Pre/post results MSQoL 54 items pre exercise phase
(Low scores are indicative of improvement)

	Item 1 Change in health	Item 2 Satisfaction with sexual function
Pre education mean	3.300	2.850
Post education mean	3.270	2.800
Maximum score	5.00	5.00
Minimum score	1.00	1.00

The educational material did not exert any influence over the items as shown in table 4.5.

4.3.2. Summary of the results of the assessment scales from the pre exercise phase

The GNDS was the only scale indicating improvement at the conclusion of the pre exercise phase of the study demonstrating change in the mean at the <0.05 level, (p value 0.017). This finding will be discussed in Chapter 6. The mean changes for all other areas assessed were not indicative of improvement. This was supported by the relevant p values. It could be concluded therefore that the provision of educational material during the pre exercise phase had little effect on physical or psychological function as determined by the assessment scales.

4.4. Section three. Results from the assessment scales for the exercise phase of the study

This section describes the results derived from the data gathered during the exercise phase of the study. The two exercise interventions will be presented separately.

It was assumed at study outset that the application of a targeted home physiotherapy programme would produce a better physical outcome than a programme that was self-selected with no specific physiotherapy input. The data collected pre and post intervention was expected to uphold this assumption.

4.4.1. Results of the data collected from the physiotherapy group

The reader is referred to Chapter 3 section 3.8 for information regarding data input and results calculation. The same procedure was adopted for the physiotherapy results and for the self-selection results. The results were calculated using a paired t test, (two-tailed), and are presented in table form with the MSQOL being shown separately due to the method of analysis required. < 0.05 was the designated significance level.

4.4.1.1. Results of the assessment scales for the physiotherapy group

Table 4.6. Pre/post physiotherapy results for the assessment scales

TEST Paired t test 2 tailed	AMCA High	GNDS Low	HAQ Low	NRS High	Walk Low	MAS Upper Limb Low	MAS Lower Limb Low	MRC Upper Limb High	MRC Lower Limb High
Physio p value	*0.022	0.713	**0.00 2	**0. 000	0.825	**0.00 2	*0.030	0.091	**0.00 3
t	2.490	0.373	3.670	4.65 6	0.224	3.666	2.333	1.773	3.310
Pre Physio Mean	37.1	18.1	20.0	5.57	20.5	.685	1.14	3.98	3.58
Post Physio Mean	40.1	17.7	14.7	6.95	21.0	.230	.801	4.26	3.95
SD	6.13	5.85	6.54	1.35	10.22	.569	.674	.707	.518
AMCA	GNDS		HAQ	NRS		MAS		MRC	
Amended Motor Club Assessment	Guys Neurological Disability Status Scale		Health Assessm ent Questio nnaire	Numerical Rating Scale		Modified Ashworth Scale		Medical Council (strength scale)	

Table 4.6. shows the pre and post physiotherapy means, p values and standard deviations. Positive change is demonstrated in the AMCA. The GNDS did not demonstrate any such gain. The HAQ showed change, as did the NRS. There was no notable improvement in the walking times after physiotherapy.

Tone, (MAS), showed improvement in the upper limb scores. The lower limb scores also showed improvement. Physiotherapy did not appear to demonstrate any gain in upper limb strength. However, lower limb strength improved.

4.4.1.2. Pre/post physiotherapy results for the MS QoL 54

Table 4.7. Pre/post physiotherapy results for the MS QoL 54

TEST Paired t test 2 tailed.	Domain 1 Physical health High	Domain 2 Limitation due to physical health High	Domain 3 Limitation due to emotional health High	Domain 4 Pain Low	Domain 5 Emotional well being High	Domain 6 Energy High
P value t	0.050 2.264	0.179 1.788	0.944 0.079	0.393 1.080	0.935 0.087	0.628 0.524
Mean pre physio	1.463	1.215	1.530	2.969	4.236	3.472
Mean post physio	1.575	1.297	1.523	2.666	4.247	3.675
SD	.157	.091	.146	.485	.278	.869

	Domain 7 Health perceptions Low	Domain 8 Social function Low	Domain 9 Cognitive function High	Domain 10 Health distress High	Domain 11 Overall quality of life High	Domain 12 Sexual function Low
P value t	0.380 0.987	0.071 3.553	*0.017 4.791	0.358 1.084	0.463 1.123	0.348 1.109
Mean pre physio	3.217	2.332	4.636	4.340	5.636	1.942
Mean post physio	3.513	2.063	4.940	4.511	5.973	2.059
SD	.671	.131	.126	.315	.424	.210

The results for the MSQoL 54 analysis for the physiotherapy group are shown in table 4.7. The words “High” and “Low” denote the direction in which the mean was required to deviate to demonstrate improvement. The only domain showing significance using a paired t test, (two-tailed), at < 0.05 level was domain 9, Cognitive Function.

4.4.1.3. Pre/post physiotherapy results for the MS QoL 54 items

Table 4.8. Pre/ post physiotherapy results for the MS QoL 54 items
(Low scores are indicative of improvement)

	Item 1 Change in health Low	Item 2 Satisfaction with sexual function Low
Pre physio mean	3.272	2.772
Post physio mean	2.809	2.761
Maximum score	4.00	5.00
Minimum score	1.00	1.00

4.4.1.4. Results summary for the physiotherapy group

The physiotherapy group demonstrated improvements in the Amended Motor Club Assessment scores, (AMCA), the Health Assessment Questionnaire, (HAQ), and the Numerical Rating Scale, (NRS). There were also improvements shown in upper and lower limb Modified Ashworth Scale, (MAS) and Medical Research Council scale, (MRC) showed gains in the lower limb.

There were no improvements in walking times, upper limb strength or in the Guy’s Neurological Disability Scale, (GNDS). The MSQoL 54 showed improvement in domain 9, Cognitive Function. There were no other changes in this scale with physiotherapy. The implications of these results will be discussed in Chapter 6.

4.4.2. Results of the data collected from the self-selection group

The reader is referred to Chapter 3 for information regarding data input and results calculation. The same procedure was adopted for the self-selection results and for the physiotherapy results. The results are presented in table form with the MSQoL being

shown separately due to the method of analysis required. The self-selection choices are also shown.

4.4.2.1 Self-selected exercise choices

There were 18 people assigned to the self-selection group. Of these four people chose to include two activities in their self- selected regime. The choices are shown in table 4.9.

Table 4.9. Self-selected exercise choices

Participant	Walking	Gym	Yoga (home)	Yoga (class)	Pilates	Home gym	Static bike	Swimming	Motorcise
1			*						
3					*			*	
4	*			*					
5							*	*	
7	*								
9				*					
12				*					
17							*		
19									*
20		*							
21		*							
25	*								
28	*								
30		*							
31						*			
33		*					*		
36								*	
40						*			

Four people, (22%), elected for an extended walking regime, four, (22%), joined a gym, one, (5%), did home yoga and three, (16%), joined a yoga class. Two people, (11%), used a home gym and three, (16%), used a static bike at home. Three, (16%), went swimming and one, (5%), undertook motorcise, a progressive cycling regime. One person joined a Pilates class.

Four people elected to pursue two exercise activities. One person did Pilates and swimming at the local gym. Another did walking and yoga. The third person used a static bike at home and went swimming and the fourth person used the local gym and a static bike at home.

The most popular exercise choices were walking and the gym. The gym involved low resistance weights and the use of the treadmill. It also included the use of the pool, Pilates classes and Yoga. Those who chose the gym were able to take advantage of a discounted membership rate that had been negotiated for use by trust patients for rehabilitation purposes. The gym in question was located in Lincoln. The researcher was unaware of any other locale that offered such concessions for the disabled in the region at the time of this study.

The paired samples t test (two-tailed) was applied to the self-selection exercise group results as with the physiotherapy group. The results are presented in table form with the MSQOL being shown separately as previously.

4.4.2.2. Results of the assessment scales for the self-selection group

Table 4.10. Pre/post self-selection results for the assessment scales

TEST Paired t test. 2 tailed.	AMCA High	GNDS Low	HA Q Low	NRS High	Walk Low	MAS Upper Limb Low	MAS Lower Limb Low	MRC Upper Limb High	MRC Lower Limb High
Self select p value t	*0.014 2.742	0.462 0.752	0.34 4 0.79 4	0.10 5 1.71 3	0.715 0.372	*0.00 0 4.291	*0.039 2.242	*0.008 2.996	0.221 1.270
Pre Self selected Mean	38.8	15.4	14.7	6.05	18.4	.587	1.03	4.34	3.77
Post self selected Mean	42.0	16.2	12.5	6.83	17.8	.110	.677	4.69	3.99
SD	4.55	4.38	9.43	1.92	6.05	.471	.675	.491	.743

Table 4.10. shows the self-selection results produced using a paired t test, (two-tailed). (See table 4.6 for key). There was significant improvement in the AMCA but no significant gains in the GNDS. Mean scores for the HAQ and the NRS improved but this was not statistically significant. The Timed Walk also did not demonstrate any gain. MAS in the upper limb and lower limb improved. Upper limb MRC improved but no such improvement was shown in the lower limb score.

4.4.2.3. Pre/post self-selection results for the MS QoL 54

The results for the paired t test including means for the self-selection group are shown in table 4.11. The words “High” and “Low” denote the direction in which the mean was required to deviate to demonstrate improvement.

Table 4.11. Pre/post self-selection results for the MS QoL 54

TEST Paired t test 2 tailed	Domain 1 Physical health High	Domain 2 Limitation due to physical health High	Domain 3 Limitation due to emotional health High	Domain 4 Pain Low	Domain 5 Emotional well being High	Domain 6 Energy High
P value t	0.527 2.083	0.054 3.015	*0.020 1.082	0.348 2.363	0.812 0.217	0.546 0.728
Pre self-selection mean	1.716	1.235	1.647	1.888	3.988	3.299
Post self-selection mean	1.688	1.471	1.777	1.740	4.210	3.677
S.D.	.042	.153	.0323	.210	1.955	1.283

TEST Paired t test 2 tailed.	Domain 7 Health perceptions Low	Domain 8 Social function Low	Domain 9 Cognitive function High	Domain 10 Health distress High	Domain 11 Overall quality of life High	Domain 12 Sexual function Low
P value t	0.812 0.018	0.138 3.382	0.893 5.193	0.342 2.742	0.266 1.231	0.252 0.457
Pre self-selection mean	3.988	2.184	5.096	4.416	5.638	1.819
Post self-selection mean	4.210	1.760	5.083	4.527	6.138	1.708
S.D	1.955	.306	.183	.197	.313	.1574

The only significant improvement was in domain 3, Limitation due to emotional health.

4.4.2.4. Pre/post self-selection results for the MS QoL 54 items
(Low scores are indicative of improvement).

Table 4.12. Pre/ post self-selection results for the MS QoL 54 items

	Item 1 Change in health Low	Item 2 Satisfaction with sexual function Low
Pre self selected activity mean	3.277	2.833
Post self selected activity mean	2.888	1.500
Maximum score	4.00	4.00
Minimum score	1.00	1.00

4.4.2.5. Results summary for the self-selection group

There was a statistically significant improvement in the Amended Motor Club Assessment, (AMCA), upper limb strength,(MRC), and upper and lower limb tone (MAS), after the self-selected programme. There were no such gains evident in the Guy’s Neurological Disability Scale, (GNDS) or the Timed Walk. The Health Assessment Questionnaire, (HAQ), and the Numeric Rating Scale, (NRS) improved their mean scores but the changes were not statistically significant on t testing. The MSQoL 54 showed changes in domain 3, Limitation due to emotional health. There were no other changes in this scale with the application of self-selected activity. The implications of these results will be discussed in Chapter 6.

4.5. Between-group comparisons of the AMCA scores post exercise

There was no between-group difference detected using an unpaired t test, (two-tailed), on the post exercise mean scores of the AMCA, the primary outcome variable (t=0.796. df=37. p=0.431. sd=3.1). The means and standard deviations are presented in table 4.13.

Table 4.13. AMCA between group means and standard deviations post exercise

Area assessed	Physiotherapy (n=21).	Self-selection (n= 18).
AMCA	Mean 40.1	Mean 42.0
AMCA	Standard deviation 10.41	Standard deviation 8.66

To confirm the absence of between group differences a two-way ANOVA calculation was carried out on the outcome data, (exercise phase), for the AMCA. The results are shown in tables 4.14 and 4.15.

Table 4.14. Tests of within subject contrasts

Tests of Within-Subjects Contrasts						
Measure: MEASURE_1						
Source	time	Type III Sum of Squares	df	Mean Square	F	Sig.
time	Linear	184.288	1	184.288	4.919	.033
time * group	Linear	.135	1	.135	.004	.953
Error(time)	Linear	1386.250	37	37.466		

Table 4.14 shows a significant probability time factor of 0.033. This indicated an improvement in both groups between the two assessed time points, ie during the exercise interventions. The interaction between time and group does not show significance (p=0.953) an indication that both groups improved over time and that the improvement was similar for both groups.

Table 4.15. Tests of between-subjects effects

Tests of Between-Subjects Effects					
Measure:MEASURE_1					
Transformed Variable:Average					
Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	120991.539	1	120991.539	977.525	.000
group	110.257	1	110.257	.891	.351
Error	4579.615	37	123.773		

Table 4.15 shows the between-subjects effects. The p value of 0.351 indicated that there was no significant difference between the groups. This upheld the null hypothesis that there was no significant difference on AMCA assessment between the two exercise approaches used in this study.

4.6. Results summary for the groups

There were significant improvements with both interventions detected by the AMCA. MAS upper limb improved in both groups but displayed a better outcome with self-selection.

MAS lower limb also improved in both groups but displayed a better outcome with physiotherapy.

GNDS, Timed walk and MSQoL 54 did not show improvement in either group.

There were significant improvements with physiotherapy on HAQ, NRS and MRC lower limb post exercise scores.

MRC upper limb scores displayed a better outcome with self-selection.

This chapter has shown how the quantitative results were analysed using the data from the assessment scales. The next chapter addresses the qualitative information gathered from the participants' journals. It will present the results of the semi-structured questionnaires contained therein and describe the process used for theme identification and generation from the participants' narratives.

Chapter Five

Subjective impact of pre exercise and exercise interventions Evidence from semi-structured questionnaires and participant comments in the journals

5.1. Introduction

This chapter will report on the information contained in the participants' journals. These journals were completed on a weekly basis throughout the study. The chapter will be divided as follows. Section one will present the results of the semi-structured questionnaire and these results will be presented in the order in which they appeared in the journal. The data for the two groups will be combined unless otherwise stated. These data are relevant to the study in that they provide a subjective perspective to results of the quantitative assessment scales. This section will also contain the results of the follow-up questionnaire. This will demonstrate the long-term effects of exercise on the participants and will provide evidence to determine whether taking part in the study changed their exercise behaviours.

Section two describes the qualitative method selected for data analysis, Interpretive Phenomenological Analysis, (IPA), and comparisons are made with other qualitative analytical methods. There then follows a description of the process followed to obtain insights into the participants' exercise experience in relation to their diary entries. The description will include the stages of transcript examination, the development of initial themes and the eventual production of theme clusters that migrated into major themes categories. The process will be supported with relevant extracts from the transcripts. This will be explored in two parts. Part one will deal with the participants' views during the pre exercise phase of the study and part two deals with the exercise phase to maintain the chronological progression of the study.

5.2. Section one. Data from the semi-structured questionnaire

The journals contained questions that allowed for a "Yes" "No" response as well as the opportunity to add comments. The reader is referred to appendix 2, the participants' journals. Firstly this section will present the pre and post responses pertinent to exercise expectations and perceived activity levels. It will then describe the participants' perceptions of the impact of the education pack and its effects on

quality of life. The physiotherapy and self-selection group results group will then be presented separately. This data was collected to capture aspects of the lived experience of the sample during the study time-scale.

5.2.1. Questions pertinent to the whole sample

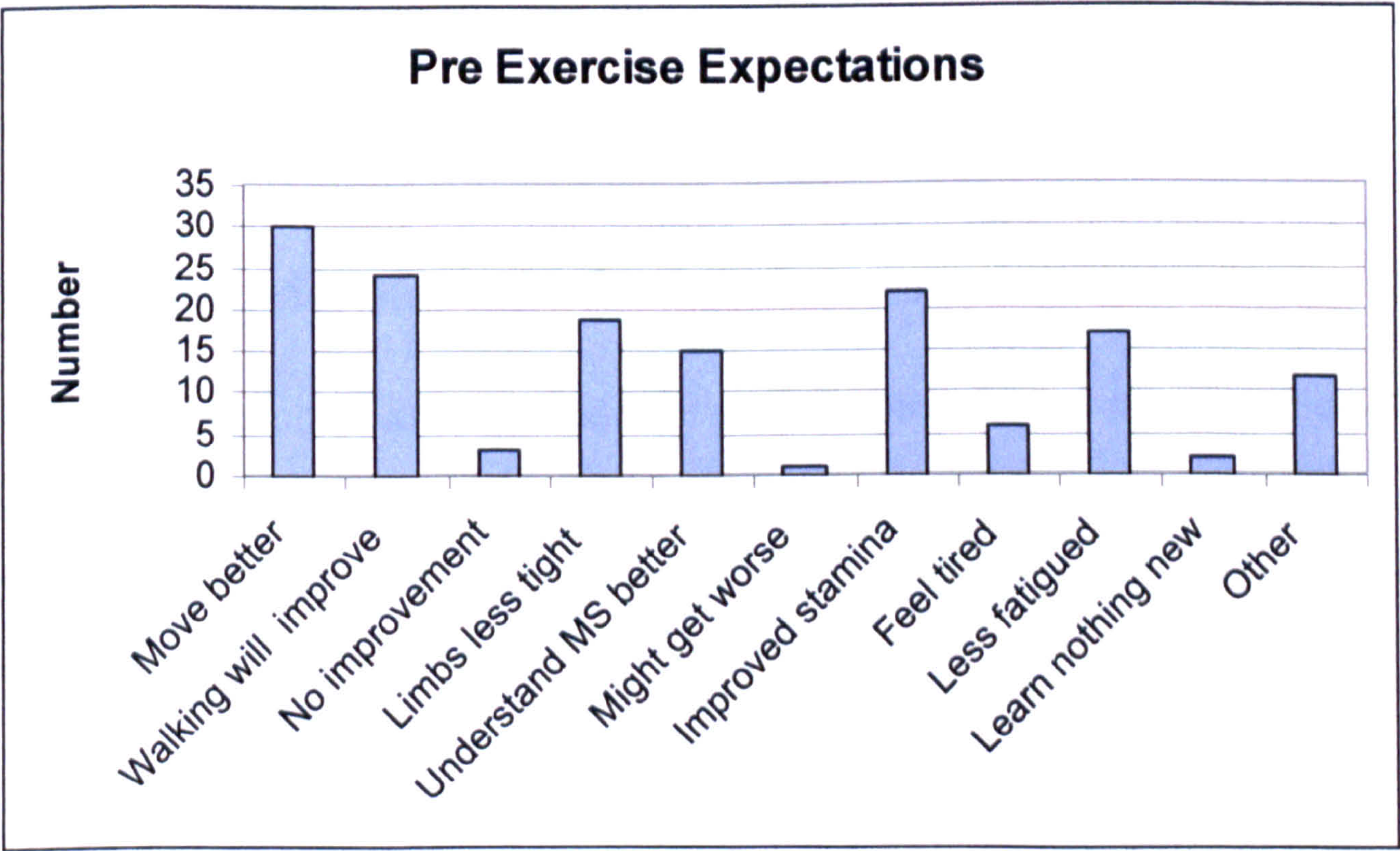
This sub-section will present the results of the questions relevant to the whole sample. These will relate to exercise expectation and exercise outcomes, perceived activity levels pre and post exercise, the participants’ opinions of the educational material and their self-assessed quality of life scores during the pre exercise phase.

5.2.2. Comparison of exercise expectation and exercise outcome for the whole sample

The participants were asked to indicate their exercise expectations by selecting from the options given. They were asked to choose as many options as applicable.

5.2.2.1. Exercise expectations for the whole sample

Figure 5.1. Pre-exercise expectations



The most prominent expectation concerned movement, not confined to walking, with 30 people, (77 %), anticipating improvement in this area. This was closely followed by improvements in walking with 24 people, (61 %), indicating an expectation in this area. There was also a number of people 22, (56 %), expecting improvements in

stamina and a similar proportion 19 people, (49 %), expecting their muscle stiffness to become easier to manage. There were also those who indicated that their fatigue levels might lessen, 17, (44 %) and 15 people, (38 %), felt that their understanding of MS might change as a result of the educational material contained in the packs.

To fully embrace the participants' expectations they were invited to add their own comments under the heading of "Other". The "Other" option was selected by 12 people, (30 %). The additional expectations they recorded were:

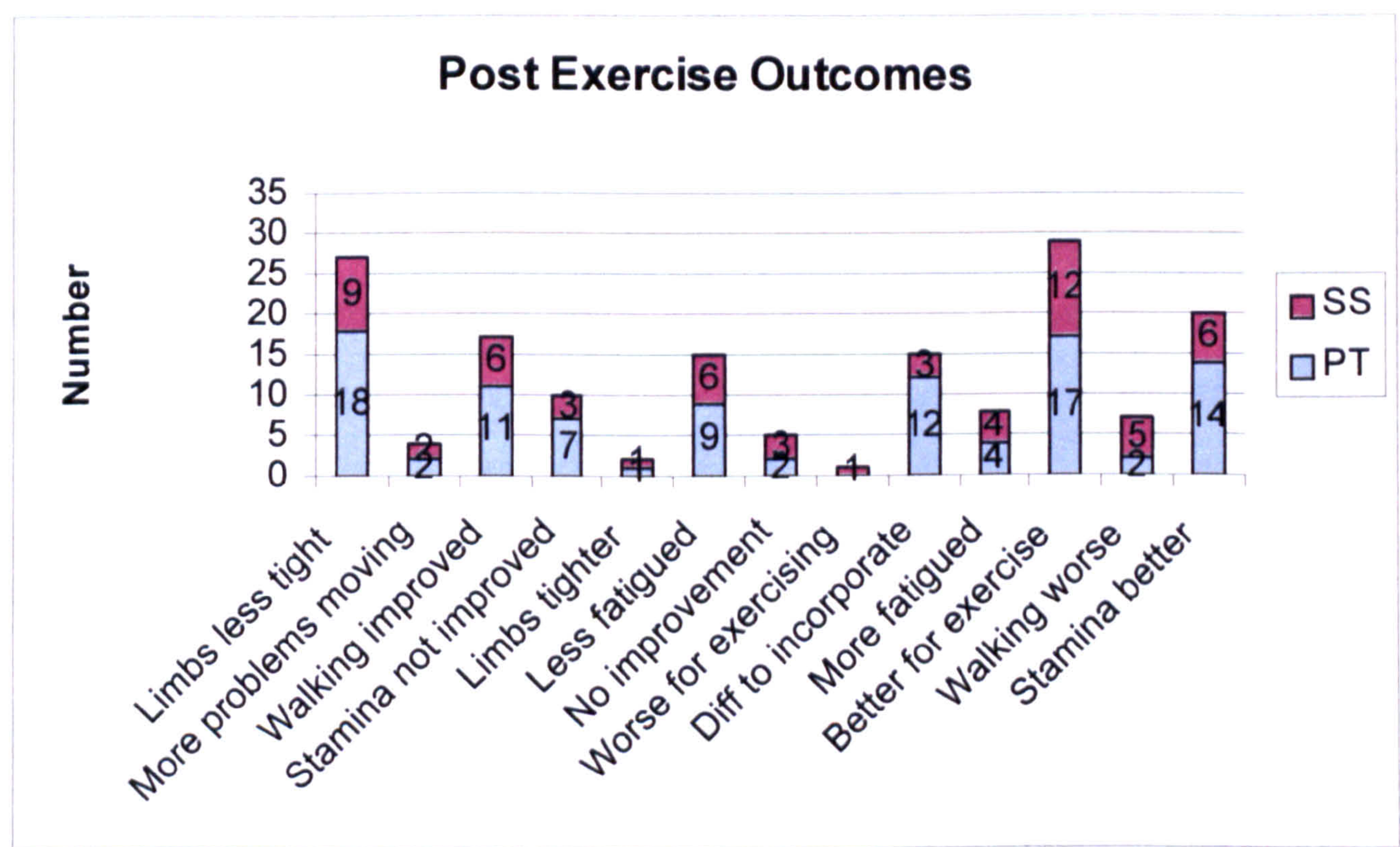
- Reduction in pain.
- To develop my own regime once the study was over.
- Improved sleep quality.
- Improved fitness.
- My condition might improve. (3 People)
- My co-ordination might improve.
- Nothing will happen.
- I might loose weight.
- Improved well being.
- Get more enjoyment from things.

No additional participant comments were offered in response to this question.

5.2.2.2. Exercise outcomes for the whole sample

After the six-month exercise phase the participants were asked to re-assess their exercise expectations and to state their perceived outcomes from exercise participation. They were asked to select all appropriate options. The results are shown in fig 5.2. PT = physiotherapy. SS = self-selection.

Figure 5.2. Post exercise outcomes



Of the 39 participants completing the study, 29, (74 %), reported that they were better for exercising. Of these, 17 were from the physiotherapy group and 12 from the self-selection group. There were perceived changes in muscle stiffness with 27 people, (69 %), reporting improvements in this area. Of these 18 were in the physiotherapy group and nine in self-selection. Other positive gains were shown in improved stamina, 20 people, (52 %), with 14 in physiotherapy and six in self-selection, improved walking ability, 17 people, (44 %), 11 in physiotherapy and six in self-selection and 15 people, (38 %), indicating an improvement in their fatigue levels. Of these nine people were in the physiotherapy group and six in self-selection.

Other outcomes were less positive. There were 10 people, (26 %), who felt that their stamina had not improved, (physiotherapy seven, self-selection two) eight people, (20 %), reported they felt more fatigued, (four in physiotherapy and four in self-selection), seven, (18 %), for whom walking was worse, (two in physiotherapy five in self-selection), five, (13 %), who felt no improvement at all, (two in physiotherapy and three in self-selection), and two, (5 %), who described their limb stiffness as being worse, (one person in each group). One person felt worse for exercising. This person was in the self-selection group.

One important consideration for exercise uptake was the difficulty experienced with incorporating exercise into daily life. There were 15 people, (38 %), who noted that

this was a problem. Of these 12 were in the physiotherapy group and three in self-selection.

Overall the outcomes reflected the initial expectations of the participants in that improvements in limb tightness, stamina, fatigue levels and walking ability were identified. At the end of their study involvement, the participants were invited to comment on the exercise regimes they had undertaken. A selection of comments is now shown.

5.2.2 3. Participants' comments on post exercise outcomes

The following comments are characteristic of the sample.

Participant 9. Group 2. (44.1).

"I think I would have managed better if I had set aside a specific time to exercise each day which is why I have had on occasion problems fitting in doing particular postures."

Participant 32. Group 1. (37.1.)

"I feel the study has helped, I feel I have a better understanding of MS and how it affects my body. It has helped me feel that I can help myself to make my condition manageable."

Participant 11. Group 1. (43.1.)

"An unexpected result of the exercises is the "feeling good" factor, both after exercising and (surprisingly), during."

Participant 40. Group 2. (41.1).

"I appreciate now how hard it is to keep a simple diary! However overall I feel I am considerably improved. I have got back to full-time work. Everyone tells me I look better - well in fact. My husband has commented on my being able to do more in the evenings- previously I just sat down quite unable to do anything much. I feel I am getting more enjoyment too."

Participant 33. Group 2. (20.1.)

“Exercise center is good for confidence in terms of being with people in public place. Not self-conscious about the difficulties I have and having a stick.”

Participant 5. Group 2. (43.1.)

“Thank you for letting me take part in the programme. I have benefited from being involved and I am sure that without the programme I would not have been on the bike or going swimming. As I enjoy exercise I shall certainly carry on with both. Hopefully it will become a better healthier lifestyle.”

Participant 27. Group 1. (37.1.)

“If I had better health throughout I’m sure my results would be better than they are.

Participant 15. Group 1. (43.1.)

“Planning exercise sessions was almost impossible due to the variety, intensity and vagaries of my symptoms. I wish I could have done a better job for the trial.”

5.2.3. Comparisons of activity levels pre and post exercise for the whole sample

As the study involved self- directed exercise, it was important to ascertain the participants’ perceptions of their activity levels before beginning their regimes. The participants were required to self-assess their levels of activity at the beginning of the study. Individuals were then assigned to activity categories based on their view of activity involvement. This indicated a base-line level of activity for each person. The categories were defined as follows:

Sedentary. Does not participate in any exercise/physical activity.

Low. Active bi-monthly or less. 30 to 60 minutes per month.

Moderate. Active/Exercises once/twice weekly. 30 to 60 minutes per week.

High. Active/Exercises up to 30 minutes per day, five days a week or more.

5.2.3.1. Activity levels pre exercise for the whole sample

Activity/exercise included prescribed exercises, yoga, Pilates, cycling, walking, swimming and any home activity, eg gardening, climbing stairs, shopping or house work.

Table 5.1. Activity levels pre exercise for the whole sample

Activity level	Level of disability		
	Mild	Moderate	Severe
Sedentary	3	14	3
Low	8	9	
Moderate	2		
High			

Table 5.1.shows the activity levels pre intervention. Pre intervention, 20 people, (50%) judged themselves to be in the sedentary category. Of these 20 people, three were severely disabled, 14 people were moderately disabled and three were in the mild group. Definitions of Mild, Moderate and Severe as pertinent to this study can be reviewed in Chapter 4.

Seventeen people, (44%) felt that they were in the low activity category. Of these 17 people, nine were from the moderate category and eight from the mild disability category. Two people, (5%), felt they were moderately active before the study began and they were both classified as mildly disabled.

5.2.3.2. Activity levels post exercise for the whole sample

Self-assessed changes in activity levels at study completion are shown in table 5.2. At this stage no one deemed themselves to be in the sedentary category, indicating a 100% increase in perceived activity levels for the group as a whole.

Table 5.2. Activity levels post exercise for the whole sample

Activity level	Level of disability		
	Mild	Moderate	Severe
Sedentary			
Low		12	3
Moderate	12	11	
High	1		

Of the 39 participants 15 people, (38%), felt they had achieved a “Low” level of activity. Of these three were from the severe category of disability and 12 were from the moderate category. Of the remaining participants 23 (59%), considered themselves to be moderately active. Of these 11 were from the moderate disability category and 12 were from the mild category. One person, (2.5%), classified themselves in the “High” category by exercising for five days a week for 30 mins per session. This person was defined as mildly disabled and had joined a yoga group and had taken up swimming with their young child as well as daily walking with the dog. It is appreciated that some people may not have advanced from their initial activity category. However as no one was deemed to be “sedentary” at study conclusion a maintained level of activity could be deemed a positive outcome. The improvements expressed by those with a more challenging disability were encouraging demonstrating that those in the highest disability category were capable of functional improvement when they were encouraged to exercise regularly.

There now follows a report of the results obtained from the journals on the pre exercise intervention.

5.2.4. Opinions on the education pack (whole sample)

Education has the potential to influence a person’s physical and psychological wellbeing. It was included in this study primarily to provide a control intervention so that the benefits of specific exercise could be distinguished from any non-specific benefits associated with participating in research and receiving home visits from the researcher. At the end of the pre exercise phase the participants were asked to state whether they felt the information provided in the education packs was beneficial or not. The results indicated that 35 people, (90 %), of the participants found the pack useful although it offered nothing new. There were four people who declared it to be of no use to them at all.

5.2.4.1. Participants' comments on the content and format of the education pack

The participants were asked to offer suggestions regarding the pack. One person found it too positive with no indication of the negative effects of MS.

Participant 17. Group 2. (6.1.)

"I feel the booklet is far too positive and based on the fact that all MS sufferers have nothing to worry about which is not the case. All I see is an ever closing tunnel in front of me and whether I will get to the end." (Next quote), "Examples of poor or negative effects of MS as well as the positive, nothing will ever happen opinion. You will be OK. What have you to worry about? Life is lovely."

One person felt the information should be available at diagnosis.

Participant 33. Group 2. (3.4.)

"Important to be aware of this information at the time of diagnosis which I wasn't"

One person raised the issue of the side effects of drugs.

Participant 25. Group 2. (4.1.)

"Personally I would have liked more info on the effects and side-effects of the drugs for relieving symptoms."

Personal accounts of how other people with MS cope were also requested.

Participant 32. Group 1. (12.1.)

"Some personal accounts from MS sufferers and their families, especially details of how different forms of MS are coped with by different people."

One person requested more information on their disease type.

Participant 37. Group 1. (11.1.)

“Some more specific information on my type of MS secondary progressive.”

Finally one person remarked that the binding could have been better. It was bound in a plastic cover that was a problem for this person to handle.

Participant 11. Group 1. (14.1.)

“Pack needs an easier to handle binding.”

5.2.5. Perception of quality of life during the twelve-week pre exercise phase (whole sample)

The participants were asked to rate their estimation of their quality of life using a numeric rating scale at Week 1, Week 12 and Week 36. Weeks 1 to 12 covered the pre exercise phase of the study.

There was evidence to show a slight decline in quality of life perception during the 12-week pre exercise phase with a minor deterioration in the mean score. This was not however significant on t testing, (baseline mean 5.89, post intervention mean 5.79, p 0.706).

5.2.5.1. Participants' comments on quality of life perception during the pre exercise phase

Participant 3. Group 2. (6.1.)

“Not a very good week, walking was naf, feeling very tired. Very bad mood swings felt like I could have given up on myself.”

Participant 19. Group 2. (5.1.)

“Still anxious and couldn't sleep in the afternoon. Got up and ironed. Started sewing again for first time since relapse. Couldn't see too well to thread the needle and had to keep resting right leg because of the pedal. Felt really down and went to bed after lunch but couldn't sleep as kept crying.”

Participant 6. Group 1. (3.1.)

“Am getting tired of not having enough energy to do things. House is a mess am tired of not having enough energy to do simple things like cooking. Went shopping and was really suffering at the end.”

Participant 15. Group1. (12.2.)

“I have kept busy but have felt tired and emotionally drained because of the problems with hands and feet.”

5.2.6. Questions on the physiotherapy programme, (physiotherapy group only)

This sub-section will report on the physiotherapy groups' responses.

5.2.6.1. Did you complete the full exercise regime during the previous week?

Once the programme was fully implemented the participants were asked whether they carried out the full regime during the previous week. Of the 21 participants in the physiotherapy group 14, (67 %), completed all of the exercises during the previous week. For the seven people who did not complete all of the prescribed exercises the reasons given were as follows:

- Fatigue.
- Poor balance in standing.
- Difficulty attaching the theraband and lack of strength.
- Time/privacy.
- Pain.

Additional difficulties were highlighted:

- One person had a pre-existing shoulder injury making some exercises difficult, and two others had back pain due to prolonged immobility and poor postural control.

- Exercise performance. One person misunderstood the study requirements and thought they needed to perform all of the exercises at one session. Others needed constantly to refer to the exercise sheet interrupting their progress.
- Weather. Some participants were exercising through the summer months and this impacted on their exercise ability.

5.2.6.2. Difficulty experienced with the physiotherapy programme at study commencement

After each set of exercises had been started the participants were asked whether they were experiencing any difficulties with the regime. The results of the responses after the third exercise set had begun are reported here as it was felt that this would offer an overview of the whole programme. After the initial eight week set up period 12 people, (57%), responded that they were experiencing difficulty with the regime. These difficulties included those associated with full exercise regime completion with the addition of:

- Difficulty with specific exercises that targeted particular areas of deficit, eg lower limb control, tonal difficulties that impeded fluidity of movement and the unexpected amount of effort required to perform seemingly simple exercises.
- Effort. Some people had underestimated the amount of effort required to commence an exercise regime.

5.2.6.3. Participants' comments on difficulty with the physiotherapy programme at study commencement

Participant 6. Group 1. (6.1.)

“Main problem is finding time and privacy to do the sitting exercises especially the ones with the band.”

Participant 8. Group 1. (21.1.)

“Still having some difficulty with the left leg which is very weak.”

Participant 14. Group 1. (25.1.)

“The standing ones are the easiest for me by far although the slow walk is worst. I didn’t realise my balance was so bad.”

Participant16. Group 1. (23.1.)

“The exercises are fine but time consuming. Am still getting muddled with the stretch exercises and have to keep reading and that stops the flow.”

5.2.6.4. Participants’ perceptions of difficulty with the physiotherapy programme at study completion

At study conclusion the participants were asked to rate the exercise experience overall and from their comments the difficulty factor was determined. There was an improvement in the perception of difficulty with the exercise after six months with 15 people, (71%), declaring that they were coping with the regime. Of the six who were still experiencing some difficulty the reasons cited remained as previously mentioned. Ill health throughout the study, family problems and lack of physical ability to perform at an acceptable level to the person were also cited as detractors to full exercise involvement.

5.2.6.5. Participants’ comments on performance of the physiotherapy programme at study completion

Participant 6. Group 1. (38.1.)

“Having the exercise regime has been a constant it has given me something different to focus on. I feel I have more control over my body.”

Participant 8. Group 1. (31.1.)

“Exercises are going well I’m doing about 8 reps for each one.” Next quote. “One thing I have noticed is that I haven’t had a fall for a while.”

Participant 14. Group 1. (38.1.)

“Found the exercises really good especially the standing ones. I did these most and found the slow walk most difficult been trying to perfect it failed miserably! Think my balance has improved through this.”

Participant 16. Group 1. (43.1.)

“The exercises have kept me fitter and I am not so stiff as I was. I also feel relaxed after doing them.”

Participant 27. Group 1. (37.1.)

“If I had better health throughout I’m sure my results would be better than they are.”

Participant 34. Group 1. (33.3.)

“A lot of the time they (Exercises) were ok but if MS is having a bad day or week the exercises don’t help.”

Participant 6. Group 1. (34.1.)

“Looking back I have had a lot of set backs and time management issues. Maybe this is life but I tend to take it personally and get really frustrated.”

5.2.6.6. Participants’ estimations of quality of life before and after physiotherapy

The study participants were asked to rate their quality of life using a Numeric Rating Scale, (NRS). Twice during the physiotherapy stage at Week 12 and Week 36. The anchor points were 1 = worst QoL and 10 = best QoL.

The pre physiotherapy mean score calculated at week 12 was 5.57; the post physiotherapy mean score calculated at week 36 was 6.98. The p value of 0.000 indicated that the mean changes were noteworthy and demonstrated an increase in quality of life perception at study conclusion.

5.2.6.7. Physiotherapy participants’ comments on quality of life at study completion

Participant 6. Group 1. (36.1.)

Has your quality of life been affected by exercise? “Yes. I don’t feel as much a victim of MS as I used to.”

Participant 14. Group1. (40.1.)

Has your quality of life been affected by exercise? “Yes. If you think you can do it then you can!”

Participant 32. Group 1. (35.1.)

Has your quality of life been affected by exercise? “Yes. I feel more positive and have a better understanding of MS and how I can live with the condition.”

These three comments were representative of the general opinion expressed by the physiotherapy participants in the study. Those who answered “No” did not offer any follow-up comments.

5.2.7. Questions on the self-selection programme (self-selection group only)

This sub-section will present the self-selection groups responses relating to their respective exercise regimes.

5.2.7.1. Self-determined exercise frequency for the self-selection group

After the first eight weeks of exercise involvement the participants were asked how often they exercised. From their accompanying remarks it was possible to determine whether they exercised daily, three times a week, twice a week or once a week. The findings are shown in figure 5.3.

Figure 5.3. Self-determined exercise frequency of the self-selection group

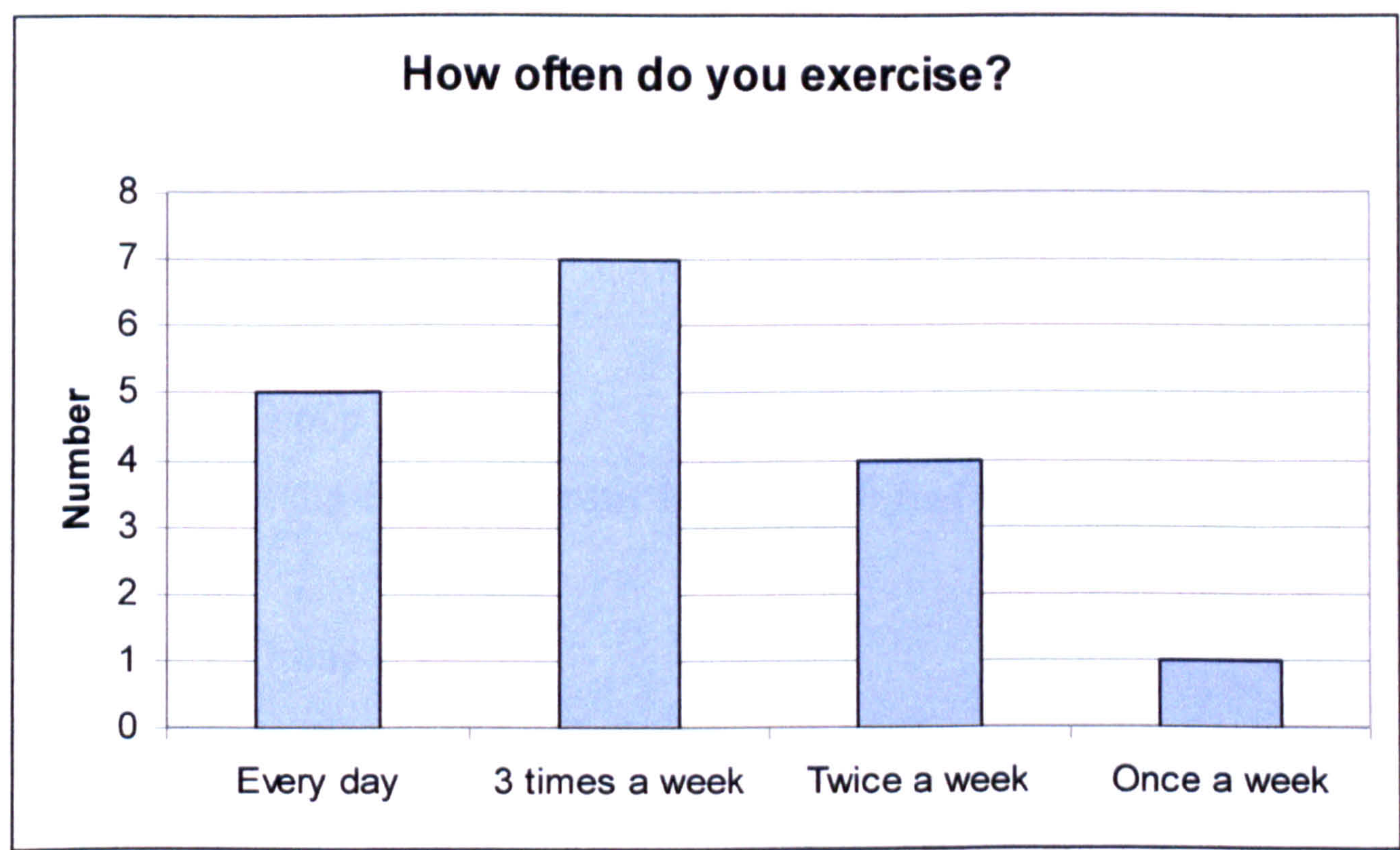


Fig 5.3 shows that five people in the group, (29%), exercised daily, seven, (41%), exercised three times a week, four, (24%), exercised twice a week and one, (6%), exercised once a week. Data were missing for one person.

There were specific reasons offered for not exercising that corresponded with those identified by the physiotherapy group. An additional impediment was motivation. This could be due in some cases to the need to leave the home to exercise that necessitated an extra effort that the physiotherapy group did not encounter.

5.2.7.2. Participants’ perceived difficulty with the self-selection exercise regimes at exercise commencement

The self-selection participants were asked whether they had any difficulties with the exercise regimes at the start of exercise involvement.

It was shown that six people, (35%), had difficulty with their regimes at the beginning of their involvement while 11, (65%), did not. Data were missing for one person. The difficulties experienced were the same as for the physiotherapy group. Nothing new was added at this stage.

5.2.7.3. Participants' comments on self-selection exercise difficulty at exercise commencement

Participant 1. Group 2. (20.1.)

"Did not enjoy yoga as much as I thought I would. Found a lot of exercises painful which they should not be."

Participant 5. Group 2. (18.1.)

"I feel ok about the exercise but my legs feel jellified when I come off the bike."

Participant 7. Group 2. (22.2.)

"I find it impossible to cope with the perceived failure as opposed to progress. I have declined to take up the offer of joining a gym"

Participant 9. Group 2. (18.2.)

"I'm feeling tired in the evenings and shattered after yoga."

5.2.7.4. Participants' perceived difficulty with self-selected exercise at study completion

At study conclusion the participants were asked to rate the exercise experience overall and from their comments the difficulty factor was determined. At study conclusion five people, (29%), were still having difficulty with their regimes with 11, (65%), managing well. Two people did not indicate whether or not this area had improved. The reasons for these difficulties were the same as those noted by the physiotherapy group plus the addition of inappropriate exercise selection related to a lack of physical ability that only became apparent during the regime. There were also unmet expectations that were identified as exercise difficulties.

5.2.7.5. Participants' comments on the self-selection programme

Participant 1. Group 2. (45.1.)

"I think yoga would be very good for younger people who are more supple and I wish I had started yoga about 10 years ago."

Participant 5. Group 2. (26.1.)

“Enjoyed the swimming and being on the bike. I shall certainly carry on doing my weekly routine when the study has finished.”

Participant 19. Group 2. (42.1.)

“The motorcise has not only provided exercise but also a social interaction.”

5.2.7.6. Participants’ estimation of quality of life at study completion

The self-selection group were asked to rate their perception of their quality of life using the NRS. The pre exercise mean for the self-selection group was 6.05; the post exercise mean was 6.83. The p value of 0.105 did not indicate that the change in mean score was noteworthy.

5.2.7.7. Participants’ comments on quality of life at study completion

Participant 1. Group 2. (43.1.)

Has your QoL been affected by exercise? “No. I don’t feel as well in myself as when I was doing the exercises from the physiotherapist. I seem to get more fatigued and my legs aren’t as steady as they used to be.”

Participant 4. Group 2. (26.1)

Has your QoL been affected by exercise? “Yes. It has given me a greater awareness of what I can and cannot achieve. I shall now endeavour to persevere with yoga and swimming where possible.”

Participant 7. Group 2. (40.1)

Has your QoL been affected by exercise? “No. At this moment I’m feeling a bit depressed tired and useless.”

Participant 17. Group 2. (18.1.)

Has your QoL been affected by exercise? “Yes. It keeps me mobile and it is a can do task.”

5.2.8. Follow-up questionnaire

The results of the follow-up questionnaire that was sent out six months after study completion will now be described. The purpose of the questionnaire was to determine whether behavioural change had extended beyond study involvement and to show the extent of continued exercise participation. Of the 39 people canvassed 34 people, (87%), responded to the follow-up questionnaire. 18 people, (53%), were in the physiotherapy group, 16 people, (47%), from the self-selection group.

5.2.8.1. Post study exercise involvement for the whole sample

The participants were asked whether they were still exercising. Of the 34 people who responded to the questionnaire 29, (85%) confirmed that they were still exercising. Of the five who were not exercising one had been involved in a road traffic accident, and four gave no response. This result appears to indicate that behavioural change had occurred and that the participants were now in the maintenance stage of exercise involvement.

The participants were then asked how often they were exercising and for how long at each session. The results are shown in tables 5.3.and 5.4.

Table. 5.3. Exercise participation six months post study

	Monthly exercise		Weekly exercise		3 times weekly exercise		>3 times weekly exercise	
	No.	%	No	%	No	%	No	%
Physio group	0	0	5.	28	11	61	2	11
Self-selection group	1	6	3	19	10	62.50	2	12.50

Table 5.4. Time spent exercising six months post study

Time pr session	< 30 mins		30 mins		45 mins		60 mins		> 60 mins	
	No	%	No	%	No	%	No	%	No	%
Physio group	0	0	16	88.8	1	5.5.	1	5.5	0	0
Self-selection group	1	6.25	10	62.50	2	12.5 0	2	12.50	1	6.25

5.2.8.2. Why are you not exercising?

The four participants who indicated they were not still exercising were asked to state why not. Only one person responded to this question. Their dog, their walking companion, had died and they had let their health club membership lapse.

5.2.8.3. Was it difficult to incorporate exercise into daily life? (whole sample)

Of the 34 responses 27 people, (79%) indicated that they now had no trouble incorporating exercise in their routines. This was indicative of behavioural change that had entered the maintenance stage. It could be assumed therefore that the behaviour was now established although the possibility of regressing to previous stages within the change model was ever present. (See sections 5.2.6.1. and 5.2.6.2. of Chapter 5 for the areas of difficulty noted).

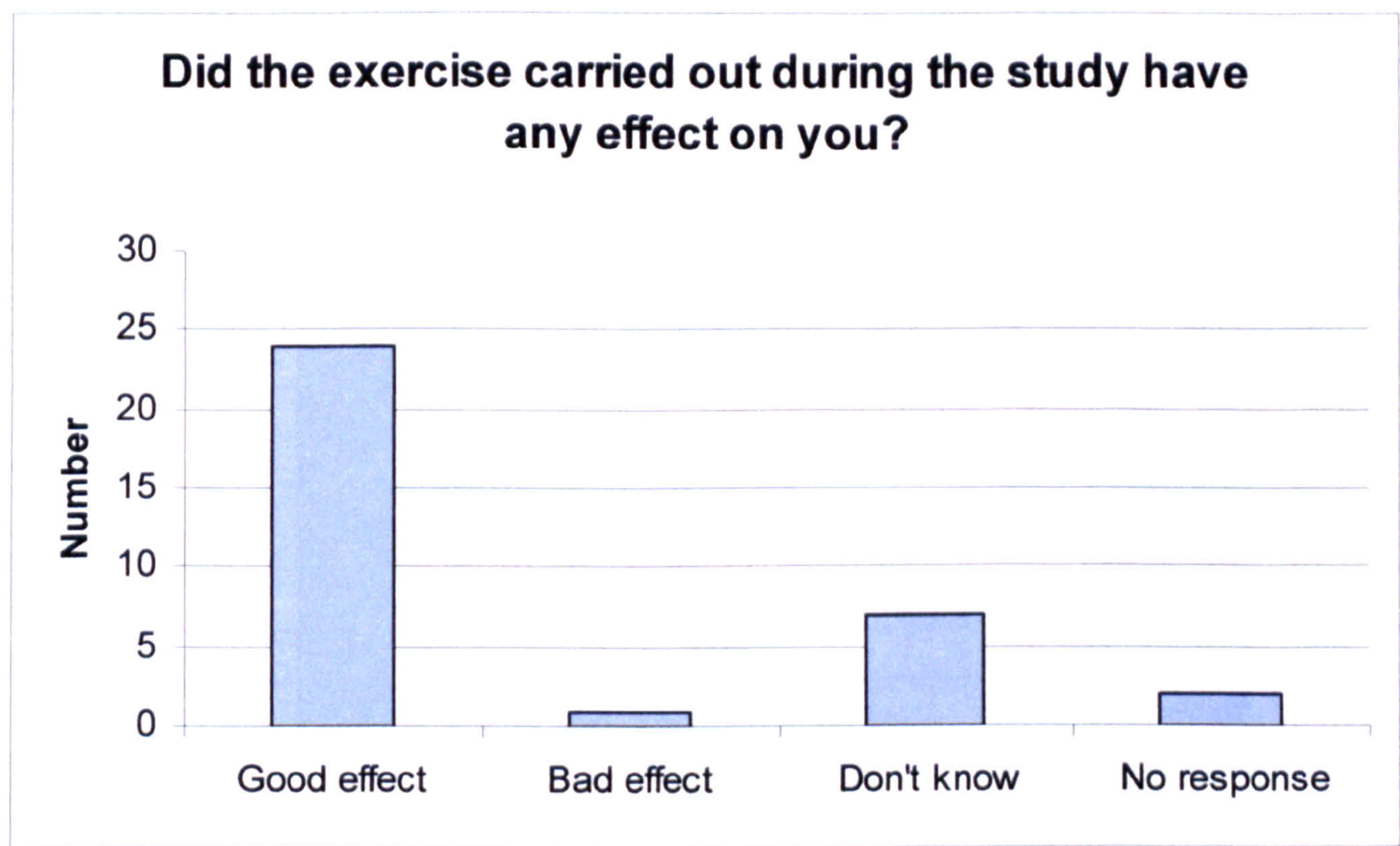
5.2.8.4. Long-term benefit of the programme on the whole sample

The participants were asked whether they felt the effort involved in adopting an exercise regime had been worth it. There was a positive response to this question with 27 people (79%), declaring that exercise had been worth the effort. Of these people 16 were in the physiotherapy group and 11 in self-selection. Only two people answered “No” one in each group and five responded “Don’t know”, one in the physiotherapy group and four in self-selection.

5.2.8.5. Effects of the exercise regimes on the whole sample

The participants were asked whether participating in exercise for the study had any effects on them. They were asked to respond with “Good”, “Bad” and “Don’t know”. Figure 5.4. shows the responses.

Figure 5.4. Exercise effect for all participants



There was a predominantly positive response to this question with 24 people, (70%), noting a “Good” effect from the exercise. There were 12 people from each group. Only one person indicated that the regime had a “Bad” effect on them in that it made them more tired overall. This person was in the physiotherapy group. Seven people responded, “Don’t know” four people were in the self-selection group and three in physiotherapy. Two people in the physiotherapy group gave no response.

5.2.8.6. How long did these effects last?

The participants were then asked how long these effects lasted. See figure 5.5.

Figure 5.5. Duration of effects

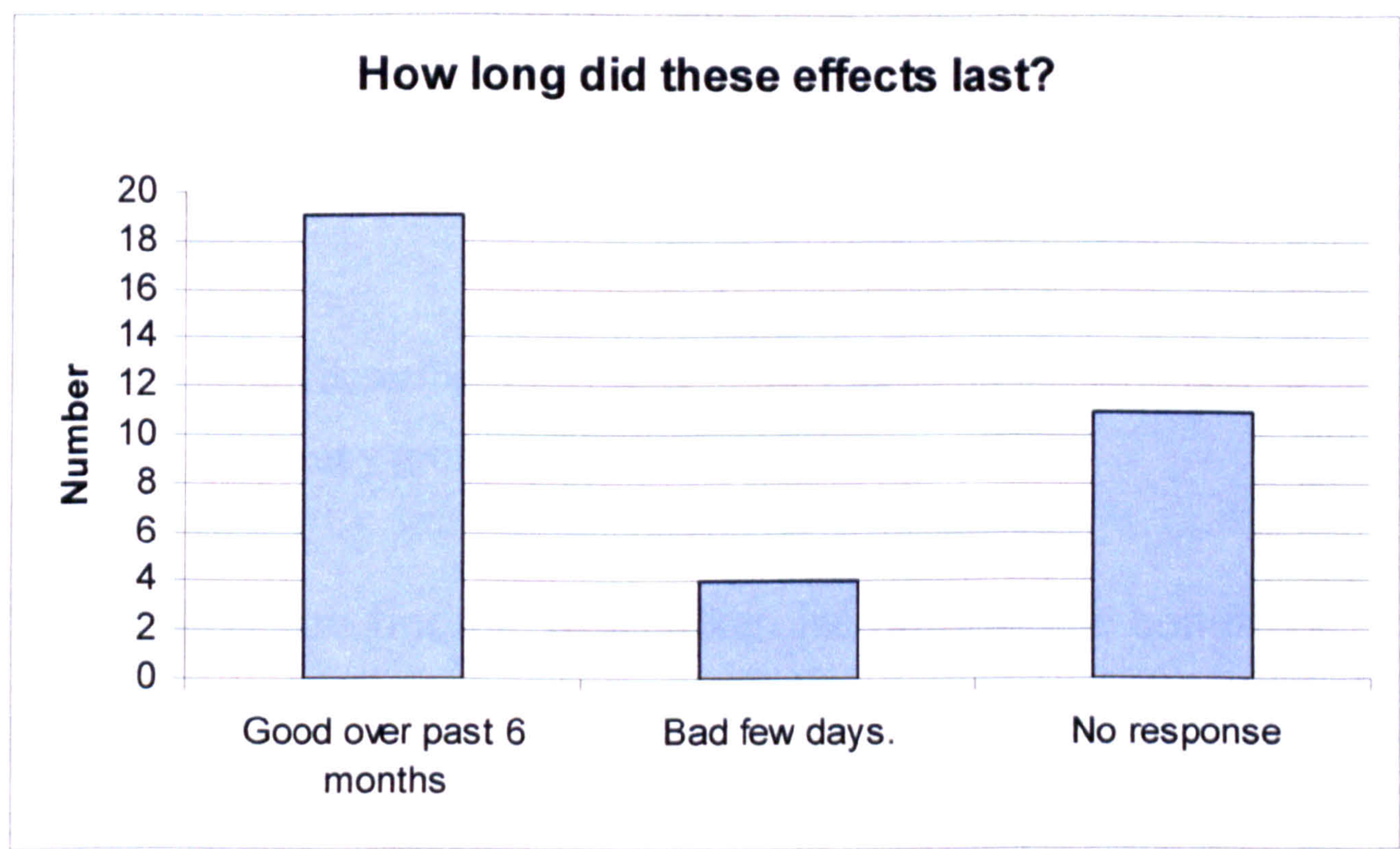


Figure 5.5 shows that 19 people, (56%), indicated that the “Good effect” from the exercise regime had extended over the preceding six months, four had a bad response that lasted only a few days and 11 people did not respond.

5.2.8.7. Areas of positive gain as a result of exercise for the whole sample

The participants were then asked to clarify the effects, good or bad by commenting on their experiences with the exercise. There were no responses from seven people.

Those who did offer comments noted the following:

- Less fatigue. Two people.
- Improved strength. Five people.
- Improved well being. Nine people.
- Improved social interaction. Two people.
- Improved walking ability. Five people.
- Improved co-ordination. Six people.
- Improved confidence. Five people.
- Improved balance. Five people.

5.2.8.8 Areas of negativity (whole sample)

- More fatigue. One person.

- Sensory problems. One person.
- Interference of MS in life. Two people.

Overall the exercise had a positive effect on those involved.

5.2.9. Responses to the follow-up questionnaire, (physiotherapy group)

This sub-section describes the results of the follow-up questionnaire pertinent to those in the physiotherapy group.

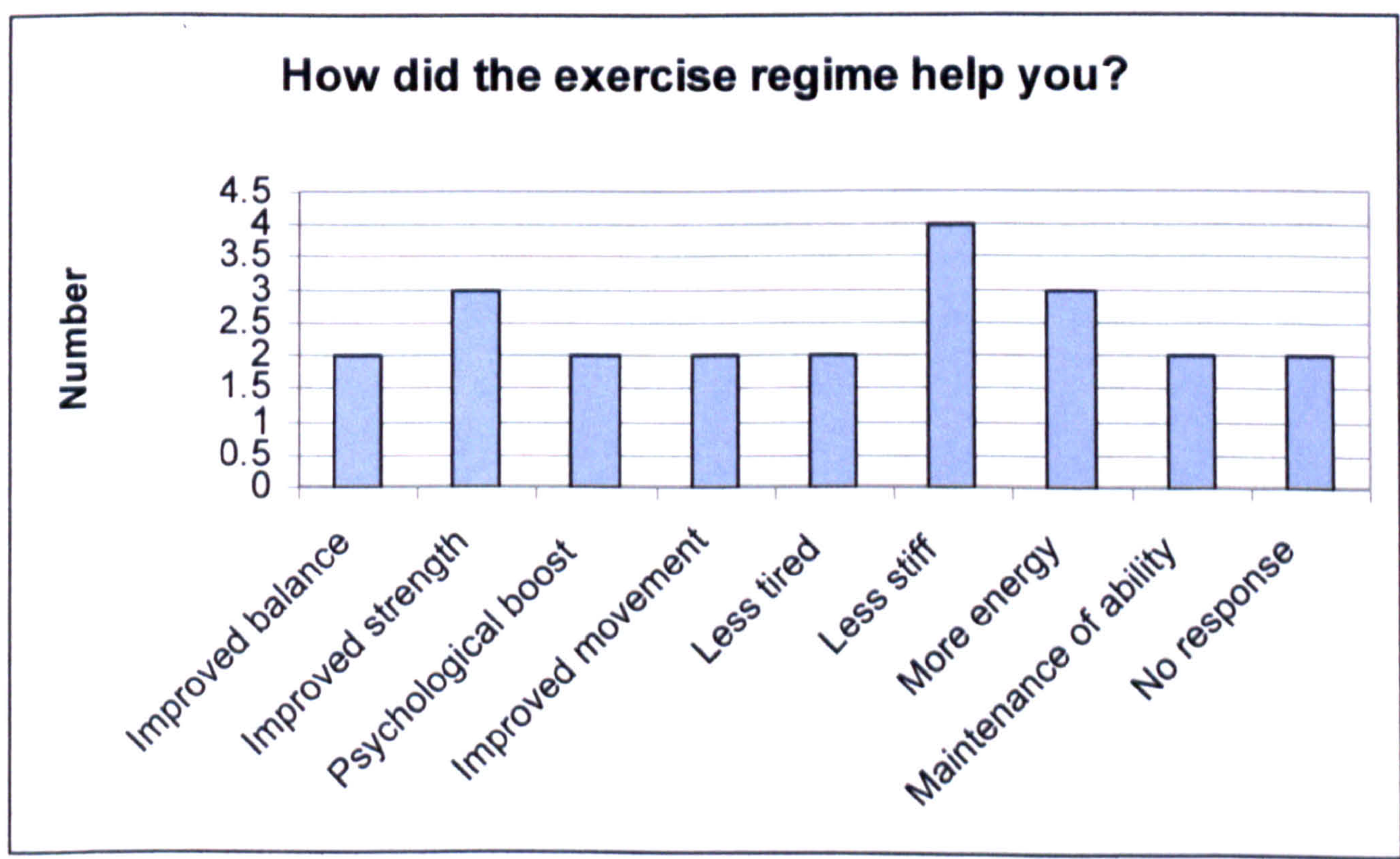
5.2.9.1. Did you find the home exercise programme beneficial?

The first question concerned the participants’ opinion of the benefit of the home exercise regime. Of the 18 respondents 17, (94%), answered yes and one person answered no. This negative response was not qualified with an explanation.

5.2.9.2. How did it help?

Those who answered “Yes” to the previous question were then asked to describe how exercise had helped. Figure 5.6. shows the responses. Most participants noted more than one response.

Figure 5.6. Exercise effect (physiotherapy group)



The responses focused on physical improvements with two people mentioning a psychological benefit. There was no response from two people.

5.2.9.3. Would you have preferred to choose your own regime?

The physiotherapy group were then asked whether they would have preferred to self-select their regime.

This result indicated that the majority of those in the physiotherapy group were happy with the exercise regime they were carrying out with 12, (67%), declaring that they would not have preferred to choose their exercise. The three who answered “Yes” said they would like to design their own exercise programmes. The three who responded “Don’t know” did not offer any reason.

5.2.10. Responses to the follow-up questionnaire (self-selection group)

This sub-section describes the results of the follow-up questionnaire pertinent to the self-selection group.

5.2.10.1. Did you find exercise beneficial?

Of the 16 participants who responded to this question 13, (81%), declared that the regime was beneficial with only two responding negatively. One person did not respond.

5.2.10.2. What exercise are you doing now?

The participants were then asked what exercise they were currently undertaking.

Figure 5.7. shows the results.

Figure 5.7. Self-selected exercise



Three people were doing two activities each. These were swimming and the static bike for two people and gym and Pilates for the third person. The results shown are further evidence of behavioural change that extended beyond the study time scale.

5.2.10.3. Would you rather have been in the physiotherapy group?

The final self-selection question asked whether the participants would have preferred to have been in the home physiotherapy regime. One person responded, "Yes" and indicated that they would have preferred more structure and supervision for their exercise. The nine who answered "No" indicated that they were happy with their own exercise choices but there were indications that they still required some physiotherapeutic input. There was no response from six people.

5.2.11. Summary of results from the follow-up questionnaire and the semi-structured questionnaire in the journal

The results described here indicated that the individuals who were not exercising at study commencement had undertaken exercise and sustained it after the study had concluded. It also showed that those who were engaged in some activity prior to the

study had increased their perceived levels of exercise involvement and maintained them. These findings will be discussed in Chapter 6.

5.3. Section Two. Theme identification and development using participants' narratives

This section describes the process of theme extraction using the participants' journals. A selection of qualitative analysis methods are briefly discussed and the rationale for selecting Interpretative Phenomenological Analysis is considered. The process followed for theme development is described and illustrated using one of the participant's journals as an example. The emergent themes will be illustrated using the participants' narratives.

5.3.1. Qualitative investigation

There are differences between the process used to analyse quantitative data and that required for the interpretation of qualitative data. The field of quantitative research depends mainly on the comparison of numerical outcomes and with its primary focus on the conduction of research in well-regulated situations (Hicks 1999). In this way variables can be controlled and more easily defined. It also allows for the collation of specifics in relation to the research question that can be measured in universally accepted numerical terms that are generalizable (Robson 1993).

Qualitative methodologies tend to shun the confines of such purist numerical outcomes by adopting a more embracing approach to the research process. Miles and Huberman (1994) offered this definition of qualitative data, "They are a source of well-grounded, rich descriptions and explanations of processes in identifiable local contexts. With qualitative data one can preserve chronological flow, see precisely which events led to which consequences and derive fruitful explanations."

Data of this type demand a more open-minded interpretation that encourages the intrusion of real world experiences by allowing them to significantly influence it. Seale and Barnard (1998) observed that multiple realities exist in the world rather than a finite number of "truths" thus to do justice to the data collected these multiple realities must form a vital component of the analysis process.

The value of qualitative studies that encroach on the lived experience of its participants is gaining credence as a relevant adjunct to quantitative data sources and the contribution of such information can no longer be overlooked. Qualitative studies now stand on their own merits (Osborn and Smith 1998. Reynolds and Prior 2003) as well as being employed in combination with quantitative techniques (Dixon-Woods et al 2005. Kersten and McLellan 1996).

5.3.2. Concepts pertinent to qualitative inquiry

This sub-section will introduce the concept of qualitative research including an overview of a selection of some of the qualitative study methods currently used.

There are accepted investigative methods used by qualitative researchers. These are governed by the research approach, how the research was conducted and what it hoped to demonstrate. According to Ashworth (2006) qualitative research aims to “...provide rich descriptive accounts of the phenomenon under investigation.” This is achieved by amassing data from interviews, transcripts and written accounts. The researcher then attempts to extract the meanings buried within the texts.

Tesch (1990) commented on the fluid and indefinable nature of qualitative research and proposed these distinctions between different language orientated qualitative approaches. Firstly there was a structural analysis that he proffered as a method of categorising data for examination with the eventual evolution of a theory. This theory building involves the distilling of categories from a classification system to develop concepts. The process evolves through a series of refinements to discover whether connections exist between the concepts identified. These concepts are then explored further to develop a theory that explains these emerging concepts. Secondly he proposed an analysis that can be described as either descriptive or interpretative in nature. The descriptive method invites a detailed description of the developing theory. The interpretive method involves the initial separation of relevant data from their content. From this data can be grouped under appropriate organisational headings and interpretations of their individual contexts offered.

5.3.3. Overview of qualitative methodologies

A selective overview of some qualitative research approaches is now presented.

5.3.3.1. Action research

Action research is a pragmatic research method that includes an active problem-solving element. French (1993) suggested that the value of this method lies in its flexibility and adaptability. It requires the researcher to examine the research situation reflect on the difficulties encountered, attempt to solve problems presented by real situations and so advance the knowledge base of the research community. This method was unsuitable for this study as the study process did not lend itself to a problem solving approach.

5.3.3.2. Case study

In a case study the researcher concentrates on one or more cases. A case may be a single person, a community, an event or an organisation. Case study methodology involves a detailed examination that produces an exploratory or confirmatory outcome (Robson, 1993). It may also involve the collation of information from several case studies. The findings from this method of investigation may not be generalisable to a wider population as they are specific to the “study” in question.

5.3.3.3. Focus groups

A focus group is a discussion conducted in a group setting involving individuals with an interest in a particular topic that is co-ordinated but not influenced by a neutral party. Stewart and Shamdasani (1990) have investigated the advantages and disadvantages of this method. On the plus side the researcher can interact with the group to clarify responses, large amounts of information can be gathered quickly and at a relatively small cost and there is the opportunity for follow-up questions to be pursued. The disadvantages lie in the lack of generalisability and the possibility of bias that could be engendered through the interaction of the group members.

5.3.3.4. Grounded Theory

Glaser and Strauss (1967) are the proponents of the Grounded Theory method of qualitative investigation. Essentially it is a method of making sense of what people say about their experiences and then attempts are made to convert these statements into a theory, (Roberts and Taylor 1998). This theory should be grounded in the data collected and is based on the assumption that people make sense of their world even if it appears to be disordered to the outsider's perspective. There is a necessity for a constant comparative analysis that requires the researcher to code the data by sorting labelling and organising each textual nugget of information. The inexperience of this researcher precluded the selection of grounded theory as a data analysis method in favour of a more user-friendly method.

5.3.3.5. Thematic Content Analysis (TCA)

Thematic Content Analysis involves the examination of text for the purpose of its classification into relevant content categories. The categories are divided into common themes that ally to the written word allowing for a natural evolution of themes to emerge. These themes can then be examined for commonalities that are applicable to the initial context categories. From this the pertinent themes can be extracted from the whole and assumptions made as to their meaning. Van Manen (1990) has described themes as “..the stars that make up the universes of meaning we live through.” TCA was considered as a data analysis method but was discarded in favour of Interpretative Phenomenological Analysis. This was because it was felt the data deserved an interpretative approach as the investigator had prior knowledge of all the participants.

5.3.3.6. Phenomenology

Phenomenological investigations have their roots in the philosophical and psychological disciplines. Seale and Barnard (1998) noted that these investigations attempt to “Describe psychological realities by uncovering the meaning of lived experience.” In other words phenomenology attempts to interpret human actions and assign meaning to them by studying the ordinary world and demonstrating individuals' personal experiences of that world. The phenomenological researcher

usually uses interviews or personal written accounts for their data sources (Finley 2006).

5.3.3.7. Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis involves the researcher learning something about the participants' psychological world thus allowing them to interpret the data presented (Smith and Osborn 2006). Usually these are transcripts from interviews but it can be applied to other forms of text-based data sources such as diaries. The method requires an intimate knowledge of the texts that facilitates the interpretive process. Psychologists refer to this as investigating the participants "Lifeworld". From this position the researcher can move towards a statement that defines the meaning in the participants' experience.

5.3.4. Implementation of Interpretative Phenomenological Analysis

This sub-section discusses the theory of IPA in more detail. It will briefly mention other works that have used this method and describes its applicability to this study.

IPA can be compared to the interpretive approach as described by Tesch (1990), as it aims to interpret the themes that develop out of the data and to explain them. It also requires the researcher to take an active role in the interpretative process. The method developed from the desire of psychologists to understand and explain personal experiences from the participants' standpoint rather than trying to merely provide an objective statement about it. Smith and Osborn (2006) indicated that IPA was a dynamic process that depended to some extent on the researcher's ability "--to get close to the participants' personal world." Conrad (1987) described this as the "insider's perspective". Smith and Osborn go on to note that although the researcher's preconceptions can be a complication they are still a necessary part of the process as they invite an interpretative activity that facilitates the analysis.

Husserl (1859-1938) is generally credited with identifying the fundamentals of phenomenology research (McConville 2001). His objective was to provide a foundation for the research disciplines, sciences, arts and humanities by establishing the meaning of their most basic concepts (Ashworth 2006). Husserl believed that what

appears *is* to be taken as a reality, therefore investigation must begin with the experience. In concert with Husserl's idea the aim of IPA is to "--explore the participants' view of the world..", while recognising the dynamic nature of the research process in relation to that exploration (Smith 1996).

It was appreciated that a method of a data organisation would be required to aid with transcript analysis in this study. The categorisation system developed by Van Manen (1990), was used as a platform from which to investigate other methods of data analysis eg TCA. This investigation led the researcher to consider Interpretative Phenomenological Analysis as the method that would best reveal the richness of the data contained in the journals. Smith and Osborn (2006) described IPA as a detailed exploration of "—how participants are making sense of their personal and social world---- the meanings particular experiences, events and states hold for the participants". This detailed exploration unearths like themes and concepts that can then be clustered to illustrate dominant themes. In other words a "re- assembling" of the data. From here the researcher can begin the process of interpretation that is central to this method of analysis.

In the case of this study the researcher's extended involvement with the participants had a relevance to the investigative process that could not be discounted. The researcher had an interest in the participants' psychological world and what it meant to them and this aspect was an integral part of the analysis process. To facilitate the IPA process it was necessary to allow for researcher conceptions that could be related to this previous involvement to intrude into the data. This helped the researcher make sense of the experiences of the participants, the process of Interpretation. This aspect of the research process was a deciding factor in the selection of IPA for this phase of data interpretation. This search for meaning could also inform future practice as far as exercise interventions are concerned was another reason for choosing IPA for this study.

IPA has been used in the evaluation of qualitative research data in a variety of specialities. These include chronic back pain, Osborn and Smith (1998), therapeutic exercise for back pain, Dean et al (2005) and quality of life for women with MS, Reynolds and Prior (2003). The Osborn and Smith work concerned the experiences

of women (n=9), suffering chronic back pain. The data was gathered using a semi-structured interview format completed by patients attending a clinic. Themes were extracted using the IPA methodology. These themes included anger and pain, loss of control, a struggle to accept the new “self” and a struggle to relate this new self as defined by the pain to life’s requirements.

Dean et al (2005) extended the back pain experience to embrace the impact of exercise. They included patients, (n=9), and physiotherapists, (n=8), in the interview process to gain an insight into the different perspectives on exercise adherence. They focused their results on one of the major aspects that emerged, that of time as a major contributor to exercise adherence.

Reynolds and Prior (2003) explored women’s’ strategies for achieving quality of life with MS, (n=27). The women they interviewed intimated that the experience was an ongoing process of “--negotiation” that involved meaningful occupation and role definition, valuing positive life experiences and clarifying beliefs to mention but a few.

5.3.5. Application of IPA to the journal transcripts from the pre exercise phase

This sub-section describes the process of theme development using the template outlined by Smith and Osborn (2006). A narrative of one of the study participants selected at random will be used to demonstrate the theme extraction and interpretative process.

5.3.5.1. Journal analysis

To facilitate analysis the transcripts were transcribed on to computer and printed copies produced. The first stage of analysis involved establishing an intimate knowledge of the transcripts by reading and re-reading them. Significant or interesting ideas were noted and indicated in the left-hand margin of the text. In stage two the text was further examined and emergent themes were annotated in the right hand margins. Stage three involved the clustering together of like themes. Finally in stage

four a table of the dominant themes was compiled with categorisation of the relevant sub-themes.

The process was repeated four times to ensure a complete representation of all the relevant information. An independent researcher also read the transcripts to aid with the sifting of information. This ensured inclusiveness of content. The analysis process will now be described using the transcript from participant 6 group 1 as an example.

5.3.5.2. IPA stage one analysis, pre exercise phase for participant 6

Table 5.5. IPA stage one analysis. Transcript for participant 6 pre exercise phase

Knowledge and symptom understanding. Hope and encouragement How I see myself.	Re info pack. The pack didn't really tell me anything new but was good re-read things. I had tended to accept some of my symptoms as being normal (eg cold feet and fatigue), so it reinforced that MS has affected me in so many different ways. Also it was encouraging to read that for instance most people with secondary progressive MS are still walking after 20 years- there is hope for me, since I don't even have MS that severely.
Fatigue. Loss of role. Control. Poor physical ability impeding participation. Enjoyment. Friendship. Coping. Plan of action.	Week not too bad. Am getting tired of not having enough energy to do things. House is a mess, am tired of not having enough energy to do simple things like cooking. Went shopping and was really suffering at the end. Must make more use of the internet. At least going out cheers me up a bit and enjoy coffee mornings.
Coping. Loss of control. Stress. Poor physical ability. Pain. Worry about father. Fatigue Obligation to fulfil a customary role. How others see me.	Really bad week. Mum went back to Ghana on Monday and S went to Belgium for the day. A didn't give me a minute to myself and has had me in tears more than once. Anyway, some progress, she is now able to climb the stairs which has taken SO much pressure off me! Just walk behind her for safety. My legs have been very stiff and I have been in a lot of pain. Also have felt very stressed because my dada was in hospital but is now ok and we now have to plan for Christmas which I HATE because S says we have "OBLIGATIONS" to family.
Accepting help. Loss of control in own home. Poor self-esteem. How others see me. Stress.	S's mum has been here this week which takes the pressure off me as she is a workaholic and keeps going all day! But my mental stress levels have gone way up because I disagree with her in a lot of ways eg hygiene in the kitchen, but I am not assertive enough to say anything. Also I think she thinks I'm just lazy so the overall benefits are lessened as my stress levels are higher.
Realisation of physical decline. Is this my own fault? Poor motivation. Can I change? Need for more detailed info.	Pack talks about exercise for the first time, I have totally got out of any routine and don't feel physically or mentally motivated to do anything. Maybe that can change The information is quite good but very generalised but that's the whole problem with MS.
Positivity engendered by New Year and lessened demands on physical function. Pride in achievement. Physical ability.	Just enjoyed quiet and relaxing Christmas with only 1 guest my sister. Feel quite positive about things and am looking forward to next year. Had a last minute panic with food and gift shopping but my legs were able to cope ok even though I had to sit down for ½ an hour in Tescos. I keep thinking about Cindy's opinion that maybe the drug is working and is preventing me from getting any worse in what has been a very stressful year.

<p>Stress. Loss. Realisation. Grieving for lost ability and independence. How others see me. Can't manage on my own must have help. Pinning hopes on exercise. ? too much</p> <p>Expectation. Will this change everything?</p> <p>Stress. Fearful ? unable to perform physically.</p> <p>Camaraderie.</p> <p>Stress. Physical ability affected by this. Poor self-esteem. Hopelessness. Can't change this.</p> <p>Taking control over future. Doing something I can do. Not physical. Excitement re future mobility opportunities.</p>	<p>More stressful week than last. I have figured out that what I hate most about MS is my loss of independence, I HATE having to accept help especially in my own home when it's given out of kindness and concern 'cos there's an obligation. I hate not having the energy and motivation to do things. Deep down I think people just think I'm lazy. I'm now starting to feel hopeful about the exercise thing – it's a new year and I need to start making my life change.</p> <p>My dad phoned and is going to help with the car I'm getting with my lump sum from work I'm so excited as he said don't skimp on the type of car. I'll get it adapted and it will give me a new lease of life.</p> <p>Am in a mad panic, going to Antwerp for wedding at weekend stress making my legs really bad.</p> <p>Re info. Part 3 has lots of useful info about sources of help reinforcing the fact that MS sufferers are not alone.</p> <p>Things are pretty bad business wise and am spending all day in the office with S while his mum looks after A. Am feeling really stressed from all angles and my legs are really bad really stiff and sore. I need to lose weight desperately and that makes me feel even worse!</p> <p>This week has been more positive have sort of decided to do an MA probably with the OU. Business looking better but S still needs my help. My dad called to say he's sending my cheque!</p> <p>On the whole the info has been useful.</p>
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Table 5.5 was annotated in the left hand margin with initial thoughts and ideas relating to the participant's entries. At this stage these represented a general overview of the emerging concepts that as yet lacked cohesion. Smith and Osborn noted that at this stage there is no need to allocate meaning to the text or to assign a comment to it.

5.3.5.3. IPA stage two analysis, pre exercise phase for participant 6

As the text was further examined emergent themes were listed in the right-hand margin.

Table 5.6. IPA stage two analysis. Transcript for participant 6 pre exercise phase

<p>Re info pack. The pack didn't really tell me anything new but was good re-read things. I had tended to accept some of my symptoms as being normal (eg cold feet and fatigue), so it reinforced that MS has affected me in so many different ways. Also it was encouraging to read that for instance most people with secondary progressive MS are still walking after 20 years- there is hope for me, since I don't even have MS that severely.</p>	Hope Self-perception.
<p>Week not too bad. Am getting tired of not having enough energy to do things. House is a mess, am tired of not having enough energy to do simple things like cooking. Went shopping and was really suffering at the end. Must make more use of the internet. At least going out cheers me up a bit and enjoy coffee mornings.</p>	Health. Symptoms. Physical ability Fatigue
<p>Really bad week. Mum went back to Ghana on Monday and S went to Belgium for the day. A didn't give me a minute to myself and has had me in tears more than once. Anyway, some progress, she is now able to climb the stairs which has taken SO much pressure off me! Just walk behind her for safety. My legs have been very stiff and I have been in a lot of pain. Also have felt very stressed because my dada was in hospital but is now ok and we now have to plan for Christmas which I HATE because S says we have "OBLIGATIONS" to family</p>	Fatigue Personal relationships. Physical ability. Stress. How others see me.
<p>S's mum has been here this week which takes the pressure off me as she is a workaholic and keeps going all day! But my mental stress levels have gone way up because I disagree with her in a lot of ways eg hygiene in the kitchen, but I am not assertive enough to say anything. Also I think she thinks I'm just lazy so the overall benefits are lessened as my stress levels are higher.</p>	Stress. Poor physical ability. How others see me. Loss of self. Fatigue
<p>Pack talks about exercise for the first time, I have totally got out of any routine and don't feel physically or mentally motivated to do anything. Maybe that can change The information is quite good but very generalised but that's the whole problem with MS.</p>	Realisation Poor motivation
<p>Just enjoyed quiet and relaxing Christmas with only 1 guest my sister. Feel quite positive about things and am looking forward to next year. Had a last minute panic with food and gift shopping but my legs were able to cope ok even though I had to sit down for ½ an hour in Tesco's. I keep thinking about Cindy's opinion that maybe the drug is working and is preventing me from getting any worse in what has been a very stressful year.</p>	Pleasure. No pressure. Pride I did it.
<p>More stressful week than last. I have figured out that what I hate most about Ms is my loss of independence, I HATE having to accept help especially in my own home when it's given out of kindness and concern 'cos there's an obligation. I hate not having the energy and motivation to do things. Deep down I think people just think I'm lazy. I'm now starting to feel hopeful about the exercise thing – it's a new year and I need to start making my life change.</p>	Realisation. Grief Loss. How others see me. Fatigue.
<p>My dad phoned and is going to help with the car I'm getting with my lump</p>	

<p>sum from work I'm so excited as he said don't skimp on the type of car. I'll get it adapted and it will give me a new lease of life.</p> <p>Am in a mad panic, going to Antwerp for wedding at weekend stress making my legs really bad.</p> <p>Re info. Part 3 has lots of useful info about sources of help reinforcing the fact that MS sufferers are not alone.</p> <p>Things are pretty bad business wise and am spending all day in the office with S while his mum looks after A. Am feeling really stressed from all angles and my legs are really bad really stiff and sore. I need to lose weight desperately and that makes me feel even worse!</p> <p>This week has been more positive have sort of decided to do an MA probably with the OU. Business looking better but S still needs my help. My dad called to say he's sending my cheque!</p> <p>On the whole the info has been useful.</p>	<p>Hope for new Year and exercise potential.</p> <p>Pleasure. Excitement at prospect of reclaimed independence. Anticipatory stress.</p> <p>Support and its importance.</p> <p>Stress. Pain spasm. Loss self-esteem.</p> <p>Self-improvement. Something for me.</p>
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5.3.5.4. IPA stage three analysis, pre exercise phase for participant 6

The third stage involved a search for connections between the themes. Firstly the themes were listed in chronological order to ensure all of them were included. The themes are listed in table 5.7.

Table 5.7. IPA stage three analysis. Initial themes for participant 6, in order of presentation

<p>Hope for improvement in MS with drug therapy</p> <p>How I see myself</p> <p>Poor health. Fear of relapse</p> <p>How others see me</p> <p>Fear for the future</p> <p>Loss</p> <p>Grief</p> <p>Mourning</p> <p>How others see me Fat Helpless</p> <p>Decision to improve self with a degree</p> <p>Re-gaining independence through use of car</p> <p>Pride</p> <p>Pleasure</p> <p>Loss of control over life and self. Normality</p> <p>Inability to cope</p> <p>Self-esteem</p>	<p>Expectation of improvement with exercise</p> <p>Life outlook</p> <p>Poor physical ability</p> <p>Lack of physio support</p> <p>Fatigue Weather</p> <p>Stress at inability to function at expected levels</p> <p>Imposed on by others</p> <p>Poor motivation</p> <p>Realisation of decreasing mobility's impact on life involvement</p> <p>Lost goals</p>
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The theme clusters began to evolve as similar concepts migrated together. Table 5.8 shows the formation of the theme clusters that began to emerge for participant 6 group 1. They exhibited physical and psychological characteristics and have been clustered under these headings.

Table 5.8. Physical and psychological theme clusters for participant 6

Physical emergent themes	Psychological emergent themes
Expectation of improvement with exercise Hope for improvement in MS with drug therapy Poor health. Fear of relapse Poor physical ability. Lack of physio support Fatigue Weather Decision to improve self with a degree Re-gaining independence through use of car	Stress at inability to function at expected levels. Imposed on by others Poor motivation Realisation of decreasing mobility's impact on life involvement Lost goals Loss Normality Fear for the future Loss of control over life and self Grief. Mourning How others see me Pride Pleasure Life outlook Fat Helpless Lazy Self-esteem Inability to cope How I see myself Lost goals

5.3.5.5. IPA stage four analysis, pre exercise phase for participant 6

A table of dominant themes for participant 6 was then formulated with the sub-themes included. (See table 5.9). They were organised using their physical and psychological qualities. This refined the theme clusters and presented a representation of the participant's perceptions by allocating them major headings.

Table 5.9. Emergent themes for participant 6

Physical themes	Psychological themes
Living with MS Fatigue Fear of relapse Stress Pain Immobility/Weather Energy Stiffness Attending to usual task Frustration	Making sense of MS Accepting help Helplessness Regret “Normality” Self-esteem Social interaction Demands from others Anger Coping Pleasure Expectation Degree Internet Need to change life outlook Hope Emotional state Lazy Ineffectual. Regret Unable to cope. Isolation Unable to perform How others see me Lack of assertiveness Disability Unable to fulfil role/lost goals Useless. Withdrawing People taking over my place Fat. How I see myself Helpless Lost self-esteem

To summarise the themes identified during the pre exercise phase for participant 6.

Physical theme. Living with MS.

Psychological themes. Making sense of MS. Coping. Emotional state. Disability.

This process was repeated on all of the other transcripts pertinent to the pre exercise phase. The themes identified for participant 6 were representative of the overall perceptions of the other participants plus the additional sub-themes itemised in table 5.10.

Table 5.10. Additional sub-themes extracted from the other transcripts

Physical themes.	Psychological themes.
Living with MS Enjoyment tempered by “MS payback” Unpredictable symptoms	Making sense of MS Anger Hopelessness Guilt at having MS Self-loathing Loss of life potential Denial Shame Coping Acceptance of MS Pleasurable anticipation (of exercise) Perseverance Emotional state Depressed. Negative emotions Poor self esteem Potential failure Disability Not normal

To demonstrate the relationship between the themes extracted from the transcripts a selection of participant comments now follows. They have been included to demonstrate the properties of the categories identified in the transcripts.

5.3.5.6. Comments from the participants’ transcripts illustrating the physical theme

Living with MS

Participant 40. Group 2. (5.4.)

“Terrible face pain developed on right side. Had this before so I know it’s neuralgia. I am really scared this is MS really hope it isn’t” Although this person is sure of the cause of their pain there is the underlying fear that MS will strike again.

Participant 30. Group 2. (1.3.)

“Sat ironing but needed to have a rest after a time as I felt tired. Took some time to get going again but when I did I was ok.” This comment illustrates the impact MS has on daily function and is a constant for those with the disease.

Participant 7. Group 2. (7.1.)

“Is all MS about relapses? I understand the message but is there something more sinister I should know about?”

Participant 11. Group 1. (6.2.)

My right hand is very, very tired. Not sure what to do about it. Rest probably which is very inconvenient.”

Participant 16. Group 1. (6.1.)

“I know I have MS and I wish I didn’t.”

Participant 11. Group 1. (3.1.)

“Becoming worryingly weaker as the week went by. I feel MS management seems to be patient driven. At present finding things out seems to be a matter of luck and having the nerve to ask.”

Participant 12. Group 2. (3.1.)

“Fell in lounge (only due to trying to answer the phone). A depressed day.”

Participant 5. Group 2. (6.1.) (9.1.)

“Saw Cindy, (physio), at rehab center. Always a boost. Am missing her visits. Don’t know what I’d do without her support.” The stress of decreasing ability was ameliorated by the physiotherapy input this person usually received.

Participant 3. Group 2. (7.3.)

“My speech was not very good at times had to really think before I got the words out sounded sometimes like I’d been drinking.”

Participant 16. Group 1. (13.3.)

“I think my worry now is I am getting worse and I am still quite young I would like the progression to be halted. I know my daughter would not be able to look after me.”

These comments illustrate the variety of problems experienced by those with MS and indicate the consequences of them.

5.3.5.7. Comments from the participants' transcripts illustrating psychological themes

Making sense of MS

Participant 4. Group 2. (4. 3.)

"If I was more self aware I could have managed better." This person was self aware as they recognised the fact but they were unable to control situations to their physical and psychological advantage.

Participant 7. Group 2. (10.4.)

"There is still a need for fun and a social life although that is unlikely as I go to bed before most children do and I do not want to spend my time with other people with MS." The whole MS experience was overwhelming and engendered this loss of participation, enjoyment of life and engagement with others. The person seems to feel that encountering others with MS would be bad for them. Perhaps this would re-enforce the fact that MS is a reality and must be faced.

Participant 10. Group 1. (12.2.)

"Having to rely on other people when you are so independent is not easy."

Participant 17. Group 2. (4.2.)

"All I see is an ever closing tunnel in front of me and whether I will get to the end."
This person sees the erosion of life's opportunities and a lack of a future.

Participant 10. Group 1. (12.1.)

"As for having MS I HATE it. They say you should not look back on what you used to do. That's easy for those who don't have it."

Coping

Participant 3. Group 2. (11.3.)

“I have just read my notes over the past few weeks. What a sad person I am! Am going to do something to shake myself up. Full of doom and gloom was not how I used to be. Will see how I can change things.”

This person made this comment after 11 weeks of journal use. It indicated an unexpected effect on self-perception.

Participant 5. Group 2. (6.3.)

“Fed up with it all. Hope for better things next week.” Despite the problems presented by MS there is always an underlying expectation that it will be better eventually.

Participant 4. Group 2. (7.4.)

“Excesses of Christmas and late nights take their toll but fresh air a tonic.”

Participant 16. Group 1. (9.2.)

“Happy to still be able to get around.”

Participant 23. Group 1. (7.2.)

“Went to retail therapy and lunch with friend felt good.”

Participant 7. Group 2. (6.1.)

“Felt a bit more at ease in myself. Went with the flow a bit more.” Allowing for a more relaxed approach has facilitated a sense of calm in this person.

Participant 19. Group 2. (12.1.)

“Had a restful day due to busy weekend. Got up early and did some housework. Went to hairdresser, M—didn’t recognise me!!” Pacing and an understanding of the effects of MS enabled a sense of control over this person’s domain, the home. A feeling of pride in their appearance was reinforced by the husband.

Participant 21. Group 2. (3.1.)

“My philosophy of life with MS. If there is a problem can I find a way round it? Accept help where necessary and defeat as a last resort. MS is a life sentence not a death sentence.” There is a clear coping strategy here that enables this person.

Participant 26. Group 1. (4.3.)

“My body feels very tired right leg dragging a bit but I’m not letting it stop me doing things I need to do.” This attitude of pushing through to maintain control could backfire with a surge of other symptoms.

There were no indications of positive perceptions of self or perception of others expressed in phase one. This does not mean they did not exist just that the participants did not mention them.

Emotional state

Participant 40. Group 2. (7.2.)

“Must watch I don’t turn into a hypochondriac. Scouring the pack for any new symptom!”

Participant 3. Group 2. (6.1.)

“Very bad mood swings felt like I could have given up on myself. ?A failure”.

Participant 34. Group1. (4.3.)

“At times I get frustrated with myself and others. To be honest I feel a bit like giving up but I shan’t.”

Participant 18. Group 1. (3.1.)

“Writing everything down gives me a shock. Yes I have got MS, (I try to pretend I don’t).”

Disability

Participant 3. Group 2. (9.3.)

“I feel that who I am talking to thinks I’m an idiot so you loose your confidence and get quite confused at times.”

Participant 12. Group 2. (14.1.)

“Family does not cope well with my disability but husband and sons great.”

Participant 8. Group 1. (7.1.)

“I wonder what my mate thinks about my waking with crutches which has got slower/ worse over the last few weeks.”

Participant 10. Group 1. (12.3.)

“When asked how you are I always say fine, what is the point of saying anything else? You would only be thought of as a moaner.”

There now follows a description of the process of theme extraction from the exercise phase for participant 6.

5.3.5.8. IPA stage one analysis, exercise phase for participant 6

The process of theme extraction previously described was repeated for the exercise phase. This will now be shown. To preserve continuity the extract selected for demonstration will be that of participant 6 as with the analysis from the pre exercise phase. Significant or interesting ideas were noted and indicated in the left-hand margin (See table 5.11).

Table 5.11. IPA stage one analysis exercise phase participant 6

Realisation. New knowledge. Regret at loss of physical ability. Control. Unaccustomed action. Coping Control Ownership.	I found it quite interesting that “exercise should be appropriate now” 2-3 years ago I was able to do 5 miles on my exercise bike and used weights 3-4 times a week. Began exercises problem with no.10 lifting leg up. Fairly awkward but not impossible. Am starting to gain a bit more control. They are manageable I have adapted them slightly. Am concentrating on the leg exercises. I have a semi routine of doing them before I go to bed am
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Regression	<p>averaging 5-6 sessions a week.</p> <p>Had a bad week feeling very disillusioned with life and MS.</p>
Poor motivation due to perceived lack of control. Mourning for past ability. Low mood.	<p>Doing the exercises most nights I have very little enthusiasm for anything and have periods where I feel I have so little control over anything. Have realised that my mind/brain has really slowed down and I have become very stupid and forgetful and loosing my confidence even to do simple things like help S in the office. I feel real mess and am wasting my life.</p>
Control	<p>Cindy brought the new sheet of exercises. It seems to be taking the programme to a higher level. The exercises are more involved. I will have to adapt them to suit me.</p>
Time privacy Ownership. Adaptation to need	<p>Main problem is finding the time and privacy to do the sitting exercises especially the ones with the band. Once I have actually begun a session it is easier to add another one.</p>
Regaining control Exercise effect Body awareness.	<p>They are starting to make me feel a little more in control of my body. I have noticed that the lying ones sometimes help me to go to sleep but at times my limbs have been tingling when I finish them and I am very aware of my legs. An interesting aspect! I'm trying to do 10 of each exercise, I think that's why I feel a bit more in control.</p>
Positivity. Exercise integration	<p>Am feeling more positive it would be nice to attribute it to the power of exercise but it's more likely S's mum is leaving on Friday! Exercises are going ok It is still much easier to do the lying ones.</p>
Panic not meeting perceived expectation of others.	<p>Help! Cindy will be here in a couple of hours and I'll have to tell her I'm behind!! Have not had a chance to do sitting exercises since Friday have just been so busy.</p>
Enjoyment. Adaptation integration to life's routine.	<p>I like the standing exercises! I can see that they are going to be easier to get onto a routine doing them. Having said that I have only had a chance to do them twice since Cindy went. My parents are here and it is lovely to see them but they are a lot of work and I'm exhausted by bed-time but ok.</p>
Time Me time	<p>Time and opportunity issues are becoming mega!</p>
Positivity exercise effect Improvement in physical ability. Exercise appreciation.	<p>I feel quite positive about the exercises. It's interesting that my body is capable of performing quite specific tasks. It may be too early to tell but I think the standing exercises will help with my balance.</p>
Coping	<p>Have had a good week with exercises.</p>
Losing the routine. Invasion of life's events	<p>Really hectic week. My parents went to London so A took up most of my time. She has so much energy and hardly ever sleeps Result not a good week for my exercises but had lots of exercise running around after A.</p>
Family pressures and responsibility. Loss me time.	<p>A ended up in L hospital for 4 days!! She can't keep anything down and so was on a drip. She then started nursery and caught a really bad cold and was off for a week. Caught another cold at nursery and when she recovered I was sick for 4 days. I have a walking stick I am still trying to get used to it trying to trust it but it is really helping me to walk about. For the first time in years I am not reliant on others to walk about as I don't have to hold onto an arm when I walk. A has not been sick this week so I have been able to do more exercises.</p>
+ve exercise effect realisation of this.. +	
New found	<p>Had my first driving lesson in an adapted car. Have not driven for so long and</p>

independence. Exercise impeded by family responsibility.	my legs wanted to take over control. A bit daunting will need quite a few lessons. Exercises ok at start of week now A has a virus. Quite positive about life in general.
Low mood daughter to demanding	Really bad few days I have been in tears most of the time. Can't cope with A she takes no notice of me when I tell her to do things.
Realisation of need to regain control	My life would be a lot simpler if I took more control of things. I now have a full house and I'm trying to take advantage of it by leaving A and spending time reading and exercising. Saw Dr S and S today. What a fiasco. Told S to drop me off and let me walk with my stick to show how independent I am. Unfortunately it was the wrong entrance and it took me 20 mins to walk to the clinic but I did it. Then I had to walk 600 yds as part of the assessment but I couldn't.
Pride in achievement then performance failure	
Looking for something to blame for unrealised achievements? +ve exercise effect	Looking back I have had lots of set backs and time management issues. Maybe this is life but I tend to take it personally and get really frustrated. Have no time for myself and on top of this S and I need to think if we want another baby. I'm going to be 40 soon and may have left it too late. I need to see past this. But I do feel positive about the programme and feel I have a bit more control of my body.
Improved physical ability	I think the lying exercises have been the most useful especially as they are convenient. I feel I have more control of my legs now they move in different positions more easily. The standing ones have definitely helped my balance.
Change of self-perception. Pride in keeping going. Found me time and enjoyed this. Something to focus on that was solely for me. Physical improvement. Physical control	Has your qol been affected by exercise? Yes. I don't feel as much a victim of MS as I used to. Being able to perform these different moves has focused my mind on my muscles esp. the leg muscles. At least I didn't give up and at times felt pleased to have a bit of "me" time to enjoy. Outcomes. My limbs feel less tight. My walking has improved. I found them difficult to incorporate into my life. I feel better for doing the exercises. My stamina has improved. Having the exercise programme has been a constant it has given me something different to focus on. I feel have more control over my body.

5.3.5.9. IPA stage two analysis, exercise phase for participant 6

As with the pre exercise phase the text was further examined and emergent themes were noted in the right hand margin. (See table 5.12)

Table 5.12. IPA stage two analysis exercise phase participant 6

I found it quite interesting that “exercise should be appropriate now” 2-3 years ago I was able to do 5 miles on my exercise bike and used weights 3-4 times a week.	Realisation. Mourning lost ability
Began exercises problem with no.10 lifting leg up. Fairly awkward but not impossible. Am starting to gain a bit more control.	Control
They are manageable I have adapted them slightly. Am concentrating on the leg exercises. I have a semi routine of doing them before I go to bed	Ownership Adaptation

am averaging 5-6 sessions a week.

Had a bad week feeling very disillusioned with life and MS.

Doing the exercises most nights I have very little enthusiasm for anything and have periods where I feel I have so little control over anything. Have realised that my mind/brain has really slowed down and I have become very stupid and forgetful and loosing my confidence even to do simple things like help S in the office. I feel real mess and am wasting my life.

Cindy brought the new sheet of exercises. It seems to be taking the programme to a higher level. The exercises are more involved. I will have to adapt them to suit me.

Main problem is finding the time and privacy to do the sitting exercises especially the ones with the band. Once I have actually begun a session it is easier to add another one.

They are starting to make me feel a little more in control of my body. I have noticed that the lying ones sometimes help me to go to sleep but at times my limbs have been tingling when I finish them and I am very aware of my legs. An interesting aspect! I'm trying to do 10 of each exercise, I think that's why I feel a bit more in control.

Am feeling more positive it would be nice to attribute it to the power of exercise but it's more likely S's mum is leaving on Friday! Exercises are going ok It is still much easier to do the lying ones.

Help! Cindy will be here in a couple of hours and I'll have to tell her I'm behind!! Have not had a chance to do sitting exercises since Friday have just been so busy.

I like the standing exercises! I can see that they are going to be easier to get onto a routine doing them. Having said that I have only had a chance to do them twice since Cindy went. My parents are here and it is lovely to see them but they are a lot of work and I'm exhausted by bed time but ok.

Time and opportunity issues are becoming mega!

I feel quite positive about the exercises. It's interesting that my body is capable of performing quite specific tasks. It may be too early to tell but I think the standing exercises will help with my balance.

Have had a good week with exercises.

Really hectic week. My parents went to London so A took up most of my time. She has so much energy and hardly ever sleeps Result not a good week for my exercises but had lots of exercise running around after A.

A ended up in L hospital for 4 days!! She can't keep anything down and so was on a drip. She then started nursery and caught a really bad cold and was off for a week. Caught another cold at nursery and when she recovered I was sick for 4 days. I have a walking stick I am still trying to get used to it trying to trust it but it is really helping me to walk about. For the first time in years I am not reliant on others to walk about as I don't have to hold onto an arm when I walk. A has not been sick this week so I have been able to do more exercises.

Had my first driving lesson in an adapted car. Have not driven for so long and my legs wanted to take over control. A bit daunting will need quite a

Mood

Poor motivation. Poor control
Realisation lost ability
How I see myself.

Ownership adaptation

Time for self.
Exercise involvement

+ve exercise effect. Control
Sensory effect
Body awareness

+veity ? cause!

How others see me.
Inappropriate perception of
expectation from others.
Appreciation of exercise
requirement
Expectations of others.
Time for self

+ve exercise effect
Improved physical ability and
body control.

No time for self.
Acceptance and integration of
walking aid. Overcome barrier
of deterioration associated
with use of an aid. Pride in
achievement regaining
independence

Freedom independence

Low mood unable to cope not

<p>few lessons. Exercises ok at start of week now A has a virus. Quite positive about life in general.</p> <p>Really bad few days I have been in tears most of the time. Can't cope with A she takes no notice of me when I tell her to do things.</p> <p>My life would be a lot simpler if I took more control of things. I now have a full house and I'm trying to take advantage of it by leaving A and spending time reading and exercising. Saw Dr S and S today. What a fiasco. Told S to drop me off and let me walk with my stick to show how independent I am. Unfortunately it was the wrong entrance and it took me 20 mins to walk to the clinic but I did it. Then I had to walk 600 yds as part of the assessment but I couldn't.</p> <p>Looking back I have had lots of set backs and time management issues. Maybe this is life but I tend to take it personally and get really frustrated. Have no time for myself and on top of this S and I need to think if we want another baby. I'm going to be 40 soon and may have left it too late. I need to see past this. But I do feel positive about the programme and feel I have a bit more control of my body.</p> <p>I think the lying exercises have been the most useful especially as they are convenient. I feel I have more control of my legs now they move in different positions more easily. The standing ones have definitely helped my balance.</p> <p>Has your qol been affected by exercise? Yes. I don't feel as much a victim of MS as I used to. Being able to perform these different moves has focused my mind on my muscles esp. the leg muscles. At least I didn't give up and at times felt pleased to have a bit of "me" time to enjoy.</p> <p>Outcomes. My limbs feel less tight. My walking has improved. I found them difficult to incorporate into my life. I feel better for doing the exercises. My stamina has improved.</p> <p>Having the exercise programme has been a constant it has given me something different to focus on. I feel have more control over my body.</p>	<p>exercise related.</p> <p>Realisation. How others see me Wanted to show off to consultant backfired!</p> <p>Life intruding on self. Family pressure. +ve exercise effect realisation of the benefit. Physical improvement.</p> <p>Exercise choice and adaptation. Ownership. Physical improvement.</p> <p>+ve exercise effect How I see myself. Pride in achievement Me time.</p> <p>Improved physical ability despite set-backs and family issues.</p> <p>Something for me to focus on Control over body and movements.</p>
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5.3.5.10. IPA stage three analysis exercise phase for participant 6

Table 5.13 shows the themes identified in chronological order for participant 6.

Table 5.13. Themes for participant 6 exercise phase, in order of presentation

Realisation of lost ability	Time
Mourning	Exercise effect
Control +ve and -ve	Symptoms
Ownership	Body awareness
Adaptation	Improved physical ability
Mood	Acceptance
Motivation	Pride
How I see myself	Freedom
How others see me.	Independence
Walking	Life intruding on self
Balance	Family pressure

The emergent themes were then clustered together to identify similarities that could be given a category heading. They have been listed according to their physical and psychological characteristics.

Table 5.14. Physical and psychological theme clusters for participant 6, exercise phase

Physical emergent themes	Psychological emergent themes
Exercise effect	How others see me
Ownership of exercise regime	Pride
Adaptation of exercise regime	Freedom
Integration	Independence
Control	Self-esteem
Wellbeing	
Time.	How I see myself.
Privacy	Family pressures
	Life intruding on self
Improved physical ability	Mood.
Strength	Mourning for lost ability
Walking	Motivation
Balance	Realisation
Goals	
Living with MS problems	
Regaining control physical and psychological	
Pride in achievement	
Freedom/independence	

5.3.5.11. IPA stage four analysis, exercise phase for participant 6

Table 5.15 shows the major theme development for participant 6 with the sub-themes included. They were organised using their physical and psychological qualities. This refined the clusters of themes that most accurately represented the participant’s perceptions.

Table 5.15. Major theme clusters for participant 6, exercise phase

Physical themes	Psychological themes
Exercise effect Improved mood Raised self-esteem Control Self perception Integration Participation Independence	How I see myself More positive/self-esteem Not a victim In control Privacy Life intruding on self Demands from family Realisation of loss
Improved physical ability Less fatigue Improved walking Improved function Coping Pride Freedom Confidence	How others see me In control Participating Valuable
Living with MS Stiffness Balance Cognitive function Sensory disturbance	

The process was then repeated for all transcripts pertinent to the exercise phase. The themes identified for participant 6 were representative of the perceptions of the others involved. There were additional sub-themes that are shown in table 5.16.

Table 5.16. Additional sub-themes extracted from the other transcripts

Physical themes	Psychological themes
Positive exercise effect. Enjoyment Perseverance Exercise benefit/Physio involvement Feel good factor Positive mental attitude Ownership Behavioural change Self esteem Self efficacy Living with MS Weather Sensory disturbance MS payback Pain Improved physical ability Sex life! Interaction Participation Endorsement from significant others Appreciation of the benefit of exercise	How I see myself Isolated Regretful/Guilty Frustrated Anxious over amount of exercise Envious Failure Normal Belonging Triumphant! Fitting in I can do this Positive attitude Confident Motivated How others see me. Participating Normal Belonging Positive attitude Confident Motivated

These themes had a cumulative effect on the participants’ behaviour regarding exercise. The concepts of behavioural change that underpin this study will be examined in relation to the participants and the relevant literature in Chapter 6. It should be noted that the theme titles for the exercise phase were different to those identified in the pre exercise phase. This was anticipated as a result of the exercise interventions and the interrelated nature of the physical and psychological aspects of the participants’ experiences. For example, “Disability” as defined in phase one was replaced with “Improved physical ability”. Likewise “Emotional state” became a more positive “How I see myself”.

To illustrate these themes, extracts from the participants’ transcripts now follow.

5.3.5.12. Comments from the participants' transcripts illustrating the physical themes

Positive Exercise effect

Participant 11. Group 1. (23.1.)

"Exercising more interesting than I expected because I can see progress."

Participant 15. Group 1. (34.1.)

Exercise helps psychologically. I love the lift it gives you."

Participant 2. Group1. (31.1.)

"I found the more exercise I did the fitter and more energetic I became. I shall keep doing some of the exercises when my time permits."

Participant 18. Group 1. (33.3.)

"One of the best side-effects of the exercises has been our sex life, for the first time in 2 years different positions are possible."

Participant 3. Group 2. (40.1.)

"Not only have these exercises helped with my balance but the rest of my body works a lot better like bowels and waterworks."

Participant 19. Group 2. (45.1.)

"The exercise has not only helped with my mobility it has also given me more focus due to improved energy levels. I have even thought of returning to work the improvement has been so marked."

Participant 21. Group 2. (30.2.)

"Exercise has become a way of life."

Participant 5. Group 2. (44.2.)

"I shall certainly carry on doing my weekly routine when the study has finished."

Participant 32. Group 1. (16. 1.)

“Found the leg exercises with band useful. Have used this exercise when legs aching and it seems to help.”

Participant 37. Group 1. (17.1.)

“The exercises are time consuming and surprisingly tiring.”

Participant 23. Group 1. (38.1.)

“Enjoyed doing exercises but finding time to do them all each day hard.”

Participant 4. Group 2. (17.1.)

“A very busy week with less time to fit in exercise time.”

Participant 9. Group 2. (44.1.)

“I think I would have managed better if I had set aside a specific time to exercise each day which is why I have had on occasions problems fitting it in.”

Participant 30. Group 2. (11.1)

“The exercise I’m doing is ok I just need to work less hours to enable me to do more.”

Living with MS

Participant 9. Group 2. (31.3.)

“Was complimented one evening got above myself and had a terrible day next day so has resulted in me being disappointed and mentally knackered.” This person’s mood went from elation to disappointment at their inability to maintain a physical state.

Participant 4. Group 2. (24.3.)

“Pushed myself a little too far and then I became overtired and rather down as a result.” This person recognised the relationship between unrealistic expectation and the feelings that resulted due to failure.

Participant 19. Group 2. (25.1.)

“Symptoms still problematic. Mouth numb fingers numb tight band round ankles.”

Participant 21. Group 2. (24.1.)

“The hot humid weather is really taking its toll. I can’t even climb onto the bike at home.”

Participant 5. Group 2. (26. 1.)

“I had a very busy weekend as I had company to stay. Consequently on Monday I had a numb left foot and I felt fatigued. I decided to give the exercises a couple of days rest.”

Participant 14. Group 1. (14.1.)

“Had a very funny experience walking up the high street, my right knee went completely numb as if it wasn’t there. It was ok this morning is this what they call an attack?”

Participant 15. Group 1. (29.1.)

“Tried to exercise but sensory disturbance on right and right arm weakness much worse when trying to use the muscles.”

Improved physical ability

Participant 9. Group 2. (34.1.)

“Went and saw S-- at the castle where I stood for 3 1/2 hours. Even managed a little dance! No significant after effects.”

Participant 40. Group 2. (30.1.)

“Pleased no ill effects from doing exercise class. Couldn’t have done this 4-6 months ago.”

Participant 25. Group 2. (30.1.)

“My walking improved and all my limb movements feel better and I feel better in myself.”

Participant 5. Group 2. (36.3.)

“Did more walking as we were out and about. I didn’t seem to get quite as tired as I have in the past.”

Participant 11. Group 1. (26.3.)

“Can stand on tip-toes now with eyes open!”

Participant 16. Group 1. (39.2.)

“Can manage the stairs 3 or 4 times a day now!”

Participant 24. Group 1. (36.1.)

“I have had less falls in the last six months and most of the time I’ve felt quite steady.”

Participant 14. Group 1. (17.2.)

“I went 10 pin bowling and found that I could do it! Hell of a boost. Felt absolutely fantastic about it as if I was walking on air.”

5.3.5.13. Comments from the participants’ transcripts illustrating psychological themes

How I see myself

Participant 40. Group 2. (37.3.)

“I must be significantly improved!”

Participant 18. Group 1. (38.2.)

“I’m a fairly positive person with a can do attitude and that has been reinforced a lot in this study.”

Participant 23. Group 1. (34.2.)

“I like to feel I’m not too bad yet.”

Participant 26. Group 1. (28.1.)

“I’m active and I have a positive mind these exercise I think have helped in this way.”

Participant 32. Group 1. (37.2.)

“Feel that I can help myself to make my condition manageable.”

Participant 1. Group 2. (40.2.)

“Went shopping on Saturday and didn’t have to stop for a rest. This is more like it!
Feeling brighter and more my old self.”

Participant 3. Group 2. (38.4.)

“I feel a really different person from the start of the study.”

Participant 5. Group 2. (23.2.)

“I feel as if I am achieving something.”

Participant 37. Group 1. (24.1.)

“I know the exercises help but I feel sometimes they and me are struggling to compete against the slow progression of this unwanted disease and how I’ve deteriorated.”

Participant 15. Group 1. (43.1.)

Planning exercise sessions was almost impossible due to the variety, intensity and vagaries of my symptoms I wish I could have done a better job for the trial, bit of a failure.”

Participant 29. Group 1. (37.1.)

“Finding it frustrating that although I maintain the exercise programme the ability to walk does not appear to get easier.”

Participant 19. Group 2. (42.1.)

“It (exercise) frustrates me as it makes you aware of your new limitations. You listen to other people discussing their lives and activities, where they’ve been what they’ve done and I’m envious.”

Participant 40. Group 2. (22.1.)

“I should be doing more. Feeling guilty for not doing enough.”

Participant 7. Group 2. (43.6.)

“I am a person who needs fairly instant gratification for whatever effort I make. Long term goals are not for me.”

How others see me

Participant 35. Group 1. (20.5.)

“I pace my days better. I enjoy staying up later with the family.”

Participant 3. Group 2. (33.3.)

“The teacher, (of Pilates), says I do better each time.”

Participant 40. Group 2. (33.1.)

“This week husband commented on more energy.”

(41. 2.)

“Everyone tells me I look better-well in fact. My husband has commented on my being able to do more in the evenings- previously I just sat down quite unable to do anything much.”

This chapter has described the results of the semi-structured and follow-up questionnaires and explained the process of data analysis used on the journal transcripts with IPA. The next chapter will discuss the results of the quantitative and qualitative methodologies in relation to the relevant literature and attempt to offer insights into these findings.

Chapter Six

Discussion

6.1. Introduction

The intention of this study was to determine whether a home based physiotherapy exercise regime produced better physical outcomes than a self-selected exercise regime. Analysis of the quantitative data suggested that: 1 both exercise interventions produced significant benefits that were not evident with the education intervention and 2 that the benefits of self-selected exercise were similar to those of the physiotherapy programme. Analysis of the qualitative data offered a number of factors that might explain these findings.

This chapter discusses the findings of the trial from the exercise and pre exercise phases of the study. It will include psychological aspects of exercise engagement that impacted on and interlinked with the physical outcomes. The chapter will adhere to the following format. Section one will discuss the study's limitations and merits plus a short discussion on the appropriateness of the selected assessment scales.

Section two will restate the four research questions and discuss the physical findings from the trial involving the two exercise interventions. This will address question 1. This section will also include an examination of the pre exercise intervention in relation to the physical outcomes produced relevant to question 4.

Section three will highlight the psychological issues identified during the trial and provide information relevant to question 2, the impact of exercise on quality of life. This section will also include relevant discussion on the psychological impact of the educational material offered during the pre exercise phase. A discussion of the search for meaning within the transcripts themes is presented and is followed by the information relating to question 3, the implantation of behavioural changes.

Section four will discuss the implications of these findings to physiotherapy, specifically community physiotherapy. It will consider the barriers faced by

community physiotherapists to exercise provision for MS people and offer recommendations for community practice.

6.2. Section one. Limitations and merits

There are inherent difficulties with any research that have the potential to impede the study's progress or alter the outcome by influencing participant compliance or the assessment procedures (Robson 1993). This study was under the control of one researcher thus highlighting difficulties peculiar to lone working. These difficulties included researcher bias and the results being the product of one point of view only, lack of managerial support from employers although the continued support and encouragement from the project supervisors was much appreciated. There were also the pressures involved in working full-time while conducting the study. There were issues around single-handedly categorising and analysing the extensive amounts of data generated although guidance from the project supervisors was once again invaluable. It could be argued that working alone will allow for a consistency that may elude other projects that have multiple researchers with differing viewpoints. Conversely it could also be proposed that lone researching excludes the possibility of important or interesting perspectives being introduced into the process as a result of the interaction of ideas and divergent interpretations. It could also be suggested that there is no "best" way to conduct research as there will be difficulties however it is done (Robson 1993). What is clear from the paucity of MS exercise studies conducted in primary care settings is the need to carry out such research in the most effective way possible thus producing viable evidence to support community interventions (Freeman and Thompson 2000).

6.2.1. Study limitations

This sub-section outlines the limitations presented by the study and some of the difficulties encountered all of which had some impact on the process and the response of the researcher to that process.

6.2.1.1. Researcher bias

To minimise the effects of researcher bias the final assessments were carried out by one of the two independent physiotherapy assessors. The researcher was experienced in the management and treatment of MS in the home and therefore it was believed that the use of independent assessors would remove the possibility of the researcher imposing their expectations on the final outcomes. There was also the issue of the researcher knowing all of the participants sometimes a relationship extending over several years. This could have been a detractor to an objective evaluation of the data. Cote and Turgeon (2005) contend that, “--an in depth understanding of phenomena cannot be achieved outside the context in which they occur.” So it could be proposed that the closeness of the investigator to the data generated could have been an advantage in this instance (Smith and Osborn 2006). The researcher was ever mindful of the possible intrusive nature of this knowledge yet believed that this unique position of intimacy allowed for an in depth understanding to evolve as the qualitative data were categorised and explored.

6.2.1.2. Sample size

It could be argued that the sample was too small thus impacting on the relevance of the results to the wider MS population and there was the possibility of a type 2 error occurring. It is true that a larger sample would have produced more rigorously generalisable evidence for the provision of community-based exercise. However the study is supported by the available literature regarding exercise benefits to those with MS, plus the importance of health behaviours and behavioural change (Marcus et al 1992. Collette et al, 1994. Kell et al 2001. van der Ploeg et al 2004. Andersen et al 1999) and the results obtained offered additional information about community exercise provision that is scantily reported elsewhere. It is acknowledged that should the study be repeated a larger sample would strengthen these associations and provide more substantial evidence to support the results obtained here. However many studies into the benefits of exercise for those with MS have yielded valuable insights despite their lack of numbers for example those by Mostert and Kesselring (2002) n=26, DeBolt and McCubbin (2004) n=29 and Mills and Allen (2000) n=8.

6.2.1.3. Generalisability of the study results

The study was conducted in Lincolnshire using a convenience sample of 39 MS individuals known to the Rehabilitation Medicine Service. As well as the question of sample size, there were additional issues surrounding the generalisable nature of this study in that it did not include ethnic minorities, those with a learning difficulty or those for whom English was not their first language. In defence of the study there were very few ethnic minorities within the study catchment area that were involved with the Rehabilitation Service at the time of the study. Had such individuals been available and had they fulfilled the inclusion criteria they would have been invited to participate. Should the study be repeated on a different MS community the method employed here could transfer into other ethnic populations. A problem may arise however with the chosen populations' exercise/health culture or with language difficulties.

The study required the recruitment of individuals who were capable of a certain level of exercise involvement and consequently it could be argued that this was not totally representative of the MS population at large. It was conceivable therefore that for this reason the results of this study could be considered to lack generalisability to the MS population as a whole.

6.2.1.4. Variations in symptoms and disabilities unrelated to the intervention

The unpredictable nature of MS could have confounded and confused the study at any stage. "Any attempt at evaluating an intervention faces the problem of separating the natural variation of the disorder from the effect of the intervention." Langdon and Thompson (1999). This is a universal problem facing those who attempt to investigate or influence an erratic condition such as MS. The issue was compounded by the inability to control the investigative environment as closely as one would like. There was always the possibility that one or more of the participants would present with an exacerbation of their condition that required drug interventions. This would have necessitated withdrawal from the study as the effects of the exercise regime could not have been properly evaluated in isolation. Five people experienced minor exacerbations that luckily did not require any intervention other than time to resolve.

One other person experienced a severe exacerbation requiring a steroid infusion necessitating their withdrawal from the study.

In this study there were also innumerable emotional, environmental and disease related factors that impacted on the participants physical and psychological wellbeing that could have impeded the research process and affected the results. It would have been impractical to try and control these events as this was real world research and real world events happen. The raft of major life events that affected the participants during this study could not have been predicted or pre-empted. This added flavour and depth to the study by offering insight into how people cope with difficult situations.

6.2.1.5. Time management by the participants

Although the participants believed they fully understood the study requirements some did remark in their journals and anecdotally that they were experiencing problems finding the time to do their exercise regimes justice. This element had to be accepted as a necessary evil of real life research. Truthful reporting of the time spent on the exercise and re-assuring the participants that they would not jeopardise the study by occasionally failing overcame this problem. In fact a more accurate picture of the elements involved in adhering to protracted periods of exercise whilst dealing with the unpredictable nature of MS was presented.

6.2.1.6. Motivation of the participants to exercise

There were issues around the amount of commitment the study required from the participants that for some people was too demanding. Six people declined to participate on this basis. One other person felt that they lacked the manual dexterity necessary to complete the journal and they were reluctant to ask their partner to complete it for them. An additional person was recruited to replace this participant.

It is acknowledged that there are many people in the community with MS who have little or no interest in exercise or who disbelieve the reports of the benefits that can accrue from its use. Milroy and O'Neil (2000) found that the ability of people to adhere to an exercise regime was dependent on their degree of motivation and that relied on a genuine desire to improve their health. The study participants wanted to

exercise despite their initial reservations and so the sample could be accused of only representing a well-motivated group with an interest in health and fitness.

The individuals included in this study were relied on to comply fully with the exercise regimes and with journal completion. Signing the consent form was taken as a written agreement to do so. However human nature dictates that enthusiasm will wane as procedures become more entrenched, especially if expected improvements were not as forthcoming as had been anticipated (Weinberg and Gould 2007). The prospect of a final assessment however did seem to encourage commitment and provided a motivation to continue that may otherwise have been lacking. There was also the secondary assumption that if the results were positive then more physiotherapists would be provided for those with MS in Lincolnshire. Rightly or wrongly this probably kept people going along the assigned exercise pathway. The study was therefore dependent on the will of those taking part to demonstrate true motivational levels that would relate to the actual experience of engaging in exercise.

6.2.1.7. Aspects associated with lone working

It was a constant struggle to pursue funding opportunities. The researcher was able to secure some support from their professional body and the MS Trust plus a few drug companies and the local MS branch. There was a lack of managerial support for the study and for the research process as a whole that was associated with a missed opportunity to raise the profile of the study intent by offering extra time to conduct the process.

The experience of conducting such a study in the community as sole researcher exposed logistical and temporal difficulties that were genuinely unforeseen and unacknowledged at study inception. Should this study be repeated it would be advisable enlist the assistance of other researchers to assist with assessments and analysis of the large quantities of data generated. It would also be encouraging to have another party with whom to confer and commiserate when things became difficult.

6.2.1.8. Information

There may have been an issue regarding the content of the educational material supplied during phase one of the study. The difficulty was in pitching the information at a level that provided useful facts for the majority with the intent of offering additional new information. This did not happen. Most participants were five years plus post diagnosis with extensive MS knowledge. The material was valuable however for distribution to the family, friends and work colleagues of the participants.

6.2.2. Suitability of the assessment scales used in the study

This sub-section will consider the appropriateness of the assessment methods used for data collection in this study. The selected assessment scales measured physical function, symptom frequency and severity and quality of life. This array of information was required to provide an overall picture of the impact exercise had on MS and to ally to the accepted methods of quantitative data collection currently available. The relative merits of qualitative inquiry have been mentioned in Chapter 5 and will not be repeated here other than to reiterate the growing necessity for a more integrated approach to data collection that embraces both quantitative and qualitative disciplines. This can only enhance and personalise the research outcomes to the benefit of the study population and the wider research community.

The variety of assessment processes available could cause confusion when selecting appropriate methods of data collection and there was a possibility that the assessment measures may have been too extensive thus affording too much information. An effort was made to select MS specific tools where possible and generic neurological tools were employed to cover aspects of strength and spasm common to this disease. There was an element of personal preference and familiarity that to some extent governed the choices made. Scale selection was also influenced by the ease of use, transportability, timely nature of completion and the analysis procedure required to extract meaning from the raw data. However there was still the possibility of over assessing in an effort “not to miss anything” that could have detracted attention from the primary outcome variable of function as influenced by exercise.

The Amended Motor Club Assessment, (AMCA), (DeSouza and Ashburn 1996) involved the assessment of a variety of functional activities that were familiar to physiotherapists generally. It provided a comprehensive measure of daily actions that were easily scored and totalled to provide a single numerical outcome and has been used in other comparative studies (Craig et al 2003). From this pre and post intervention scores were easily compared and changes demonstrated. This scale was a valuable addition to the assessment battery used in this study as it was user friendly yet still offered a comprehensive assessment of activity.

The Guy's Neurological Disability Scale, (GNDS), (Sharrack and Hughes 1999) is MS specific and is gaining in popularity as an MS assessment tool, (Rossier and Wade 2002. Storr et al 2006). From this scale a picture of subjective symptom presentation was obtained and a score assigned to each area of enquiry. 12 such scores were subsequently obtained that were totalled for the final outcome. This scale was easy to administer and presented the investigator with a useful method of symptom prioritisation as defined by the participant. The scale was easily reproducible and timely in completion.

The Health Assessment Questionnaire, (HAQ), was selected as a subjective measure of ability illustrating difficulties with daily living. This was one of only two self-completed questionnaires used the other being the MSQOL54. The HAQ was utilised by Redondo et al (2006) in their study on coping and disease adjustment in rheumatoid patients and it provided the basis for the work on ethnic, gender and disease severity by Sathy (2004). It focused on specific tasks such as turning on taps, opening a car door and dressing and grooming. This measure was included to demonstrate practical changes that the participant could readily relate to pre and post intervention. It took five-six minutes to complete and was easily understood by the participant and interpreted by the investigator.

The Timed Walk is an assessment that is commonly utilised in neurological rehabilitation (Wade 1992). It was not used as a separate measure in this study as it was included as part of the AMCA. It was extracted for individual examination as it was the self-selection exercise choice of four, (22%), of the group 2 participants. The walk was a measured ten-meter length that extended over an uninterrupted span.

The use of this assessment required a ten-meter rope for measuring and a stopwatch for timing. The recorded times were rounded up/down to the nearest second. The walk was completed indoors. Luckily there were no environments that did not have the requisite span to complete the walk. Undoubtedly the walking test would be easier to administer in an outpatient setting with a permanently marked ten-meter measure, however this study has shown that this test was transferable into the community and could be accurately applied.

Tone and strength were measured using the Modified Ashworth Scale, (MAS), (Ashworth 1964) and the Medical Research Council, (MRC), strength scale adapted for use in neurological conditions by Demeurise et al (1980). Both these scales are commonly used in neurological assessment, (Great Lakes ALS Study Group 2003. Van den Berg Vos et al 2002. Aldridge et al 2004), and were familiar to the investigator and the independent assessors. As with all subjective assessments there was scope for discrepancies that could nullify the results by providing too great a variation in scoring. Examination of the results demonstrated that there were improvements within most areas that did not indicate an overenthusiastic assignment of value to the tests. The familiarity of these tests plus the lack of any other comparable tools made their inclusion in the assessment battery a necessity.

Quality of life information was gathered using the NRS, the MSQoL 54 (Vickrey et al 1995) and the journals. The use of the journals in this study has proven invaluable in seeking out and exposing the undercurrents that accompany conventional research. The addition of this human element revealed issues that may not have been self-evident. The NRS was included in the journal at three stages to allow for a subjective quality of life evaluation to be included. It was envisaged that this would provide a simple numerical rating of quality of life that would compliment the results of the MSQoL54 and the themes extracted from the journals. The NRS anchor points were 1 to 10 with 1 being the lowest rating and 10 the highest. This type of scale was easy to use and provided a readily quantifiable outcome of current emotional state.

The MSQoL54 was included in the assessment book and was self-completed. Overall it was complicated to administer and even after completing the questionnaire there were people who required clarification on the second or third attempt. The analysis

was difficult and involved due to the variation of responses that alternated between high being the desirable result to high being undesirable. The two items that were related to two of the domains though separate from them were also difficult to reconcile to the rest of the results obtained. The difficulty with analysis in this instance could have been due to researcher inexperience in data management. It was felt that the MS QoL 54 was not totally fit for purpose as far as this study was concerned. Clearly a quality of life scale was required but should the study be repeated the results could be strengthened by the introduction of a different quality of life tool that could determine self-perception of health status more closely in relation to the intervention and be more user-friendly.

6.2.3. Appropriateness of the study methodology

The diverse nature of MS and the requirements of this study demanded an extensive battery of measurement tools that could embrace as much of the MS spectrum as possible. This was necessary because this study included individuals who demonstrated a wide range of physical disabilities rather than concentrating on a group of mild, moderately or severely disabled recruits as other studies have (Solari et al 1999. Mostert and Kesselring 2001). As mentioned previously this extensive assessment procedure could have hampered the research process by confusing the research questions with an excess of data. There was also a need to include the psychological aspects that present with MS as it was this element that would significantly influence the success or failure of long-term exercise involvement.

In contrast to this quantitative approach the journals designed for this study supplied a subjective perspective that added value to the functional assessments. The use of subjective information in research has gained credence in recent years and the research community in general is beginning to appreciate the inclusion of a human perspective on health related research as a useful adjunct to traditional research methods (Dodd et al 2006. Ong and Richardson 2006). A wealth of relevant data regarding the exercise experience was thus amassed.

The two-phase approach proved to be important in that it allowed for the initial stages of the Stages of Change Model (Prochaska and DiClemente 1984) to become

established. This was a necessary preparatory phase that laid the foundation for the exercise interventions. This also provided a washout period to eliminate any previously acquired exercise effects thus providing a true physical ability assessment before exercise began. The comparative element adopted in phase two provided the information regarding the effectiveness of the chosen regimes. It allowed the investigator to determine the differences between the two interventions and draw conclusions from them. This study demonstrated the appropriateness of the pre test/post test comparative method of inquiry that produced measurable outcomes to inform the future provision of exercise for those with MS in the community.

6.2.4. Strengths of the study

This study is one of the few randomised controlled trials of its kind. Its strengths lie the fact that it concentrated on comparing physiotherapy with self-selected exercise, it was exclusively community based, it included a mixed ability group of people with MS, there was only one drop out due to an exacerbation of MS and it compared a traditional physiotherapeutic approach with exercise that was selected by the participants. Despite the problems and potential drawbacks previously noted the results did demonstrate measurable physical outcomes with both approaches as shown by the assessment results and significant qualitative gains as detailed in the journal transcripts. The resilience and determination of the participants was acknowledged as was their commitment to the study procedure. They were eager to participate and provided valuable insights into their experiences during the study in their journal entries. The researcher felt that the journals offered a perspective into the MS experience that could inform the practice of other therapists and medical practitioners. A subjective element should be included in trials of this type as it enriches the outcome by adding the real experience to the purist perspective. Another success was the recruitment of the two experienced physiotherapists who ably completed the final assessments and helped to eliminate researcher bias at study conclusion.

The study was also able to demonstrate the influence of the two theoretical underpinnings of the study by the use of the follow-up questionnaire. Of the 39 participants who completed the study 34 (87%), responded to the follow-up

questionnaire six months later and 29 (85%) were still exercising. This was clear evidence of the successful implantation of behavioural change.

The study has been a steep learning curve for the researcher by extending experience and understanding of the physical and psychosocial impact of MS. It afforded an opportunity to lead an investigation and control the processes involved. It served to highlight the difficulties inherent in research and provided the researcher with the insight to appreciate the research process in more depth. It is as yet unclear whether this has helped or hindered daily practice as it has illustrated areas of deficit that are outside the control of the researcher.

As previously mentioned a major advantage of the study was its exclusively community-based format without the benefits afforded by a physiotherapy department or rehabilitation facility. It was this design element that separated it from most other MS exercise studies. The comparison between home-based physiotherapy and self-selected exercise provided valuable evidence regarding the two exercise interventions. Finally the study benefited from the dual methodological approach that produced a varied spectrum of MS data to inform the outcome. The inclusion of the qualitative methodology strengthened the study's real world perspective and enhanced the overall understanding of the process (Freeman and Thompson 2001). This diversity of data collection produced information that would otherwise have not materialised. This included the appreciation by the participants of the benefit of exercise, the use of reflection as a method of coping and the cathartic effect of diary keeping.

6.3. Section two. Evaluation of the physical study findings

A discussion of the effects of exercise on the physical function of all the study participants is now presented. This will address the primary research question of whether better functional gains were accrued from a physiotherapy home exercise programme when compared to self-selected exercise. It will consider the impact of exercise on activity and impairment plus the physical themes identified in Chapter 5.

6.3.1. The research questions

The purpose of this study was to discover whether a home-based physiotherapy programme could produce a better functional outcome when compared to exercise that was self-selected. Three additional research questions developed out of the initial study intention. These four questions will now be re-stated:

- Would a home-based physiotherapy exercise programme provide better functional outcomes than a regime of self-selected exercise?
- Would a home-based physiotherapy/self-selected exercise programme have an effect on quality of life?
- Would the theory of behavioural change explain the exercise uptake?
- What would be the effects of the pre exercise intervention alone?

6.3.2. Exercise and physical function

This sub-section will first describe the impact of exercise on the ICF categories of activity and impairment. This will address the primary research question of whether there was a better functional outcome with physiotherapy over the self-selected exercise regimes. A between groups comparison was carried out on the AMCA exercise scores to ensure that there were no significant differences that could have influenced the results, (unpaired t test, 2 tailed). A two-way ANOVA was also applied to the AMCA exercise data. No differences were found. Despite this it should be remembered that when comparing multiple means a type 1 error could occur. Consequently apparently significant results could have occurred by chance. Results with probabilities greater than 0.01 should therefore, be treated with caution. The section will then discuss the themes of “Positive exercise effect”, “Living with MS” and “Improved physical ability” identified in Chapter 5. It will also present a discussion of the physical aspects of the pre exercise intervention.

6.3.2.1. Effects of exercise on activity

Activity was assessed using the AMCA the HAQ and the Timed Walk with the AMCA being the primary functional indicator. From the AMCA results

improvements in activity were evident in both groups after exercise that were significant on t-testing, (paired 2 tailed). Unfortunately the differences on between group comparison testing (two-way ANOVA), using the AMCA data did not indicate the benefit of one exercise approach over the other. The result did demonstrate the potential for exercise to improve function with the proviso that the exercise was appropriate to the functional ability of the person.

The physiotherapy group demonstrated an improvement in the HAQ that does indicate a better outcome compared with the self-selection group. This could be attributed to the type of exercise undertaken. The physiotherapy exercises were geared towards specific muscle group activation with a resultant improvement in movement patterns. The exercise studies by DeBolt et al (2004) and Dodd et al (2006) also adhered to this prescriptive approach and their results are similar to the findings of this exercise study showing that targeting specific areas of deficit will improve outcomes. The self-selection activities were far more generalised and did not target areas of deficit in a way that would be expected to produce such a result. It could be argued therefore that the self-selection group were disadvantaged in this respect.

The scores from the Timed Walk indicated a slight improvement in walking ability in the self-selection group, but the result was not statistically significant on t testing. There was a corresponding minimal deterioration in walking time in the physiotherapy group. This was an unexpected result. As walking and strength training were included in the physiotherapy regime the assumption was that there would be measurable improvements due to a practice effect. The physiotherapy group were required to practice an amended walking pattern as part of the exercise regime and then transfer this into their normal walking pattern to encourage regular gait rehabilitation.

Other studies have shown that extended walking practice and strength training do improve walking patterns and balance awareness in MS (Giesser et al 2007. Gutierrez et al 2005). The quality of walking did improve in this study also as noted in the journals but the speed of walking as assessed by the Timed Walk did not. One explanation for this may be the lack of emphasis placed on an extended walking phase. It was possible that the participants perceived the “walk” as an exercise rather

than something that was transferable into daily use. This would imply that once the exercise was completed the principles were not applied outside the exercise session. The researcher assumed from this that the instructions provided were not specific enough to ensure correct exercise adherence. This conclusion re-enforces the need for guidance where exercise is concerned (Hillsdon et al 2002). The possibility also existed that the group 1 participants were more walking impaired overall than the group 2 people and consequently they did not have the capacity to walk faster but there was capability to improve the quality of the walk. Of the 21 people assigned to the physiotherapy group 14 people were classed a moderately disabled and two of the severely disabled people were also in this group. This fact could have contributed to the relatively poor walking speed performance of the physiotherapy group in comparison to the self-selection group.

There is evidence to show however that the more severely disabled an individual the greater an improvement can be realised after a period of in-patient rehabilitation, (Lui et al 2003. Kidd et al 1995). This exercise study has extended this premise to include community-based subjects with the results also indicating an overall improvement in some of the assessments of those in the more disabled brackets. This finding may be due to the greater inherent potential for improvement of the more disabled people. There was also a corresponding effect from the less disabled people in that they did not show the greater levels of improvement that they had perhaps anticipated. It could be argued that they were at or near their best activity level within the confines of their MS symptoms at the time of the study. This could mean that they had less potential for improvement as they were already at or near their peak levels of activity achievement thus lowering the scope for more substantial gains to present.

Overall both groups demonstrated improvement in the activity domain as defined by ICF (2001) classifications. This provided a positive reinforcement for the prolonged benefits of exercise that many people had not anticipated and fuelled the desire to continue. It can be concluded therefore that exercise was responsible for this as no other intervention was undertaken during this time. However there was no definitive evidence offered by any of the activity assessment scales to determine which approach was better than the other. The comparison tables for all scores can be reviewed in Chapter 4.

6.3.2.2. Effects of exercise on impairment

Impairment was assessed using the GNDS, the MAS and the MRC. The results of the GNDS indicated that the participants perceived their symptoms to have worsened with exercise. This was an outcome that did not ally to the positive outcomes shown by the other results for example improved strength (MRC), less stiffness (MAS) and fatigue and more stamina (journal entries). It is possible that some people experienced a worsening of symptoms that impinged on the overall scores but there could be other explanations. One such explanation could be a belief that reports of worsening symptoms may prompt more professional input. Some people mentioned that they felt a little isolated during the study despite the fact they still had access to the rehabilitation medicine service. They valued independence yet still needed a professional sounding board. This may appear to contradict the current shift towards autonomy and empowerment, (Townsend et al 2006. MacLaren 1996), yet the fears and uncertainties that accompany MS sometimes require an outsider's stabilising influence. The survey conducted by Somerset et al (2001) identified support and access to appropriately skilled professionals as important to the people they polled, (n= 417) and Thornton and Lea, (1992) also highlighted this issue in their investigation of need in MS, (n=40).

There was also the possibility that some participants were not entirely accurate in their estimations of their symptoms during previous assessments. The researcher attempted to negate the effects of researcher bias by utilising the skills of two independent physiotherapy assessors for the final assessment. It is conceivable that this backfired with the final assessment providing a more accurate picture of symptom presentation than that previously offered. Perhaps the participants were trying to please the researcher during the first two assessments yet had no such allegiance for the final one. This is only speculation at this time as the true reason for this perceived deterioration cannot be precisely identified from the information gathered in this study.

The MAS assessed muscle tone and there were improvements shown in both groups with corresponding supporting evidence recorded in the journals. This result was

expected as it has been shown that exercise and increases in physical activity will positively influence tone both hypertonic and hypotonic in nature, (Petajan and White 1999. Haselkorn and Loomis 2005). The results of this study showed that individuals were able to exert control over their problems with limb stiffness through the use of exercise although once again the optimum exercise regimen was not clearly evidenced. This might indicate that muscular activation rather than a specific exercise regime is key to reducing muscle tone although it must be appreciated that not all muscle activation is good activation. For example a compromised CNS would struggle to accommodate high intensity, explosive or fast repetitious movements (Sheean 1998) that do not allow for reciprocal relaxation and intermittent “recharging”.

Both groups demonstrated improvement in the MRC with physiotherapy fairing better in the lower limb assessment and self-selection doing better on upper limb scores. This was to be expected in the physiotherapy group as a strengthening regime was included in the exercise programme. However the self-selection group had no such specific strength targeting so the better upper limb results were unexpected. The findings of DeBolt et al (2004) and Dodd et al (2006) indicated that targeted strength training was a safe method of positively influencing muscle strength in MS. Strength training has also been shown to impact on central activation and muscular recruitment (Onambele and Degens 2006) with subsequent improvements in balance. Although the results of the MRC were not conclusively on the side of physiotherapy, exercise in general did seem to impact positively on this area of deficit.

Other authors have found that exercise did not impact on impairment (Patti et al 2003) yet the results of this study indicated that exercise did positively influence two of the three areas of impairment assessed. This may be due to the extended time scale of exercise involvement used in this study that contrasted with the Patti et al study that concentrated on short-term interventions, (six weeks). This finding re-enforces the need for extended periods of involvement to ensure maximum benefit from exercise interventions for those with MS.

6.3.3. Effects of exercise on the physical themes identified in the participants' transcripts

This sub-section considers the physical themes identified in Chapter 5. These were “Positive exercise effect”, “Living with MS” and “Improved physical ability”.

Although there were difficulties at exercise commencement for a few people in the study they did not present as a major factor therefore a “Negative exercise effect” category did not evolve.

6.3.3.1. Positive exercise effect

The evolution of a positive exercise effect was directly related to the theory of Planned Behaviours (see Chapter 1). Exercise psychologists have recognised its importance in enabling exercise performance in athletes (Weinberg and Gould 2007) and this study has illustrated its relevance to those with a physical disability. The three stages of the theory were ably demonstrated by the participants in this study and were shown in their attitudes to exercise. This was evident in their perceptions of what they felt they would get out of it, by the amount of effort they believed they would have to put into it and whether they were up to the task plus their perception of what significant others felt about their exercise attempts. So it could be posited that the establishment of a positive exercise effect on those in this study required a re-evaluation of the meaning exercise in relation to their expectations and physical capabilities. This re-evaluation involved the concepts of cumulative exercise benefits, low levels of exercise intensity (Blair and Connelly 1996. Haskell 1994) and an acceptance that exercise was a safe option for those with MS (Stuifbergen 1997). Once these had been considered it was possible to establish a working relationship with exercise that would encourage the behavioural changes necessary for long-term involvement. This necessitated ownership of the process and a controlling interest in the procedure, an autonomy that “---is meaningful in respect of outcomes held to be important by people with MS.” Somerset et al (2003). For those who are physically challenged it becomes imperative that they attain this control over exercise as this will positively impact on life involvement (MacLaren 1996). The participants in this study demonstrated the relevance of exercise uptake in their daily interactions that infiltrated into a wider social and environmental context. Other authors have also found that relevant functional gains can be attributed to exercise (Petajan and White

1999. Brown and Kraft 2005. Solari et al 1999. Sutherland et al 2001. Lord et al 1998). This exercise study reinforced the notion that a positive exercise effect was produced over time with short bursts of exercise and that to accrue benefits from exercise one does not need to engage in prolonged exertions. This finding concurs with the opinion of Pate et al (1995) who also noted the benefits of accumulated activity.

The appreciation of accumulated benefit is an important concept for those with MS with finite amounts of energy available throughout the day. One person noted that they had changed their ideas about exercise. “---I have broadened my perception of what exercise is.” They showed an understanding of the need to balance exercise against their available function and to discard preconceived notions of exercise requirement that generally involved maximum effort for maximum gain. This approach may work for the able bodied but can be a recipe for disaster to a damaged CNS.

The positive effects of exercise on general health and wellbeing have been documented in a healthy population (Klein1996. Taylor et al 1985) and the improvements demonstrated by most of this study’s participants were consistent with these findings. The changes were not as dramatic as those found in the general population but their significance to mobility-impaired people was notable. One person mentioned that she was able to stay up later with her family due to lowered fatigue levels and another enjoyed extended shopping trips with friends. There were exceptions however, mostly the few who suffered a minor resurgence of symptoms that precluded full exercise engagement, (five people). Three other people did not fully comply with their regimes and remarks were made regarding their exercise preferences. For one person this meant not doing any exercise at all. This person did however do a lot of walking without associating this with “exercise”. Milroy and O’Neil (2000) also found that compliance diminishes if people are not committed to their regimes or if they have them imposed upon them and this could have been an underlying reason for the difficulties experienced by these people.

Fostering a positive exercise effect in any population requires encouragement and is not easy to achieve. The trial by Hillsdon et al (2002) examined the impact of

advising people to take up exercise in primary care settings. They concluded that “-- blanket physical activity promotion in primary care is not effective.” In other words simply telling people they need to increase their activity levels will have very little impact on their daily lives. This finding was applicable to the participants in this study who were well aware that they should be doing some form of exercise and had been told by medical professionals in the past that this would benefit them. However it was their participation in this study that encouraged them to exercise regularly and to maintain it. The use of a specialist physiotherapist in the community has the potential to promote a positive exercise affect by involving people in disparate exercise opportunities that are appropriate and enjoyable.

By study conclusion most people had achieved some degree of control over their programmes by deciding on location, time allocation and amount of exercise completed. It was this aspect that contributed towards a healthy relationship with exercise that should extend beyond study completion by positively impacting on motivation, wellbeing and activities of daily living.

6.3.3.2. Living with MS

Living with MS was a composite of the physical problems that the participants experienced on a daily basis. The pre exercise phase unearthed problems with strength, balance, muscle stiffness, walking, fatigue and the effects of temperature changes that negatively impacted on MS. Although exercise did not have the ability to erase these difficulties it did appear to impact on various aspects of them. For instance increases in strength affected balance that impacted on walking ability although as previously noted not necessarily on speed. This interaction of cause and effect was a revelation for some participants who could rationalise the association of exercising in sitting to improve standing and walking based on the improvements they saw.

An understanding of the participants' responses to heat and cold also prompted an awareness in a few people of how to control for these unpredictable events. The effects of temperature changes on those with MS have been well documented, with results confirming the necessity of maintaining a stable core temperature to prevent the onset of MS symptoms. (Nelson and McDowell 1959. Petajan and White 1999.

Mostert and Kesselring 2002). It is the belief of Brown and Kraft (2005) that an increase of as little as 1 degree in temperature can be enough to bring on heat related symptoms. The ability to regulate one's core temperature was as relevant for lower temperatures as for temperature raises. Unsurprisingly this is not true of all people with MS and even in this small study there was evidence that increases in temperature were welcomed by a minority of the participants, (n=4).

Other MS deficits identified during the pre exercise phase such as muscle stiffness and lack of strength also improved with exercise. These findings are in concert with other similar works assessing muscular activity and exercise (DiFabio et al 1998. Kent-Braun et al 2004). The participants had begun to arrest the muscular deconditioning common in MS that results from inactivity with a consequent improvement in daily function.

Cognitive difficulties especially with memory and organisation of tasks were mentioned by a few people in the journals but were glossed over for the most part. This could be indicative of deeper problems the seriousness of which were either unrecognised or the person was in denial about. It was not within the purview of this study to pursue this issue further.

The variability of MS symptoms was a constant feature to be considered throughout the study. There was little that exercise could do to prevent a relapse or control the unpredictable weather that affected so many of the participants. However, many people noticed that the regimes helped them to maintain a life-balance throughout these difficult times and conserve acceptable levels of function.

6.3.3.3. Improved physical ability

Improved physical ability was one of the most satisfying areas of improvement for the study participants. Many people in this study identified specific physical activities as goals they aspired to. The use of goal setting has proven useful in the general population when undertaking sport (Ward and Carnes 2002. Brobst and Ward 2002), and has also shown benefits for this study's cohort. One person was able to stand to clean her teeth for the first time in many months and another was able to attend a pop

concert. This linked to a developing understanding and appreciation of the benefit of exercise and the realisation that it was an achievable goal. Other exercise studies in MS although carried out in more controlled environments have produced similar improvements in physical abilities to those found in this study (Hale et al 2003. Freeman and Allison 2004. Kileff and Ashburn 2005).

A constant irritation to those in this study were the physical barriers that have been cited as a major deterrent for many people with a physical disability who contemplate exercise uptake (Sluijs et al 1993). The desire to increase activity levels can often be overridden by the efforts required to overcome such barriers (Stuifbergen and Becker 2001). Those in the self-selection group indicated that access to buildings and transport to exercise facilities sometimes interfered with their good intentions. The problems associated with barriers to exercise also included our automated society, (ie too much dependence on the Internet and remote controls), and sedentary lifestyles (Klein 1996. Hillsdon et al 2002). It is an unfortunate reality that physical barriers to exercise exist for those with MS and that they act as deterrents to exercise engagement (Kinne et al 1999. Chan and Heck 2000).

The barriers to exercise need not be confined to availability of suitable equipment or building access, but can also encompass lack of necessary assistance to become active, fear of solitary activity participation or self- consciousness at the thought of engaging in activity with the able bodied (van der Ploeg et al 2004). Improvements in physical ability overcame some of these problems and this was an unexpected bonus for some of the participants. Some people remarked that they were better able to negotiate stairs and experienced an improvement in walking distances with a more secure balance appreciation. Others noted that they felt better equipped to cope with exercise in an able bodied environment.

It could be surmised then that exercise improved physical ability in the participants thus boosting function in a variety of environmental situations. Stuifbergen (1997) noted that the adoption of positive health habits such as exercise had the ability to change a person's response to disease. Although the disease process cannot be influenced by exercise its effects can be. The participants in this study displayed demonstrable improvements in physical function with measurable goals being

achieved. Thompson (2000) proposed goal achievement as a viable method of measuring the success of a patient undergoing rehabilitation and self-selected goals did show measurable improvements in the study participants. These encouraging goal acquisitions could be attributed to the exercise regimes and testify to the success of the programmes used.

There were also improvements in other areas of physical ability for example sexual function. One person in this study mentioned such improvements. Sexual function in the disabled is often regarded as a taboo subject that rarely infiltrates into the usual assessment or rehabilitative sphere of most professionals (Sipski 2001). Life does not end with disability and it was heartening to observe that exercise influenced an area of intimacy that was important to one couple.

6.3.4. Summary of discussion points

Changes in exercise perception and an appreciation of how to engage with exercise were evident. Many people were surprised at the results they achieved. This prompted an enthusiasm to continue and to integrate exercise as a management strategy for the future. There was very little improvement for the most part in the ability of the participants to effectively thermoregulate and to compensate for the problems caused by temperature changes. This difficulty appeared to be a constant for most people despite verbal advice regarding core temperature mediation in the heat and cold. This was an area that must be governed by the individuals concerned.

The practical problems presented by physical barriers to integration and participation remained unchanged. However there was an improvement in physical ability enabling the participants to overcome these barriers more successfully and this elevated the participants' perceptions of self-esteem and self-belief.

These results offer evidence to support exercise opportunities that embrace a more community-based approach. The assumption that exercise can positively impact on physical ability thus improving environmental integration has been endorsed. However as demonstrated by the results of the assessment scales no significant

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differences between the two exercise approaches was found that could promote the benefits of one regime over the other.

6.3.5. Discussion of the findings from the pre exercise phase

This section will discuss the effects of the educational material on physical function that formed the pre exercise intervention. It will first consider education as an element of disease management.

6.3.6. Education and disease management

It is generally agreed that education equates to power and the empowerment of the individual is becoming more desirable, (Department of Health The Expert Patient 2006. Department of Health NSF for Long-term Conditions 2005). MacLaren (1996), contended that “--empowerment aims to equip the client with the requisite knowledge and support to continue to make decisions about their health.” However not all people will want this level of personal responsibility for their care, “ There will always be a group of clients for whom this may not even be suitable.” MacLaren (1996). People undergoing rehabilitation may fall into two categories – those who react positively to the information acquired from an education process, and those who may respond negatively. This could be for a variety of reasons ranging from cognitive deficit to a protective disassociation from the problem both of which will impact on learning and subsequent self-management ability.

The way in which information is presented will also influence an individual’s responses (Honey and Mumford 1982) and patients who are offered factual information in a non-judgemental and timely manner may be able to make better health related decisions than those who remain uninformed, (MacLaren 1996. Ennis et al 2006). For the participants in this study their knowledge of MS was experiential rather than instructional and it is conceivable that this affected their subsequent ability to deal with MS. Consequently many of the study participants noted in their journals that the information offered in the education pack although useful could have served them better had it been available sooner, a finding that has been reported by other authors (Natterland and Ahlstrom 1999. Shabas and Heffner 2005). However, information that was presented too early in the disease process could also have a

negative impact on coping and adaptation. One participant's husband who sought answers from the library after she was diagnosed demonstrated one example of the need for timely information. He returned home feeling physically sick at the poor prognosis the information portrayed. This scenario highlighted the need for timely information provision and some participants in this study indicated that this would have benefited them.

The work by Somerset et al (2001) supported the argument that timely information was a necessary requirement for those with MS. In a postal survey of MS patients (n=318), they found that 75% reported a lack of advice on at least one MS problem. Also of note was the fact that 41% cited lack of advice on appropriate exercise as a major deficiency.

People with MS may also feel detached from the world. The causes are multifaceted and range from the impact of the physical deficit to a lack of understanding of the psychological effects of the disease. This can alter the perspective of some people and produces a cognitive disablement that can be as restrictive as the physical loss. Brown and Kraft (2005) have identified cognitive deficits as being responsible for interfering with new information acquisition and information retrieval.

Specific strategies that positively impacted on possible cognitive deficits for those in this study included the use of written instructions as with the physiotherapy group and the involvement of exercise trainers as with those who attended local gyms. Written and verbal reinforcement enabled a more positive approach to the exercise experience by aiding with memory and providing emphasis to the activities. The work by Heesen et al (2006) also advocated continued supervision as a necessary ingredient to maintain exercise benefits and avoid harmful effects.

From these observations it could be surmised that information is important, that most people need to engage with the process at some time during their disease progression (Thornton and Lea 1992) but that methods of offering education plus the need for support needs careful consideration. It would be counterproductive for example, if the professional involved assumed control of the information supply (Saunders 2003). This paternalistic approach to the provision of information could deter the individual

from assuming an active part in their management. Conversely they may be offered little or no information prompting them to seek answers elsewhere with the possibility of detrimental effects presenting.

The information contained in the education pack was generalised in nature and attempted to cover most of the issues common to MS without overstating or sensationalising the problems. The next section will show whether the educational material provided during the pre exercise phase had any impact on the physical function of the study participants.

6.3.7. Effects of the educational material on physical function

This sub-section addresses question four by investigating whether the educational material supplied during the pre exercise phase influenced the ICF domains of activity and impairment. A between group comparisons carried out at baseline indicated no significant differences between the groups, (unpaired t test, 2 tailed). A discussion of the theme of “Living with MS” as identified in Chapter 5 is also presented.

6.3.7.1. Effects of the educational material on activity

Activity was assessed using the AMCA, HAQ and the Timed Walk. There was no significant improvement with the introduction of information in any of these scales. The reader is referred to Chapter 4 for the table of results.

For the educational material to have had any measurable effect on activity, specific instructions regarding function would need to have been included in the education pack. This specificity of educational delivery was shown to be effective by Ennis et al (2006). It has also been proposed that for changes to become entrenched a degree of supervision is required, (Heesen et al 2006). This would imply that support and guidance would need to accompany the instructions given. The results could therefore be attributable to the fact that nothing functionally specific was offered and no supervisory input was received. The decrease in activity measures could also have been influenced by the three-month period of inactivity that the study required. Inactivity has been shown to negatively impact on physical function in MS

(Ponichtera-Mulcare 1993. Romberg et al 2005) so a deterioration in activity scores was a likely outcome during the pre exercise phase.

6.3.7.2. Effects of the educational material on impairment

Impairment was assessed using the GNDS, MAS and MRC. The GNDS was the only scale that showed improvement with the introduction of the education pack. This showed change at the < 0.05 level (p value 0.017). This result could have been influenced by the participants' desire to offer the responses they believed would best suit the needs of the study and please the assessor. As the investigator knew all of the participants this may have motivated the positive slant in this scale's results.

It is accepted that paying attention to an individual whether positively or negatively, can affect a person's perceptions and subsequently their compliance (Charmaz 1983), a phenomenon not unlike the Hawthorne effect. This effect describes an introduction of bias where the presence of a second party influences the behaviour or in this case the responses of the participants, (Gale 2004. Merrett 2006). The effect has "--entered into the literature as a key fact to be reckoned with in many practical contexts." Jones (1992). The presence of the investigator could conceivably have produced such an effect. There was also the possibility that perception of symptoms was genuinely altered as a result of the educational material supplied although conclusive evidence to support this notion is not available.

There was however a corresponding deterioration in the MAS and MRC scores. Improvements in these areas of impairment were not anticipated because of the period of inactivity that encouraged tonal alterations and loss of strength. The absence of exercise would be detrimental in both of these areas and the work by Freeman et al (1997) also found that inactivity had a negative effect on activity and participation on their control group. There is evidence to show however that when activity recommences the CNS can reacquire ability that had been dampened by disuse or injury (Stein and Hoffffman 2003. Diaz-Arribas et al 2006). The three-month period of inactivity was therefore unlikely to produce long-term deficits to those involved. This assumption was borne out by the quantitative results obtained during the exercise phase of the study. From these results it seems that the education pack had no positive

impact on activity and a minimal positive impact on impairment in one assessment scale only.

6.3.8. Effects of the educational material on the physical theme identified in the participants transcripts

This sub-section will discuss the elements pertinent to the theme of “Living with MS”. The discussion will include reference to relevant literature and will consider three areas that impacted on this theme. They were functional limitation, fatigue and environmental barriers. It is recognised that these issues were not confined to the physical manifestations of the condition but migrated into psychological domains that were interlinked. For the purposes of this discussion the physical and psychological domains will interact to better explore the themes. The sub-themes pertinent to this category can be reviewed in Chapter 5.

6.3.8.1. Functional limitations

Those involved in this exercise study identified several functional limitations associated with the theme of “Living with MS”. The most disabling and oft cited of these was walking, (100% of participants) closely followed by fatigue, (95% of participants). These functional limitations impacted on daily life and were linked to the evolution of the person’s disability. Functional limitation as identified by the study participants was associated with the need for professional involvement most notably that of a physiotherapist. It was intimated that such involvement could positively impact on coping. One person described this as a “---metaphorical handholding”.

Some participants remarked on how others reacted to their functional limitations and how they felt unable to voice their difficulties for fear of being labelled “—a moaner”. Other researchers have also shown that the reactions of peers and significant others can influence the amount of freedom people felt they had in voicing their difficulties, (Isaksson and Ahlstrom 2006). The reactions of others also influenced the concept of self-perception in relation to the functional limitations of some of the participants. One person felt overcome by their deficits and indicated that family members had

ceased to include them in family discussions. This re-enforced an overwhelming sense of loss at the inability to meet family expectations.

This finding was supported by the work of Stuifbergen (1997) (n=13) in her study of fatigue and self-care strategies in those with MS. She discovered that many of her study participants described the inability to meet spousal expectations due to decreasing physical ability and fatigue as a distressing consequence of MS generally. These expectations, ranging from doing the housework to social interaction to sexual function were identified as areas that were best left unexplored. Many people in this exercise study also coped with functional deficits by completely ignoring them. By denying the problem's existence they were no longer required to acknowledge it and the risks of being labelled a "moaner" were diminished. This "denial" was one method of dealing with diminishing physical abilities that offered an easy opt out for several of this study's participants.

The work by Burnfield (1995) considered the psychosocial impact of MS and highlighted the concept of denial as pivotal to the psychological adaptation of many people with MS. He described a certain level of security in denial that disguised the underlying bereavement that inevitably follows as ability is inexorably eroded. This can become a coping strategy that acts as a defence against the reality of MS. However he felt that without confronting problems at the appropriate time the capacity to cope in the long term was significantly diminished. One person in this exercise study exhibited such coping difficulties and acknowledged that they responded to most challenging situations with unfettered anger at their physical ineptitude.

6.3.8.2. Fatigue

Fatigue is a devastating, emotionally draining symptom which many people report as their worst problem. It is the silent detractor and has been identified as a factor negatively impacting on impairment and activity (Multiple Sclerosis Council 1998). Stuifbergen (1997) has described fatigue as, "...a multidimensional, multicausal symptom that virtually defies definition or description." Its effects are frequently underestimated as it pervades the body and the mind with a resultant emotional and

physical collapse that many find impossible to combat effectively (Ritvo et al 1996. Schwartz et al 1996). Of those included in this exercise study 95% noted it as a significant problem impacting on physical function. This finding coincides with the survey carried out by the MS Trust (2006) that looked at symptom prevalence in people with MS (n=226). That study found that 96 % of those polled cited fatigue as a major difficulty (TiMS 2006). Such invisible symptoms promoted feelings of inadequacy and a “fraud status” (Thornton and Lea 1992) in the eyes of significant others and the wider community.

Fatigue was associated with temperature changes, environmental factors and mood. One person mentioned the overwhelming tiredness she experienced after returning from shopping that she found quite depressing and another was unable to function during warm spells. The impact of such factors on one’s ability to function has been reported by other authors, (Gulick et al 1989. Kersten and McLellan 1996). Fatigue also impacted on other areas of physical functioning such as strength, muscle stiffness and walking ability a finding similar to that of Stuifbergen and Rogers (1997).

There was no specific advice in the education pack concerning the need for activity pacing and avoidance of significant temperature changes that could worsen fatigue. This shows that the education pack did not influence their ability to cope with fatigue and indicated that future educational compilations should perhaps concentrate more on this area. The reader is referred to Chapter 1, (1.2.2.4) and Chapter 2, (2.5.1.1.) for further information on fatigue in MS.

6.3.8.3. Barriers presented by the environment

Environmental barriers were identified by a significant number of people in this exercise study as impediments to physical function (n=26). These barriers included access to buildings, provision of toilet facilities and comfort in the work place. There was also the additional element of temperature variation plus the barrier presented by the attitudes of employers to those participants who were still working, (six full-time, 10 part-time). Three of the study participants remarked how slight changes in work place environments produced problems that were unrecognised by employers.

The presence of barriers such as stairs, doors, toilets and distance from the desired goals have been identified as influential in the ability to integrate for those with a physical deficit, (Freeman 2001). A study conducted by Stuifbergen (1995) on health promoting behaviours and quality of life in MS discovered barriers to health promoting behaviours that included both physical and emotional elements. Barriers could also include financial and travelling constraints, (Becker and Stuifbergen 2004). The impact of environmental factors to social integration was noted by Maloney et al (1985). They highlighted the relevance of the environment to one's ability to integrate and that the "illness" must not be considered in isolation but within the context of the individual's existence. One's context within the space we inhabit governs the responses we offer to situations and enhances or detracts from the experience.

These physical practicalities could be perceived as potential threats to function and integration. Although the participants in this study did not specifically state that they felt threatened by their environments, difficulties that could be construed as threats were noted for example attending social gatherings and going on holiday. This finding identifies with the work of Thornton and Lea (1992). They investigated the needs of people living with MS and they highlighted threats that impacted on "...bodily integrity and comfort ...and threats to emotional equilibrium." It is these difficulties that impede the ability to fulfil one's customary role and Kirkpatrick (1988) described an accompanying sense of powerlessness to changing circumstances plus frustration and anger at these impositions. The Thornton and Lea (1992) study also identified an element of discrimination towards their respondents due to a perception of burdening society with their disability. This viewpoint was also evident from the comments of the employed participants in this study who appeared to conform in an effort to minimise the impact of their disability.

Attitudes to employing the disabled were the focus of the Scope document on employment compiled by Daone and Scott (2003). In this document 23% of the employers surveyed felt that they had environmental issues that would impede the employment of a disabled person. In contrast 86% of disabled people polled felt that "...physical access barriers prevented many companies from employing disabled people." Minden et al (1993) found that 71%-75% of people diagnosed with MS felt compelled to terminate their employment and issues both physical and psychological

in nature were the causes a conclusion also reached by Johnson (2004). In this exercise study 20 people mentioned that they were unable to continue to work due to MS problems such as poor physical ability, fatigue and lack of understanding from employers.

To compensate for their deficiencies and overcome these barriers many disabled people adopt an attitude of circumvention. This avoidance behaviour as described by Folkman and Lazarus (1980) is a well-established coping mechanism employed on many levels to lessen the effects of the stressor that is perceived to be beyond the person's control. An able bodied person would probably have felt more comfortable voicing their concerns and have expected a positive response to them. This ability appeared lacking in the participants in this study with many of them opting to discontinue the activity. This circumvention could be attributable to a lack of self-confidence in the face of a predominantly able bodied environment (Kennedy 1999).

Another barrier to physical function cited by the study participants were the effects of temperature variations. Shephard (2002) identified exercise induced immune changes that were exacerbated by thermal loading with a possible link to heat collapse. For those with MS any activity that the damaged CNS perceives as exertional may precipitate thermal changes that present as fatigue and loss of physical function. These problems could impede the ability to cope with physical barriers and several of the study participants mentioned this. As with fatigue it would appear that specific advice on temperature mediation and its effects on MS could have improved the value of the education pack

From these observations it would appear that the educational material had no effect on the physical theme identified in Chapter 5 during the pre exercise phase. This lack of improvement could be as a result of insufficiencies within the pack as well as the three-month period of inactivity that the study required that may have induced a state of muscular deconditioning common to those with MS. Other authors have found that such periods of inactivity will impact on these areas (Petajan and White 1999) and this study agrees with their findings.

6.3.9. Summary of discussion points

This section discussed the elements of activity and impairment in relation to the educational material offered during the pre exercise phase and considered the issues associated with the major physical theme identified in Chapter 5. The disease process had for some people overridden everything and was severely compromising life involvement. For others it was ignored and attempts to work through its limitations produced concomitant difficulties that intensified the symptoms. Realisation of the deficits imposed by MS and the loss of life goals was also shown.

The common binding thread appeared to be the MS experience that encompassed mutual physical and psychological difficulties irrespective of age, sex, time since diagnosis or physical deficit. This migrated into all life domains. There was also an underlying resilience that enabled some people to combat the disparate MS dilemmas encountered.

Physical barriers compounded by a lack of physical ability were a constant irritation for the participants and they identified not only the physicality of dysfunction as a major detractor to their daily lives but also the effect that this had on their engagement with the world as a whole.

It would appear from these results that the educational material supplied during the pre exercise phase of the study had no effect on the outcomes of the selected scales or on the subjective perspectives relating to physical function recorded in the journals. There were comments in the journals that the information was useful if not for the participants themselves but for others. Some people passed it on to family members or employers and one person offered it to a newly diagnosed individual who was facing a six-month wait for their follow up appointment. Other reasons for the lack of effect of educational material on the scale results could be that the information had already been acquired through other means and people had already formed their own strategies for managing their condition. Also as one person mentioned it arrived too late in their MS journey to be of use to them. These findings do not negate the benefit of education but they re-enforce the need for timely and appropriate information to be provided.

6.3.10. Conclusion

This section has discussed the impact of exercise on the physical manifestations of MS. It has also looked at the stand-alone impact on physical function of the educational material offered during the pre exercise phase of the study. It can be concluded from the discussion offered here and scale results presented in Chapter 4 that exercise was an important factor in changing physical ability, overcoming physical barriers and promoting integration. The impact of the educational material provided in this study was far less effective in influencing these problem areas. This highlights the issue of education for those with MS and it raise questions as to the timely nature of its presentation, its content and the level of responsibility assumed by patient and professional. From these results it is evident that education did not have the same benefits on physical function as those provided by exercise.

6.4. Section three. Evaluation of the psychological study findings

This section will present the discussion relating to the psychological impact of exercise and its relationship to QoL as assessed by the scales and as uncovered in the journal entries. This will address question 2. It will also include the relevant psychological information from the pre exercise phase that applies to question 4.

6.4.1. Exercise and psychological function

The effect of exercise on quality of life will be discussed in relation to the results of the MSQOL54 and the NRS. The section will also include a discussion of the psychological themes identified in Chapter 5. It will begin with an introduction to the concepts of disability perception and the "Disability Paradox" as elements that can influence exercise uptake.

6.4.1.1. Disability perception as an influencing factor in exercise participation in MS

The distinction between illness and disability is problematic and is an important consideration when attempting to engage disabled people in exercise. Many people lose physical ability for a variety of reasons through trauma, disease or old age but

they do not perceive themselves as being ill (Oliver 1996). Some people may however view the disability or their physical loss as an illness and their subsequent behaviours will be governed by this viewpoint. It could be inferred therefore that those who perceived themselves to be ill as a result of having MS may perform less effectively than those who saw themselves as disabled by the disease.

In this study it was discovered that neither group indicated any improvement in health perception as shown by the MSQoL 54 despite the physical improvements shown on the assessment scales. This could indicate an altered perception of the meaning of health. It would be interesting to discover whether “health” equated to illness or disability in this instance. If it equated to disability then the perception could be more allied to loss of ability rather than being ill. If health were perceived to be more an issue of actually being ill then that would infer that the person was sick rather than lacking in physical ability and therefore unable to function as a result.

The concept of health perception was considered by Albrecht and Devlieger in their 1999 work. They suggested the possibility that if one has a disability then they cannot be considered to have good health. Lerner and Levine (1994) however approach this concept from a different perspective and view it as critical not to equate quality of life solely to health related issues. It was their contention supported by Grimby et al (1988) that quality of life embraced many concepts including physical and social functioning and mental health. These factors will color one’s disability perception more subtly than a one dimensional health perspective and they were significant elements of the subjective findings extracted from the journals. However the fact remains that if a person perceives himself or herself to be ill rather than disabled a different perception of function and social interaction will present.

6.4.1.2. The “Disability Paradox” as it impacts on exercise for those with MS

Disability perception is closely linked to the concept of the “Disability Paradox” (Albrecht and Devlieger 1999). On examining the changes evidenced by the addition of exercise to those in this study it became clear that quality of life improvements were shown and these gains did not necessarily equate to the level of improvement

achieved. That guides one to the theory proposed by Albrecht and Devlieger (1999) of the “Disability Paradox”. This is an extension of the work by Levine (1987) that investigated the disadvantaged and the disenfranchised in relation to quality of life. They proposed that quality of life was dependant on a mind, body and spirit balance that facilitates “--establishing and maintaining an harmonious set of relationships within the person’s social context and external environment.”

The paradox revolves around the personal experience of disability that defines one within the world. The balance of relationships can be destabilised by the effects of MS. Consequently the person’s place and perceptions of worth within their social context can be altered due to “--shattered preconceived expectations and norms” Albrecht and Devlieger (1999) and their accepted concepts and ideas of well-being are put in doubt.

The exploration of real world experience in response to disability attempts to clarify the perception of quality of life. The paradox is the unexpectedly elevated quality of life perceptions of the severely disabled person in comparison to the lower appreciation of someone less affected. It is clear that high quality of life perception is a combination of control, adaptation, understanding and empowerment (Lerner and Levine 1994). It must therefore be accepted that one’s level of disability will not act as the sole predictor of the quality of life impressions of a disabled person but that the perception of disability must be included as a factor (Levine 1987). The disability paradox was a consideration in this study with some of the moderate/severely affected participants seemingly able to embrace life and its small pleasures more readily than those less affected.

6.4.1.3. Effects of exercise on activity/participation/impairment

Quality of life has been described as a dynamic construct by Murrell et al (1999). In their study on persons with severe disability associated with MS (n=22), they found that it was dependant on a complicated interaction of physical and psychological elements to produce feelings of wellbeing and satisfaction with life. They concluded that it required measurement over predetermined time scales to allow its emergent properties to evolve. Quality of life is individualistic in its presentation and is not

readily transferable between individuals. Thus determining the amount of “Quality of Life” a person experiences in relation to their life constraints is difficult. In the case of this study it must be accepted that the self-assessment of quality of life expressed in the NRS and the MSQoL 54 was influenced by the events of the day/week, MS symptoms present and the emotional state prevailing at the time.

Although minor gains were made in the NRS in both groups compared to the pre exercise scores, physiotherapy appears to have produced a better outcome on t testing. These gains were re-enforced by comments in the journals of 20 of the participants, (15 physiotherapy, five self-selection). One reason for the positivity expressed could be an “end of study syndrome” a concept that occurred during the journal analysis process. For some this could have involved a positive final submission at the end of the journal that was more assured than the reality warranted. This could be likened to examination completion, the final hurdle is overcome and one will say anything to complete the task sometimes without thoroughly thinking through the response. Another reason for the perceived improvement in quality of life in the physiotherapy group could be that the more severely affected happened to be in this group. It has been mentioned earlier that the more disabled people did show better physical improvements relative to those less affected. These gains had the potential to impact on quality of life as with the person who could stand to clean her teeth. These possibilities were not measured specifically but it should be appreciated that these phenomena could have influenced the responses.

Unexpected positive results were shown by the MSQoL 54 in domain 9, Cognitive function in the physiotherapy group and domain 3, Limitation due to emotional health in the self-selection group. It is possible that these results should be attributed to chance rather than the effects of the intervention in view of the fact they are unsupported by gains in any other domains. There was also some improvement in the mean score of item 2, Satisfaction with sexual function that did not reflect in the corresponding domain score. Asking people about sexual activity can be controversial and for many it is an area that should remain behind closed doors, (Burnfield 1995) This reticence could account for the anomaly in results for this area of investigation. Although the MSQoL54 was completed unaided by the participants, the investigator was present and many people felt the need to probe the nature of this and other

questions after the form was completed. It is this researcher's opinion that can only be submitted subjectively that deeper sexual problems existed that could not be addressed during the course of this study. There was also the possibility that problems of a sexual nature would have presented in the relationship anyway and were not necessarily MS related (Sipski 2001). This does not diminish their importance but it does introduce a separate element to these difficulties that would require further investigation in an appropriate arena.

The results of the MSQoL 54 did not reflect the positivity expressed in the journals. This illustrates the importance of allowing subjective data to augment established data collection methods as discrepancies can often be found that could influence the results or change their perspective. The dynamic nature of qualitative investigation demonstrates a need for such additional data sources.

6.4.2. Effect of exercise on the psychological themes identified in the transcripts

This sub-section will consider the themes of "How others see me" and "How I see myself" identified in Chapter 5.

6.4.2.1. "How others see me"

The poor preconceptions regarding the opinions of others expressed in the pre exercise phase themes of "Coping" and "Emotional State" were altered for the better at study conclusion. This was a governing factor in respect of self-esteem and the ability to integrate with the world. There was a shift of self-perception away from the helplessness and overall feelings of loss that pervaded the pre exercise phase mainly in the themes of "Making sense of MS" and "Disability" with a subsequent elevation in mood. This was reflected in the journals and was identified by the participants as being due in part to the introduction of exercise into their daily routines.

During the pre exercise phase many people perceived their "value" to be determined to some extent by their physical condition and their subsequent physical ability. This was re-enforced by significant others, an observation also mentioned in the work by Reynolds and Prior (2003). Grytten and Maseide (2006) described this as the stigma

of having MS that was fed by the overemphasis placed on the mostly negative aspects of the condition by others. Overly “helpful” individuals whose attentions only served to lessen the self-esteem of the person concerned highlighted the perception of one’s decreased value (Barton et al 1994).

Exercise promoted a shift away from this perspective to a more accommodating attitude that was less defined by the opinion or interference of others. It could be assumed that improved physical ability and the resulting quality of life perceptions were in part responsible for this change a supposition in line with the Sutherland and Andersen (2001) study. This appeared to crystallise the participants’ over-view of their place within their family and social groups promoting the notion that it was permissible to have MS and to experience the problems it brings without loss of self-esteem or social standing. This realisation was significant in positively influencing feelings of low mood and depression and correlates to the findings of McIvor et al (1984) who identified a positive link between the degree of disability and severity of depression. Mediating the physical effects of MS appeared to lessen the psychological impact of these symptoms. The disease was a part of whom they were and as such had to be acknowledged and accepted (Reynolds and Prior 2003). It was true that this was not the case for all the participants and for some this acknowledgement of the condition still represented a submission to the limitations it imposed. Other authors have identified the need to adapt to changing disease presentations, (Dimond and Jones 1983. Woods et al 1989. Stuifbergen 1995) and acknowledged this as a core aspect of one’s ability to cope with MS.

There was also an alteration in the participants’ attitudes towards loss, both physical and psychological. Loss due to disability was illustrated in the work by Rando (1984). He described two distinct types of loss that were physical and symbolic in nature. The former was easily identified in the progressive depletion of physical function that is commonly exhibited with MS. The symbolic loss was less obvious but no less devastating in its effect. This was recognised as the insidious psychosocial decimation of life involvement that progressed as an undercurrent to the more obvious physical manifestations of the condition. This phenomenon has also been recognised as presenting as excessive loneliness and a perceived loss of self that accompanies functional decline (Barton et al 1994. Rokach et al 2006).

Those involved in this study experienced loss on various levels and this impacted on their perceptions of “how others saw them”. The effects of this perception varied in relation to the levels of physical deficit they were facing, disease progression and to the impact MS had on their family and social dynamics. For some of the participants the introduction of the exercise regimes did alter their concept of loss by returning a degree of physical ability that impacted positively on their quality of life. One person said she was able to go on holiday without being totally gripped by fatigue and another was able to attend a Christmas party.

Other people expressed both satisfaction and surprise at their exercise performance and at the improvements they achieved. These reports of improved physical and psychological state in this study’s participants confirmed the importance of long-term exercise involvement for those with MS. This is not a new proposal. Previous works by Stuifbergen et al (2006) and Sutherland et al (2001) also advocated the value of long-term exercise involvement and acknowledged the impact it can have on physical and psychological function. This is also supported by the works of Ashburn and DeSouza (1988) and Schapiro et al (1988).

Unfortunately there were those who although expressing benefit at participating in the study did not display such positive outcomes. These people still mentioned difficulties with excessive fatigue, stamina and general physical abilities. These must be acknowledged as a part of human nature and there will always be a minority in any group that do not follow the majority trend.

The evidence from this exercise study indicated that exercise did impact on psychological functioning and quality of life. However this is not the opinion of all in the research community. Romberg et al (2005) for example did not report any corresponding quality of life gains as evidenced by the HRQoL results of their sample receiving an exercise programme, (n=48). They did propose that the result could be due to the insensitivity of the assessment scale used and advocated that the test be repeated with an alternative quality of life measure.

Many respondents in this study expressed quality of life gains as an added enjoyment of life events, as an improvement in physical ability that enabled social involvement and for some it was a new understanding of MS. Some people noted that this new outlook influenced their perception of how they felt others saw them, not firstly disabled and secondly a person but just a person who happens to be disabled. The success of the exercise regimes that impacted on self-esteem was augmented by positive feedback received by significant others. This concept of peer/family support and approval is well documented, (McIvor et al 1984. Wineman 1990) and formed an integral part of the exercise outcome. It also allies to the theory of planned behaviour belief that underpinned the study.

6.4.2.2. "How I see myself"

Quality of life was a major driver as far as improvements in the participants overall feelings of self-efficacy and confidence were concerned. This was to some degree governed by the level of disability experienced but not wholly so. Minor physical gains that were experienced by the more disabled participants appeared to project significant quality of life improvements in some cases. Freeman's study (2006) on improving mobility and functional independence in MS also found this to be true. It did not follow therefore that those with better physical ability expressed the greatest quality of life gains in their journals a confirmation of the disability paradox referred to earlier, (Albrecht and Devlieger 1999).

This phenomenon could be directly related to the individual's perspective regarding their level of disability. Some people were better able to rationalise the deficits they experienced in relation to their life needs and expectations than others. Allison et al (1997) investigated quality of life and described it as a dynamic construct. They believed that the individual's external environment changed, in this case physical ability, while their core appreciation of wellbeing remained constant. They concluded that the person was altering these internal standards to accommodate the change. In other words they were able to adapt to the physical changes while maintaining their internal stability. It could be suggested that for the participants in this study adaptation was increased as they integrated more freely due to improvements gained through exercise. Some people remarked that they felt "more normal" as a result.

Unfortunately there were others who were unable to adopt this adaptational mechanism. Four people made comments in their journals indicating that they still had difficulties that impacted on their self-perception. One person still felt they were perceived as “--not normal” and this attitude extended beyond the ability of exercise to positively influence. For them the level of disability overwhelmed their self-perceptions and impeded life involvement. This perception can be reinforced by some health professionals who may view health and wellness in a purely biomedical sense that is detached from the person’s perception (Lerner and Levine 1994). As a result little credence is assigned to the importance of a person’s perception of health and their ability to perform social roles (Lohr 1992. Schor et al 1994).

Seeing ones self as physically disabled can also contribute to a cognitive disablement that feeds the physical deficit. Accepting the disability and incorporating it into life promotes a re-evaluation of ability. Harrison et al (2004) investigated marriage, acceptance and impairment in a mixed sample of MS individuals and found that married men demonstrated a greater acceptance of disability with less perceived impairment than women. The men were however more concerned about how it affected their sexual relationships than the women.

This exercise study did not totally agree with the findings of Harrison et al (2004) as far as disability acceptance was concerned. Four of the men included in this study expressed feelings of distress and anger at their MS deficits. This study did however produce evidence to support the idea that those with good family networks exhibited better disability acceptance overall. It could have been the case that the men in question were lacking this element of support in their home lives. For those who were able to accept their changing physical circumstances this did not indicate acquiescence, more an understanding that facilitated coping.

There was also the possibility that those with fewer manifestations of physical disability demanded more of themselves and expected to demonstrate more dramatic physical changes than the disease could accommodate. This is only speculation in this study but the desire to over perform because of one’s perceptions of previous abilities has been recognised in athletes (Wyner 2005). Expectations were in some cases set at

unattainable levels that the investigator attempted to moderate during the pre exercise phase of the study. Unfortunately, this was not possible in all cases and some final outcomes reflected the disappointment experienced by a few people when anticipated improvements were not achieved. These individuals could have perceived themselves as failures due to these unrealistic expectations.

Despite some disappointments regarding expected improvements and exercise involvement most people did record quality of life improvements that they felt were attributable to the exercise programmes they undertook. This finding concurs with that of Sutherland et al (2001) who noted the positive effect of aerobic exercise on those with MS. Similar positive effects on quality of life after exercise were also mentioned by other authors, (Stuifbergen et al 2006. Sutherland and Andersen 2001. Solari et al 1999). These conclusions support the value of exercise not only physiologically but also psychologically. This outcome could be construed as a positive view of self that increased the quality of life perspective.

It should be noted that there were a barrage of life-altering events that impacted on the participants during this study. These events included the suicide attempt of a partner and the loss of close relatives and it would be detrimental to the study to ignore these events. However it appeared from the journal narratives that the participants continued to exercise throughout these difficult times. There were no specific comments regarding the benefit of the regimes in respect of these events other than one person who contended with a divorce. She mentioned that the exercise was a constant throughout and it helped her regain a degree of control over her life throughout the chaos.

Some people described a social isolation due to their physical limitations during the pre exercise phase that appeared to be lessened after exercise. This was accompanied by feelings of raised self-esteem, pride in achievement and an appreciation of the impact of exercise on physical function. Stuifbergen (1992) also found that exercise had a mediating effect not only on physical deficits but also on self-esteem and in her study exercise was cited as the most used method of self-management for those with MS.

These assumptions that exercise had a mediating effect on self-perception ally to Oliver's work (1996) on disability. He proposed that disability was related to functional limitations and psychological loss. The positive changes exhibited in this exercise study demonstrated that it was possible to influence the disability persona despite the deteriorating nature of MS. Exercise appeared to have the ability to interject along the disease continuum and lessen the impact of the changing disease process. It was this realisation that appeared to offer some hope and encouragement to the study participants.

Some people acknowledged a better understanding of MS at study conclusion that seemingly evolved through exercise engagement rather than as a result of the educational material offered. Living with an incurable degenerative condition leads to an uneasy familiarity that is infrequently examined. This study encouraged this examination of MS and its impact on the participants by allowing for unfettered comments to be recorded in the journals. Many people found this to be a cathartic experience and described anecdotally a certain release of tension as a result of their expression. This allowed some of them to re-evaluate their perceptions of self and in a few cases change them for the better.

Therefore it could be concluded that the positive changes in the participants' self-perception appeared to be a result of the exercise they had undertaken. Indications of increased confidence in social interaction, raised mood and a reaffirmation of one's place in the group emerged and this seemed related to the improving physical condition. These phenomena were also identified by Wiles et al (2001) as well as in the study by Henderson and Bedini (1995) highlighting the role of physical activity in leisure as well as a therapy. This use of exercise for leisure became a reality for some of the participants who elected to attend the local gym. They indicated in their journal narratives that it was becoming a pleasurable event rather than an exercise chore. This is an important element of exercise adherence that often goes unrecognised. The need for exercise to be meaningful and enjoyable will determine its effectiveness and the degree to which the person will continue with it. Morgan (2001) argued that many exercise activities such as treadmill walking and stair climbing were regarded as non-purposeful activities yet they were the type of exercises that were routinely prescribed. There is of course a need to practice such activities when walking and

strength are compromised as in MS however they need to be tempered by variety and personal relevance to promote enjoyment and encourage adherence.

It would be unrealistic to attribute these quality of life changes entirely to the effects of exercise. However, the efforts required to perform the exercise regimes appeared to have engaged the participants in an activity that they could control. This successful endeavour could be responsible for encouraging them to enter into new or discarded behaviours with increased confidence, eg one participant took up gliding and another rediscovered her swimming prowess. The knock-on effect being one of renewed determination and a greater ability to participate in life.

6.4.3. Summary of discussion points

Post exercise the participants remarked on their elevated levels of optimism related to improved physical abilities that projected them into society with renewed confidence. The issue of “normality” that was noted in the pre exercise phase was re-visited and it appeared that the implementation of the exercise regimes was influential in positively altering both physical and psychological life domains.

Many of the participants believed the gains accrued through exercise were instrumental in enhancing their quality of life and this was documented in many journals. As a result of this improvement the feelings of low self-esteem and helplessness that were evident in the pre exercise phase became less prominent. This altered perception could have been attributable to a renewed sense of achievement in the case of the participant or from the approval of significant others who appreciated the efforts being made to control and manage MS symptoms. The shift from passive non-participant to active engager could be perceived as a positive action to regain control.

Sutherland and Andersen (2001) have noted that although there was a wealth of evidence to support the efficacy of exercise for those with MS, there was little information to endorse its effect on psychological functioning. They did note however, “Considering reports that the MS population exhibits a high prevalence of life-altering problems that can detract from well-being and quality of life it would

seem participation in regular physical activity may also positively influence mental health for people with MS.” Although the QoL measure used in this study did not offer definitive evidence to support this supposition the comments in the journals did. This could indicate that subjective evidence should be afforded a higher profile when investigating quality of life issues.

Relationships also appear to have benefited from the uptake of exercise. Many people noted enhanced interactions with family and friends due to their improving physical condition. In one respect this was a valuable forward step towards re-integration. Conversely it could be viewed as a sad reflection on our understanding of disability and our ability to embrace anything that steps outside our able-bodied concept of “normality”. This also serves to highlight the lack of effort made to involve the disabled in mainstream society. Unfortunately the pre exercise intervention of educational material did not have the same beneficial impact on psychological domains as did the introduction of exercise. The disease process had for some people overridden everything and was severely compromising life involvement. For others it was ignored and attempts to work through its limitations produced concomitant difficulties that intensified the symptoms. Realisation of the deficits imposed by MS and the loss of life goals was also shown.

6.4.4. Education and psychological function

This sub-section will address the influence of the educational material offered during the pre exercise phase on the NRS and MSQoL 54. It will also include the relevant psychological themes identified in Chapter 5. These themes were “Coping”, “Making sense of MS”, “Emotional state” and “Disability”.

6.4.4.1. Effects of the educational material on the psychological aspects of activity, impairment and participation

Despite the improvements in impairment reported in the GNDS a corresponding perceived improvement in quality of life was not reflected in the NRS scores. It was unlikely that the participants recalled their previous responses completed 12 weeks earlier so the determination of quality of life was probably accurate at the time. In regards to the MSQoL 54 domain 8, Social function, did show a positive change that cannot be explained or supported by the other results. No other domains showed

significance after paired t testing indicating that the education pack had no positive effect on the other areas of activity, impairment or participation as assessed by this scale.

The explanation may lie with the participants' perception of quality of life. Improvements in the specific symptomatic areas considered by the GNDS could have been seen as simply that, problem specific. If this was the case then the gains that the participants indicated were confined to the questions proffered and the subject areas that were specifically investigated did not overlap into their perceptions of quality of life. Rogerson (1995) observed with reference to quality of life perception that "-- patients are idiosyncratic in their criteria identification and thus their evaluation may be at odds with a diagnosis undertaken by clinicians and medical staff." He goes on to say that the relationship between objective indicators as used by the medical profession and the patients' subjective evaluations are diverse. Thus actual physical changes as itemised in a questionnaire may not have projected into the quality of life perception of the interviewees.

It was also possible that for the participants in this exercise study the concept of quality of life could have been a more ethereal notion that involved how they interacted within their family and social groups. This is of course true and was a major determinant of quality of life perceptions for most people. However it appeared to have been seen in isolation at this stage rather than as a product of symptom change. This raises questions as to the correlation between symptom presentation and disability perception and its impact on quality of life. The participants although reporting an improved perception of symptom presentation still indicated reduced quality of life scores. The concept of disability perception has been discussed in section 6.4.1. of this chapter but essentially it describes two interpretations of disability: in one the person perceives themselves to be ill in the second they see themselves as disabled yet healthy. It could have been that the majority of people had a perception of "illness" and that impacted on the quality of life scores but not on the GNDS scores.

6.4.5. Effect of the educational material on the psychological themes identified in the transcripts

There now follows a discussion of the pre exercise psychological themes identified in Chapter 5. These were “Coping”, “Making sense of MS”, “Emotional state” and “Disability”. Education is known to be valuable to the coping process necessary in long-term disability and has been shown to influence long-term disease management (MacLaren 1996. NSF 2005. Ennis et al 2006) this section will show whether it demonstrated these beneficial effects on those in this study.

6.4.5.1. Coping

People generally seem to have an inherent capacity to cope with distressing and life altering situations, for example in theaters of war and during terminal illness and death. Those with MS are no different and their ability to endure what to an outsider may appear an intolerable situation is demonstrated on a daily basis. The participants in this exercise study were exposed to MS consequences that to them were a normal part of life. However there were additional stressors that at first glance seemed too much to bear. For example one person was faced with the attempted suicide of her partner and the accompanying guilt that this caused while another underwent an acrimonious divorce.

Research has identified two methods of coping that relate to MS. These have been described as “Emotional coping” and “Problem coping” (Kroencke and Denny 1999. McCabe et al 2004. Wineman et al 1994), and correlations with stress and uncertainty have been noted with the two coping methods interrelating (Lode et al 2007). Lazarus (2000) has defined the two states as follows: the emotional coping strategy involves the person trying to minimise the distress without actually addressing the problem whereas the second approach involves addressing the problem directly in an effort to resolve it. There is evidence to suggest that the problem orientated style of coping produces better adjustment and lowered stress responses whereas emotional coping fares less well and can be a precursor to depression (Folkman et al 1986).

With reference to the two participant scenarios mentioned previously the researcher was aware of the outcomes and can speculate as to the type of approach adopted in

each case. The person who encountered the attempted suicide seemed to adopt an emotional response that was probably to be expected. She tried to block the impact of the problem by taking anti depressants and had little in the way of family support throughout. The second scenario involving the divorce was handled as a direct frontal “attack” on the problem at hand. This participant found a fulfilling job, changed her “look” and started going out with friends. This approach served her well and despite the personal grief she felt at her betrayal she actively took ownership of her situation with a resulting positive effect on her quality of life. This person had an extensive family and friend network that she felt was an invaluable coping aid.

Despite the fact that these two scenarios were not MS specific the impact on the participants’ physical condition was evident and demonstrated the inability to separate the physical nature of MS from its psychological consequences. The person who adopted the “Emotional” approach reported an increase in pain and a decrease in walking ability for several days after the event. The second participant reported an improvement in energy and felt in control of her situation. This finding although anecdotal, concurs with the work of Aikens et al (1997) who found a direct relationship between the problem solving approach and quality of life. However there are other works that find no such correlation (Jean et al 1999) and still others who believe that there is scope to investigate the relationship between coping strategy and disease progression (Montel and Bungener 2007). This demonstrates the difficulties involved in investigating coping strategies that are affected by a life-changing disease such as MS in which dynamic coping strategies are a necessity (Reynolds and Prior 2003).

It would be interesting to discover if there was in fact a link between coping strategies and MS symptomology. Unfortunately this is beyond the scope of this study. What can be noted as far as this exercise study was concerned was that coping was a central component of the participants’ lives it was highly personal and was to some extent determined by their inner strengths and support networks.

6.4.5.2. Making sense of “MS”

There was evidence in the journals to suggest that the participants were struggling to rationalise their life changes and consequently assign some meaning to them. The work by Reynolds and Prior (2003) also identified this type of difficulty while Brown and Kraft (2005) surmised that it is the uncertainty of living with MS that compounded the physicality of the disease experience. This presents a challenge to both the person concerned and those attempting to influence the disease process. These attempts were evident in comments relating to a worsening or lessening of symptoms/functional difficulties that impacted on the psyche. Smith et al (1997) described a process of making sense of health and illness in their work on the psychology of illness that can be applied to those in this exercise study. They proposed that when illness or disability occurred the person considered their identity to be under threat. This concept emerged in some participant journals and presented as a need for a positive reinforcement of self-worth. This re-enforcement was dependent to some degree on the personal and social resources available to the person, a concept identified by Fournier et al (1999). The need to be valued by and valuable to significant others was an important element of the attempt to make sense of MS.

The perception of MS was also important and impacted on the participants' abilities to cope with its vagaries. MS was represented in several participants' journals as something to be tolerated, endured and hated in varying degrees. It also assumed a personal role and was referred to by several people as “--my MS”. This personalised perception of “disease” was explored by Taylor (1983) in her qualitative work examining patients' perceptions of chronic illness. She discussed the strategies employed by cancer sufferers to cope with the illness and proposed that three central themes existed: a search for some meaning in the experience, an attempt to re-gain control over one's life and the re-establishing of some degree of self-esteem. The pre exercise comments in the transcripts of this study's participants also demonstrated a need to understand their illness and this influenced the resultant viewpoint they formed of themselves. There were recurring references to perceived “Loss” plus indications of helplessness at some peoples' inability to influence the loss. Overwhelming helplessness was highlighted in an MS population by McGuinness (1996). He described it as “Learned helplessness” and proposed that there was a link between

disease status and disease activity. The themes of loss of control and diminished self-esteem were also echoed in the transcripts of the participants in this study and co-existed with helplessness. One person noted that they felt overwhelmed by close relatives who took over their place in the family leaving them feeling superfluous and detached. Their response to this was to withdraw even further thus compounding the problem. Thus efforts to understand the disease process and its consequences could be a causal factor in the identified feelings of helplessness in this study's sample. Some people also believed that they were viewed as somewhat less than "normal" in the eyes of others.

The perception of loss of normality as alluded to previously, was a common theme expressed by the participants in the study carried out by Albrecht and Devlieger in 1999. They considered the apparent mismatch of high quality of life and adverse health experiences. Many people in that study believed they were treated as mere "cases" and not as "--fellow human beings with a disability". This altered the social dynamic as physical deficit eroded ability. Often attempts to offer assistance were viewed with suspicion, a wresting away of control from the participant so lessening their self-esteem. However this was not always the case and Albrecht and Devlieger (1999) did identify individuals who had such clear personal values with an accompanying mind/body balance that self-esteem was increased despite the disability experience.

It could be proposed that self-esteem is central to one's core values and Schain (1980) indicated that it was the sum total of a persons' perception of self. If this perception is compromised then fulfilling significant life goals becomes almost impossible a problem compounded by limited physical ability. One person in this study had a toddler who she was unable to control. The child had discovered her mothers "weakness" and continuously tested the extent to which she could misbehave. The situation was a constant reminder of the mother's loss of control and reinforced her low self-esteem.

Research into the link between physical disability and body esteem has added to the evidence demonstrating the causes of loss of self-esteem. The work by Taleporos and McCabe (2005) examined this link focusing on severity and duration of physical

disability and they concluded that a strong association was demonstrated. For the participant mentioned previously her life goal of successfully raising her child was seemingly slipping away from her impacting significantly on her self-esteem and compounding her feelings of loss. Added to this she also expressed dissatisfaction with her appearance that she associated with the effects of MS.

6.4.5.3. Emotional state

The participants in the pre exercise phase of the study noted feelings of regret and loneliness as social circles slipped away. This was for varying reasons notably fatigue, loss of physical ability and embarrassment at changing body state all of which negatively impacted on their emotional state. This alteration of emotional state at changing circumstances is not unusual as shown by the work of Rokach et al (2006). Their study investigated the loneliness experienced by people with physical disabilities and they noted that: “Loneliness has been found to be a frequent companion to those with chronic illnesses that result in physical disabilities.” Often social isolation was responsible for increased loneliness that fuelled feelings of inadequacy. In many cases this was the effect of a gradual withdrawing by the participants as a result of physical/psychological difficulties that impeded integration (Sutherland and Andersen 2001). Some participants in this exercise study demonstrated such withdrawal by declining social invitations and withdrawing from previously enjoyed activities. Those participants who retrospectively recognised this process remarked that it had happened insidiously. This insidious withdrawal was recognised in the work by Kennedy (1999) who referred to the architectural and social inaccessibility of our able bodied society as the “disabling environment”. It is entirely likely that this concept of a “disabling environment” did impact on this study’s participants facilitating a quiet withdrawal from circulation.

Withdrawal from social interaction and the subsequent loneliness that results is not peculiar to those with MS. It is a normal emotional response to changing physical and psychological circumstances that pervade life in general. It has been suggested that a large proportion of the general population frequently feel lonely, (Rokach and Brock 1997). The feelings appear however to have been heightened by the effects of MS. The physical manifestations of MS can be misinterpreted as mental deficiency, drug

abuse or alcoholism (Gordon et al 1998. Thornton and Lea 1992). There was a specific comment made by one person in this exercise study who had been accused of being drunk on many occasions due to her ataxia. It is often this misunderstanding that initiates the beginnings of withdrawal and introversion that disrupts one's emotional balance. One other person in this study also noted that she felt she was perceived as stupid because she could not fully participate in conversations when she was tired due to slurring of her speech.

It was evident that emotional state affected many of the study participants' abilities to interact with others a conclusion also reached by Burnfield (1995). Some people mentioned that when their MS was "playing up" they felt unable to socialise or in extreme cases leave the house at all. This was a combination of physical problems and the psychological impact these problems had on the person's perception of self. The work on emotional state in MS by Dalos et al (1983) revealed that this emotional disturbance was directly related to an increase in disease activity. Their study concluded that the emotional disturbance was not solely dependant on sensorimotor deficits but that the fear of exacerbation and the possible resulting deterioration in ability reinforced this emotional collapse. Often the anticipation of the event overshadowed the resulting reality and as reported by Dalos (1983) this impacted on coping. This finding was relevant to those in this study with one notable mention of the fear of an impending social gathering being worse than the actuality of the event.

Emotional state will govern one's self-perception and it could be argued that our ability to form a positive perception of ourselves defines our existence (Reynolds and Prior 2003). This insight allows us to forge links with others, enables us to contribute to society and to interact successfully in life's situational presentations. This human experience is usually guided by our home life, school experiences and work and leisure encounters. Some people in this study indicated that they felt diminished by MS and this seemed to negatively affect their previously acquired values. A possible knock-on effect of altered self-perception could be depression. Some study participants did exhibit depressive tendencies that they indicated were directly linked to the consequences of MS. Depression has been identified as a common MS problem (Acorn and Andersen 1990) and although the purpose of this study was to examine the effects of exercise on MS this important aspect of MS affectation was appreciated.

6.4.5.4. Disability

It would be logical to assume that our reaction to a given situation could be predicted by the preceding accumulation of our life experiences as mentioned in the previous section. In most cases this may be true however it is the addition of a life-changing event like a disability that has the potential to alter one's ability to react either predictably or in some cases rationally (Dalos et al 1983). For some people in this study the intrusion of disability into their lives interfered with this element of predictability and altered their relationship perspectives.

The work by Oliver (1996) mentioned previously has identified the "problem" of disability that these people encounter as existing within the individual. He contended that it was directly related to the functional limitations or psychological losses that emerge as a result of the disability. He went on to describe the "personal tragedy theory of disability" that suggested that disability was a terrible chance randomisation of events on unfortunate individuals. It could be argued that this was the opinion of some of this exercise study's participants during the pre exercise phase with the "Why me?" question overshadowing their adaptational ability. A belief in random affectation and the consequent inability to influence the outcome may allow the consequences of MS to overtake them. This could foster an accompanying relinquishing of responsibility for their engagement in life as a whole. Parsons (1952) identified this as the "sick role" and extended it to include the exemption from customary role obligations plus the need for a negative attitude toward the illness and towards the duty to get well. Berglas (1985) went further and described this phenomenon as "self-handicapping" the notion that the randomness of the disease's insinuation into their lives permitted a withdrawal from interaction and participation.

The disengagement from life's role obligations described by Parsons and later by Berglas could be attributed to the physical effects of MS. The fact that loss of physical function is a devastating consequence of MS is not in dispute, what could be called into question is the response that the individual exhibits to this loss. Berglas (1985) proposed that the individual can protect themselves from the negative opinions of

others that accompany a disability by one of two approaches: firstly by creating barriers to a good performance either physical or psychological in nature.

The second method involved withdrawing their effort all together encouraging the subject to “self-handicap” thereby retaining their positive self image as previous successes had not been challenged by a potential failure.

This process of self-handicapping must seem inviting to many people with MS as it offers a method to circumvent difficult or demanding situations without losing face. It was shown in some of the journal entries of this study’s participants during the pre exercise phase that this process occurred. Some people chose to limit their life involvement citing environmental difficulties as the reason, a method of self-protection from challenging situations. There was also evidence of complete withdrawal with a delegation of customary tasks to others for example household management tasks.

Self-handicapping could also be described as a self-defence mechanism that was adopted in an effort to guard against the life-demands that some people felt ill equipped to face. Unfortunately this reinforced a spiralling pattern of loss of role and purpose. Thornton and Lea (1992) in their work on living with MS noted that, “...people are often unable to find “citizenship” either in the world of the healthy or in the world of the sick”, a situation that impeded adjustment. In attempting to cope with this situation people accentuated or minimised their symptoms as they tried to rationalise the effects of MS. In this study coping appeared to be imposed on them by well meaning relatives, “trying to be helpful”. One person remarked that this was intolerable for her but she felt unable to confront the relative about it. Conversely there were those who constantly struggled against the effects of disability. Although they did not fit the profile proposed by Berglas they still disadvantaged themselves by their inability to adapt to changing physical conditions. The education pack did not appear to have impacted positively on the identified themes.

6.4.6. Summary of discussion points

In the pre exercise phase the common binding thread appeared to be the MS experience that encompassed mutual physical and psychological difficulties

irrespective of age, sex, time since diagnosis or physical deficit. This migrated into all themes. There was also an underlying resilience that enabled some people to combat the disparate MS dilemmas encountered. There were a number of issues that impacted significantly on the life experiences of the participants. These were their attempts to understand MS, their emotional state and the impact of disability on the psyche. There was an indication that many people felt lessened as individuals. This resulted in a regression into the disabled persona that they believed was expected of them. During the pre exercise phase the participants exhibited relationship displacement in their dealings with family friends and with their concept of self as affected by MS. Physical barriers compounded by a lack of physical ability were a constant irritation for the participants fuelling the psychological manifestations previously mentioned. The participants identified not only the physicality of dysfunction as a major detractor to their daily lives but also the effect that this had on their engagement with the world as a whole.

6.4.7. Conclusion

This section discussed the psychological effects of exercise and the impact of the educational material offered during the pre exercise phase. The exercise interventions produced significant measurable benefits to the quality of life perspectives of the participants and this was ably demonstrated in the journal narratives. The overall perception of self and the subsequent opinions proffered by others appeared to have improved with a concomitant reaffirmation of role and value. Exercise impacted on physical function as demonstrated by the scale results and it was anticipated that a slight impact on psychological function would also present. However on reading and categorising the journal data it could be argued that for some people the psychological gains outweighed the physical and this demonstrated the interrelationship between the physical and the psychological elements of MS and exercise. It could be proposed therefore that for a truly relevant picture of the impact of exercise on the total MS experience significant attention should be paid to its psychological presentations in relation to exercise.

In contrast it would appear from these observations that the educational material had no effect on the subjective perspectives recorded in the journals. There were

comments recorded during the pre exercise phase that the information was useful if not for the participants themselves then for others. Some people passed it on to family members or employers and one person offered it to a newly diagnosed individual who was facing a six-month wait for their follow up appointment. Other reasons for the lack of effect of educational material could be that the information had already been acquired through other means and people had already formed their own strategies for managing their condition. These findings do not devalue the benefit of education but they re-enforce the need for timely and appropriate information to be provided.

6.4.8. Search for meaning within the transcript themes

Throughout the process of theme clustering and identification carried out in Chapter 5 the requirement to find meaning in the experiences of the participants predominated. The themes from the pre exercise phase were not entirely comparable to those in the exercise phase. This was to be expected as the introduction of exercise had altered both the physical and psychological perspectives of the participants.

The participants demonstrated many difficulties mainly in the pre exercise phase that could be attributable to the effects of living with a long-term neurological disease. They expressed frustration at their physical limitations and at the impact this had on their personal interactions and self-esteem. The researcher was therefore directed to consider whether the physicality of exercise intruded beyond the purely “physical” influences that would be expected. This prompted the search for a link to the psychological aspects of disability that interconnected with the physical. On examination of the participants’ journal entries links between the exercise experience and the identified themes began to appear. The exercise effect appeared to influence both self-perception and the opinion of significant others plus a myriad of other intrusions into the psychological experience of having MS. This exercise study allowed the participants to examine the physicality of exercise by charting their changing physical condition with their psychological states being revealed more subtly within their journal entries. It is this researcher’s contention that an awareness of the positive effects of exercise enabled the participants to adopt exercise as a self-help strategy that influenced their psychological outlook.

Another possible explanation could be allied to the indications that the participants were engaging in something they could control completely. Other researchers have cited loss of control over social roles, physical function and valued life involvement as a contributing factor towards poor self-esteem and even depression in those with MS (Barton et al 1994. Shuman 1996). In the case of this study exercise appeared to introduce an element of control into the participants' lives that were in some cases in disarray. The exercise appeared to improve self-perception a finding that concurs with the opinion of Sutherland et al (2001) and efforts to maintain or regain their value and position within their social group paid dividends with people being able to attend social gatherings and truly feel they were contributing to the experience. It was indicated by some people that significant others appreciated the effort they were making to "take charge" of their lives. Charmaz (1983) describes the effort of taking charge as a constant struggle to maintain positive and worthwhile perspective of ones self that in some cases in this exercise study were moderated.

Perhaps then one possible interpretation of meaning could lie within the interconnections between the physical and psychological domains and the changes that exercise exerted over them. Other researchers have remarked on the positive and negative fluctuations in function and mood that accompany MS (Reynolds and Prior 2003. Dodd et al 2006). During the pre exercise phase the participants projected predominantly negative attitudes towards their physical and psychological states. This viewpoint did alter during the exercise stage and showed in most cases more positive connotations at study conclusion. This does not mean of course that if a person with MS exercises regularly that all will be well in their world. It also does not mean that once the transition from negative to positive has taken place that the outcome will become fixed. This notion was demonstrated in the journal transcript where people described a week/day of successes followed by a downturn in function and mood that one person described as "...MS payback". This illustrates the constant state of flux that people often find themselves in as the effects of MS changes their physical and psychological stability. However, this study showed that exercise did have a mitigating effect on these MS fluctuations and that these effects extended beyond the purely physical state.

As exercise was the one constant throughout the study and it offered the participants a tangible, do-able self-help strategy it could be suggested that it played a small part in the formation of a more balanced life view. It is proposed therefore that exercise had positively influenced the MS experience in both its physical and psychological manifestations for the participants in this study. The study results can only be viewed as provisional at this time and further investigation with a larger sample would be required to corroborate the findings. However, the analysis of the information gathered in this study has offered some insights into the underlying MS life experience in relation to exercise.

6.4.9. Continued exercise involvement in relation to the theoretical underpinning of the study

This sub-section will address question three, does the theory of behavioural change explain the uptake of exercise for those in this study? This question will be answered using the results of the follow-up questionnaire.

The theoretical principles underpinning this study were the Theory of Planned Behaviour Beliefs and the Stages of Change Model (Transtheoretical Model of Change). These theories can be reviewed in Chapter 1 and involved the initiation of changes required to engage in exercise. These changes are transferable to the wider health concept that has been defined by Pender (1987) as, “--activities directed toward increasing the level of well-being and actualising the health potential of individuals, families, communities and societies.” As behaviour governs the response to any changing situation it has been argued that behaviour should be the focus of any final outcome in health research (Kaplan 1990). Consequently it was felt that the application of behavioural models to this study would enabled the investigation into how people with MS responded to exercise. The three-month pre exercise phase in this study allowed for the first three parts of the Stages of Change Model necessary for successful exercise engagement to become established. This was an unforeseen benefit that only became apparent as the study progressed. Stages four and five were laid down during the exercise phase.

The progress in exercise participation made by the study participants could be attributable to the interaction between the Stages of Change Model and the Theory of

Planned Behaviour Beliefs enhanced by the extended time scale of exercise involvement. It is the contention of this researcher that the muscular deconditioning and neuronal deactivation that commonly presents in MS cannot be successfully affected without an extended exercise effort. So despite the additional encumbrance of MS the process for change remained constant and these two models seem to be suitable underpinnings for studies of this type provided the unpredictable nature of MS is appreciated as a variable.

To answer question three, at study conclusion there had been evidence of encouraging behavioural changes in respect of exercise uptake and maintenance. However, this effect was still under the influence of the study experience, ie being part of the study. To find out whether these changes were established as a set behaviour the follow-up questionnaire was sent out six months later. Of the 39 participants who were sent a questionnaire 34 people (87%) responded. Of the respondents 29 people, (85%) were still actively engaged in some kind of exercise six months post study involvement indicating that behavioural changes had taken place and that the new health behaviour had become established.

This new health behaviour involved the initiation of a number of interrelated self-directed strategies that are reliant upon the commitment of the participant for their success (Dishman 1991). They are also dependant on a long-term application of effort to fix the new behaviour (American College of Sports Medicine 1990.) These outcomes will impact on future health, an opinion that coincides with the conclusions of Haskell (1994) and Phillips et al (1996). To extend the health behaviour concept the work by Pratt (1999) and Dunn et al (1999) included lifestyle activity interventions as another viable means of improving and maintaining physical activity.

The positive results indicated by the follow-up questionnaires should not be taken as concrete confirmation of the fixation of the new behaviours. These behaviours are fluid in their application and it is acknowledged that people will dip in and out of them as their lifestyles, time and health demands (Prochaska et al 1992). The positive aspect is the fact that the behaviour had been sampled by the study participants and so will be easier to reinstate should they suffer an interruption in their exercise

engagements. The intervention of a specialist physiotherapist could positively influence this aspect of exercise behaviour.

This study showed that people have an opinion on exercise and are willing to accept it as a new behaviour when it has been proven to positively affect their physical performance. This must gel with the available resources and the needs of the person. For some this will be a home programme if there are no other options or because that is their choice. For others the investigation of other exercise environments may be the answer. As this study has shown, both approaches produced physical and psychological gains and opportunities to provide exercise in a variety of settings should be investigated. This could be the aim of community rehabilitation in the 21st century.

6.5. Section four. Implications for physiotherapy

The issues that have been identified throughout this study have implications for community physiotherapy that deserve consideration. Physiotherapy has been identified in the NICE guidelines (2003) as a desirable element in the MS care continuum and those included in this study highlighted its importance to them as a support mechanism as well as a therapy resource. This next section will expand on the importance of the physiotherapist to the implementation of exercise as a management strategy, consider some of the barriers that physiotherapists face in the community and offer some suggestions for community exercise provision in MS.

6.5.1. Relevance of physiotherapy to the exercise process

Physiotherapy has for many years been a mainstay of the many treatment options available for those with MS (MS Trust 2006). Consequently it is an anomaly that there is little scientific evidence to support or refute its effectiveness in the primary care setting (Freeman and Thompson 2001). One reason could be the inherent difficulties of conducting studies that are rigorous enough to satisfy the scientific community (Freeman 2006) and there will always be problems researching the real life effects of interventions out with a controlled environment (Robson 1993). With this in mind the inclusion of subjective information should be considered as an adjunct to the accepted research methods that usually provide the hard data preferred by most researchers (Clanet and Brassat 2000). As shown in this study this

information expanded the knowledge and understanding of the realities of exercising with MS. This is an important consideration for physiotherapists working with people with MS as it will enable their exercise strategies and aid with empowerment of the individual.

Irrespective of group allocation 75% (28) of the participants in this study expressed the desire for physiotherapeutic involvement as evidenced by their comments in the journals. They indicated that physiotherapy was important for guiding the exercise process as well as offering psychological support. There seemed to be a link between exercise and physiotherapy that had the ability to influence the success of the exercise intervention and Dodd et al (2006) agreed that people with knowledge of exercise enhance the experience for the participants. In the case of MS a familiarity with neurological deficit is also important. The work by Somerset et al (2001) on the needs of MS patients and the Leskelae et al (2000) study on physiotherapy services in the Netherlands confirmed this need for physiotherapeutic involvement. It was also noted by Wiles et al (2001) that significant improvement in subjective wellbeing and mood can accrue with therapeutic exercise but due to the lack of long-term physiotherapy intervention this was short-lived. This finding supports the proposal made by this study that long-term physiotherapy intervention for those with MS has far-reaching benefits that impact beyond the actual intervention. In the study by Kinne et al (1999) the lack of help from professionals was cited as a deterrent to exercise involvement also suggesting that the requirement for physiotherapeutic involvement was desirable.

Many people with MS do pronounce exercise to be an important aspect of disease management that they feel necessary for their continued wellbeing (Thornton and Lea 1992. Brown and Kraft 2005). The involvement of the physiotherapist has been shown to be a significant adjunct to the exercise process, (Leskelea et al 2000. Somerset et al 2001). DeSouza and Worthingtons' work (1987) on long-term physiotherapy input for those with MS found that correctly supervised exercise interventions minimised disabilities and maximised function. This valuable contribution of the therapist has been reiterated here as evidenced by some participant comments:

Participant 12. Group 2. (22.1.)

“I enjoy being able to exercise from home, (yoga) but like the input from the physio too.”

Participant 39. Group 1. (38.1.)

“Physio has been fantastic, she encouraged me all the time and I am pleased I have met her.”

Participant 7. Group 2. (44.2.)

“Physiotherapy is important to me.”

Participant 13. Group 1. (37.2.)

“I used to go for physio at the hospital with another person and I enjoyed this.”

Participant 13. Group 1. (14.2.)

“Hardest thing is to get into a routine on your own. Felt better after doing the exercise but like to have the physio here.”

It could be argued that due its ever-changing presentation MS demands an extended professional involvement, a niche that physiotherapy expertly fills. It has been proven ineffective to practice damage limitation by dipping in and out of the condition as crises develop (DeSouza 1983). It is also clear that therapists wholly involved in crisis management, will never appreciate the value of their involvement in this life-long process. Consequently they may come to view their treatment of physical problems as failures (Ashburn et al 1997). The successful management of MS can be demanding on the therapist as well as the participant. There will be no miraculous cures or dramatic improvements. The whole process must be seen as a dynamic progression that enables the person to cope with MS and move forward with their lives. This is the primary role of the physiotherapist in MS management and it can be successfully tackled from the community setting. Unfortunately community physiotherapists often face additional pressures surrounding time spent travelling versus the relatively low number of face-to-face contacts made per day. This problem could be moderated with programmes initiated by the therapist and carried out by the participant with distanced monitoring and the programme could be augmented by the use of rehabilitation

assistants working along side the physiotherapist. In their work on developing physiotherapy services for MS Ashburn et al (1997) instigated an extended physiotherapy programme involving group sessions to initiate the exercise regimes with the intent to continue the programme at home. There were yearly follow-ups with a full assessment being performed at that stage. The study has been running for several years and the participants identified three key benefits from this approach, peer support, maintenance of physical function and access to therapists.

The evidence gathered in this exercise study showed that appropriate self-directed exercise did produce physical gains in most of the participants yet there was a still the desire for someone to provide the answers and rationalisations for the disturbances that MS produces on a daily basis. Physiotherapists are ideally placed to fulfil this role. So, it could be concluded that the positive effects of exercise evident in this study could depend to some degree on the skill of the professional involved and the relationship they developed with the person.

6.5.2. Barriers encountered by physiotherapists to exercise provision for those with MS

It has been cited throughout this study that exercise is beneficial for those with MS. It can positively influence physical function and quality of life (White and Dressendorfer 2004. Petajan and White 1999). The problem facing those who work with the neurologically disadvantaged is to discover ways to fulfil these requirements in the face of diminishing resources (Frontline 2006). The problem is not easily solved (Freeman and Thompson 2001). There are many barriers both financial and environmental that constantly inhibit the establishment of suitable exercise provisions in the community (Sluijs et al 1993. van der Ploeg 2004.) and it frequently falls to the resourcefulness and persistence of individuals to meet the need. Many exercise options are available and some of these have been shown to be effective as demonstrated by the results of this small study. It has been proposed that these could provide a viable bridge between a sedentary life-style and a more active one. However these options should be both physically and emotionally rewarding to promote exercise adherence (McDermott and Mernitz 2006) and personal preference must be a consideration (Ruland and Moore 2001. Weinberg and Gould 2007).

People with MS can exercise safely (Gehlsen et al 1984. Brown and Kraft 2005). More importantly they must realise that the exercise benefits that others accrue can also be applied to them. This requires not only an ownership of the exercise process and a commitment to its execution but also a tailoring of the activity to the current physical ability of the person (Schaal Fletcher and Banasik 2001).

Other potential barriers to the provision of exercise for those with MS include the unpredictable nature of a compromised CNS plus the issues of fatigue that many people face on a daily basis (Stuifbergen and Rogers 1997). This implies that the provision of exercise for those with a neurological dysfunction is not as clear-cut as for those with an intact nervous system and people with these difficulties require exercise advice from an appropriately qualified professional (Somerset et al 2001). Arguably, this advice could be supplied by a therapist possessing the knowledge and expertise to guide the person through these difficulties (Barnes 2004). If this is lacking then the person will most likely discontinue their exercise involvement (Hillsdon et al 2002).

To summarise, the barriers a community physiotherapist faces in attempting to initiate exercise as a management strategy for those with MS include: lack of resources both financial and human, poor local facilities, lack of client motivation and disbelief as to the potential benefits that exercise can offer, diminished physical ability and lack of commitment to participate. It requires an experienced and committed individual to tackle such detractors.

6.5.3. Recommendations for community physiotherapy practice

From the findings of this study the following recommendations can be made:

- Despite the raft of anecdotal evidence supporting the need for physiotherapy and exercise in the community there is limited research evidence to support this provision. This study has provided such evidence by demonstrating measurable physical and psychological benefits and has consequently added to the existing knowledge base concerning exercise and MS. It is now incumbent upon service providers to consider improving physiotherapy services in the

community with a view to fulfilling this need in line with the NICE (2003) guidelines.

- Exercise can be safely provided in a variety of settings and still produce measurable gains (Stuifbergen 1997. Stuifbergen et al 2006). Therefore physiotherapists should consider utilising local gyms and swimming pools as alternate sources of exercise engagement as well as allowing for personal choice to assume a more prominent role. Exercise should to be viewed as a self-management strategy to be integrated over the long term and not as a damage limitation event (DeSouza and Worthington 1987).
- The variety of presentations and symptom severity common to MS does not preclude exercise rather it requires an adaptable approach to exercise provision. An opportunity exists to re-integrate individuals into the wider community by capitalising on remaining exercise capacity and focusing efforts to promote physical abilities and social integration.
- The value of the home-programme has not been lessened by these results. Rather its importance as a physiotherapeutic intervention has been strengthened by the positive results obtained in this study. It could however be an integral part of a more eclectic approach to physiotherapy interventions.
- Financial constraints may deter people from engaging in gym or swimming pool facilities (Becker and Stuifbergen 2004). There is scope to negotiate reduced rates for clinically needy groups as occurred in Lincoln. This requires further investigation.
- The quality of life perspective is central to any rehabilitation process and as such should form a more integral part of such considerations. This implies that more credence should be afforded to the psychological aspects of any physical interventions routinely undertaken (Weinberg and Gould 2007).

This study has shown that a move away from the traditional in/out patient treatment method is possible and that it will produce measurable physical gains as well as relevant psychological ones. There are issues around travelling long distances to visit a limited number of people when in the community that may deter service providers. The approach proffered in this study suggested that the discrete supervisory role of the

therapist coupled with the empowered involvement of the participants could produce a quality service that offered meaningful outcomes.

6.5.4. Conclusion

From the evidence discussed in this chapter it can be surmised that exercise had a significant impact on both the physical and psychological function of the participants. It was also shown that the introduction of educational material alone did not produce such notable gains. The reasons for these differences in outcomes have been discussed in relation to the relevant literature and the results of this study concur with most of the available research on the impact of exercise on MS. The novel outcomes were: the implantation of behavioural changes that allied to the extended time scale of the study and that were still demonstrable six months after the study had finished: the impact that exercise had on psychological function that only became evident through analysis of the journal transcripts: the underlying need for physiotherapy involvement and most importantly the revelation that exercise need not adhere to a rigid physiotherapeutic paradigm but that self-selected exercise choices can be effective providing the failings of the compromised CNS are accommodated.

Chapter Seven

Conclusions recommendations and the implications for future research

7.1. Introduction

This chapter draws together the findings of this study. It recaps the study findings and restates the relevance of this study to clinical practice and why it was useful to provide this evidence at this time. It also shows the justification for the provision of exercise in the long term for those with MS and the relevance of this to MS management. Finally recommendations for future research will be offered.

The study's intention was to discover whether differences in physical outcomes were demonstrable when a home-based physiotherapy exercise programme was compared to a self-selected exercise regime. This contributes to the existing body of knowledge regarding MS and exercise provision by offering information from an exclusively community based perspective gathered over an extended timescale whilst under discrete physiotherapeutic supervision. Most other MS exercise studies have been conducted in a controlled in/out-patient environment and were limited to a few weeks with a concerted physiotherapy intervention.

Four research questions emerged. The first question concerned the comparison of the two exercise interventions. The second question revolved around the influence of exercise on quality of life. The third question explored the uptake of exercise in relation to the theory of Planned Behaviour Beliefs and Stages of Change Model as outlined in Chapter 1. The final question determined whether the pre exercise intervention, educational material, had the ability to positively impact on physical function or quality of life as a stand-alone intervention. There were no disease state limitations other than the ability to carry out an exercise regime. This allowed for the inclusion of people from each of the three recognised severity categories of MS. This was necessary to emulate the referral patterns that routinely present in the community.

7.2. Study findings

The two-fold nature of data collection elicited quantitative and qualitative outcomes the latter serving to personalise the research process. The participants were assessed using conventional neurological measurement tools that provided information on physical and psychological functions in relation to the pre exercise and exercise phases of the study. These were described in Chapter 4. The journals provided information in response to the semi-structured questions therein plus a diary commentary running along side the educational and exercise experiences. These were described in Chapter 5.

In response to question 1, whether home-based physiotherapy offered better physical outcomes than self-selected exercise, it was shown that there were significant functional improvements with both approaches as demonstrated by the results of the AMCA. There was however no definitive evidence to promote one exercise intervention over the other. This finding is in agreement with the Cochrane review carried out by Reitberg et al (2004) which, after examination of nine randomised controlled trials, declared that “..it is impossible to state the best “dose” of treatment to achieve optimal beneficial effects of exercise therapy in terms of activities and participation for patients suffering from MS.”

Question two concerned the quality of life changes evinced as an effect of exercise uptake and this was addressed by an examination of the qualitative data elicited from the scores of the NRS and the MSQoL54 plus the journal transcripts. The journals supplied a wealth of information that allowed for the quantitative results to be considered in the context of living with MS. The information was common to both groups and did not relate to the specific programme undertaken. Strong evidence emerged to support the benefit of exercise for a mix of MS abilities. Areas of improvement presented in the journals that, at study outset were not consciously considered, eg improved sexual enjoyment and inclusion in one's social sphere. Many issues were raised in the journals that provided a cathartic release for some people who had had little opportunity in the past to state their feelings in such an overt

manner. There were several comments at the end of the journals recognising this opportunity and confirming the benefit of reflection on one's condition and its effect on life.

The information in the journals upheld the notion that people with MS recognised the benefits that exercise can afford and showed that they were willing to investigate and attempt many avenues in an effort to participate. Such an enthusiastic group should be assisted in their efforts to maintain their abilities and continue to function as valuable members of society. The interventions evaluated in this study can enable this goal to materialise.

The third question concerned the study's theoretical underpinnings of Planned Behaviour Beliefs and the Stages of Change Model governing the implantation of behavioural changes that extended beyond the study time frame. The follow-up questionnaire provided the evidence to surmise that the theories had been appropriately applied to this method of investigation. There was also evidence supplied by the follow-up questionnaire to conclude that the behavioural change necessary to adopt exercise had taken root.

The final question asked whether the educational material supplied during the pre exercise phase had any affect on physical/psychological functioning. This was answered in the negative. The information supplied did not change these areas of enquiry. However, many people found the information pack of great interest to partners and work colleagues who hitherto had little or no knowledge of MS.

7.3. Relevance of the study results to clinical practice

Recent years have seen a gradual shift of health care provision away from the acute sector to primary care and the problems that this change has produced are not unique to Lincolnshire. There was a culture of cost cutting and service shrinkage that impacted on all areas of rehabilitation (Tallis 2003). The Department of Health (1997) promised that, "--patients will get fair access to consistently high quality, prompt and accessible services right across the country". For many this is a promise that is still

awaiting fulfilment and promises made on behalf of those at the coalface are seldom followed up with adequate resources.

The findings of this exercise study have shown that exercise can be successfully implemented in the community but that it is not feasible to simply hand out exercise regimes, (Simons et al 1998. Roddey et al 2002), or recommend gym attendances if the specialist knowledge in CNS function and disease management are missing. Monitoring and review are vitally important to pre-empt unnecessary secondary complications and physiotherapists are ideally placed to fulfil this role, (Ashburn and DeSouza 1988).

This exercise study attempted to address one area of service provision by examining the exercise requirements of a small sample of community-based MS people in Lincolnshire. The results showed that exercise could be effectively delivered by a variety of methods over a disparate disability group spread out over a large geographical area. It is now incumbent upon the service providers and budget holders to appreciate the benefits accruable for this client group and to adequately fund community physiotherapy services to fulfil this need. Often telephone contact is enough to assuage fears and solve problems. This could decrease the amount of travelling involved in daily caseload management yet still offer an effective service at a reasonable cost, (DeBolt et al 2004).

The evidence supplied by the journals has re-enforced the importance of physiotherapy to those with MS. Despite the fact that there was no demonstrable difference between the two exercise interventions, the overriding impression was for the involvement of a physiotherapist to be available. Freeman and Thompson (2004) noted that no studies have as yet compared supply and demand as far as community services are concerned. It would be almost a forgone conclusion that the demand will outstrip the resources available. Consequently it is necessary to provide options that bridge the supply gap and specialist physiotherapists could provide the answer.

7.4. Justification for long-term exercise provision for people with MS

The incidence of MS in the UK is currently estimated to be 140 per 100,000 of the population with 2,500 new cases being diagnosed yearly, (MS Trust 2006). It is more prevalent in the temperate latitudes with a predominantly white population, and tends to occur in regions that are more affluent, economically developed and industrialised, (Bashir and Whitaker 2002). It affects those in the prime of life usually with family and employment responsibilities and impacts on future life events. It causes physical, psychological and cognitive disablements that are difficult to appreciate from the unaffected perspective and produces economic consequences that are often overlooked. It is a life-long burden that requires targeted interventions.

In 2004 Professor Kesselring published a paper asking what was the evidence base for neurological rehabilitation in MS. He defined rehabilitation as, “--an active process of education and enablement that is focused on the proper management of disability and on minimising handicap with the goal of achieving full recovery.” In the case of MS this is clearly an unattainable goal. Does that then preclude those with MS from the rehabilitation arena? If they are in effect “unrehabilitatable” do they even warrant the effort of rehabilitation? He concluded that definitions of the best treatments are still unclear but that there is a requirement for a more individualistic approach by rehabilitation medicine services towards MS.

It was evident from the information gathered in this study that exercise was important to people with MS as a method of self-management but that it was not as readily available or as accessible as required. Exercise does significantly affect physical functioning (Petajan et al 1996. Kidd et al 1997. Greenspun et al 1987). Exercise does positively affect tonal problems and improve strength (Jones et al 1996. Dodd et al 2006). Exercise has far-reaching psychological outcomes that may not be immediately self evident (Sutherland and Andersen 2001. Stuifbergen et al 2006). This was a concept illustrated in the participants’ journals. These psychological outcomes included adaptation to disease limitations, integration into mainstream activity, raised self-esteem and insight into the cycle of change that can positively influence future exercise involvement. Exercise must therefore be an option for all of those with MS who have the will and the physical ability to participate (Petajan and White 1999).

This could possibly be achieved through support groups meeting in pre selected community locations with input from the therapist/rehabilitation team. Ashburn et al (1997) advocated this method as aiding compliance and lessening the overall dependence some people form on team members.

Other researchers have investigated the efficacy of exercise for those with MS (Dodd et al 2006. Wiles et al 2001. Thompson 2002. Solari et al 1999) and concluded that the timely application of rehabilitative strategies of which exercise is one have proven beneficial for this disease group. The diverse disease presentation is appreciated and accommodated in these works supporting the supposition that MS deserves consideration in the rehabilitation arena. This was also one conclusion reached in this study.

7.5. Relevance of the study findings to MS management

As previously stated this study offered evidence that upholds the provision of exercise to a disparate group of MS people with divergent symptomatic presentations over an extended time-scale covering a large geographical area. The study by Stuijbergen et al (2006) was in concert with this conclusion. Their study was conducted over five years and demonstrated the beneficial impact of exercise on the long-term progression of functional limitation and quality of life for those with MS. In accord with Stuijbergen et al this exercise study also indicated that people with MS had the desire to participate in exercise and that measurable benefits could be obtained as a result. There were also indications that the involvement of a physiotherapist was desirable.

Disparity in NHS resources produced a lottery of service provision that impacted on community services nationwide (Freeman and Thompson 2000). The culture of budgetary cost cutting was set to continue for the foreseeable future. This significantly affected the provision of physiotherapy in specialist community services as well as those in the acute sector (Frontline 2006). The discrete intervention of a physiotherapist in a diverse range of exercise interventions has been shown by this study to produce results that influence both physical and psychological domains. This could potentially reduce demand on the acute sector. These results support the

requirement for specialist physiotherapy in the community to engage and enable the growing MS population.

The long-term nature of the data collection process demonstrated that exercise carried out in a community situation could be successfully accomplished over an extended time-scale. The relevance of this aspect lies in the longitudinal nature of MS. Short sharp bursts of rehabilitation are generally instigated as damage limitation strategies (Ashburn and DeSouza 1988). They often produce beneficial outcomes but rarely are these transferred into the community and carried out as long-term management strategies.

One of the most demonstrable aspects of this study was the need to support a growing population of younger adults in the prime earning and reproductive stages of life that were affected by MS nationwide (MS Trust 2006). The NICE guidelines (2003) recommended that exercise be available for those with MS with the involvement of a specialist physiotherapist. This study coincided with the publication of these recommendations and offered the evidence to support this by demonstrating significant physical and psychological improvements that have enhanced the ability of the participants to cope at work, with family life and in the wider community.

7.6. Recommendations for future research

Evidence exists to support the value of community physiotherapy in other disability groups (Green et al 2003. Nieuwboer et al, 2001. Husain and Kelleher 2005). This study has discovered that a paucity of evidence exists where community exercise interventions for MS is concerned. Difficulties in conducting research of this type in an uncontrolled environment may be the reason for this deficiency. However if community based exercise interventions for those with MS are to flourish, the evidence base will need to expand to support it therefore more studies of this type are required to promote the benefits of community-based exercise provisions.

More qualitative evidence in relation to exercise uptake would augment these findings by expanding on the difficulties experienced by those living with MS whilst attempting to alter their entrenched non-exercise behaviours. The research around

planned behaviour beliefs and the adoption of exercise is extensive, unfortunately it does not include evidence to support its application to those with MS. However this study has shown that this theory was as relevant to those with MS as to other disease types.

The non-compliance of those with MS in respect of exercise engagement deserves further study. There are many reasons why people disengage from activity. Those in this study encountered a myriad of difficulties and personal tragedies yet still continued to exercise. Exercise was a constant feature that could be controlled within the lives of the participants and was an influencing factor that was identified in this study. Further investigation may support this.

There is scope for further research to investigate the more intangible attitudes towards exercise and MS such as did men or women embrace the exercise experience more readily, and what influenced this. Was there a link between exercise compliance and degree of disease severity and how much influence did a person's perception of how others saw them hinder or help their exercise engagement? Some of the unresolved questions unrelated to exercise that were unearthed by this study included the most appropriate time for and type of information required, the actual meaning of quality of life to someone with MS and the relationship between disease type and of coping strategies adopted. There were also issues regarding cognitive ability, sexual function and depression that were unfortunately out with this study's remit. Answers to these questions may provide better insight into the mind-set of the MS exerciser. If repeated, this exercise study would benefit from the recruitment of a larger sample to eliminate the possibility of a type 2 error occurring.

7.7. Conclusion

This study found that there was no appreciable difference in physical function between home physiotherapy and self-selected exercise. It did produce convincing evidence of the benefit of exercise to those with MS and that to successfully engage in exercise those with MS desire and require the presence of a specialist physiotherapist to guide the process.

In conclusion, the positive results of this study supporting the provision of exercise for those with MS are attributable to the commitment of the participants' the behavioural changes that developed and the influence that exercise exerted over the group as a whole. It was encouraging that all the participants improved their physical functioning as a direct result of the exercise they undertook. It was also important to acknowledge the quality of life gains evidenced in the journal entries by 38 out of the 39 who completed the study. These positive outcomes were obtained despite the diversity of disease severity, psychological distress, MS symptomology and the interference of life events.

The participants identified a need for the involvement of a physiotherapist with specialist MS knowledge as an adjunct to the exercise itself. Most of the study participants agreed that the 24-week period of self directed activity whether physiotherapy or self-selection would have been easier and possibly less intimidating had the therapist been more evident throughout. This did not require a weekly visit more a tentative contact to reassure and advise. This study has reinforced the existing evidence that promotes the use of exercise in MS management. It offered additional comparative evidence that demonstrated the successful implementation of community based exercise interventions over an extended time scale to a disparate ability MS population in Lincolnshire.

Finally the study demonstrated the positive effects of exercise over the complexity of living with a disability that is moulded by physical limitations, psychological distress and social and cultural conventions.

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APPENDIX 1

Multiple Sclerosis Exercise Study

Assessment Book

Participant Number.....
Date of Assessment.....

Amended Motor Club Functional Assessment Instructions for use

Activities.

1. Supine to left side lying: from supine, roll towards the left side. Pulling on a mat or mattress is an aid and is scored 2.
2. Supine to right side; from supine roll towards the right side. Pulling on mat or bed counts as an aid and scores 2.
3. Bridging; from crook lying, lift the pelvis until the hips are straight. Use of the upper limbs to help is an aid and scores 2. If one leg straightens out in front whilst lifting the pelvis this scores 2.
4. Sitting balance (60 secs.); sitting on a bed or stool with the feet on the floor and the arms in lap for 60 secs scores 3. If the patient uses the arm(s) for support, this must be recorded as aid (score 2). Any manual assistance will score 1. If more than one helper is required a score of 0 must be recorded.
5. Sitting, touch the floor and return; from sitting the patient must lean forwards and touch the floor in front (not to the side) with the hands. Support on going down or up is an aid and scores 2.
6. Sitting to standing; stand up from sitting. Use of the arms to help or pushing on the bed or chair is use of an aid and scores as 2.
7. Standing balance (30 secs); both feet on the floor. (see 4 for score notes)
8. Standing on the left leg (5 secs). (see 4 for score notes).
9. Standing on the right leg (5 secs) see 4 for score notes.
10. Standing; get down to the floor; lower the body to the floor from standing. Any manner of getting down is acceptable and use of the hands scores 3. Use of sticks, chairs stool etc scores 2.
11. Kneel stand balance.(10 secs); must get into position and hold it for the timed period to score 3. See notes for no. 4.
12. Half-kneel standing-left. See no.11.
13. Half-kneel standing-right. See no.11.
14. Get up from the floor to standing; get up from the floor. Use of stick, stool chair etc scores 2.
15. Transfer from sitting on a chair to lying on a bed; Use of stick etc scores 2. Pushing on furniture scores 3.
16. Transfer from lying on a bed to sitting on a chair; See no.15.
17. Walking; walking is timed over a ten meter measured distance. Record type of aid used, any assistance given and the time taken in seconds.

Scoring. X-unable. 0 = manual assistance of two or more. 1 = manual assistance of one. 2 = aid. 3 = no aid.

Score Sheet

Activity	Notes	Grade	Comments.
1. Supine to left side lying	Pulling on edge of bed = aid		
2. Supine to right side lying.	Pulling on edge of bed = aid.		
3. Bridging.	Using one leg to help the other leg straighten = aid.		
4. Sitting balance (60 secs).	Use of hands for support = aid.		
5. Sitting touch floor and return.	Use of hands for support going up or down = aid.		
6. Sitting to standing.	Use of hands to push down on chair for standing = aid.		
7. Standing balance (30 secs).	Must have both feet on the floor. Use of chair, stick etc = aid.		
8. Standing on left leg. (5 secs).	Use of chair, stick etc = aid.		
9. Standing on right leg. (5 secs).	Use of chair, stick etc = aid.		
10. Standing to get down to floor.	Use of chair stick etc = aid.		
11. Kneel standing balance. (10 secs).	Use of stool etc = aid.		
12. ½ kneel standing left. (5 secs).	Use of stool etc = aid.		
13. ½ kneel standing right (5 secs).	Use of stool etc = aid.		
14. Get up from floor to standing.	Use of stool etc = aid.		
15. Transfer sitting on chair to lying on bed.	Use of stick etc = aid. Support on bed or chair = 0		
16. Transfer lying on bed to sitting in chair.	Use of stick etc = aid. Support on bed or chair = 0.		
17. Walking 10 meters.	Type of aid.		Time.
Total Score			

Guy's Neurological Disability Scale

Instructions

This scale is designed to assess disability in patients with Multiple Sclerosis. It has 12 separate categories each with an interview and scoring section. The total GNDS score is the sum of the 12 separate scores. The questions are directed to assess the disability in the previous one month.

1. Cognitive ability

A Interview

Do you have problems with your memory or your ability to concentrate and work things out? Yes No

Do your family or friends think you have such a problem?

If the answer to either question is “Yes”

Do you need help from other people for planning your normal daily affairs, handling money or making decisions?

Yes No

If "Yes" (To the examiner)
Is the patient orientated in time, place and person?
Yes fully
Yes partially
No totally disorientated

If the patient is not fully orientated all their answers should be verified by the main carer whose answers should take precedence.

B Scoring

- 0 No cognitive problems
- 1 Cognitive problems not noticeable to family or friends
- 2 Cognitive problems noticeable to family or friends but not requiring help from others
- 3 Cognitive problems requiring help from others for normal daily affairs; patient is fully orientated in time, place and person
- 4 Cognitive problems requiring help from others for normal daily affairs; patient is not fully orientated
- 5 patient is completely disorientated in time place and person

2. Mood disability

A Interview

Have you been feeling anxious depressed irritable or had any mood swings during the last month?

Yes No

Are you taking any medication for such problems?

Yes No

If the answer to the first question is “Yes”
Has the problem affected your ability to do any of your usual daily activities such as work, housework or normal social activities with family or friends?

Yes No

If “Yes”
Has this problem been severe enough to prevent you from doing all your usual activities?

Yes No

Have you been admitted to hospital for treatment of your mood problem during the last month?

Yes No

B Scoring

- 0 No mood problems
- 1 Asymptomatic on current drug treatment
- 2 Mood problems present but not affecting the patients ability to perform any of their usual daily activities
- 3 Mood problems affecting the patient’s ability to perform some of their usual daily activities
- 4 Mood problems preventing the patient from doing all their usual daily activities
- 5 Mood problems requiring in-patient management
- 6 X Unknown (please score as the mean of the cognitive and fatigue disability scores rounded to the nearest integer)

3. Visual disability

A Interview

Do you have any problems with your vision that can't be corrected with ordinary glasses?

Yes	No
-----	----

If "Yes"

Can you read ordinary newspaper print (with glasses if worn but not a magnifying lens)?

If “No”

Can you read large newspaper print?

If “No”

Can you count your fingers if you hold your hand out in front of you?

Yes	No
-----	----

If "No"

Can you see your hand if you move it in front of you?

Yes	No
-----	----

B Scoring

- 0 No visual problems
- 1 Visual problems (blurred vision, diplopia, scotomas) but patient is still able to read ordinary newspaper print
- 2 Unable to read ordinary newspaper print
- 3 Unable to read large newspaper print
- 4 Unable to count fingers in they hold their hand out in front of them
- 5 Unable to see hand movement f they move their hand in front of them

4. Speech and Communication

A Interview

Do you have any problems with your speech?
Yes No

If “Yes”
Do you have to repeat yourself when speaking to family or close friends?
Yes No

If “Yes”
Do you need to use sign language or the help of your carer to make people understand you?
Yes No

If “Yes” (To the examiner)
Is the patient able to communicate effectively using these methods?
Yes No

B Scoring

- 0 No speech problems
- 1 Speech problems which do not require the patient to repeat themselves when speaking to strangers
- 2 Speech problems which require the patient to repeat themselves when speaking to strangers
- 3 Speech problems which require the patient to repeat themselves when speaking to family and close friends
- 4 Speech problems making speech difficult to understand: patient is able to communicate effectively by using sign language or the help of their carers
- 5 Speech problems making speech difficult to understand, patient is unable to communicate effectively by using sign language or the help of their carers

5. Swallowing disability

A Interview

Do you have to take care when you swallow solids or fluids?
Yes No

If “Yes”
Do you have to take care when swallowing with most meals?
Yes No

If “Yes”
Do you need a special diet such as soft or liquidated food to help you with your swallowing?
Yes No

If “Yes”
Do you choke with most meals?
Yes No

If “Yes”
Do you have a feeding tube (nasogastric or gastrostomy tube)?
Yes No

B Scoring

- 0 No swallowing problems
- 1 Needs to be careful when swallowing solids or liquids but not with most meals
- 2 Needs to be careful when swallowing solids or liquids with most meals, patient is able to eat meals of normal consistency
- 3 Needs specially prepared food of modified consistency
- 4 Tendency to choke with most meals
- 5 Dysphagia requiring nasogastric or gastrostomy tube

6. Upper limb disability

A Interview

Do you have any problems with your hands or arms?	Yes	No
If “Yes”		
Do you have any difficulty in doing any of your zips or buttons?	Yes	No
If “Yes”		
Are you able to do all of your zips and buttons without help?	Yes	No
Do you have any difficulty in tying bows in laces of string?	Yes	No
If “Yes”		
Are you able to tie a bow in laces or strings without help?	Yes	No
Do you have any difficulty washing and brushing your hair?	Yes	No
If “Yes”		
Are you able to wash and brush your hair without help?	Yes	No
Do you have any difficulty feeding yourself?	Yes	No
If “Yes”		
Are you able to feed yourself without help?	Yes	No
If unable to do any of the functions listed		
Can you use your hands or arms for any other functions?	Yes	No

B Scoring

- 0 No upper limb problems
- 1 Problems in one or both arms not affecting the ability to do any of the functions listed.
- 2 Problems in one or both arms not affecting some but not preventing some of the functions listed
- 3 Problems in one or both arms affecting all or preventing one or two f the functions listed
- 4 Problems in one or both arms preventing three or all of the functions listed
- 5 Unable to use either arm for any purposeful movement

7. Lower limb disability

A Interview

Do you have any problems with your walking?
Yes No

If “Yes”
Do you use a walking aid?
Yes No

If “Yes”
A How do you usually get around outdoors?
• Without aid
• With one stick or crutch or holding on to someone’s arm
• With two sticks or crutches or one stick or crutch and holding on to someone’s arm
• With a wheelchair

B How do you usually get around indoors?
• Without aid
• With one stick or crutch or holding on to someone’s arm
• With two sticks or crutches or one stick or crutch and holding on to someone’s arm
• With a wheelchair

If you use a wheelchair
Can you stand and walk a few steps with help?
Yes No

B Scoring

- 0 Walking is not affected
- 1 Walking is affected but patient is able to walk independently
- 2 Usually uses unilateral support (single stick or crutch one arm) to walk outdoors but walks independently indoors
- 3 Usually uses bilateral support (two sticks or crutches frame or two arms) to walk outdoors or unilateral support (single stick or crutch or one arm) to walk indoors
- 4 Usually uses wheelchair to travel outdoors or bilateral support (two sticks or crutches frame or two arms) to walk indoors
- 5 Usually uses a wheelchair indoors

8. Bladder disability

A Interview

Do you have any problems with your bladder?	Yes	No
Are you taking medication for such problems?	Yes	No
If the answer to the first question is “Yes”		
Do you have to rush to the toilet go frequently or have difficulty in starting to pass urine?	Yes	No
Have you been incontinent in the past month?	Yes	No
If “Yes”		
Have you been incontinent in the last week?	Yes	No
If “Yes”		
Have you been incontinent every day?	Yes	No
Do you use a catheter to empty your bladder?	Yes	No
Do you need a permanent catheter in the bladder or (for men only) do you use a sheath to collect your urine?	Yes	No

B Scoring

- 0 Normal bladder function
- 1 Asymptomatic on current medication
- 2 Urinary frequency, urgency or hesitancy with no incontinence
- 3 Occasional urinary incontinence once or more during the past month but not every week) or intermittent catheterisation without incontinence
- 4 Frequent urinary incontinence (once a week or more during the past month but not daily) or occasional urinary incontinence despite regular intermittent catheterisation
- 5 Daily urinary incontinence or permanent catheter (urethral/suprapubic) or penile sheath

9. Bowel disability

A Interview

Do you have any problems with your bowel movements?	Yes	No
Are you on any medicines for such problems?	Yes	No
If the answer to the first question is “Yes” Do you suffer from constipation?	Yes	No
If “Yes” Do you need to take any laxatives or use suppositories for this?	Yes	No
Do you usually use enemas?	Yes	No
Do you usually evacuate your stools manually?	Yes	No
Do you have to rush to the toilet to open your bowels?	Yes	No
Have you had bowel accidents (been incontinent of faeces) in the last week?	Yes	No
If “Yes” Have you had bowel accidents every week?	Yes	No

B Scoring

- 0 No bowel problems
- 1 Asymptomatic on current drug treatment or constipation not requiring any treatment
- 2 Constipation requiring laxatives or suppositories or faecal urgency
- 3 Constipation requiring the use of enemas
- 4 Constipation requiring manual evacuation of stool or occasional faecal incontinence
- 5 Weekly faecal incontinence

10. Sexual disabilities

A Interview

The next set of questions relates to sexual function. Do you mind if I ask you about this?

Yes	No
Not applicable (celibate)	

If the patient agrees
Do you have any problems in relation to your sexual function?

Yes	No
-----	----

If “Yes”
Do you suffer with lack of sexual interest?

Yes	No
-----	----

Do you have any problems satisfying yourself or your sexual partner?

Yes	No
-----	----

Is your sexual function affected by any physical problems such as altered genital sensation pain or spasm?

Yes	No
-----	----

Do you have any problems with
For men erection/ejaculation?
For women vaginal lubrication/orgasm?

Yes	No
-----	----

If physical or sexual problems are present
Do any of these difficulties prevent your sexual activities?

Yes	No
-----	----

B Scoring

- 0 Normal sexual function or persons who are voluntarily celibate
- 1 Reduced sexual interest
- 2 Problems satisfying one’s self or sexual partner
- 3 Physical problems interfering but not preventing sexual function
- 4 Autonomic problems interfering but not preventing sexual function
- 5 Physical or autonomic problems totally preventing sexual function
- X Unknown (pleas score as the mean of the lower limb, bladder and bowel disability scores rounded to the nearest integer)

11. Fatigue

A Interview

Have you been feeling tired or getting tired easily in the last month?
Yes No

If “Yes”
Have you been feeling tired most days?
Yes No

Has this tiredness affected your ability to do any of your usual activities such as work, housework or normal social activity with family and friends?
Yes No

If “Yes”
Has this tiredness been severe enough to prevent you from doing all of your usual activities?
Yes No

If “Yes”
Has the tiredness been severe enough to prevent you from doing all physical activities?
Yes No

B Scoring

- 0 Absent
- 1 Occasional fatigue (present some days)
- 2 Frequent fatigue (present most days)
- 3 Fatigue affecting the patient’s ability to perform some of their usual daily activities
- 4 Fatigue preventing the patient from doing all their usual daily activities
- 5 Fatigue preventing the patient doing all their physical activities
- 0 X Unknown (please score as the mean of the cognitive and mood disability scores rounded to the nearest integer)

12. Other disabilities

A Interview

Do you have any other problems due to MS such as spasm, pain, dizziness that have not been mentioned so far?

Yes No

Are you taking any medicines for such problems?

Yes No

If the answer to either question is “Yes”

Please name your worst
problem.....

Has this problem affected your ability to do any of your usual daily activities?

Yes No

Has this problem been severe enough to prevent you from doing all you usual daily activities?

Yes No

Have you been admitted to hospital for treatment of this problem?

Yes No

B Scoring

- 0 Absent
- 1 Asymptomatic on current drug treatment
- 2 Problems present but are not affecting the patient’s ability to perform any of their usual daily activities
- 3 Problems affecting the patient’s ability to perform some of their usual daily activities
- 4 Problems preventing the patient from doing all their usual daily activities
- 5 Problems requiring hospital admission for assessment or treatment

Health Assessment Questionnaire

We are interested in learning how your condition affects your ability to function in daily life. Please feel free to add any comments at the end of this form. Please choose from the answers given.

Answers

- 0 = without Any help.
- 1 = with Some difficulty.
- 2 = with Much difficulty.
- 3 = unable to do.

Item	Answer (score)
------	-------------------

1. Dressing and grooming
Are you able to:

- Dress yourself, including tying shoelaces and doing up buttons?
- Shampoo your own hair?

2. Rising
Are you able to:

- Stand up from an armless straight chair?
- Get in and out of bed?

3. Eating
Are you able to:

- Cut your meat?
- Lift a full cup or glass to your mouth?
- Open a new carton of milk (or soap powder)?

4. Walking
Are you able to:

- Walk outdoors on flat ground?
- Climb up five steps?

5. Hygiene

Are you able to:

Wash and dry your own hair?

Take a bath?

Get on and off the toilet?

6. Reach

Are you able to:

Reach and get a 5lb (2kg) object from above your head
(for example a bag of potatoes)?

Bend down and pick up clothing from the floor?

7. Grip

Are you able to:

Open car doors?

Open jars which have previously been opened?

Turn taps on and off?

8. Activities

Are you able to:

Run errands and go shopping?

Get in and out of the car?

Do chores such as vacuuming, housework or
light gardening?

Guidelines For Use Of The Modified Ashworth Scale

(As described for use during National Cannabis Trial 2001)

All movements should be performed after the patient has been lying supine for fifteen minutes.

Elbow

Perform each movement with the patient lying supine, the arms close to the side of the body. Each movement should be done slowly and steadily to the count of “one thousand and one”, repeat the movement three times maximum.

With one hand, hold and stabilise the patient’s upper arm.

With your other hand hold the patient’s forearm just proximal to the wrist.

From the position of maximum flexion, slowly and steadily extend the patient’s elbow to the position of maximal extension.

Grade the spasticity in accordance with the scale and record the appropriate number on the data collection sheet.

Wrist

Perform each movement with the patient in supine. The shoulder should be stable, the elbow in 45 degrees of flexion, the forearm in mid-prone and the fingers in their resting position.

With one hand hold and stabilise the patient’s forearm just proximal to the wrist.

With your other hand hold the patients metacarpo-phalangeal joints.

From the position of maximum flexion, slowly and steadily extend the patient’s wrist to the position of maximal extension.

Grade the spasticity according to the scale and record.

Fingers

Perform each movement with the patient in supine with the fingers resting. Stabilise the shoulder, the elbow in 45 degrees of flexion, the forearm in midprone and the fingers in their resting position.

With one hand hold and stabilise the metacarpal bones.

Place the other hand pointing distally over the patient’s fingers on the dorsal aspect.

From a position of maximal flexion, slowly and steadily open out (extend) the patient’s fingers to the position of maximal extension.

Grade the spasticity and record.

Hip Adductors

Perform each movement with the patient in supine.

With one hand hold the lower leg, ensuring knee extension and neutral hip rotation.

With the other hand stabilise the pelvis at the contra-lateral Anterior Superior Iliac Spine. Abduct the leg to the greatest possible extent.

Knee Extensors/Flexors

Perform each movement with the patient in supine.

With one hand under the knee, the other over the ankle joint, flex the lower limb to approximately 45 degrees and then stabilise.
Flex and then extend the lower limb to assess tone.

Plantar Flexors

Perform each movement with the patient in supine.

With one hand hold the lower leg in a neutral position.
With the other hand grasp the calcaneus and wrap the forearm around the foot and toes. Ensure neutral in/eversion, pro/supination. Move the entire foot into dorsiflexion to assess tone.

Grading of Spasticity using the Modified Ashworth Scale

- 0 Normal tone.
- 1 Slight catch and release or minimal resistance through the range.
- 1+ Slight catch with minimal resistance and increase in tone through the range.
- 2 Marked increase in tone through most of the range but part easily moved.
- 3 Considerable increase in tone passive movement difficult.
- 4 Affected part is rigid with minimal passive movement.

Areas Assessed

Upper limb Modified Ashworth score	Left	Right
Elbow		
Wrist		
Fingers		

Lower limb Modified Ashworth score	Left	Right
Hip adductors		
Knee flexors		
Knee extensors		
Plantar flexors		

MRC Strength Assessment

	Right Upper Limb	Left Upper Limb
Shoulder. Forward flexion		
Elevation		
Extension		
Abduction		
Adduction		
Elbow. Flexion		
Extension		
Wrist. Flexion		
Extension		
Grip.		

	Right lower limb	Left Lower Limb
Hip. Flexion		
Extension		
Abduction		
Adduction		
Medial Rotation		
Lateral Rotation		
Knee. Flexion		
Extension		
Ankle. Dorsiflexion		
Plantaflexion		

Muscle strength grading

- 0 No contraction.
- 1 Flicker or trace of movement.
- 2 Active movement gravity eliminated.
- 3 Active movement against gravity.
- 4 Active movement against gravity and resistance.
- 5 Normal power.

Assessments are to be carried out with the person in supine lying.

Multiple Sclerosis Quality of Life (MSQoL 54) Instrument

Instructions

This survey asks about your health and daily activities. Answer every question by circling the appropriate number (1, 2, 3,...)

If you are unsure about how to answer a question, please give the best answer you can and write a comment or explanation in the margin.

Please feel free to ask someone to assist you if you need help reading or marking the form.

1. In general, would you say your health is: (Circle one number)

- Excellent..... 1
- Very good..... 2
- Good..... 3
- Fair..... 4
- Poor..... 5

2. Compared to one year ago, how would you rate your health in general now? (Circle one number)

- Much better now than one year ago..... 1
- Somewhat better now than one year ago..... 2
- About the same..... 3
- Somewhat worse now than one year ago..... 4
- Much worse now than one year ago..... 5

3-12. The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so how much? (Circle 1, 2, or 3 on each line).

	Yes Limited a Lot	Yes Limited a Little	No Not Limited at All
3. <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports			
4. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling or playing golf			
5. Lifting or carrying groceries			
6. Climbing <u>several</u> flights of stairs			
7. Climbing <u>one</u> flight of stairs			
8. Bending, kneeling or stooping			
9. Walking <u>more than one mile</u>			
10. Walking <u>several blocks</u>			
11. Walking <u>one block</u>			
12. Bathing and dressing yourself.			

13-16. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?
(Circle one number on each line)

	Yes	No
13. Cut down on the <u>amount of time</u> you could spend on work or other activities?	1	2
14. <u>Accomplished less</u> than you would like?	1	2
15. Were limited in the <u>kind of</u> work or other activities?	1	2
16. Had <u>difficulty</u> performing the work or other activities (for example it took extra effort)	1	2

17-19. During the past 4 weeks, have you had any of the following problems with work or other regular daily activities as a result of emotional problems (such as feeling depressed or anxious)
(Circle one number on each line)

	Yes	No
17. Cut down on the <u>amount of time</u> <u>you</u> could spend on work or other activities?	1	2
18. <u>Accomplished less</u> than you would like?	1	2
19. Didn't do work or other activities as <u>carefully</u> as usual?	1	2

20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

(Circle one number)

- Not at all..... 1
- Slightly..... 2
- Moderately..... 3
- Quite a bit..... 4
- Extremely..... 5

Pain

21 How much bodily pain have you had during the past 4 weeks?

(Circle one number)

- None..... 1
- Very mild..... 2
- Mild..... 3
- Moderate..... 4
- Very severe..... 5

21. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(Circle one number)

- Not at all..... 1
- A little bit..... 2
- Moderately..... 3
- Quite a bit..... 4
- Extremely..... 5

23-32. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks ..

(Circle one number on each line)

	All of the Time	Most of the Time	A Good bit of the Time	Some of the Time	A little of the Time	None of the Time
23. Did you feel full of pep?	1	2	3	4	5	6
24. Have you been a very nervous person?	1	2	3	4	5	6
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
26. Have you felt peaceful and calm?	1	2	3	4	5	6
27. Did you have a lot of energy?	1	2	3	4	5	6
28. Have you felt downhearted and blue?	1	2	3	4	5	6
29. Did you feel worn out?	1	2	3	4	5	6
30. Have you been a happy person	1	2	3	4	5	6
31. Did you feel tired?	1	2	3	4	5	6
32. Did you feel rested on waking in the morning?	1	2	3	4	5	6

33. During the past 4 weeks how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends relatives, etc)?

(Circle one number)

- All of the time..... 1
- Most of the time..... 2
- Some of the time..... 3
- A little of the time..... 4
- None of the time..... 5

Health in General

34-37. How TRUE or FALSE is each of the following statements for you?

(Circle one number on each line)

	Definitely True	Mostly True	Not Sure	Mostly false	Definitely False
34. I seem to get sick a little easier than other people					
35. I am as healthy as anybody I know					
36. I expect my health to get worse					
37. My health is excellent					

Health Distress

38-41. How much of the time during the past 4 weeks...

(Circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A little of the Time	None of the Time
38. Were you discouraged by your health problems?	1	2	3	4	5	6
39. Were you frustrated about your health?	1	2	3	4	5	6
40. Was your health a worry in your life?	1	2	3	4	5	6
41. Did you feel weighed down by your health problems?	1	2	3	4	5	6

Cognitive Function

42-45. How much of the time during the past 4 weeks...

(Circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A little of the Time	None of the Time
42. Have you had difficulty concentrating and thinking?	1	2	3	4	5	6
43. Did you have trouble keeping your attention on an activity for long?	1	2	3	4	5	6
44. Have you had trouble with your memory?	1	2	3	4	5	6
45. Have others, such as family members or friends noticed that you have trouble with your memory or problems with your concentration?	1	2	3	4	5	6

Sexual Function

46-50. The next set of questions are about your sexual function and your satisfaction with your sexual function. Please answer as accurately as possible about your function **during the past 4 weeks only.**

How much of a problem was each of the following for you **during the past 4 weeks?**

(Circle one number on each line)

Men	Not a problem	A little of a problem	Somewhat of a problem	Very much a problem
46. Lack of sexual interest	1	2	3	4
47. Difficulty getting or keeping an erection	1	2	3	4
48. Difficulty having orgasm	1	2	3	4
49. Ability to satisfy sexual partner	1	2	3	4

(Circle one number on each line)

Women	Not a problem	A little of a problem	Somewhat of a problem	Very much a problem
46. Lack of sexual interest	1	2	3	4
47. Inadequate lubrication	1	2	3	4
48. Difficulty having orgasm	1	2	3	4
49. Ability to satisfy sexual partner	1	2	3	4

50. Overall how satisfied were you with your sexual function during the past 4 weeks?

(Circle one number)

- Very satisfied..... 1
- Somewhat satisfied..... 2
- Neither satisfied nor
Dissatisfied..... 3
- Somewhat dissatisfied..... 4
- Very dissatisfied..... 5

51. During the past 4 weeks, to what extent have problems with your bowel or bladder function interfered with your normal social activities with family friends neighbours or groups?

(Circle one number)

- Not at all..... 1
- Slightly..... 2
- Moderately..... 3
- Quite a bit..... 4
- Extremely..... 5

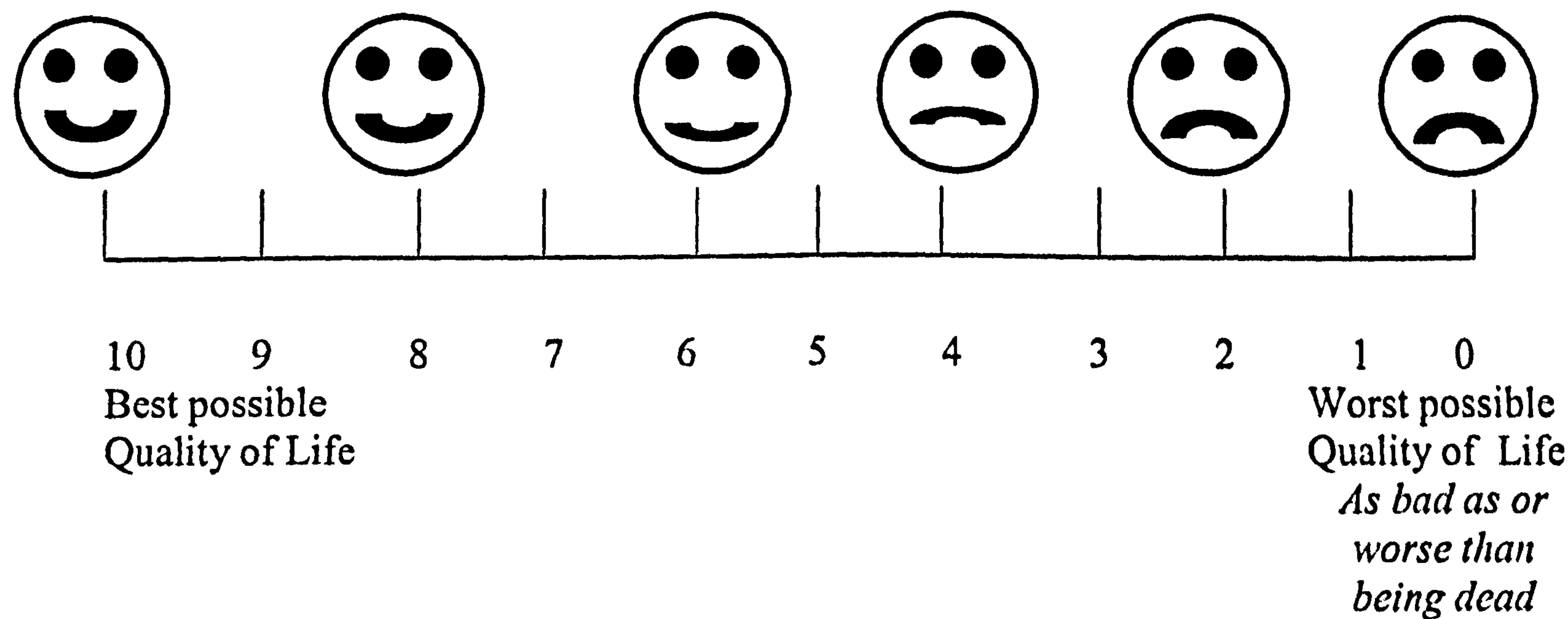
52. During the past 4 weeks, how much did pain interfere with your enjoyment of life?

(Circle one number)

- Not at all..... 1
- Slightly..... 2
- Moderately..... 3
- Quite a bit..... 4
- Extremely..... 5

53. Overall how would you rate your own quality of life?

(Circle one number on the scale below)



54. Which best describes how you feel about your life as a whole?

(Circle one number)

- | | |
|---|---|
| Terrible..... | 1 |
| Unhappy..... | 2 |
| Mostly dissatisfied..... | 3 |
| Mixed, about equally
Satisfied and dissatisfied..... | 4 |
| Mostly satisfied..... | 5 |
| Pleased..... | 6 |
| Delighted..... | 7 |

APPENDIX 2

Multiple Sclerosis Exercise Study

Record of Participation

Name. _____

Participant Number _____

Multiple Sclerosis Education and Exercise Study
Record of participation

(This section is to be completed at the beginning of the information programme)

Date

Please use the space below to describe a typical week's activity. Please include how often you climb the stairs in any one day, any daily exercise you may do eg yoga or walking out of doors and any difficulties you experience when performing your routine.

Please also include any unusual activity you may have undertaken eg walking an unaccustomed distance and describe if you can how this affected you.

Monday

Tuesday

Wednesday

Thursday

Friday

Saturday

Sunday

Self-determination of Physical Condition Participant Expectations

What do you expect will happen by your participation in the study? Please select items from the list below. Circle as many items as you feel appropriate

1. I will be able to move better.
2. My walking will improve
3. There will be no improvement
4. My limbs will feel less tight
5. I will understand MS better.
6. My condition might worsen.
7. My stamina will improve.
8. I will feel tired.
9. My fatigue will improve.
10. I will learn nothing new.
11. Other anticipations. (Please list)

How active do you think you are? Please circle one of the options below.

- Do no activity at all.
- Active twice a month for 30-60 mins.
- Active once/twice a week for 30-60 mins per week.
- Active five days a week or more for 30 mins per day

Can you mark on the scale below your estimation of your quality of life today.

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
(worst) (best)

During this week you will be visited by the investigator for your first assessment

Week one

Date

This week you will be issued with part one of the information pack.
Please take the time to read the information pack carefully and note in the space below any comments you would like to make.

Week two

Date

Week three
Date

Week four
Date

During this week you will be issued with part two of the information pack.
Please take the time to read part two of the info pack and note in the space below any
comments you would like to make.

Week five
Date

Week six
Date

Week seven
Date

Week eight
Date

During this week you will be issued with part three of the information pack and a “Tips to living with MS” booklet from MS Trust. Please take the time to read part three of the info pack and the accompanying MS trust booklet and note in the space below any comments you would like to make.

Week nine
Date

--

Week ten
Date

--

Week 11
Date

Week 12
Date

This week you will be visited by the investigator and your current abilities will be re-assessed as previously. You will also begin your lying exercise regime.

Did you find the Education and Information supplied over the previous twelve weeks useful?

Yes

No

What would have improved the pack, if anything?

Can you mark on the scale below your estimation of your quality of life today.

(worst) 1-----2-----3-----4-----5-----6-----7-----8-----9-----10 (best)

Record of Exercise Participation

Week 13
Date

Week 14
Date

Please complete this section after you have performed the lying exercises for two weeks.

Did you do all of the lying exercises on a daily basis?
Yes No

If you answered No, can you say why?

Did you experience any difficulties with the exercises?
Yes No

If you answered Yes, can you describe the problem you had?

How do you feel about the exercises?

Week 15
Date

Week 16

Date

This week you will begin the Sitting exercises. Please do both lying and sitting exercise for the next four weeks.

Week 17

Date

Week 18

Date

Please complete this section after you have performed both sets of exercise for two weeks.

Did you do all of the lying and sitting exercises throughout the week?

Yes No

If you answered No, can you say why?

Did you experience any difficulties with the exercises?

Yes No

If you answered Yes, can you describe the problems you had?

How do you feel about the exercises?

Week 19
Date

Week 20

Date

This week you will begin the Standing exercises.
Please do all three sets of exercises if possible or a selection from them for the next sixteen weeks. Please perform some or all of the regime for a minimum of 20 minutes five times a week if you can.

Week 21

Date

Week 22
Date

Please complete this section after you have performed your exercise regime for two weeks.

Did you complete the full exercise regime during the previous week?
Yes No

If you answered No, can you say why?

Did you experience any difficulties with the exercises?
Yes No

If you answered Yes, can you describe the problems you had?

How do you feel about the exercises?

Please note in this space the exercises you performed.

Week 23

Date

Please continue with your exercise programme for the next 13 weeks recording on a weekly basis any comments you may have.

Week 24

Date

Week 25
Date

Week 26
Date

Week 27
Date

--

Week 28
Date

--

Week 29
Date

--

Week 30
Date

--

Week 31
Date

Week 32
Date

Week 33
Date

--

Week 34
Date

--

Week 35
Date

--

Week 36
Date

You will now have been doing the exercise regime for six months. An assessor will visit you this week to carry out a re-assessment of the scales you completed previously.

Please use the space below to record your comments and observations regarding the programme, including any views you may have regarding the information provided at the beginning of the study.

Can you mark on the scale below your estimation of your quality of life today.

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
(worst) (best)

Has your quality of life been influenced at all by the programme?
Yes No

If you answered Yes, can you say how

How active do you think you are now after taking part in this study? Please circle one of the options below.

- 1. Do no activity at all.
- 2. Active twice a month for 30-60 mins.
- 3. Active once/twice a week for 30-60 mins per week.
- 4. Active five days a week or more for 30 mins per day.

Self determined Outcomes of Exercise Programme
How are you now after the 6-month exercise programme?

A list of outcomes is provided below. Please consider the options given and in the Outcome column tick as many as you feel approximate to your perceptions of the past six months of exercise.

Outcomes

- 1 My limbs feel less tight.
- 2 I have more problems moving.
- 3 My walking has improved.
- 4 My stamina not has improved.
- 5 My limbs feel tighter.
- 6 I feel less fatigued than before.
- 7 I feel no improvement at all.
- 8 I feel worse for doing the exercises.
- 9 I found them difficult to incorporate onto my daily life.
- 10 I feel more fatigued after the exercises.
- 11 I feel better for doing the exercises.
- 12 My walking is worse.
- 13 My stamina has improved.

Outcome	Tick
1	
2	
3	
4	
5	
6	
7	
8	
9	
10	
11	
12	
13	

Please use this page to record any additional comments you may have.

Please can you hand over the diary to the assessor at your final assessment after you have had time to complete any final entries in the space above.

Thank you for taking part in this study.

**Record of Participation
Information and Instructions for use**

This is your own record book in which you can write down your thoughts and feelings about the education pack and the exercise regime you are undertaking.

Please use the spaces provided to note down anything you wish.

Please write clearly using a pen or biro.

Please date each entry.

Please answer the questions as honestly as you can.

Please try to record your thoughts weekly in the spaces indicated.

Your comments will be used by the investigator to add extra detail to the assessment scales and questionnaires you will complete during the study.

You will be required to hand the record book in at the end of the study.

YOUR ENTRIES WILL BE TREATED IN THE STRICTEST CONFIDENCE.

You will be assigned a number to maintain your anonymity.

Only fill in your name on the front of the book if you want to.

After the analysis is completed all information gathered during the study will be destroyed.

Thank you for participating in this study.

Contact number: Cindy Davis, Lead investigator. 01522 577070

Pages for Self-selection journal

Week 11
Date

Week 12
Date

This week you will be visited by the investigator and your current abilities will be re-assessed as previously. You will also begin your chosen exercise regime.

Please describe below the exercise regime you have chosen.

Can you mark on the scale below your estimation of your quality of life today.
(worst) 1-----2-----3-----4-----5-----6-----7-----8-----9-----10 (best)

Record of Exercise Participation

Week 13

Date

Did you find the information supplied over the previous twelve weeks useful?

Yes

No

What would have improved the pack, if anything?

--

Week 14

Date

You will now have been performing your chosen exercise regime for two weeks.

Do you exercise every day?

Yes

No

If you answered no can you say why?

--

Did you experience difficulty with your exercise?

Yes

No

If you answered yes can you describe the problem you had?

--

Week 16

Date

This week you will receive a check visit from the investigator.

Week 17

Date

Week 18

Date

You have now been performing your chosen exercise regime for six weeks.

How often are you exercising? (Number of sessions per week).

Are you experiencing any difficulty with your regime?

Yes

No

If you answered Yes can you describe the problem?

How do you feel about the regime you are following?

Week 19
Date

Week 20
Date

This week you will receive your final check visit from the investigator. Please continue with your regime for the next 16 weeks.

Week 21
Date

Week 22
Date

You will now have been performing your exercise regime for 12 weeks.

How often do you exercise? (Number of times per week).

Do you have any problems with your regime?
Yes No

If you answered yes can you describe any problems you have?

How do you feel about the regime you are doing?

Please describe the regime you follow most regularly.

Please describe any regime you follow occasionally.

Further comments about the regime and your feelings about any progress or improvements you have noticed.

APPENDIX 3

**Multiple Sclerosis Exercise Study
Follow-up Questionnaire
Group 1**

You participated in the study assessing the benefit of exercise to people with MS.

The purpose of this questionnaire is to ask you about any good or bad effects you are still experiencing six months after study completion.

Please could you take a few minutes to complete this questionnaire.

1. Did you find your home exercise programme beneficial?

Yes

No

2. If you answered “Yes” can you say how it helped?

3. Are you still exercising?

Yes

No

4. How often are you exercising? Please tick one.

Not at all

Once a month

Once a week

Three times a week

More often

5. For how long do you exercise at each session? Please tick the one closest to your estimation.

30 minutes

45 minutes

60 minutes

Longer

6. If you are not exercising can you say why?

7. Have you found it easy to include exercise into daily life?

Yes

No

8. Has the programme been worth the effort?

Yes

No

Don't know

9. Would you have preferred to choose your own exercise regime?

Yes

No

Don't know

10. If you answered “Yes”, can you say why?

11. Did the study have any effects on you?

Yes/good

Yes/bad

Don't know

12. How long did the effects last?

13. Can you say what the effects were?

Thank you for taking the time to complete this questionnaire without your kind assistance this project would not have been possible.

Please return the completed questionnaire in the SAE provided.

**Multiple Sclerosis Exercise Study
Follow-up questionnaire
Group 2**

You participated in the study assessing the benefit of exercise to people with MS.

The purpose of this questionnaire is to ask you about any good or bad effects you are still experiencing six months after study completion.

Please could you take a few minutes to complete this questionnaire.

1. Did you find exercise beneficial?

Yes

No

2. What exercise did you do?

3. Are you still exercising?

Yes

No

4. How often are you exercising? Please tick one.

Not at all

Once a month.

Once a week

Three times a week

More often

5. For how long are you exercising at each session? Please tick the one that is closest to your estimation.

30 minutes.

45 minutes.

60 minutes.

Longer.

6. If you are not exercising can you say why?

7. Have you found it easy to include exercise in your routine?

Yes

No

Don't know

8. Has your regime been worth the effort?

Yes

No

Don't know

9. Would you have preferred to be in the home physiotherapy group?

Yes

No

Don't know

10. If you answered “Yes”, can you say why?

11. Did the study have any effect on you?

Yes/good

Yes/bad

Don't know

12. How long did the effects last?

13. Can you say what the effects were?

**Thank you for taking the time to complete this questionnaire without your kind assistance this project would not have been possible.
Please return the completed questionnaire in the SAE provided.**

APPENDIX 4

Lincolnshire Local Research Ethics Committee

Beech House
Witham Park
Waterside South
Lincoln
LN5 7JH

Tel: 01522 806 619
Fax: 01522 806 615

Mrs C Davis
Senior 1 Neurophysiotherapist
Community Rehab Centre
St Georges Hospital
Long Leys Road
Lincoln
LN1 1FS

Dear Mrs Davis,

Full title of study: An evaluation of the benefit of home-based exercise programmes for individuals with Multiple Sclerosis

REC reference number: LREC/02/1/664

Protocol number: 1

Amendment number: 1

Amendment date: October 2004

The above amendment was reviewed by the Sub-Committee of the Lincolnshire Research Ethics Committee at the meeting held on 11th October 2004.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Multiple Sclerosis Exercise Study Follow Up Questionnaire Group 1 (v1, October 2004)

Multiple Sclerosis Exercise Study Follow Up Questionnaire Group 2 (v1, October 2004)

Management approval

Before implementing the amendment, you should check with the host organisation whether it affects their approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number: 02/1/664	Please quote this number on all correspondence
---------------------------------------	---

Yours sincerely,

Verity Green

**Miss Verity Green
Committee Administrator**

Copy to: *Professor O Eremin, R&D Lead, ULHT*

Enclosures *List of names and professions of members who were present at the meeting
and those who submitted written comments*

APPENDIX 5

Please ask for: Verity Green
Telephone: 01522 806619
E-Mail address: verity.green@eastlincs-pct.nhs.uk
Our Ref: TWW/VG/LREC/02/1/664
Your Ref:

Lincolnshire

Research Ethics Committee

Chairman: Mr Terence W Wiseman
Co-ordinator: Miss Verity Green

Beech House
Witham Park
Waterside South
Lincoln
LN5 7JH

Mrs C Davis
Senior 1 Neurophysiotherapist
Community Rehabilitation Centre
St Georges Hospital
Long Leys Road
Lincoln
LN1 1FS

Tel: 01522 806619
Fax: 01522 806615

11th July 2003

Dear Mrs Davis

Re: Research Protocol No: LREC/02/1/664 – Re-submission (please quote this number on all future correspondence)
Title of Study: An Evaluation of the Benefit of Home-based Exercise Programmes for Individuals with Multiple Sclerosis

Thank you for your application, which was considered by the Committee on 10th July 2003.

The Committee is pleased to APPROVE your application with the following comment:

- o The Patient Information Sheet requires to be proof-read.

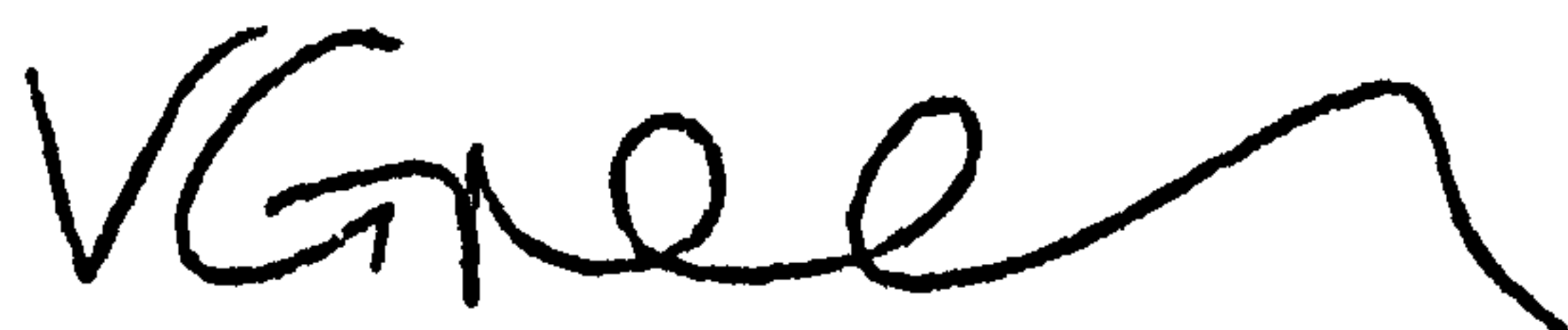
We would remind you of the following:

- a) You must comply with the protocol *exactly* as submitted to the Committee (as amended where appropriate).
- b) Any changes to the protocol must be submitted to the Committee for approval
- c) Should any untoward event occur during the conduct of the protocol, the Chairman or Vice-Chairman of the committee must be informed immediately.
- d) Should you leave your post before completion of the study/project, the Committee must be advised, and, if it is to continue, the details of the new researcher(s) submitted.
- e) You must submit a progress report annually and a final report on completion of the study.

We wish you every success with your study.

In accordance with the requirements of the Research Governance Framework, a copy of this letter has been sent to the relevant Trust Chief Executive.

Yours sincerely,



Dictated by
Mr Terence W Wiseman
CHAIRMAN, LINCOLNSHIRE RESEARCH ETHICS COMMITTEE ONE
And signed in his absence

APPENDIX 6

**Patient Information Sheet
(Version 5)**

Date

Title: An Evaluation of the Value of Home-Based Exercise Programmes for Individuals with Multiple Sclerosis.

Introduction

You are invited to participate in a research study. Please take the time to read the following information sheet carefully. Please ask if there is anything that is unclear, or if you require any further information. Please take time to decide whether or not you wish to participate.

What is the purpose of the study?

Multiple Sclerosis is a disease that affects the Central Nervous System. Consequently it can cause disruptions in mobility, co-ordination, balance and sensation. It affects everyone differently, and is unpredictable in its progression.

It is the aim of this study to determine if exercise, when performed at home, can show improvements in functional ability and mobility over time.

It is anticipated that your participation in the study will last 36 weeks to allow for the data collection process to be completed.

Why have I been chosen?

You have been asked to participate because you have a confirmed diagnosis of Multiple Sclerosis.

Do I have to take part?

Participation in the project is entirely voluntary. If you do decide to take part, you have the right to withdraw at any time during the study without prejudice to your current or future treatment.

What will happen if I agree to take part?

You will be participating in a Research Project consisting of two parts, an information part and an activity part. This means you will be involved in two parts of a study that follow each other. You will be visited at home six times during the study by the investigator. Each visit will last approximately forty- five minutes.

The first visit will be to assess your mobility, strength, balance, co-ordination, the mobility in your joints and your walking speed.

You will then be allocated into one of the following groups for the duration of the study.

Group 1 Programme

Base-line assessments will be done at the beginning of the study and you will be issued with a three-part education pack over a 12-week period. The assessments will be repeated after 12 weeks.

You will also be given a Diary at the beginning of the study and you will be asked to record your activities and feelings regarding the value of the programme on a weekly basis. You will then begin the exercise regime. This will consist of three stages, Lying, Sitting and Standing, given out over a 12-week period. You will be asked to continue with the exercises for 24 weeks with guidance and support from the investigator.

The final assessment will be carried out at 36 weeks at the end of the study.

Group 2 Programme

This group will undergo the same assessment procedures as group 1 including the issue of a Diary and the education pack over a 12-week period.

This group will be asked to participate in a standard exercise regime of their choosing. This may include Yoga, Swimming, Walking, low resistance gym work or cycling. You will be visited at home three times by the investigator who will continue to provide advice and support to you during this time.

You will be asked to continue with the exercise you have chosen for a total of 24 weeks with guidance and support from the investigator.
At the end of the 36 weeks study period, you will be re-assessed, a total of three assessments in all.

What do I have to do?

You will be required to participate fully in the activity programme, providing your health permits. You will be required to complete the diary on a weekly basis.

What are the possible disadvantages of taking part?

No disadvantages have been identified.

What are the possible benefits of taking part?

It is hoped to prove that with regular exercise performed at home your mobility, posture, strength and overall well being will improve.

What happens when the study ends?

All participants will be given the option to continue with an activity programme. Confidential information collected during the study will be destroyed.

Will my taking part in this study be kept confidential?

Only the investigator and the GP will know of the participants in the study.

What happens to the results of the study?

The results will be written up as a Doctoral Thesis by the investigator.

The results may be published in an appropriate medical journal.

The results will be used to validate the need for Community input to provide a necessary service to this client group.

Who is organising and funding the research?

The study is being organised by the investigator and supervised by Professor CD Ward, Head of Department, Ageing and Disability Research Unit, Nottingham University, Nottingham.

Funding is being sought from the following organisations

1. The Multiple Sclerosis Society
2. Ipsen
3. The Chartered Society of Physiotherapy
4. The HAS Charitable Trust

Who has reviewed the study?

Lincolnshire NHS Research Ethics Committee.

Contact for further information

Mrs Cindy Davis,
Senior Neurophysiotherapist,
Community Rehabilitation Center,
St. Georges Hospital,
Long Leys Road,
Lincoln. LN1 1FS
Tel 01526 57707

Thank you for your assistance with this project.

APPENDIX 7

BEST COPY

AVAILABLE

Some text bound close to
the spine.

1000 Centre Number: :
Study Number:
Patient Identification Number for this trial:

CONSENT FORM

Title of Project: An Evaluation of the Benefit of Home-Based Exercise Programmes for Individuals with Multiple Sclerosis

Name of Researcher: Mrs. Cindy Davis , MSc, BSc (Hons), Grad-Dip-Phys, MCSP, HCP.

Please initial box

1. I confirm that I have read and understand the information sheet dated
(version) for the above study and have had the opportunity to ask questions.

☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time,
without giving any reason, without my medical care or legal rights being affected.

☐
3. I agree to take part in the above study.

☐

Name of Patient	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes
FILENAME \p |CC:\RehabTeam\Ann.E\Cindy\Application Guidance Notes.doc

Revd: Feb 2001



APPENDIX 8

Multiple Sclerosis Exercise Study

Information Pack

Part One

Contents

Facts about Multiple Sclerosis

Types of Multiple Sclerosis

Common signs and symptoms of Multiple Sclerosis

Useful contacts

Some Facts about Multiple Sclerosis

Multiple Sclerosis (MS) is a condition that affects the white matter of the Central nervous System (CNS), in other words the brain and spinal cord. This system provides the basis for our ability to move feel breath speak swallow and think. When this system is damaged one or more of these systems may be affected. MS is just one of a broad category of Demyelinating diseases that can affect the CNS.

All the nerves within the body are covered in a substance called myelin. This fatty material forms a protective sheath around the nerves enabling them to conduct electrical impulses from the brain around the body at an almost instantaneous rate. When the myelin sheath is damaged or destroyed the rate of conductivity of the nerves is diminished or in extreme cases interrupted entirely. This what occurs in MS when scarring or plaques form on the myelin sheath thus impeding the nerve's ability to conduct impulses effectively.

The problems this causes can be extremely varied and are dependent on the location of the plaques in the brain or spinal cord. It is possible to have a great many plaques with very few symptoms and vice versa. However it is more common to have a variety of differing symptoms that can change with annoying unpredictability. MS is the most commonly diagnosed neurological disorder in the UK. It affects people of all ages and is more common in women than men the ratio being 3:2.

The caused of MS remain as yet unknown. It is believed to be an autoimmune response to the body's mistaken belief that the myelin of the CNS is a threat and must be destroyed.

The immune system is the body's self defence mechanism and it protects the body from attack from viruses and poisonous substances that may cause harm. In MS the immune system is "Turned on" inappropriately and begins to fight its own systems as if they were a threat. It is believed that certain factors may predispose some people to develop the condition for example a virus contracted in early life could be a trigger to the development of MS in later life.

MS is not contagious and it is not hereditary. However cases have been recorded of different family members of one family developing the disease. People do not inherit MS. They may however inherit an immune system that could become overactive if stimulated in a certain way. This could lead to the disease developing.

MS shows a marked geographical variation. A general pattern can be seen the further away from the equator in either hemisphere a person lives. For example in countries with temperate climates like the UK a high incidence of MS can be found compared to more equatorial latitudes. In more northerly regions the condition is less common and is virtually unknown in Inuit races.

MS is unique in that it is one of the few conditions that affects only one body system. Apart from the demyelination, of the CNS no other body system is affected. This is because only the specific cells found within the CNS are damaged. To date no cure has been found for MS so the emphasis remains on coping and disease management.

Types of MS

Three distinct types of MS have been identified. These are:

Primary progressive

This type involves a steady deterioration that is accompanied by a gradual loss of ability. People experience a worsening of their symptoms over time. In some cases this can be rapid with accompanying onset of disability early on in the course of the disease.

This type is not the most common presentation of MS.

Relapsing/Remitting

This is the most common presentation in which the person experiences a series of attacks followed by periods of recovery. An attack can last from a few days to several weeks and will vary in severity from mild to acute. There may be some residual disability after recovery takes place.

The periods between attacks are generally characterised by no further disease progression. The degree of recovery is usually greater following the first attack, therefore the more attacks a person has the more likely it is that problems will become permanent.

Symptoms of rapid onset are more likely to recover quickly than those that come on more slowly. It is unlikely that symptoms that have persisted for two years or more will ever resolve. The nature of the symptoms is also important. Eye and facial problems almost always recover. Problems with larger nerves that may influence balance or walking can be more persistent.

Secondary progressive

This type presents as a slow deterioration of functional abilities that is a progression from the relapsing remitting type and occurs as the disease type changes over time. Often there are no further relapses more the slow progression of disability. The rate of deterioration varies and is very unpredictable.

IT IS NOT ALL DOOM AND GLOOM!! It is important to note that two third of people diagnosed with MS are still walking 20 years after of living with the disease.

Medical advances over the years have enabled many people with MS to continue to lead fulfilling lives around the physical difficulties of MS.

The development of Disease Modifying Drugs, (DMD) which will be discussed later in this pack, are a step in the right direction in the quest to control and possibly even reverse the disease process and are becoming far more readily available on the NHS.

Remember YOU are in control. Having MS will mean changes and adaptations to life but that does not mean life is over.

Common signs and symptoms of MS

Visual disturbances

Many people with MS complain at some time or other about problems with their eyes. This difficulty can take on many forms from double vision, to spots before the eyes, to a cling-film like effect over the field of vision to temporary blindness in one eye. It is common for visual disturbances to present in the early stages of the disease process and this can often be the first indication that MS is present.

Visual disturbances often right themselves in most cases but for some people they may remain as a permanent feature of the disease.

Sensory disturbances

These symptoms are another common feature of MS and are difficult to adapt to. This is because the CNS relies heavily on information from the outside world to enable it to protect the body from harm and to move it in a smooth unhindered fashion. When information from the world around you becomes corrupted movement becomes difficult and inco-ordinated.

This will include your ability to feel objects and where your body is in relation to its environment. An example of this would be when a person is unsure of the position of their feet. Without looking to verify this they may trip or worse fall. There is a good reason for this. If the brain is not fully aware of the body's position it cannot compensate for the movement.

Sensory loss can and often does affect the hands. This causes difficulties with daily tasks especially those requiring fine control.

People sometimes find that using their vision to re-enforce the sensory information the brain is receiving can help with this problem. Other sensory problems may include a feeling of crawling on the skin, pins and needles or numbness in a part or all of a limb. This can also be felt in the stomach or the back.

Often people report feelings of tightness around a limb or the trunk. This can be mistaken for a spasm or spasticity when in fact it is a result of the damage to the sensory nerves supplying the brain with a false impression.

Motor disturbances

Problems with movements are a common feature of MS and can present in many different ways. An inability to co-ordinate movements for example when walking or using the hands is a problem most often reported. The limb appears to have a mind of its own and any attempt to control it results in an undesired movement. When this affects the legs it is often referred to as Ataxia.

Many people experience the frustration of trying to initiate a movement when the limb just will not function as they want. Sometimes the problem is confined to one limb and frequently accompanied by some degree of sensory loss. This can make the problem more difficult to adapt to and re-training of the required movement may be necessary.

Spasticity

A problem frequently described by those with MS is spasticity. This is most often noticed as a result of movement difficulties. This problem is characterised by an abnormal stiffening of the muscles inhibiting free movements and causing the muscles to tire quickly due to the extra effort needed to move. This occurs due to the location of plaques on the motor areas of the CNS.

There is a battery of drugs commonly available to combat spasticity and these will be discussed later in this pack.

Exercise can also be very useful in reducing the effects of spasticity by reducing the stiffness common to this problem and re-educating movement patterns. Stretching is also a useful method of reducing too much stiffness and can be done quite easily as part of a home regime.

Bladder and Bowel problems

A person with MS may find they have difficulty in controlling the bladder and feel the need to go to the toilet more often than usual. They may also find it difficult to start the flow. Sometimes the problem may be one of urgency or an inability to control the bladder resulting in inappropriate voiding of the bladder.

Constipation can frequently result as a consequence of MS again as a result of reduced effective nerve conductivity. Increasing ones fluid intake on a daily basis is a good way to ensure good bladder and bowel function.

Often some drug intervention may be needed to assist with bladder or bowel management and the advice of a specialist nurse could make all the difference to coping with these worrying difficulties.

Fatigue

This is a commonly reported problem that affects people in different ways. For some it is an inconvenient symptom that with rest and a re-organisation of daily tasks can be dealt with reasonably easily. For others it becomes a draining all consuming problem that dominates their lives. It can seriously disrupt a person's ability to participate in social activities and even cope with day-to-day life.

People often report a worsening of this symptom in warm weather, when they feel stressed or upset or when they have done too much the day before. The element of fatigue seems to heighten the other manifestations of MS and can be very disabling. Unfortunately it is an unseen consequence of MS that family and friend may find difficult to understand or sympathise with.

Tremor

Tremor presents as an uncontrollable shaking, usually of a limb but in extreme cases it can originate in the trunk causing the person to appear as if they are rocking to and fro. At rest there can be no tremor at all but once one tries to move it begins. This is commonly referred to as an intention tremor. Tremor can sometimes come and go and is one of the most difficult symptoms of MS to treat. There are some drugs available for the treatment of tremor but they are only intermittently successful and it is very much a trial and error approach.

Pain

Many people experience pain as a symptom of MS. This is referred to as a neurogenic pain as its origins lie in the disruption the disease has caused to the nerves. The pain can start almost anywhere but is commonly found in the face. This is known as trigeminal neuralgia. It can also be present in the limbs. This is a deep-seated ache from which there is no relief and that cannot be pinpointed.

There are some very effective drug therapies for the treatment of pain but it is advisable to discuss the possibilities with your doctor. They will be best able to advise as you on the best option for you and provide you with the relevant information.

Other symptoms

Some people experience other symptoms that present as a result of the nerve damage. These can include dizziness, twitching or jerking of the limbs, loss of balance (especially in the dark), and shaking when attempting to move. Loss of co-ordination speech difficulties and memory problems may also be a feature of MS as can sexual difficulties and depression.

It is important to remember that the symptom list is not exhaustive and that it is extremely unlikely that any one person will have all of them. Most will have a combination of two or three and this is dependent on the number and severity of the attacks.

Useful Local Contacts

Rehabilitation Medicine Service

01522 577019

Consultants, Dr S Ahmed and Dr R Prasad

Secretary, Linda Hulme

Community Outreach Team

01522 577070/577025

Specialist Occupational Therapist Mrs Anne Lewis.

Specialist Neurophysiotherapist. Mrs Cindy Davis

Specialist Nurses, Mrs Sally Robbins and Mrs Carol Gent.

ARMS Center.

01522 543333

Local MS Branch

Your GP

Useful national Contacts

MS Society 0171 610 7171

MS Trust 01462 476710

MS Resource Center 0800 783 0518

Multiple Sclerosis Exercise Study

Information Pack

Part Two

Contents
Managing a Relapse
Treatment during a Relapse
Exercise and MS
Disease Modifying Drugs
Other useful Drugs

Managing a relapse

MS is usually described as a relapsing/remitting condition. This means that symptoms come and go over a period of time. They improve partially or totally depending on their severity. Many people refer to this as an attack as they can describe precisely the period of time they felt unwell or experienced a resurgence of symptoms.

In a relapse symptoms usually come on over a short period of time ie hours or days. They can remain for a number of weeks although this is variable. The time between relapses when the disease is stable is the remission stage and this can last for weeks to many years.

What happens in a relapse?

A relapse occurs when the myelin sheath is attacked by the immune system causing swelling around the affected nerve. This interrupts the nerve's ability to conduct electrical impulses thus preventing the messages from the brain from reaching their destination. When the swelling subsides the nerve is no longer compressed and the relapse could be deemed to be over.

Unfortunately some permanent damage may have been caused to the nerve and this can mean some loss of ability. It is important to remember that you can recover fully from a relapse even if some nerve damage remains, but if the same area is attacked repeatedly recovery will be less likely.

Not all symptoms are a relapse

There are certain events that appear to be the beginnings of an attack. For example if you become too hot with an infection or during hot weather. This can impede function. If permanent damage has occurred to the nerves this could contribute to a return of symptoms. These usually disappear when the body cools down. Unfortunately some people have given up exercise altogether in the mistaken belief that it will make their MS problems worse. This is not true and exercise will be discussed later in this booklet.

What can trigger a relapse?

No clearly defined cause has been identified as a trigger for a relapse. However evidence exists that suggests that certain factors could play a part. These include trauma including surgery, stress, some vaccinations and infections especially respiratory or urinary.

Treatment during a relapse

Many people are treated with steroids during a relapse. These are synthetic versions of the corticosteroids that are produced naturally in the body by the adrenal glands. They should not be confused with Anabolic steroids that are sometimes taken by athletes to build muscle and improve performance.

It is believed that the use of steroids shortens the duration of the relapse by reducing the inflammation that surrounds the nerves. They do not however influence the amount of recovery that takes place.

There is no clear guideline as to the use of steroids in the UK although most neurologists do limit the number of times a person is prescribed them in any one year. They also tend to disagree with the prescription of steroids by GP's.

Generally speaking neurologists will choose to administer steroids intravenously and use Methylprednisolone to treat severe relapses. This may require a hospital admission. Oral steroids are also prescribed but these are believed to be less effective than the intravenous route.

Unfortunately as with most drugs there are some side effects with steroids that need to be considered. These may include mood swings, increased heart rate, hot flushes, local swelling, sleep disturbances and sometimes an increased need to urinate especially at night.

There are also concerns for long-term steroid use that should be noted. These are:

1. Osteoporosis. This is a condition in which calcium is lost from the bones. It can increase the risk of breaking a bone should you fall. It is possible to counter this by eating a well balanced diet plus the addition of calcium supplements as recommended by your doctor or dietician.
2. Diabetes. This is a disease in which the production of insulin in the body becomes diminished or in extreme cases entirely absent. This leads to an excess of sugar being left in the body that upsets the metabolic balance. Sometimes this can be controlled by diet but if you suspect you may be diabetic you must seek advice from your GP.

Other treatments

As the symptoms experienced during a relapse can vary so much many different problems may arise that can be treated by the intervention of someone from the outreach team available in Lincoln.

The core team members are an occupational therapist, specialist nurses and a physiotherapist. There is also access to a speech and language therapist, a dietician, a clinical engineer, a clinical psychologist and the wheelchair service. The rehabilitation medicine consultant can also be contacted through the team.

The team is here to assist you when you need it. They can provide advice and therapeutic interventions to get you through difficult times. You can access the team directly and do not need a doctor's referral once you are known to us.

Remember the team is here for your benefit and should be used as and when you feel the need for advice or assistance.

Exercise and MS

Many people with MS mistakenly believe that they will no longer be able to participate in any form of exercise once they have a diagnosis of MS. They often believe that to do so will make their condition worse. If a traditional view of exercise is taken ie, working out hard and pushing oneself to the limit, then yes, exercise is not going to be of benefit to you.

If however a new perspective on exercise participation can be adopted then you can safely continue to enjoy many activities. Exercise should be designed to influence the areas of deficit that have been caused by MS. The CNS has a special property known as “plasticity”. This means that in the early stages after it has been damaged it has the ability to re-route impulses from the brain and so re-learn movements.

With the long-term affects that MS imposes on the CNS the ability to adapt is diminished. It is still possible though to remind the system how to move and so prevent problems from worsening.

Repetitive movements and gentle stretching exercises are useful ways in which you can influence your movements without too much effort or stress. By being aware of the affects the condition has had on the nerves you can adjust your activity to suit the capabilities of the muscles.

For example, previously you may have enjoyed swimming. The supportive medium of the water makes this an ideal way to exercise and your ability to swim will still be there. Just remember to swim shorter distances and rest frequently to gradually build up your stamina again for this activity.

Many other activities are also suitable for those with MS such as: yoga, cycling either on a static bike or outside, aqua aerobics pilates and walking. Just remember your abilities may have lessened and exercise within them.

Regular exercise is of benefit to most people irrespective of disability. The restrictions that MS may impose on you will mean that exercise needs to be adapted to accommodate these restrictions.

Importantly: EXERCISE SHOULD BE APPROPRIATE TO NOW!!

Do not be too discouraged if you suffer a relapse and are unable to exercise. Your abilities will return as you recover over time. The most important thing is to work within your capabilities and you are the best judge of that.

One other important point to remember is not to push yourself too hard if you do suffer a relapse. The inflammatory process affecting the nerves will mean that exercise done at this time will only stress them further. Be patient and ride it out. When your symptoms start to subside then gentle exercising can re-commence.

Disease modifying drugs

Extensive research has demonstrated convincing evidence that Beta interferons, (Avonex and Rebif), and Glatiramer acetate, (Copaxone), can reduce the frequency of attacks in relapsing remitting MS by roughly 30%.

Individuals who fulfil the criteria for prescription of these drugs, ie have two relapses a year and are able to walk a set distance, are eligible for these drugs on the NHS. If you think you are eligible, you will need to be assessed by a neurologist before one of the drugs can be prescribed.

There is also a “Risk Sharing” scheme with a ten-year follow-up of people on these drugs to determine their effectiveness. Please contact the MS Society for further details and for information and publications on disease modifiers.

Another drug currently being trialled is Natalizumab, (Antegren). This drug works by preventing the inflammatory cells that attack the CNS myelin from crossing the blood/brain barrier with the effect of lessening plaque formation and subsequent scarring on the nerves.

There is also Mitoxantrone and intravenous immunoglobulins but these are as yet unlicensed for use in the UK.

Other useful drugs

There are many drugs that have been used successfully to treat the many problems produced by MS. The most often reported problems are spasticity in the limbs, pain and poor bladder function. The next section will highlight the drugs most commonly used for these difficulties.

Baclofen

If you have a problem with spasticity or spasms in your limbs or body baclofen is often the first drug that is prescribed to relieve them. Spasticity is caused because the muscles contract excessively. This can be painful and inhibit your ability to move freely. Your movements may become slow and inco-ordinated with an accompanying feeling of stiffness in the affected part of your body.

Other drugs that are prescribed for spasticity are Dantrolene, Zanaflex and sometimes Diazepam. It is down to the response of the individual as which drug is given.

For localised problems in one set of muscles or a limb there is also the option of an injection of Botulinum toxin. This has the effect of temporarily paralysing the junction over which the electrical impulse must jump to conduct electricity to “power” the nerve. This will have the effect of temporarily paralysing the nerves ability to conduct at that point and so relieve the spasticity. The effects last for about three months before re-growth of the nerve around the junction occurs with a possible return of symptoms.

The treatment can then be repeated provided there were no side effects.

In more extreme case an injection of phenol can provide permanent relief as this kills the nerve endings. The effects are therefore permanent.

Spasticity can also be relieved by controlled exercise programmes and by stretching of the affected muscles. It is beneficial to continue to move the affected muscles despite the stiffness and to try and normalise your movements with slow rhythmic repetitious activity. This will assist the nervous system to remember how to move and prevent the muscles from shortening.

Oxybutinin

This drug works on the muscles that control the bladder wall. It is commonly used to alleviate incontinence and is often combined successfully with other techniques of bladder management. For example, using cranberry juice in regulated amounts, (too much can cause kidney stones!), adequate water intake and sometimes the use of intermittent catheterisation. The specialist nurse will be able to advise you on these matters.

Tegratol

Many people with MS suffer with neurogenic pain. This is a pain that is caused by the damage to the nerves. It often does not respond to conventional pain relieving drugs.

A common complaint of a facial pain called trigeminal neuralgia. This affects one side of the face and can be extremely severe. Tegratol can be very effective at relieving this pain.

Gabapentin

Many people complain of a deep-seated limb pain. Gabapentin has been found to be an extremely effective treatment for this pain presentation. You will need to see your GP or consultant to receive this drug and in some cases blood tests are required.

There are many other drugs available that may help with MS problems. It is always advisable to consult your doctor regarding any specific issues you may have.

Multiple Sclerosis Exercise Study

Information Pack

Part Three

Contents
Who can help?
The Outreach Team
Local Services
Medical support

Who can help?

Many people with MS lead normal lives continuing with their jobs and usual social activities. For others however the unpredictability of the disease can present a barrier to coping and so interfere significantly with life in general. It is important to remember that you do not have to just live with it. There are people who can help you and offer advice on ways to manage within the confines of MS.

Occupational therapy

The role of the OT in assisting with MS management is varied. They do not only supply equipment on the home. Their skills include specialised regimes to assist with sensory loss, advice about managing fatigue, work related issues and driving as well as mobility aids. They also provide splints and small aids for the home that can make a huge difference to the ability of a person to maintain their independence. They can also advise and supply appropriate wheelchairs should this be needed.

Specialist nurse

The Lincoln Rehab Medicine Service has the advantage of specialist nurses within the outreach team. They can advise on many issues ranging from bladder and bowel problems to sexual dysfunction. They also provide a vital link between the community the consultant and other local agencies. Often they are the instigators of other support networks eg fatigue management and they lead incontinence clinics.

Physiotherapy

It is often beneficial for those with MS to seek the advice and support of a physiotherapist when contemplating exercise or to help you maintain your activity levels. Physiotherapy does not need to be performed in a gym or outpatient department or for that matter need a physio in attendance. The advice given can easily be transferred to home use and the physio can supervise where necessary. The key to success with this is for you to take charge of your exercise. That way you will benefit fully from your own individualised regime.

The physio can also assess you for seating, assist with teaching transfers and coping around the home, as well as the recommendation of aids for home and work. As you can see the OT and physio have a close working link and this overlap provides a great benefit for you and your requirements.

Dietician

Some people feel that the adoption of a special diet will influence the course of the disease. Although there is little evidence to support the idea that one dietary regime is better than another if you find something that suits you and is healthy then stick with it. Dieticians will recommend a healthy eating regime incorporating a balance of fresh fruit and vegetables with proteins being supplied by white meat and fish.

Dietary supplements are also popular but should be taken with caution and advice sought as their long-term effects, especially if you are on a drug regime.

Speech therapy

Most people with MS will never require the services of a speech therapist. However should the need arise, they are available as part of the team to assist you with swallowing difficulties as well as re-educating speech.

Clinical psychologist

Some people find coming to terms with MS a daunting prospect. Often there is no-one else you know of with MS, or worse still someone you know who has very advanced MS that are frightening to you and cause you great distress.

Please remember, ALL PEOPLE WITH MS ARE DIFFERENT.

The clinical psychologist can help you to adjust to MS and enable you to cope with the day-to-day problems it presents. They are also invaluable in assisting with the memory problems that some people experience. They provide strategies to help you manage as well as support for your family.

Local agencies

Lincolnshire has many active MS support groups should you feel this may help you. Some are run by the MS society and some by the MS trust. There are others that are simply self-managed groups for locals with similar difficulties. There is also the fatigue management group run by the OT and specialist nurse. This is held three or four times a year at differing locations around the county. For further information and contact numbers please refer to part one of booklet.

Neurologist

Many people only see a neurologist once, at the time of diagnosis. However it can be beneficial to have a yearly review with a specialist who can monitor you and keep you informed of new developments regarding treatment or drug trials.

Rehabilitation medicine consultant

This is a valuable resource available in Lincolnshire for people with neurological conditions. They can provide a link with all the other agencies you may need. They also provide expert opinions and advice on medical issues that may worry you. They can be accessed locally in Lincoln and Boston.

Often the availability of a rehab consultant alleviates many worries or fears and their expertise in many fields is of great benefit to those with neurological problems living in the county.

Your GP

Although not a member of the team, your GP can provide a close and direct link to the team should you need it. Information on the service is available in the surgery.

YOU

The most important team member. Remember we are here to assist and advise as you require. In some cases this will be very infrequently. Other people will need more support and help and they can ring us directly without being referred by the doctor once they are known to the service.

Acknowledgements and further reading

Freeman, J., Hatch, J., Johnson, J., et al., 1997. Standards of Health Care for people with MS. MS Society

Graham, J., (1998). What is MS? The Multiple Sclerosis Society of Great Britain.

Roberts, G., (1997). Treating MS symptoms. The MS Society of Great Britain.

Schapiro, R.T., 1998. Symptom Management in Multiple Sclerosis. 2nd edition. New York. Demos.

MS Society.

MS Trust.

APPENDIX 9

Dear Dr
For your information only

An evaluation of the benefit of home based exercise for people with Multiple Sclerosis.

A selection of Multiple Sclerosis patients attending your practice will be invited to participate in a randomised, comparative pilot study to evaluate the benefits of home-based exercises.

The study will take place over a nine month period. The participant will be given an education pack over a three month period and be required to take part in one of the two sections of the project.

Group one will be asked to follow a structured exercise programme at home for six months. They will be asked to record their experiences of the programme in a diary. Data will be collected at various stages during the study to record any changes in motor ability, spasticity, quality of life and function.

Group two will be asked to participate in an exercise regime of their choosing. This may include walking, swimming, yoga or low resistance exercises in a gym. They will also be supplied with a diary to record their own perceptions of the selected regime. Data collection will be the same as for group one.

After six months data collection will be complete and the participants will be free to continue their existing programme or to change to an alternative.

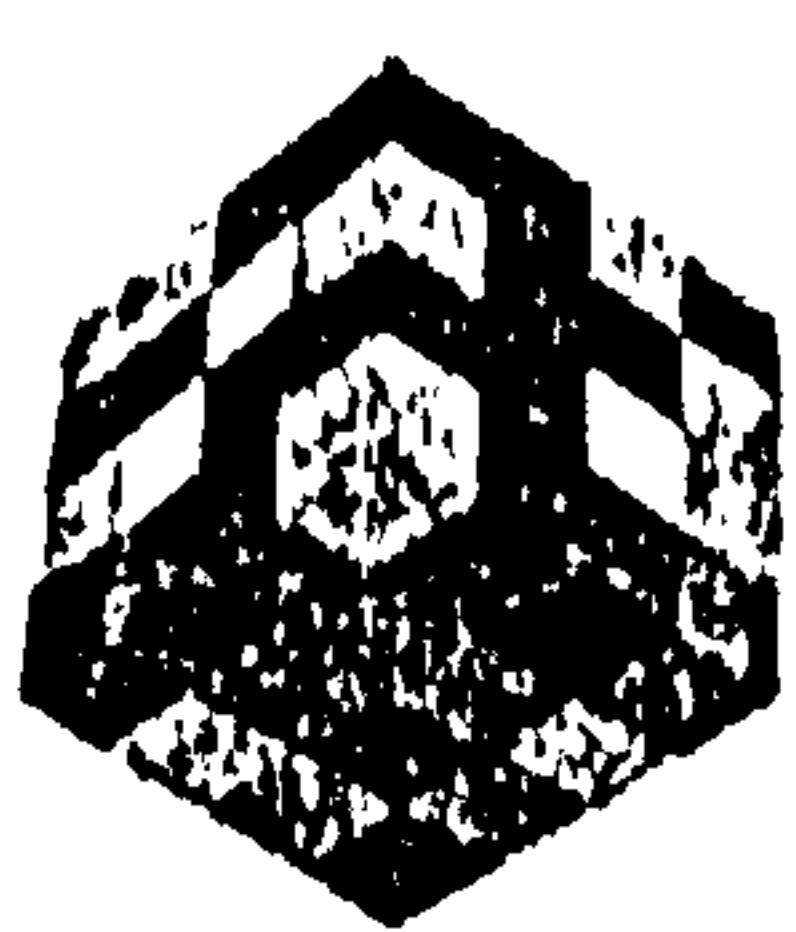
The participants will be supplied with an information sheet and be fully informed of the procedures required for participation. Written consent will also be obtained.

Participants will remain anonymous and data will be destroyed at the end of the study.

Yours Sincerely,

Mrs Cindy Davis, MSc, BSc(Hons), Grad-Dip-Phys, MCSP, SRP.
Senior Neurophysiotherapist.

APPENDIX 10



Tools RG
Know how to show how

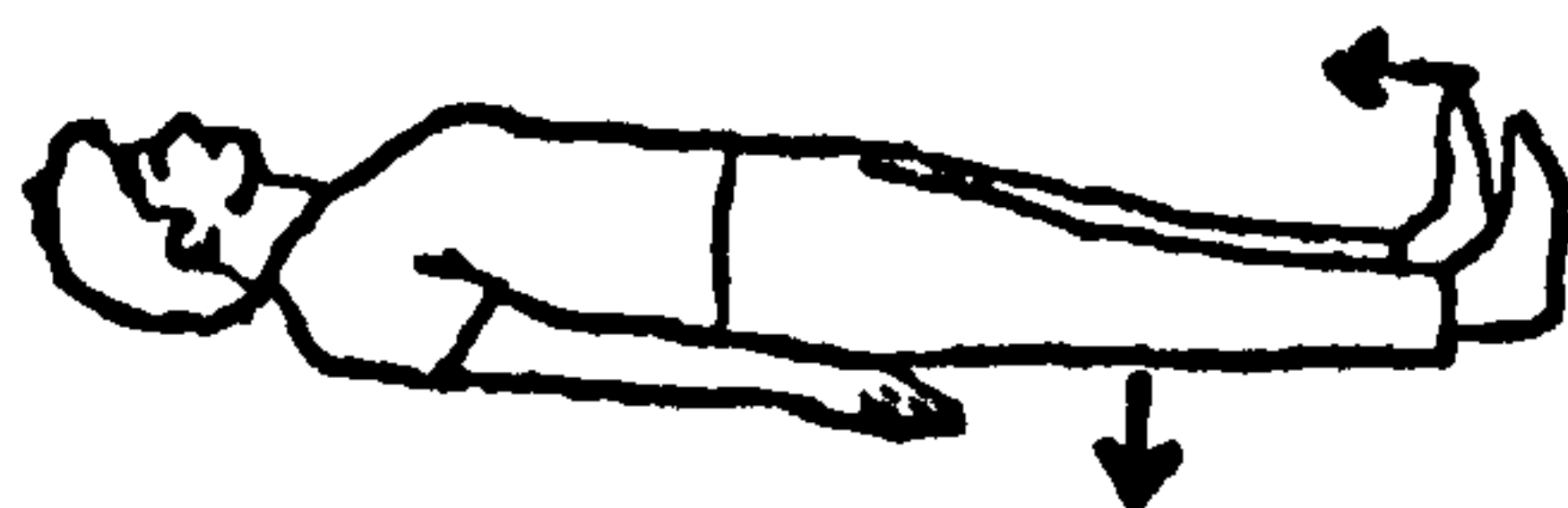
MS Exercise Study. Lying Exercises

Group One.

These exercises are to be performed in lying. You can lie on the bed or the floor, whichever you prefer. Please ensure you are comfortable and do not hurt your back whilst doing this programme. If any of the exercises cause you a problem, please report this to the investigator as soon as possible.

Lying on your back, tighten up the thigh on the right leg, hold for a count of three and relax. Repeat with the other thigh.

Repeat _ times with each leg.

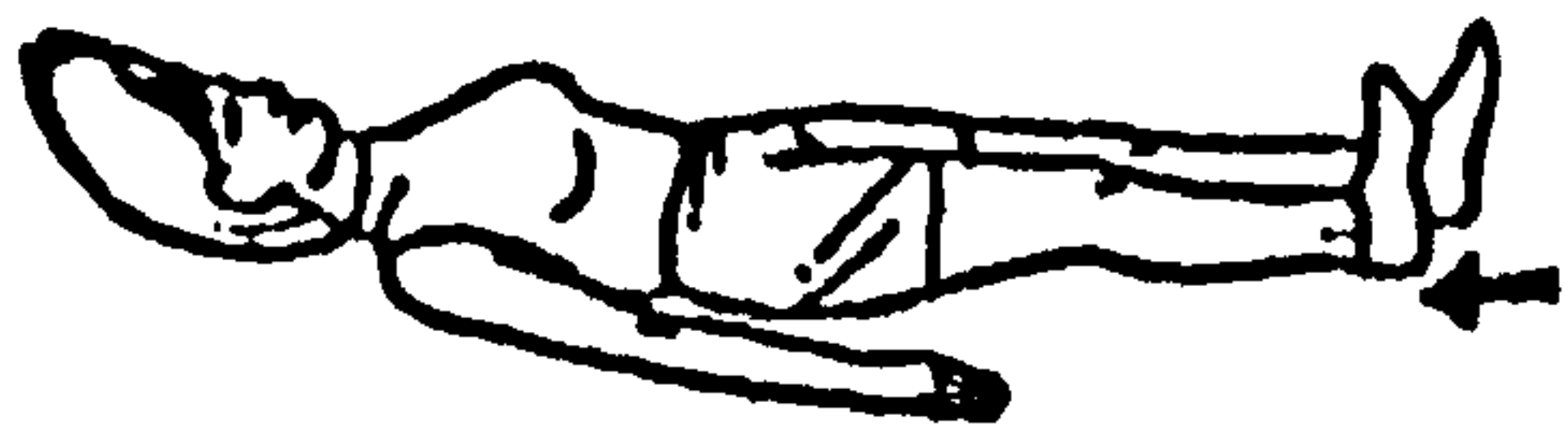


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Lying on your back.

Pull one leg up at the hip to shorten the leg. Repeat with other leg.

Repeat ____ times.



PhysioTools Ltd

Tighten up the buttocks, hold for a count of three and relax.

Repeat _ times.



PhysioTools Ltd

Lying on your back with legs straight.

Pull up your ankle and push your knee down firmly against the bed. Hold for a count of three and relax. Repeat with the other knee

Repeat ____ times.



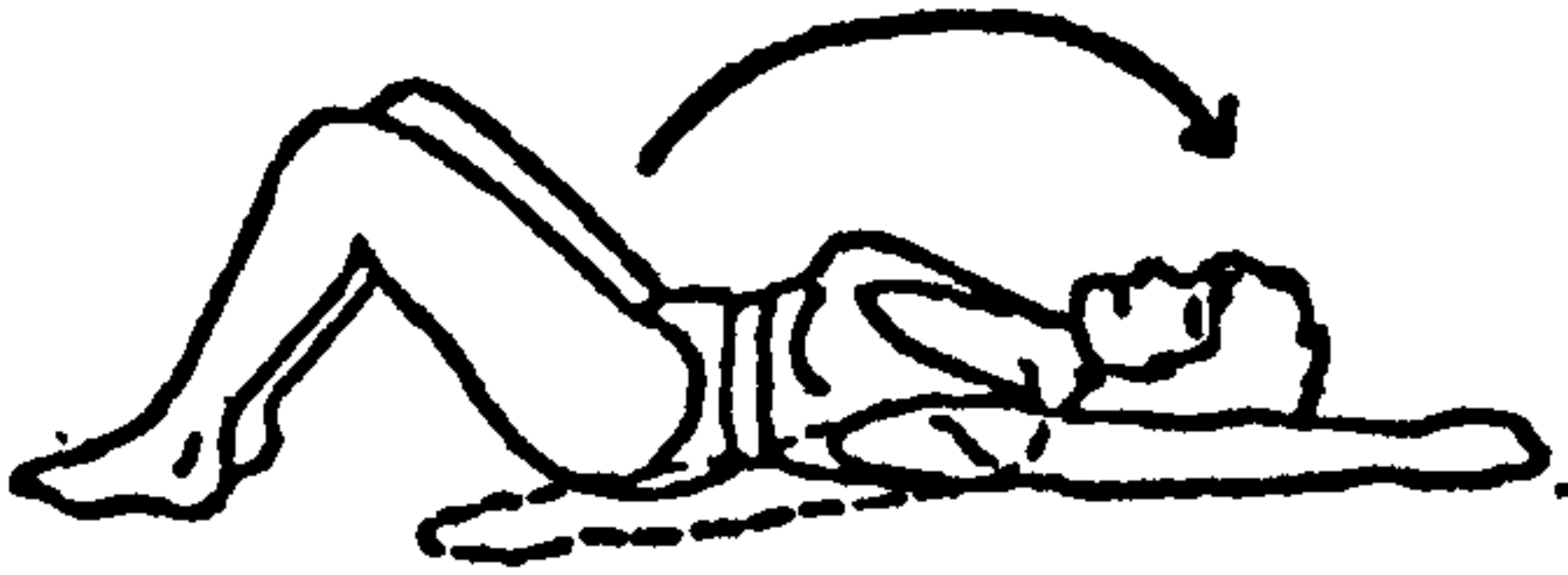
PhysioTools Ltd

Will on Tools® RG

Lying on your back.

Bring your arm up and over your head keeping your arm close to your ear.

Repeat ____ times.

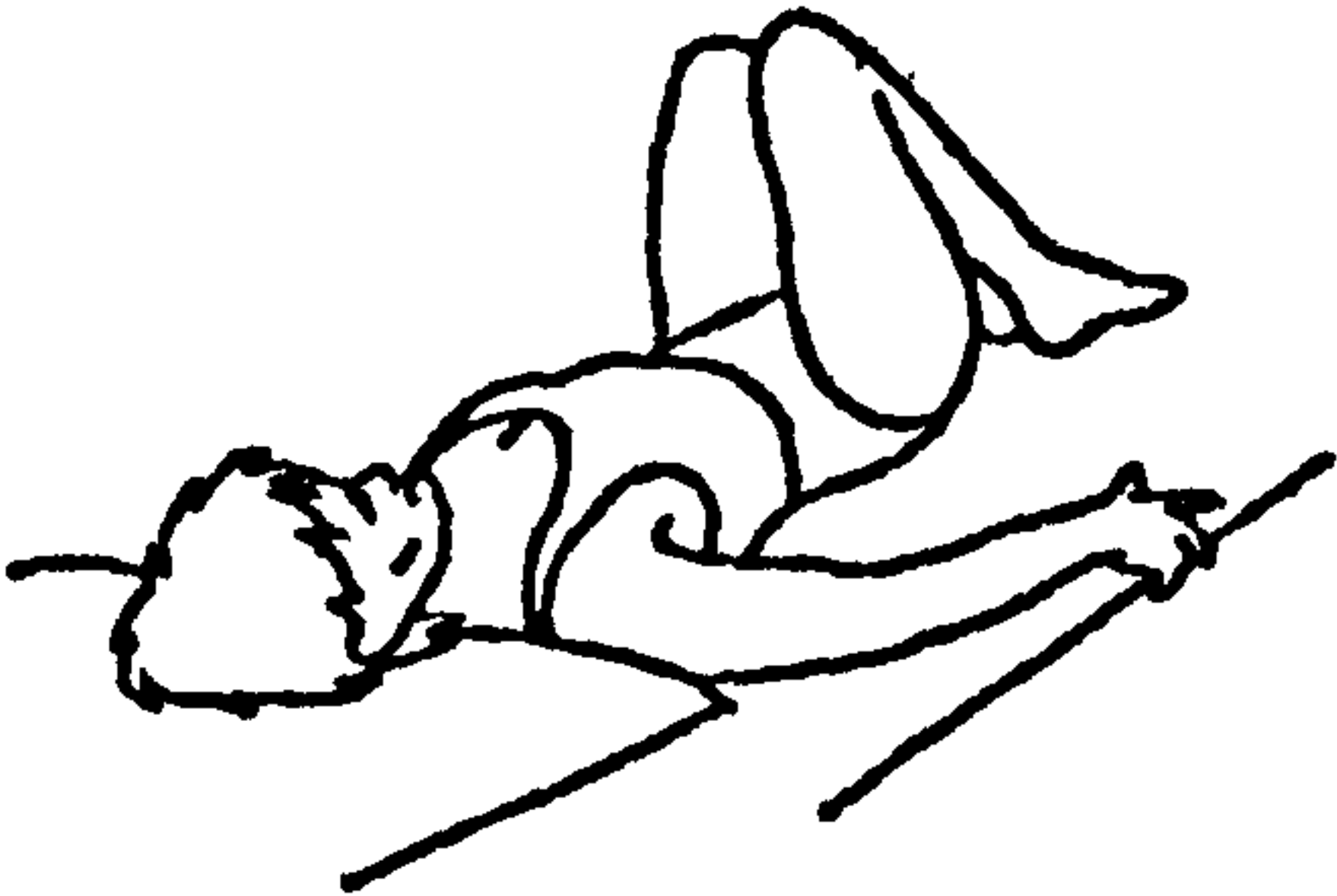


© PhysioTools Ltd

Lying on your back with knees together and bent.

Slowly roll your knees from side to side keeping your upper trunk still.

Repeat ____ times.

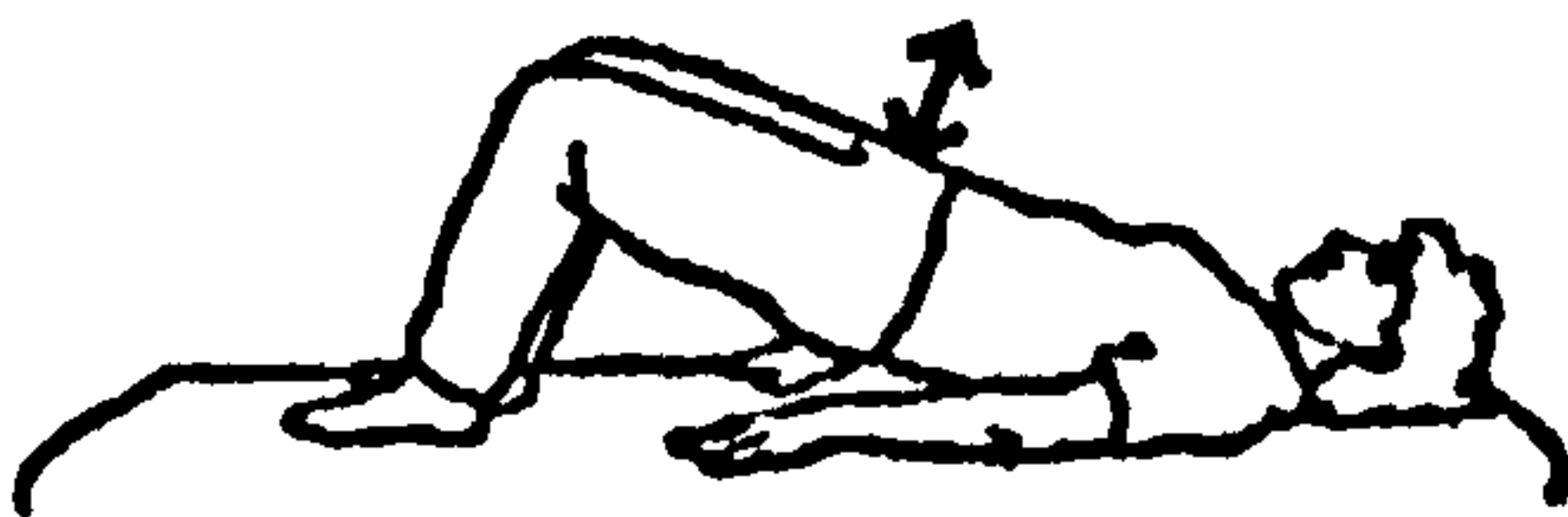


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Lying on your back with knees bent and feet on the floor.

Lift your pelvis and lower back (gradually vertebra by vertebra) off the floor. Hold the position. Lower down slowly returning to starting position.

Repeat ____ times.

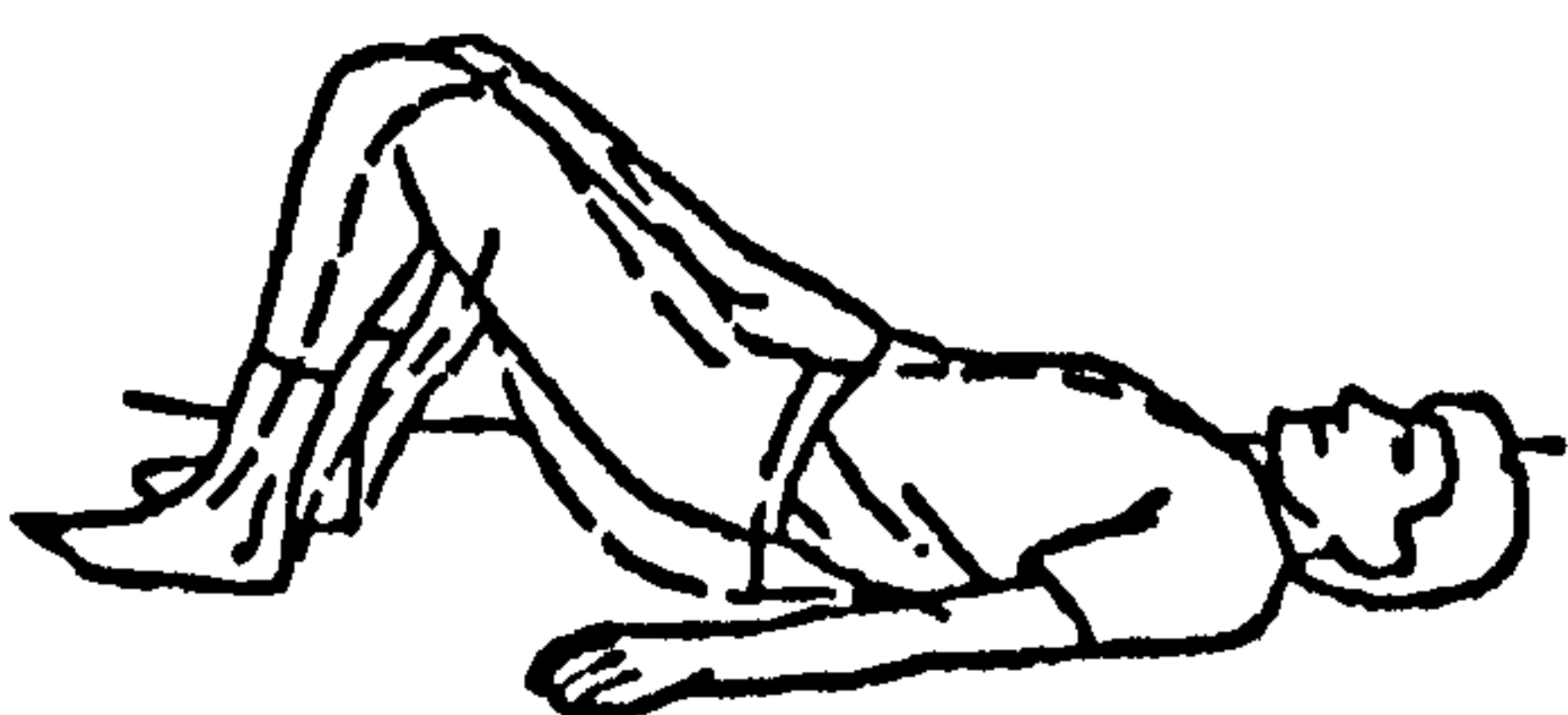


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Lying on your back with your knees bent.

Straighten one leg keeping the knees together. This will stretch the muscles at the back of the thigh.

Repeat _ times with each leg.

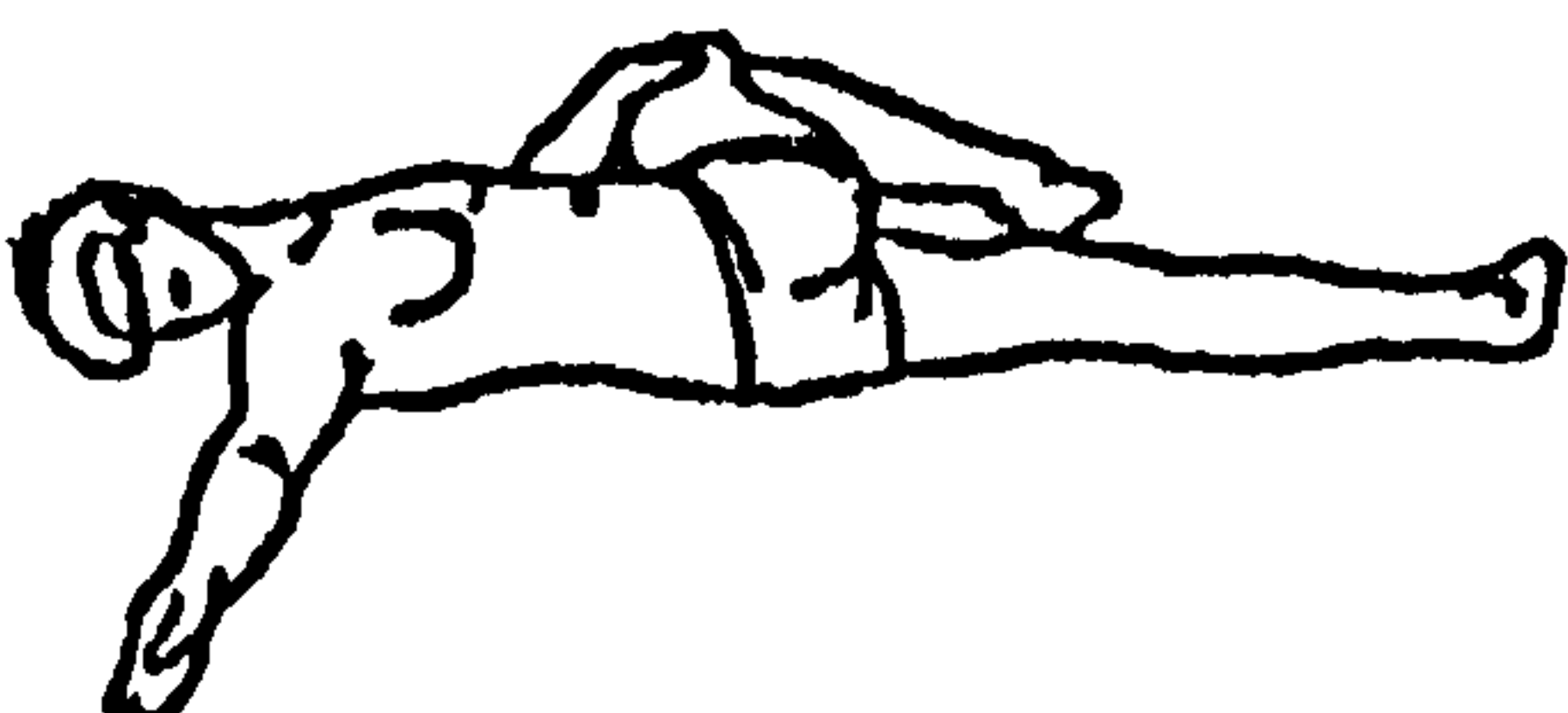


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Lying on your side with one leg bent. Hold your bent knee with the hand closest to the floor.

Lift your upper arm up and over, following the movement with your head, so that you rotate at the waist. Try to place the back of this hand as close to the floor (bed) behind you as you can. Return to the start position.

Repeat_ times on each side.

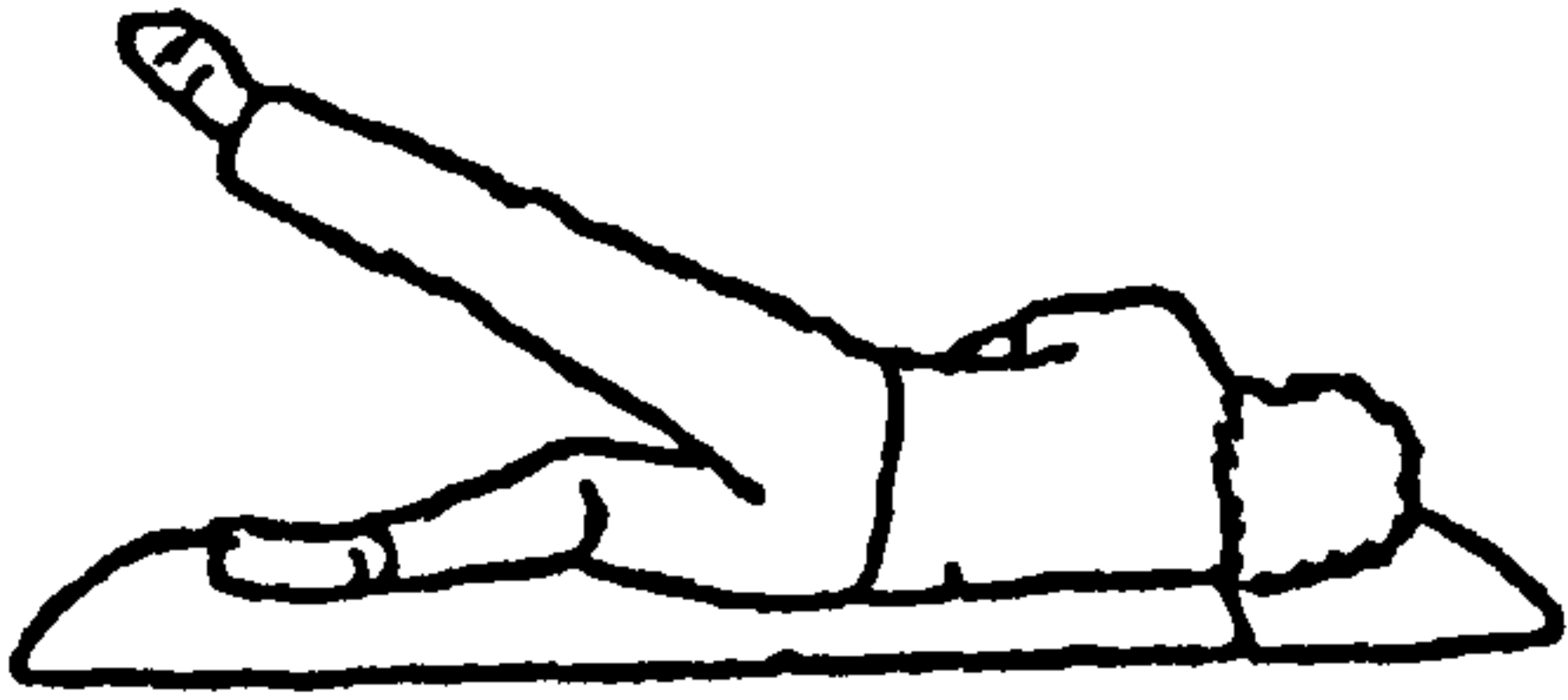


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Sidelying. Keep the leg on the bed bent and the upper leg straight.

Lift the upper leg straight up with ankle flexed and the heel leading the movement.

Repeat ____ times.



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Repeat exercises 9 and 10 on the other side.

These exercises will help you to feel the difference between muscles that are contracted and those that are relaxed. They will stretch out the trunk muscles that often shorten due to poor posture and they will encourage stability around the pelvis in preparation for walking.

You may increase the repetitions you perform up to a maximum of ten per exercise. Do not exceed more than this as it could become too time consuming.

Remember, the exercises are for the Central Nervous System (CNS). Therefore they must be done steadily and frequently to enable the CNS to adapt to the movement patterns.

Please try and do these exercises five times a week.

Please note in your record book any comments you would like to make regarding this section of the programme.

APPENDIX 11

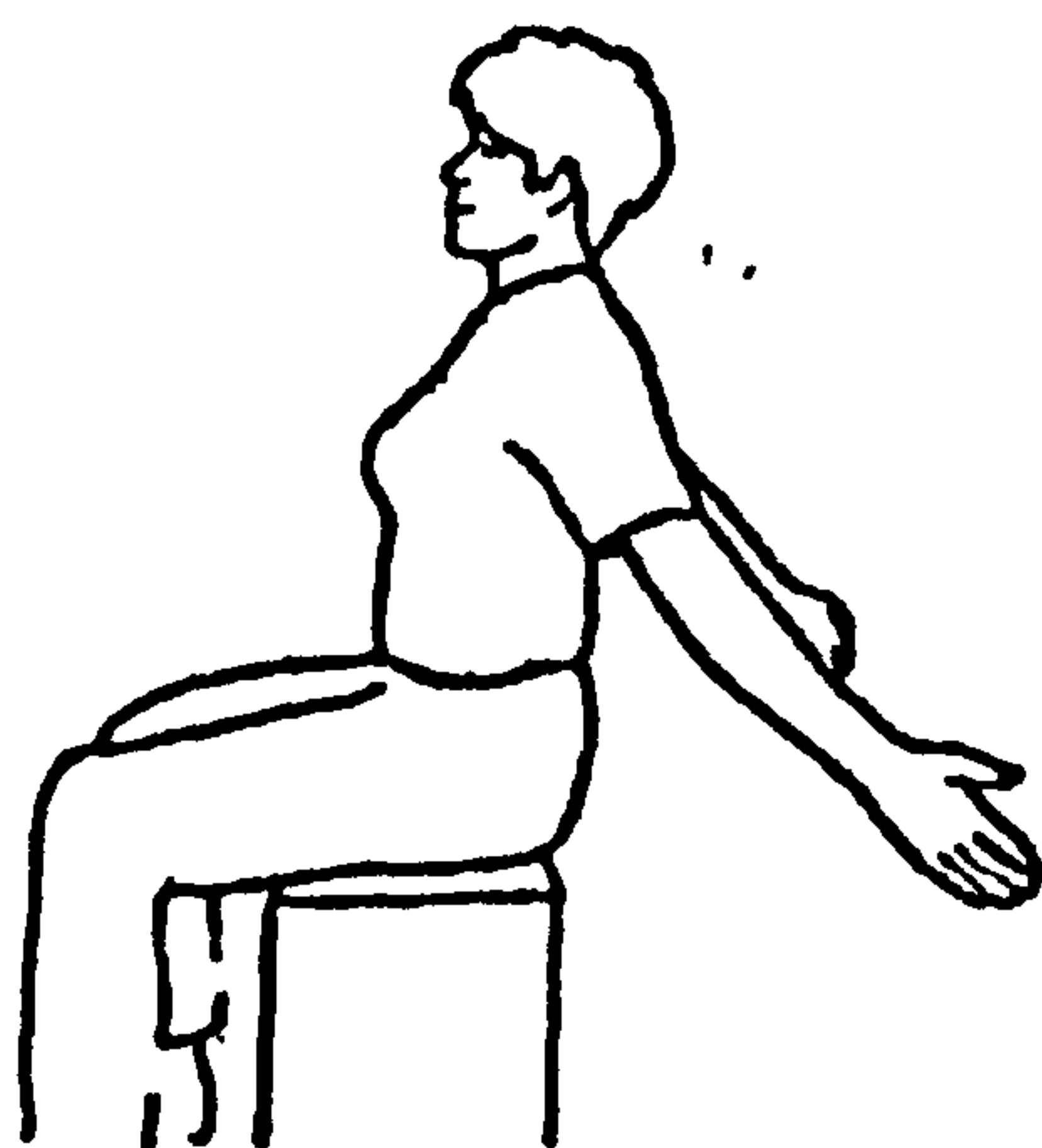


Tools RG
Know how to show how

MS Exercise Study. Sitting Exercises.

Group One.

Sit comfortably on a dining room chair, or similar, preferably without arms. Keep your feet on the floor and make sure that you have enough room in front and at either side to bend over.



Sit so that you are not leaning on the back rest of the chair.

With your arms relaxed, straighten your back and grow tall in the chair. Stretch your arms back so that you arch your lower back slightly and tilt your pelvis forward slightly as you grow.
Hold for a count of three and relax.

Repeat__ times.

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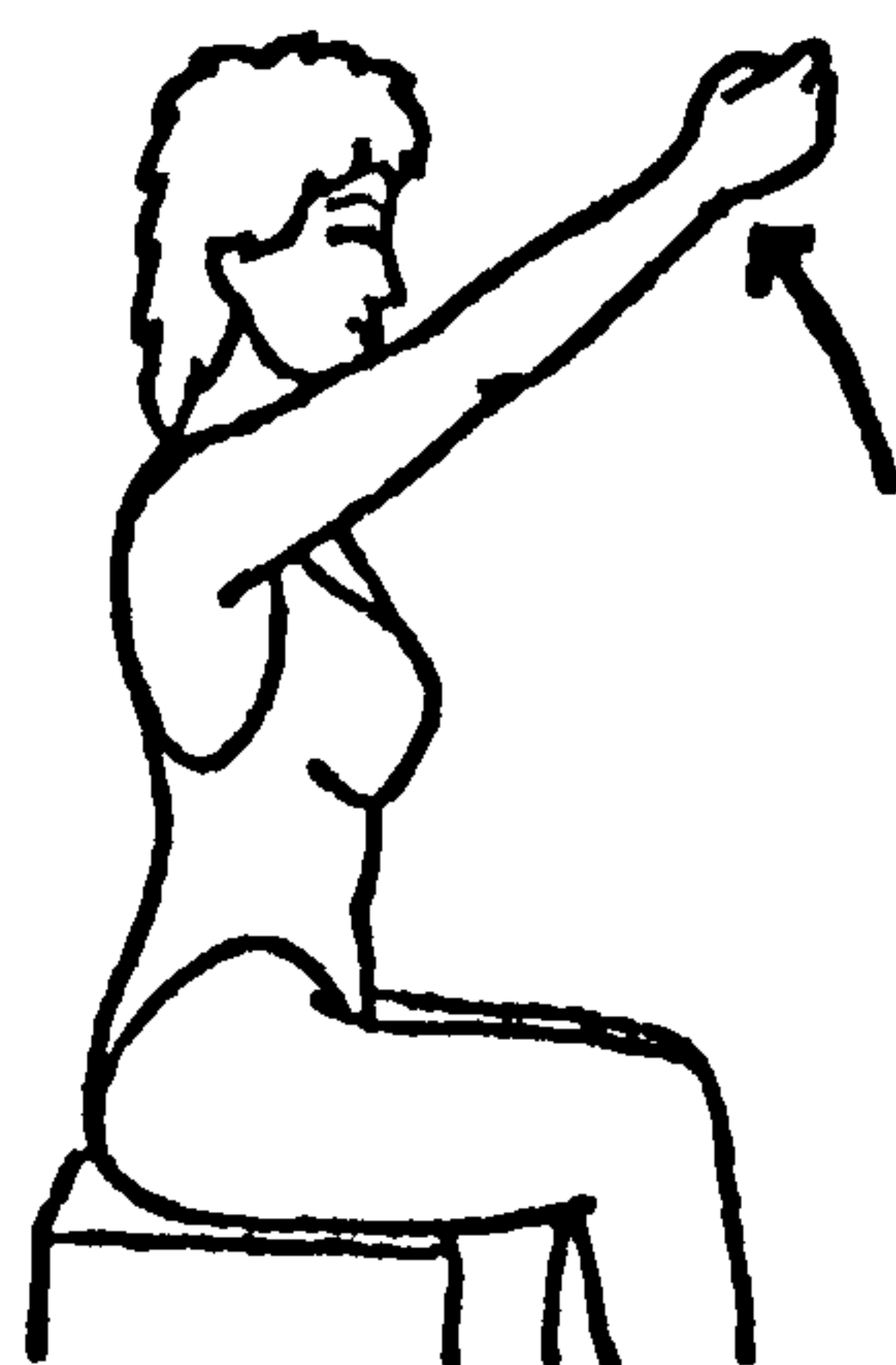


Start with both hands on your knees.

Run your fingers over your knees towards your feet, curling the spine forwards as you go. Slowly straighten up again until an upright position is achieved.

Repeat__ times.

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Reach up into the air with alternate arms, stretching out the side of the ribcage. Hold for a count of three and relax down again.

Repeat__ times.

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Sitting on a chair as before, reach out to the side with alternate arms until the buttock on the opposite side just begins to lift up off the chair. A gentle rocking motion.

Repeat__ times.

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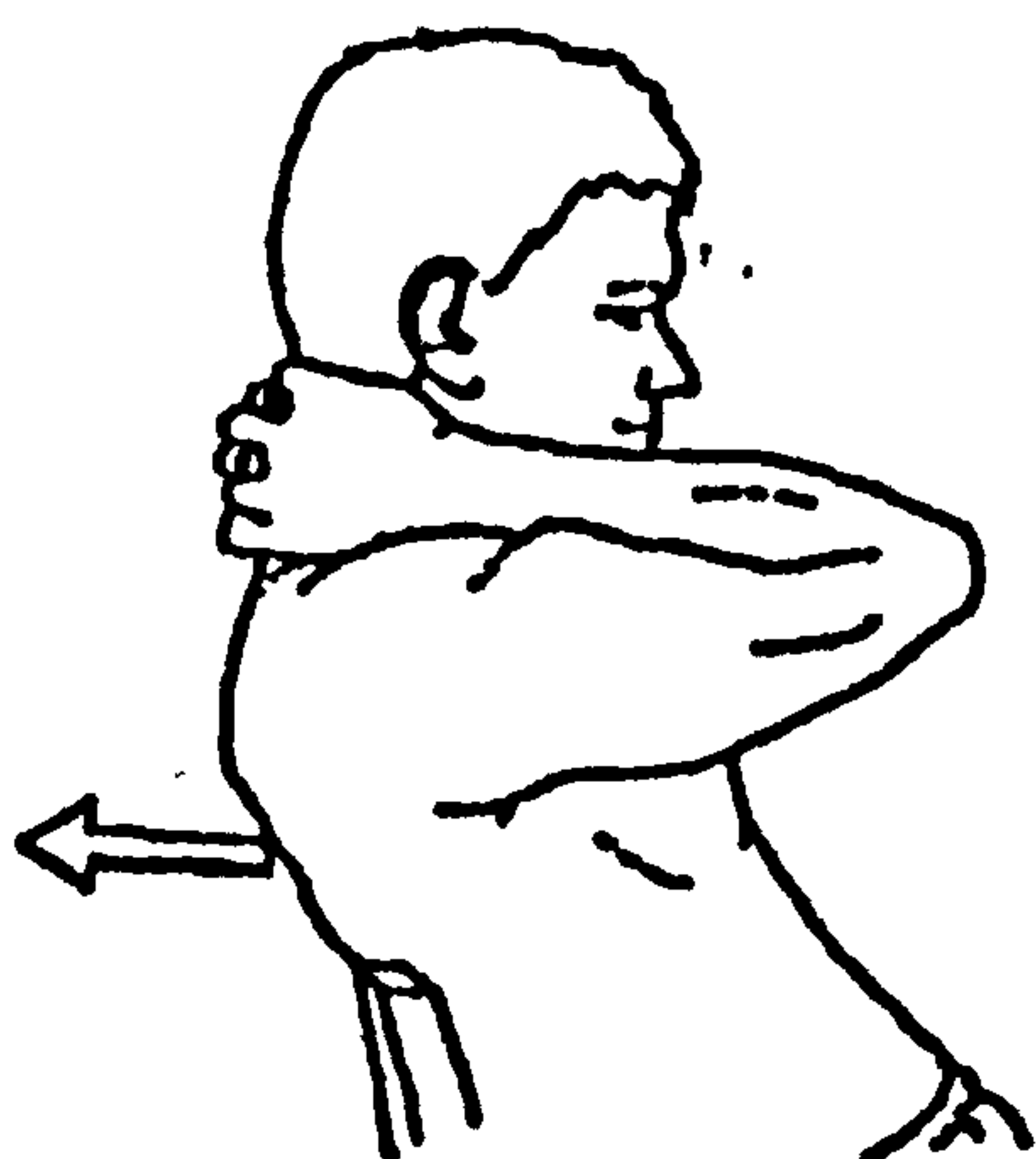
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Place the hands on the shoulders or the waist and rotate slowly from left to right.

Repeat__ times.

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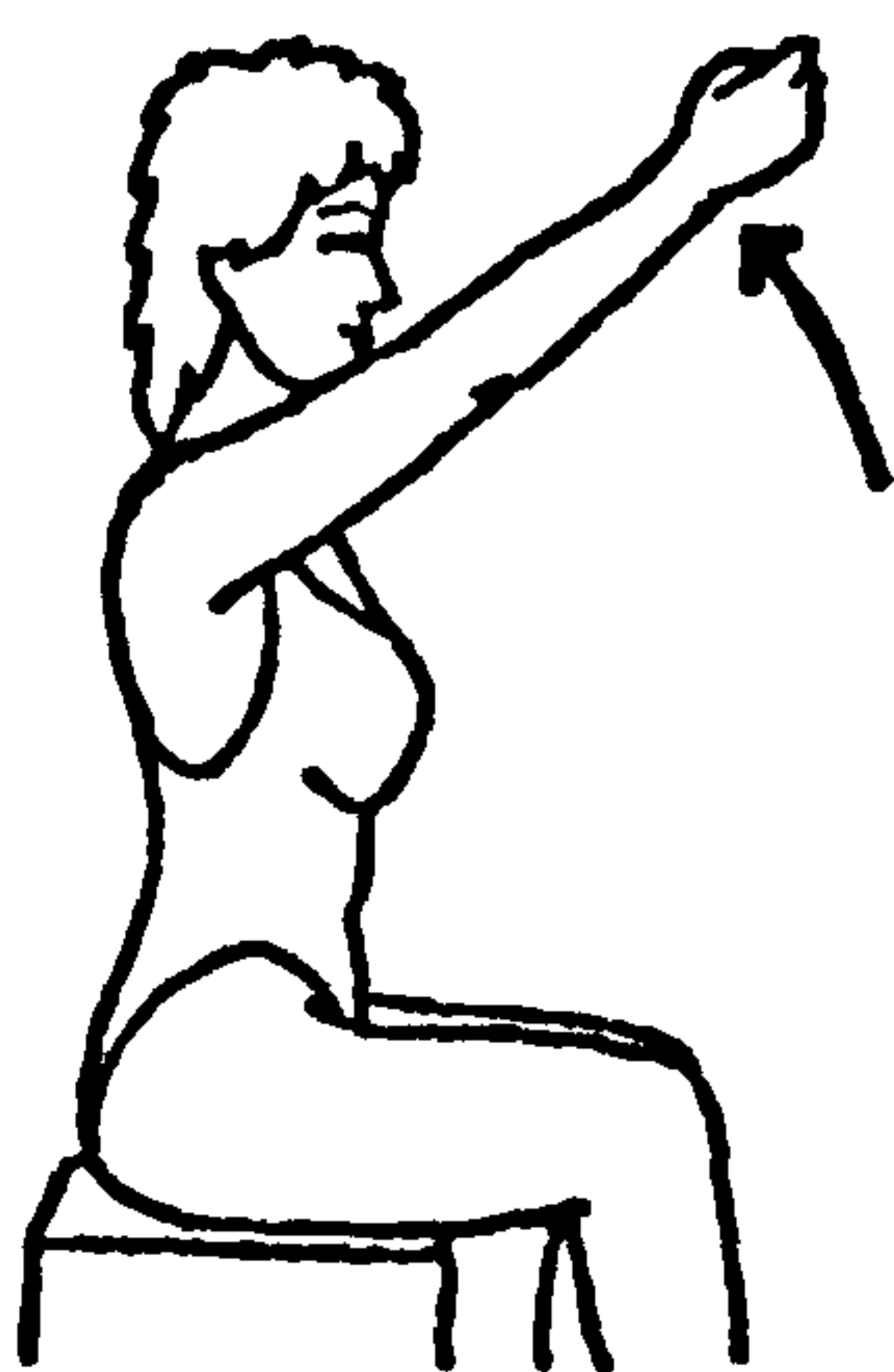


Place the hands behind the neck or on the waist.

Pull the elbows backwards trying to bring the shoulder blades as close together as you can. Relax.

Repeat__ times.

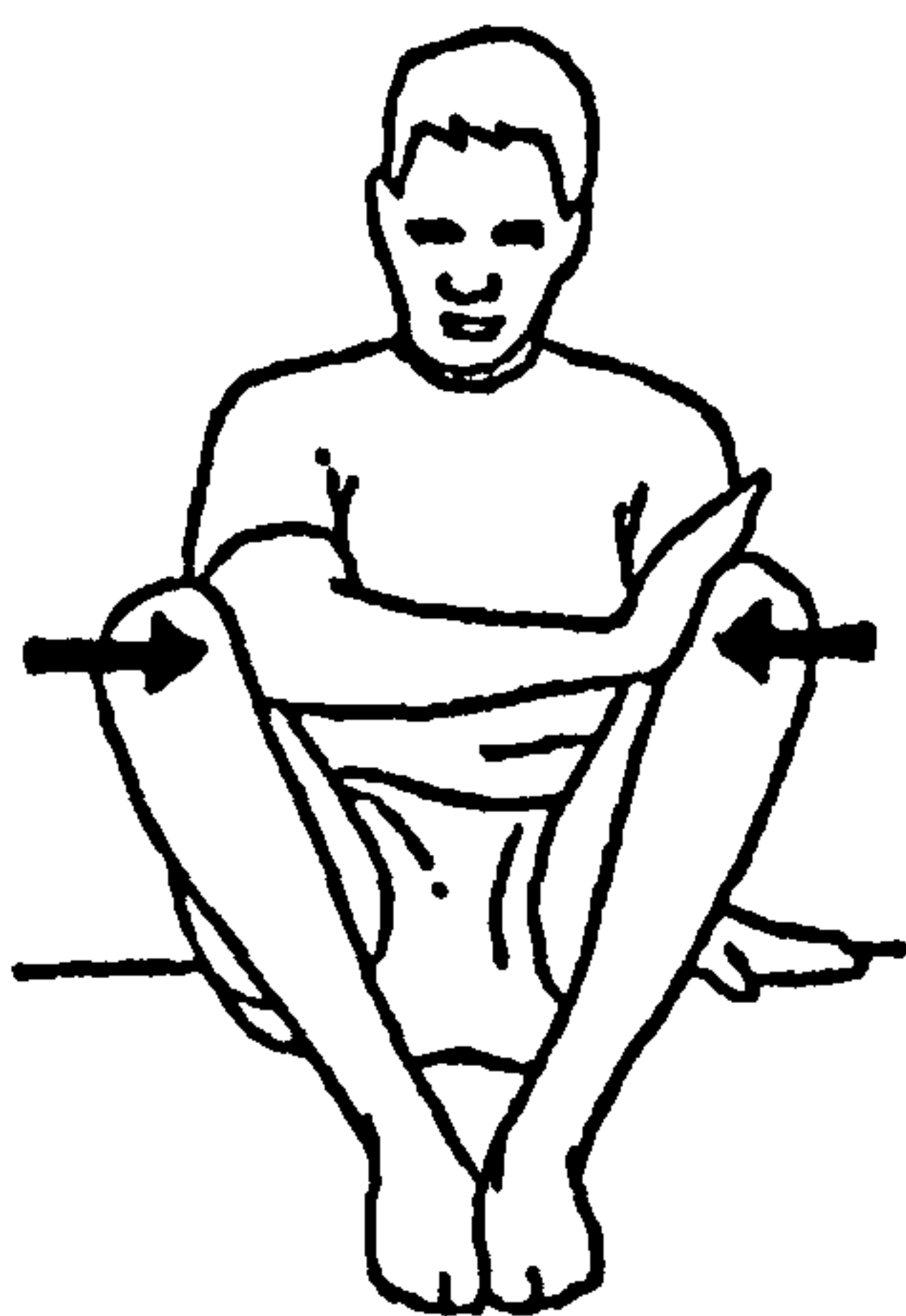
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Clasp your hands together and straighten the arms out in front of you. Push both hands away from you stretching out the arms. Relax.

Repeat__ times.

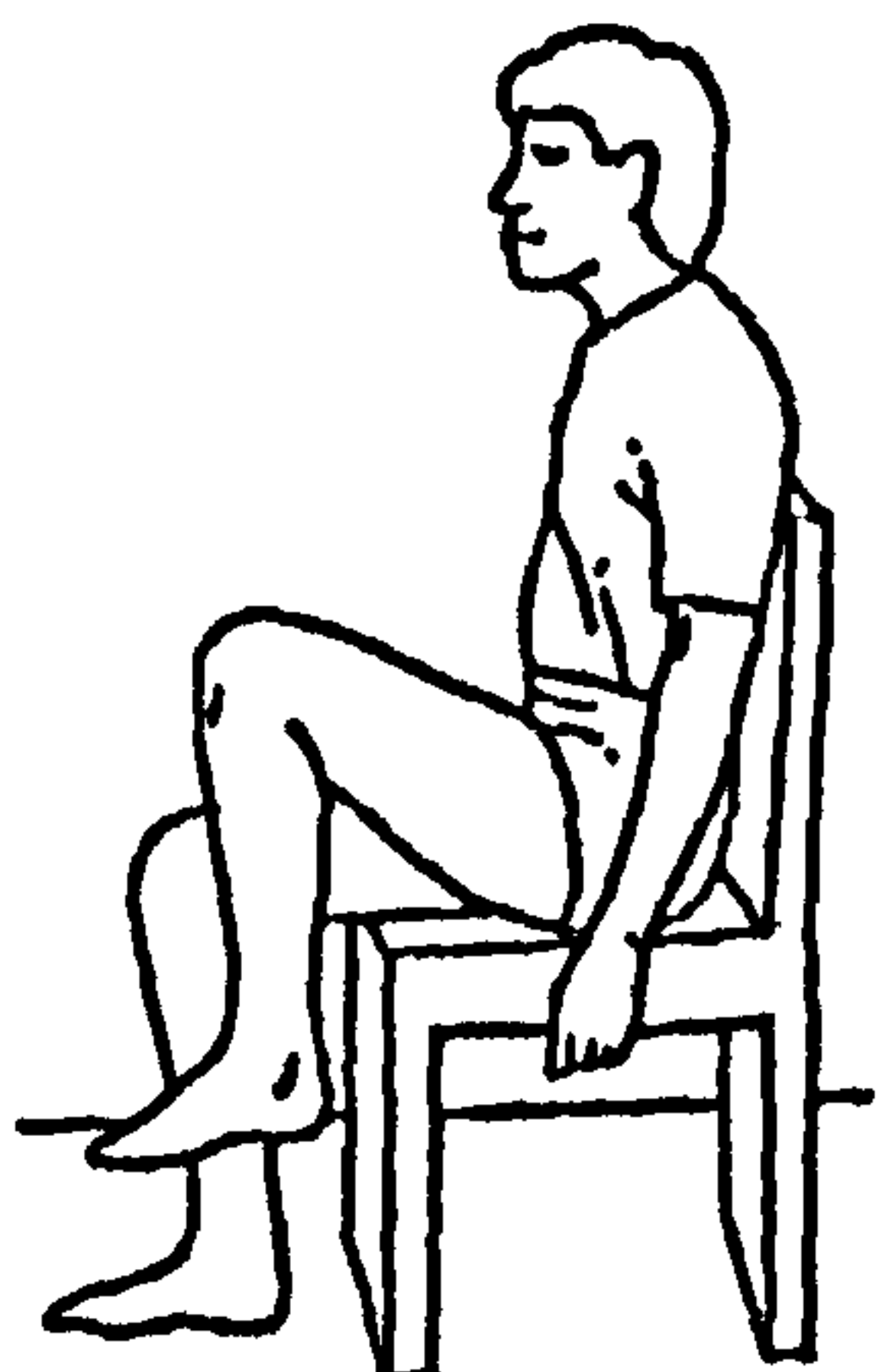
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Pull both knees together firmly, hold for a count of three and relax.

Repeat__ times.

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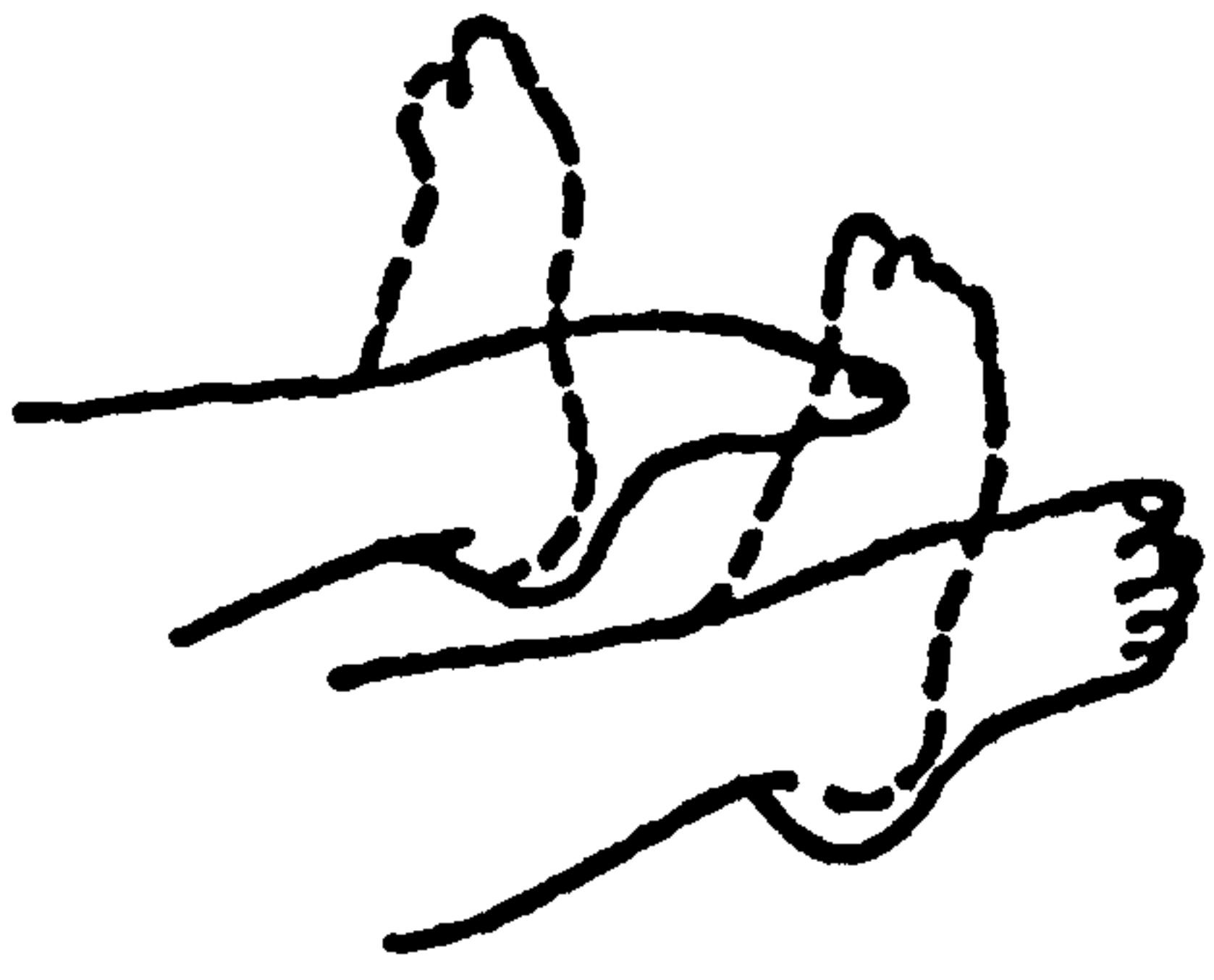
Lift up alternate knees about six inches, hold and relax.

Repeat__ times.

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Rock onto the heels and then onto the toes. Keep your hips and knees at about 90 degrees.



Repeat__ times.

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These exercises will help with your sitting balance mechanisms and assist with trunk movements which are necessary to enable you to move and walk freely.

Please do both the lying and sitting exercises until the next visit from the investigator. Try and spend about 20 minutes a day, five days a week on them.

You can increase the repetitions up to a maximum of ten as previously.

If you have any problems with the exercises, please report them to the investigator as soon as possible.



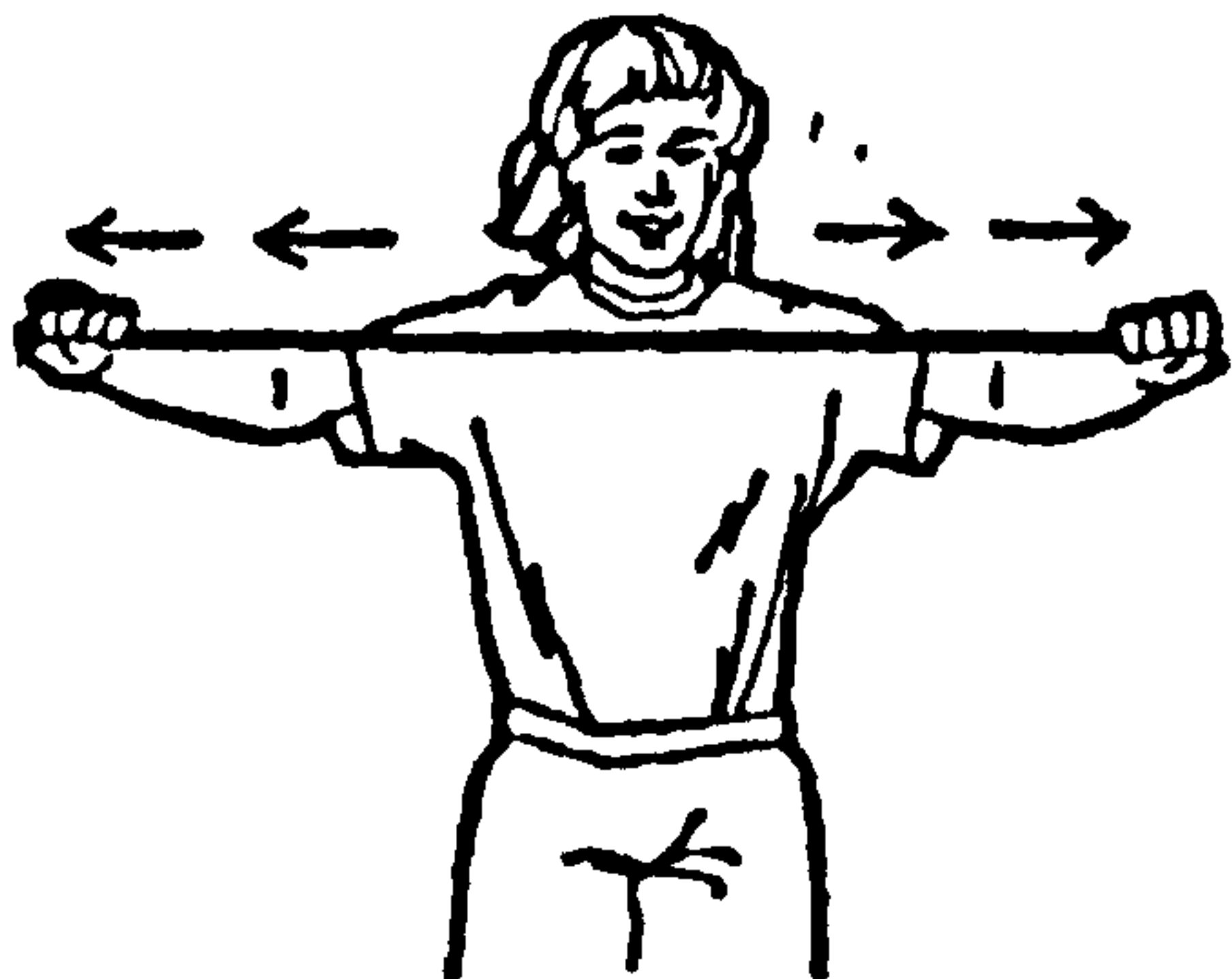
Tools RG
Know how to show how

MS Exercise Study. Theraband Strengthening.

Group One

Always do these exercises after you have done your stretches from one of the other exercise sheets, your muscles will then have warmed up and will be ready to perform strength work.

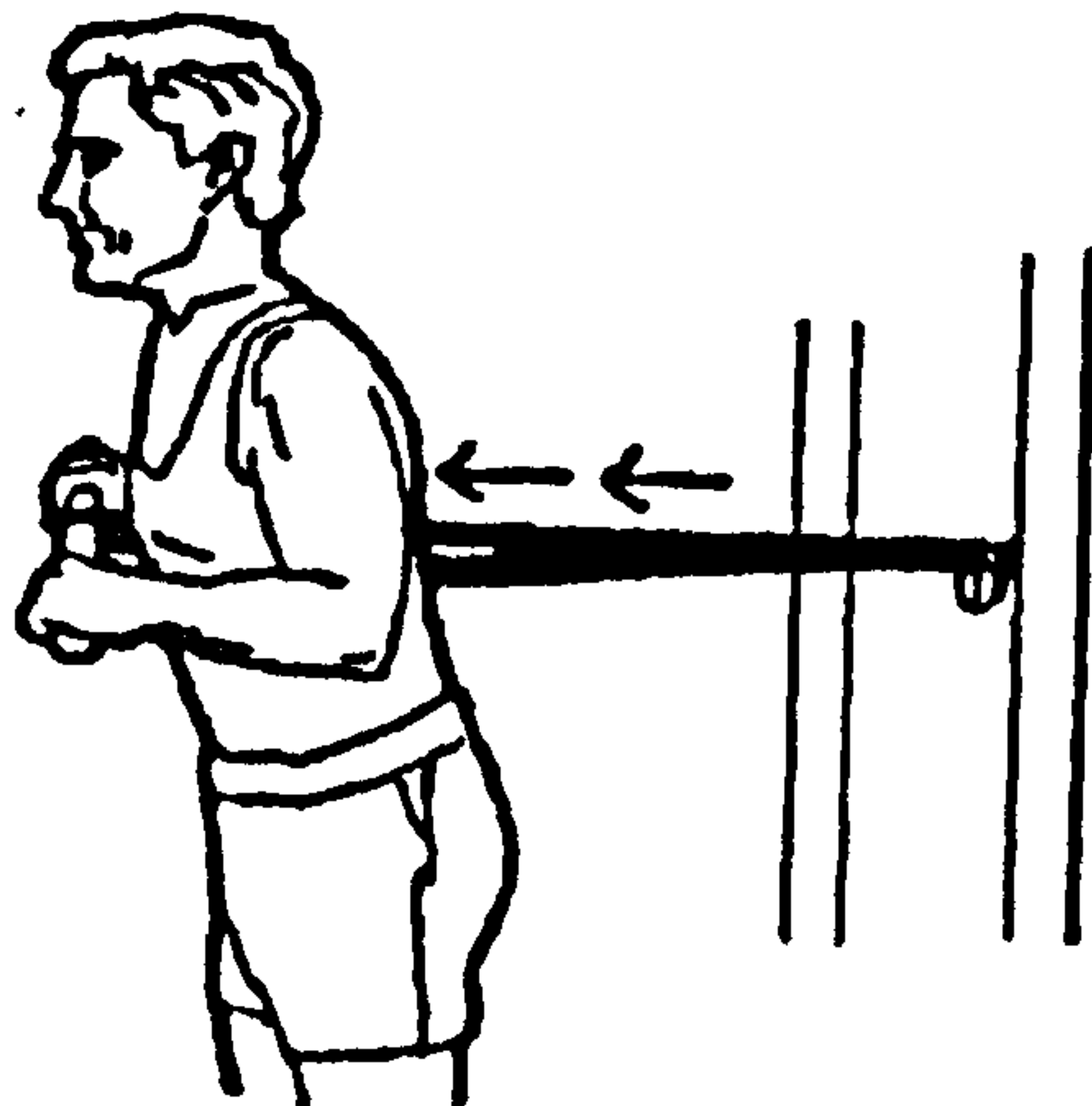
Sit on a supportive chair, preferably a dining chair.



Hold the band in each hand and keep your arms in front of you. Slowly pull your hands apart against the resistance of the band.
Hold for a count of three and relax.

Repeat__ times.

© The Hygenic Corporation

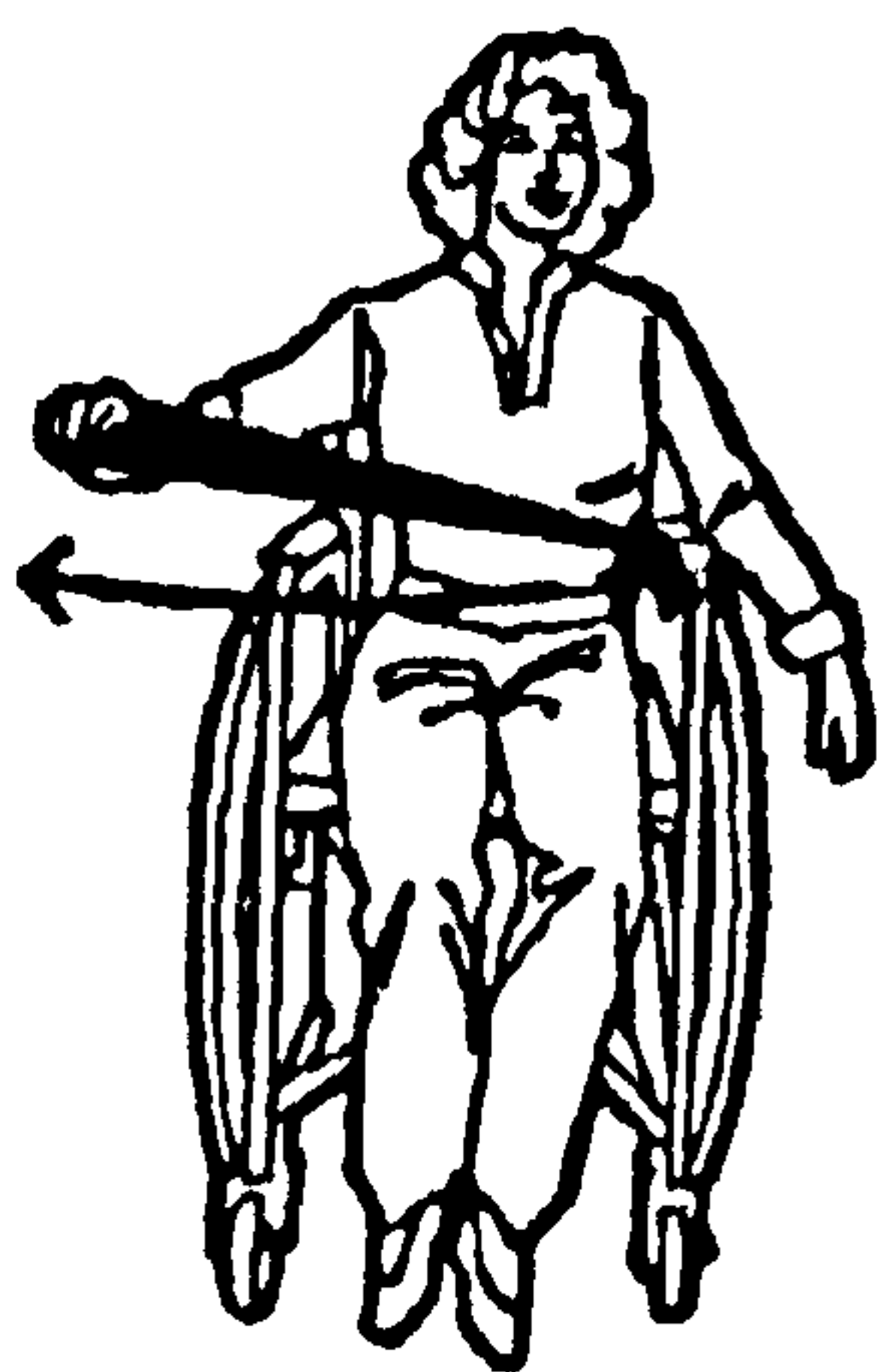


Hook the band around the back of the chair at one side. With your elbow tucked in, grasp the band with your hand. Straighten your arm by pulling forwards on the band then slowly relax.

Do not let the band pull you back. Control the release.

Repeat__ times on both sides.

© The Hygenic Corporation



Keep the band around the back of the chair. With your opposite hand, pull the band out to the side away from your body ie, right to left or left to right.

Slowly release.

Repeat__ times with each arm.

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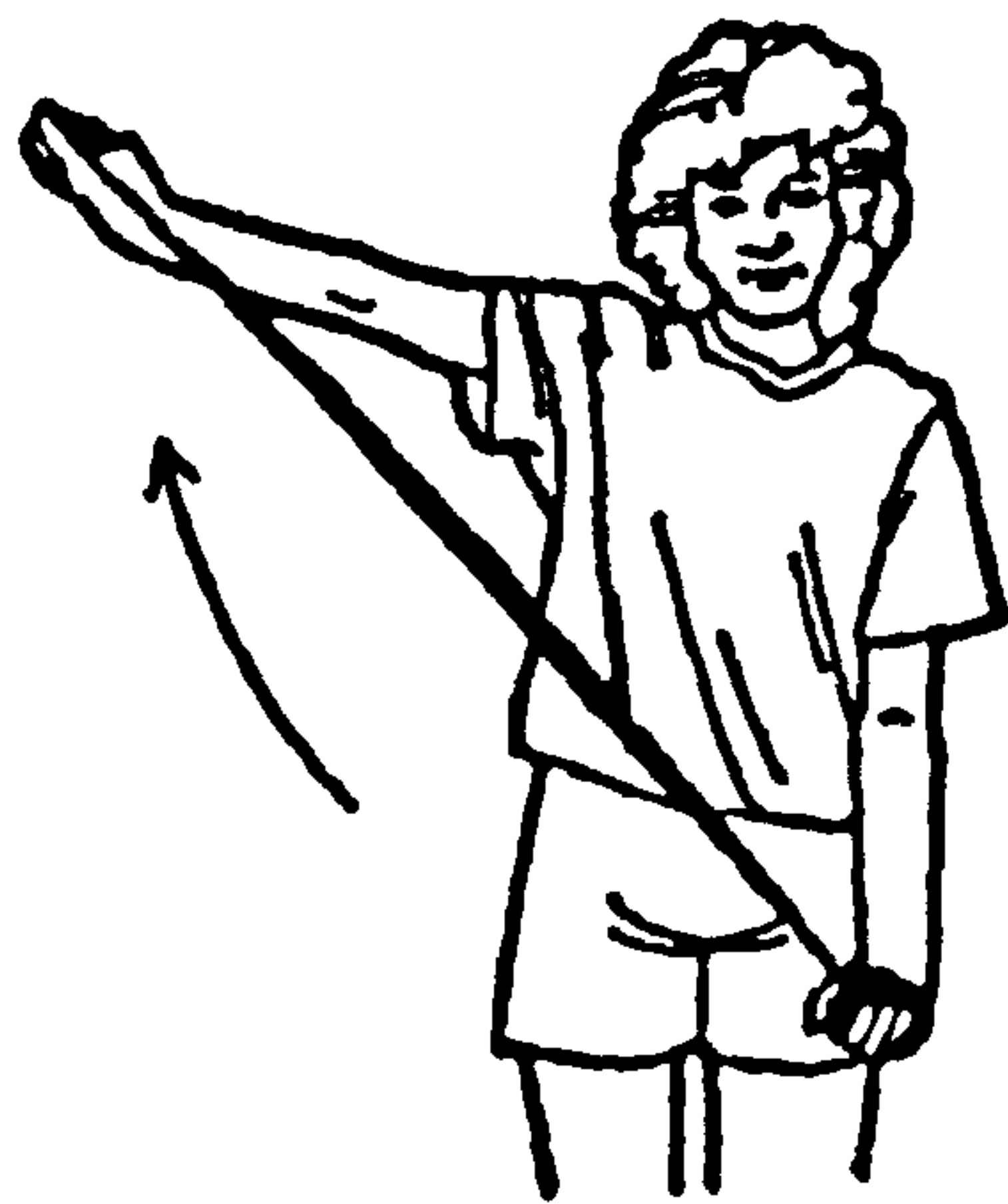
Loop the band under your foot, right foot if you are doing the right arm.
Hold the two ends of the band firmly with the palm of your hand facing upwards.
Pull up on the band and try to get your fist as close to your shoulder as you can.

Slowly release and relax.

Repeat__ times with each arm.

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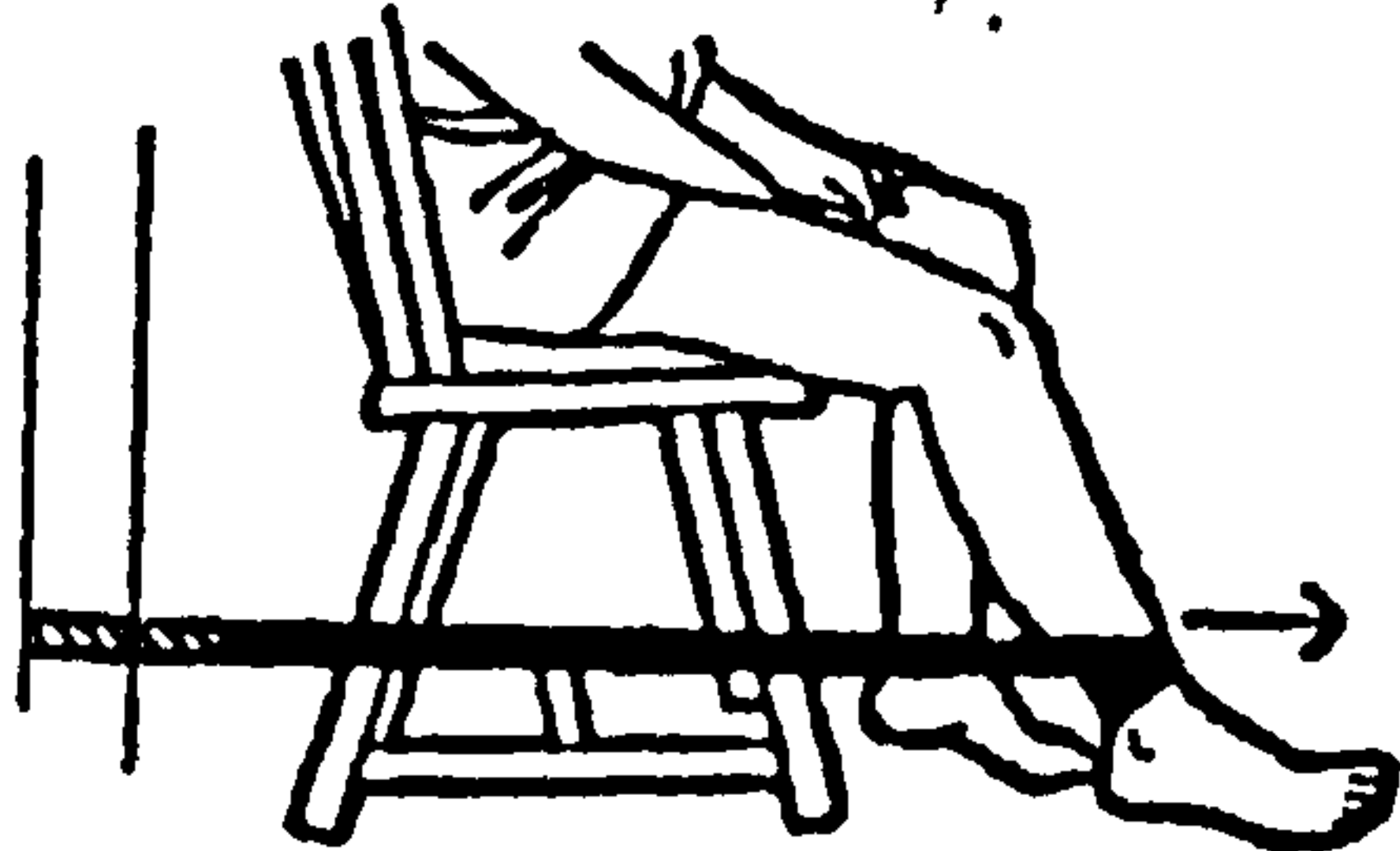


Keep the band under your foot or grip it in your hand as shown.

With the opposite hand, grip the band and slowly pull up and back so your elbow comes out to the side. Slowly release.

Repeat__ times with each arm.

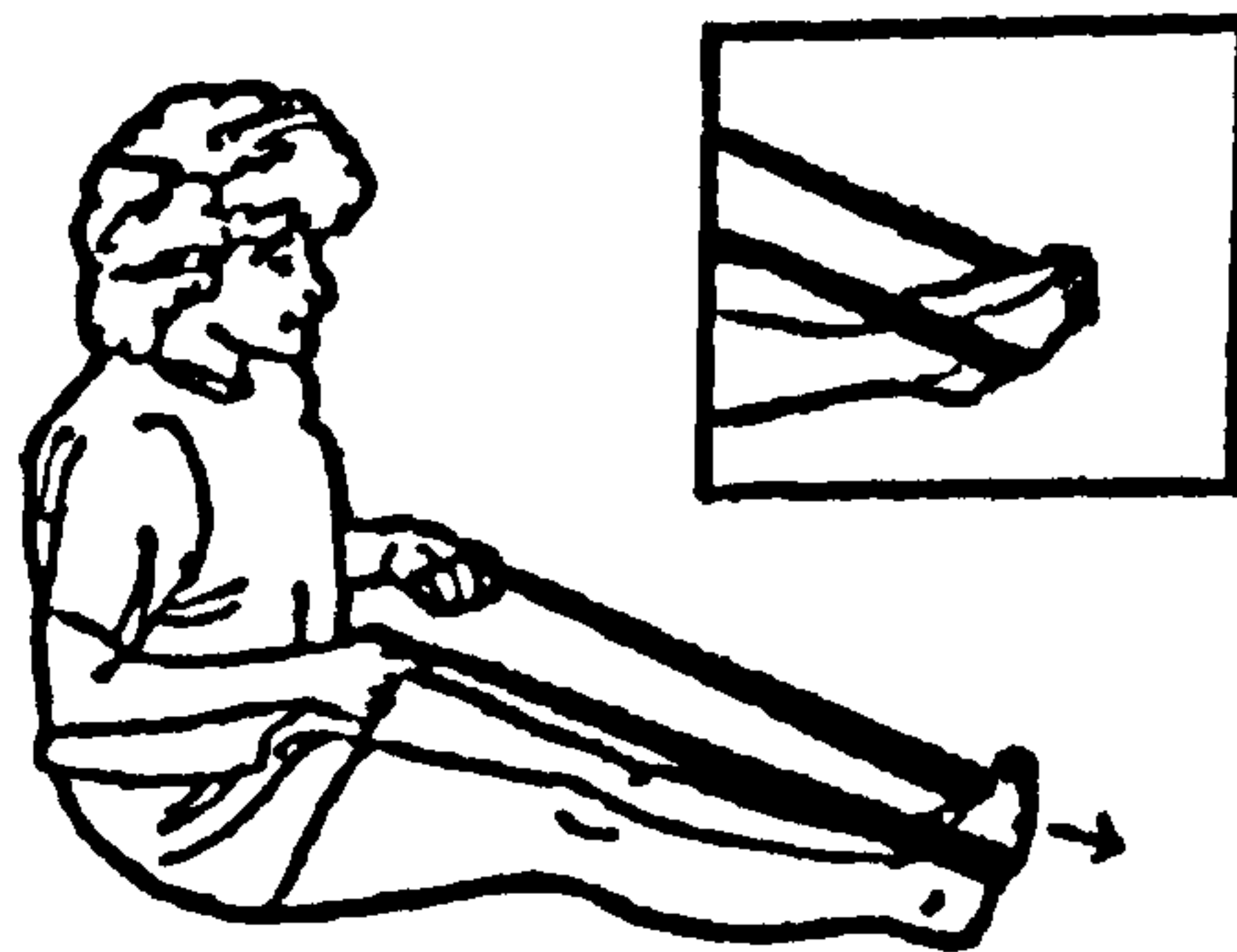
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Sit on a chair with the band secured behind you. Loop the band around your ankle and slowly straighten your knee against the resistance of the band. Relax.

Repeat__ times with each leg.

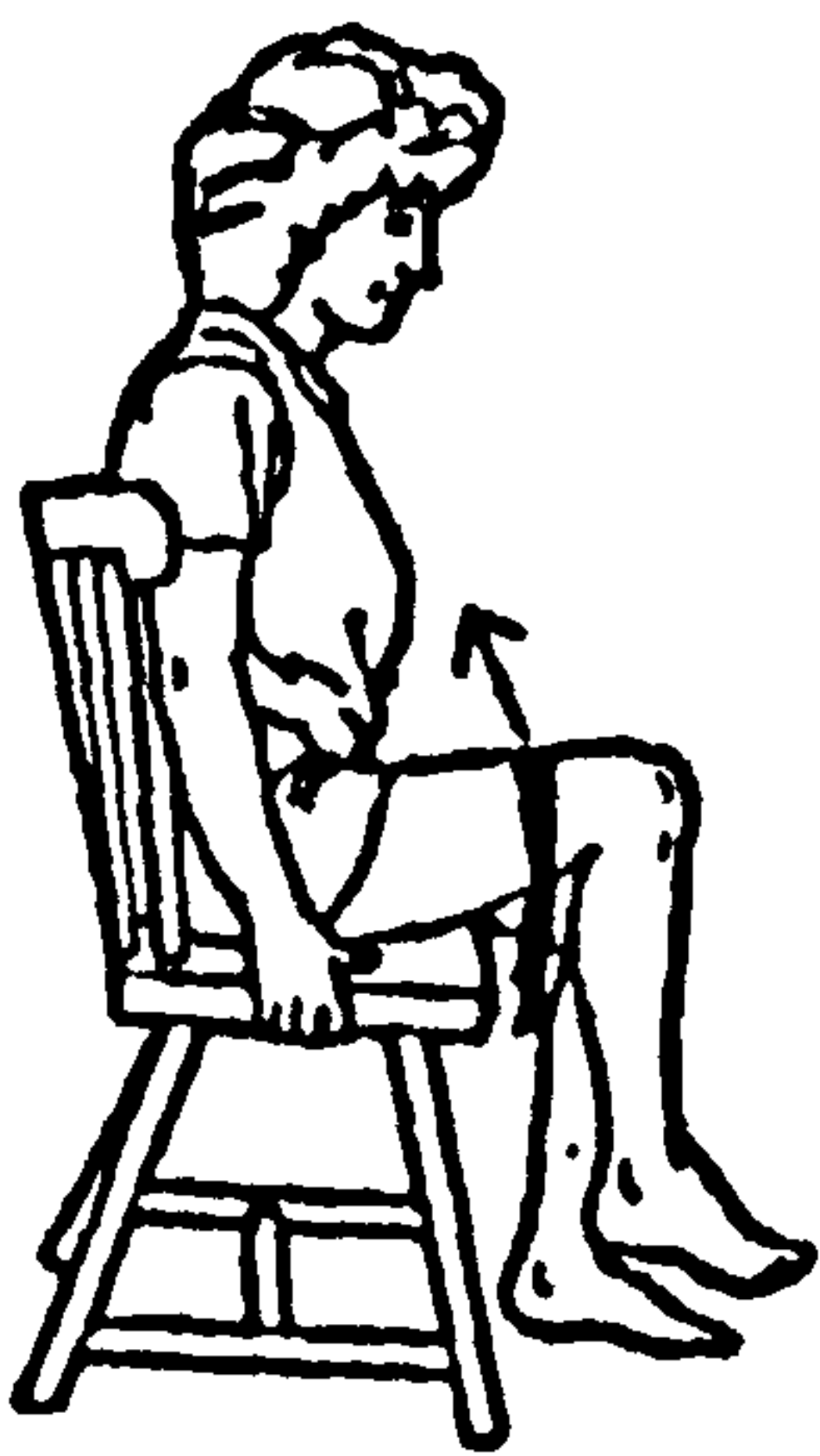
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Loop the band under your foot. Keeping it taut, push your foot down against the resistance and relax.

Repeat__ times with each foot.

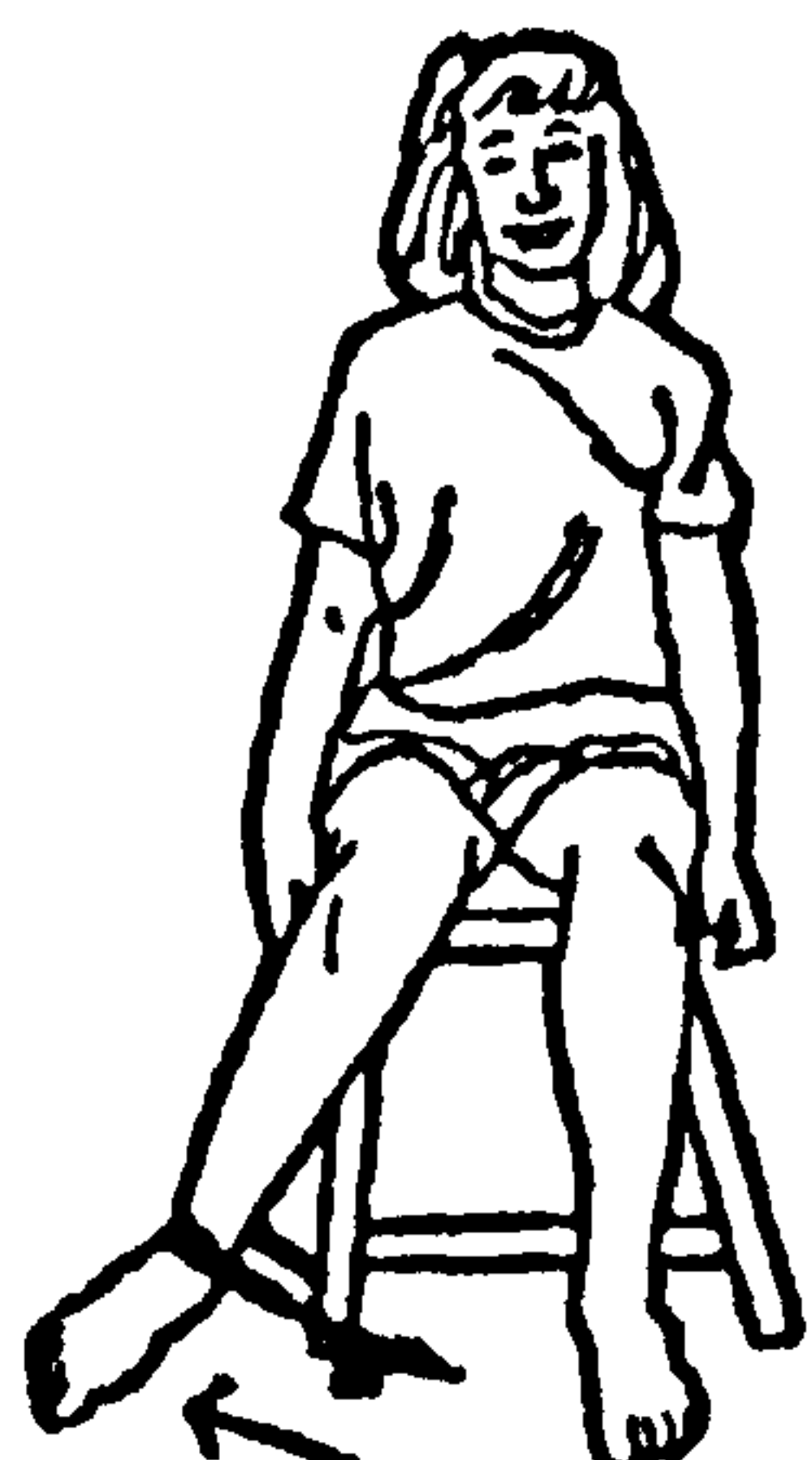
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Sit on a chair with the theraband under one foot. Loop the band and secure it around the opposite knee. Lift this knee up and pull against the resistance of the band.

Repeat__ times with each leg.

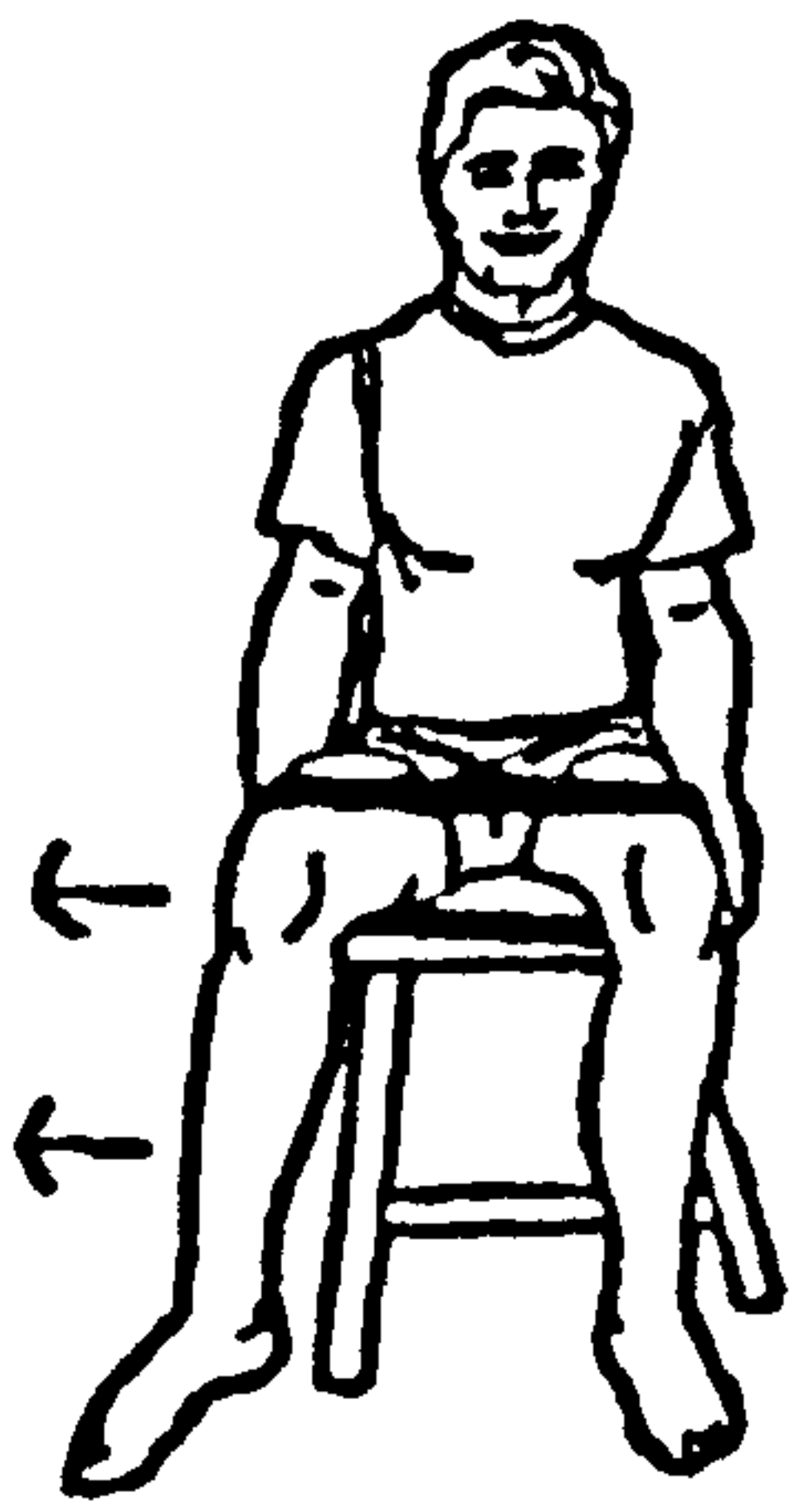
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Secure the band to a stable object in front of you. Loop the other end around your ankle. Pull back against the resistance.

Repeat__ times with each leg.

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Loop the band around your knees and slowly pull your knees apart against the resistance of the band. Relax.

.Repeat__ times.

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APPENDIX 12

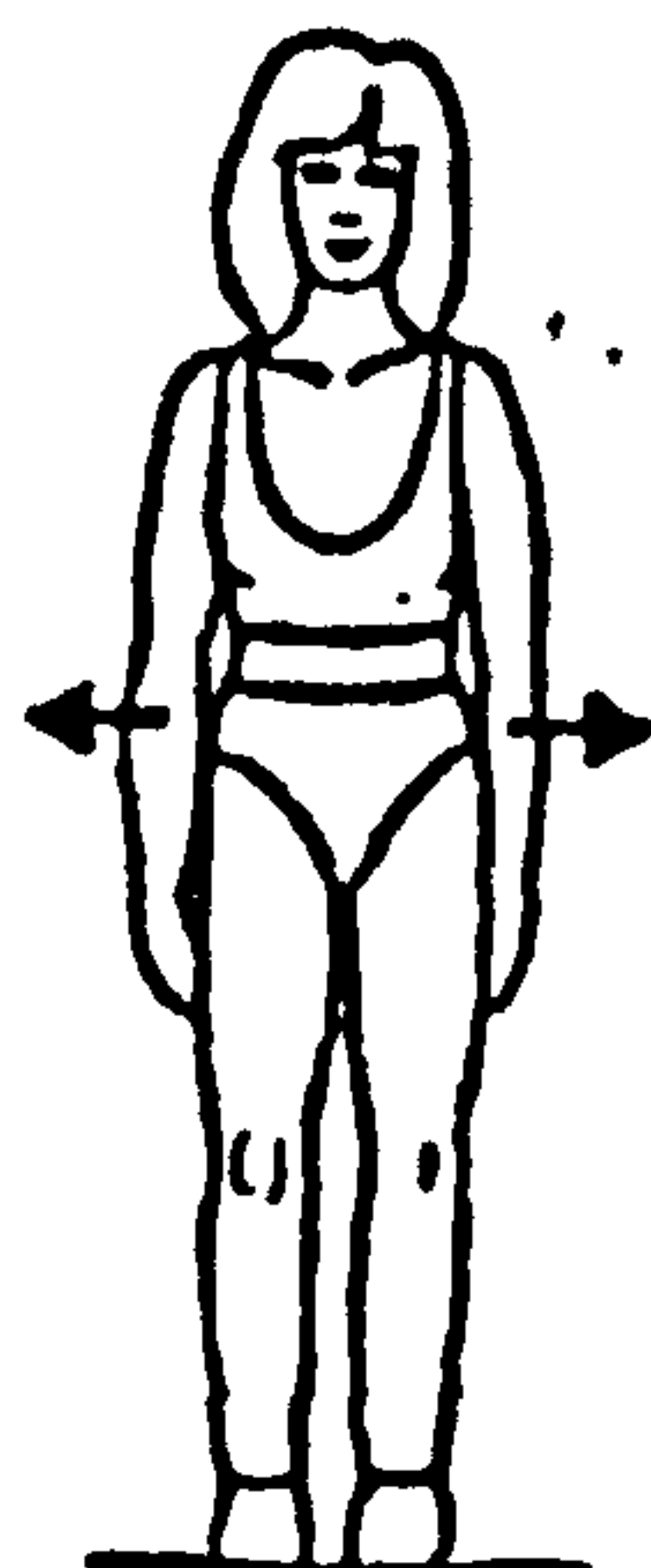


Tools RG
Know how to show how

MS Exercise Study. Standing Exercises.

Group One.

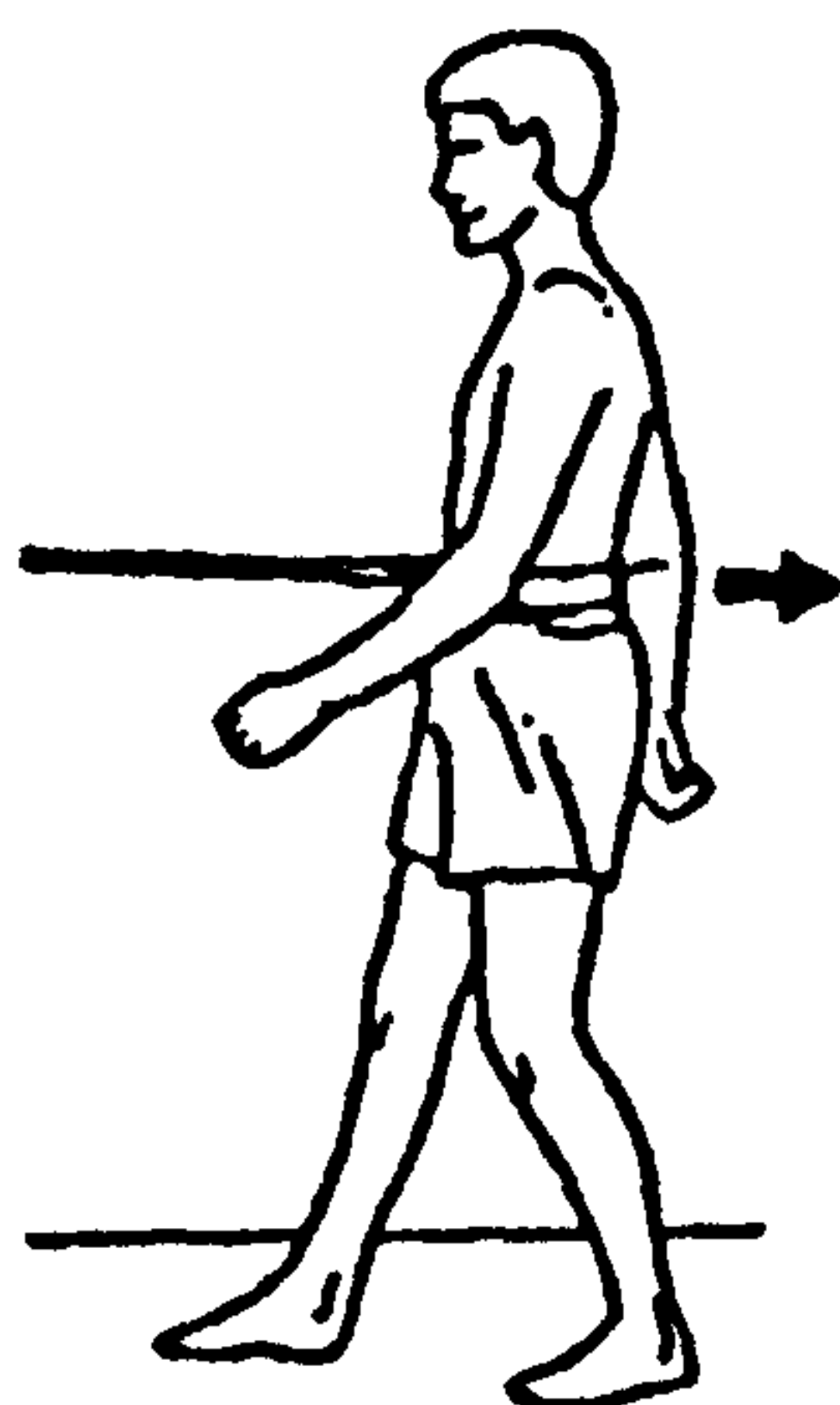
Stand in an area free of obstacles. You may use a kitchen work surface or something similar for support if you wish.



Stand with the feet slightly apart. Rock your weight from side to side transferring your weight from one foot to the other.

Repeat__ times.

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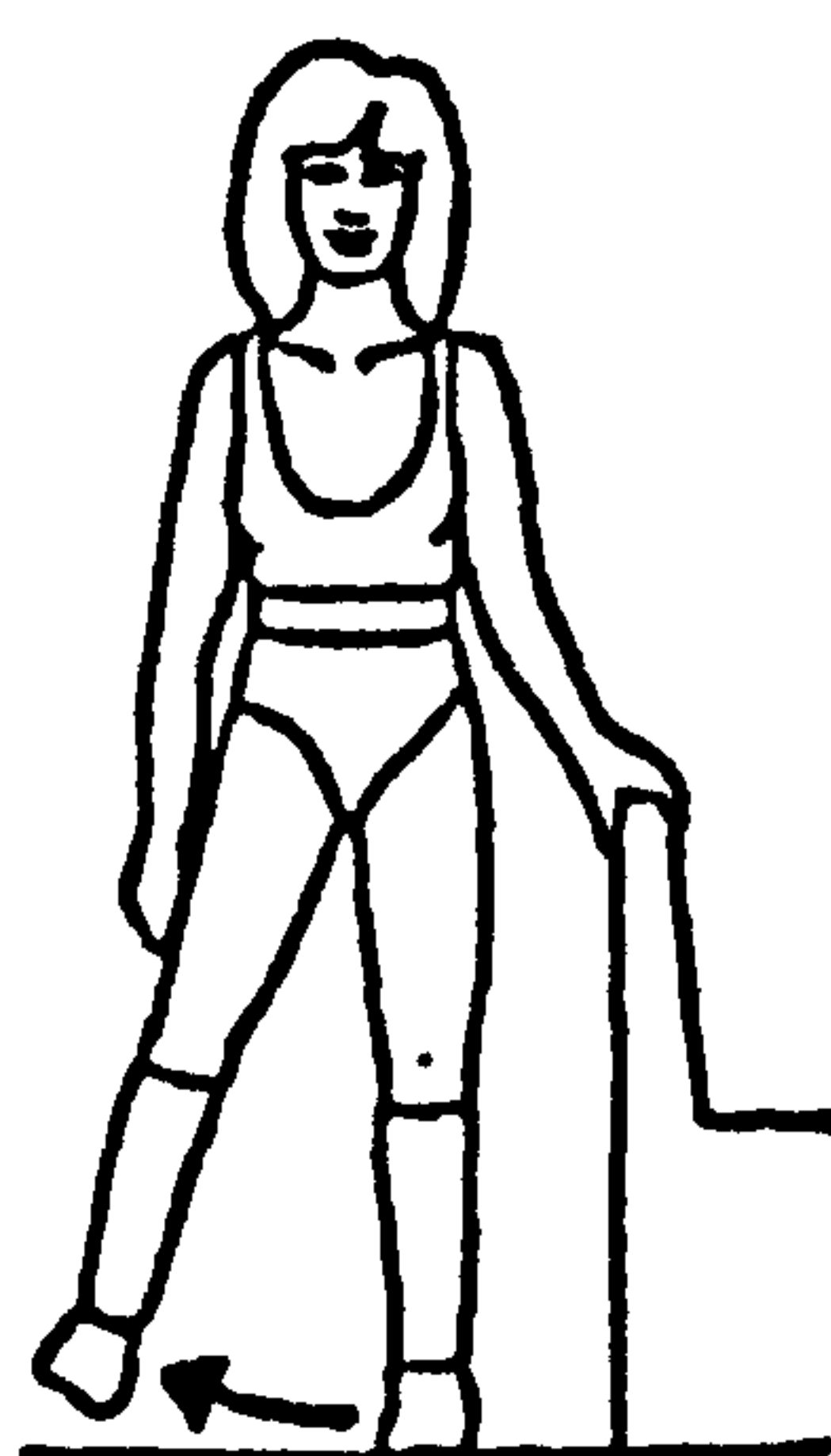


Place one foot slightly in front of the other. Rock your weight slowly from the front foot to the back foot.

Repeat__ times.

Place the other foot in front and repeat the exercise.

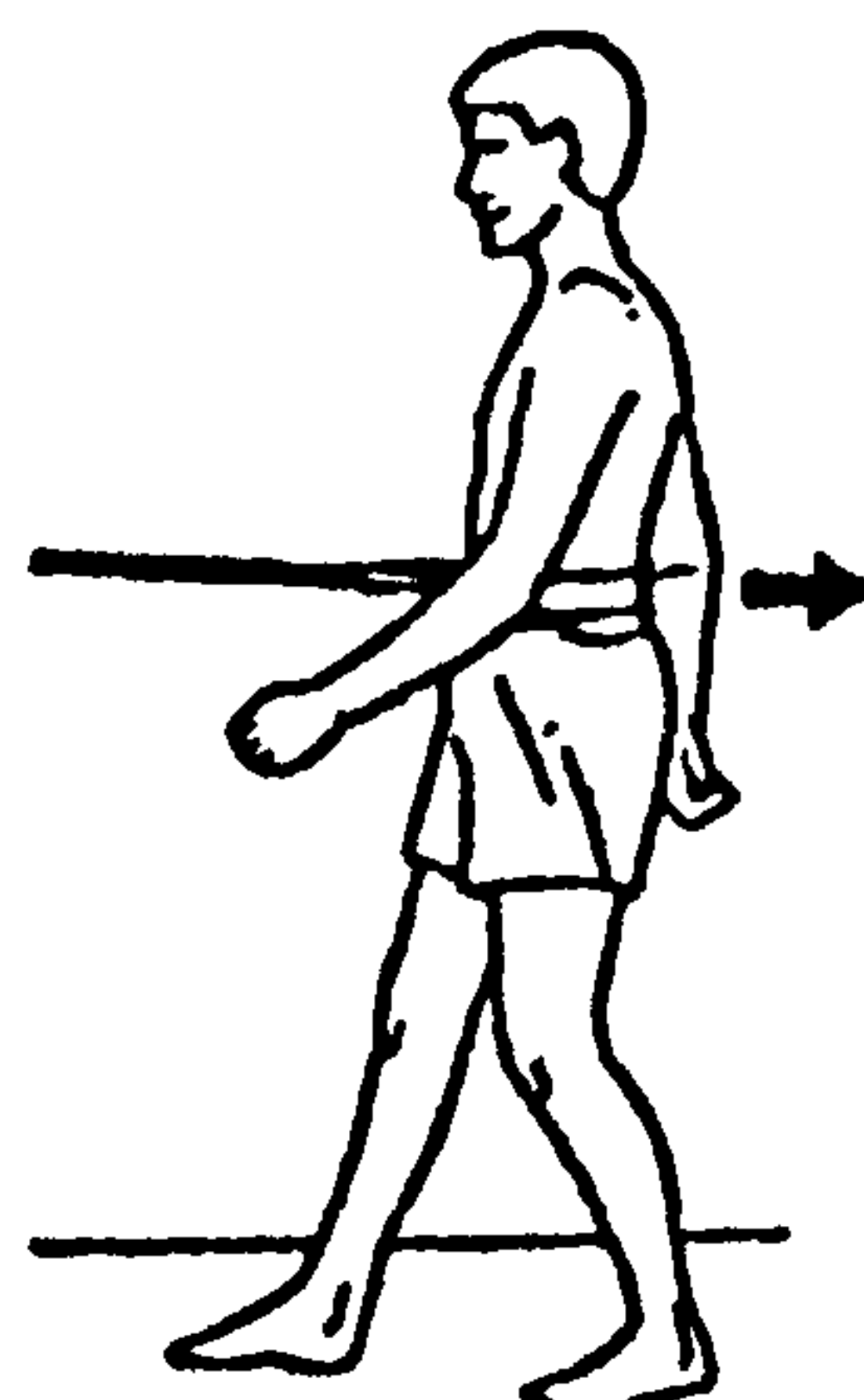
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With the feet slightly apart, step the right foot away from the left and return to the start position. Alternate sides.

Repeat__ times.

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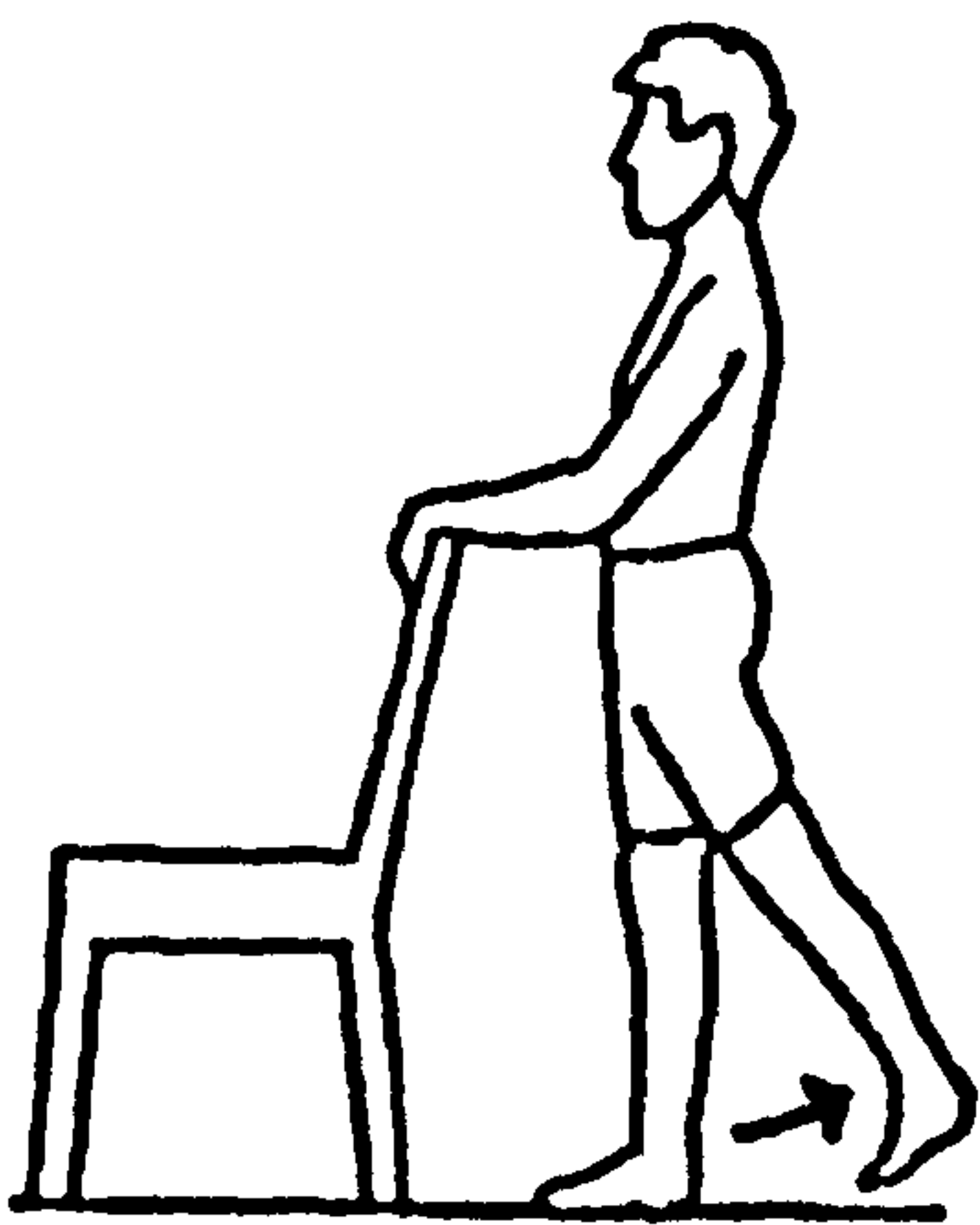


Stand with the feet slightly apart and take a small step forwards. Return to the start position. Do this alternately with each foot.

Repeat__ times.

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Stand with the feet slightly apart and take a small step backwards. Return to the start position. Do this alternately with each foot.

Repeat__ times.

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With the feet slightly apart and without holding on, alternately raise one arm above your head and return to the starting position.

Repeat__ times with each arm.

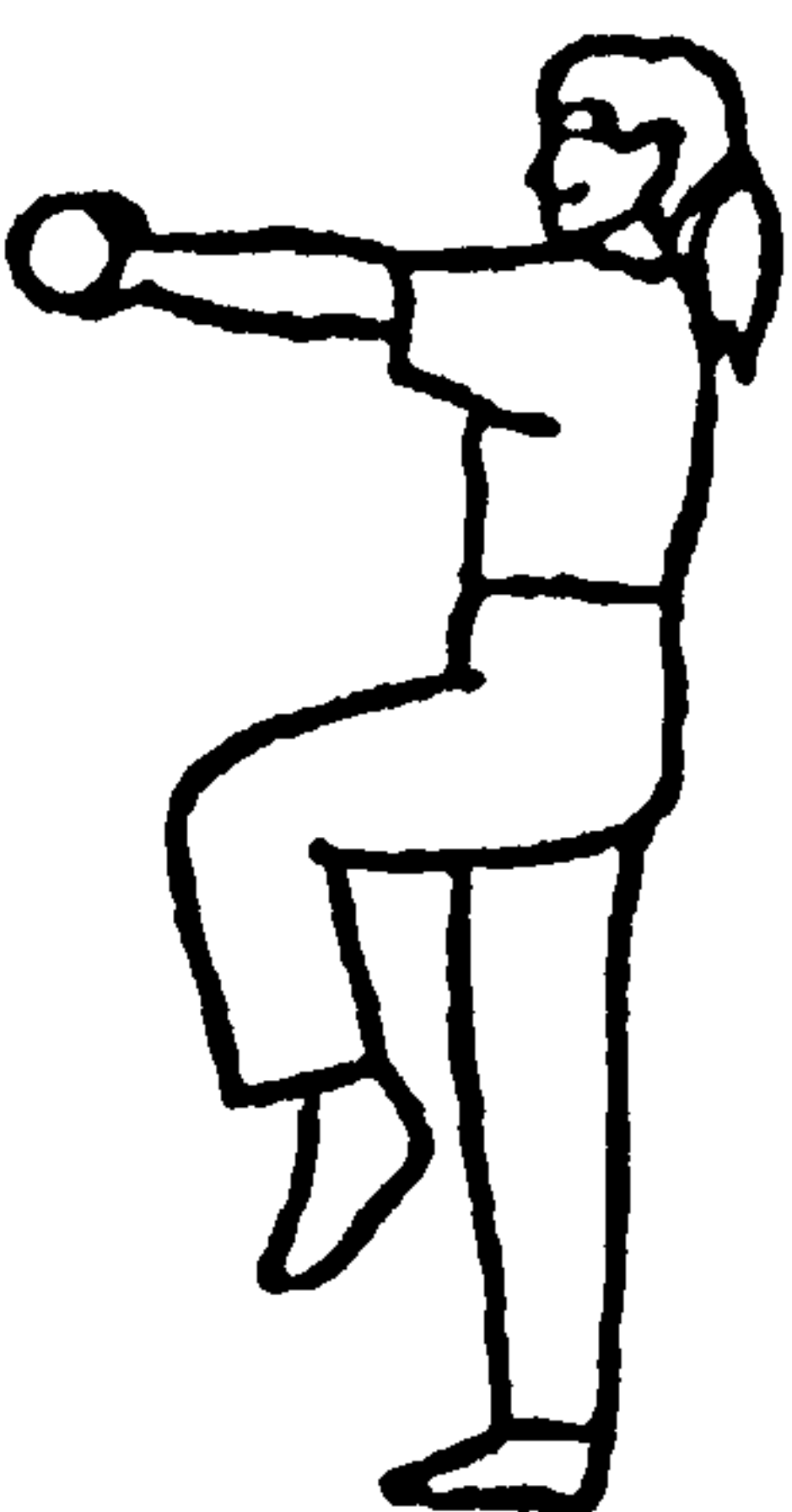
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With the feet slightly apart and without holding on, place your right hand on your opposite shoulder and with the left hand hold your right elbow. Now rotate round to the left at the waist and KEEP your Balance!

Repeat__ times in each direction.

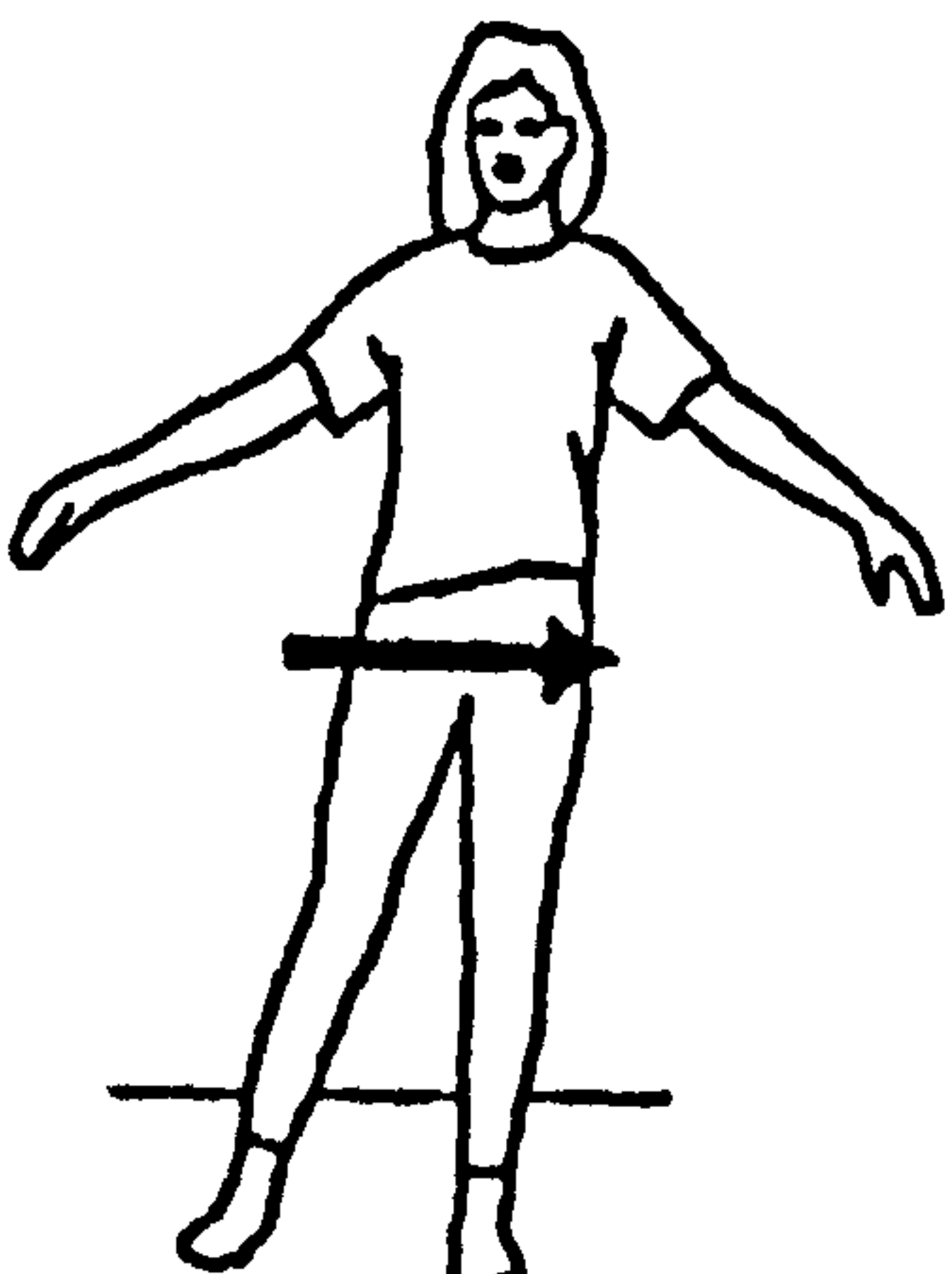
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Stand with the feet slightly apart and alternately lift up one knee. return to the starting position.

Repeat__ times.

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Stand with your legs apart and your feet parallel.

Transfer your weight to your right leg and slowly lift the left leg away from your body, maintaining your balance as you do so. Return to the start position. Repeat with alternate legs.

Repeat__ times.

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Now you have worked on your balance in standing, try and apply the movements you have been practicing to walking.

Start by walking slowly around the kitchen using the work surfaces for support if necessary. Use a heel toe pattern and remember to transfer your weight from side to side to allow free movement of the forward leg.

Try and remain relaxed in the trunk and arms.

Repeat as often as you can

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You may increase the repetitions to a maximum of ten per exercise as previously.

These exercises performed in standing will re-inforce the movement pattern required to initiate walking. Sometimes people with MS need a bit of “thinking” time before they move off. Often the simple rocking movements described here can prevent stumbling and produce a smoother gait pattern.

Please do all three sets of exercise for the next week. Then you may choose which ones you feel are the most beneficial or that you prefer.

Try and do some of the programme at least five times a week, more often if you can for a minimum of 20 minutes per session..

Continue with the programme for the next 16 weeks.