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Client/Patient Need at the Interface between Health and Social Services on Discharge from an Acute General Hospital.

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CHAPTER 4

Patients who were Referred to Social Workers

Chapter 4.

Patients who were referred to the Social Workers

Introduction - Reasons for Referral

1064 patients were referred to the social workers, 382 men and 682 women. They were selected by their referrers - usually the medical and paramedical staff, for three main reasons. First, because discharge from hospital might be delayed for social reasons after the doctor had pronounced a person fit to go home, or had stated that nothing more could be done medically. Pressure was then exerted on the nursing staff and social workers to get the person removed from hospital so that the next patient admission could be speedily effected, and statistical targets for economy of bed usage were satisfied. As Murray and Mitchell (1984) pointed out, 'Social problems are liable to appear much more urgent if the patient is blocking a hospital bed'. This is not a new phenomenon. (Medical Social work 1967).

The second reason for referral was to meet the requirement for patient safety on discharge from hospital. This became explicit after February 1989, when the Department of Health issued Circular HC(89)5, for action by Regional Health Authorities, District Health Authorities and Special Health

Authorities for London postgraduate Teaching Hospitals. This Circular, replacing HM(63)24 'emphasises the importance of ensuring that, before patients are discharged form hospital, proper arrangements are made for their return home and any continuing care which may be necessary'. By means of the circular, the Department of Health stated that 'existing discharge procedures in all wards and departments should be reviewed, and any necessary changes made, in consultation with all those responsible who may be involved with the return of patients to the community'. The Hospital Managers and social work staff possessed copies of the circular and regarded it as a policy document, although no formal discharge policy existed.

The third reason for referral stemmed from the hospital staff's own perception of their patients' deficits in kin/friend community support when an individual would be felt and seen to be 'at risk' on discharge.

Hospital staff attitudes

The social workers made personal observations about hospital staff attitudes which they discussed in supervision and in team meetings. They found in the course of their multidisciplinary working that nursing staff expressed a high degree of humanitarian concern for their patients - involving empathy and sympathy for the plight of elderly people, and some knowledge about community, kin and friendship structures of available care. However, there were patients, male and female, among those referred to the social workers, who had no carers. When the nursing staff were aware of this fact, in combination with a patients extreme old age, physical disability, chronic illness, frailty, mental impairment or pending death, it was considered to be an addition to the other 'risk' factors, and therefore added to the need for social work help. However, their perceptions were variable and dependent on pressures of admission/discharge numbers based on doctor's decisions, shortage of ward staff, and the particular experience and socially oriented understanding of patient needs by individual members of the nursing staff.

It was also quite apparent that the relationship between social worker and ward sister was a highly significant factor with regard to referral rates. If a social worker did not act promptly, take responsibility for ward/patient communication and make considerable efforts to consolidate and maintain the relationship, referral numbers would fall off and the social worker would be seen not only as ineffective but also unnecessary.

This also applied to the Discharge Scheme Co-ordinator. When she was able to form a working team relationship with staff on the wards, they said that they could not manage without the scheme. Where she was not able to become an everyday part of a ward or department, the consciousness of the availability of the scheme and awareness of patients who might need it, quickly faded. This was illustrated in one section of the hospital, when, eighteen months into the scheme, the staff nurses were surprised that it existed, and had not been informed about it by their line manager.

The social workers felt that the responsibility of always having to be pro-active was a considerable burden, and not fair. Occasionally they found themselves with referrals from the nursing staff, which, after an assessment, revealed that the patients had no problems at all. These had resulted from nursing staff's general anxiety that 'something' might be a problem socially for the patient, but the problem had not been discussed with the patient or their relatives. Information which should have been recorded on the nursing process and written on to the social work referrals was sometimes deficient concerning the referrals, and often the referrer was a young and relatively inexperienced nurse.

Occasionally, inaccurate information about a patient was passed on to the social worker, who then had the task of not only completing an assessment which was inappropriate but also had to go to the nursing staff to have their

information corrected. If these situations had not been handled with great tact by the social worker, inter-disciplinary friction would have arisen.
Any confrontation between nursing staff and social workers resulted in diffidence and non-referral of patients. Quite frequently the nursing staff referred patients to the social worker without telling the patients or relatives that they had done so. They either did not think it was necessary or were too busy to go back and communicate. This had always to be kept in mind as a possibility when the patient was visited by the social worker who then had to explain the reason for the visit and who had made the referral.
Sometimes an element of surprise and defensiveness had to be dealt with before the interview process could begin.

Doctors rarely referred patients to the social workers, but reviews of geriatricians' patients after ward rounds did include the social workers, and some referrals were collected as a result.
It was clear that doctors saw themselves as having ultimate authority regarding discharge. Their attitude towards the social workers' views of family problems was sometimes very condescending. The social workers encountered this attitude when discharge arrangements were difficult to organise with family carers, and this was revealed in their supervision notes on the occasions that pressure by doctors to

discharge a particular patient actually **created tension** between professional workers and families. It was not uncommon for a doctor to label family and other carers as 'difficult', 'rejecting', or 'neglectful', when family difficulties were seen to be the reason for a delayed discharge. This attitude immediately cut off the possibility of relevant dialogue between doctor and carers. The authoritarian and paternalistic attitudes of some doctors affected nursing staff's views and reduced patients rights to decide about their needs for future care. (Coppeard M.-in Badawi and Biamonti, 1990).

The Social Work Referrals

The referrals were made by nursing staff after patients had been admitted to the hospital wards. Social Work administrative staff collected them daily, and social workers usually expected to see the patients within 24 hours. However, some patients were either sent home, transferred to another hospital, or died suddenly before the social worker could get to them. The nursing or medical staff rarely informed the social workers that this had occurred and s/he usually found out in the course of visiting the ward. The patients who had moved, therefore, were not seen but any concerns were relayed to the hospital where they had been transferred, and to area social work offices if they had gone home.

Social work support was provided to some patients who were dying. If they died very quickly it was sometimes not possible to obtain information about them or their carers, and these cases were simply closed.

4:1. Breakdown of Social Work referrals by patient age, sex, marital status and whether they lived alone

Table 27 - Patient referrals to the social workers by sex and age.

1064=100% Men 382=36% Women 682=64%

Age	-65		65-69		70-74		75-79		80-84		85-89		90+	
	No	%	No	%	No	%	No	%	No	%	No	%	No	%
Men	95	25	43	11	62	16	77	20	71	19	27	7	7	2
Women	106	16	69	10	81	12	143	21	133	20	113	17	37	5
All	201	19	112	11	143	13	220	21	204	19	140	13	44	4

Women outnumbered men by almost 2:1, and their numbers increased steadily in the higher age groups.

Table 28 - Patients referred to the social workers who lived alone and their age

Age	-65		65-69		70-74		75-79		80-84		85-89		90+	
	No	%	No	%	No	%	No	%	No	%	No	%	No	%
Men	25	19	9	7	20	15	29	22	37	28	9	7	3	2
Women	17	5	23	7	46	14	78	23	80	24	68	20	24	7
All	42	9	32	7	66	14	107	23	117	25	77	16	27	6

All patients = 1064= 100% Living alone - 468=44% Men 132=12% Women 336=32%

382 men were referred to the social workers, and 132 of these (35%) lived alone. 682 women were referred, and 336 (49%) lived alone.

Forty four per cent of the referred patients lived alone and women outnumbered men by almost 3:1. More younger men were referred aged under 65 years, than younger women, and more women were referred who were over the age of 85 years.

Table 29 - Patients who were married, by sex and age.

Age	-65		65-69		70-74		75-79		80-84		85-89		90+	
	No	%	No	%	No	%	No	%	No	%	No	%	No	%
Men	36	19	30	16	35	19	45	23	27	15	12	6	3	2
Women	58	30	39	20	24	12	39	20	24	12	8	4	1	1
All	94	25	69	18	59	16	81	21	51	13	20	5	4	1

1064=100% Men 185=17% Women 193=18% Married 379=36%

Almost half of the referred men were married, compared to just over a quarter of the women. Women under the age of 70 were more likely to be married than the younger men.

Table 30 - Patients who were single, by age and sex

Age	-65		65-69		70-74		75-79		80-84		85-89		90+	
	No	%	No	%	No	%	No	%	No	%	No	%	No	%
Men	43	73	2	3	5	8	2	3	7	12	-	-	-	-
Women	25	45	2	4	6	11	9	16	5	9	7	13	1	2
All	68	60	4	4	11	9	11	9	12	11	7	6	1	1

1064=100% Single 114=11% Men 59=6% Women 55=5%

Only 11% of patients were single, and men outnumbered women by almost 2:1, especially if they were aged under 65 years.

Table 31 - Patients who were widowed, by age and sex.

Age	-65		65-69		70-74		75-79		80-84		85-89		90+	
	No	%	No	%	No	%	No	%	No	%	No	%	No	%
Men	8	6	10	8	22	17	33	26	37	29	15	12	4	3
Women	10	2	23	6	50	12	93	23	103	25	109	26	24	6
All	18	3	33	6	72	13	126	23	140	26	124	23	28	5

1064=100%   Widowed 541=51%

Men 129=12%   Women 412=39%

The proportion of widowed women was almost double that of widowed men. The table shows that widowed men under the age of 85 years and women over the age of 85 years were more likely to be referred.

Men and women who were divorced

8 men under 65 years
1 man 65-69 years
Total 9 (2% of all men)

13 women under 65 years
5 women 65-69 years
2 women 75-79 years
1 woman 80-84 years
Total 21 (3% of all women)

Total divorced patients = 30 (3% of all patients referred)

<u>Analysis of the tables.</u>

The tables showing the sex, age and marital status of the patients who were referred to the social workers reveal some interesting characteristics of this group as a whole, and some significant differences between men and women.

Firstly, 81% of all patients were aged over 65, and 70% of these (863) were aged over 75 years. It was estimated by the managers of Mansfield General Hospital at the time of this research that roughly 65-70% of all patients admitted were over 65 years of age, even though the hospital only catered for patients with acute illnesses. The hospital beds were therefore the most costly per patient in the whole hospital group. The current cost in 1989 was a minimum of £150 per day.

Badawi and Biamonti (1990) commented that the elderly are probably the largest group of people who would be referred to hospital social workers. 'In one district general hospital 70% of referrals for one year were for people over pensionable age and most of these were for people over 80!' It is logical to suppose that as more elderly people are cared for in the community rather than in geriatric hospitals, and as their numbers increase in proportion to the rest of the general population, that they will need to be treated for their illnesses and traumas, at least in the first instance, through the acute NHS services based in general hospitals. These are becoming the main access route to young disabled units, geriatric hospitals whatever their title, orthopaedic rehabilitation services for the elderly and sometimes for psychiatric care also. There is no doubt that the acute NHS services have become an antecedent to residential care, in the form of Part 111 homes, private residential and nursing homes, and to community services provided by the formal and voluntary sectors.

Previous studies in America have showed that very old patients tend to be sicker when admitted to hospital, stay longer as in patients, and receive more medical procedures than their younger counterparts (Garnick D., Short T. 1985).

The largest number of patients referred were women (64%). Overall, they were much older than their male counterparts, 426 were aged over 75 years compared with 182 men. The over 75's represented 70% of the whole group, and this reflects almost exactly their proportion of the over 75's in the general population. 'Among people aged 60 or more, women outnumber men by almost 50%, and among the very elderly (those aged over 75) women are 70% of the total.' (Bornatt, Phillipson and Ward 1985). The earlier deaths of men due to circulatory and respiratory illness, among others, and industrial disease is evident statistically at the age of 75, and strikingly so after the age of 85. By the time the 90+ age range is reached, there are over five times as many women as men.

Another significant difference is between the men and women who lived alone. This is clearly shown in Table 28. After the age of 65 years, 319 (75%) women compared to 107 (25%) men were living alone. These proportions are virtually mirrored by the proportions of men and women in the general population who were widowed where men account for 22%, and women for 78%. Bornat et al. also comment on this situation as follows 'Among women, even among the relatively young (60-64), only two thirds are married, among the 3.2 million aged 70 or more as many as three out of four used to be married but are no longer. Four fifths of these are widowed, the rest separated or divorced. Women are therefore surviving their partners and having to live alone, with the accompanying problems of isolation and loneliness'.

The number of one person households has increased in Great Britain from 12% in 1961, to 26% in 1988 (Social Trends 1990). Goldring (1990) points out that living alone is a major problem to be faced in the future, not only in terms of sufficient and adequate housing provision, but also, since man is a social being needing the support of family and friends, we can expect an increase in social and mental problems from this fact alone - in particular among elderly people, and especially older women.

A further difference between men and women shows in Table 30 There were more single men than women, and the majority of both sexes were under 65 years. After 65, there were 30 single women fairly evenly distributed up to the age of 89 years (one aged 90+). There were only 16 men aged between 65 and 84 years, but even so, there were proportionally more men in the age ranges overall given the total numbers of men and women referred to the social workers.

The low number of single women appears to reflect the shifts in marital status during this century. In 1901 approximately 14% of women between 45 and 60 were unmarried, but by 1971 only 8% were unmarried. (Moroney 1976). The single women in this research amounted to 5% of patients referred to social workers.

4.2. Illness Categories among patients referred to the Social workers

The Mansfield General Hospital accepted patients suffering from the whole range of acute medical and surgical conditions. Those who were referred to the social workers were mostly elderly and very elderly, and the spread of their illness categories reflected this fact.

Three categories predominated. The largest was orthopaedic, with 277 women and 170 men suffering from these conditions. More women were admitted with fractured femurs, following a fall at home. They also suffered more with arthritis and osteoporosis which made fractures more likely.

The second largest category was cardio-vascular disease, and this involved more men (29%) than women (23%). Thirdly, 11% of the patients had illness of the digestive tract, and again there were proportionally more men (14%) than women (10%).

More men than women suffered from respiratory problems, and almost equal proportions had cancer, neurological and psychiatric conditions.

Slightly more men than women were admitted for treatment of endocrine and urological illness. Table 32 illustrates the illness categories of these patients.

Table 32

Table to show Primary Illness affecting men and women

Illness Category	**Nos. of men**	**%**	**Nos. of women**	**%**	**Total patients**	**%**
Orthopaedic	70	18	277	41	**347**	**33**
Digestive Tract	53	14	67	10	**120**	**11**
Cardio-vascular	109	29	156	23	**265**	**25**
Respiratory	39	10	27	4	**66**	**6**
Cancer	30	8	47	7	**77**	**7**
Endocrine	9	2	6	<1	**15**	**1**
Urology	11	3	6	<1	**17**	**2**
Psychiatric	15	4	19	3	**34**	**3**
Neurology	11	3	17	3	**28**	**3**
Other	32	8	49	7	**81**	**8**
Totals	**379**	**100**	**671**	**100**	**1050**	**100**

Referrals to Social Workers - total patients - 1050 = 100%

Table 32 provides information about factors linking health and social care needs. The main consequence of orthopaedic disease or trauma, especially among elderly people is functional disability, particularly mobility. A third of the referred patients suffered from an orthopaedic condition as a primary illness. In a separate study (Bayliss Ward report, 1990 - unpublished) a social work follow-up visit one month post discharge after acute hospital admission, showed that there was an increase by 426% of patients who were housebound after treatment for and rehabilitation following fractured femurs.
Orthopaedic conditions are not fatal, but the high incidence of infection and vascular illness following operations for fractured femur puts these orthopaedic patients at serious risk of death. The change in lifestyle for these elderly people, their loss of independence and needs for personal and domestic care are greatly increased. The most disabled are likely to experience episodes of acute health need, along with those who suffer traumas, and will be admitted to an acute hospital. Hospital social workers therefore will meet those with the most serious disabling conditions, who become concentrated in the acute hospital setting.

The second most prevalent condition among patients referred to the social workers was cardio-vascular illness. In this study, this category included iscaemic heart disease, strokes, peripheral vascular diseases and any other diseases of the circulatory system. Collectively, these conditions were the main causes of death among males and females aged between 60-84 years, in England in 1984. (Alderson and Ashwood, 1985)

Following this comparison, lung cancer and chronic obstructive pulmonary disease (chronic bronchitis) was the second most frequent cause of death among older patients, and the third most frequent illness category referrals to the social workers.

The third cause of death in females and fourth in males was malignancy of the digestive tract. Illness of the digestive tract was the fourth most prevalent condition that the social workers encountered.

Other medical conditions were not so specific, and data were difficult to compare accurately. However, the OPC Survey 1985 Table 111 shows clearly that the conditions/illnesses discussed follow a trend by frequency of death, discharge from hospital and GP consultancy, that relates to frequency of referral to the hospital social workers.

In section 3 - Discharges and Deaths, in this study, it is shown that 6% of the referred patients died. A further 12% were transferred to the local geriatric hospital where some died very soon, within one or two weeks. The nursing staff did not refer them as dying patients, even though the social workers observed this for themselves.

Contact with nursing staff involved comments such as 'This patient is only here for TLC (tender loving care)', 'this patient isn't going anywhere', or 'this patient isn't going to make it'. The referrals were made because all of the dying patients were actually, or potentially, blocking acute hospital beds. There was an active taboo regarding the reality of approaching death (Dickenson and Johnson, 1993), which made appropriate referral to and viable intervention by the social workers very difficult indeed. They were anxious and concerned about the treatment of dying patients. They felt that overall the hospital staff's objective was to remove dying people from the acute wards as fast as possible, by whatever route. They observed very sick patients being discharged to relatives' care who were readmitted quickly once, or perhaps twice, and then died. They also observed that a number of very sick people, whom they considered were terminally ill, were directed by consultants to nursing home care. The social workers were not supposed to be involved with the private sector admissions, but they found themselves supporting relatives who were very worried about their patients' fitness to be moved. A number of patients died before they could be discharged to nursing home places.

In the case of patients who had no family, the social workers did act as advocate and supported them as they would for Part 111 admissions. In each situation the senior social worker agreed to take full responsibility for what was in fact the execution of a moral duty to ensure the safety and proper care of elderly frail people, in order to protect against possible criticism of the social workers' actions.

4.3. Discharges and Deaths.

Discharge arrangements for the Patients who were referred to the Social Workers.

After patients had been treated on the acute wards at Mansfield General Hospital, the aim of all professionals was that they should return to their own homes in the community, to resume independent living. Many patients had been needing formal routine services such as home help and meals on wheels before admission, and services were resumed or increased to support the patients' needs on discharge. Even so, a number of patients did not go back to their own homes because they were too frail or ill. Some needed very much more care than routine services could provide. If there had been convalescent facilities, no doubt they would have used them. As there were none, some of these patients went to stay with informal carers instead.

A further group of patients also needed continuing medical care in other acute hospitals, or longer term rehabilitation in the geriatric hospital and were transferred in due course.

Some men and women died on the acute wards before discharge.

Table 33 shows where the patients went on discharge, and how many patients died.

Table 33- Destination of Discharged Patients

1064 pts = 100%

	Men	Women	Total	%
1. Deaths	33	35	68	6
2. Transferred to another hospital				
Geriatric hospital	37	93		
Acute specialist hospital	4	12		
Orthopaedic hospital	1	1		
Psychogeriatric hospital	1	6		
Hospice	1	-		
Young Disabled Unit	-	2		
Mental Illness Unit	-	2		
Total	44	116	160	15
	Men	Women	Total	%
3. Admitted to residential care				
Private Nursing Home	9	28		
Private Rest Home		7		
Part 111 LA - long term	7	16		
Part 111 LA - short term	1	5		
Hostels		2		
Private home - convalescence		1		
	17	59	76	7
4. Discharged to relatives homes (and friends)				
Daughter	4	11		
Daughter and son-in-law/boyfriend	1	1		
Son	1	4		
Son and daughter-in-law	1	4		
Sister		2		
Niece		2		
Nephew and niece		1		
	7	25	32	3
All Patients			268	25

In three cases friends and relatives moved into the patients' home to care for them on discharge, otherwise they

could not have been discharged safely.
One son moved in with his father (patient) and mother, one sister-in-law moved in with her brother-in-law (patient) and friends moved into the home of one elderly female patient.
Table 33 shows that 25% of patients referred to the social workers did not go home from the acute hospital setting. Nine percent of the men died, and so did five percent of the women.

The 15% who were transferred to other medical specialist units for treatment appeared at first sight to be part of a health related situation, rather than one requiring social work intervention. This was so for the patients who needed to go to the orthopaedic hospital, and other acute specialist hospitals. In some cases the patients who were transferred to the geriatric hospital did not need a social worker at the time of referral because they were too ill, and they were transferred before the social worker managed to see them.

Some patients who were eventually transferred to the geriatric hospital went there as a result of social work assessment, especially when their families/informal carers were found to be unable to cope at home, or when residential care was not immediately available. If the geriatric hospital beds were full, there was a great deal more

pressure laid on the social workers by medical and nursing staff to get the patient discharged somehow.
The hospice patient had to travel 12 miles from Mansfield. The social worker initiated the transfer because of his own knowledge and working relationship with hospice staff in Nottingham. The patients who went to the Young Disabled Unit, the mental illness unit and psychogeriatric hospital, were all transferred after a rather extended and awkward inpatient stay on the acute wards. The absence of nursing staff's knowledge about other NHS facilities coupled with an apparent reluctance by consultants in the General Hospital to refer speedily to psychiatrists, resulted in intense pressure on the social workers to get systems and professionals together for patient care and safety. On several occasions, very disturbed elderly people needing psychiatric care created stress and anxiety among staff and other patients because of the noise, interference and aggravation they caused. Staffing levels in the acute wards were not at all adequate to cope with challenging behaviour, and everyone experienced a state of unpleasant tension during their stay. Social workers and nurses together had to press the medical staff to take responsibility, sometimes involving the hospital managers for support.

The issues concerning the Young Disabled Unit and social work intervention were very interesting. The social workers percieved that the staff on the acute wards did not have a clear understanding about rehabilitation, the needs of the two patients in the medium or long term, and the difficulties that their carers would face. The pressure that the social workers exerted on the medical and nursing staff resulted in the transfers, and much longer term work with a specialist social worker for physical disability.

The dilemmas and stress for the social workers concerning transfers and appropriate care\treatment for these patients was in reality the responsibility of NHS staff, particularly medical staff who somehow had to be persuaded to get things moving with other consultants. Junior doctors, on some occasions, demonstrated unpleasantness and diffidence towards nurses and social workers who felt a professional duty and moral obligation to advocate on patients and carers behalf.

The care needs of the 32 patients who went to stay with friends and relatives were greatly increased as a result of their illness. Thr social workers considered that they would have benefitted from convalescent facilities with nursing care, based on their previous experiences of patient recovery in convalescent care facilities. In fact most of their carers asked the hospital nursing staff if convalescent homes were available. Their requests were

directed to the social workers because hospital staff thought this could be arranged. However, the last remaining convalescent home in the Central Nottinghamshire Health Authority area closed in 1988, and this type of care, which used to be accepted as a need following a variety of acute illnesses, was no longer available.
Other types of convalescent care organised for example by the Miners' Welfare Association, were not available either. The voluntary organisation's homes which were sited on the East coast at Mablethorpe and Skegness and were totally unsuitable for frail elderly people. The Local Authority Part 111 homes could not provide this type of support for a number of reasons. If a person needed nursing care, it was not available in Part 111, and in any case no policy initiative had been attempted to enable discharged patients to formally be received from hospital for convalescence. The hospital social workers had tried on a number of occasions to have people admitted for a brief recovery period into Part 111 and this was met in all the Social Services areas with apprehension and refusal to admit.

The relatives and friends who were faced with the situation of a very dependent frail and ill person for whom they cared, therefore, had two choices. Either they had to find a private nursing home, or take the old person home. Most carers struggled on and coped somehow. They usually managed if only one elderly person was involved, but where very frail interdependent couples were equally in need of care, very few carers could cope with both partners.

The need for convalescent care has disappeared from Hospital Management concerns and no Health Authority is currently supporting its provision. The closure of convalescent homes or annexes of hospitals previously used, were among the first cuts in expenditure. This applied not only to those establishments funded directly by Area Health Authorities, but also to those jointly run with voluntary organisations such as the Red Cross.

In Central Nottinghamshire, the last, and largest convalescent home was sold by the Health Authority in the late 1980's and became a private nursing home.

The need for convalescent care post discharge applied to 6% of the 935 patients whose circumstances were known to the social workers., The roles of their carers were drastically changed when they met this need themselves and did not refuse to take the patients home with them for safety. Some of the old people were so frail that any temporary arrangement in the relatives home was likely to become permanent if the carers could cope.

This situation usually presented to the social workers in two ways. Firstly, the hospital staff would be pressing for the discharge of their patient and secondly, the relatives would make an appointment with the social worker to say that they could not cope if the patient were sent home. In some cases the care they were providing for the patients' partner was stretching them to their limits. The amount of stress that was generated because of the double dilemma, lack of resources and shortage of time was on occasions, almost unbearable for the carers and the hospital social workers. A few carers were on the verge of panic, fearing that their own families would break down with stress. If area domiciliary support had been available prior to admission, that service was not adequate to meet these new circumstances. If area social workers had been involved before admission, they tended to see the problem as belonging to the hospital social workers. They would not become involved in making private nursing home arrangements because of the Social Services prevailing political attitudes towards the use of private care.

Had the hospital social workers also taken this attitude, these patients and their carers would have been virtually abandoned at a time of acute crisis, when they all really needed a great deal of sensitive professional support, advice and advocacy. Hospital consultants responded by pressing the relatives to find private nursing home places, or transferred the patients to the local geriatric hospital.

4.4. Informal carers for patients who were referred to the social workers

The total number of patients referred to the Social Workers was 1064 ie. 382 men and 682 women. Information about carers was not available for 36 men and 93 women, because of death, transfer to another hospital, premature discharge or because they came from private residential care or Part 111. Carer information was available for 935 patients, ie 346 men (37%) and 589 women (63%).

It was apparent during the social work assessment of referrals that some people did not have carers. As this seemed to indicate a higher level of vulnerability for them on discharge, special attention is given to who they were, and their social circumstances later in the chapter. The other patients were cared for mainly by family in gender and inter-generational combinations, or by a sole carer. There were 'others' involved such as friends, neighbours, wardens, lodgers and a volunteer. Appendix 1 shows in detail who the informal carers were. This information was collated during the process of the social work assessments and care packaging for safe discharge from hospital. The patients were asked who cared for them, the carer was then contacted and involved in the assessment for help needs, areas of discussion about personal risk, and in planning formal and/or informal systems of support. The final care package aimed to address both carer and patient's needs.

4.5. <u>Carers for Patients who did not live alone</u>

There were 477 patients who did <u>not</u> live alone, that is 216 men and 261 women. Table 34 shows who their carers were.

Table 34. Carers for Patients who did not live alone.

Carers	Men		Women		% all pts
	No	%	No	%	
Husbands only			59	22.5	12
Husbands with other kin			85	32.5	18
Wives only	75	35			16
Wife and other kin	52	24			11
Son (and daughter -in-law if sons were married)	16	7	29	11	9
Son and other kin	6	3	13	5	4
Daughter (and sons -in-law where daughters were married)	17	8	31	12	10
Daughters and other kin	9	4	12	4.5	4
Other kin	22	10	20	7.5	9
Non-kin	9	4	4	1.5	3
Pts living with dependent family member	10	5	8	3	4
216	261	477=100%			

Men = 216 =100%   Women = 261 = 100%

Table 34 shows that just over half of the patients were actually living with their carers. More carers overall were spouses, 30% husbands and 27% were wives respectively. Other kin were helping 59% of the husbands, and 41% of the wives

in their caring roles. This left two fifths of the husbands, and three fifths of wives as sole carers, which meant that the providers of care for these elderly patients were elderly themselves.
Sons, both single and married (in which case their wives were usually involved in caring as well) were named as primary carers for ten percent of the men and 16% of the women. Other kin helped the sons with just under half of the male and female patients for whom they cared. Slightly more daughters had their dependent parents living with them, these amounted to 12% of elderly fathers, and 16.5% of elderly mothers. Other kin were helping them with a third of the men and just under a third of the women. If the daughters were married, their husbands appeared to help in some cases.

One chronically disabled women had an eight year old daughter who was her only carer, and they did not even have a telephone at home to call for help in an emergency.

42 patients, that is 22 men and 20 women were living with other kin. These relatives amounted to a fifth overall as carers for the patients who were not living alone.
A smaller proportion of men and women (3%) were living with non-kin whom they named as their carers, but among this group, there were twice as many men as women. The men, if

they were in lodgings, named their landlady or other lodgers as their carers. No women were living in lodgings as formal tenants. Ten men who were living with someone else were actually carers themselves, and eight women were in the same situation.

4.6. Carers for Patients who lived alone

Those patients who lived alone were mostly widowed and a smaller number were single. None had spouses, therefore it was most important to identify those people - both kin and non-kin who took up the caring role when the elderly person was finally left in a situation of living alone.

Table 35. Carers for men and women who lived alone

Carers	Men	%	Women	%
Son	10	9	46	15
Daughter	29	26	90	30
Son and daughter	6	5	24	8
Son and other kin	4	4	12	4
Daughter and other kin	2	1	14	5
Son and non-kin	4	4	13	4
Daughter and non-kin	5	5	11	3
Other kin only	19	17	40	13
Other kin and non-kin	7	6	13	4
Non-kin only	25	23	42	14
Totals	**111**	**100**	**305**	**100**

111 men = 100%   305 women = 100%

Family Carers.

Table 35 shows that daughters had become the main carers for patients who lived alone. They had become sole carers for over a quarter, and were the main carers for just over another quarter even though other kin and non-kin were actively involved.

Sons were named as sole carers for a fifth of the patients and shared care with others for a further three fifths. If they were married, their wives were usually caring as well. Both sons and daughters were being equally supported by kin and non-kin in about the same small proportions.

'Other kin' were slightly more supportive to sons than daughters. 'Other kin' only were carers for just under two fifths of the men and women, without the presence of either sons or daughters. When 'other kin' who were involved in the caring role with non-kin were included, two fifths of the patients were receiving their support.

'Other kin' were brothers, sisters, nieces and nephews, cousins, aunts and uncles, grandsons or grandaughters, a mother-in-law, sister and brothers-in-law. Their roles as carers spanned three generations, sometimes they were the patient's only carer, sometimes the mixture of carers would be older kin, sometimes younger and older kin were sharing the caring role together. In fact other kin were represented in all possible family combinations. The maximum number of different family members named in one care network was five.

All the referred patients needed increased help on discharge from hospital, at least in the short term. Their families were the main source of care, but some stated that family members were not able or willing to care for a variety of reasons. Illness and disability was not therefore a guarantee that the whole family would rally round because someone was ill or deteriorating. In some cases it was very clear that caring was left to one or two relatives, in spite of research (Stoller and East, 1983) which found that caregiving networks increased in size and complexity as a person's functional capacity declined. However, their finding that the helping network was more likely to include formal caregivers as care requirements intensified was very significant for these patients.

Neighbours and Friends as Carers.

Neighbours featured as carers in 27 different combinations with family members, and were the only carers for nine men and 20 women who lived alone.

Friends were involved with others as carers for 13 men and 19 women, and were the only carers for nine men and 12 women.

Discharge Vulnerability

Once patients had been treated in hospital they were dispatched as quickly as possible into the community, mainly to be cared for by their spouses, family, friends and neighbours, and with whatever statutory and voluntary help they could get. The fact that 15% overall needed social work support to enable them to leave hospital safely was indicative of problems in getting care arrangements confirmed and organised.

This applied to the elderly in general, and especially for people with no obvious carer. The last situation was compounded sometimes because the patient was the only available carer for someone else left at home. When this was the case, the social worker found herself dealing with two clients with inter-related but different needs. This applied whilst the carer was in hospital, and went on for some time after discharge.

The report on the Continuing Care Project - Going Home, (Age Concern 1975) commented on the effects of hospitalisation as follows :

The elderly are particularly vulnerable immediately after discharge from hospital. 'The hospital process will have been a major disruption of their routine, and it can take days before that routine is re-established. They are often unwell and weak, and in need of continuing care ... if (their) variety of needs (are) not catered for from the date of discharge, considerable hardship can follow. If they continue unmet for several days, even weeks, they can result in appalling suffering, possibly undoing the good work done in the hospital - even raising the question of re-admission'. The experience of the social workers at Mansfield General Hospital in the years preceding this research, had been that a number of patients who were re-admitted to hospital so frequently could be described as having a 'revolving door syndrome' (Coppeard, 1990). The medical and nursing staff considered that their problems were 'social' at least in part. The social workers felt also that underlying chronic illness was a factor not properly addressed before they were discharged. These patients, if they lived alone and had no carer, usually ended up in a nursing home or Part 111 and a small number went on to occupy long stay beds in the local geriatric hospital.

Summary of Informal Carers for patients who were referred to the Hospital Social Workers

Sections 4,5 and 6 of this chapter have concentrated on informal carers, and present a scenario of family members, spouses, adult children and other kin mostly looking after elderly dependent men and women. A much smaller number were cared for by friends and neighbours, usually when family members were not available, or did not exist.

The Informal Carers Survey (Green, 1985, Table 2.3) showed that family members predominantly cared for relatives, and that the peak age for caring was between the ages of 45-64 years. Among the referred patients this was also the case, given that 80% were aged over 65 years, and two-thirds of these were aged 75+ years. Research suggests (Arber and Ginn 1991) that a third of the providers of informal care for elderly people are elderly themselves.

The larger proportion of older carers in this study was likely to be over the average because of the large number of 65+ married patients. Female spouse carers outnumbered males as only carers in a ratio 35%:23%, and this trend was also found in the Carers Survey where older women were more likely to be caring for their husbands in the ratio of 11%:8%. In spite of the popular image of older women being cared for, they are more likely to be providing care. (General Household Survey, 1988)

Overall, more women than men were carers in this research, whether they were wives, daughters or other kin. This fact was also found in the Informal Carers Survey (Table 2.1 and Fig 5B) in that 59% of women compared with 45% of men were carrying the main burden of care, either alone or with secondary support. The survey also showed that the older the dependent person, the more likely s(h)e is to need assistance with personal care (Fig 4D). Also, if carers were looking after someone aged over 85 years, most other forms of help were much more likely to be needed, such as giving medicines, physical help, with walking, financial help, practical help at home, companionship, leisure circumstances, and generally having an eye kept on them.

The age and dependency factors applied to many patients who were referred, therefore the social workers were most likely to encounter carers at the heavy end of the 'care burden'. Another important fact was that all of the patients were currently suffering from acute illness. This in itself increased the spectrum and frequency of care needs in the context of personal and domestic assistance, safety monitoring, sometimes not being able to be left alone at home, administration of medicines, and needing someone to be present when community health professionals called.

Many carers expressed apprehension about the state of their dependents' health, fully expecting them not to get better or really be fit for discharge. This applied particularly to people who had terminal illnesses, and those who had become chronically and severely disabled due to the effects of a stroke, amputation or serious heart attack.

4. 7.Patients who had no Carers.

There were 29 men who had no carers. Table 36 shows who they were , their ages, marital status, and whether or not they lived alone.

Table 36. **Male patients referred to the Social Workers who had no Carers.**

Men - by age group, living alone, and marital status

Males	-65	65-69	70-74	75-79	80-84	85-89	90+	Men	%
Living alone	9	2	-	2	5	1	-	19	66
Married	1	-	2	4	2	-	-	9	31
Single	7	1	-	1	1	-	-	10	34
Widowed	1	1	-	2	3	1	-	8	28
Divorced	2	-	-	-	-	-	-	2	7
Total	11	2	2	7	6	1	-	29	100

Total men with no carers = 29 = 100%
Total men living alone = 19 = 66% (half of these had someone dependent on them)

The men without carers were almost equally likely to be married, single or widowed, but most of the single men were aged under 65 years.

The social workers recorded the situations of the nine married men as follows:

1. Patient 16-65. 'Other' illness
He was a married/separated man living with his mother who suffered from severe arthritis. He was her sole carer.

2. Patient 70-74. Bowel disease
He was admitted for terminal care, and had been the sole carer for his wife who had Alzheimer's Disease - she could not cope alone. Son was in Oxford, daughter in Worcester. The family agreed that husband and wife should go into a private nursing home.

3. Patient 70-74 Diabetes and heart disease
His wife was ill and frail - could not cope alone. She had been totally dependent on him for care, and they had no family. She was admitted to a geriatric hospital after his hospitalisation.

4. Patient 75-79. Heart disease
He lived with his frail elderly wife who depended on him to care for her and to manage their domestic affairs. She needed help daily from Domiciliary Services in order to cope alone.

5. Patient 75-79. Cancer, leg ulcers
This man was the sole carer for his elderly dependent wife

who was depressed. She was not doing any housework or even feeding herself since his admission. Daily domiciliary care was needed.

6. Patient 75-79. Hernia
This man who cared for his elderly wife who had degenerative disease of her spine. She could get up and dress herself, but he was her sole carer. The couple really depended on each other, but needed regular domiciliary help to do the shopping, domestic tasks and for her personal care.

7. Patient 75-79. Urinary problems and incontinence
This man had a chronically sick and handicapped wife who depended on him totally., She was admitted to short term care whilst he was in hospital.

8. Patient 80-84. Bowel problem
Patient was caring for his wife who was chronically physically handicapped. He needed a break from the strain of caring

9. Patient 80-84. Bowel disease
This patient was partially sighted and also had poor mobility. He was the sole carer for his wife who was frail and elderly, and domiciliary care was organised for her.

Only two of these married men did not have a chronic illness. The seven who did were admitted to hospital in an acute stage of that chronic illness, and none could expect to be 'cured' by their hospital treatment. They all needed a degree of care for themselves on return home. This was true of the man with the hernia also, leaving one man aged under 65 with a genuine improvement in his health, and hopefully, improved strength to continue caring.

Except for one, all of the married men had dependents with chronic illnesses or disabilities, and the care that those dependents needed had to either be arranged or co-ordinated in a formal way or provided by the statutory Social Services. Apparently, none of the dependents was able to organise the care they needed for themselves. At least, they did not do so, because once in hospital it was their carers, who alerted the social workers (via the nursing staff) to their needs. There was no system of voluntary or informal care which could have been easily called upon.

Men with no carers who lived alone

The next group of men with no carers were 19 who lived alone. There were seven single, one widowed and one divorced man aged under 65; a single and a widowed man between the ages of 65-69; two widowed and one single man aged 75-79; one single and three widowed men aged 80-84; and one widowed man aged 85-89.

The medical and social situations of these men were as follows:

Seven single men aged under 65 living alone, with no carers

1. Bowel disease

This patient had been bereaved two days ago. He had no-one locally to care for him, and would have to go to his family in Glasgow for care after discharge.

2. Fractured femur

This man needed someone to organise a contact for legal aid following an accident. He had no-one to give him informal support.

3. Self harm

This patient was in care as a child, now classified as a Schedule 1 offender, with children on the 'at risk' register. Not allowed near his family home. Had several overdoses recently, no employment, no accommodation. Only support/care is provided by voluntary probation in Scunthorpe.

4. CVA

A single man whose only support and care was via an are-based social worker. He was previously chronically disabled.

5. Psychiatric illness/self harm

A young man with psychiatric/behaviour problems, who had a head injury when he was 5 years old. He was homeless because of uncontrollable rages, overdoses and other suicide attempts. He said he would go to London and try to seek psychological help there.

6. Burned feet. Accident

This was a man with cerebral palsy, and a severe speech defect. He came from 'up North' eighteen months ago, and had been in an institution. He had no family, no carers and no community connections. His burned feet made him totally immobile. He required an extensive package of formal care on discharge.

7. Oesophageal stricture

A single man who was physically debilitated and had lost his appetite due to illness. He lived alone in a second floor flat, and had no carers, formal or informal. He needed someone to pop in on a daily basis after discharge, to give him practical and emotional support as well as a social contact.

Only one of these seven men had any family to turn to in a health crisis, and for him this meant travelling a considerable distance away from his own locality. The remaining six men had experienced a critical health situation which turned into a critical social situation. The circumstances of the two patients (Nos 3 and 5) with self-harm diagnoses, and the physically disabled man with cerebral palsy who had burned his feet, are representative of areas of deficiency in formal community care. All three had previously been in contact with medical, psychiatric and social work agencies, but there was no evidence of any support system which might have been regarded as preventative to offset their health crises.

They show very clearly how the Accident and Emergency Department of a general hospital really is the only viable point of public access for care. When chronically sick or disabled individuals have had their links and contacts with formal care systems either taken away or withheld, their route to appropriate systems of care is very difficult to re-establish. The hospital social workers, engaged with the situational crises at the clients' level experienced for themselves the virtual impossibility of service access on behalf of their clients in each case. No-one who had been involved before was available to take professinal responsibility in the event of the acute health care situation.

There were three older single men without carers. They had chronic health problems, a primary presenting illness and social situations which appeared to be very serious

1. Patient 65-69. Falls, poor mobility

This man lived alone, and was admitted because of his repeated falls. He had no family, and on discharge needed home help, meals on wheels, OT aids and an area social worker. He needed an advocate to deal with the Coal Board - his coal fires did not provide enough heat and he could not manage them independently.

2. Patient 75-79. Chest problems and hernia

This patient lived alone and had no carers at all. He arrived at hospital in a neglected malnourished state and was eventually transferred to a geriatric hospital.

3. Patient 80-84. Heart disease. Myocardial infarction

This man lived alone, and was blind. There were no identifiable carers. His heart condition did not improve and he died within days of his admission

Eight men who had no carers were widowed. All were aged over 65 years. Their circumstances were as follows:

1. Patient -65. Arthritis and falls.

This man was totally alone and had severe arthritis. He was supported solely by an area based social worker who visited him in hospital and continued post-discharge.

2. Patient 65-69. Cancer - bowel problems

He had lost contact with his family whom, he thought, were 'abroad'. He had been widowed 20 years, hospitalised several times and had no will to live. He died.

3. Patient 75-79. Heart disease

He lived alone with no formal or informal community supports. He was eventually discharged, referred to a day centre, and a community nurse link/liaiason was set up with an area social worker.

4. Patient 75-79. Bowel problems.

This patient lived with his son who neither wanted nor cared for him. On admission he was filthy and neglected, malnourished and needed proper clothes. He was eventually discharged to his son's home with supervison from an area social worker.

5. Patient 80-84. Anaemia and prostate problems

This man lived alone and had no family to care for him. He had also been falling at home. He told the social worker he would like to go into residential care because he couldn't look after himself. He died before he was discharged.

6. Patient 80-84. Chronic back pain.

This man lived alone, his condition was chronic. His only son was living in Scotland and they had no contact with each other. After admission a niece and nephew visited occasionally. Patient was transferred to a geriatric hospital for long-term rehabilitation.

7. Patient 80-84. Cancer and falls.
Patient lived alone - he had been falling, not eating and his short term memory had recently got worse. No relative were in contact with him but through the housing warden, a nephew made contact with the social worker after his death because the patient's dog had be destroyed.

8. Patient 85-89. Diabetes.
This man was admitted as an emergency because he had been found at home in a hypoglycaemic coma. He had been discharged from another hospital a week previously, needing a district nurse and meals on wheels daily. A referral had been made to the area social services office. The district nurse had called, but no meals on wheels arrived. A check by the hospital social worker revealed that the area domiciliary services had no record of the request for meals on wheels and therefore the service had not commenced.

Finally, there were two divorced men under 65 years of age, who had no carer.

1. Patient under 65, with leg ulcers and diabetes.
This man lived alone, and said that his relative 'lived

away'. He claimed to have a fiancee in Aylesbury, but she was not in contact with him. He needed help to claim his welfare rights benefit.

2. Patient under 65. 'Other' illness
This man lived with his mother, who had severe arthritis and needed an assessment by the area OT. The patient demonstrated abusive behaviour to the nursing staff, and was discharged as quickly as possible because of this. The social worker could not engage his co-operation.

A key point about this group of men without carers, whether they lived alone or had someone else dependent on them, was that no opportunities for informal care seemed available to them in the absence of kin, and would not become available to them in the future. There were no other informal care systems either in crisis or in the longer term which had arisen spontaneously in the community, or had been initiated by the formal care organisations. The only back up systems to provide the bare essentials of care came from formal structures within Health and Social Services.

The case of the 85-89 year-old man with diabetes illustrated what happened when there was failure in communication between those organisations, and the consequence of an unnecessary re-admisison to hospital. If he had not been found accidentally he would have died within a few hours.

The total number of patients in this group of men with no carers, who had health and socially related problems of a chronic nature came to 28. The number of people with care needs that came to the social workers' attention was actually 37, because of the dependent relatives at home.

All of the patients circumstances indicated a possibility of relapse and more crises in the near future. Given that their problems were severe and chronic, it was doubtful whether access to any voluntary organisation would actually be available to the patients or their dependents. It seemed unlikely that a voluntary organisation would be able to find a positive role when health and personal needs were so pressing. Such situations have many faceted complexities which require a stringent assessment format in order to identify both needs and helping strategies.

Several of the patients were near to death when help was requested for them. Sometimes - but rarely - these patients asked for help to get their affairs in order and were able to impart vital information and their wishes to the social worker. When they did not the worker was faced with other unforeseen tasks such as appropriate disposal of property, effects and pets, and attempts to find distant relatives who could take responsibility.

Women patients who were referred to the social workers, who had no carers.

589 women were referred, 31 of these had no carers, 23 lived alone. Table 37 shows who they were.

Table 37. Women with no carers, by age group, living alone and marital status

Age group	-65	65-69	70-74	75-79	80-84	85-89	90+	Total
no carers	5	1	3	7	7	6	2	31=100%
living alone	2	1	2	4	7	6	1	23=74%
married	2			1				3=13%
single	1		1	2	2			6=19%
widowed	1	1	2	3	5	6	2	20=65%
divorced	1			1				2= 6%
Total	5	1	3	7	7	6	2	31=100%

The social workers recorded the following situations for the eight women with no carer who did not live alone.

1. Patient -65, physical injury

Patient was separated from her violent husband, admitted to hospital as a result of injury by him. She was living in a women's refuge, needing advice and support re violence, legal situation, and financial aid.

2. Patient -65, heart disease

Patient lived with her disabled husband and alcoholic son. She had to get the son removed from home because of stress and his behaviour. Her husband was very dependent on her for daily personal care, he attended a Social Services Day Centre three days each week.

3. Patient -65, second CVA

This patient was a one-parent family living with her eight year old daughter. She had a congenital disability to one arm and leg. Her daughter was her carer for domestic and some personal tasks, and the only person who could fetch help when her mother was taken ill. The social worker had a telephone installed for them and provided practical assistance and counselling.

4. Patient 70-74, 'other' illness

This patient was a widow, living with her husband's brother who was older than her, frail and dependent on her. She returned home with services.

5. Patient 75-79, falls

A women who lived with her very elderly mother in appalling filthy circumstances. Both were open cases to an area social worker, but they refused home help and short-term residential care. They could not care for themselves adequately. The patient was transferred to a geriatric hospital.

6. Patient 75-79, fractured femur and dementia

A mentally deteriorated woman who had a dependent husband with Alzheimers disease and heart trouble. The nursing and medical staff asked the social worker to get her a place in a private nursing home. She was eventually transferred to a psycho-geriatric hospital, the area domiciliary services and a social worker were left to provide care for her husband.

7. Patient 75-79, heart disease

A married women caring for her chronically ill husband at home. He constantly needed oxygen and someone to administer it to him. Her admission created panic about his care because the statutory community care agencies could not be on demand for his irregular needs and level of personal dependency. It was left with community physio and nursing staff to try and help. He was not seen to need admission to hospital.

8. Patient 90+, frailty, very old age

A very frail elderly women, too ill generally to go to Part 111. After social work assessment she was sent to a geriatric hospital. An elderly relative interdependent with her remained at home with domiciliary support.

The number of women here who needed care for themselves was eight. The number of people needing care, when the women had been admitted to hospital became fifteen, this was because of dependent others left at home, a similar situation previously described about the men who had no carer and were not living alone. Five of these patients returned to their own home and three were transferred to a geriatric hospital.

Women without carers who lived alone

There were 23 women without carers who lived alone. They represented three quarters of this group, and the majority of them were aged 80-89 years. This is much older than the similar group of men. Case details of women without carers who lived alone are shown in Appendix 2.

Summary for Women who had no Carers.

There was only one woman - aged under 65 who had been injured by her husband - in this group of 31 patients, who did not have chronic and deteriorating health problems. All the others had been treated for medical problems in the community, and although there were no records available to verify this in the context of this research, quite a number had been admitted to hospital before, on more than one occasion.

Even though most of the patients were very elderly, suffering from illness that would not be cured, and either had no carers or someone else dependent on them, only six were transferred to a geriatric hospital. The social workers were satisfied, as were the geriatricians, that this was the appropriate course of action. Those transferred were not physically well enough to be admitted to Local Authority Part 111 care, and certainly could not have been supported at home by domiciliary care.

Those who were discharged home with some improvement in their chronic ill health, did not need the Discharge Scheme. Their own needs, and those of their dependents if they had any, were for intensive routinised help from domiciliary services, aids to daily living and some day care. It was clear to the social workers that most of these patients should be followed up by visits from a district nurse. However, the nursing staff were responsible for referring for that service, and only sometimes confirmed with the social worker that this had been done.

When the time came for these patients to be discharged, fourteen returned home to the community whence they had come, including an 'out of area' patient who went to relatives temporarily. One patient went to a nursing home and one was admitted to Part 111 accommodation.
Six more patients were transferred to the geriatric hospital and one patient died.

39% of these patients therefore did not return to their own homes.

4.8. Patients who were interdependent on their partner or carer.

In the course of the Hollins and Abbott wards screening project, the Discharge Scheme Co-ordinator encountered a number of patients who were interdependent with their partner or carer at home, because both were suffering from illness, frailty, chronic disabilities and/or general debility due to extreme old age. The Co-ordinator commented that it was difficult to determine who was actually caring for whom, and that the care that each gave to the other was reciprocal. These situations appeared to contain just enough support for frail interdependent couples to remain at home together - until an episode of acute illness with one partner caused a serious change to take place. When that partner was admitted to hospital, the social worker's assessment of need and the consequences of change showed that for some couples, this meant that the end of their relationship and independent living at home, had arrived. It also meant that someone else would eventually make a decision about the type of care that each partner received for the rest of their lives, and that the decision would be dictated by force of circumstances.

Eleven patients fell into this category of extremely fragile interdependence. Their circumstances, and the final outcome for both partners was a follows.

1. A male patient aged 83 was admitted with retention of urine and kidney problems. His elderly wife was at the same time in King's Mill Hospital and had just received surgery. The couple had no children, and formal services could not have supported them adequately or safely at home. The patient was transferred to the geriatric hospital, and his wife joined him there. Neither went home again. The decision about their place of care was made by two separate consultants.

2. A woman aged 75 was admitted with oedematous legs, in a very dirty neglected condition. An assessment of her home circumstances showed that she lived with her twin brother in the most appalling filthy conditions. Neither was physically well or able to manage their domestic or personal needs properly. Both, however, preferred to be independent and refused to accept formal help. There were no other family members. The patient really needed Part 111 residential accommodation to ensure her proper future care, but her brother refused to allow her to go. She was transferred to

the geriatric hospital for long term care, and her brother remained at home alone.

3. A man aged 81 was admitted for a sigmoid colectomy, this treatment was part of a chronic bowel problem and he was very frail. His elderly wife was in Harlow Wood Hospital waiting to go home after treatment for a hip replacement and severe arthritis. They had managed to care for each other with help from their daughter, but after hopitalisation they were not fit enough to go home. The patient went to live with his daughter in her home, and his wife was admitted permanently to a nursing home. The daughter and a hospital consultant made this decision.

4. A female patient aged 79, who had been suffering from Alzheimer's Disease for some time, had fallen and fractured a femur. Her husband, who was her only carer suffered from severe heart disease and could not manage her care after rehabilitation. He remained at home with domiciliary services support, and she was admitted to a psycho-geriatric hospital because her mental condition was worse after surgery. A psycho-geriatrician made this decision.

5. A patient aged 75 who had been suffering from cancer was admitted following a stroke. She had been interdependent with her husband who had previously had a

full leg amputation. The patient died, and her husband was too dependent to remain at home alone. He was taken to his son's home in Doncaster to live there permanently.

6. A man aged 79 was admitted for a partial gastrectomy. He lived with his wife who had been suffering from Alzheimer's disease for some time. Although their daughter had also cared for them, the deterioration in his health increased the burden of care to such an extent that she could not cope with both her parents' needs. After the daughter's consultation with a social worker, both partners were admitted to a private nursing home.

7. A female patient aged 93 was admitted following a fall and fracture of femur. She also had liver problems. She lived with her elderly sister-in-law who was also ill and disabled. They had managed to care for each other with minimal help from the patient's adopted daughter. When the patient was admitted, her sister-in-law had to also be admitted to the geriatric hospital because informal family carers and domiciliary services were not able to cope with her needs. The adopted daughter and her family demanded that Social Services and the NHS should take responsibility for the old ladies, both of whom ended up on separate long stay wards in the geriatric hospital.

8. A husband aged 91 and his wife aged 84 were admitted to

hospital on separate days, both suffering from chronic bowel problems. They had been helped by their daughter, but when they could no longer care for each other, she could not cope with their combined dependency. This couple were admitted to a private nursing home, and the decision was made by their daughter and a geriatrician.

9. A man aged 75 was admitted with a fractured femur. His wife had severe arthritis and poor vision. They had no children and a nephew was the only caring relative. He arranged a private nursing home place for the patient, the wife stayed at home alone.

10. A man aged 82 who had previously had an amputation and suffered from Parkinson's disease, was admitted after being in a road traffic accident with his elderly wife. They had no children, and were totally interdependent before the accident. Unfortunately, she died as result of the accident, and because he did not have any other informal carers, he had to be admitted permanently to Part 111 accommodation.

11. A man aged 74 was admitted for a large bowel resection and had reached the stage where he needed care for a terminal condition. He had been interdependent with his wife, who suffered from Alzheimer's disease. Their children

lived in Oxford and Worcester, and could not provide the intensive support that their parents needed. Their daughter came to see the social worker, and subsequently found a place for both parents in a private nursing home.

These situations of interdependency show that there are a small number of elderly people who have no-one else to depend on, and who become extremely vulnerable when their physical health deteriorates, or sudden trauma necessitates an acute hospital admission.

The sum of their ability to care for each other is just adequate to keep them together at home but when separated, they cannot maintain individual independence.

When both are approaching the margins of need for some kind of residential or nursing home care, they are potentially at risk of being separated by acute illness, and a general hospital admission for one or both will be an enforced turning point in their lives.

The case studies show that these eleven couples were seriously at risk, and this meant losing any autonomy which they had struggled to maintain, because of their loss of health. Out of a total of 22 elderly people only three were able to stay in their own home. Three couples were able to stay together as a result of their relatives' decisions that they should be admitted to private nursing home care, and two couples were accommodated in the same geriatric hospital where they at least could have contact with each other, as a result of the geriatrician's decision. This group of patients were, overall, at the highest risk of being admitted to institutional care, or being separated from their last life-time partner.

There were a further 27 patients who were frail and interdependent with a partner, who did manage to return home. Even so, six of their partners were admitted to the geriatric hospital until the patients at Mansfield General Hospital were discharged. Two other patients were so worried about their dependent partner at home that they refused to have their operations and took their own discharges against medical advice.

One patient aged 78 was living with her mentally disabled daughter before admission. Their home had no electricity, was squalid and infested. The social worker in this case had to place the daughter in temporary Part 111 accommodation, and call in the Environmental Health Officers to make their property fit for habitation before either was discharged.

Another patient aged 76 who suffered a compacted fracture of her ankle had been caring for her deaf, mentally deteriorated and incontinent husband at home. Their house was delapidated and very filthy. Their only son lived 10 miles away and did not care for them. They had not received any help from domiciliary services before the patient was admitted and because of the awful squalor, the domiciliary services manager refused to help. The social worker, with the patient's consent, placed the husband in temporary Part 111 accommodation, and employed a private agency to clean the house.

One patient went to a friend's home whilst still in a full leg plaster, and eventually she and her husband went home together. After that they were adequately supported by a domiciliary care package.

One exceptional circumstance which occurred was that of three elderly siblings who were dependent on each other. The youngest sister aged 72 had already had a heart attack, and was admitted to hospital following a stroke. She lived with her dependent sister aged 91, and also helped her brother aged 85. The patient was admitted to a private nursing home, and her brother moved into her place at her sister's home. The two oldest siblings were then supported by a nephew and niece, with help from Social Services.
24 patients and their interdependent partner were able to be supported by intensive domiciliary services and two more employed private help to care for their partner at home, and

themselves when they were discharged. Other elderly relatives, adult children, neighbours and friends managed to provide some of the extra care that was needed.

26 out of the 38 interdependent couples had no children. In all cases their expressed preference would have been to return to their own homes if that had been possible.

4.9. Patients whose sons and daughters lived far away from Mansfield.

Some patients had adult children or other relatives who lived away from the area, and therefore were not informal carers on a day to day basis. In a few cases however, those family members living away demonstrated considerable concern for their elderly parents if there were problems on discharge. The social workers were usually contacted by a relative for an appointment to talk through the patient's difficulties, and a few relatives subsequently came to patients' homes to ensure that discharge from hospital was achieved safely. Those sons and daughters who did not or could not return to support their parent were either living very far distant, or had difficult family relationships which apparently had caused the caring relationship to be abandoned.

There were 28 patients (3%) whose adult children or other family members lived away. Some did have other family members still living in the area, and they usually took on the day-to-day caring role. Neighbours, in some cases, also rose to the occasion and became substitute carers.
The informal care situations for the 28 patients are shown in Appendix 3.

The circumstances of these patients demonstrated that when adult children - or other family members - lived away, that informal caring support became very sparse indeed. If family members did not live locally, then care fell to friends and neighbours. Even if they were prepared to care, the risk of an elderly frail or ill person ending up with no carers at all was greatly increased. In these situations the social workers were faced with difficulties. They had to make an informed decision, based on assessment of risk, that patients should not be discharged from hospital - in spite of the fact that the patients themselves wanted very much to go back to their own homes. The options of private nursing home care or transfer to the geriatric hospital when daily care needs were so great, had to be discussed with the consultant, the ward staff, the patient and the patient's relatives - however far away they lived. The patients almost without exception wanted their relatives to make the final decision for them, but had little opportunity to discuss the matter unless the relatives made this possible by coming to the hospital. The task of co-ordinating everyone concerned and exploration of everyone's feelings usually fell to the social worker. Most relatives who lived far away made appointments to see the social workers,and they then needed information about the private homes in the area, how to choose an appropriate residence, payment of fees and DSS benefits, sale of property if the patient owned their own home, and sometimes - how to obtain Power of Attorney or receivership through the Court of Protection

If a patient was eventually admitted to a private nursing home, discharge from hospital was delayed for days, or even weeks. Sometimes patients had to endure another unwelcome move to the geriatric hospital to wait for their nursing home place to be arranged, because the acute NHS bed at Mansfield General Hospital was urgently needed for another patient.

4.10. Housing and Heating - Patients referred to Social Workers

The circumstances regarding type of housing and heating arrangements were known for a total of 946 patients, that is 346 men and 600 women.

Three hundred and seventeen lived in owner-occupied property, mostly houses. Proportionally more of these patients were women (37%) than men (28%). Equal proportions of men and women were private tenants (6%).

The largest number were council house tenants. 54% of the men, and 59% of women had this type of property, but more women than men were living in council bungalows. Two percent of patients were living in Coal Board houses, and three quarters of these used coal-fired heating.

74 patients were living in someone else's home, thus technically having 'lodger' status. However, none of the women were paying lodgers in the home of someone who was not related to them. Five men only were living in privately rented lodgings.

21% of men, and 23% of women were in warden aided accommodation. Sometimes the wardens were living on site and called daily, in other situations the wardens were on call for part of the day through a central telephone call/link system and only came in emergencies.

Almost a quarter of all the patients had coal fired heating overall, and most of these lived in houses rather than bungalows or flats.

The tables entitled 'Housing and Heating' illustrate these data.(Tables 38 and 39)

Referrals to the Social Workers. Table 38

MEN - HOUSING and HEATING.

The TOTAL number of MEN referred was 382.
Number with circumstances unknown 34
Men who came from private residential care 2

The TOTAL number of men for whom data on Housing and Heating in their own homes was available was therefore 346.

Table to show tenure, type, warden aided housing, and those with coal fires.

TENURE	TYPE of HOUSE			WARDEN		COAL-FIRE	
Owner Occupier	Bungalow	29		-		5	
	House	66		-		19	
	Mobile Home	1		-		-	
	TOTAL	96	28%			24	25%
Private Tenancy	Bungalow	2		-			
	House	12		1		6	
	Gr.Floor Flat	3		-		-	
	Upstairs Flat	4		1		1	
	Other	1		-		-	
	TOTAL	22	6%	2	9%	7	32%
Council	Bungalow	17		-		-	
	with warden	46		46		6	
	House	80		-		34	
	Gr.Fl.Flat	28		20		2	
	Up.St.Flat	15		4		1	
	TOTAL	186	54%	70	38%	43	23%
Coal Board	House	10	3%	-		7	70%
Lodgings	Bungalow	3		-		2	
	House	24		-		5	
	Gr Fl.Flat	1		-		-	
	Up.St.Flat	1		-		-	
	Other	3		-		-	
	TOTAL	32	9%	-		7	22%
TOTAL - ALL MEN IN THE COMMUNITY		346 100%		72 21%		88 25%	

Men living in houses-192 30%-58 had their beds downstairs.

Referrals to the Social Workers. Table 39

WOMEN - HOUSING AND HEATING.

The TOTAL number of WOMEN referred was 682.
The number whose circumstances were unknown were 61.
Women who were admitted from residential care Part 111 - 7.
Women who were admitted from private rest homes or nursing homes numbered 14.
Total women : 621 - 100% Total from residential care : 21 - 3%

The number of women for whom data on Housing and Heating in their own homes was available was therefore 600.

Table to show tenure, type, warden-aided housing and those with coal fires.

TENURE	TYPE OF HOUSE			WARDEN		COAL FIRE	
Owner Occupier	Bungalow	62		-		5	
	House	156		-		32	
	Gr.Fl.Flat	1		-		-	
	Other	2		-		-	
	TOTAL	221	37%	-		37	17%
Private Tenancy	Bungalow	5		2		-	
	House	24		1		-	
	Gr.Fl.Flat	3		2		-	
	Upst.Flat	2		1		-	
	TOTAL	34	6%	6	18%	-	
Council	Bungalow	110		82		20	
	House	103		1		41	
	G.F.Flat	63		38		6	
	Up.Flat	19		9		1	
	TOTAL	295	49%	130	44%	68	23%
Coal Board	House	8	1%	-		6	75%
Lodgings	Bungalow	9		-		1	
	House	30		1		6	
	Up.Flat	1		-		-	
	Other	2		-		1	
	TOTAL	42	7%	1	2%	8	19%
TOTAL - ALL WOMEN IN THE COMMUNITY		600 100%		137 23%		133 22%	

Total number of women living in Houses 321 - 54% 123 of these i.e.38% had their beds downstairs.

Housing Problems

Patients who were referred with housing problems presented a variety of situations which needed assessment, advice and action. Their needs ranged from rehousing to liaison with GPs, consultants and Housing Departments to arrangements for repairs, rebuilding and structural alterations. The most difficult problems were with very old properties - usually Coal Board owned or purchased by patients, which were in poor states of repair and which had poor quality amenities. When patients who were home-owners needed council accommodation, they found themselves placed on a separate waiting list, which in some cases took two more years than council house tenants for property allocation. The social workers both wrote letters to Housing Departments on patients' behalf and obtained consultants letter of recommendation for rehousing. Upstairs bathrooms and toilets were very difficult for patients who had fractured femurs, strokes, heart disease and extreme physical frailty. Coal fired heating systems with back boilers created problems with both heating and hot water supplies; some older properties had poorly insulated water pipes which froze and burst in winter.

When no immediate family was at hand to help, the social workers found themselves negotiating with plumbers, builders and electricians on the patient's behalf, and needed to arrange alternative accommodation for a few patients after discharge whilst the work was completed.

Four properties were in such neglected conditions and piled with debris and rubbish from long-standing neglect due to patients' total inability to cope within their own homes, that Domiciliary Services would not consider entering the houses. In these circumstances the hospital social workers became involved with Environmental Health Departments, private cleaning agencies and rubbish removal firms. They had to obtain patients' permission to remove any property even if it was rubbish, and on two occasions, whilst the patients were being rehabilitated, took them out to their own homes to help sift through the contents.

Some of the housing problems used many hours of social work time not only during the course of numerous telephone calls to housing departments, but in dealing with the practicalities of rearranging and purchasing new furniture when it was needed.

Table 40 - Table to show the number of Housing referrals

	Men	Women	All patients
All SW referrals	346 (100%)	621 (100%)	967(100%)
Housing referrals	19 (6%)	27 (4%)	46 (5%)

Proportionally, rates of referral for men and women with housing problems were very similar.

Bathroom and Toilet Facilities

Almost all of the 946 patients had bathroom facilities. In fact, only one woman had no access to either a bath or shower. 235 patients out of a total of 518 who lived in houses had upstairs toilets only. Many patients had both upstairs and downstairs toilets, and 25 also had a toilet outside. Only seven patients had access only to an outside toilet.

70 patients already had a commode when they were admitted to hospital, most of these were living in houses where the toilet was upstairs.

4.11. Formal Help needed from Domiciliary Services, before and after admission

285 patients were receiving support at home from Domiciliary Services before admission to hospital. There were 95 men, and 190 women, which amounted to 30% of the referred patients whose circumstances were known. 91 of these either went on to other hospitals, or to live with relatives, were admitted to residential care or, in some cases, died.

When the remaining 194 went home to their original circumstances 131 needed reinstatement of the same level of domiciliary support, and 63 not only needed reinstatement, but also an increase in their service.

There were 135 (14%) patients who needed some domiciliary support who had managed independently or with relatives help before they were admitted.
On discharge therefore, a total of 329 patients were found to need a community care assistant, and there was a 5% increase overall.
If those patients who did not go home had actually done so, then 45% would have needed domiciliary support, giving an increase of 15% in need for formal services.

Table 41 - Table to show the needs for domiciliary help before and after admission

	No of patients	%
Receiving help before admission	285	30
Did not go home	91	10
Needed same level of service on discharge	131	14
Needed an increase in services	63	7
New referrals	135	14

Total number of patients needing help with domiciliary services: 329 = 35%

935 patients = 100%

Meals on Wheels

A total of 137 patients ie 15%, were receiving meals on wheels before admission. There were 49 men and 88 women. 66 of these needed the same number of meals on discharge, and six asked for an increase in the service. There were 64 new referrals for patients who had not received meals on wheels previously. The user rate on discharge remained at 15%.

Most of these service users also received help from domiciliary services. Very few took meals on wheels alone.

The total number of patients needing meals on wheels assessment, reinstatement and an increase in the service were 136.

Day Centre and Day Care - Part 111

A small number of men and women had been attending day centres or Part III homes for day care before admission. 11 men and 31 women - a total of 42 - attended a day centre. Two men and ten women attended a Part 111 home for several days care each week. These services were resumed on discharge from hospital. Overall 6% of the 935 patients referred used these services.

4.12. Use of voluntary clubs and other social organisations

Very few of the patients referred to the social workers were involved in community based activities.

Table 42 - Table to show patients attending social clubs/organisations

	Lunch club	Church	OAP club	other
men	7	2	2	7
women	21	12	11	13
Total	28 (3%)	14 (1%)	13 (1%)	20 (2%)

4.13. Private Domestic Help

42 patients ie seven men and 35 women employed their own domestic private help at home before admission.

This amounted to only 4% of the referred patients. This percentage of paid carers was also found in the Informal Carers Survey, 1985 (Table 5:5)
The paid helpers were friends, neighbours, and an occasional relative, who had usually been helping these patients for some years. The personal relationship involved in this structure of help seemed to be very important - and often the paid helper would visit the patient in hospital. The patients invariably said that they did not want Social Services to be involved, and were quite independent about asking their private helpers for whatever they would need on discharge from hospital.

In all cases the private help arrangement seemed to be very flexible, and could be relied on to be at hand quickly on discharge from hospital. Patients themselves, or relatives usually organised the extra time needed.

4.14. Residential Care

Two men were admitted to hospital from private rest homes. Neither returned there, one was transferred to a geriatric hospital, and the other died.
15 women also came from private residential homes, and

only five returned there on discharge.

4 women were admitted from Local Authority Part 111 homes and only one returned. The other three were transferred for longer-term care to the geriatric hospital.

A total of 20 patients (2% of those referred) came to hospital from residential care therefore, but less than 1% were able to be discharged to the same place.

A very much larger number of patients actually went into residential care after they had been referred to and assessed by the social workers.

33 men needed residential care of some kind on discharge, and 77 women. The total number going into residential care from hospital came to 110, which was 12% of the patients referred, and 1% of the overall patient population in the hospital during the research period of one year.

The decision that residential care was needed was made during the social worker's assessment process. This involved the medical and nursing staff, the patient and relatives on all occasions where they were available. Older people often deferred to their adult children. As Soldo, Aree and Wold (1989) found, kin were typically active participants in the decision to admit older relatives to residential care.

4.15. Community Based Health Service Provision before Admission

It was possible to identify those patients who had been receiving the services of a district nurse, or bath attendant, and who had been using day hospital or respite care services before admission. At the time of discharge however, the responsibility for re-instating those services, or for new referrals, belonged to the nursing or medical staff. The social workers were not always told when this would be done, and no check could be made on numbers.

Table 43 - Table to show patients who received community based health services before admission

Service received	District nurse	Bath Att.	Day Hosp	Respite care
Men	51	16	5	2
Women	71	33	13	2
Total	122 (13%)	49 (5%)	18 (2%)	4 (<1%)

Total pts 935 = 100%

NB 1 Some patients were receiving more than one service
NB2 It was likely that a number of other patients than those referred to the social workers were receiving these services, but they were not included in the research

The social workers felt that lack of communication about the District Nurse/Health Visior role was a problem for them, in the context of arranging comprehensive care packages for safety and service delivery when patients were discharged. They wanted to include the Community Nurses role and timing of visits in the information which they provided for patients, particularly when a Bath Attendant was required. However, neither the hospital staff nor the district nursing service was able to supply accurate information or confirm that the community service was available, so the social workers were left as uninformed as the patients. The NHS referral system appeared to work on the basis of assumption that once alerted the District Nurse would call as soon as possible.

Similarly, the needs for Day Hospital care and transport arrangements were difficult to confirm and co-ordinate as part of the package of post discharge care. Hospital nursing staff were unclear about their responsibility for making referrals to the Day Hospital, and medical staff other than geriatricians did not refer.

4.16. Welfare Rights, Benefits and Finances

The social workers received referrals from the ward staff for patients who had DSS benefit problems, and found a number of other patients with these problems who had been referred for other reasons.
Other financial difficulties involved, for example, grants from voluntary agencies, grants or loans from Social Services or the Independent Living Fund, and occasionally with Occupational Pensions. None of the patients was employed, so salaries were not an issue for them, but sometimes carers were employed and needed advice about payment for time off work when dependents were ill.

The DSS benefit problems ranged from giving advice and alerting someone to their right to claim, to liaison with DSS offices and appeal tribunal situations. Occasionally pension books were lost in the DSS system, various sections of DSS benefit offices had muddled information and benefits were delayed. In a few instances the social workers had to provide small one-off grants from the League of Friends budget to help with travel costs or a meal.

Table 44 - Table to show no. of men and women who needed help with Welfare Rights and Finances.

	Men	Women	All Pts
Social work referrals	346(100%)	589(100%)	967(100%)
Welfare rights and finances	90(26%)	105(17%)	195(20%)

20% of the referred patients therefore needed active help with welfare rights, benefits and finances. Women proportionally needed less than men at 17% : 26%.

The principal difficulty that the social workers encountered in providing this type of help to patients and their carers was in communication with DSS offices. Information was frequently held in several sections of the same offices, and not co-ordinated by the workers in DSS. Many time-consuming telephone calls had to be made to establish what levels of benefit were being paid, repeated call-backs because DSS information files were out to other sections, and because giros simply did not arrive as promised and when expected.

Patient and carer access to DSS information was very problematic. The patients themselves were rarely able to use a telephone to resolve their queries, and had problems with understanding the DSS structure of benefits. When changes occurred in benefit provision, this had to be explained very carefully and the social workers had to provide the appropriate leaflets and application forms from their own Resource Room. No system within the hospital otherwise addressed the DSS difficulties and needs.

4.17. Occupational Therapy Referrals

The social workers and occupational therapists, and to a lesser extent physiotherapists, experienced and maintained a close working relationship at Mansfield General Hospital. This was essential given the number of old and functionally disabled people who were referred to them jointly for daily living assessments and social problems. All these disciplines relied on medical and nursing staff to make referrals to them, and they also referred to each other when they found a patient in need who had not been detected by other staff.

It was not unusual for the social workers in the course of their assessment to perceive the need for an OT to assess a patient's functional ability. In situations where patients had communication difficulties - eg aphasia or dysphasia, the two disciplines worked closely to share their professional information and opinions. One or the other would usually be

responsible for referral to a speech therapist.
When home assessments were needed, they worked together on tasks that no-one specifically had a brief to undertake, for example getting a patient's bed downstairs, advising on environmental changes and equipment used by carers or other family members at home, fetching equipment from home loans so that a discharge could take place, and sometimes removing equipment that was no longer needed.

Table 45 - Social work referrals and involvement with occupational therapists

	Men	Women	All pts
All SW referrals	346 (100%)	621 (100%)	967 (100%)
OT referrals	52 (15%)	115 (19%)	167 (17%)

Proportionally more women than men were referred -
15% : 19%

It was very clear that OT equipment, such as bath aids, zimmer frames and trolleys were immediately needed when patients returned home, for their physical safety and independent living abilities to be realised. However, the Social Services Area occupational therapists held the budgets for and responsibility for supplying this equipment. The area OT's also needed to assess the patient's home situation before the equipment was provided, even though the hospital OT's had already made their assessment. It could not be guaranteed that the area OT would be able to assess at the time required, or to provide equipment promptly. Frequent telephone calls were received by the social workers from patients and their carers, up to several weeks post discharge, to say that equipment was not yet to hand, and that serious difficulties were being experienced with most basic functions such as getting drinks and food from the kitchen to the living room.

When larger items to assist daily living were required, such as rails, ramps and stairlifts, many months could elapse. It was not unusual for patients to say, once in hospital, that they had been waiting for a year or even two, for stairlifts, showers and other major alterations. Usually the wait was indefinite because of lack of OT funding for these major expenses.

4.18. Patients who were referred to the social workers who were categorised as having 'family problems'

The category of 'family problems' is used as an uncomplicated means of grouping together a number of patient/client referrals which presented the social workers with very complex problems. These were varied according to family circumstances, interpersonal relationships and environmental stresses.

There were 90 families concerned in all, and they could, on analysis, be broken down into seven groups with distinct characteristics, as follows:

1.	Families in dispute	10
2.	Abuse and neglect	16
3.	Sexual abuse	2
4.	Abuse of carer	1
5.	Overdoses and self harm	16
6.	Learning disabilities	9
7.	Families with severe chronic stress	36
	Total	90

It was an observed fact that all of the patients and carers in these groups, and those previously described in this chapter as in a situation of fragile interdependence, were suffering from stress. The other main feature for them all, including those with fragile interdependence, was that their personal and family circumstances seemed to have reached a stage of difficulty which was beyond the control of the individual referred, and indeed, of their family group.

Their primary need was for an assessment by a social worker who could use professional skills to put the 'problem' into a framework of understanding which could then be used as a basis for family evaluation, dialogue, counselling, task-centred work and problem solving. In many cases the social worker was met with anxiety, confusion and arguments among family members. Quite often the families' first statement was 'we can't have him/her back home'. A serious difficulty presented in some families where different members had taken opposing sides in their attempts to answer the patient-related problem prior to hospital admission.

Sometimes they were not speaking to each other and had settled into blaming their relatives for not taking responsibility, or not sharing responsibility for the care needs of the patient.

It was clear to the social workers that all of the patients were likely to present a 'discharge from hospital' problem. Often, this was perceived by the referring ward staff, but they had no time to deal with the resolution of dysfunctional family dynamics, community based resource strategies and the need for flexibility in making appointments to interview all the relatives concerned. They did not have the skills or receive training to do so. Even so they needed regular briefing about the problem-solving progress by the social workers, so that they could co-operate and be effective in discharge planning, advising medical staff, in operating patient safety and giving appropriate family support on the ward.

Interdisciplinary team work, trust and open channels of communication and an acceptance by professionals, was needed by social work, nursing, medical and other staff for maintenance of ongoing working relationships.

Group 1 - Families in Dispute

There were 10 patients whose families were in serious dispute with them and other members.

Two were men aged 22 years, and 88 years respectively. Both had partners. The younger man was a drug abuser, and his common-law wife refused to have him home because of his socially disruptive behaviour, and destructive effect on their relationship. His mother conditionally accepted him to her home on discharge.

The older man was confused, incontinent and had fallen. His wife wanted him home from hospital, and disregarded the stress that care for him, care for her (she was also ill) and care for a brother who was terminally ill, was causing for their sons and daughter. The dispute was centred between mother and daughter. The latter withdrew her support when her father was discharged. As a result he was readmitted to hospital within 24 hours, because his wife had to call the GP as an emergency. He was later admitted to the geriatric hospital for longer-term - possibly permanent care. Neither the mother or daughter really wanted this, but the mother blamed the daughter and retained her power in the family group.

In both of these situations concerning men, the central issues in the disputes were between female family members either taking power or responsibility, when circumstances became practically and emotionally unbearable. The separation of the most dependent person ie. the male, because of hospitalisation, from the ongoing family dynamics appeared to create an opportunity for radical change to occur - even if that meant a complete breach of former relationships.

There were eight female patients in this group, four were married, and four were widowed.
Three of the married women asked for help with their situations, and all were suffering from heart disease. The two younger women, aged 42 and 51 years, had endured marital disagreement for some years, and both became separated from their partners after hospitalisation. In each case adult children took sides with their male partners, and both women ended up in temporary accommodation.

The third woman had a dispute with a male - in this case her alcoholic son, who was living at home. His dependency/disruptive behaviour was more than she could cope with, given that she was also the carer for her severely disabled husband. Her own admission to hospital and chance to talk the situation over with an impartial counsellor, provided her with an opportunity to make a decision. It was that her son should leave home before she returned.

The fourth married woman was totally dependent on her own and her husband's adult children from their previous marriages. She had Alzheimer's Disease, he was frail and diabetic. The family dispute here was between the adult children of both parties, neither group having accepted their parents second marriage. There were arguments about who should care for step-parents, how much of each parent's money had been invested in the property, and how wrong the parents had been to marry. Each set of adult children took their parent away, and the marriage was ended. The husband went to live with his family, the female patient ended up in a nursing home.

Three out of the four married women here were finally in a situation of isolation - without their families, and away from their former homes.

The remaining four women were widowed, and all lived alone. Their family disputes were centred around sons or sons-in-law.

The youngest aged 71 years, was in a strange power relationship with her son, and rejecting of her daughters in collusion with him. She was discharged to her daughter's home following an unnecessarily lengthy stay in hospital. After a short period of time serious arguments developed between the daughter and mother, seemingly because her son was no longer in an 'available' position in her life where they could manipulate or collude with each other.

The second patient aged 72 years had a breached relationship with her daughter and son-in-law. They did not help her even when she was hospitalized.

The third patient, aged 75, did not like her son-in-law. She thought that she should have prior claim to her daughter, and they fell into serious dispute. The daughter did not help her mother when she was discharged.

The last patient was in dispute with her son and daughter-in-law. He wanted to control the family situation, which also concerned his mentally ill sister. He saw the answers to the family's problems in separation and isolation, his mother saw answers in reuniting and caring. The social worker (female) was blamed for supporting the patient.

Conclusion

All of those patients whose families were in dispute showed patterns of behaviour which had been existing for years. In some cases old family problems re-surfaced because they had not been adequately resolved. Dysfunctional relationships between parents and children became intensified, ending in separation which seemed long overdue.

Separation from the family due to illness altered the dynamics in these cases. The individual or joint dysfunction made it difficult for any of the parties involved to reunite on the same pre-separation basis. Hospitalization created an opportunity to end a family relationship in eight out of the ten families.

Group 2 - Patients who were abused and neglected

Abused Patients - their ages and who abused them

In the course of their assessments, the two social workers discovered fifteen patients who were being abused and/or neglected at home, by a small range of carers.

Ten women's ages ranged from 63-85 years, with an average age of 77 years. The majority of abused patients - ie. 8 women who were aged over 75 years fitted conclusions from American studies (Tomalin 1989) that the classic victim of elder abuse was over 75, roleless, female, functionally impaired,lonely and fearful. The American studies also found that victims were most likely to be living at home with an adult child, but this was not the finding of this study. Only one of the 8 patients lived with an adult child, who was her son. He and his wife were seriously neglecting her, and stole her money.

The other seven women aged over 75 years, were living alone, and their abusers were 3 daughters, two sons and daughters in law, one grandson, and an unrelated male landlord posing as the patient's nephew.

Three women under the age of 75 years were being abused by husbands in two cases, and a young male 'friend/carer' in the third. They were not living alone.

*There was one instance where the female patient aged 69 years was abusing her brother, with whom she lived.

Four men were being abused and neglected. Their ages ranged from 73-79 years, with an average age of 77 years. One man lived alone, and was being abused by his son. Two more were living with a son, and son with daughter-in-law respectively. The fourth man lived with his wife.

The profile of the abusers was as follows, in Table 46 showing that nine were female, and eleven were male:-

Table 46. Patients and their Abusers.

Abusers		Abused
Son + daughter in law	65%	3 women + 1 man
daughter		3 women
sons		2 men
husbands	10%	2 women
wife	5%	1 man
grandson	5%	1 woman
*sister	5%	1 men
non-family male	10%	2 women

This picture differs from the one shown by Garrod (1993) where only 25% of abused elderly people were mistreated by sons or daughters, 6.6% by a husband or wife and 16.7% by other family members. He does point out however,that abuse is as likely to be inflicted by other carers, neighbours and strangers as by members of their family.

This study shows that 55% of abusers were male, and 45% female. The same pattern was found in the SSI study (1992) where 54% were male and 46% were female, and 80% of the abusers were principal carers for the elderly people.

Homer and Gilleard (1990) found that those living with a family member other than a spouse were more likely than married people or those living alone, to be subjected to a range of abuse. Again, the situation for patients at Mansfield General was different. Only four patients were living with family members, other than spouses, and seven were living alone. Differences among statistical data are likely to be influenced by the sample groups from which the data are drawn - in this case especially,because it was an acute hospital setting.

There are no other comparable studies from hospitals, but there is evidence in the Scottish Office Central Research Unit report (Connor and Tibbitt, 1988) that patients were at risk, abused or neglected. However analysis is confined to a 'few instances of suspicion of the elderly person being abused or neglected by others in the home'

Categories of abuse

There is no authoritative definition of what consitutes abuse, but suggested categories are physical, emotional, sexual and financial and neglect. All of these categories or only one have been found to apply to elderly abused people, sexual abuse can be one strand in a complex abusive relationship, perhaps including financial and physical abuse as well (Pritchard 1993).

No patients in this study were found to fit into a single category of abuse. All had been suffering for some long time at the hands of their carer/abusers.

Eight were underfed, unclean and in a very poor state of health when admitted to hospital. The nursing staff picked the issue of neglect up in a few cases,but it was the social work assessment of both patient and home circumstances that brought the full picture to light.

Referrals to the social workers were based, for the most part, on a perceived need for services, such a home help or meals on wheels, and the possibility of delayed hopital discharge. It was during the social workers' further investigations into the original problems, that cases became more complex. (Connor and Tibbitt 1988). Very few of the patients had recieved formal care services before admission, though they had clearly needed them. If their 'carers' had bothered to ask for support, in all cases they would have qualified for help.

In the worst cases, the carers had not even asked for medical assistance from the patient's GP. This had happened in two cases, and a distict nurse had been asked to call. It was she who pressed the GPs to admit to hospital, because both patients were beyond surviving with help at home.

There were seven patients who had been physically asaulted, and all had been subjected to emotional and psychological abuse also. Verbal aggression was par for the course and part of everyday life.

Four patients were badly malnourished, two to the point of emaciation. They were all living with their carers/relatives and could not get food for themselves.

Neglect amounted to cruelty, and the patients were deprived not only of food, but of clean clothing and bedding, personal cleanliness and health care. It was obvious too that their relatives dealt with their pensions and other income, and although this was not noted as financial abuse because it was not direct theft, these patients did not have any money.

In four instances patients' money was being stolen - blatantly and persistently by two non-related family males, one grandson who kicked his grandmother and shouted at her, and one son and daughter in law together. The thefts had been long-standing and the abusers thought they had a right to take the money on a regular basis.

The male landlord was belligerent towards the social worker when she approached him for the patient's possessions, and refused to allow entry into the patient's rented home. Police intervention was needed to resolve the situation.

The other non-related male actually visited the patient on the ward, and told the social worker that he was her nephew and used to collect her pension. When the social worker visited the patient's home she realised that 'nephew' and patient were sleeping together, as there was only one double bed, and that something was seriously wrong. Eventually the patient admitted that the 'nephew' was not related, had moved into her home against her will, stole her money and regularly had sexual intercourse with her. She did not know what to do.

A number of patients said they were afraid of their carers/relatives, but even when assault and theft had taken place, they did not want to press charges or involve the Police. They were fearful of recrimination (SSI London Region Survey, 1992) and seemed frozen into compliance with their abusers ill treatment. Their secrets were as powerful and as well protected as those described in child abuse literature. Some even seemed to have developed a masochistic type of conditioning. As Sally Greengross states (Greengross, 1986) 'Frequently, the victim does not wish to report this type of incident, perhaps because of continuing dependence, or a wish to avoid a public acknowledgement of family stress, or a fear of being put into an institution.' None of the referred patients directly reported the abuse they were suffering.

Denial by patients that abuse was happening occurred in most cases. Homer notes this as a barrier to obtaining accurate figures for elder abuse (Homer 1993), and states that 'the reasons for this include embarrassment, guilt, and the fear that the abusing relative will be taken away and they will be left alone' especially if the abuser is the abused person's main support in the community. 'Family loyalty is likely to prevail despite the abuse'

Relationship between abused and abusers

Abuse of patients was happening in the context of family relationships for all but two women. Within these relationships the patients were very dependent due to their frailty and daily needs for care. Stress on their carers no doubt played a part in changing the nature of the relationship with adult children and spouses. As Tomalin (1989) points out, carers are usually compassionate people, but constant pressure on them may make frustration and anger overspill into violence. Eastman and Sutton (1982) also argue that lack of support for carers has a definite bearing in situations of abuse where one adult is left to carry out all the care for an elderly dependent relative with inadequate support from both Health and Social Services Departments.

It would be easy to jump to the conclusion that stress on carers is a major factor in abuse, but increasingly, attention has been drawn to the health, both mental and physical, of the abuser (Pillemer and Finkelhor, 1989). Although the abused person may appear to be the more frail, often it is the abuser who is dependent on the victim, and abuse can occur in both directions (McCreedie, 1991). This was certainly the case where one patient's husband was ill with multiple sclerosis, and another patient's daughter was mentally ill. The situation of brother and sister living together was inextricably woven by interdependence and the deteriorating health of both.

Godkin, Wolf and Pillemer (1989) showed too, that in later life, due to sickness or disability, that marital roles shift and needs are reversed - as in the case of the male patient aged 73, who was admitted with heart disease. Also, marital abuse can continue into old age even leading to violence and physical trauma, illustrated by the female patient aged 73, who was injured by her husband.

It was apparent that abuse to patients was not triggered by any one event, but had happened as a result of deteriorating relationships between increasingly dependent elderly people and 'carers' who were either unequal to, or unprepared for the work involved. Coppeard (1990) suggests that the point at which rejection of elderly relatives occurs is when adult-child role reversals take place - creating pain and anger. The situation is exacerbated when families do not acknowledge the need for help, and will not allow Social Services in.

Abuse can take place because of rigid and regimented§ demands/behaviour by carers, and especially by male carers who are embarrassed about incontinence and handling the aspects of personal, intimate cleaning of parents. In five instances among the abused and neglected patients, sons were the principal carers for their parents - all of whom were in great need of personal physical care. Their responses to these needs was to opt out and to leave them unmet, until the parents were in a degraded filthy state and someone else - eventually - dealt with the problem.

One further aspect of child-parent relationships is discussed by Hicks (1988), with regard to emotional tensions that may have been dormant for years whilst the child had left home to raise her own family and pursue her career. If she is obliged to return to her parent and take over as carer, the tensions can

resurface and grow stronger, tipping into resentment and anger. 'Illness and diability can provide the perfect cover for emotional manipulation, and a parent who has always been possessive and domineering may become even more so ... conversely, a woman who has never managed to break the child/parent bond ... may find herself relating to the same traumas she thought she had left behind ... for those who are forced into the intimacy and isolation of looking after a parent, there can grow a neurotic and destructive bond which neither side is able or willing to break .. '
No family is perfect in its interpersonal caring relationships, and therefore past suffering, family discord and psychopathology are all relative in relationship outcomes (Stevenson, 1989). Abuse can also occur when other family problems arise, which are not specifically caused by the elderly person, but nevertheless create tensions, anger and severe stress.

Also, patterns of uncaring are likely to be learned from parents and come into play when parents themselves need care - but adult children have neither the knowledge nor experience to provide such care.

Possibly the family most at risk is the one where serious breaches of relationships have happened when children are young, and enforced separation is the result. If such children become carers of their parents, and were abused themselves, there seems to be no reason why the cycle of abuse should not continue.

Conclusion

The number of elderly patients who were found to have been abused at Mansfield General Hospital, was small, amounting to 1% of the social work referrals and a very tiny proportion of the overall patient population. There were undoubtedly many more who were abused and not discovered, especially because this research took place in an acute hospital setting and because all research so far has found victims to be mentally or physically very frail, dependent and in a deteriorating state of health that requires increasing care by families and formal services. (Cloke, 1983). Also, as other parts of this research show, the carers of elderly people in hospital were frequently under severe stress, and were experiencing multiple disabilities and high incidences of illness among other family members, which stretched informal carers to their limits.

The OPCS National research findings (1992) suggested that up to 400,000 elderly people might be abused by relatives, in their own homes. Evidence from the OPCS indicates that 10% of people over the age of 65 years, who are supported at home by care-giving relatives may be at risk (Eastman and Sutton, 1982).

On that assumption some 500,000 elderly people in the UK could be victims of abuse. The actual incidence is not known, and as this research shows, not all elderly people who are abused are actually living with their carers. Those living alone are equally likely to be abused, if not more so, and abuse also occurs in residential settings, and in elderly peoples' own homes by non-related carers.

Table 47 provides a reference summary of patients who were abused, and the context of abuse and abusers.

Table 47

Illustrates the situations of women who were abused.

Table to show patients referred by sex, age, illness, abuser and type of abuse

a) Women Total = 12

	Sex	**Age**	**Illness**	**Family relationship**	**Abuser**	**Living with**	**Type of abuse/neglect**	**Dis.to**
1.	F	63	injury to hand	wife	h'band	tog	physical aggression, emotional abuse h'band ill with M.S.	home with husband
2.	* F	69	cellulitis	sister and brother	sister	tog	underfed, physical neglect, left alone, blind, bilateral amputee, poor health	home to brother
3.	F	72	falls	none	male	tog	stole money, kept her pension book, sleeping with her. She was afraid to go home	P.N.H. (legal action)
4.	F	73	fractures and alcoholism	wife and h'band	h'band	tog	physical violence and aggression in marital relationship	Women's Refuge (legal action)
5.	F	77	C.V.A.	mother and daughter	dau'	alone	physical and verbal aggression, Daughter mentally ill	home alone
6.	F	77	Angina Parkinson's	mother, son and grandson	g'son	alone	g'son harrassed her for money. Son did not intervene	home alone
7.	F	79	ill and emaciated	mother, son and dau/law	son & dau/law	tog. in pt's home	underfed, emaciated, dirty & physically neglected. Abusers took her money	home to abusers

Table 47 cont'd

	Sex	**Age**	**Illness**	**Family relationship**	**Abuser**	**Living with**	**Type of abuse/neglect**	**Dis.to**
8.	F	80	head injury	mother and daughter	dau'	alone	physical assault and harrassment. Afraid to go home	Residential Care
9.	F	82	fractured arm	mother, son and dau/law	son & dau/law	alone	physical assault	home alone
10.	F	84	injured shoulder	mother and daughter	dau'	alone	Shouted at, threatened and pushed about	Home alone
11.	F	85	Alzhiemers fractured femur head injury	mother, son and dau/law	son & dau/law	alone	physical neglect, passive disregard of danger patient was in	S.T.C. then home alone
12.	F	85	painful hips, poor mobility	none	male landlord posing as nephew	alone	defrauded her of pension. Pt. afraid of him	P.N.H. (legal action)

* patient was the abuser

7 out of the 12 women were living alone
They were most likely to be aged over 70 years, with an average age of 77 years.
Their abusers were: husbands - 2
sister - 1
daughters - 3
son + dau/law - 3
grandson - 1
non family male - 2

Legal action was needed for 3 women

6 women were injured - 6 suffered physical abuse
2 were financially defrauded by non family
2 were financially defrauded by family
3 needed residential care
1 needed S.T.C.

Table 47 cont'd

b) Men Total = 4

	Sex	**Age**	**Illness**	**Family relationship**	**Abuser**	**Living with**	**Type of abuse/neglect**	**Dis.to**
1.	M	73	heart disease	husband & wife	wife	tog	uderfed, no personal care. Neglect ? physical abuse. Finances	home to abuser
2.	M	77	collapse, chest infection	father, son & dau/law	son & dau law	tog	dirty, neglected, no personal care, emotional abuse, patient afraid	Geriatric Hospital
3.	M	78	peripheral vascular accident	father and son	son	alone	dirty, neglected, home in an appalling state	rehousedto warden aided accommodation
4.	M	79	C.V.A.	father and son	son	tog	kept in upstairs room. Untreated sores. Underfed, soiled with faeces, neglect, no personal care	home to abuser

None of the men were injured
Their abusers were: sons - 2
son & dau/law - 1
wife - 1
2 men went home to their abusers
1 was rehoused in warden aided accommodation

All were dirty, neglected and in need of personal care

Only one was living alone

Average age = 77 years

Group 3 - Sexual Abuse

Two male patients only were referred who had been involved with sexual abuse, in both cases they were abusers themselves.

The first man, aged 24 years, was admitted after taking an overdose. His whole family was involved in a multiple incest/sexual abuse situation. He had had intercourse with his sister, and his brother had raped her. They lived with their father who was epileptic. The patient was referred to a psychiatrist, and admitted for treatment in a psychiatric unit.

The second man was aged 42 years, and admitted with a head injury. He had sexually abused his children, and his wife refused to have him home. He was discharged to his parents' home.

Group 4 - Abuse of Carers

One man aged 67, who was admitted with a chest infection, was found to be abusing his two daughters, who were his carers. They had taken on the 'carer' role after his wife died a few years previously. Apparently he had been physically violent to his wife and bullied her. He transferred his behaviour to his daughters, and they came to the social worker in distress, frightened and angry about their father's treatment of them. They were too guilty to withdraw their dutiful care. As he became older and more dependent his behaviour had worsened. The daughters felt that they could not go on caring for him, and wished the social worker to 'have him put away'. They were offered counselling and practical support. He decided to go home, still in control of the situation, and his daughters resumed their care under protest.

Group 5 - Overdose and self-harm

Numbers of Patients attempting self harm and admission to hospital

During the time period of this research, five hundred patients were admitted to the Accident and Emergency Department who had taken overdoses and inflicted self harm. Twenty one were dead on arrival, or died very soon afterwards. Ten patients who were critically ill, were admitted straight into the intensive care unit. If they recovered they were transferred to the acute wards, and discharged home once the doctor declared that they were fit enough.

Three hundred and sixty one patients were admitted direct to the acute wards at Mansfield General and KingsMill Hospital, depending on the 'on take' rota for and Accident and Emergency each week.

Some patients were referred to a psychiatrist, and six were admitted to the mental illness unit at another hospital.

Social Work Referrals

Only 16 patients that is 11 men and five women were referred to the hospital social workers, who dealt with

them as part of their generic caseloads.
Their ages ranged from sixteen to 79 years, with an average age of 36 years for men and 47 years for women.

Six of the men had no carers, and the oldest woman had no-one to care for her. One man and one woman only were married.

The situations which faced the social workers were very individual, and some of the patients, especially those with alcohol and drug user problems were almost impossible to help.

Only two of the referred patients had specific diagnosed mental illnesses, and one had an old brain injury which resulted in anti-social and disturbed behaviour. The remainder presented with combinations of needs for support, help with dependents, relationships, financial dificulties, accommodation problems, counselling, advice, and one needed residential care. The tables entitled 'Overdose and Self Harm' illustrate the patients' circumstances of those referred, showing age, sex, who they lived with, their carers, needs and problems, and where they went on discharge.

Support needs for patients attempting self harm

One of the hospital social workers was approved under the Mental Helath Act 1983, and was therefore on site to assess patients who were mentally ill. In the course of the year, he completed only four Mental Health Act Assessments on the Hospital site in spite of the large numbers of self-harm presentations. He concluded that 'mental illness' was an inappropriate construct for almost all patients referred to the Department, having assessed their personal situations.

He and his colleague found that crisis intervention assessment, and psycho-social/counselling approaches were more appropriate methods for dealing with the problems that very obviously were causing distress, hopelessness, panic and depression among the referred patients. As Catalan(1982) stated 'Most instances of self poisoning or self injury are preceded by stressful events' involving a relationship with a key person, chronic problems with partners, children, religion, sexuality, work, finances, alcohol, accidents or operations. He also found that there was a greater incidence of poor health and recent hospital admissions among suicide attempters than would be expected of the average population, especially among women.

Unemployment among men was common among male attempters, in Catalan's and other studies. (Holiday, Buglass, Duffy and Krietman, 1977). None of the referred male patients were employed, although all the males were of employment age. Three would have been umemployable, given their condition of mental illness or learning disability. The women of employment age were not at work either.

Every patient referred had problems which originated at home, in the community, and none (except the adolescent male from a Local Authority foster home) had received support from Social Services previously. The man on probation was not in touch with a probation officer and those patients who had been in contact with their GPs or with hospital based doctors were not receiving any active medical support. None had been directed to local helping agencies.

One female who attempted suicide because she needed a termination of pregnancy, had been seen by a consultant gynaecologist at Kingsmill Hospital. Although an abortion counselling facility was provided by the hospital social worker on site, she had not been referred for help.

It was clear when the circumstances of the referred patients were assessed, that only two could not be helped. The remainder would have benefitted from preventative work in the community before they resorted to self harm.

The patient who had an old brain injury could not have been helped by either health or social services, because no provision of any sort existed for him. The social worker for physical disability who was based at Kings Mill Hospital had a further seventeen people in her caseload with previous brain injury - and forsaw similar crises for them because no policy, or planning for service provision existed. People with brain injuries clearly fell between a range of services - psychiatry, medicine, neurosurgery, clinical psychology, social services and the police. Invariably the burden of care fell on families until they reached breaking point.

Hawton and Catalan (1982) sum up this situation very well, by stating that attempted suicide occupies a major position in terms of contemporary health care needs. 'The necessity for finding effective ways of management is all too apparent. The heterogeity of difficulties faced by attempted suicide patients means that a wide range of treatment options should be available to meet patients' needs. Most have problems of a social kind, some have serious psychiatric disorder and others have resorted to the behaviour in response to a transient crisis. Clearly a standard therapeutic response to such problems is not appropriate ... each case must undergo a thorough assessment .. appropriate training must be provided for staff who take responsibility for the assessment ... this aspect of patient care has received scant attention over recent years despite the increase in the number of patients requiring help'

Health Service responses

At Mansfield General Hospital the primary management - or non-management - of patients' needs following attempted suicide lay with the medical staff in Accident and Emergency. Patients attempting suicide were a small proportion - 500:63,000 per year attending the department. Two consultants were in charge, with a group of housemen treating most patients. The housemen changed every six months, and no training was organised for them with any other professional group in the hospital. Social workers grappled with this changing pattern of medical staff. In general, the nurses and medical staff's attitudes were negative towards patients, where self-induced disorder was seen as an umwelcome extra workload, particularly where this had occurred in response to problems of living rather than illness.

Clearly these attitudes influenced the referral rate of patients to social workers, as only 3% of attempted self harm incidents were referred. In Accident and Emergency, as with other departments and wards in the hospital, the threat of being stuck with a patient - indicating the use of a hospital bed and nowhere else to send him or her - was the precipitating factor for referral.

Although the group of patients referred to in this study is small, it is most significant because the case for offering support through multi-disciplinary team structures existed. This was clearly spelt out in previous research and the Suicide Act as far back as 1961, and the Hill Report - Central and Scottish Health Service Councils 1968. No-one in the Accident and Emergency Department, or among the hospital managers at Mansfield General Hospital were aware of the Act or the Hill Report recommendations. Social Service managers were not interested, considering that this was a matter for the Health Service and therefore no planning initiatives were needed.

Author's note:
It was very difficult to obtain the figures used in this section of Chapter 5, because all Acccident and Emergency attendances were simply recorded in an admissions book by a clerk/receptionist. Very reluctantly the hospital management allowed the Social Work Department to borrow the book for two evenings, and the figures were extracted by hand. The social workers were not allowed to have the book on subsequent occasions, but in later years the Community Physician published a brief report on figures of actual suicides in the Health Authority area (See Suicides 65+ years - North Notts Health Authority see Figure 11). This shows very clearly that after 1988-89 where actual deaths totalled 21 (all age groups) that each year produced an increase of suicides, with a proportional rise among people aged 65+ years.

Fig 11

Suicides 65+ Years - North Notts H.A.

YEAR	AGE/SEX	METHOD	DISTRICT COUNCIL	TOTAL ALL AGES
1990	68 F	Hanging	Newark & Sherwood	11
	74 M	Drug Overdose	Mansfield)	12
	66 F	Cut Wrists	Mansfield)	
	-	-	Ashfield	3
TOTAL:	3		CNHA	26
1991	68 M	Hanging	Ashfield)	
	68 M	Hanging	Ashfield)	
	75 M	Cut Wrists	Ashfield)	11
	75 M	Drug Overdose	Ashfield)	
	80 M	Unascertainable	Ashfield)	
	66 F	Drug Overdose	Mansfield)	11
	85 F	Unascertainable	Mansfield)	
	65 F	Drug Overdose	Newark & Sherwood	8
TOTAL	8		CNHA	30
1992	75 F	Drug Overdose	Ashfield)	8
	73 M	Multiple injuries	Ashfield)	
	66 M	Car exhaust gas	Bassetlaw)	16
	83 F	Plastic bag over face	Bassetlaw)	
	66 M	Car exhaust gas	Mansfield)	
	66 M	Drowning	Mansfield)	11
	74 M	Car exhaust gas	Mansfield)	
	83 M	Self-strangulation	Mansfield)	
		Drowning	Newark & Sherwood)	
	75 F	Drowning	Newark & Sherwood)	18
	70 M	Multiple injuries	Newark & Sherwood)	
	71 M	Electrocution	Newark & Sherwood)	
	80 M			
TOTAL:	12		NNHA	52
1993	-	-	-	11
1990/93	23	-	-	119 (19.32%)

Supplied by Dr. North Nottinghamshire Health Authority

Age and Sex Distribution - Overdose and Self Harm

In Britain there are typical distributions by age an sex of people attempting self-harm. (Hawton and Catalan, 1982). Deliberate self poisoning and self injury is more common among females than males, in the range of 2:1. In the Central Nottinghamshire Health Authority catchment areas the range was 5:4, showing an atypical distribution, with many more males attempting suicide.

The highest rates for both sexes overall is between 15 and 30 years, after which age the rates decline substantially in middle age, and are low after the age of 60 (Cook and Oltjenbrums, 1989). The figures at Mansfield General Hospital followed this pattern. Among adolescents, self poisoning is a problem, with variable rates across the country. In this study, exactly the same number of individuals under the age of 15 years attempted suicide as the age group 64-75 years, ie 3.4% = 17 cases. None of these were referred to the social workers.

Catalan notes that self poisoning behaviour is extremely rare among children under the age of 12 years. The Accident and Emergency records contained three children aged 3, 3 and 4 years as having taken overdoses. Whether these were actually self harm attempts, accidental ingestion or over administration of tablets by an adult is not at all clear. In any event, the children were not referred to Social Services, in the hospital or the Area.

Among older people, over the age of 60 years, suicide attempts are more likely to result in death than in all other age groups. Less frequent forms of self injury, such at shooting, attempted drowning and jumping from heights tend to involve older people and are associated with serious suicidal intent (Catalan, 1982). The previous North Notts table illustrates this situation very well, and also shows the rising number of deaths among older people. In 1988-89, 18 women and 14 men aged 65+ were brought to the Accident and Emergency Department after taking overdoses, including one 72 year old woman who had drunk Domestos. One woman only out of 32 admissions was referred to the social worker - not because she had taken an overdose, but because she could not be returned home safely, and needed residential care.

Gray and Isaacs (1979) commented that suicide rates rise steadily thoughout life, and especially between the ages of 65 and 74. For these older people who attempt suicide, whether this is a part of loss, depression, isolation, guilt or despair. 'There is a great deal that can be done through counselling, dedication and increased social opportunities - in short through approaching a very old person who appears depressed as one would anyone else but with an understanding of the special factors which underlie their condition' (Stevenson, 1989).

Overdose and self harm

Table 48

Tables to show patients referred by sex, age, problems and needs

a) Men Total = 11

	Age	Presenting illness	Living with	Carers	Problems	Needs	Dis. to
1.	16	Overdose	foster parents	f/ps	theft in foster home	support from area Social Worker	fosterhome
2.	22	Overdose	alone	none	regular drug user	refused help	home
3.	22	Overdose	alone	none	marital problems. Sch 1 offender. On probation	money and night shelter	?
4.	25	Overdose	parents	rejected	old brain injury. Disturbed behaviour. Neglected by parents.	no help available	London
5.	28	Overdose (2nd)	alone	none	homeless. Unemployed. Separated from wife and child	Mental Health Team Accommodation	New home
6.	29	Overdose	wife	wife	marital problems	Legal advice	Home
7.	31	Overdose	c/l wife	c/l wife	mental illness Elderly parents. Alcohol, unco-operative	Refused help	Home
8.	35	Schizophrenia	parents	parents	stress at home. Debts. Severely disabled child	financial help. Advice. Respite care for child. Support	D.S.S. and home
9.	42	Overdose Mental illness Learning difficulties	alone	none	isolated. No social network	Day Care. Support from C.P.N.	home
10.	44	Overdose	mother	none	could not cope with self-care and senile mother	Domiciliary services for mother M.H.Team support	home
11.	49	attempted hanging	alone	none	alcohol. Mortgage arrears. Eviction pending	Contact with family Sister and aunts paid debts and organised him	home

Men: Two men refused help. Two had alcohol related problems, one was a drug user. One had been brain injured years ago, and no formal help was available. Six men had no carers.
Five men lived alone. Only one was married, one had a common law wife. Three had previous mental illness and all needed help from a specialist team or worker.
Average age of men = 36 years

b) Women Total = 5

	Age	Presenting illness	Living with	Carers	Problems	Needs	Dis. to
1.	21	Overdose	family	family	had been refused termination of pregnancy. No partner	referral for termination	home
2.	27	Overdose Depressed	child	parents	financial problems No partner. Depression	financial advice. Support from M.E.T.	home
3.	47	Overdose	husband	husband	marital problems. Assault by husband	Counselling with Social Worker	home
4.	63	Head injury	alone	son & sister/law	mentally ill. Violent behaviour, carers couldn't cope	admission to psychiatric unit	psychiatric unit
5.	79	Overdose	alone	none	isolated. No close family. Parkinson's Disease	P.R. home	

Women: the elderly woman had no carers. Only one woman was married, and the problem was marital. One woman had been mentally ill previously and needed specialist help.

Average age of women = 47 years (only one elderly woman)

Conclusion

Although the numbers of referrals to social workers for overdoses and self harm were very small, their context in the whole picture of numbers of patients presenting to Accident and Emergency shows that a very large area of unmet need existed. Very many more of the patients could have been helped - if they had been assessed through anything other than a medical model influenced by hospital staff's negative attitudes.

The whole hospital and Social Services response to attempted suicide at Mansfield General Hospital needed to be examined thoroughly, and restructured from senior management down to the interface of Health and Social care. Newson-Smith and Hirsch (1979) showed in their study of asessments by psychiatrists, other medical officers, nurses, and social workers, that treatment and support strategies could be constructed for this group of patients. Further more, that social workers appeared to be more aware than other staff of the relevance of interpersonal and family problems. They therefore suggested that social workers should be involved in assessment of all attempted suicide patients, with a psychiatrist available for emergencies and consultation with the social worker if necessary. These issues remained as unmet need at Mansfield

General Hospital.

Group 6 - Learning Disabilities

Nine patients with learning disabilities were referred to the social workers. There were five men and four women. As with the overdose/self harm category, these patients tended to be younger, with an average age of 35 years for men, and 60 years for women.

Four men lived with their families who also had learning disabilities, and one lived with his common-law wife who was also disabled. Three were the main family carer. All five men eventually went home, and the social workers found themselves meeting the needs of whole families,not just those of the patients.

They provided practical help, debt advice, organisation of basic living conditions, liaison and linking with area workers and a range of other resources.

The four women lived with family members who were disabled. Three were main carers themselves, for others in the family. All were discharged home, and once again the social workers were needed to provide help not only for the patients, but for their other family members also. One dependent son with severe learning disabilities had to be admitted to residential care because his mother could not cope with him after her health had deteriorated.

The living conditions of all of these patients were squalid at least, and in a state of disorganisation that had gone unchecked for some years. None were receiving support from the Community Mental Handicap teams, although some were closed cases to area social workers. None had help from voluntary agencies. None of the patients or their dependents had any idea of where to go for help, and furthermore did not expect it.

Table 49 shows the patients ages, illness, who they were living with, their problems, needs and destinations on discharge.

Group 6 Learning disabilities

Table 49

Table to show patients with learning disabilities who were referred by age, sex, illness, problem and need

a) Males Total = 5

No.	**Age**	**Illness**	**Living with**	**Problem**	**Need**	**Dis. to**
1	16	Self harm Accident	Family	Family not coping as all had learning disabilities	C.M.H.T. Food, financial help and practical family support	Home
2	16	Assault by family bruises and abrasions	Family	Squalid family home Violent family all with learning disabilities	Help with debts Practical help and cleaning of home Area S.W. support	Home
3	25	Pneumonia	Father	Father had learning difficulties and couldn't cope alone	More support from area S.W. & primary health care team Patient took own discharge	Home
4	42	Heart attack	Common-law wife	Wife couldn't care for herself. No family	Domiciliary support for self and wife on discharge	Home
5	78	Gastric & Intestinal bleeding	Adult daughter with learning difficulties	No electricity, infested house Daughter unable to cope	Environmental Health. Care for daughter. D.S.S. benefits. Furniture & bedding. C.M.H.T.	Part III for patient S.T.C. for daughter

4 patients lived with family who also had learning disabilities

1 patient lived with his common-law wife, who was also disabled.

All five eventually went home. All patients and family members needed practical help, debts advice and organisation of basic living conditions.

Table 49

b) Females Total = 4

No.	**Age**	**Illness**	**Living with**	**Problem**	**Need**	**Dis. to**
1	24	Abdominal pains	Mother & disabled sister	No heating or cooking facilities	D.S.S. benefits Bedding. Financial advice	Home
2	62	Gall bladder	Husband - disabled	Husband incontinent and completely dependant on patient	5 day per week Day Centre for husband & Domiciliary Services	Home
3	76	Fractured femur Parkinson's	Son - disabled	Son severely disabled. Home in a mess. Son and mother sleeping together	Residential care for son. Domiciliary Services for patient	Home alone
4	77	C.V.A.	Brother - disabled	Brother dependant on patient	Services for patient & brother on discharge	Home

All four women went home

The overall picture of this identified patient group showed a clear need for assessment and social work intervention which was crisis oriented, task centred and psycho-social in context (Pincus and Minahan, 1984). This could be met in the very short term by the hospital social workers, but needs also existed for the use of ongoing community based resources, such as residential care, day care, domiciliary care and ongoing support for some by Community Mental Handicap Teams. The difficulties that the social workers experienced in engaging the latter were due to the fact that the local CMHT's had adopted a community developmental role which addressed global needs for its client group and were not geared to individual person support.

The hospital social workers - on a very tight timescale since some of the clients could not be discharged from hospital due to social problems - sorted out the clearing and cleaning, direct service delivery and DSS/financial problems, leaving the families in a fair state of organisation. However, no care plan could be viably set up to ensure that this was maintained, and follow-up support remained a rather vague target.

The collective statemnt of the CMHT's, being collated at the time of this study was as follows : 'Effort needs to be directed to a range of preventative measures to help avoid family and other crises. Advice, support and appropriate services should be available from birth, and as required. The availability of such provision will usually be important with regard to the psychological, social and often economic well-being of people with mental handicaps and their families' (Nottinghamshire County Council Social Services 1990).

On the subject of community support for patients with mental health and mental handicap difficulties, Brochstein et al(1990), considered that social workers, with their background in treating their clients in an holistic and humanistic manner, should play a central role in the process of ensuring that their needs are identified and met. But they also commented that 'The inability of primary care and mental health systems to adequately provide comprehensive services to patients is a profound dilemma in health care today'

Wenger (1984) observed among her case studies, which included a number of people with mental handicap, that even where a family was in contact with Social Services, that the parents remained under considerable stress and had little day to day support. She also identified, as this study shows, that carer networks in these particular families were small, and consisted mostly of immediate family members, with perhaps some support from a neighbour and only incidental contact with other people, such as the breadman and postman who called to deliver at home.

Again, with reference to mental handicap Davies and Challis (1986) pointed out that informal carers cope with the vast majority of dependents at home, with little cost to health or social care agencies.

A paper by Graif Ketley-King (1986) stated that 'in an ideal world (parents of mentally handicapped people) would be supported by family, friends and neighbours, as well as by statutory, social, education and health care services .. In practice a parent looking after a mentally handicapped offspring may receive pitifully little support. Some battle on until they are of an age when they are physically incapable of coping further, ... enormous gaps remain in services, and those which are available may be unused because of the parents' ignorance of them'.

The referred patients were all from social classes 1V and V, and therefore likely to be socially and economically disadvantaged in many aspects of their lives. Their home circumstances strongly reflected this, and as two thirds of them were the main family carer, they were under severe pressures in their daily lives. How some of them had coped for so long - especially the women who were older than the men, was very difficult to comprehend.

The General Nursing Council of Scotland (Circular 1980/8) drew attention to the nature of care as follows 'Care of mentally handicapped people - especially if they have moderate or severe dependency is physically and emotionally exhausting, especially resulting from intense and intimate contact over a long period of time - even for formal care staff'.

In conclusion, the patients and their families had multiple needs - all of which had existed before the presenting family crises and illnesses had been precipitated at Mansfield General Hospital.

A summary of the patients' needs is as follows: (see over)

They were for : food
money and access to DSS systems
gas and electricity services
bedding, furniture and clothes
Environmental Health cleansing
day centre attendance
domiciliary care at home
residential care - mental handicap
residential care - STC and LTC, elderly Part 111
advocacy
community support - direction by gp's
links with voluntary organisations
carer support
individual and group social work intervention and support in crisis and long term.

The total number of people needing direct help was 23.

Group 7.

Families with severe chronic stress

There were 37 patients (21 women and 15 men) referred to the social workers whose families - by their own admission - were under severe stress which had been going on for a very long period of time.

No formal measurement for stress was used in any way by the workers to identify these families. They noted as part of their casework recording that the stress levels which they perceived were severe enough to cause some form of mental and/or physical breakdown for one or more family carers.

In some cases, the stress was very obviously caused by the numbers of family members who were ill and disabled at the same time. A few families had hardly anyone fit enough to be a carer, and even though the admitted patient was acutely ill, others at home were severely disabled and ill as well.

A few patients were dying, and 16 were known to have been readmitted repeatedly around the hospital group. For nine women and nine men, this hospital admission signified the end of their living at home. All must have been on the margins of residential care for some time and some of their carers were disrupting their lives in order to look after them. For example, one daughter was sleeping in her mother's hallway in a sleeping bag, and a grandaughter was missing school to look after her grandmother. Children and parents had split up in one case in order to accommodate their elderly grandparents, children were displaced from their bedrooms in another.

Many of the patients needed 24-hour care, and their families could not provide it, however hard they tried.

The two men and five women who did go home were obviously almost needing residential care, and their admission was just a matter of time.

Tables 50 and 51 show the patients, their carers, stress areas and needs for support.

Table 50 **Families with Severe Chronic Stress - table to show women referred**

No.	Age	Illness	Living with	Stress area	Need	Discharged to
1	55	Myotonic Dystrophy	Husband & son	Husband ill - off work Son - E.S.N. + Myotonic Dystrophy Husband refused services	Family support O.T. aids	Home but re-admitted to hospital 4 times in 3 month
2	60	Back pain	Son & D/law	Son - agrophobia D/law - full-time work 7 yr old G.son - E.S.N.	Rehousing	Home
3	67	M.I. & falls	Alone	Family gave limited help - all at work G/dau off school acting as carer	Domiciliary support	Home
4	69	Alzheimer's Disease	Husband	Husband had C.V.A. Daughter couldn't care for both	Care for patient Referred to Psycho-geriatrician	Geriatric Hospital
5	71	Cardiac failure	Son & D/law	Carers couldn't cope this was 3rd hospital admission and they refused to have her home	Residential care for patient	P.N.H.
6	71	Falls - chronically disabled with poliomyelitis	Husband	Husband - C.V.A. & arthritis Died while patient was in hospital. Daughter couldn't cope	Residential care	P.N.H.
7	71	Back pain and chest problems - stress related	Alone	Daughter - only carer admitted to hospital Patient couldn't cope without her	Anxiety/stress management - referred to Mental Health Team	Home
8	73	Cancer & mobility problems	Alone	Daughter - carer Son/law had Parkinson's disease Dau. moved in with mother-sleeping in hallway in sleeping bag	Domiciliary support MacMillan Nurse	Home
9	75	Breast cancer	Husband	Husband had Alzheimer's Disease - doubly incontinent - admitted to hospital	Care for husband in hospital & 24 hour care for patient	Niece's home
10	78	Alzheimer's Disease and malnourished Alcoholism	Alone	Patient was alcoholic and couldn't care for herself Incontinent. Daughter couldn't cope anymore	24 hour care - medical treatment	Geriatric Hospital

Table 50 cont'd

No.	**Age**	**Illness**	**Living with**	**Stress area**	**Need**	**Discharged to**
11	78	Chronic arthritis painful ankle	Alone	Son taking time off work to care for her - in danger of losing employment	24 hour care	P.N.H.
12	79	Heart attack	Husband	Husband ill - daughter caring for both - had a back problem. No formal services	Support services at home	Home
13	81	Back pains	Son, Dau/law & grandchildren	Patient occupying child's bedroom. Children 6 & 11 years sleeping together. Whole family stressed by care demands	24 hour care	P.N.H. (patient didn't want to go)
14	82	Fractured hip Bronchitis	Son & D/law	Both carers working - needed a break	Shared care - residential home	Home with Part III shared care
15	84	Injuries from falls.	Alone	Alcohol. Not co-operative with family. Patient also had a colostomy	Family support to manage care. Detoxification	Geriatric Hospital and then home
16	85	Falls & Cerebral	Aged sister	Aged sister couldn't cope No formal services	Support from area Mental Health Team & shared res. care	Home & Part III shared care
17	87	Hematemisis Gastric ulcer	Daughter	Daughter getting patient up at 5:30am, then going to work. Other daughter working. Carers couldn't cope	Shared care - residential and domiciliary support	Geriatric Hospital and then Part III shared care
18	88	Fractured pelvis Asthma Alzheimer's	Nephew	Doubly incontinent Carer couldn't cope but wouldn't give up	Residential care - refused by hephew	Home but re-admitted 5 times in 3 month to Geriatric Hospital
19	88	Fractured femur	Daughter & Son/law	Carers couldn't cope any longer, Couldn't have her back home	Residential care	P.N.H.
20	89	Fractured femur Falls. C.V.A.	Alone	Daughter nursing patient in bed for weeks - she had severe osteo-arthritis	24 hour care	Geriatric Hospital
21	95	Injuries from R.T.A. Alzheimer's	Alone	Sons and families tried to care - couldn't cope. Beyond formal services care Family refused to let her go home	24 hour care	Part III and then Geriatric Hospital where patient died

Table 51 **Families with Severe Chronic Stress - table to show men who were referred**

No.	**Age**	**Illness**	**Living with**	**Stress area**	**Need**	**Discharged to**
1	52	Cancer	Wife, son & dau/law	Management of terminal illness. Patient did not know diagnosis. Family had emotional problems. re: his care	Family counselling Advice re: illness management. Bereavement counselling	Home and re-admitted Patient died
2	55	Cardiac failure	Mother with Alzheimer's	Couldn't cope with care of elderly mother. Was sleeping downstairs with her. No help given by Geriatrician	Residential care for mother S.T.C. only given	Home
3	62	Fractured hip C.V.A.	Wife & daughter	Wife had C.V.A. - daughter couldn't cope with father's unco-operative behaviour Dau. was up and down all night	Support for carer with patient's wife 24 hour care for patient	Geriatric Hospital
4	63	C.V.A. Hematemisis & Melaena	Wife with M.S.	2 sons and daughter trying to care for parents but couldn't cope. One son took both parents home - his children went to his brother's home. Split the family and they couldn't cope	24 hour care for for patient	Son's home and then re-admitted to Geriatric Hospital
5	65	Chest pains Parkinson's Disease	Wife	Wife had chest pains & mental illness. She also cared for her elderly mother - confused and incontinent. Couldn't cope	24 hour care for for patient	Home and then re-admitted to Geriatric Hospital
6	70	Fits Alcoholism	Wife, dau. & son/law	Patient alcoholic and aggressive. Wife blind and deaf. Daughter had cancer. Son/law worked full time. Family couldn't cope.	24 hour care for	Geriatric Hospital
7	70	Hypertension Chronic chest disease	Wife	Wife refused to have him home because he was too dependant and demanding	24 hour care	P.N.H.
8	72	Cyst on knee Poor mobility	Wife	Wife had a C.V.A. and depression. Wanted to divorce her husband while he was in hospital	Marital therapy for longstanding problems	Home

Table 51 cont'd

No.	**Age**	**Illness**	**Living with**	**Stress area**	**Need**	**Discharged to**
9	75	Mental illness	Alone	Patient soaked his bungalow with urine. Sexually hyper-active. Confused. No Psychogeriatric or G.P. support, Family couldn't cope	Psychogeriatric treatment and specialized care	Psychogeriatric Hospital
10	76	C.V.A.	Wife	Wife physically disabled and receiving psychiatric treatment. Couldn't have him home	Residential care	Part III
11	77	Cardiac failure	Alone	Daughter caring for several years. Patient refused formal services. She couldn't cope and refused to have him home. He refused residential care.	Residential care	Geriatric Hospital
12	78	Muscular Dystrophy	Wife	Wife wheelchair dependant Both needed residential care. Patient refused to go Expected exhausted daughter to give 24 hour care	Residential care	Home with Domiciliary Services
13	79	Cardiac failure Chest disease	Wife	Wife wheelchair dependant Daughter sleeping overnight at their home. Sons helped but family couldn't cope.	Residential care	P.N.H. with partner
14	84	Fractured femur	Wife	Daughter died - son/law main carer with 3 sons. Wife had poor eyesight & cancer. Son/law couldn't cope with ill father/law	24 hour care support for son/law	Geriatric Hospital
15	85	Bowel cancer	Son & dau/law	Son & dau/law exhausted, needed a break.	S.T.C.	Part III S.T.C.

Other problems

The final category of social work referrals was termed 'other'. This was a convenient catchall for situations where the workers were involved with a whole variety of needs, some generated by the hospital and social service systems, others by patient/carer requests for information and advice. A small number were about carer support for dependents in the community - usually related to the patient or carer but not directly related to the patients themselves.

The hospital linked 'other' problems included support for ward staff where behaviour problems, carer distress and complaints were involved. Sometimes the Community Health Council was consulted or informed, sometimes enquiries needed to be made about other health-related resources, such as the geriatric hospital, a Young Disabled Unit or Mental Illness facility. There was a lack of knowledge among nursing staff - and especially among the junior and frequently changing medical staff about County based resources and an almost total lack of awareness about National specialist resources.

'Other' problems also involved relationship with, and patient/carer use of voluntary agencies, especially

Carer Support groups. The Carers' Support Scheme in Central Nottinghamshire was a developing resource at that time, and not universally available. Referral to groups therefore had to be made on an individual basis with considerable discussion with the carer to try and define possible benefits in joining groups.

In all there were 244 patients/carers who needed the social workers' support for 'other' problems.

Table 52: Patients' needs in relation to Social Work Referrals.

Total number of patients referred = 1064
Number of patients who could not be helped = 129
(died, transferred, discharged-not seen)
Number of patients supported by social worker = 935

Area of need	no of patients
Welfare rights	195
Domiciliary Services	329
Meals on Wheels	136
OT aids	167
Housing and heating	46
Family problems	90
Help with dependent	11
Residential care	110
Day centre/ residential home day care	42
Private domestic help	42
Other problems	244
Total	1412

NB Some patients had more than one area of need which the social workers addressed, therefore the number adds up to more than 935.

It must be noted too that the category of 'family problems' actually generated a complexity of tasks that are not reflected in the range of social work tasks which the data here is able to illustrate.

Due to the fact also that various numbers of people in patients' families and social networks needed support as well as the patients, the actual number of individuals whom the social workers helped is not known, and could not be accurately counted.

CHAPTER 5

Patients who were referred to the Discharge Scheme

Chapter 5

Patients who were referred to the Discharge Scheme

5.1. Introduction

Once the social workers had made an assessment of their referred patients, in conjunction with nursing staff, sometimes the medical staff, the OT and physios, occasionally speech therapist, psychiatrist, psychologist, stoma nurse and any other specialist worker in the hospital, and had determined the need for formal support services in the community with both the patient and her/his carers, there still remained a number of discharge circumstances where safety at home was a problem.

Some patients decided that they wanted to go to their own home rather than into residential care, despite all their carers - and the social workers' concerns for their safety. Even though the outcomes of their assessments of need had affirmed that they would not cope at home, patient choice was the key principle for discharge outcome.

The patient's consultant - if he was a geriatrician, was always aware of high risk circumstances such as these, and his decision to keep his patient safely in hospital and to prevent discharge was a possibility. In severe risk (life threatening) situations, the consultant agreed to hold the bed open - even though this was an acute bed - whilst the patient went on an extended home assessment/trial visit for up to 36 hours to test the possibilities. If the situation broke down during that time, the patient would be brought straight back to hospital by the most expedient person and transport to hand. Then the situation would be reviewed and replanned.

The social workers arranged domiciliary care and meals on wheels with up to five different area Social Services offices which were within the Health Authority catchment area, and were informed about shortages of resources as they occurred. Service shortage was a serious problem for patients being discharged at Bank Holidays, and at weekends. Obviously, the lack of essential services at home could delay discharges and create problems of bed availability in the hospital for up to a week. This in turn caused high levels of anxiety for the hospital social workers, and the patients' carers and ward staff who had to set up definite discharge arrangements.

For these, and other reasons central to community care needs, the social workers referred to the Discharge Scheme Co-ordinator for the use of a flexible volunteer care resource that would address unmet needs at home, bridging service gaps and deficiencies whilst ensuring safety and effecting patient choice.

One very important structural/organisational feature of the

volunteers' intervention was that they immediately became a direct line of communication between patient and hospital if something went wrong, or if a crisis occurred. This also applied for feedback on patient safety and care systems at home, to the Co-ordinator and/or the social worker.
During the first year of operation, 169 patients - ie 14% of the social work referrals, were referred to the Discharge Scheme.

5.2. Profile of referred patients.

Table 53 shows referred patients by age, sex, marital status and living alone

This table shows that of patients referred, one third were men, and two thirds were women. Most patients of both sexes were within the ages 70-84 years, with proportionally more men than women aged 75-79. More women than men were under the age of 65 years (12:5%) and more over were aged over 90 years. (5%:2%).
The largest number of referrals overall were for widowed women, followed by widowed men. Proportionally more men than women were married, and divorced, the proportions of single men and women were almost equal.

PROFILE OF REFERRED PATIENTS

TABLE 53

Table to show patients referred to the Discharge Scheme by sex, age and marital status, and whether they lived alone.

MEN

Age	Married	Single	Widowed	Divorced	Total	%	Living Alone
-65	1	2			3	5	2
65-69	4		1	1	6	10	2
70-74	2	4	4		10	17	7
75-79	6	1	12	1	20	34	13
80-84	2		9		11	19	9
85-89	2		5		7	12	5
90+			1		1	2	1
TOTAL	17	7	32	2	58		39
	(29%)	**(12%)**	**(55%)**	(3%)	**(100%)**		**(67%)**

WOMEN

Age	Married	Single	Widowed	Divorced	Total	%	Living Alone
-65	7	2	4		13	12	3
65-68		3	7		10	9	10
70-74	4	2	12		18	16	14
75-79	5	1	15	1	22	20	16
80-84	3	2	25		30	27	28
85-89		2	10		12	11	12
90+			6		6	5	5
TOTAL	19	12	79	1	111		88
	(17%)	**(11%)**	**(71%)**	**(1%)**	**(100%)**		**(79%)**

Total all pts. = 169

Men = 58 (34%)	Living Alone = 39 (67% of men)
Women 111 (66%)	Living Alone = 88 (79% of women)

A comparison with the marital status of the general population aged over 65 (GHS 1985) shows some differences and similarities with the group of patients referred to the Discharge Scheme. Only a quarter of the male patients were married, compared to three quarters of men generally, twice as many men were single (12%:6%), three times as many were widowed, and the same percentages were divorced.

The picture is different for women. A sixth of the women patients were married, compared to just over a third of women over 65 generally, proportions of single women were almost equal, and fewer women were divorced.

The proportion of elderly people of either sex who lived alone increased with age, but overall more elderly women were likely to do so. In the community some 20% of men and 48% of women aged over 65 years lived alone. (GHS 1986). Among referred patients, living alone was a very significant factor at 67% of men and 79% of women.
In the age groupings for women of 80+ years, 94% were§ living alone, compared to only 61% in the general population (Social Trends 1987).

The most significant features about patients 'at risk' were therefore that they were :

- living alone
- widowed
- male to female in a ratio of 1:2
- males, mostly aged 70 years and over
- females, mostly aged over 70 years and with a much larger number aged over 80 than men.

The pattern of increasing numbers of referrals among older people and living alone, was very similar to that found in the South Glamorgan Discharge Service. (Russell J, 1989). The patients studied in that service were in the ratio of 40% male to 60% female, comparable with the national balance of men and women aged over 65 years. (CSO 1988). The Mansfield study showed a balance of 34% male to 66% female. 74% lived alone, compared with 78% in the South Glamorgan study.

The likelihood of living alone increased for both men and women as they grew older, but more women overall lived alone.

Divorced patients were the smallest proportion of men and women referred. As their percentages showed little variation from those to be found in the general population (GHS 1985) divorce did not appear to have particular significance in the context of the Mansfield study.

Concerns have been expressed that the national divorce rate will affect client/patient/carer need for help in the future, as that rate rises (Parker G, 1990). It seems likely because the numbers of divorces are rising in the general population that there will be an increasing number of divorcees of both sexes entering hospital and requiring support, and that the numbers of older married people will decline, especially women.

It may be that the balance of numbers in each group will affect each other by proportion, and in relation to age groups, by decade, as the numbers of divorced people rise.

5.3. Illness categories among patients referred to the Discharge Scheme

Patients with a range of illnesses were referred, reflecting overall the illness categories of patients referred to the social workers. The greatest number of referrals, as with the social work patients, were for women with orthopaedic trauma/illness, followed by men with similar condition. This was to be expected since functional disability at home - especially of sudden onset - meant that these patients had basic needs for help with mobility, and could not fetch and carry so well as before. Many were old and frail before admission, and their hospital experience left them not only with decreased functional ability, but also with loss of confidence and an unclear view of their future capabilities.

The occupational therapists and social workers often heard patients say, 'I'll cope somehow', knowing very well that this was optimistic but unrealistic, and that however well a patient appeared to manage in the limited setting of a warm comfortable ward, coping at home was likely to present more difficulties.

Home visits before discharge proved the case when patients had to encounter a step from the living room to kitchen for example, and neither a zimmer frame nor an Etwall trolley could be manoeuvred over it, especially if a cup of tea was carried as well. Furniture which was too close together, low easy chairs, loose rugs and coal fires all presented hazards for patients with poor mobility.

Even when a person's home had been re-arranged, with bed downstairs and a commode nearby, there remained a considerable risk of falling, tripping or stumbling among those whose movements were impaired, had transient ischaemic attacks, dizziness, joint pain or had urgency in using the toilet.

Referrals to the Discharge Scheme

- total patients =169 100%

Table 54 - to show primary illness affecting men and women

Illness Category	No of men	%	No of women	%	Total pts	%
Orthopaedic	22	37	67	60	89	53
Digestive tract	15	26	11	10	26	15
Cardio-vascular	7	12	16	14	23	14
Respiratory	6	10	3	3	9	5
Cancer	3	5	5	5	8	5
Endocrine	1	2	2	2	3	2
Urology	2	4	2	2	4	2
Psychiatric	-	-	1	1	1	1
Neurology	1	2	-	-	1	1
Other	1	2	4	4	5	3
Total	58	100	111	100	169	100

Except for orthopaedic illness/trauma, the medical conditions of the patients referred, by proportional sequence, followed the general pattern of causes of death, as did those of the patients referred to the social workers.

During the screening process undertaken by the Discharge Scheme Co-ordinator, other health/disability problems were recorded in case there would be difficulties with for example, communication, when the volunteers were helping patients in the community.
Table 55 illustrates these problems.

Table 55 - Further Health/disability Problems among Patients

	Men	%	Women	%
Poor eyesight	18	26	34	31
Hearing loss	11	16	26	23
Special dietary needs	5	7	16	14
Poor mobility	39	57	81	73
Emotional problems	19	28	10	9
Mental illness	2	3	6	5
Learning disability	2	3	-	-
Communication	9	13	12	11
Receiving medication	39	57	79	71

Total patients = 169 = 100% Men 68=100% Women 111=100%

Some patients had combinations of sensory impairment, poor mobility and other difficulties shown in the categories above. More women than men had poor mobility, and more were receiving medication.

These data give a picture of frail vulnerable people, for whom living alone would be problematic, stressful and a serious struggle. Coupled with the circumstances of very old age, poor standards of housing and coal fired heating, daily living for some was a miserable business. In spite of this, and in some cases very little or no family support, the patients all wanted to go home and did not consider that residential care was a better option.

Some patients were terminally ill, but still wanted to return home. This wish was expressed when Discharge Scheme screening took place, but as the data in section 4 show, not all were able to leave hospital.

5.4. Discharges and Deaths

All patients who were referred to the Discharge Scheme were expected to return home by health and social service workers, at the time of referral. Some, however, experienced a deterioration in health after referral, and either died or had to be transferred to the geriatric hospital.

Unexpected circumstances occurred for others, which prevented help from being provided by volunteers.

In total, 131 patients were actually helped at home, the remaining 38 were not helped for the following reasons:

3 died on the acute wards
2 remained in hospital
7 were transferred to the geriatric hospital
1 was admitted to a private nursing home
1 was admitted to a private rest home
4 were admitted to Part 111 from the acute wards
1 was discharged too soon, ward staff forgot to inform the social work department or Discharge Scheme
3 were taken to their daughters' homes
1 was taken to a son's home
11 were screened, and family/carer support was adequate in spite of the social worker's assessment
1 no volunteer was available in that geographical area
1 the Co-ordinator refused to allow a volunteer to go into a disreputable lodging house
1 the volunteer was cancelled because a male patient really wanted an unpaid housemaid
1 a volunteer appeared unexpectedly from the Red Cross
Total = 38 patients

13 patients among those referred proved to be too ill to be discharged home. Three patients died in hospital, and six more died at home after discharge with volunteer support built into their home care network.

Five patients were too frail and dependent to be discharged home, and the social worker admitted four directly into Part 111 residences.
Four more went home with volunteer support, but could not remain there safely. After a short period of time, they too were admitted to Part 111 from the community. In one instance, the volunteer transported and admitted the patient she had been supporting.
One more patient was admitted to a private nursing home, after trying to remain at home, bringing the total to two.

Four patients were re-admitted to the Acute hospital because their health worsened, one of these died and one went into Part 111 at the second discharge.

The total number of patients who died therefore came to 10 (6%), and the numbers who were admitted to residential or nursing home care was finally 11 (7%).
Four patients who had adult children were taken directly to their homes. They were sure that their elderly parents would not cope alone. Two more patients were removed from their homes by a son and a daughter after trying to manage alone with volunteer support, bringing the total who went to live with others to six. Families rarely moved into an elderly person's home to ensure her/his safety - this only happened on one occasion.

5.5. Personal/domestic help needed by Patients before Admission, and after Discharge from hospital

A screening process which was used for for patients referred to the Discharge Scheme provided an opportunity to record the kind of help that patients had needed before they came into hospital. This information was given by the patients and their carers who were consulted during the screening by the Co-ordinator.

The Scheme monitoring process for each patient after discharge and throughout the course of volunteer intervention enabled the Co-ordinator to ascertain increased need and types of help that they required after their period of illness in hospital. The volunteers reported in to the Co-ordinator after the patients had been home for 24 hours, and the Discharge Screening Form (See Appendix E, Chapter 1) was updated.

The Co-ordinator also wrote a running record for each patient as the volunteers reported back and was able to check the areas of formal service that the patients received. She was also able to record which service did not arrive after they had been requested, and whether the patients found them to be satisfactory. Table 55a shows the numbers of men and women by types of help needed, before and after their hospitalization.

The screening forms and records show that levels of help

Table 55A Personal and domestic nelp needed before hospital admission, and after discharge.

Help needed with	MEN			WOMEN			ALL PTS.			
	Before	After	%	Before	After	%	Before	%	After	%
Shopping	25	43	74	65	97	87	90	53	140	83
Laundry	30	39	67	51	77	69	81	48	116	67
Pension	21	31	53	54	72	65	75	44	103	61
Cleaning	29	39	67	63	85	77	92	54	124	73
Meals	28	38	66	43	70	63	71	42	108	64
Fire-lighting	8	12	21	15	26	23	23	14	38	22
Dressing	9	9	16	9	15	14	18	11	24	14
Washing/ Bathing	10	10	17	7	14	13	17	10	24	14
Toileting	8	8	14	6	9	8	14	8	17	10
Pet	3	5	9	6	9	8	9	5	14	8
Transport	21	26	45	45	59	53	66	39	85	50
Prescript.	23	31	53	54	64	58	77	46	95	56
Getting up	8	9	16	11	15	14	19	11	24	14
Going to bed	8	10	17	10	14	13	18	11	24	14
169 = 100%	n = 58			n = 111			n=169		n=169	

needed both before and after discharge were considerable. Women in particular needed more help with tasks that involved mobility and getting out of their homes, such as shopping, having their pension fetched, with transport and prescriptions.

Laundry, cleaning, meals and firelighting (for those with coal fires) posed similar problems for men and women. In all areas of help that the patients required before admission to hospital, increases were needed on discharge. Inevitably, the mixture of families, neighbours and friends who were carers, found themselves taking on more tasks and a greater burden of care. Some of the patients clearly had been on the margins of residential care before admission (Allen, Hogg and Peace, 1992) but this course of action was a very last resort.

Informal and formal carers together made up combined care support systems to keep people at home. Although formal care was not in any way meant to replace informal care systems, or to displace informal carers, it was clear that both support systems undertook the same types of tasks. The differences between the systems were in quantity of time - measured by hours in case of Domiciliary Services, and unmeasured in time by informal carers, and by the nature of relationships that informal carers had with their dependants.

5.6. Needs for Formal Services before Admission and after Discharge from hospital

Some of the referred patients were known to both or either Health and Social Services in the community before they were admitted to hospital. After discharge, they needed reinstatement, and/or increases, in their services.
Usually, once a hospital social worker had referred on to the Area Office for home help or meals on wheels, that was the last contact made and no-one was informed if a service failed to arrive, or was delayed.
When the volunteers were supporting discharge packages of care, they reported back to the Co-ordinator about service delivery, and a number of service deficits came to light. The service delays caused great concern to the volunteers, and the problems sometimes had to be referred back to the social workers for action. Service delays and failures were very stressful for patients and carers, and some people were very obviously at risk as a result.

Domiciliary Services - Home Help

38% of the patients had received home help services before admission, that was 21 men (36% of men) and 43 women (39% of women). On discharge, 8 men and 21 women needed an increase in their service, and 21 more men and 39 more women needed a home help for the first time.

On discharge therefore, 73% of patients needed help, showing an increase overall of 38% on the original number of patients. However, as the section entitled 'Discharges and Deaths' has already shown, 23 patients were not able to return home, and could not have received domiciliary services. This reduced the original number from 169 to 146, and the proportion of patients actually needing a home help at home on discharge became 84%.

Sixteen instances of dissatisfaction/service failures were reported to the volunteers. Delays in service arrival were most common, with two cases of a three-day delay before assessment by the domiciliary organiser, one seven-day delay, one eight day delay and one thirteen day delay before a home help arrived.

Services did not arrive at all for one patient, and no services were available for another. In two cases the domiciliary care organisers stated that they could not provide the type of help needed, or at the time it was needed, and in another that they were not to meet a carer's needs.

One patient's needs were regarded as 'low priority' and not met. In this instance, the patient employed a private helper instead.

At the time of discharge for one dependent patient, the hospital social worker was unable to make telephone contact with the domiciliary services for several days, because workers were either at meetings, or had not come back to the office. No other system for referral was available. Patients complained about home helps being 'erratic' or inconsistent, and generally that their help time was not sufficient. Two patients felt that the service was to expensive, and four refused to accept it because they could not pay.

11% of patients receiving domiciliary service support overall did not have their needs met as expected.

Meals on Wheels.

More men than women had received meals on wheels before admission (29% : 17%). On discharge slightly fewer requested reinstatement of their service, and only 2% of those originally having meals on wheels needed an increase in the number of meals per week.

Thirteen men (22% of men) and 32 women (29%) needed the service for the first time when they left hospital. This made a total of 75 patients (44%) showing a 6% increase on discharge.

There were four instances of service failure, one involving a delayed provision by eight days, and two where an appropriate diet was not available. One of these was for a diabetic patient, the other for a vegetarian. In one case only, meals did not arrive at all. One patient complained about the quality of meals, and cancelled her service. Several found the delivery times inconvenient. The service failure rate was low at 5%.

Day Centre and Day Care Attendance.

Two men and seven women had been attending a Social Services day centre pre-admission, and all resumed their attendance when they went home.

Two women only had attended a Part 111 home for day care. On discharge one needed an increase in her number of days each week, the other was admitted to Part 111 for short term care.

Occupational Therapy Aids

Many of the patients had been visited at home by area-based occupational therapists before admission, and already had aids and adaptations. Some had been assessed by OT's during a previous hospital stay, they too possessed a range of aids.

Whilst the social workers were dealing with their referrals, they requested OT assessments for 12 men and 29 women. This meant that over a quarter of the patients who went home needed aids for the first time, or an extra aid.

Complaints about the length of time that OT aids took to arrive were very common. As already mentioned in the Chapter for Social Work referrals, some patients were housebound because ramps had not been fitted, rails not supplied, and trolleys, raised toilet seats and bath seats were not available when people needed them most.

Among this group of patients, the volunteers recorded the following OT service provision deficits:

3 needed stair rails and had not been assessed
1 patient's bath seat had been taken away and she needed it, not reassessed
1 bath seat needed, not assessed
1 had to stand in the kitchen to eat her meals because a trolley was not available
1 had to wait for 2 months for a rail and raised toilet seat
1 was sent home without a walking frame and had fallen. She was readmitted to hospital
1 patient's zimmer was too big and she could not use it safely
1 could not use her zimmer frame because her room was too small
1 waited for over 2 weeks for a zimmer frame, she also needed a rail for her passage and bathroom

1 needed a high chair - not assessed
1 needed a high chair and raised toilet seat, she had not been assessed.
1 needed a bath rail, stair rail, raised toilet seat and a dressing aid. She had not been assessed
1 needed a ramp, raised toilet seat and rail. She had not been assessed
This list of problems shows that not only were aids and adaptations delayed, but that a number of patients had not been assessed for their needs for OT aids.

Seven patients more were assessed after they went home because the volunteers perceived their needs, and referred back to the social workers. This brought the total of patients needing aids and adaptations after discharge to 48.

Home assessments were carried out for some patients, usually at the request of the social worker. This meant that home environments were re-arranged for safety, but that did not guarantee that aids would be available on time, because the area occupational therapists - not the hospital OT's, were responsible for supplying them.

There was duplication of hospital/area OT assessment at different times. The area OT's held long waiting lists for equipment already for people referred from the community, and had to fit the hospital referrals in a quickly as they could. They also held the budgets for equipment, and larger items sometimes had to be carried forward to the next year's budgets, causing delays of months before a ramp or stair lift could be supplied.

Home loans provided most of the equipment, which had to be delivered from a central store. Delivery days were once or twice a week to different areas, and this also caused delays because hospital discharges could not be matched with the delivery days. Social workers encouraged patients' relatives to collect equipment from home loans, but where there were no relatives, or friends with transport, they and the volunteers ended up collecting and delivering the aids themselves.
Absence of essential OT equipment placed some patients at risk, and increased the burden of care on families and friends.

5.7. Health Service provision.

Community health services were used by some patients before admission. District nurses had been attending 9 men and 12 women (12% of all patients), two men and seven women had needed bath attendants and four women had been attending the

local geriatric day hospital.
Most patients had already been admitted to acute hospital beds during the last year, and several had also been in-patients for longer periods of health care in the geriatric hospital. However well the community services had cared for them, they seemed destined to a cycle of progression though acute hospital beds, to geriatric hospital beds, to the community and then back to the acute hospital at various intervals of time.

It was not possible to identify any increase in community health service provision after this particular stay in Mansfield General Hospital, for the same reasons given in Chapter 4. The acute hospital staff either referred for district nurse support during the last two days of the acute episode, pre-discharge, or left it to the GP to identify need once the patient had gone home. Either way, they could not reliably inform the social workers what had happened. There were two patients whose district nurse did not call after discharge, and one whose bath attendant did not arrive. These situations were reported by volunteers.

Health Service equipment on Discharge

Some of the more dependent patients who were discharged with needs for nursing care, also needed health service equipment at home.

The ward nursing staff were responsible for arranging delivery of this equipment, and whether the patient received equipment or not depended on their perceptions of how carers would cope, and their lateral thinking about what the patient had needed for adequate nursing care in hospital. As with referrals for district nurses, the social workers did not know what and if items had been ordered, until a carer complained post-discharge that they had problems.

The volunteers reported several instances of need back to the co-ordinator, who then pursued provision of equipment. They found one carer who had been told to go and buy incontinence pads, which should have been supplied though a Health Centre, and another carer had not received special support pillows or an air ring for her husband with lung cancer who was nursed in bed.
Two patients needed hospital beds which had not been ordered, another needed cot sides to prevent him from falling out of bed.
Wheelchairs had not been ordered in three cases, which caused a great deal of difficulty for the patients and carers involved. In one situation a wheelchair was not available in hospital to get a patient from the ward into the ambulance when she went home.
One patient needed surgical stockings, following a stroke.

She was not told how to obtain them, and they were not ordered before she went home. Another patient needed a urinal, and one more with chronic obstructive airways disease needed sputum containers which were not supplied.

Altogether, there were 12 patients who did not have NHS equipment when they went home. The Co-odinator and the hospital social workers could not order the equipment themselves, because they were not authorised to do so. A referral back to the ward staff was useless, since the patients' records had already been sent from the ward to medical records and could not be recalled. The ward staff could only suggest that the person with the information about non-provision of equipment should go to the patient's GP, or district nurses and make a request.

In some cases the ward staff did not seem to know that referring for equipment was their responsibility, and were affronted by the suggestion that they had not dealt with discharge needs adequately. Clearly, they had not related their own experience of nursing care needs to that of carers who would be coping with the same needs at home, and had no formal instructions about provision of equipment.

Both carers and patients experienced practical and physical struggles to cope without NHS equipment, in fact the unmet needs here converted to social needs in the community, at considerable cost to carers.

Other Health Service related problems on discharge.

The difficulties for patients and carers that were actively created in the hospital setting were not confined to lack of equipment on discharge.
Information and communication with families and other professionals was sometimes unreliable or absent, and a range of problems emerged as follows:

- patient's discharge date was altered, and the ward staff did not inform the family, social worker or discharge scheme co-ordinator even though a care plan around the original date, involving services and a volunteer had already been agreed with them.

- patient was readmitted quite quickly and the ward staff did not think to tell anyone involved in a complex care package set up a the first discharge because of the patient's dependency, when the second discharge took place.

- patient was discharged and could not be found in the community, by social workers or the volunteer. The ward staff did not know where the patient had been discharged to, and it was some weeks later that her whereabouts were discovered.

- patient was to be discharged to a nursing home, planned by the ward staff and family. At the last minute the patient decided to go home instead, and the ward staff failed to inform the social workers even though the patient was dependent and at risk.

- two patients were not referred for community physiotherapy services because the ward staff/physiotherapists were not clear about their responsibilities for referral.

- ward staff had written a patient's telephone number wrongly in their records, and passed this on to other professionals.

- ward staff had the wrong address for one patient and the ambulance took the patient there first, causing a lot of confusion. The social workers, discharge scheme and formal services were all confused. The information about the correct address was not passed on to them, and the correct address was found several days later by the Co-ordinator.

- patient died. In spite of a complex care package which had been set up for a specific discharge date, ward staff did not inform anyone.

- a discharge did not take place because an ambulance did not come. Ward staff did not inform the social workers or co-ordinator about a change of date.

- a discharge date, agreed between a housing warden and the ward staff was muddled and no-one was at home to meet the patient as expected.

- one carer had no idea how to manage her husband's terminal illness, and had no instruction at all from the ward staff, who did not check her coping abilities before the patient went home.

- out patient appointments were not checked and organised for one patient who was to attend four different clinics after she went home. The patient was mildly confused and could not organise herself. She missed an appointment, and was not ready for the ambulance for a second appointment.

- a patient's wife came to the ward to help him on discharge. She was elderly and had no transport, but even so, was not allowed to accompany him in the ambulance. The ward staff suggested she order a taxi, but the discharge scheme co-odinator stepped in and took her home after the patient had arrived there.

- poor communication between ward staff and a patient's relatives who lived away from Mansfield resulted in discharge arrangements being completely disorganised, and a delayed discharge. The relatives were very frustrated.

- a GP's letter was not sent from the ward and there was a five day delay before the GP visited the patient.

Fifteen patients (10%) experienced difficulties on discharge, out of a total of 151 who went back into the community.

These situations, for patients who had been discharged, were identified throught he invovlement of the Discharge Scheme. The information about them was taken from the Co-ordinator's records and feedback from the volunteers, who were working with the patients in their own homes, except for the patients who died.

The social worker in this instance went to the ward to try and clarify the patient's discharge destination, because no-one knew where she was.

The descriptions of these patient circumstances are not intended to impute blame on the nursing staff, but to draw attention to the actual problems of communication as patients leave the hospital system.

When patients were discharged from hsoptial and did not use the Discharge Scheme, or have support follow-up from hosptial social workers, no-one knew whether such difficulties existed or not.

The particular group of patients were judged by the social workers and Discharge Scheme volunteers to be particularly vulnerable. They had all been assessed by the social workers, and needed more than formal community services to ensure their safety.

The discharge arrangements for people who are not independent, or who do not have family who can take responsibility for them actually add more work to the ward staff's daily routines. Where more workers of any designation become part of the discharge equation, communication for ward staff becomes more complex, and perhaps increases the potential for disfuntional communication.

5.8. Private help at Home

Private paid help had been used by four men and six women at home. They amounted to 6% of referred patients, which was slightly more than the 4% referred only to the social workers in Chapter 4.

5.9. Use of Voluntary Clubs and other Social Organisations

It is already clear from the data in this Chapter that the patients needing volunteer support were very dependent on help to manage at home before they were admitted.

Even so, a small number had managed to get out of their homes to be engaged with some social activities, in the community. Thirteen (six men and seven women) had attended a luncheon club. In most cases the club had been part of their warden complex activities and included organisational involvement by the housing warden.

One man and seven women had been travelling further afield to Old Age Pensioners' clubs, and 12 people (four men and eight women) had attended some other social events on a regular basis.

Six women only were involved with their local church.

Overall, almost a quarter of the patients had social group involvements, but women were much more likely than men to have either the ability or motivation to do so, i.e. 12 men compared to 28 women.

5.10. Housing, Heating and Bathroom Facilities.

Housing tenure and types of property.

The patients lived in a variety of types of housing, as owner occupiers, tenants of private and council properties, local coal board houses, or were in lodgings. 36% were in warden aided accommodation, and most of those were women. Their housing situations are shown in Tables 5 and 6.

Table 56. Types of Housing Tenure for the Patients referred to the Discharge Scheme

	Owner occupiers	Private tenants	Council tenants	Coal Board	Lodgings	Warden
Men	17(29%)	4(7%)	34(58%)	2(3%)	1(2%)	21(36%)
Women	45(41%)	9(8%)	57(51%)	-	-	40(36%)
All	62(37%)	13(8%)	91(54%)	2(1%)	1(<1%)	61(36%)

Men = 58=100%   Women = 111=100%

Types of property occupied.

	House	Bungalow	Upstairs flat	Ground floor flat
Men	23(40%)	21(36%)	6(10%)	8(14%)
Women	50(45%)	39(35%)	7(6%)	15(14%)
All	73(43%)	60(36%)	13(8%)	23(14%)

(all percentages are rounded upwards)

The most significant features about the housing circumstances of this group of patients were, like those referred only to the social workers, that less than 40% were owner occupiers, over half were council tenants, and a small percentage were private tenants or living in coal board properties.

More women than men owned their homes in both groups. Fewer men and women had 'lodger' status, that is lived in someone else's home, among those referred to the Discharge Scheme.

The single biggest difference between the two groups was for patients who lived in council properties, and had a housing warden.

Among those referred only to the social workers, 44% of women and 38% of men had wardens, compared to 70% of women and 62% of men referred to the Discharge Scheme.

The fact that any of the patients in either group had been rehoused to warden aided accommodation indicated that they had already experienced housing difficulties, were elderly and had personal/health problems which would involve calling for help in an emergency.

In many cases, it had been the housing warden who had called for help before the patients' most recent hospital admission, and in conversation with the social workers when discharge plans were being made, they expressed great concerns about the levels of dependency which they had observed among the patients.

They felt that some elderly people were left too long before adequate formal services were provided, and that services were not frequent enough. They considered that some of their elderly residents were quite severely at risk after a period in hospital, in particular those who had had fractured femurs.

It was apparent to the social workers that wardens became very stressed by responding repeatedly to some tenants' crises. They felt that expectations of them were too high by some residents, and that both Social Services and Housing officials ignored their concerns.

Housing Problems

Housing problems emerged concerning six patients (one man and five women) during the social work assessment process. Outside steps to an upstairs flat caused an elderly women to be housebound when she went home, and there was no way that she could leave the flat safely without assistance from two other people.

A warden intercom contact had been broken for a number of weeks, and was not repaired even though it had been reported.

One woman had been awaiting rehousing for over two years, and was living in the downstairs rooms of her old house, unable to get to the upstairs bathroom or the outside toilet. She had to use a commode which she could not empty herself.

Another woman was discharged to her old house which was so small that she could not have her bed moved downstairs, and so had to sleep on a settee. She was already on the council rehousing list, with added points for health reasons, but no property was available.
One man lived in an equally old property which was neglected, dirty, and in need of structural repairs which he could not afford. Heating was a serious problem for him, and an electric fan heater was bought by Social Services for his use on discharge. Otherwise, there was no heating, and his electric wiring was in a very poor state.
The last patient was in a warden aided flat, but only had access via two flights of stairs, and then she was virtually stranded. There was no ground floor accommodation for rehousing.

The hospital social workers became involved with Housing Departments as advocates for patients, when they discovered that such problems existed. If rehousing was needed, they contacted consultants and GP's for letters to Housing, in order to acquire extra housing points. Sometimes they actually drafted the medical officer's letter, and sometimes were able to write directly.

In a few instances difficulties arose because the police had had to break into a person's home in an emergency. The social workers contacted glazing firms and builders to get broken door locks replaced, or for replacement windows following temporary repairs. These situations usually occurred for people who lived alone, without any close family who could have taken responsibility.

Housing problems always created social problems for patients, affecting their everyday quality of life, increasing health risks and their needs for personal and domestic care.

Heating and Bathroom Facilities.

Most patients had houses with gas fires, or gas fired central heating, and could manage to operate their system independently.

Men and women living in coal board properties, or in owner occupied old property purchased from the coal board, had coal fires which caused serious heating problems. This also applied to old properties which were being privately rented, and to some older council properties as well.

13 men (22%) and 34 women (31%) had coal fires and needed help not only to light and clear them out, but also to fetch coal in from outside sheds and bunkers. Some patients would have liked to have changed their solid fuel to gas, but no funding was available for improvements. In a few cases patients could have afforded to change to gas themselves, or

their relatives could have helped them, but they decided not to change. They felt that coal fires were better for their chests, if they had breathing problems, or simply did not want to change because they liked coal fires.

Four patients with coal fires were without bathroom facilities, and had to wash in their sinks.

Six had outside toilet facilities only, and this necessitated the use of a commode in their houses and the need for someone else to help with emptying on a daily basis.

A heating problem occurred for one patient, which was quite unusual. His relatives decided that he should not be discharged from hospital because his central heating had been cut off due to coal board repairs and subsidence. No other form of heating was available, and the coal board had no means of dealing with the man's need for heating - although they had caused it in the first place.

He could not go home, and was given the choice of Local Authority residential care, or the option of staying with relatives who did not really want him. He had to go to relatives, finally, and stayed there until the Coal Board re-connected his heating system.

One other man, referred to later in the chapter, had learning disabilities and was living in a filthy neglected house, had no heating at all. At some time there had been a gas supply - long since cut off because he could not read or write - and therefore could not pay his bills. This problem was dealt with by the social worker, who also made arrangements for his future support and special consideration by British Gas.

The Coal Board in the Mansfield/Ashfield districts made coal or heating allowances in lieu to retired miners and their widows. One man found that his heating allowance was insufficient when he became ill. The social worker organised extra heating allowances for him via a MacMillan fund grant during his terminal illness.

5.11. Informal Carers.

Carers for men and women referred to the Discharge Scheme

The patients who were referred to the Discharge Scheme, like those who were referred to the social workers, had a range of single carers, a mixture of intergenerational kin, and some were supported entirely by friends and neighbours. A number of patients had no carers.

Some of the patients were carers themselves, and part of the volunteer role was to support not only the carer as s/he left hospital, but to give help to the dependent at home also. Table 57 shows who the carers were.

Table 57 - Carers for patients referred to the Discharge Scheme

Carer(s)	Men	Women	All patients	%	Living alone
No carers	6	10	16	9	15
Son(s)	5	14	19	11	18
Daughter(s)	5	13	18	11	13
Husband	-	7	7	4	-
Wife	7	-	7	4	-
Mother	-	1	1	-	-
Son and daughter	4	6	10	6	9
Son, daughter and husband	1	-	1	-	-
Son, daughter and niece	-	1	1	-	1
Son, daughter and neighbours	-	1	1	-	1
Granddaughter	-	1	1	-	1
Son and husband	-	1	1	-	-
Son and wife	1	-	1	-	-
Son and grandson	1	1	2	1	1
Son and granddaughter	-	1	1	-	-
Son and brother	-	1	1	-	1
Son and sister	-	1	1	-	1
Son, sister, granddaughter and neighbour	-	1	1	-	1
Son and neighbour	-	4	4	2	4
Daughter and husband	-	1	1	-	-
Daughter and wife	2	-	2	1	-
Daughter and grandson	1	2	3	1	2
Daughter and granddaughter	1	1	2	1	2
Daughter, grandson and granddaughter	-	1	1	-	1
Daughter, brother and neighbour	1	-	1	-	1
Daughter, stepson and neighbour	1	-	1	-	1
Daughter, sister, neighbour and friend	-	1	1	-	1
Daughter and neighbour	3	2	5	3	4
Daughter and friend	1	1	2	1	1

Husband and niece	-	1	1	-	1
Granddaughter, niece and friend	-	1	1	-	1
Grandson, grandaughter and neighbour	-	1	1	-	1
Brother	-	1	1	-	1
Sister	-	5	5	3	4
Brother and sister	-	1	1	-	1
Brother and neighbour	2	1	3	1	2
Sister, neighbour and Salvation Army	1	-	1	-	-
Sister and neighbour	-	1	1	-	-
Niece	-	1	1	-	1
Niece and nephew	1	-	1	-	1
Nephew	1	-	1	-	1
Nephew and friend	1	1	2	1	2
Brother-in-law and neighbour	1	-	1	-	1
Neighbour	4	14	18	11	17
Friend	4	7	11	7	11
Friend and neighbour	1	1	2	1	2
Neighbour and warden	-	1	1	-	1
Warden	-	1	1	-	1
Volunteer - X-roads	1	-	1	-	-
Other lodgers	1	-	1	-	1

Total patients = 169 = 100%

Men - 58 = 34% Living alone - 39 = 67%

Women-111 = 66% Living alone - 88 = 79%

Living alone - 127 = 75% all patients

This group of patients had fewer informal carers overall. The percentages of those with no carers increased from 6% - social work referrals, to 10% - referred to the Discharge Scheme.

There were fewer spouse carers, due to the fact that a larger number of men and women were widowed, and very significantly, fewer daughters were carers. 26% of the patients referred to the social workers were cared for by daughters, compared to 18% in the Discharge Scheme.

The percentages of sons and daughters caring together were the same, and so were sons as principal/only carers. Other kin carers were also similar, but non-kin were the only carers for 21%, compared to 7% of social work referrals. Table58 shows the carers in kin and non-kin groups for easy reference.

Table 58 - Kin and non-kin carers of patients referred to the Discharge Scheme.

Carers	Men	Women %	Principal carers
No carers	11	9	10%
Wives only	12	-	
Husbands only	-	6	Spouse
Wife + adult child	5	-	
Husband + adult child	-	1	13%
Husband + other kin	-	1	
Son only	9	13	Son
Son + other kin	2	4	
Son, other kin + non-kin	-	1	17%
Son + non-kin	-	4	
Son + daughter	7	6	Son + daughter
Son, daughter + other kin	-	1	7%
Daughter only	9	12	Daughter
Daughter, other kin + non-kin	3	1	
Daughter + non-kin	7	3	18%
Other kin only	3	7	Other kin
Other kin + non-kin	9	6	13%
Non-kin only	19	22	21%

Percentages rounded to nearest 1%

A quarter of the patients had main carers who were as old, or older, than they were. Most of these had health problems, and needed support from Social Services for themselves on a regular basis.

5.12. Support provided by the Discharge Scheme.

Patients who had no carers.

Six men and ten women were without informal carers. Fifteen were living alone, and one was living with a dependent, terminally ill spouse.

MEN who had no Carers.

The six men all lived alone, and three had no living family members to their knowledge. One had a niece, whom he said visited every six months, and another had a niece and sister in Blackpool who were in contact very occasionally.

Two men had housing wardens who were in contact with them and performed some domestic tasks. A district nurse had been calling three times each week to attend burns for the youngest man, who was also physically disabled. Otherwise, there had been no formal service inputs pre-admission of any kind. All six men were very isolated when they became ill or had an accident.

The Discharge Scheme Co-ordinator and the volunteers were struck by the desolation of these men, and the poverty of human relationships and care which they faced in the future.

Four of the men hardly ever went out of their homes, and the single man with learning difficulties was immobilized by a fractured ankle after his accident. The man worked, stapling boxes together in a local factory. None of his fellow workers had ever visited him at home, and when he did not arrive at work, following his accident, they assumed that he had ceased working voluntarily. He could not use the telephone or write, and had no idea about claiming sickness benefit, so his income stopped. His accident put him in a situation of considerable risk, which fortunately was recognised by the nursing staff in Accident and Emergency, and the hospital social worker. The outcome for this man was very good, as he did eventually return to work. The personnel staff at his factory were shocked by his circumstances and agreed to monitor him in future. His male volunteer also decided to keep an eye on him long term, after his Discharge Scheme duties had finished.

Old age was not the most significant factor for the six men. Living alone, having no family carers, no social network and having a period of acute ill-health were the underlying causes of their situational distress and need.

Women who had no Carers.

Ten women were without carers, and nine of these lived alone. As with the men, both their social circumstances and illness were causative factors of their need for help. Table 59 illustrates their circumstances.

Table 59. Women without carers, showing illness, age, marital status and social contacts

Illness	Age	Marital status	Family	Other contacts	Preadmission formal services
Neurosurgery + drug withdrawal	43	M	terminally ill husband	none	clinical psychologist Hospital
Fractured arm	65+	S	cousin 8 miles away	neighbour needing support	none
Fractured pelvis	65+	S	none	2 young men possibly Mormons	none
Diabetes Glaucoma	65+	W	sister in Sth Wales	neighbour popped in	none
Oesophogeal stricture	65+	W	daughter 20 miles away and pregnant	none	none
Colostomy	75+	W	none	none	Home help
Fractured leg	80+	W	daughter in Peterboro'	elderly neighbours popped in	none
Pulmonary embolism	80+	S	none	none	housing warden who left
Fractured femur	80+	W	niece called occasionally	none	none
Fractured arm Parkinson's disease	80+	S	none	neighbours popped in	none

* This table provides only the simplest picture of the ten women's circumstances.

Their illness categories show that most women had an ill-health episode of sudden onset, and pre-admission, they had needed very little personal/domestic help. They had not received help or contact from family members since only half had living family, and they could not have become carers even in a crisis. Two women had daughters, both of whom lived far away from Mansfield and only helped intermittently.

Three women did have contact with neighbours, but all these were elderly. One was in a reciprocal helping situation with the patient. There seemed to be a strange lack of friends among the women, indicating that other factors of isolation were current in their lives. In fact, their circumstances were more complex than appeared at first sight.

Their risks in living alone and becoming ill/hospitalized included hidden difficulties in access to formal support systems which they needed after discharge. Voluntary agencies did not feature at all in their social networks or daily lives.

Summary for Patients with no Carers - need and unmet need.

The case records for the sixteen patients illustrated that on discharge, they were in need of both formal and informal support.

Their needs for home care services were assessed by the social workers. Four needed domiciliary services only, and nine needed a combination of both Home Help and Meals on Wheels. 88% therefore needed formal services.
The Discharge Scheme Co-ordinator's screening of these patients indicated that informal care was also needed, for safety monitoring, and with practical tasks at home until formal services arrived.

Whilst the volunteers were supporting the 16 patients without carers they discovered other needs for help, some of which occurred because the patients became ill again, and others which had not been found during assessment or screening. These needs and those found during screening, would have been 'unmet' if the volunteers had not been present immediately after discharge, and in some instances, while the patients were still in hospital.

There were nineteen different areas of potential 'unmet' need, and the volunteers undertook the following tasks as a result:

1. Secured a patient's home, which would have been unlocked

for over a week.

2. Fed animals for several days. The animals might not have died, but they would have been without food or water
3. Supported a patient who wanted to cancel his operation because he could not leave his cats alone. If he had not been enabled to go into hospital, he would have been substantially functionally dependent and eventually disabled.
4. Completed sickness benefit forms for a man who would not read or write. He would have had no income, and would certainly have lost his future employment
5. Helped patients to claim Attendance Allowance and who otherwise would not have realised their entitlement
6. Cleaned up a patient's very squalid home, which the domiciliary services would not touch because it was too dirty. Helped the same man to acquire some second hand furniture, bedding and floor covering
7. Supported a severely disabled patient who was at risk of self neglect, accident and re-admission to hospital when home help and meals on wheels failed to arrive
8. Prevented total isolation for a man with multiple disabilities
9. Offset personal risk for a man who was sick, elderly and depressed
10. Stepped in to help when a housing warden went away

11. Provided meals and food to nine patients who could not cope independently
12. Helped with legal and personal affairs for one patient whose spouse was dying
13. Gave bereavement counselling
14. Enabled a patient to keep her Out-patient appointments which she would have otherwise missed
15. Lit fires for two weeks, because of formal service failure, and provided draught exclusion measures
16. Shopped when no-one else was available
17. Had a patient readmitted to hospital after a fall. This patient was at risk of hypothermia
18. Communicated service delays/failures in nine instances. In several cases the services would not have arrived at all
19. (Co-ordinator) Performed many tasks for a couple with serious health and social problems, in the absence of any available formal community-based services. One most important task was that she enabled the dying husband to receive hospital treatment outside the Central Notts Health Authority. Neither the district nurse nor the GP addressed this need, which was passed back and forth between hospital departments and two ambulance services.

The areas of unmet need listed here show how flexibly the volunteers responded to the needs of patients without informal carers. Not only did they act a 'good neighbours', taking on the tasks that neighbours might perform, but also responded as family members at times, and as semi-formal advocates in the context of formal NHS and SSD services.

The important aspect of their work in referring back when services did not arrive, or were inadequate, was that they did this with confidence, knowing that the formal workers, their co-ordinator, the hospital social workers and Senior Social Worker would act promptly in the patient/client's best interests. Communication was direct and the volunteers comments and observations on all occasions were valued. This is not always the case when family/friends and service users have to approach formal service providers. Often, communication patterns are confusing and set up with filters, such as duty officer delays because the same message has to be passed on several times to different people, and risks that messages can be lost in the system.

Interdependent couples/carers.

The volunteers supported a number of people who were in situations of interdependency, some of whom had no family, and others whose family help was limited.

One couple were elderly and had received home help once a week before the wife was admitted to hospital with thyroid problems, diabetes, high blood pressure and an infection.

Her husband was already chronically ill with asthma, arthritis and had a fractured arm.
It was clear that a considerable increase in domiciliary support was needed, but this was not immediately available. The volunteer began to visit before the patient was discharged, and continued after she went home.
Both patient and wife were surprised that the volunteer was male. He undertook any tasks that were requested, and over a period of four days, cleaned the windows, prepared vegetables, fed the cat and took the patient with him to collect her weekly shopping. He monitored the couple for their safety and general well-being, and ceased visiting when the home help was able to take over laundry, domestic tasks and met needs for personal help.

A second situation concerned an elderly widow without children, who was semi-resident with her equally elderly friends, a couple who had at one time been her employers. She had her own bungalow, but as her health deteriorated, and when her friend Mrs C became ill with heart problems, she moved in to help Mrs C care for her husband who had had a stroke and suffered from Alzheimer's Disease.
All three had become more dependent as time went by.
Finally, Mrs C was admitted to hospital, followed by Mrs T (the patient referred to the Discharge Scheme).

At this point Mr and Mrs C's son became his father's carer, travelling to Mansfield to check him each morning, cook his lunch and deal with domestic tasks. A housing warden was helpful, and the possibility of domiciliary services was considered. This proved difficult, since Christmas was approaching and few services were available.

Each of the women, Mrs C and Mrs T were in different hospitals, and their consultants separately decided to discharge them home before Christmas. The prospect of having three very dependent people in their eighties, all needing care together alarmed Mrs C's son, who decided that he had no responsibility for Mrs T anyway. The housing warden, who felt that she could look in on Mr and Mrs C since they were 'her' residents, felt that she could not take any responsibility for Mrs T since she had her own bungalow.

The Discharge Scheme Co-ordinator received a referral on 15th December, and had a volunteer on stand-by on the 16th ready to give support as each woman was discharged.

On 20th December, Mrs C's son rang to say that he was taking both his parents to his own home for Christmas, or possibly longer, and Mrs T could not return to their warden aided bungalow. Mrs T was not discharged, but transferred to the geriatric hospital just before Christmas. The ward staff did not inform the social worker or Co-ordinator until 30th December, and the Scheme was therefore not used.

Nevertheless, the volunteer stood by all through the Christmas period and would have supported Mrs T in her own home, if needed. Eventually, the outcome for all three elderly people was residential care.

Seventeen couples were referred who did have adult children, or other relatives. Unfortunately, the family networks were only able to provide limited support, and a range of NHS and Social Services provision was required, as well as the Discharge Scheme.

Table 60 shows the situations of all the seventeen interdependent couples referred, the tasks undertaken by volunteers, and the number of visits and hours involved.

Table 60

Interdependant couples/carers who had other family support.
Patient need for volunteer support in addition to formal and informal care.

	Patient and Carer	Illness	Family	Formal support needs on dis.	Volunteer support needs	No. of visits	No. of hours
1.	Wife Husband	Stomach bleed Relapsed hernia	3 daughters out of county	Home Care	Arranged ambulance, contacted G.P. Monitored services	2	2
2.	Husband Wife	Bowel op. M.I.	Son & daughter living out of county	Home Care	Monitored services Social/moral support	2	3
3.	Husband Wife	Ca. bowel (in hosp.) Heart dis.	2 daughters working. Son & dau/law working only popped in	District Nurse M.O.W. Home Care	Monitored services and safety	1	1
4.	Husband Wife	Fracture Alzheimers, blind Respite care in hospital. After husband was discharged wife remained in hospital	3 daus. 1 son only partially supportive to parents before admission. Became supportive to father on discharge	District Nurse Physiotherapy O.P. appt. M.O.W. Home Care	Changed bed. Took patient to visit wife in hospital Took patient home from hospital. Cleared out stale food. Haircut. Monitored services. Stood by to stay with patient and wife at home assessment	6	6
5.	Husband Wife	C.V.A. arthritis catheterized In wheelchair couldn't be left alone Diabetes, C.V.A. slipped disc	Dau. & working g/dau. helping with grand-parents	District Nurse Home Care	Took wife shopping. Sat with patient. Contacted services which did not arrive on time Delivered G.P. letter. Helped with lifting	5	5
6.	Widow Daughter	Heart disease Very frail Mental illness	Son & dau/law (both ill) G/son. Son living away. Family wanted mother to go into Residential Care but she refused	Home Care	Social company for patient Supported patient and daughter emotionally. Monitored safety	2	2

(cont)

	Patient and Carer	Illness	Family	Formal support needs on dis.	Volunteer support needs	No. of visits	No. of hours
7.	Wife	? bone cancer in arms.	Daughter nearly going blind. Cann't help practically. Son-in-law working.	Home Care. D.S.M. told patient to call for help when husband became bedfast.	Took patient home from hospital. Pegged out washing Ironing. Supported husband when wife went back to hospital for bone scan. Monitored safety and complained about Home Care to social worker.	3	4
	Husband	Angina.c.a.bladder Diverticulitis Heart disease Communication problems.					
8.	Husband	Nervous breakdown. Heart attack. Pacemaker already fitted.	Son in Balderton. Daughter in Norfolk. Elderly sister.	Home Care. Day Centre. B. Attendant.	Monitored wife's safety. Walked dog. Social company-reassurance. On call for emergency.	1	2
	Wife	Arthritis - in a wheelchair.					
9.	Wife	Partially sighted. Falls. Fractured arm. Psychiatric illness. O/D. Incontinent.	Niece and nephew. Unable to help, temporarily.	Day Centre 5 times a week. Home Care.	Domestic tasks. Took husband shopping. Acquired a new glass eye for patient. Obtained incontinence pads. Monitored over Easter.	3	6
	Husband	Diabetes Very frail.					
10.	Mother (94)	Frail. Falls. Deaf. Fractured clavicle.	2 Grandsons.	Home Care.	Monitor safety. Support daughter.	2	2
	Daughter (70)	Arthritis Poor mobility.					
11.	Husband	Angina. ? Heart attack.	Daughter and son-in-law. (on holiday)	Lunch club 2 times a week. Home care refused - paid neighbour instead.	Fetched prescription. Visited daily to monitor. Contacted G.P. Stood in for rels.	7	3
	Wife	Frail, elderly.					
12.	Husband	Fractured femur. Renal failure. Angina.	Daughter (on holiday)	None decided to pay neighbour instead.	Collected prescriptions for wife. Monitored for safety. Contacted G.P. Stood in for daughter.	7	4
	Wife	Frail and elderly.					

(cont)

	Patient and Carer	Illness	Family	Formal support needs on dis.	Volunteer support needs	No. of visits	No. of hours
13.	Wife Husband	Frail & elderly. Emotional problems. Fractured wrist. In hospital. Bereaved. Falls. Mentally ill & aggressive.	Daughter supporting mother has nothing to do with father. (Wife refused to have husband home.)	M.O.W. Home Care failed to arrive. (Patient eventually refused to have services)	Monitored services Emotional support for wife and daughter. Contacted S.W. re: problems with husband and marital breakdown.	3	3
14.	Husband Wife	Gastrectomy. Arthritis - in a wheelchair.	Sister 2 brothers.	District nurse.	Monitored wife's safety and care network.	1	1
15.	Wife Husband	Fractured arm. Hip replacement. Blind in one eye. Partially sighted. Confused.	Son in Stratford-on-Avon came to visit.	Home Care. Phased care Part III. Physiotherapy. M.O.W.	Social support. Phone no. left for emergency. Monitored services.	2	2
16.	Wife Husband	Falls. Fractured femur. Having leg amputated. In hospital - due for discharge.	Son & daughter-in-law working. Only called in.	M.O.W. Needed Home Care for firelighting. Service failed to arrive. Patient refused services.	Made fire seven mornings Shopping. Made bed twice. Monitored safety and services.	7	7
17.	Wife Husband	Elderly and frail. Fractured arm. Right sided C.V.A. Very dependant. Liver damage.	Sister. Son in London.	Home Care. Patient refused services.	Social support. Monitored safety and informed care network.	1	1

Table 60 shows that interdependency among couples/carers, mostly involved married people. Fifteen out of seventeen were married, the other two situations involved older daughters caring for very elderly mothers.

The patients referred from Acute wards were 7 wives, 8 husbands, and two mothers. They had been admitted in 8 instances because of acute sudden trauma/illness, and in 9 instances because of an acute episode in the context of existing chronic illness.

All of their carers/interdependent others were experiencing chronic illness also. Four had mental illness or confusion, and four were also hospitalized at the same time as their partner.

The 17 patients had other family members who provided varying degrees of support, from a distance, since none of them lived with the interdependent couples. Three had sons and/or daughters who lived outside the Mansfield area, three had adult children who were working and who did not or could not alter their working situations to care for their parents.

One grandaughter and two grandsons were part of the informal care network for three couples. Elderly brothers and sisters were supporting two more. A niece and nephew together were helping one couple occasionally, but were not available to provide enough care when discharge from hospital occurred.

Family 'problems' caused difficulties in the informal support systems in two instances. One was a breakdown of the relationship between a father, his wife and daughter, the other involved male aggression by a husband towards his wife. In both instances the hospitalization of one partner created a separation of husband and wife circumstantially, and the patients did not go home.

These two situations, like those described in Chapter 4 where family relationships were breached with elderly people, resulted in a permanent separation of the parties involved.

Formal Care Needs

Table 60 shows that 15 out of the 17 couples (including the mother/daughter carers), needed home care support on discharge from hospital.

In five situations the Home Care Service failed to meet their needs. Two failures were because Domiciliary Service managers did not or could not meet the carer's expressed requirements about tasks that they needed help with. Two more involved service delays. Here the patients/carers

found that they could enlist support from neighbours, and decided to pay their neighbours for help instead.
One other patient, of very independent disposition decided that she would persevere without home care, even though everyone else thought that she needed it.

Volunteer support

Volunteers were able to bridge the gap between patients leaving hospital and the introduction of formal services in all cases. 17 patients were referred, but there were in reality, 34 people requiring support.

Some of the referrals were made because the dependent person at home needed either monitoring or help. The flexibility of volunteer support, which could be introduced at any time with very short notice, both allayed anxiety about the safety of someone left at home, and facilitated problem free discharges for those who were admitted.

The length of time that volunteers were involved was also flexible, and operated in a needs-led way. If services did not arrive, volunteers continued to maintain safe environments in the community as necessary.
Once again, their personal interactions with the interdependent couples were both informal as they expressed concerns and performed tasks as family and neighbours might

have done, and semi-formal as they interacted with professionals who operated the formal systems of service requirements.

The tasks which they performed - for example in removing stale, inedible food from one patient's home illustrated an important point about family support. In this case, family were available and in contact with the patient and wife, who were both hospitalised at the same time. However, when the time came for discharge of the elderly husband, the family made no attempt to prepare his home or to deal with his immediate practical needs.

Family support for elderly patients was variable. Some sons and daughters only 'popped in' to see their parents, some were ill and felt that the burden of care was too much for them. Others made great efforts to come and give support, even though they lived many miles away.

The assessment of the reality of family support, including illness, attitudes, divided loyalties and abilities of carers was crucial in establishing need and matching volunteers to existing family care structures.

Assessment for this group of patients, like others, involved a large collection of information especially about the dependency needs of partners/relative and the systems of support available or not to them. The social workers and volunteers found that assumptions that either informal or formal care systems would be adequate, when there was doubt about definite commitment, availability or information, was not safe. These situations invariably contained unmet need and possible risks to patients or their dependents.

Patients who were dying.

18 patients with malignant/terminal illnesses, some of whom were actually dying, were referred for volunteer support. At the time of referral it was clear that they wished to go home, and would be very dependent for care needs once there. Their proximity to death was not known, of course, and four patients died very quickly. (They have been included in the figures for discharges and deaths in section 4).

Two patients who were referred and screened did not actually receive volunteer help because family carers took time off work to support them.

One female patient, aged 57 years, who had bone cancer did receive volunteer help, and her situation has already been described in the section entitled 'interdependent couples'.

This left a total of eleven other patients who were dying, who needed and received help from the Scheme.

They were a group of people whose circumstances and complex needs required more hours of volunteer support than any others. As their following case stories show, these patients and their carers were subjected to many difficulties in the community because formal care services were not geared to meet their needs. The death factor in every case influenced the patient/carers needs.

Case stories of the eleven patients who were dying

1. Home situation

Mrs A - a widow aged 73, living alone, in a house with a coal fire.
Illness - terminal cancer, catheterised
Formal support - home help 5/7, District nurse 3/7
Informal support - 2 sons popped in 2/7, lived several miles away
2 sisters calling in 3/7
grandson and granddaughter popping in
neighbour calling every day
All OT and health service aids were at home before admission.

14:11:88 - Discharge Scheme screening

Ward staff informed the social worker and co-ordinator that Mrs A was 'failing fast', but desperately wanted to go home to die.

It was agreed that a 2-day home assessment trial could be arranged, and the consultant allowed the acute bed to be held open for that time. The social worker and D/S co-ordinator were to transport the patient home, and a volunteer would oversee her safety during the two days.

15:11:88

A rota of care, involving formal and informal carers was drawn up by the social worker, in consultation with her sons, as follows -

son 1 - to call in the morning, on his way to work
home help - 9-9:30 am - breakfast
District nurse - 10:00 am - to attend to sores and splint
Meals on wheels - 12:30 pm - main meal
Volunteer - to stay with patient during the afternoon
Son 2 - to call in the evening - 7:30. Put mother to bed, and call again at 10:30 to check her safety.
(UNMET NEED FOR NIGHT CARE - NO SERVICE AVAILABLE)

21:11:88

Patient was taken home. Her health had deteriorated, but she was determined to go. The care plan began immediately, and the volunteer called in the afternoon. She stayed past tea time, but observed that Mrs A - who was in bed, could not call for help if she had an accident.(ie fell out of bed.) She felt that she was not safe to be left alone.

Later, one of the sons called. He decided that he could not stay because of his band practice, and left his mother alone.

The second son, who worked late into the evening felt so guilty about his mother's situation that he turned round on his way home and visited her. She was left alone all night.

<u>22:11:88</u>

The volunteer called in the morning on her own initiative and concern. Mrs A confided to her that she would not remain at home because she could not bear to be a burden on her sons. She described herself as a 'matriarch', and knew that they would not over-ride her decisions, even in her best interests.

She was collected by ambulance at lunch time, and taken back to Mansfield General Hospital.

The social worker had sensed that there was a difficulty in the mother/sons relationship, and that talking about death was subject to an active taboo. She held two counselling sessions with them, and found that the home assessment trial had helped them to face the risks and danger of mother's decision to leave hospital, her total dependency on others, and her impending death.

They were then able to go to the ward with the social

worker, and to share their feelings with Mrs A, who later died in peace.
The sons acknowledged that the Discharge Scheme volunteer and social worker had played a most important facilitating role in helping their family to face risks and responsibilities, and to overcome long standing attitude difficulties about gender-related control and fear, during their mother's last days.

The volunteer help time was 5 hours, during 2 visits.

2. Mr B - married man, aged 58, living with his wife in their own home.
illness - brain tumour already operated on, now in terminal stage.
Formal support - none.
Informal support - sister with mental illness, son and daughter living in Essex.

In November 1988, the social worker who had supported Mr B whilst her husband was in hospital requested help from the Discharge Scheme on a 24 hour telephone life-line at home. Mr B had been discharged. His wife was very anguished by his illness, and had no-one to turn to in a crisis.

Whilst he had been in hospital the medical and nursing staff had told the family that he had a fast-growing brain tumour which could not be cured. The manner in which they had been informed had left them confused, angry and unsupported. The social worker had been left to pick up the pieces, and did not know that the information had been withheld from the patient. He mentioned that the brain tumour could be terminal, unfortunately in the patient's presence. Although Mr B suffered from periods of amnesia, he remembered this and became distraught. The family's emotional distress became severe, and the senior social worker intervened with support.

(UNMET NEED - APPROPRIATE METHOD OF INFORMING PATIENT AND FAMILY ABOUT TERMINAL ILLNESS, MANAGEMENT AND PROGNOSIS.

UNMET NEED - LACK OF MILTIDISCIPLINARY STRUCTURE FOR MANAGEMENT OF PATIENT CARE, ROLES AND SUPPORT SYSTEMS IN THE COMMUNITY.

UNMET NEED - NO SPECIALIST NEUROLOGY NHS STAFF

UNMET NEED - NO NHS CARE PLAN AFTER DISCHARGE)

<u>8:11:88</u>

A volunteer was organised to visit Mr and Mrs B, to support them both as needed. She was chosen because she had counselling skills, bereavement counselling training, and her own husband had also died from a brain tumour.

<u>10:11:88</u>

The volunteer informed the Co-ordinator that Mrs B was at her wits' end, her husband was deteriorating and his behaviour was unmanageable. His sister was adding stress by making elaborate plans for Mr B 'when he got better'. The GP was contacted, and readmitted Mr B to hospital - for two days.

The volunteer continued to visit Mrs B to help her off-load her feelings, and to make some plans for family involvement. On 14:11:89, her son arrived from Essex, and agreed to stay with his father whilst Mrs B had a few hours respite alone, out of the house. The volunteer stood by to help.

<u>15:11:89</u>

Mr B died at home, with his family present. The volunteer continued to see Mrs B weekly after they had gone home, to help her work through her emotions. She had not been able to express her love or affection for her husband, or to talk through any last wishes he had about their joint affairs.

In due course, the volunteer was able to put Mrs B in touch with Cruse.

(UNMET NEED- NO COMMUNITY HEALTH SERVICE SUPPORT OTHER THAN GP FOR RE-ADMISSION

UNMET NEED - CARER SUPPORT NEEDS COMPLETELY OVERLOOKED BY PRIMARY HEALTH CARE TEAM

UNMET NEED - APPROPRIATE COUNSELLING PROVISION)

Volunteer help time was 12 hours, during 6 visits.

3. Mr C - widower aged 76, lived alone in an upstairs flat.
Illness - bowel cancer with metasteses. Had operation.
Formal support before admission - none
After discharge - MOW 1/7. Home care assessment.
District nurse. McMillan nurse. Mobile warden by phone only.
Informal support - friend pops in. Son visits when he can.

Mr C was an independent man who used to go out for company before his operation. On discharge he was frail and almost immobile. The social worker organised home care services on discharge, and with the hospital nursing staff ensured that the district nurse and MacMillan nurses would provide support.

A referral was made for volunteer visits because the patient's informal network of friend and son appeared to be unreliable and infrequent.

When the Co-ordinator screened him, she discovered that he needed rails to get up and down stairs, when he was able, or he would be confined to his flat.

He was also anxious about his sister, who was in ill health and recently bereaved. He did not know her address.

He had lost his doorkey, and his discharge was delayed for two days.

(UNMET NEED - DURING THE SOCIAL WORK ASSESSMENT NEED FOR RAILS HAD BEEN MISSED. WARD STAFF ALSO MISSED THIS NEED. THE SOCIAL WORKER HAD NOT PICKED UP PATIENTS' CONCERN ABOUT HIS SISTER.

UNMET NEED - WARD STAFF DID NOT CHECK THAT PT HAD HIS DOORKEY ON ADMISSION)

Mr B was discharged on 25:11:88 and the volunteer met him at home to settle him in. He found that the flat was 'in a state' and Mr B could not get around unaided. His son and friend were not available immediately, and home care services would not attend until next day.

The volunteer bought food, mended the hoover and vacuumed the carpets. He bought Mr C a pair of slippers, and observed that his bed was unsafe. It was wedged upright with canvas and Marley tiles. He mended this, and reported a broken light and other electrical problems to the Council, for repair.

During the first two days post discharge, the volunteer was Mr C's main support. A nephew turned up and informed him that his sister had died, and his son eventually came to help. His friend informed him that he could not visit very often because he had a low income, and no transport.

Home care services and the MacMillan nurse arrived two days after discharge, and took over from the volunteer and son.

(UNMET NEED - SERVICES WERE NEEDED IMMEDIATELY AFTER

DISCHARGE, IN ORDER TO ENSURE THAT PT'S ENVIRONMENT WAS SUITABLE AND SAFE, AND FOR HIS POST-OPERATIVE NURSING CARE)

The volunteer stayed in touch with Mr C for seven days. His final report was that Mr C had become more independent, after 5 days, but that the Council had not responded to the need for electrical repairs.
(UNMET NEED - DELAY IN RESPONSE FOR URGENT ELECTRICAL REPAIR BY COUNCIL HOUSING DEPT - ESPECIALLY FOR A FRAIL OLD PERSON JUST DISCHARGED FROM HOSPITAL. LACK OF PRIORITY BY COUNCIL)

The volunteer provided 4 hours of help during 4 visits.

4. Mr D - aged 66 years, cohabiting with younger partner in her mother's house.
Illness - cancer of the bronchus, using oxygen at home
Formal support - District nurse before admission and on discharge.
Informal support - cohabitee, 24 hour carer
cohabitee's brother, popped in
patient's daughter in Holland

<u>14:3:89</u>

The hospital social worker referred Mr D to the Scheme after he had been discharged

(UNMET NEED - SOCIAL WORKER HAD NOT ASSESSED NEEDS AND INCLUDED DISCHARGE SCHEME IN CARE PLANNING PRE-DISCHARGE)

The patient's cohabitee rang the social worker, desperate for help because she could not leave him alone at all.
A volunteer was contacted, and went to help immediately.
She discovered that a sitting service was really needed, but none was available.
The hospital social worker had referred to home care services, but hey could not offer appropriate help.
The district nurse was calling, but offered no practical, emotional, or psychological support to patient or carers.
She assisted carer with bedbathing on one occasion only, in spite of a number of requests.
(UNMET NEED - SITTING SERVICE TO RELIEVE CARER. PRACTICAL HELP WITH PERSONAL PATIENT CARE. NO EMOTIONAL OR PSYCHOLOGICAL SUPPORT FOR CARER. PROBLEMS RE ROLES OF DISTRICT NURSE/HOME CARE IN DEALING WITH PERSONAL CARE)

<u>15:3:89</u>

Volunteer calling daily. A crisis occurred because Mr D's oxygen ran out, and there were no instructions with the new cylinder about changing the valve appliance. The cohabitee panicked, volunteer called the chemist and took instructions over the telephone. The patient was blue.
The social worker had made an appointment for a home visit

but he did not arrive. The carer was distressed and angry.
(UNMET NEED - INSTRUCTIONS FOR USE OF OXYGEN CYLINDER NOT SUPPLIED CAUSING SERIOUS HEALTH RISK.
SOCIAL WORKER DID NOT INFORM CARER THAT HE HAD CANCELLED HOME VISIT)

17:3:89

Volunteer took carer to the hairdresser and for shopping, whilst Mr D's brother sat with him for a few hours. She provided emotional and practical support, and confirmed that the district nurse was unhelpful.
The Co-ordinator contacted the social worker about the home visit, and he had simply forgotten to go. He was due to go on leave, but contacted the MacMillan nurse before he went.
(UNMET NEED - MACMILLAN NURSES SHOULD HAVE BEEN ORGANIZED AS PART OF THE DISCHARGE CARE PLAN, BY WARD STAFF. THEY FAILED TO DO SO.)

20:3:89

The phsyiotherapist made a home visit.
Carer was still waiting for the MacMillan nurses so that she could get some sleep. She was by this time sitting up all night with Mr D.
The volunteer tried to persuade him to have his bed downstairs, so that his carer did not have to keep on going up and down all day.

21:3:89

Volunteer observed that Mr D was having great problems swallowing his medication to combat his pain. She contacted the Co-ordinator for advice, and then the GP. She requested liquid medication. Her visits became longer because the carer was finding it very difficult to cope with so little sleep.

(UNMET NEED - DISTRICT NURSE AND GP TAKING A REACTIVE ROLE
RE PATIENT'S MEDICAL/NURSING CARE
NOW NINE DAYS POST DISCHARGE AND MACMILLAN NURSES STILL HAD NOT ARRIVED. CARER BECOMING EXHAUSTED)

The volunteer arranged to take the carer out for a social visit and ordered more oxygen for the Easter holiday.

22:3:89

The Co-ordinator arranged an off loading session for the volunteer who had helped to date, and organised a second volunteer to take over. The original volunteer had arranged to go away with her family at Easter.
The second volunteer visited immediately.

23:3:89

Mr D died. The second volunteer supported the carer, and helped to organise the family contacts needed for his funeral.

29:3:89

Volunteer still supporting the carer. She did the washing and arranged for the hairdresser to call on 30th. Funeral for 31st March.

30:3:89

THIS IS THE VOLUNTEER'S REPORT

Home visit. Mr D's daughter from Holland had arrived for the funeral. I stayed for 1 1/2 hours. (The carer) needed to shed her anger - this was especially directed towards the NHS.

The GP had been unsupportive throughout (Mr D's) illness.

(The carer) had lost faith in the hospital - as during his week on Hollins Ward he had not been bathed, in fact she herself had to give him a bed bath on one of her hospital visits.

The district nurse has been of little use. Despite (the carer's) asking for help, the nurse has constantly put her off and had only helped with this task on one occasion.

Because (the cohabitee) wasn't married to Mr D, his family had virtually taken over the funeral, etc, despite the fact that they had hardly been near when he was alive ..... Her brother, whose house it is - was close and very supportive.

She thanked me, as she felt that the only real support of recent had come from S (the original volunteer) and the one night that the Marie Curie nurses had taken over.

The second volunteer handed back to S on 2nd April. S called on the carer, and promised to stay in touch with her until she felt settled.

The carer asked the volunteer to take the Welfare Rights pack back to the social worker because it had been of no use to her.

Finally, the Co-ordinator supported the volunteer in a feedback and off-loading session.

The volunteer help time recorded was 17 hours during the course of 12 visits.

(Much more time was taken with travelling, telephone calls, visits to the Co-ordinator etc, but this was not recorded)

5. Mrs E aged 60 years, had an operation to relieve pressure for cerebral tumour.

Informal support - husband working full-time

Mrs E was referred for Discharge Scheme support by the social worker, after she was discharged from hospital.

Her husband needed help with his wife during the day. He had tried to support her and work full-time. Domiciliary services were unable to help in the way that he needed them to, and the couple were left in the community, to cope as best they could.

(UNMET NEED - NO MULTI-DISCIPLINARY ASSESSMENT

PRE-DISCHARGE. CARER'S NEEDS NOT ASSESSED. NO MEDICAL ADVICE RE MANAGEMENT OF PATIENT WITH A BRAIN TUMOUR. NO COMMUNITY NURSING SERVICES TO MONITOR AND SUPPORT POST-DISCHARGE. NO SITTING SERVICE)

1:2:89 Situation Screened by the Co-ordinator

She discovered that Mr E worked in insurance, and left for work each day at 8:00 am. He was getting up at 5:30 am to do the housework, and prepare dinner. At 9:15 am he returned home to get his wife up and bath her. Her mobility was poor, she had no confidence to walk unaided because of impaired balance, and sometimes became muddled. She could not have called for help in an emergency.

At 10:15am Mr. E returned to the office, leaving his wife in bed or sitting downstairs. At 12:30pm he returned home again to give her lunch, went back to work at 2:00pm and finally came home from work early at 4:00pm.

His work was suffering, and he was very anxious. He needed someone to be with his wife during the day, encouraging and reassuring her, and to assist her with some rehabilitation into a daily routine.

A volunteer became involved after 3 days, and was able to spend several hours with Mrs E on Mondays and Tuesdays each week. This relieved her husband's interrupted work hours, and the stress of concern about his wife's safety.

The volunteer was 'on call' on other days in case of emergency.

She helped Mrs E to get up and dress herself, to have breakfast and walk about the house. She suggested that a walking stick would help, and this was obtained from the hospital. As time went on, Mrs E became more confident, and attempted some light housework whilst the volunteer was present.

Their activities together progressed to walks outside the house, some soft toy making and cooking.

After two months the social worker and Co-ordinator set a review date, to discuss progress and withdrawal of the volunteer. It was agreed at the review that Mrs E had improved a great deal, she was medically stable and her husband had been able to continue to work regularly. The volunteer was to be withdrawn at the end of April, and her help time was reduced to Mondays only.

Mrs E was admitted to hospital briefly after the review, and the volunteer continued to support more intensively on discharge. She was able to withdraw finally at the end of May.

Both Mr and Mrs E were extremely grateful for the support that had been given by the Discharge Scheme. Without it, Mr E would have undoubtedly given up work, and Mrs E would not have been confident enough to finally manage at home alone.

The volunteer visited 58 times, and spent 112 hours with Mrs E.

The tasks she undertook were numerous, as and when required. The main benefits were to the quality of life for Mr and Mrs E, and the stabilization of their daily home existence.

6. Mrs F aged 80 years. Admitted with a fractured femur, also suffering from cancer of the liver with bone metasteses.

Patient lived alone in a house with coal fires.

Informal support - 2 sons and her sister

Formal services before admission - home care 5/7, district nurse 7/7

Mrs F was well supported at home before admission, but on discharge had become frailer and weaker as a result of her trauma. Her family and the hospital social worker were very sceptical about her ability to manage at home again, but she wished to return there. She knew of her cancer diagnosis, and that she would die in a short time.

The social worker discussed her wish to go home, and asked the Co-ordinator if a 2 day home trial period could be arranged, with formal services, family help and volunteer support.

On 21:11:8,8 Mrs F was discharged, the volunteer was at home at home to receive her and settle her in. The social worker transported her home so that there were no ambulance waiting times.

The downstairs furniture had to be re-arranged, and the patient was unable to get on an off her bed independently. She was unable to transfer to her commode, but she was determined to stay in spite of the risks of falling, or not being able to call for help.

(UNMET NEED - NO NIGHT SITTING SERVICE. NO HOME CARE SERVICES AFTER 5PM OR BEFORE 8:30 AM)

The volunteer stayed with Mrs F until her son came from work, and left her in his care until next day. The social worker rang him at 8:00pm that evening, to check that he was coping. He confided that he felt that his mother needed 24 hour nursing supervision, but would try to cope until the next day as promised.

The volunteer visited at 8:00 am on the next morning, and Mrs F told her that she would go back to hospital. She rang the social worker, and an ambulance came to readmit Mrs F at 10:00am on 22:11:88.

The volunteer waited until she had been collected, and then reported back to the co-ordinator.

The social worker talked to both sons, and discussed residential or hospice care for their mother. They agreed to hospice care, but unfortunately Mrs F deteriorated rapidly and died before she could be transferred.

The volunteer made 2 visits and spent four hours with Mrs F, ensuring that her wish to go home to die if possible was granted. She also helped the family to look at the possible options and wishes of caring for their mother at home, and was available during times that home care did not provide a service.

7. Mr G, a widower who lived alone, was discharged home with terminal cancer and abdominal ascites.
Informal support - daughter doing his shopping, laundry, cleaning, providing transport and fetching prescriptions. She worked 6am-6pm for four days per week.
Formal support - MOW 3 days per week.

Mr G's physical condition deteriorated whilst he was in hospital, but he wanted to go home to die. He agreed to try home care services, since the burden of caring for him was too much for his daughter. A volunteer was requested to help her and support him during the post discharge period until services arrived.
He was discharged on 26:9:89, and the volunteer helped to settle him at home. His daughter took over in the evening, and the volunteer called again twice next day. Mr G felt very weak, and spent most of his time in bed, or lying on

the settee.

On 28:9:89, the Home Care Organiser called to assess him for services. He was alone and unable to get off the settee. When the volunteer called later she found him very distressed, and worried about the home care assessment. The organiser had searched through his drawers without permission to find his pension book, and savings books, he did not understand the papers that she gave him to sign, and was worried that he might be paying for services he could not afford.

The volunteer rang the Co-ordinator, who tried to contact the organiser at the Area Office. The Organiser was on a course, but had arranged for a care assistant to call on 29:9:89. When Mr G was informed of the cost of services, he refused to accept them.

The volunteer continued to support whilst his daughter discussed his care needs, and finally decided to take him to her own home for the time he had left.

The volunteer spent 10 hours helping Mr G, and visited him 5 times. Her support enabled his daughter to stay at work, prevented some risk when home care services caused problems, and enabled him to stay at home for as long as possible. (UNMET NEED - SENSITIVE ASSESSMENT FOR HOME CARE SERVICE, AND CLEAR EXPLANATION ABOUT COSTS. NO SITTING SERVICE FOR

CLIENT ALONE AND ILL)

8. Mr H was a single man (retired Canon) aged 74.
He lived in an old rambling house with his nephew who was deaf and speech impaired. He had coped with shopping and cooking before admission to hospital, and a employed a local lad to do his cleaning. His nephew managed to light the coal fires each day. Mr H suffered two major heart attacks before admission to hospital.
Informal support - nephew and two friends in the Church.
Formal support - none.

Mr H knew that he was dying before he left hospital. The social worker assessed his needs for commode, Home Care Services, meals on wheels and the Discharge Scheme volunteer. He was very reluctant to accept services, but welcomed the idea of voluntary help.

He was discharged on 16:10:89, having been introduced to his volunteer. She found that she could communicate with his nephew, using signs and pictures. The nephew informed her that he could not cope with personal tasks for his uncle, such as hygiene or emptying a commode.
However, Mr H was still reluctant to pay for formal services. The volunteer carried out domestic tasks, settled Mr H and reassessed his nephew.

In the evening, his friends came to stay with him and took the volunteer's number to call for help if needed.

At 10:30 pm on 17:10:89, the friends called the volunteer. because they could not get Mr H out of bed, and he was in some distress. The volunteer advised them to call the GP, and went to the house immediately.

At 2:00pm the volunteer called the Co-ordinator. Mr H had agreed to have MOW and home care services. He was assessed on the same day, but the Home Care Organiser felt that he needed nursing care.

The Co-ordinator discussed this with ward staff, who agreed to refer to the district nursing service for a visit.

(UNMET NEED - REFERRAL FOR DISTRICT NURSING SERVICE NOT MADE BY WARD STAFF, BEFORE DISCHARGE)

During the night, he had fallen out of bed several times, and needed a hospital bed with cot sides. The hospital ward aide ordered a bed, but this could not be delivered for three days. Mr H's friends agreed to collect it from the Home Loans Dept.

The volunteer stayed with Mr H until his nephew returned home, and helped prepare a meal for them both. The friends returned in the evening, with the volunteer on call at home all night.

At 6:30 am on 18:10:89, the friends called the volunteer because they were worried about Mr H. they had been up all night with him, and he had become incontinent. The volunteer called the GP, who visited and left him at home. A district nurse was promised for later in the morning. She arrived at 11:20 am, just as Mr H arrested. The volunteer and district nurse resuscitated him, and called for an ambulance, but unfortunately, he died half an hour later, in hospital.

The volunteer called the friends who had stayed with him, and asked the GP to see his nephew who was very distressed. She stayed with him until the friends returned from hospital, and until he had been sedated.
Next day she called to see him again. He told her that ╗150 was missing from his uncle's clothing, which had been brought back from hospital.
A chat with the ward staff by the Co-ordinator revealed that the money had been left in the General Office safe, and arrangements were made to send it to Mr H's solicitor.

(WARD STAFF SHOULD HAVE RETURNED MONEY AT TIME OF DISCHARGE)

The volunteer continued to support Mr H's nephew daily, until the funeral took place on 26:10:89.
She cared for the nephew's animals for the day, and continued to visit him until he had recovered from the

immediate shock of losing his uncle.

Fortunately, prior to his death, Mr H had made arrangements for his nephew to be cared for by the close friends from the Church who had helped him.

The volunteer supported Mr H and his nephew for a total of 20 hours, and made seven visits to them. She acted in loco familis for the nephew, and gave support to Mr H as if she had been a close family member.

Formal services could not have provided an on-call service, or responded so flexibly to Mr H's needs.

9. Mr J was a married man aged 76 years. He lived with his wife, who was also elderly, and had rheumatoid arthritis in her hands and knees. He had a history of tuberculosis, and was currently in the terminal stages of lung cancer. He was aware of his illness and prognosis.

Informal care - provided by his wife.

Formal care - care assistant daily to help to get up and dressed.

When Mr J was discharged, the social worker requested volunteer help for his wife to continue caring at home. She needed a sitting service to allow her to get out of the house several times during the week.

Mr J was coughing a lot, and too anxious to be left alone.

Before he was admitted to hospital, she had not been out for many weeks.

On the first day after discharge, the volunteer made an introductory visit, and to set up some sitting dates. She found that Mrs J was not claiming attendance allowance, and acquired an application form for her. Later she helped her to fill in the form.

(UNMET NEED - SITTING SERVICE FOR CARERS. SOCIAL WORKER HAD NOT ASSESSED WELFARE RIGHTS ENTITLEMENT)

The volunteer arranged to sit with Mr J on alternate Tuesdays each week so that Mrs J could attend her Salvation Army meetings. On these occasions she also washed pots and helped to clear up the house.

She discovered that Mr J needed sputum containers with covers but these had not been supplied. She obtained some from the hospital, via the Co-odinator.

After two weeks, the volunteer introduced Mrs J to the local Carers Group, and went with her for the first meeting. Subsequently, she sat with Mr J whilst his wife went to the group for support.

During the next month, Mr J was admitted to a Nottingham hospital for 5 days chemotherapy, and the volunteer visited Mrs J at home to give her moral support.

Later in the month, Mrs J fell on the pavement and sustained facial injuries. The volunteer reported the incident to the Council. She then took Mrs J to Nottingham to see her husband, and for a shopping expedition.

(UNMET NEED - HOSPICE CARE NOT AVAILABLE)

Mr J's condition deteriorated, and he decided to stay in hospital in Nottingham. The volunteer accompanied his wife to visit the hospital. The arrangement continued until he died.

After his death the volunteer accompanied his wife to the Citadel for a prayer meeting, and stayed with her until 9:30pm. She offered to go with Mrs J to see her husband's body.

She continued to support her until after the funeral, and offered to stay with her for a short time if needed.

Overall, the volunteer's support spanned 87 days. She visited Mr J 14 times, taking 44 hours in all. She made more visits (uncounted) to his wife, and did not measure the time spent with her giving moral support and friendship.

10. Mr K was a man of 82 years, living with his common-law wife. He was suffering from liver cancer, with metastases.

Informal support - partner.

Son in Grimsby helping at weekends, sometimes.

Formal support - none

When Mr K was due to leave hospital, the social worker assessed his needs for meals on wheels, and the ward staff referred him to the district nursing services.

His partner was very afraid of his illness, and would not leave him alone in the house. A volunteer was requested to support the carer, and to enable her to take some respite out of the house for shopping, and to have a break from caring full-time.

The patient did not know that he was terminally ill, and this caused tension for his partner who could not discuss their affairs with him, or show her feelings pending his death.

The volunteer discussed this problem with the Co-ordinator, and ward sister. Subsequently the patient was informed of his illness and prognosis, and the situation was somewhat allieviated.

(UNMET NEED - PATIENT WAS NOT PROPERLY INFORMED OF HIS CONDITION BY MEDICAL STAFF PRIOR TO DISCHARGE. CARER'S NEEDS WERE OVERLOOKED. NO SITTING SERVICE)

During the following week, the volunteer visited and sat with Mr K, and gave him social company as well as performing some light domestic tasks to help his carer. One her third visit she prepared a light fish meal for them both.

Mr K deteriorated quite quickly, and the volunteer helped to feed him with fluids.

She continued to sit with him to provide breaks for his wife and helped her with personal tasks as he became more dependent.

The district nurse felt that a CCA was needed for getting him out of bed, but the home care organiser disputed this, saying that it was a nursing task.

(UNMET NEED - HELP WITH PERSONAL TASKS NOT AVAILABLE BECAUSE OF WORK BOUNDARY DISPUTES BETWEEN HEALTH AND SOCIAL SERVICES.)

After two weeks, the GP called and said that Mr K's death with imminent. A night nurse was requested, but failed to arrive.

Mr K's son stopped visiting, and the family resentments began to build up. The volunteer talked this over at length with his wife, and asked the social worker to contact the son. It transpired that the son was very afraid to watch his father dying.

Two nights later a Marie Curie nurse arrived and stayed with him during the night. The GP called again, and said that he would organise some night sedation for Mr K, who was confused, irritable and doubly incontinent.

The medication did not arrive, and no incontinence equipment was supplied.

(UNMET NEED - MEDICATION NOT PRESCRIBED BY GP WHEN NEEDED. NO INCONTINENCE EQUIPMENT PROVIDED BY COMMUNITY HEALTH)

Three days later, injections were prescribed by the GP, and Mr K began to sleep for extended periods of time.

During the volunteer's twelfth visit, Mr K died. The family requested that the volunteer should attend the funeral with them, which she did, and continued to support the carer for several days afterwards.

The volunteer made fifteen visits in all, spending 60 hours with the patient and carer.

Her role was both semi-formal, in monitoring the services and finding solutions to service problems, as well as that of a good neighbour, friend and adopted family member.

11. Mrs L was a married woman of 58 years, living at home with her second husband. Her bed was downstairs. She had been suffering from bone cancer metasteses, following a mastectomy, for some months. Her husband had a history of heart failure.

Informal support - husband

Formal support , district nurse popping in once a week.

The referral for Mrs L came via the social worker, from the Out Patient Orthopaedic Department. Mr L had become very

stressed in caring for his wife, particularly as she suffered so much pain, had no standing balance, and was unable to walk.
The hospital registrar referred to the GP to organise some pain control measures, and to provide a MacMillan nurse for home care.

The social worker assessed Mr L's need for some respite breaks, and female company for his wife via the Discharge Scheme.

At her first visit, the volunteer found Mr L desperate for help, especially with toileting. His wife tended to slip off the commode, having no balance. Moving her, if she slipped or fell, caused great pain. Her bed was a problem, and the volunteer felt that a hospital bed was needed to give adequate support. Both Mr L and his wife knew that she was dying, but however ill she became, neither wanted to be separated by a hospital admission.

(UNMET NEED - PATIENT WAS NOT ASSESSED FULLY BY OT FOR TOILET AIDS, OR BY NURSING STAFF FOR A HOSPITAL BED.)

The patient's husband talked about his life, and the problems he had in being his wife's Carer. He told how she had threatened to take an overdose if her drugs were left within reach, and his anxiety about monitoring her drugs.

No family support was forthcoming despite the fact that his wife's brother lived close by.

Mr. l had given up bowling in order to care for his wife. the volunteer offered to sit with her so that he could go out for a game, and he was 'over the moon' about this.
The Volunteer stayed with Mrs. L for 4 hours to relieve her husband.
Volunteer reported back to the Co-Ordinator who requested a full assessment from an Area Office Social Worker.

2.3.90. Volunteer discovered on her second visit that Mrs. L had not been assessed for the Attendance Allowance, and arranged for a form to be completed.

(UNMET NEED - NO WELFARE RIGHTS ADVICE OR ASSESSMENT BY HOSPITAL SOCIAL WORKER.)

5.3.90.
During the Volunteer's 3rd visit Mr. L expressed concern about prescription charges. She obtained DSS forms for Invalid Care Allowance, and gave him information about prescriptions.
The Hospital OT confirmed with the Co-Ordinator that she had made a referral to the Area OT.

(UNMET NEED - NO ADVICE RE. PRESCRIPTIONS BY HOSPITAL OR

S.W. STAFF. DELAY IN OT RESPONSE FOR ASSESSMENT FOR EQUIPMENT AFTER DISCHARGE.)

9.3.90.

Volunteer continued to support Mr. and Mrs. L. She offered to sit with her to give her husband some respite time.When she called this time she found that Mrs.L had fallen, and helped the District Nurse to bath her. The GP called, and said that she could have some respite care in hospital, but she did not want this for fear of dying in hospital. D.N. supplied incontinence sheets because Mrs. L no longer able to use the commode. Physiotherapist still not visiting.

(UNMET NEED - PHYSIOTHERAPY SERVICES REQUESTED 2 WEEKS AGO, STILL NOT VISITED.)

22.3.90.

Volunteer still visiting. She reported that Mrs. L has now been assessed for pain relief, and a MacMillan Nurse will be visiting.

Mrs. L told the Volunteer that she thinks she will die in May, and has begun to put her life in order by telling Mr. L what she wants to give away.

3.4.90.

Volunteer continues to visit and support the couple.

5.4.90.

Mrs. L died peacefully in her sleep. Volunteer visited Mr. L and has been asked to attend the funeral.

10.4.90.

Volunteer visited Mr. L to give him support.

11.4.90.

Volunteer attended the funeral, and made 2 more visits to Mr. L to help him by giving emotional and practical help.

The Volunteer made 10 visits in all, and spent 30 hours with this couple.

Summary of Patients who were Dying.

This small group of patients consisted of four women and seven men, who were much younger than the patients overall referred to the Discharge Scheme.
Their average age was 70 years, ranging from 58 to 82. Six were living with partners, one with a nephew, and four lived alone.

On discharge from hospital they received a high level of support from both Health and Social Services :

- 9 from a District Nurse

- 3 called in services from a GP
- 2 had McMillan nurses for night care
- 5 received meals on wheels
- 8 used domiciliary services.

After their hospital discharge six patients were readmitted to acute beds, where three died. One patient died in an ambulance on his way back to hospital, and four more died at home.

When volunteers from the Discharge Scheme finally withdrew, only three patients were still alive.

Volunteer support to the patients and their carers involved 135 visits and 318 hours of care.

Unmet Need

The details of care and needs described in the patients' case histories show a formidable array of unmet need, service delays and unco-ordinated care planning.

Carers' needs were mostly overlooked, and assessed hardly at all.

The most frequently expressed need from patients and carers together was fo a sitting service at home. Volunteers were able to meet this need to a limited extent, and the flexibility of the Discharge Scheme enabled them to do so. A formal recognition of this need, and a properly co-ordinated sitting service would have been appropriate.

The second need, although not stated by professionals involved with this group, was for Hospice care. The only hospice available was 14 miles away, in another Health Authority.

The one patient who might have gone to the hospice died before transfer. The distance for relatives to travel would have offset the benefits of the service.

Eight patients needed hospice care, especially those who were readmitted to acute hospital beds.

Unmet needs and service delays or failures were inextricably linked together. These are shown by numbers of patients, the service responsible, and circumstances in Table 61.

Table 61: Patients with unmet needs and service delivery failure

Service - Health Care, Community and Hospital.

No of patients	Circumstances
1	no information about management of terminal illness and prognosis
1	no medical help with management of brain tumour
1	patient not properly informed about his terminal illness
1	no specialist neurology staff available
1	referral not made for district nurse by ward staff
1	no nursing care plan on discharge
1	no bath given in hospital by ward staff
1	hospital bed not ordered for patient before
1	ward staff did not check whereabouts of doorkey
1	ward staff did not arrange to send patient's money to him on discharge
1	hospital OT did not assess need for stair rails
--	
11	instances

Service - Hospital and Social Work staff jointly. NHS and SSD

4	no assessment of carer's practical needs
1	help for toileting not assessed
1	patient's concern re a dying relative ignored
1	no multi-disciplinary assessment

1	no assessment of carer's physical ability to cope
--	
8	instances

<u>Service - Hospital Social Workers. SSD</u>

1	no pre-bereavement or bereavement counselling arranged
1	inappropriate welfare rights information provided
1	need for Discharge Scheme not assessed
1	no assessment of home environment
2	no assessment of welfare rights needs
1	emotional and psychological needs of carer
1	Social Worker forgot to make a§home visit.
8	instances

<u>Service - Domiciliary care. SSD</u>

1	no service before 8:30am or after 5:30pm
1	insensitive financial assessment and not enough information given about costs
1	personal care not given because of task/boundary disputes with district nurses
1	confusion of roles between home care and district nurses - care not given
1	no services available at the time of discharge
--	
5	instances

Service - Community Nursing, NHS

1	night nurse failed to arrive for 3 nights
1	incontinence equipment not provided
1	no flexible help in the evening
1	district nurse was not practically supportive to carer - would not listen to her needs
1	no community bathing available
1	no community nursing specialising in neurology
1	McMillan nurses delayed for 9 days - carer exhausted
1	nurse operated only a reactive role to carer re patient's medication needs
--	
8	instances

Service - GP, NHS

1	medication not prescribed when needed
1	GP reactive only to carer re medication and pain control
1	no specialist medical knowledge of neurology or behaviour management
--	
3	instances

Service - Housing Department, LA

1	electrical repairs not carried out

Service - Chemist

1 no instructions for use of new oxygen mask and cylinder connections

The total instances of service problems/delays/failures came to 45 for the eleven patients and their carers. The largest cluster of unmet needs was originated in hospital, and the table shows that every patient was involved. Therefore there was a 100% certainty that each dying patient would leave hospital with a problem.

The next most frequent area of service difficulty was with the hospital social workers, whose lack of assessment or referral for services meant that two thirds of the patients left hospital with another unmet need.

Equally likely was a failure or shortage of service among the community nursing staff, leaving two thirds of patients and carers with unmet needs.

Half of the domiciliary service provision did not meet patient or carer needs either.

GP support was the service least given to the patients, and when it was, proved to be inadequate.

Formal services failed the users and carers individually and jointly, overall care planning and communication between services was needed but appeared to be structurally impossible in the context of discharge from acute hospital beds. No one professional had the responsibility of co-ordinating a patient's care plan and then ensure that all other service providers were informed and timed to take part.

Collectively, these patients needed the closest working together of Health and Social Services, since they needed the most areas of care. Their experience was of the greatest number of service failures and delays of patients referred.

Carers were rarely involved in discharge planning, but they were the most important people concerned, since patient safety and quality of life depended on them when their relatives went home. The patients themselves were not noticeably involved either, and this situation is not uncommon.

In a study within Parkside Health Authority, Young (1991) found that there was generally little attempt to involve elderly people or their carers in discharge planning, nor was adequate information given to them.

In 1989 the British Geriatrics Society and the Association of Social Services also commented on the problems and inadequate care arrangements that patients faced on discharge because so many professionals shared some responsibilities, had different operational philosophies and different understanding of patients' needs.

The concerns for the patients who are dying are not new. In 1972 a national symposium was organised to address the care needs of terminally ill patients, and produced a report entitled 'Care of the Dying' (Dept of Health and Social Security, 1973). The first speaker, JM Holford, commented 'It is generally admitted that concepts of terminal care in this country are largely unformulated and that arrangements for it are consequently haphazard ... It is clear that terminal care cuts across all divisions in the NHS. All sections have a part to play but their roles need further defining ... the total care of the patient at home involves a wide variety of services and people ... There are likely to be heavy calls on the home nurse for technical nursing procedures and a heavy load on the family for the more domestic part of total nursing care'.
Dr. Cicely Saunders emphasised that patients and families could be separated by unshared knowledge, at a time when they needed help to be brought closer together. She and other speakers addressed the difficulties that patients and carers experienced, especially with regard to pain control,when patients could not eat, and the distress of

carers who found themselves alone with relatives in agony, and no-one to turn to.

Overall, the information shared at the Symposium illustrated all the areas of unmet need that patients and their carers in this study were still experiencing some seventeen years later.

The benefits of hospice care were compared by examples from St Christopher's Hospice, and clearly even in 1972, two standards of care for terminally ill patients were operating.

A paper by Ms BJ McNulty SRN described the close working relationships between professionals, the careful attention to detail and planning for care needs which enabled dying patients to live at home with constant support, safely and comfortably, and with someone to call on even at night in a crisis. She concluded 'It is self evident that support at home should include not only the continuity of medical care, increased night nursing facilities, realistic financial help, but also the immediate availability of relevant aids, and all this must be given with an understanding of the urgency because there is so little time'.

The lack of care and fragmentation of the care systems for the dying patients from Mansfield General Hospital was a concentration of problems that other patients faced.

When more service providers were involved, the greater the levels of unmet need and stress to patients and carers became. The structures of acute hospital care with its fast throughput of patients could not provide a return for after care as a hospice would, or ensure any accountability for service delivery post-discharge.

This is not to say that individual professionals were unaware of the needs of terminally ill patients. Many publications for both Health and Social Services professionals have provided research and information and have examined these needs carefully (Murphy, 1977; Butrym, Horder, 1983; Kubler-Ross, 1974; Saunders, 1984).

From a nursing perspective, Kelsey (1992), makes a most important and crucial point about the attitudes and roles of medical staff, in care of the dying. His study found that in 53% of cases, medical staff did not discuss treatment with nurses, 47% of nurses were concerned that their patients may not have received satisfactory treatment, and 59% of nurses had never been approached by medical staff for advice about the needs of a terminal patient.

He concluded that it is doctors who appear to decide policy, and do not fully regard nurses as equal members of the team, leaving them with little authority when caring for terminally ill patients.

Throughout the whole system of acute hospital care, patients who have complex needs do not receive a focus of specialism which is operated in either Hospices, Young Disabled Units or units for care of the elderly. It seems that routinised service delivery, which is governed by budget efficiency and broad policies in both Health and Social Services cannot provide the close gearing of operation, communication and individuality which such patients and their carers require. The outcome of the volunteers' roles in the Discharge Scheme illustrated the complexity of need and the consequences of the acute hospital system. They were filling in gaps, being communicators and problem-solvers whilst providing comfort and personal support to people like themselves in the community. They were overall, performing a special kind of human giving, which was epitomized by Dr. Cicely Saunders, as follows -

'They (the terminally ill patients, and carers) need more than sympathy and sedatives, they need something that was summed up for us for all time with the words "Watch with me". I think that phrase means persevering with the practical and developing the many skills that can help. But I think above all it means listening without necessarily knowing the answers, it means, do not forget to be simple and be prepared just to be there. We must somehow say to these people "you matter because you are you", and give everything that will enable the patient to live up until he dies and the family to go on living afterwards'.

4. Other Patients who were referred to the Discharge Scheme.

Parts 1, 2 and 3 of Section 12 have shown the details of twenty one men and twenty three women who were found to need very considerable amounts of help from the Volunteers when they were discharged from hospital. Their circumstances were characterised by the facts that they were without any informal Carers, were interdependent on partners or Carers, or were dying.

Eighty one other patients were referred. Most of these did have family support, but this was not sufficient to ensure completely safe discharges, either because the family members were in poor health, not available, lived some distance away from the patients' homes, or had other family members who were ill and disabled and therefore needed their time and care instead. In three situations family disputes created difficulties, and prevented Carers from giving the care that patients needed.

The support that the Volunteers gave fell into several categories, such as domestic and/or personal care, help with health care needs, practical assistance to Carers, communication with other agencies, financial help, emotional and psychological reassurance, social support and safety monitoring.

Domestic help included many household tasks, including cleaning and hoovering, shopping, putting up curtains, (a shower curtain in one instance); watering plants, looking after pets, preparing meals, doing the laundry, fetching coal and lighting fires; clearing out fridges and freezers; mending plugs, a hoover and a television, getting radiators and toilets to work; buying furniture, pots and pans; bedmaking; undertaking rubbish disposal and gardening, and getting other house repairs organised.

Personal care involved helping patients to wash, bath, dress and undress; to go to the toilet, empty commodes and help with incontinence equipment disposal; with hair care, nail care, dentures and in one case, a glass eye.
This type of care was needed by patients who still felt ill and weak after their illness, or were restricted temporarily, following a cataract operation for example, and particularly by those who still had a limb in plaster or§ splint.
If the patients had nutritional problems the Volunteers monitored their diets and eating habits, and encouraged them to eat if necessary.

Help with healthcare needs was sometimes carried out with supervision from a District Nurse, but more often because no formal agency support appeared when needed. Patients needed

help with medication, especially topical applications such as eyedrops and eardrops. These tasks did not seem to be the responsibility of either nursing or domiciliary staff, and while the professionals debated about whose job this was, the Volunteers got on with it.
The same difficulty was encountered with leg and foot braces, which elderly people found hard to manage if they could not bend, and with elastic stockings which were too taut and strong for them to put on if they had arthritis or a dexterity disability.

The Volunteers used their own cars, public transport and taxis, mostly in the context of healthcare needs, to collect prescriptions, equipment from home loans, and to escort patients back to hospital, to GP's surgeries, or to visit ill partners or relatives still in hospital.

They helped to get wheelchairs repaired, and spent a great deal of time liaising with District Nurses, Social Workers, Dentists, Opticians, Chiropodists and hospital staff.
They found that some patients had actually needed attention to their eyes, ears or teeth for considerable amounts of time, even before their last hospital admission. Nothing had been done simply because there had not been an informal Carer to help, advise or encourage with the healthcare needed.

Many of the patients were found to need help with finance management at home, and volunteers completed DSS forms, made DSS enquiries, went to banks and building societies with patients, and helped to get bills paid that had been outstanding whilst the patients were in hospital. In two cases they helped to make arrangements to pay off arrears of rent, electricity, gas and water bills, and undoubtedly prevented services from being disconnected.

Their support to Carers in many instances involved doing the tasks already described, because Carers were not able to. In others, tasks were performed for the carer such as minding a child, looking after a shop and giving the time for Carers to talk through their feelings when they were stressed or felt they could not cope.

The volunteers provided short respite breaks for Carers by sitting with patients when needed. They were available early in the morning or later at night to give help with personal tasks when formal service providers were not available. On a few occasions, the volunteers gave Carers their home telephone numbers in case help was needed during the night.

Whenever advice was sought, the volunteers were able either to give it themselves or obtain information through their Co-ordinator and the hospital social workers.

Possibly the most important volunteer function overall was that of monitoring services and unmet need. There were many instances of service delays or mistiming, and these were reported back to the Co-ordinator and social workers, who were then able to contact the providers concerned.

It was evident too, that however well a social worker's assessment had been completed, that other needs for care and support emerged once patients returned home. If these needs required formal service input, this would then be arranged. In others, especially with regard to the categories of support described, volunteers undertook to meet these needs themselves and completed numerous tasks which undoubtedly improved the patients' confidence, self-esteem and feelings of security.

It was clear that whilst the volunteers did their work, that they had become community advocates for the patients and Carers. They were very aware of the isolation and loneliness among some patients who lived alone, and continued to visit and support them after their volunteering task had officially ended.

In a few cases, the volunteer's contact with patients' neighbours stimulated concern and informal support which had not been available before, simply because the neighbours did not know that help was needed and the patients had not been able to ask. In this way they may have actually been undertaking a restorative process in reconstructing social relationships which had been lost when the patients became isolated and housebound during periods of illness, and when they were not able to ask for help for themselves.

5.13. Summary of Chapter 5 - Patients who were referred to the Discharge Scheme

The data and case histories of patients who were referred to the Discharge Scheme show that volunteer support was essential for a wide variety of reasons and different types of need.

When the Scheme began, it was anticipated that volunteers would mostly be using their time to undertake domestic and personal tasks for discharged patients, that they would be able to report back to the Co-ordinator when formal service delivery failed, and that the periods of support would probably be for short periods of time, rarely exceeding two weeks.

Once the volunteers were engaged with patients, and because they had freedom of choice with regard to the way they gave their time and skills, it became apparent that very much more unmet need existed than was known about beforehand.

The full extent of suffering, anxiety and stress which was experienced by patients and Carers where needs a discharge were complex, and particularly where terminal illness was an issue emerged with great clarity. It became obvious that formal services for these people who were close to death were either absent or fragmented, and their needs were marginalised by a generalist and non-specialised approach

from both Health and Social Services.
Those patients who had no carers, and those who were interdependent and frail were found to be significantly at risk when they went home. A formidable array of unmet needs were dealt with for them by the volunteers, and these two groups in particualr illustrate the consequences of being isolated from the informal care support systems of family or friends.

The key issue about the patients who were referred was that no empirical information existed which could show their needs, risks and circumstances following Acute Hospital discharge. Consequently, there had been no feedback previously to service providers, to alert them to delay, failures or gaps in service structures. The service which a discharge scheme can perform, therefore, can be used as a means of influencing service standards, to identify gaps and structural difficulties in service response.

Characteristics of patients referred

Prior to the Discharge Scheme feedback information, the hospital social workers and ward staff had thought and felt that some patients were at risk more on discharge. When they encountered such patients, they referred them to the Discharge Scheme, and for the most part, their perceptions were found to be correct.

An analysis of the data in Chapter 5 enabled a broad classification of the characteristics of the 169 referred patients to be drawn together This is shown in Table 62, and relates directly to the availability of informal carers in the community.

Table 62 - to show important characteristics of patients referred to the Discharge Scheme

169=100%

	Patient Characteristic	Size of patient group		
No		Nos	by %	
1	patients without informal carers	16	9	Group 1 - individuals and
2	interdependent couples without other carers	2	1	couples 'remaindered' for informal care structures
3	interdependent couples with family carers	17	10	
4	patients living alone with informal carers	104	62	
5	living with single adult child carer	4	2	Group 2 -
6	child as main carer	1	<1	insufficiency or
7	family living far away	35	21	fragmentation of
8	uncertain attitudes to care by informal carers	13	8	informal (family) care
9	poor living environment - dirty or structural	11	7	
10	recently bereaved	10	6	
12	needing formal social services	64	38	Group 3 -
13	needing residential care	15	9	needs exceeding
14	dying	12	7	the coping
15	having malignant illness	15	9	capacity of
16	readmitted to hospital	8	5	informal carers

NB Total of patients exceeds 169 as some patients had more than one characteristic .

Table 62 illustrates the patients by different characteristics which can be divided further into three groups.

Group 1 - shows that those patients with characteristics 1 and 2 had no family or other carers that they could depend on for help. They were totally isolated.

Those with characteristics 3-10 in Group 2 had family care stuctures which were fragmented or insufficient to meet their needs.

Characteristics 3-10 applied to the majority of patients and since several characteristics were found to co-exist for a number of patients, their totals add up to more than 116, at 70%.

Group 3, showing characteristics 11-15, are 34 patients whose needs exceeded the caring and coping capacities of their family carers. Most were simply too dependent and ill and close to death to be cared for by family members. They urgently required specialist Health Service support, which was not available, and high levels of personal care to cope with the complex needs associated with terminal illness.

The table of characteristics, when defined in this way shows how essential it is to assess informal care structures before patients are discharged from hospital.

Almost 90% of of patients referred to the Discharge Scheme were potentially at risk in the community because of their recent episode of ill health AND the scarcity or absence of informal family care.

Those in Group 3 were especially in need because of the severity of their illnesses and impending death. Their needs and the lack of specialist Health resources in effect concentrated a pool of unmet severe need for patients and carers alike.

Volume of work undertaken by volunteers

Twenty-one volunteers gave their time and energy which spanned a total of 1566 days. During this time they made 515 visits to patients' homes, taking 965 hours to complete their supportive tasks.

This gave an average of 12 days, 4 visits and 7.5 hours per patient in order to meet their needs.

The support to people who were very ill and dying required the longest periods of time and numbers of visits. The single greatest time was 155 days with 10 visits and 23 hours. This contrasted sharply with the single least amount of time for patient support which was on one day, with one visit for half an hour.

The volunteers were asked to record their time and visits undertken for the Discharge Scheme. They tended to do this on a task-centred basis.

They did not always record times which they spent simply having a cup of tea or chatting to patients because they thought that was too ordinary to count.

The Co-Ordinator attempted to make a time estimate of the 'ordinary social activity' and considered that a further 500 hours at least had been given in this way.

The Discharge Scheme - structure and volunteer profile.

The outcome of one year's performance by the Discharge Scheme was extremely successful and was related specifically to two key factors.

These were, 1) the actual§ structure of the Scheme which enabled a smooth operation to take place, and 2) the volunteers, who actually dealt with the patients' needs.

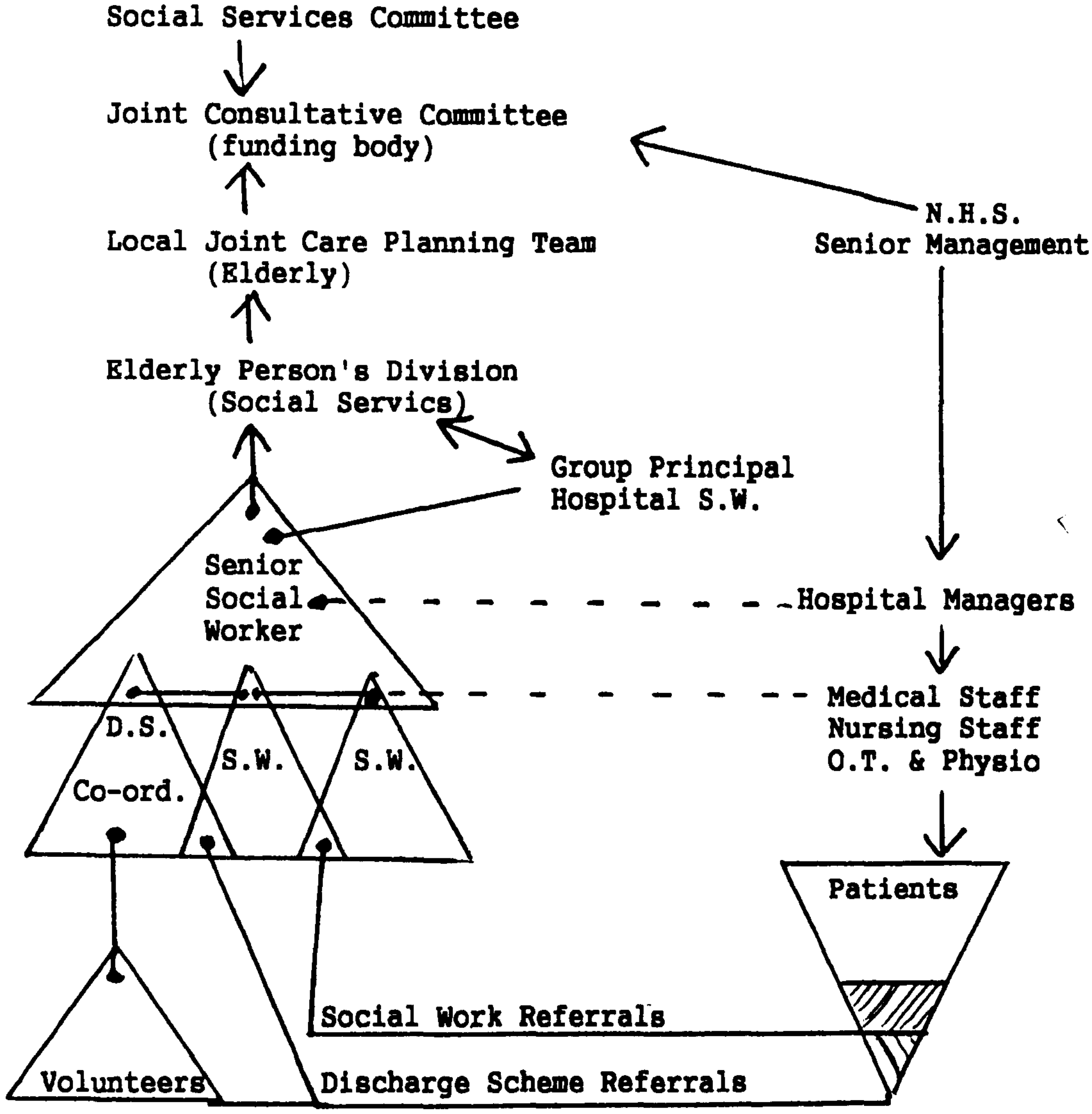
The Discharge Scheme Structure.

The structure of the Scheme was designed in order that the Co-Ordinator would have a formal role as part of the Social Work Unit, and so have the closest possible working relationship and direct communication links with the Social workers and the Senior, who was also her line manager.

The referral route to the Scheme was via the Social Workers, underpinned by the assumption that patients at risk on discharge and therefore most in need would already have been referred to them in first instance.
It was known that other Home from Hospital schemes were not organised in this way, and that referral routes were usually§ open to all hospital based staff, patients, Carers and anyone else who thought that a volunteer might be needed.
Three different types of schemes were operating close by in Nottingham and Derbyshire. An investigation into their operations revealed that an open referral route had led to between 30 - 50% of referrals not actuallly being appropriate for volunteer support, and the co-ordinators had spent a great deal of time redirecting referrals to other agencies.
All three schemes were operated by voluntary sector organisations and no formal links existed with hospital social workers.

The structure of the Mansfield General Hospital Discharge Scheme is shown in Figure 12, and the referral route by Figure 13. The theory underpinning the structure was based on Likert's linkpin theory of overlapping roles and communication. (1967) It was anticipated that this model would reduce the amount of inappropriate referrals to the Scheme and eliminate any waste of time in dealing with other agency-related tasks.

FIG 12- The Integration of the Social Work Unit and the Discharge Scheme

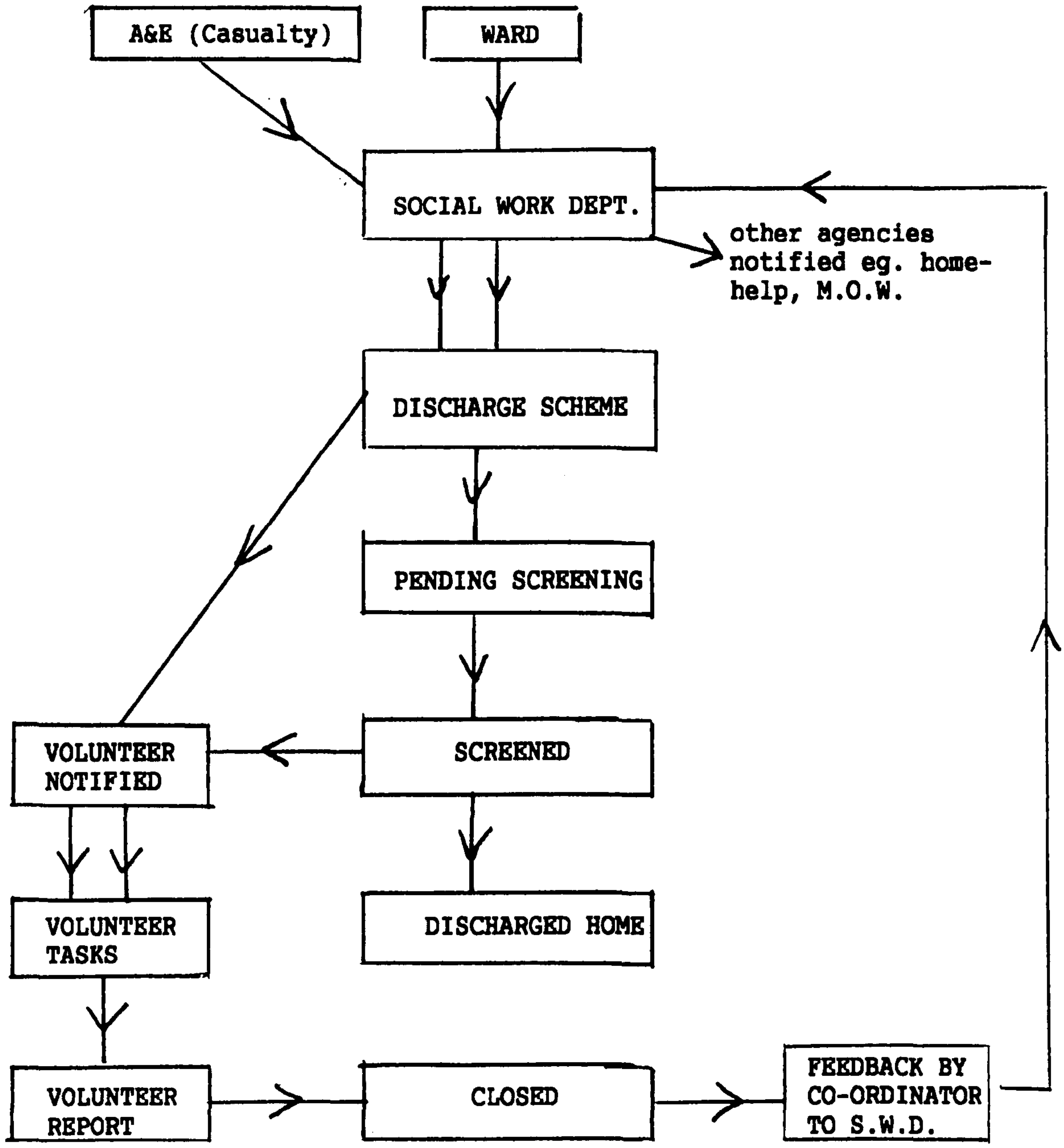


* The model uses Likert's Link pin theory, and shows the possible areas for shared responsibility - where the triangles overlap. (The overlap indicates the extent to which an individual can move into another's role).

The continuous lines also denote formal communication pathways.

The dotted lines denote the insecurity of both accountability and communication between the formal organisations.

FIG 13- DISCHARGE SCHEME REFERRAL ROUTE



The Volunteers

The volunteers who came forward to join the scheme proved to be very effective in terms of commitment, skill and understanding of patient/carer needs. They were all part of the local community infrastructure insofar that they had. all lived locally for a number of years, had mostly been, or still were Carers themselves, and wanted to be actively involved with community work.

In terms of gender mix, sixteen volunteers were women, aged between 20 and 72 years, with an average age of 49 years. Three were retired, one was in full-time employment, and one was receiving long-term sickness benefit.
Nine women described themselves as housewives. Two who were single needed work experience to help them obtain employment.

Eight women were married, one was separated, two were widowed and two were divorced.
Nine women were family carers, and 14 had had previous experience of working in other volunteeer siuations, such as St. Johns Ambulance, Mencap, Age Concern, the Samaritans, in hospitals and schools, and with Disabled Person's§ groups.
Their reasons for joining the discharge scheme were stated as 'having time on their hands', recognising that a need

existed for support to patients leaving hospital, and actively wanting to give something back to their local community because they had received help themselves in the past.

Five volunteers were male, and they were aged between 25 and 72 years, with an average age of 55 years. Three had had volunteer experience previously, and they were also caring for a dependent family member.

One young male volunteer needed work experience, one had time to spare,and the other three recognised that there was a need for the Discharge Scheme.

As a group, the volunteers were similar to others by virtue of their ages, marital status and previous volunteering experience.

They accepted that some training would be needed for work with the Scheme. In the beginning, most volunteers attended group meetings where different professionals explained their roles and functions, demonstrated the use of OT aids to daily living, and provided information about services that patients might need following hospital discharge.

During the group meetings, which were attended by professionals from within and outside the hospital various issues were the subject of lively debate.

The volunteers were asked for their opinions on the social and domestic roles of men and women, how family obligations

and duties were perceived, why some elderly people became isolated , their views on formal sector services, and where they as volunteers fitted in with Health, Social Services , and informal community care systems.
The volunteers had assertive statements to make about all of these issues. One male was quite clear that he had had to learn how to do women's work (when his wife became ill), and subsequently applied this in his volunteering tasks.

Almost all felt that professional nursing staff in the Community could not give enough time to care properly for the individuals who they attended; they expressed irritation about the roles of home helps/community care assistants with regard to the personal care which they were supposed to provide.
They felt that cleaning a person's home was very important, because older people wanted to be clean and tidy, and to see the standards of their living environment maintained when they were unable to perform all the tasks themselves.
The male volunteer previously mentioned felt that one of his most important tasks was to get a persons home situation in order,sometimes by hoovering and doing considerable amounts of housework if this was needed, when a patient returned home.
The volunteers believed that the state of a persons home was

very important for social wellbeing and a personal sense of pride.

Their attitudes to patient/client choice when risks were involved, were variable. They considered that whilst elderly people clearly wanted to remain their own homes, even when their physical and mental health became very deteriorated, if they became at risk and neglected themselves seriously and became to much for carers to cope with, then Social Services should be more pro-active about getting them into residential care.

They felt too that doctors and social work professionals passed responsibility for action backwards and forwards to each other until a crisis - such as a fall and fracture resulted, and the outcome too often was admission to the Accident and Emergency department in Hospital.
Debate about these areas of risk and accident sometimes became quite heated, and everyone had their own story to tell about professional neglect. Statements were frequently made that professionals did not listen to patients or their families, and that they did not care enough.

The volunteers judgement about professionals, and families caring or non-caring attitudes were a mixture of hegemonous beliefs and views constructed from their own experiences. They believed that younger people did not care so much about older family members as they used to and that society's caring attitude overall was in decline. They saw this manifested in poor housing, problems in obtaining social and medical care, lack of attention to the needs of people with Alzheimer's disease, lack of equipment in the form of O.T aids from Social Services for physically disabled people, and especially with regard to the scarce cover by wardens in sheltered housing.

The interactions at the volunteer group meetings always resulted in some individual conversations with either the Co-Ordinator or hospital social workers afterwards. Meetings were informal and relaxed, with invitations to those who were shy in groups to express their opinions. As they developed confidence to speak the group , some spoke about difficulties that they were experiencing at home. One woman cared for a husband with Alzheimers disease, and shared her feelings with the other volunteers, and gained social support for herself which she could not get at home. In a number of ways the volunteers took different things for themselves through their helping activities, and expressed positive feelings of achievement because they were valued and seen as part the total hospital discharge process.

In time the volunteers and professional staff came to know each other very well. Discussions took place and were shared about patients who were currently being helped. Opinions about the scheme served as an educative process to all participants.

Not all the volunteers came to group meetings. Those who did not attend stated that they did not have enough time, or felt that they would not gain anything by attending a group. They preferred instead to have their support individually from the co-ordinator and social workers when they came for their travelling expenses, and over the telephone as they helped individual clients.
In situations of complex needs, emotional stress and difficult family relationships they met with the Co-ordinator and social workers, and became part of the care planning for individual patients. The issue of length of time for involvement was determined on an individual basis.

As some instances in Chapter 5 show, patients were not always better in health after hospitalisation because they were suffering from a progressive illness or were dying, and their carers needed ongoing support. The volunteers then continued to help for longer periods of time, according to their own choice and motivation. Their tasks became a part of family system support, with the added dimension of understanding some basic professional methods of dealing with difficult situations.

It was very clear that they derived the greatest satisfaction in giving of themselves, their time and knowledge. Some enjoyed a counselling opportunity_ and one volunteer who had been trained used this skill whenever she could.
Generally, the skills that the volunteers brought with them were very person centred and labour intensive. The services that they offered did not usually fall within a professional service delivery remit, and their flexibility with time and situational response was a valuable complementary element to direct services.

Also the amount and frequency of help they offered was based on their own perceptions of patient/client need. It was clear that they felt valued and needed. This was confirmed by professional staff and by the patients they helped, except in one or two instances when they were actively insulted by people they were trying to support. They rationalised these situations through their own knowledge of 'personality types' and the unshakeable unpleasantness of some old people. They appreciated very well how difficult life became for some carers.

CHAPTER 6.

Summary and Conclusions.

Chapter 6

Summary and Conclusions

Introduction.

This chapter aims to reflect on the research into patient/client need, and to draw out the important issues that are found through the action research methodology. Chapter 2, which described the research methodology, stated that both quantitative and qualitative research methods would be used, and that the research team of co-action researchers would be conducting the research concurrently with the day to day work.

Some issues about the research team will be addressed. Chapter 6 also revisits the aims of the research, which were stated in the Preface to the thesis. Since these aims underpinned the thinking and work of the research team, and myself in particular as lead researcher, they are stated again here to provide the focus for discussion.

The aims were to address four issues and questions, as follows:

- are patient/client needs identified and met by Health and Social Services professionals,
- are formal and informal care structures linked effectively to provide a safe and adequate transition from hospital to home,
- do formal and informal care structures meet care needs in the community as they are expected to and is is there a role for volunteers within the existing structures of care?
- is a seamless pattern of care possible

1. Overview of the research.

The purpose of chosing three different patient groups was to create an overview of patients as they moved through the hospital system, from admission to discharge, to try to identify patterns of need, and links between health and social care needs, during the research process.

The inter-relationship of health and social needs.

Everyone, whether a patient or not has a range of needs, as Doyal and Gough's theory of human need shows (Doyal and Gough, 1991), but patients in an acute hospital by virtue of their admission for medical treatment can be established as already having a need for health care which they cannot meet for themselves. A key area of knowledge about a hospital population is that of the range of health care needs which patients have.

Patients also have social needs, because they are human beings, but those whose needs cannot be dealt with by independently or by informal care processes, are identified by their referrals to formal social care agents, or social workers. The issue about social care needs, then, is how they appear through social work referrals in the hospital setting. A second key area of knowledge about a hospital population is that of the range of social needs which patients have.

Social care needs in health care settings have been identified in different ways. Chapter 1 looked at the contextual meaning of client/patient need in relation to hospital populations, and shows that different people have different needs because of health conditions and a whole range of social circumstances and different events which preceded admission.

In Chapter 1, the demographic characteristics of people likely to have health care needs as a result of their living environments, life experiences and life choices were explored, and attention was drawn to groups of people whose needs for health care were caused by a range of circumstances, including major disasters, self harm and trauma.

The important issue is that health care needs can be set in many different environmental contexts, and a whole range of social needs can be identified among patients who are ill. Predisposing factors in social situations give rise to health care needs, and the opposite is also true, since health care factors also give rise to social care needs.

It behoves the professionals in health and social services who are working together to recognize that one set of needs impacts on all others, since needs are located in each person and interrelate. **How they interrelate** is the key issue for the professionals.

If we take one patient who has had a stroke, for example, medical treatment for the stroke is one area of need, but there are differences in right sided and left sided strokes. The outcome in terms of social need for each one might be very different, and the more severe the stroke, the more the different needs become intensified. If a social worker is the person who assesses the social needs of a person who has had a stroke, she will have to understand the outcomes of the medical condition in order to recognise and foresee the person's social needs, and to plan accordingly. If she cannot do this, then important needs will remain unmet and the person will be disabled not only in a pathological sense, but also in terms of social functioning and life participation.

The consequences of illness and trauma as this example shows, are health care need outputs to social care structures, whereby social needs will have to be met.

This is so at the level of an individual patient, and also at a collective level when all patients in a hospital are seen in the same way.

Hospitalization is a time of change.

A hospital episode is a time of change for people as patients, some recover to an optimum level of health, but others do not. When ill-health can only be treated minimally, and chronic ill-health remains, social needs are precipitated by the disabling effects of illness. The hospital can be seen as a system of change for better or worse for different patients.

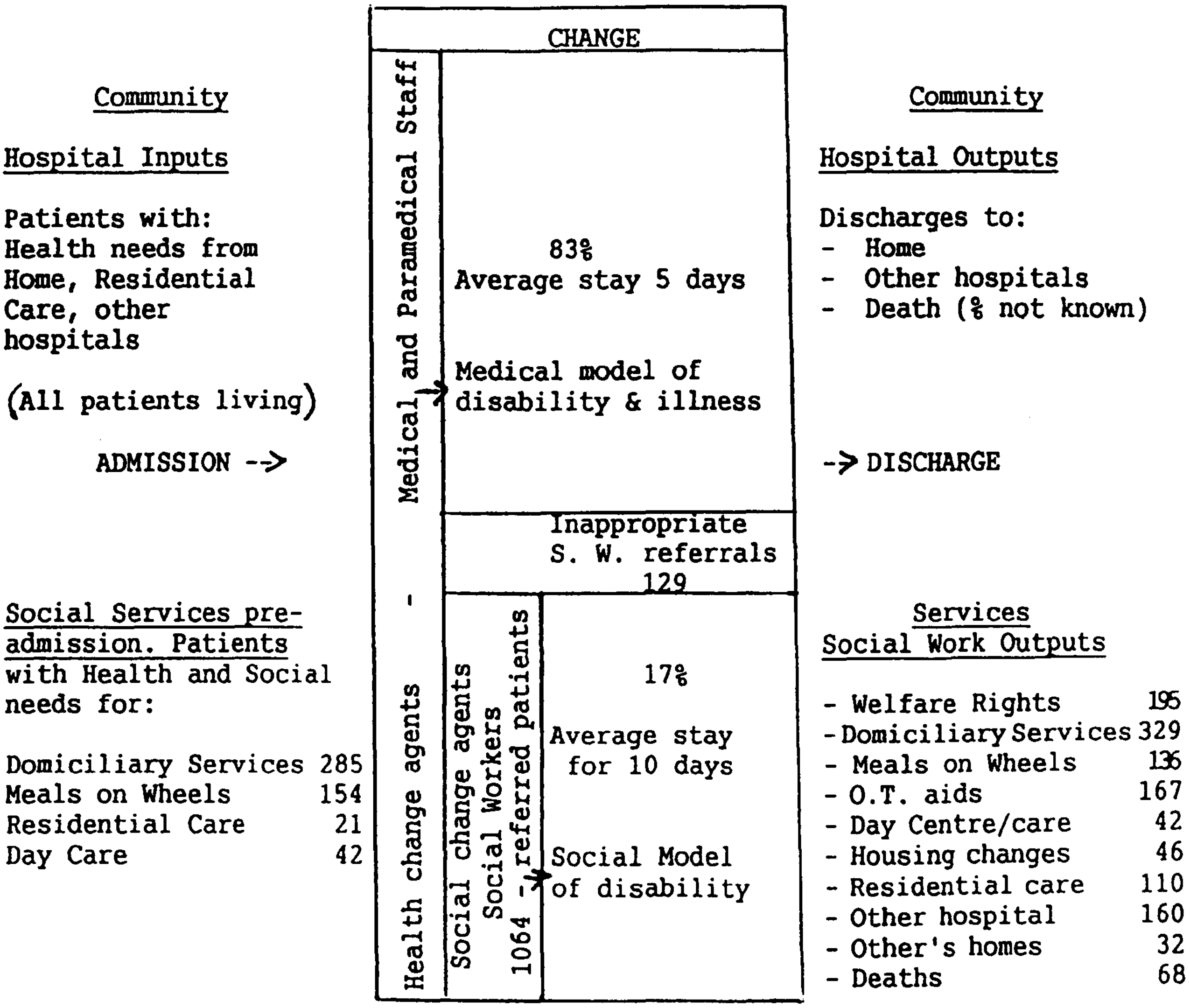
Fig. 14 shows the Mansfield General Hospital in this way. In Fig. 14 the hospital is shown as a system of change which involves medical and social care needs. Some patients died in hospital, others whose health care needs were met went home in an improved state of health. Together, these patients were in the majority at 83%. They only needed an average hospital stay of five days.

The data collected as a result of 17% of the hospital population in need of social work support, illustate the social changes which came about following health care intervention. These patients spent an average of ten days in hospital, which is twice the length of stay of the majority.

Fig. 14

The Acute Hospital as a Medical and Social Care System - based on data from Mansfield General Hospital

THE ACUTE HOSPITAL
(Medical and Social Care System)



CHANGE

Community

Hospital Inputs

Patients with:
Health needs from Home, Residential Care, other hospitals

(All patients living)

ADMISSION ->

Medical and Paramedical Staff - Health change agents

83%
Average stay 5 days

Medical model of disability & illness

Inappropriate S. W. referrals 129

Social change agents
Social Workers
1064 - referred patients

17%

Average stay for 10 days

Social Model of disability

Community

Hospital Outputs

Discharges to:
- Home
- Other hospitals
- Death (% not known)

-> DISCHARGE

Social Services pre-admission. Patients with Health and Social needs for:

Domiciliary Services	285
Meals on Wheels	154
Residential Care	21
Day Care	42

Services
Social Work Outputs

- Welfare Rights	195
- Domiciliary Services	329
- Meals on Wheels	136
- O.T. aids	167
- Day Centre/care	42
- Housing changes	46
- Residential care	110
- Other hospital	160
- Other's homes	32
- Deaths	68

N.B. This diagram shows the Acute Hospital as a change system, the agents within it are Health and Social Service professionals. The change in Social Service provision to meet need is shown in actual patient numbers.

Within this group there were 160 patients who needed to go on to other hospitals. Most were transferred to local geriatric hospitals, but a smaller number needed to go for specialist treatment in cardiac, mental illness, neurology and orthopaedic units in specialist hospitals. Overall, their health needs were greater than the majority of patients.

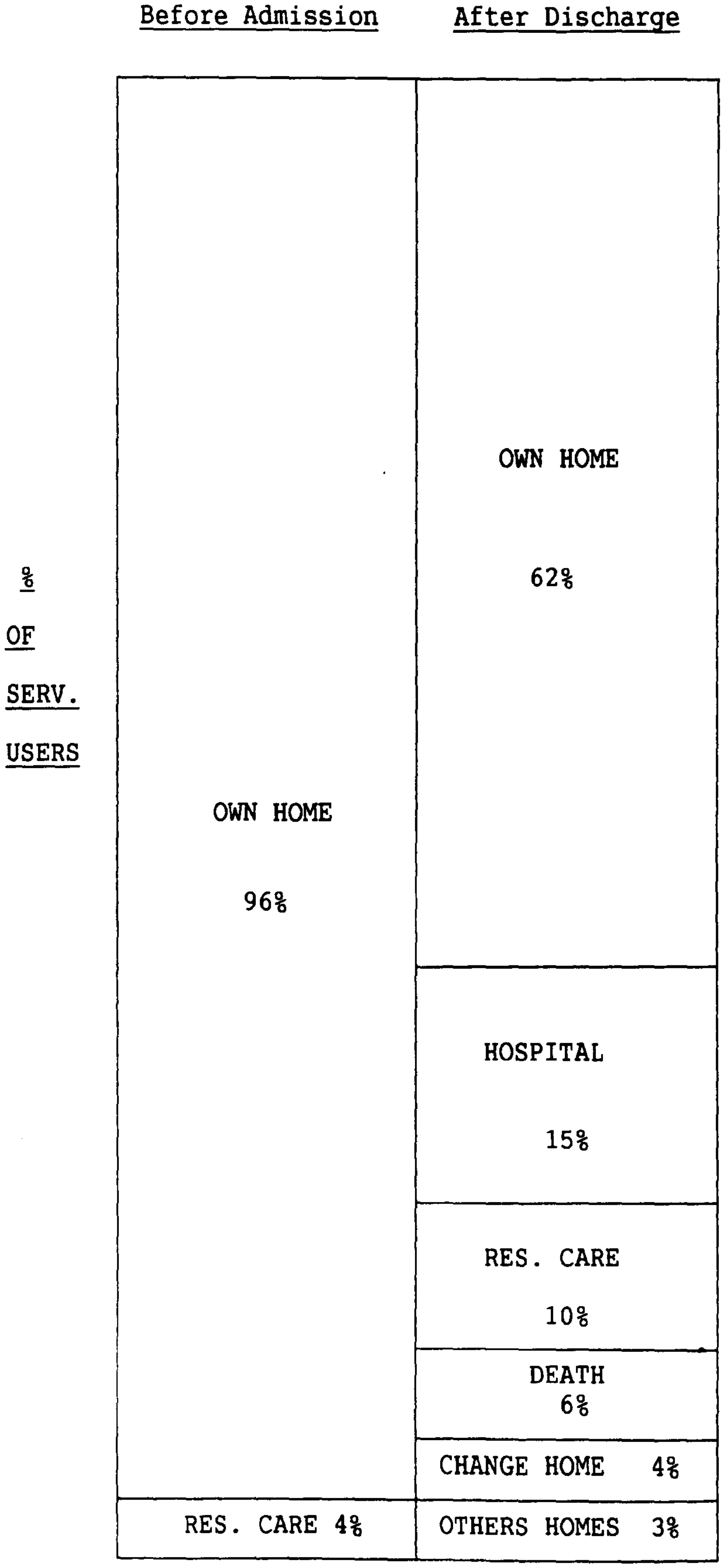
Two important areas of change are embedded within the hospital system outputs via the social work referrals. The first is change in accommodation. Fig. 15 shows this area of change, 96% of patients were admitted from their own homes, only 62% returned. 15% went on to another hospital, and 6% died. Only 4% of patients were admitted from all types of residential care, but on discharge, 10% needed such care, and did not go home.

A further 4% had to go and live in someone else's home because they could not cope alone. The other option for these patients would have been residential care, but neither they nor their families wanted this.

Finally, 4% of patients needed a change of home. Their need was extreme, and enforced by their acute health care episode in hospital. They needed another home because they could not continue to live in the one they had, due to loss of ability, and overall because their

Fig 15

Changes in accommodation on discharge.



previous homes had now become environments where they could not be cared for safely.

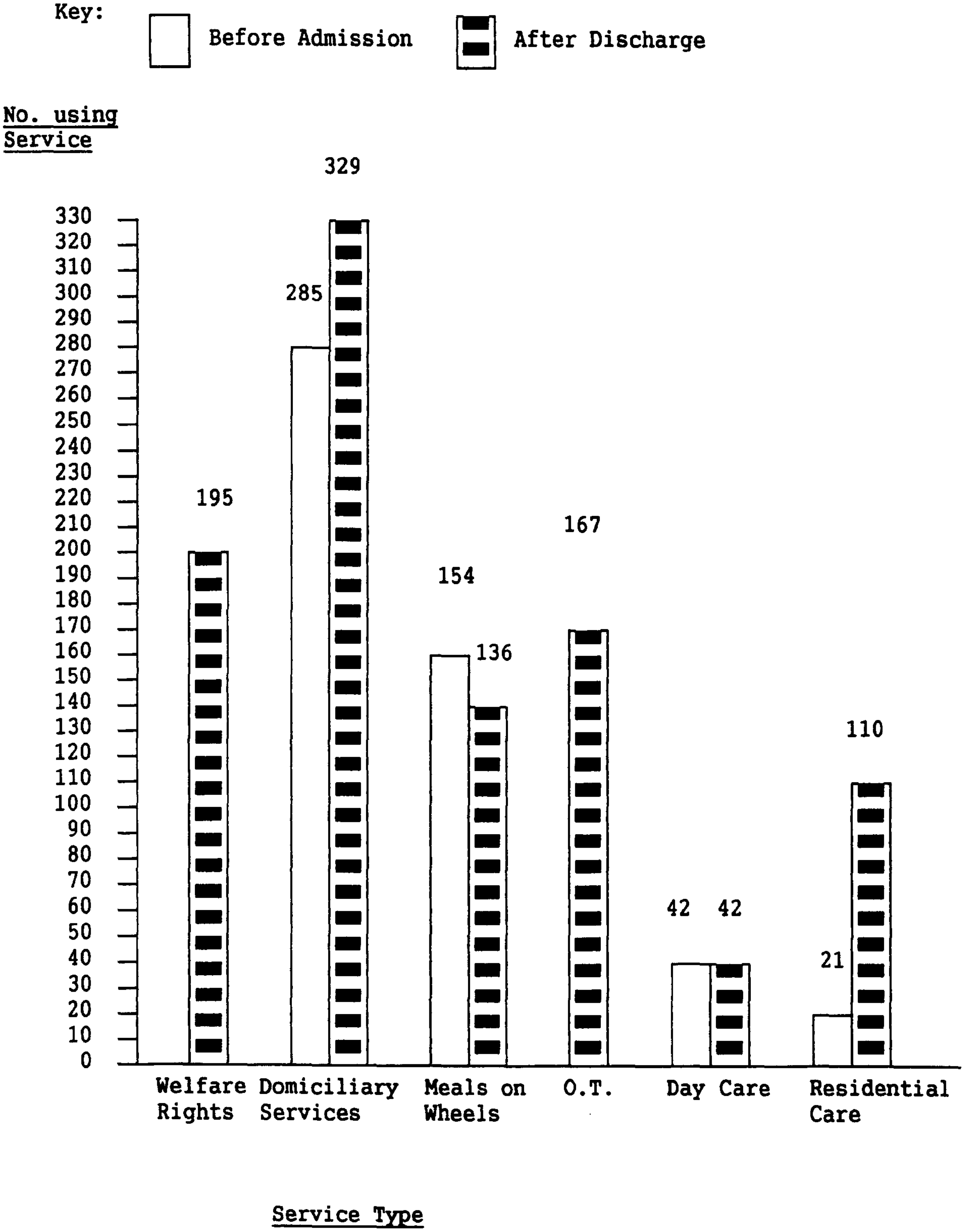
The second area of change is shown in Fig. 16, and is that of a change in formal service requirements. After their hospital treatment, more patients needed formal services than they did prior to admission. This area of change informs us that some patients needed more help at home through public service provision as a result of their illness. They were more disabled after medical treatment, and needed help in order that their basic needs were met in their home environment.

These two areas of change provide a baseline of information about **changes of need,** which in this case affected 17% of an acute hospital population.

Whether these changes would be found for all hospital patients is not known. Unless there was a long-term data base which showed these needs in any given hospital population, as Davies and Challis (1986) suggest there should be, the measurement remains unknown.

Fig 16

Changes in services before admission and after discharge.



This measurement is important. Davies and Challis (1986) provided information about the costs of services which have to be estimated and met in terms of public sector service provisions, both for Health and Social Services. If change in need in hospitals could be measured at a basic level as shown by the Figs. 15 and 16, then these services could also be costed as a outputs from acute general hospitals. The relationship between this area of Health and Social Services could then be put into a more informed framework of the costs which are consequent upon acute hospital episodes. Such a measurement could be applied to any other hospital, by using an appropriate data base which captured the information.

The two areas of need which are identified here are only part of the picture, and only tell us about some of the services provided to patients on discharge to their community environment.

A further element of cost which should be included here, is that of employing social workers and any other ancillary employees who work with patients in the hospital setting. Thus would provide the cost of the assessment of need process and of organising services as a result.

Complexity of need.

The work of Social Services staff in hospitals varies from patient to patient, depending on the complexity of the social situations which surrounded them as people in the community, and the events which pre-disposed their hospital admission.
Chapter 1, which looked at different groups of people who were likely to become hospital patients attempted to show some of these complexities in terms of their needs, and thereby gave indications of the work which might possibly be required to meet them.
Chapter 1 is not a total picture, it could only address a small proportion of client/patient need by its description of the groups. Even so, the fact that predisposing events and social circumstances could be extremely complex was shown.

Complexity of need is an important factor, and must be acknowledged since it affects the overall social work task, and adds a dimension of difference in task for individual patients when they are assessed.
There is no doubt that medical intervention is also different in terms of complexity. A patient who needs to have a toenail removed, for example, has different needs to one who has sustained multiple injuries as a

result of a road traffic accident.

This is easy to understand, complexity of trauma and illness requires complex interventions, and most probably a longer stay in hospital.

The more complex and damaging the disease or trauma, the more likely it will be that the effects of the damage will lead to loss of function and ability on the part of the patient. These losses or disabilities, by whatever degree they occur, are transferred from hospital to community when the patient is discharged.

The point of this discussion is to establish that complexity is an issue for Health and Social Services workers. Just as health and social needs are interrelated, degrees of complexity of patient/client needs are also interrelated and therefore are become a dimension of interaction for the workers and the outcome of their work for the satisfaction of client/patient need.

Complexities of health and social circumstances therefore should be seen as equally important, and this leads to an interesting question. Do health care staff and social services staff see each others' work with their different foci on meeting needs as equally important?

During the period of research, the experiences of the social workers suggest that this is not so. The medical pressure which was exerted upon patients with complex social needs to leave hospital beds without doctors, and in some instances nurses, even knowing what that complexity entailed in terms of risks and needs subordinated social need to medical need, or organisational need to attainment of targets for reduced inpatient stay.

Another question arises from this, which is about the focus of social work agency tasks towards ensuring that personal and domestic *care needs* are met. Are social needs associated with the core roles of informal carers, who are mostly women, therefore not as important as the highly technical professional roles in medicine which are usually controlled by men?

In the context of this debate, were hospital organisational targets to reduce the length of stay in hospital beds more important than social care needs?

If no measurement of social needs is available it cannot be brought into a calculation of need which is focussed on the use of hospital beds. Millard and McClean (1994) have identified this as an issue in their work which uses mathematical calculations to assist the modelling of hospital resource use. They state, 'what we particularly lack in Social Services is data to enable us to define and recognize the characteristics of clients which make a particular investment decision (for want of a better word) about a package of services, the best one when taken in relation to the longer term view of the requirements of that client, for as long as he or she will remain our responsibility. That period of time is increasingly becoming larger' (p10)

Millard and McClean (1994) also note the need for rehabilitation, but do not identify whose task rehabilitation will be, or indicate whether social rehabilitation is an element to be included.

Rehabilitation has usually come to mean that it is a process of helping a patient to regain functional abilities, and is seen to focus on the skills of physiotherapists and occupational therapists within their hospital departments.

A human being, however, is made up of many parts which can be disabled by disease or trauma, mental, psychological and emotional and social abilities are all equally important as physical abilities and affect a person's potential to function in a socially appropriate lifestyle.

If there is a need for rehabilitation, it can be a complex process, and may require the skills of other specialist workers ot help the patient to recover all her abilities to an optimum level.

There are two other issues linked to that of rehabilitation, which are, where the rehabilitation will take place, and who else needs to be involved.

The disabling effect of illness impact on others who participate in an ill or disabled person's life, and these are not only public service workers, but also the person's own family and carers. If a person is to receive rehabilitation, where they live and how they will be supported by formal or informal carers is crucially important. Carers need to be included in a rehabilitation process, in order to maintain the progress and skills which their dependent other is relearning, and the environment in which they live will have to be appropriately adapted or altered to facilitate opportunities for maximum independent functioning.

Once again, the change of need must be seen in a social as well as a medical context, and the fact that individual changes of need impact on carers and change their roles and tasks has to be equally recognised.

Availability of informal care resources.

When this debate is pursued, the next logical enquiries must address the issue of informal care resources. Are such resources available, and are they adequate to meet health and social needs?

In order to address this question, the data about carers which was collected during the research at Mansfield General Hospital provides some, though not all, of the answers.

In Chapters 3, 4 and 5, the patient and carer information shows that most people who were leaving hospital did actually have informal carers available to help them. Whether patients lived with a carer, or alone, most had someone who was part of their community social infrastructure who could be called a carer. The availability of informal carers enabled the majority to go home.

Informal carers were the people who ensured the patients' safety, that their physical needs were met, and they were involved also, to a lessor or greater extent, in meeting their social, psychological and emotional needs as well.

The informal carer availability was not the same for all patients however. The data show that a number of patients were vulnerable because their carers were in poor health or disabled. For these patients, the level of carer support was reduced, and the resource was limited. In some cases, the carers actually needed help themselves, and their needs too became interrelated with the needs of the patients.

A small number of patients had carers who were interdependent upon them, and no other carers were available. When they were separated by hospitalization, the care needs of each were separated also and both lost their only informal care support system. The situations of interdependence and separation precipitated both people into a state of change which resulted in the needs for formal care in order to survive.

Theirs was a compound situation of needs and risks, with threats to health and autonomy for both.

In joint situations of interrelated health and social needs such as these, each person's need for the other had to be given a significance as part of their needs spectrum, because of the potential serious loss of relationship bonds which were elemental for meeting their emotional and psychological needs.

These patients were among the most vulnerable in the hospital population. Their presence is an indicator with a special characteristic of serious health and

social care needs. This should be maintained as part of a long term data base, because such interdependent couples are at risk of having no informal carers at all and therefore of becoming totally dependent on the care which public sector services can provide instead.
The interdependent couples, as the data show, were not always married people. They did include married couples, and few of them had children. Other people were aged siblings, aged single parents with older dependent children, and in a few instances more distant blood relatives who were caring for each other.

The other group of people who were equally at risk were the small number of people who were already without informal carers. When their health needs resulted in acute hospitalization they became dependent on formal service providers, and they too needed to be identified in terms of the social risks which had become a danger to their future health and lifestyle. Some were even at risk of dying alone, without care, because they did not have any significant bonds with other people by whom their needs could have been seen.

The data on carers showed another important factor about availability of informal care support. Some older people had family and friends who cared about them, but they did not live near enough to provide regular practical support. Although neighbours helped and sometimes even gave more time caring than some family members, many of them were also very old and had health problems too. Even so, when family members lived far away, the older patients needed them to help with, or actually make decisions about the biggest life changes of entering residential care.

Isolation and lack of family carers are shown by these data to be very significant threats to the health and social care needs of older people in the acute hospital population. The potential for isolation among this group is shown as a small percentage of the patients overall, and they had all been part of family groups at some time in the past. Very few were single or divorced, and they belonged to the family structures of 50 years ago or more, when families were larger, women were obliged to stay at home and social systems within the community were closely bonded together. In future, changes in family structures will result in different outcomes for people who are ageing. Smaller families, the change in women's roles, greater family mobility and more frequent family separation and divorce suggest that there are likely to be more isolated very old people, and more who find themselves without carers when they need them most.

Characteristics of the patients and indications of health and social care needs.

So far, this overview of the hospital population has brought a number of important issues to light, which are:

- that health and social care needs interrelate
- the hospital system is a time of change in need
- a proportion of the population of patients will need more social care because of their health needs
- some patients will have a complexity of need either for health or social care or both
- the availability of informal social care in the community is central to meeting both health and social care needs
- when informal care supports are fragile or absent a need for public sector recognition of these factors is crucial so that state care provision can be provided instead.

The patient/client data in chapters 3, 4 and 5 was collated quantitatively by socio-demographic characteristics. Comparisons of the data for the three groups showed their relevance to Health and Social Care needs.

Table 63 shows this comparison by the characteristics of sex, age and living alone.

The table shows that patients in Group 1, who were screened on admission were younger overall than those referred to the social workers, or to the Discharge Scheme.

Even among Group 1, who were representative in this study of the 83% of all patients who went home independently, it can be seen that a fifth of the men and about a quarter of the women lived alone, which is proportionally more than people generally in the community.

When these patients are compared to the other two groups who were referred to the Social Workers because of social care needs, the table shows that the incidence of living alone had increased, particularly among patients who were aged over 75years. In group 3, the patients who were helped by the Discharge Scheme were even more likely to live alone, after the age of 70 years for men, and 65 years for women.

TABLE 63 compares patients screened, referred to Social Workers, and to the Discharge Scheme by age and living alone.

MEN

	Screened Patients		Social Workers		Discharge Scheme	
Age	%	% Living Alone	%	% Living Alone	%	% Living Alone
-65	47	5	25	7	5	3
65-69	17	3	11	2	10	3
70-74	14	5	16	5	17	12
75-79	14	2	20	8	34	22
80-84	7	4	19	10	19	16
85-89	< 1	-	7	2	12	9
90+	< 1	< 1	2	2	< 2	2
TOTAL	100	20	100	35	100	67
	n = 111		n = 382		n = 58	

WOMEN

	Screened Patients		Social Workers		Discharge Scheme	
	%	% Living Alone	%	% Living Alone	%	% Living Alone
-65	53	6	16	2	12	3
65-69	10	3	10	3	9	9
70-74	17	6	12	7	16	13
75-79	9	5	21	11	20	14
80-84	5	3	20	12	27	25
85-89	6	1	17	10	11	11
90+	-	-	< 5	4	5	5
TOTAL	100	24	100	49	100	80
	n = 78		n = 682		n = 111	

The groups provide a three part spectrum of patient need for social care as it emerged through the hospital system., and evidences a trend of living alone associated with the need for formal care support. The Discharge Scheme group is special, because its volunteers provided an informal care supplement for those patients with the least amount of family or others who could care for them.

The three groups, when compared by ages show the same trend. The men and women who were referred for social care assessment were more likely to be aged over 75 years, and more women were older than men.

Those referred to the Discharge Scheme were older still by majority, but their need for supplemental volunteer support was clearly related to living alone because the trend of patients needing support moves to men who are aged only 70+, and to women who are even younger at 65+ years.

Other demographic factors of the three Groups are shown in Table 64 which includes a comparative illustration of age marital status, living alone, and having no carers.

Table 64

Comparative Table of Groups 1,2,3
by age, marital status, living alone and number of carers

1) Hollins and Abbott

	Men	%	Total pts %	Women	%
	111	100	100	78	100
Single	9	8	8	7	9
Widowed	22	20	24	23	29
Married	75	68	64	45	58
Div	5	4	4	3	4

3% - no carers (all men) - 0% women
51% aged 65+
18% lived alone (75% over 65 years) (men)
24% " (74% ") (women)

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2) Social Workers

	382	36		682	64
Single	59	15	11	55	8
Widowed	129	34	51	412	60
Married	185	48	36	193	28
Div	9	2	3	21	3

81% over 65+

Men - 35% LAL
81% 65+
8% no carers (29)

Women - 49% LAL (336)
95% 65+
5% no carers (31)

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3) Discharge Scheme

	58	34		111	66
Single	7	12	11	12	11
Widowed	32	55	66	79	71
Married	17	29	21	19	17
Div	2	3	2	1	1

Total 58 = 100%

Men - 67% LAL (39)
65+ - 63%
75+ - 48%

10% - no carers
95% - 65+
67% - 75+

Women - 79% LAL (88)
65+ - 79%
75+ - 55% (61)

9% - no carers (10)
88% - 65+
63% - 75+

When the groups are compared, they show that on admission only 3% of men were without carers. Those patients referred to the social workers were more likely to be living alone. The table shows that they were more likely to be widowed, and were beginning to show a higher percentage without carers. at 8% for men and 5% for women.

The third group was even more likely to be without carers, at 10% for men, and 9% for women.

The incidence of being widowed follows an increasing trend through the groups, but single people and divorced people remained at the same percentage as one would expect in the general population.

The significant factors that can be taken as indicators of social need from these data, are old and very old age, being widowed living alone , and having an acute hospital episode (see Figs 17 and 17A). The social risk which needs to be uncovered by assessment because older patients represent over half the hospital population, is that of not having a carer at all.

Fig. 17 Bar chart to show percentages of men and women living alone in the three groups.

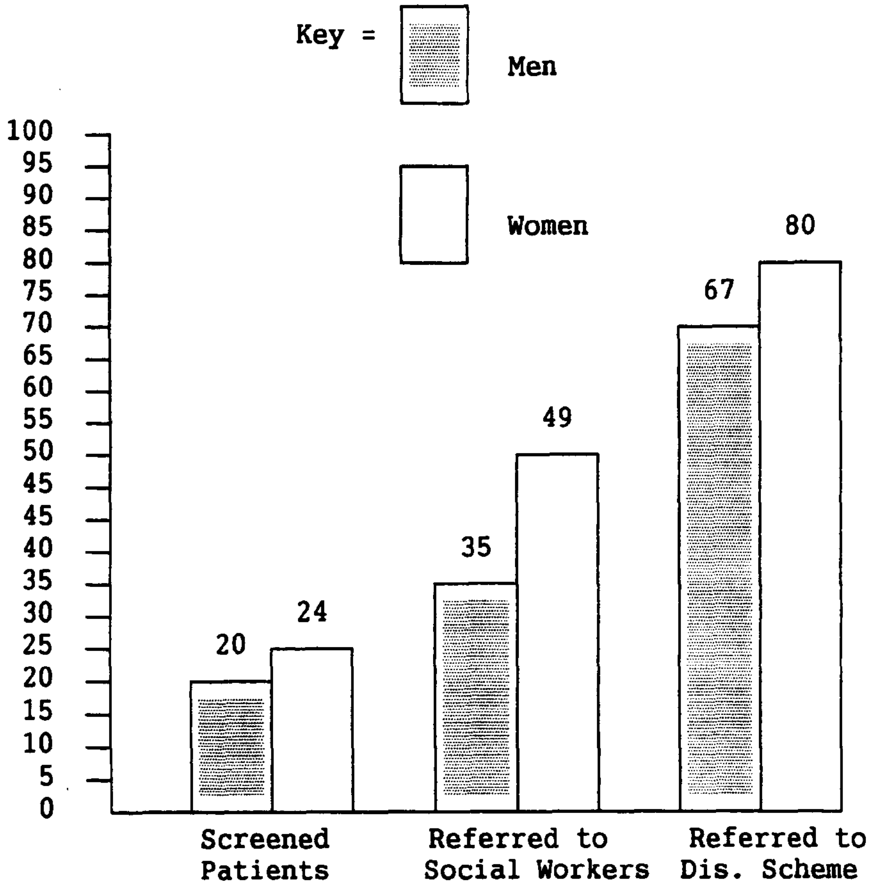
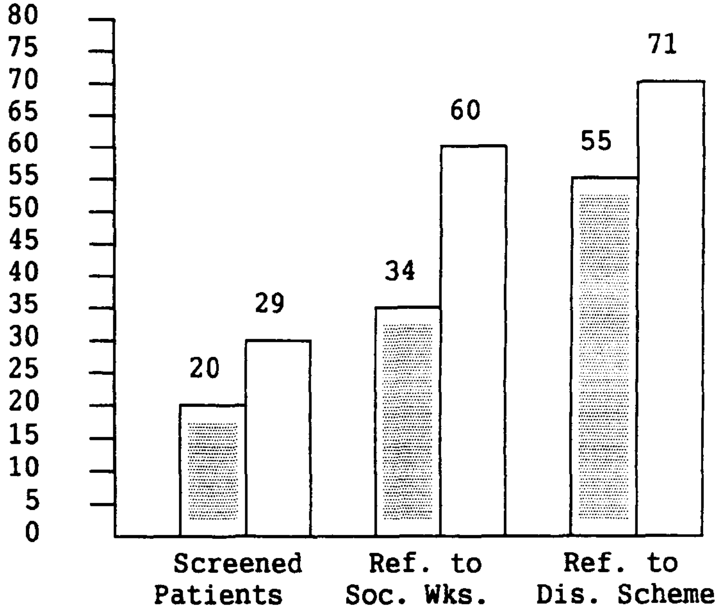


Fig. 17A Bar chart to illustrate percentage of widowed patients.



The data for age, marital status and living alone, when considered together all provide indicators of need for social care for patients in an Acute Hospital environment. This applies to the majority of the patients shown by the data, but there is a small incidence of younger people too, and their presence is important.

The reasons for their referral to Social Workers, indicate a range of social needs which came about because of predisposing social circumstances which did not apply to the majority of older patients. These included trauma following abuse, marital violence, severe physical disability, behavioural disability due to head injuries, mental illness and learning disabilities, and a special situation for two men who were admitted to hospital following the Kegworth Air Disaster.

Except for these two men , behaviour and other disabilities had led to disruption in their family care systems, and had caused such intolerable social stress to carers that dislocation from families had occurred.

These patients were identified among those who were grouped in Chapter 4 under the heading of 'Family

Problems'. The tables showing the circumstances of the patients in their seven groups contained details of the younger patients.

It was very difficult to disentangle the needs of these patients from the needs of their carers in order to show them clearly, but the tables do serve the purpose of illustrating that stress was a recurrent theme, and that in many cases informal carers were also supporting other family members with various disabilities and illnesses. In some families, carer support was limited to one person and where other family members were being cared for at home, that single carer had reached breaking point and could not cope.

Embedded in these accounts of family circumstances is the evidence of a range of enduring disabilities and dysfunction. It is here that people who were suffering from Parkinsons Disease, Alcoholic related problems, Sensory Disabilities among adult children, Myotonic Dystrophy, Multiple Sclerosis, early onset Alzheimers Disease, ageing with Poliomyelitis, Schizophrenia and Drug abuse begin to emerge. The brief notes about their family circumstances show that chronically difficult and volatile social environments made life so stressful that rejection and exclusion was occurring for individuals when so many urgent needs existed collectively and conjointly within the family group or network. The experiences with these families are not understated by describing them as desperate. Perhaps it is not surprising therefore, to find a number of younger and older people who came to the hospital following attempted suicide and self-harm.

All of the patients identified in the seven groups in Chapter 4 can be seen to have complex social needs, and in many cases, their family environments were not places to which they could return with any guarrantees of safety, or where their health or social care needs would be met. Although their course of life events could not be followed after discharge, all were likely to be readmitted to hospital with health care needs.

The indicators of need for health and social care which can be drawn out so far as the patients have been discussed relate to age, since the majority of patients were aged over 65, being widowed and living alone. Younger people with needs for health and social care were more likely to be living alone if they were male. If they were male or female and living within a family group, illness, physical and sensory disabilities, dysfunctional behaviour, disorganisation at home and disruptive, conflict prone relationships were found to be factors associated with their presentation of need. Most of the families were in a condition of chronic and increasing social need which affected all their members.

The health care workers in hospital could only meet immediate and acute health care needs for those family members who were admitted to hospital, they could not effectively address long-term chronic needs. The social workers, when presented with evidence of chronic social needs, could only offer limited support because of the continuous demands made by the pressure of new hospital referrals. They had to rely on colleagues working in area and specialist community based teams to provide continuing support and intervention, by referring the patients on to them.

6.6 Chronic illness and mortality.

Data was collected for all three groups of patients which showed their presenting illness in hospital. The Hollins and Abbott ward screening project patients, although they were admitted for acute health care reasons, were found to have a pattern of types of chronic illness which matched closely with the main causes of death in Central Nottinghamshire. Chronic illnesses, with associated levels of disability predispose incidence and causes of death.
The same pattern of chronic illness was reflected in the data for patients who were referred to the social workers, and to the Discharge Scheme. it was found to be repeated by type and proportion, and therefore can be linked to situations of social need.

One type of disability which was not a cause of death was also found to be significant, and that was orthopaedic disability associated with arthritis. Falls and other orthopaedic problems associated with arthritis were the primary and most frequent cause of disability among older patients, and the underlying reason for their needs for social care.

The overall pattern of chronic illness for all three groups was as follows:
orthopaedic illness, cardio-vascular disease, respiratory disease, malignant disease of the digestive tract, and disease of other body organs.
A cause of death which is not directly associated with chronic illness is suicide, but even this factor was shown to be linked to the social context of need, through the incidence of attempted suicide and self harm which were referred to the social workers.

The relationship between chronic disease, mortality statistics and social need, when set in the context of the patient/client data in this research, establishes that the need for health and social care are directly linked.
Chronic disease and consequent disability is an underlying and persistent factor in the lives of a proportion of older people. It is linked to their lifetime experiences of the effects of industrialized working environments, working class struggles and the inevitable outcomes of restricted ability to make choices about lifestyles, accomodation and opportunities to provide an adequate income for their families.

When chronic ill health is part of their lives, so is the likelihood of admission to hospital for acute health care needs, and the need for care at home as they become progressively more disabled until they die.

This means that in long established mining areas such as the catchment for Mansfield General Hospital, a large proportion of older people in the community are living with the effect of lifetime experiences of stress, poverty and unemployment accumulated during this century, and their families are tied to their resulting dependency and costs of need for care.

The point was made earlier in the thesis that there are inequalities in health care provision across the Country. This applies to some areas in the North of England in particular, where large teaching hospitals are not available to attract high levels of government funding. These areas do not have adequate income to provide the resources needed for high standards of health care provision. Central Nottinghamshire Health Authority is such an area, receiving the lowest level of funding in the whole Trent Health Region.

The patients at Mansfield General Hospital within their local working class community were therefore affected by two major environmental factors, that of their working lives and unemployment, and the low level of public health care investment. As such they were destined to suffer from two significant factors of inequality. Their needs as patients or clients on discharge from hospital reflected these factors.

Organisational issues within the hospital.

Once patients were admitted to hospital, they became subjected to its structures and systems which were established to meet their needs for care. These involved the processes of assessment, communication and collaboration which the professional workers used in order to identify, plan and address the care needs which each individual person brought with them. An overview of these processes during the research period raised issues which need to be discussed.

Assessment.

Assessment of a patient's needs overall in hospital was undertaken by a number of different professionals who had a specific focus through their separate activities to meet different areas of need.

The first key assessment area was for medical care and treatment, undertaken by medical staff, who made a record of the diagnosis in medical notes, and arranged for appropriate biological tests to be made to guide them through the most appropriate course of medical intervention. The medical records were used by a small number of medical staff working together but at separate times.

Nursing staff made their nursing needs assessment concurrently with medical staff. The tasks undertaken by these two professional groups together formed the main platform of medical treatment and care. The nurses too had their own records for each patient, but these were created separately from the medical notes. The nursing records were the property of the ward for the period of time that the patient was there. If the patient was transferred to another ward, the nursing and medical records went with them.

The difference between the contents of the nursing and medical records was that more nurses made entries into their records than doctors because of patterns of shift changes, and the nurses were of different grades of staff who had higher or lower levels of skill and training. Even when a primary nurse attachment to patient system was in operation, there was no guarantee that the same primary nurse would be available at any given time.

The nursing staff had a key role overall for each patient. They were the focal point for communication with patients, carers and doctors, and for bringing information together during a person's hospital stay in order to plan a safe discharge. They were also responsible for making referrals to primary Health care workers in the community when patients were discharged, and for ensuring that Out-Patient appointments and transport were organised.

Both nurses and doctors related to and depended upon other professionals when paramedical therapies were found to be needed. Doctors usually made referrals to a third professional group, who were physiotherapists, because their task related closely to the success of medical intervention in a bio-medical context. Physiotherapists then assessed the patients, and created records of their plans and interventions.

A fourth group of professional workers who became involved were occupational therapists. Their work, as a professional collective group, was spread over all the wards of the hospital. Referrals to them depended on recognition by nurses or doctors or physiotherapists that any particular patient needed functional support

because of physical disability which would impair their ability to manage daily living tasks safely.
When the occupational therapists were engaged in the therapeutic processes they too assessed patient need and created their own official records.

The fifth group of workers who became involved because any of the four previous groups referred to them, were social workers. They responded because other professionals had identified social problems which needed to be assessed. Once engaged by referral, the social workers also created their own record.

As a result of the different areas of need that a patient might present therefore, five different assessments and five separate records could be generated. It was then the responsibility of all the different professional workers to communicate and collaborate to link the assessments and care plans together for each patient, and to jointly ensure that patient needs were met prior to hospital discharge.

The experiences of the social workers during this research period indicate that the process of linking assessments and working together was not always straightforward or easy.

The following difficulties were observed:

1) Medical and surgical staff did not generally communicate with social workers. When patients had complex social needs, the doctors decided that patients could be discharged at the point where medical intervention was completed. Any communication about social need had to be relayed through the nursing staff, and sometimes the occupational therapists and physiotherapists.

This was not always effective, patients were discharged in some instances before social care plans were arranged, and the social workers were not informed by anyone. They found out by contacting the ward that the patient had already gone home.

An exception in doctor/social worker communication was among Geriatricians. Their focus on patient need was more holistic and included a need to know about social circumstances, the safety of living environments and carer availability.

2) Occupational therapists did not always receive referrals from medical and nursing staff when a patient needed their intervention. Whilst the social workers were undertaking the assessment of social need, they too became referring agents to the occupational therapists because they observed that functional

disability would create risks at home.
These referrals were appropriate, but in effect they were not made at the right time, and occupational therapists were under pressure to respond because the patient's discharge date was already being considered by the medical staff.

3) Nursing staff sometimes failed to identify social need, but this was found by physiotherapists and occupational therapists. The discharge date in these instances was being arranged before social care needs had been assessed, and the social worker was then under pressure to respond immediately instead of planning and arranging support systems within the usual flow of work.
In other situations, nursing staff made referrals to the social worker for occupational therapy aids such as commodes, bath aids and walking frames, and these had to be passed on by the social workers.

4) Particular problems arose on Fridays when discharges were decided at a doctor's Friday morning ward round. the nursing staff were told to discharge the patient, who said that they could not go home without services. Nursing staff then rang the social workers expecting them to comply with the Friday afternoon or weekend

discharge, which they could not do.
Some of these patients were discharged anyway, without services, and others were seen to be blocking hospital beds which were needed for the weekend intake.

5) The social workers sometimes received referrals for patients who needed other specialist health care intervention, which had not been identified by doctors or nurses. The patients were those who needed psychiatric referrals, clinical psychology assessments, health care for terminal illness, specialist neurology assessment and ongoing medical and nursing care. These referrals should have been made to other specialists by medical staff, and in conjunction with the nursing assessments of need. The outcome was that the social workers had to go to the medical and nursing staff, and ask them to take the problems back because they could not respond to them, and because they were medical problems.
The patients had to stay in the acute wards until they did so, but even after the social workers had made contact with the nursing and medical staff, enquiries were still made to them about what actions they intended to make in order to get the patient discharged.

These problems were identified during the social workers supervision sessions, and discussed at their Unit meetings. As a qualitative research tool, they were recorded as '*professional frustrations*', because this was a felt outcome of interprofessional misunderstanding of each others roles and responsibilities.

The problems caused by each professional group not making appropriate referrals led to situations of unmet need when patients were discharged. They were not usually identified because there was no established method of feedback from the community to the hospital about unmet need, but the Discharge Scheme was able to capture this information about patients who were referred for support. The Volunteer records illustrated a range of unmet needs which included needs for equipment, referrals to district nurses, MacMillan nurses and for transport arrangements to out patient clinics.

An overview of these events cannot be seen solely as a communication difficulty, but also as a need for all professionals to be clear about their own roles and responsibilities, and to have a clear understanding of the roles and responsibilities of other worker groups within the hospital.

No clear statements about roles and responsibilities existed which could have facilitated such understanding. Workers seemed ot be expected to learn through experience and practice. For new workers, the cultural environment created a learning curve which involved making mistakes and internalising professional misunderstandings.

Loxley (1997) addresses the difficulties of interprofessional working, and suggests that interprofessional training is a way forward. This would most certainly be helpful, but so would a working set of professional guidelines within any given hospital organisation.

I would propose that helpful tools on site in hospitals would be formal statements by each professional group which clearly set out their roles, responsibilities and tasks, and that these should be used in conjunction with interprofessional inductions and reviews within the hospital system.

In addition to these statements, a referral route guide showing when and how to refer to other professionals would help to establish an easier linking process between different worker groups.

Different types of assessment.

I have already stated that each professional group in the hospital made separate assessments of patient need, and generated their own records.

The assessments for each had a specific focus, and applied to different aspects of need.

In relation to Doyal and Gough's theory of human need (1991) these foci can be seen as assessments of different parts of a person because she had patient status. Need is addressed as follows:

1) the medical and surgical health need is assessed by medical staff

2) health care needs during treatment are assessed by nursing staff

3) paramedical health care need as an ancillary to medical and nursing care is assessed by physiotherapists

4) personal functional need is assessed by occupational therapists

5) social care needs are assessed by social workers

As all the needs which are being assessed separately actually reside together in one patient/client, and because all needs interrelate (Doyal and Gough, 1991), the assessments and care plan outcomes, quite logically, should be brought together as a holistic needs meeting process.

The issue for this overview is how the assessments appeared to be brought together for patients at Mansfield General Hospital.

All the records created by different professional groups were available to each of them for reference and entries by other worker, if they considered them to be necessary. **Open access to records by workers, but not patients or their carers, was an element of working practice.**

The medical records showed an initial diagnosis based on medical examination, with updating notes as each doctor saw the patient. These were kept on the ward, separately from the nursing notes as long as the patient remained there. The nursing notes contained a Waterlow Scale assessment for some patients, especially those who were being nursed in bed, and for those who had had operations. This assessment showed tissue viability risks, and determined the patient's physical needs in order to prevent body tissue from breaking down.

During the period of research some wards also began to use the 1987 Braden Risk Assessment Calculation which related to pressure area care and prevention. This assessment formula was applicable for ill and physically deteriorating patients, especially those with continuing health care needs.

A nursing assessment and care plan was completed for all patients, and this was followed by daily record updates of patient progress.

Nursing assessments were never copied and sent to other professional workers. If they needed information from the nursing or medical notes, they had to visit the ward and read them for information.

Physiotherapists had their own assessment formulae, but how they undertook their assessments, and what method they used was not known Social workers never received any of these assessments in written form but referred to the physiotherapy notes entered in nursing and medical records on the wards. Information about their assessments was communicated by worker interactions, and some visits to each of the departments. Notes about needs were then entered into respective workers' own records.

The situation with Occupational Therapist assessments was different. These workers completed a Bartel Method scoring chart for Activities of Daily Living . Copies of the assessment charts were given to ward staff,

social workers and physiotherapists for patients who were moderately or severely functionally disabled.
The assessments were then discussed by the social workers and therapists, and they worked closely together with those patients who needed home assessments, up to the point of discharge. It was also possible to refer back to Occupational Therapists after discharge, and to discuss any further problems which had occurred.

Social Workers did not have a formal assessment document. Their working notes served this purpose, beginning with a brief resume of the patient's circumstances and problems, and then followed by notes in chronological order about actions needed and taken whilst work was in progress.
Occupational Therapists sometimes referred to their records, but no other professionals asked to see them. If there were situations of complex social need and risk the social workers wrote a special report which was copied and sent to all the other professionals for information and inclusion in their files.

On specific occasions, when a Psychologist or Speech Therapist was called to see a patient, these professionals always wrote reports and circulated them to other workers. They were mostly contacted by Social Workers in the first instance, with the Doctor's agreement.

Overall, assessment documents were generated by different workers and then kept in the worker's own department. Except for those which have been mentioned which were shared, assessments were made, recorded and retained as separate documents.
Interprofessional sharing was by person to person interaction, and by annotating records.

There was no formally agreed method of bringing all the assessments together, and no central point where assessment information could be anchored. The whole process depended on co-operative working practice which had built up over the years, and to a large extent on the workers' relationships with each other.

The implicit aims of assessment were to determine whether health, social care and intermediate needs for living and surviving were met, and to deliver services which would ensure physical health, safety and minimally disabled social participation. (Doyal and Gough, 1991).

The worker interaction system for integrating different assessment information apparently worked quite well for patients who were only slightly or moderately disabled by their illness, or whose carers were available and able to look after them. It was not adequate for linking either assessments or care plans for patients with complex health and social care needs, continuing health care needs or for patients who were dying.

The term which was used to identify these patients, through qualitative research methodology in Social Work supervision, was '*difficult case*'.
All of the patients who became part of the categories of 'Family Problems' in Chapter 4 were identified in this way, and so were the inappropriate referrals to the Social Workers.
If social need was complex, and a patient could not be discharged, the Social Worker had to approach other professionals to discuss their views and opinions.
The workers jointly came ot a consensus view that discharge had to be delayed while complicated family circumstances were explored, and a decision could be made about any possibility of discharge, and where to.
If the decision was to use residential or nursing home care, everyone had to wait until the resource and funding was identified.

If the patients was too ill or dying, the workers formed a consensus opinion about this, and then became a pressure group to oppose the doctor's decision. On five occasions, the hospital nurse managers were called upon to tell the doctors that particular patients must stay in hospital, because they would not agree with the other workers. High levels of anxiety and tension arose among worker groups when 'difficult cases' were blocking hospital beds.

Whilst usual working practices were adequate for the majority of patients whose needs were fairly straightforward, they were not reliable or robust enough to support the process of finding adequate and appropriate resolutions for circumstances of complex needs.

Therefore, the risks of not finding ways of meeting client/patient need were greatest for those whose needs were potentially life-threatening.

The uncertainty of how to deal with these contexts of need created confusion, and some carers, who had been told by doctors that their relative was to be discharged came to the social workers and nurses charged with anxiety, panic and anger. Some sound means of dealing appropriately with these situations was urgently needed within the hospital system. (It must be borne in mind that these data were collected in 1988/89, and at that time the issues of complex need and need for continuing health care had not been addressed). There was no way of monitoring how many patients were involved, and they had to be dealt with on a one at a time basis.

This research collected early evidence of complex and continuing health care need, and was shared at muti-disciplinary hospital Management Forum. Here, recognition was given to the problems, and a management working group was set up to examine the evidence of need, and explore methods and means of dealing with complex and continuing care needs.

* The outcome of assessments which the social workers completed, resulted in the labels of simple and complex need. Table 65 shows the patients referred to them in fourteen areas of need found on assessment, whether the area of need was simple or complex, and the outcome for the patients by destination on discharge. Group 1 were either transferred to another hospital, or died. They were inappropriate referrals to the social workers, since the patients had continuing health care needs, or were very close to death.

Table 65

Table to illustrate simple and comlex needs of referred patients in relation to discharge destination

Area of need	346=100% Men	%	589=100% Women	%	935=100% Total	%	Possible destination on discharge
1. Not known	36	10	93	16	129	12	Another hospital or death
2. Private help, simple	7	2	35	6	42	4	Home
3. Meals on wheels, simple	49	14	88	15	137	15	Home
4. Domiciliary Services, simple	135	39	224	38	359	38	Home
5. Welfare rights for patients & carers, simple and complex	90	30	105	18	195	21	Home, another hospital, res. care
6. Occupational Therapy needs simple and complex	52	15	115	19	167	18	Home
7. Day Care simple and complex	11	3	31	5	42	4	Home
8. Social and medical care Advice or information Simple and complex	44	12	116	20	160	15	Transfer to other hospital or specialist health care unit
9. Housing problems simple and complex	19	5	27	6	46	5	Home, res. care
10. Social Care - high dependancy (convalescence) complex	7	2	25	4	32	3	Relatives and friends homes. Death.
11. Severe chronic stress complex	15	4	21	4	26	4	Home, res. care, hospital; death
12. Interdependancy complex	7	2	4	<1	11	1	Home, res. care, hospital; death
13. Family problems, abuse, self harm, learning disabilities, family disbutes complex	22	6	29	5	51	5	Home, res. care, hospital; death
14. Residential Care complex	33	10	77	13	110	12	Part III, private Res. Home, private Nursing Home

N.B. Numbers of patients and percentages do not add up to 100% because some patients had more than one area of need

6.8 Communication

'If what is said is not what is meant, then what is meant is not what is said. If what is said is not what is meant, then what ought to be done remains undone' (Confucius, source unknown)

Communication has been an issue throughout this research on patient/client need. It was identified as a problem for patients, carers and workers in Chapter 1, as an issue in organisational theory in Chapter 2, and evidenced as a problem in Chapters 4 and 5, during hospital interface working. As a qualitative research phrase the research team decided to identify communication difficulties by the following statements:
'*Nobody told me*' and '*one person tells me one thing, another person tells me something else*'. These statements were heard to be made in relation to information between patient and professional worker, professional workers and other workers, carers and professional workers, patients, carers and volunteers. The lack of clarity about what was meant and what was certain gave rise to confusion about tasks which were meant to be done, when they were to be done and who by. Sometimes, patients and carers did not know who to

believe, and could not remember who had said what because they did not identify the worker's professional status. Physiotherapists were mistaken for occupational therapists quite often, patients were unclear what the social workers reasons for seeing them, nurses did not tell those who needed to know about discharge arrangements and doctors told patients that they were going to be discharged without asking if care arrangements were organised.

The problems of communication did not all belong to workers within the hospital. The records of volunteer information cite instances of services not arriving as expected, domiciliary managers were certain that referrals had not been received, ambulances delivered patients to the wrong home addresses. The potential for miscommunication seemed to exist at every junction in the processes of patient care, within and without the hospital. When the action research team sat down and considered communication, they identified the following factors:

1) communication was made by a variety of methods, verbal communication was person to person, or by telephone. This was spoken communication.

2) Communication was made through written documents and notes in patient records, but this was silent information, and depended on the reader's response.

Both types of communication were used interprofessionally but the former was used mostly with patients and carers. They were not privy to professional records, and apart from prescriptions, out patient appointments or specific instructions on how to manage diets etc, they were informed verbally about what was happening.

Professionals did write instructions down sometimes for patients and carers, especially if the patient had a communication disability, but overall, there was a high level of dependency on the spoken work, person to person.

The telephone as a means of communication caused frustration every day. All professionals complained about time consuming call-backs, unanswered messages and people not being available.

The opinions of nursing staff were invited. Their experience of communication was similar in some ways, and different in others. They had the same difficulties with telephone communication, and often had to repeat calls to make contact. They said that they could hardly ever make contact with the social workers by telephone - they were always out.

They found communication with physiotherpy and OT much easier, because they knew each day when they were in their departments, and when they would be working on the wards. Person to person communication would take place between 10am and 3:30 pm, and before and after these times telephone communication was effective.

Communication between nurses and doctors was reported as variable. Doctors could be called by pager bleep at any times, and spent some time on the ward after ward rounds in the doctors' office. The housemen relied on the nursing staff to share information about patient care and progress, and communcation occurred every day, but not always at the same time. Doctors did not always arrive on time for ward rounds. This upset ward routine plans, and then communication after the round was rushed, the next tasks had to be completed, and nursing staff felt that if the doctors could find some way of fitting into more predictable routine times, communication would improve with patients and other staff.

The nurses felt that they were constantly being approached by people for information, when they were trying to carry out other tasks. They were interrupted by patients, medical staff, social workers, and relatives, all making demands on them. Communication was rushed and information given as a result was piecemeal. The outcome of the discussion with the nurses was that Social workers would join in at their shift handover meetings, weekly, to share information, and so that the nurses could update the records at that time. The Discharge Scheme Co-ordinator was invited too, and decided to join each ward meeting when she could, depending on her programme of work.

This was an attempt to structure communication and reduce interruption and demands on very busy nursing staff.

There were no stated rules about verbal communications in the hospital, which could guide professionals in their interface working at ward level, and yet this seemed to be the site at which most of these communications occurred, and also the site at which information was transmitted to patients and their carers. The issue was therefore, to find some ways of capturing the content of such communication in order to render it more effective and useable.

The Audit Commission Report (1993) which addresses communication in hospitals shows clearly that verbal communication alone is only partially effective for those who receive it. When verbal communication is supported by written information patients, carers and professionals are better informed about diagnosis, receive better advice, understand the purpose fo treatments, and what the outcomes of hospital treatment will be.

The findings of the report led to recommendations that communication could be improved by structuring multi-disciplinary and team working, developing expertise in communication and awareness of patients' points of view, and closing the gap between clinical work and general management.

In the light of the report's findings, the problem of communication at Mansfield General Hospital could be seen more clearly, and gave a sense of direction towards actual methods which could be employed to improve the overall situation.

More information needed to be anchored in the written records which existed, and to be supported by the verbal communication which after all provided opportunities for explanation of content and clarification of understanding.

If different worker groups know how the routines of their colleagues sites of work operation are organised, they can co-operate by building in the most appropriate times when communication can be shared and anchored.

Research discussions with the nursing staff revealed two other issues. Firstly, they felt that they were the key workers who had to collate all the communications for other professionals. Reading and re-reading the nursing notes, medical records and reports which they received was difficult when they were trying to plan safe discharges for patients. They thought that if the stages of progress and other worker actions could be recorded in a different way, which was available to patients and carers, there would be an anchor point for information which was not disseminated among different pieces of documentation. The idea emerged that collation of such information might be possible in the form of a record which could be put at the end of a patient's bed, giving everyone open access to information, including the patient and carers. All who needed to could then refer to it, add their information and see at a glance what plans were evolving.
It was agreed to take the idea to the management forum for further discussion. It was thought that such a record might reduce the number of telephone calls, and interruptions to ward staff.

The second issue that emerged was that nursing staff were reasonably clear about the tasks of most working groups, but not very clear about the roles and responsibilities of the social workers. Their communications by telephone, person and documents were pieces of information through which they built up a general picture of what social workers did. The same applied to the Discharge Scheme. The idea emerged from this discussion that a clear written statement showing what the social workers' key tasks entailed, and what the Discharge Scheme could provide, should be prepared and placed on the wards where all staff and patients could read it. It was suggested that an outline of this statement should be included in a patient booklet, which was currently being prepared for the hospital.
This idea was put into practice , the statement was prepared for each of the wards, and later included in the patient booklet.

During the discussions, the issue of when to make referrals was also discussed, including concerns about patients who were most at risk, and how they could be identified.
This resulted in an exchange of information about how each group assessed risk, and their different methods. The risk guide for nursing staff was the Waterlow Scale

of tissue viability. The social workers did not have anything written down, but kept it in their minds when assessing patient circumstances, and by reading the patients' nursing and medical notes. Their own assessment of risk indicators had never been thought through or formally collated.

The risk indicators which they held ideologically as a work group were discussed, and emerged as the same factors which caused concern for the nurses about discharge planning and delayed discharges.

They were characteristics of patients who presented with psychiatric illness, who had been readmitted frequently, unable to comply with medications or medical treatments and advice, who had no family or other carers who could confirm informal support arrangements, carers who said they could not cope or who refused to take a patient home, patients who had unexplained injuries, patients who did not want to be discharged, and patients who stayed in hospital because their recovery from illness did not occur.

All of these characteristics created interprofessional dilemmas about how to plan for patients' discharges, and in fact were indicators of complex health and social care needs, continuing health care needs and patients who were dying.

It was agreed that in order to progress the outcomes of the discussion, that the social workers would make a list of the risk indicators as they perceived them, and that this too could be prototyped as a working tool in conjunction with the Waterlow Scale.
The became another issue which was to be taken to the Multi-disciplinary Management Forum for discussion, and formalisation. The outcome was formalised in due course, and the documents which were generated are shown in appendices to Chapter 6, entitled '*Health and Social Services 'AT RISK' guidelines*'.

It can be seen that the discussions between nurses and social workers began to address not only the problems of communication, which held the organisation of the hospital together, but began to identify indicators for improved co-operation, interprofessional understanding of roles and tasks, and more structurally organised methods of multidisciplinary working.

6.9 Collaboration.

The previous discussion concerning communication showed that there is a need for professionals to converge in order to communicate. This means facilitating a structure for communication at working interface levels, where client/patient need is being assessed, and where care pans can be made which are inclusive of all professional inputs.

A second level of communication is needed for interprofessionals to share their understanding of client/patient need, and also to examine their working structures of co-operation and collaboration. If the structures of communication, co-operation and collaboration are not under control, individual workers and groups are only able to deliver care and services within the boundaries of their professional task.

Organisational theory tells us that when worker groups are under pressure or threat because other groups have more power, they are subject to strain and anxiety, will close their professional boundaries and retreat to culturally held beliefs about other worker groups, and their own cultural methods of coping with their work.

Collaboration is then restricted, progressive and developmental opportunities are missed, and changes within the whole organisation become very difficult. Loxley (1991) finds that collaboration, as it has been addressed in the context of Health and Social Services agencies working together, is based on assumptions that it is a rational response to the linking of the separate structures, 'to be a purposeful activity aimed at comprehensiveness, despite the division of labour, and to be driven by an altruism which puts the notion of a greater good before sectional interest. In practice, the difficulties often experienced and described witness to irrationality, competition for power and resources, and a defensive holding on to what is known, understood and practised' (pp76-77)

She suggests that the issues of collaboration need to be addressed by theories which are relevant to social exchanges between people, the systems which operate in organisations, and the structures which support their activities and aims. These theories can be brought together to provide a framework for collaboration, which is illustrated in Fig 18.

With this theoretical framework, Loxley points out that **co-operation theory** makes it clear that each worker group needs enough power to react effectively if oppressed, but able to maintain the principles of trust and pursuit of working co-operatively.

Social Exchange theory explains the need for open exchange within an organisational framework, and once again worker groups need sufficient power to be competent to engage and deliver their skills and services without being exploited by others who might wish to dominate them.

Systems theory shows that in order for structures to maintain their functions, information sharing has to be carried out across boundaries, but this depends on the willingness of workers to open their boundaries to others, and to co-operate in the informal sharing process. Within systems theory, power is acknowledged to belong to separate groups, but their autonomy is not fixed. Power may have to shift and be shared in relation to needs which have to be met.

Loxley's framework for collaboration demonstrates how the social elements of an organisation can be harnessed and creatively focussed on core skills, which in their turn enable and support the aims of the organisation, by assessment of resources, by building structures, managing the processes, and evaluating its outcomes. The question is, in terms of this research, how can the theoretical perspectives be applied to the structures, systems and work activities of the hospital in terms of client/patient need?

The research findings so far have shown that organised information sharing and structures were weak but a bottom-up suggestion for improving them could be elicited by interprofessional discussion between nurses and social workers.

The power positions in the hospital were maintained by professional ideologies and the identities held by different working groups. Coalitions of power formed to pressure the dominant medical profession in order to maintain patient safety and preserve the right for patient health care needs to be met, and hospital managers had to be enlisted at times to sway the balance of power.

Managing the processes overall was the responsibility of the hospital managers and administrators, and they also held the tools for evaluating the organisational outcomes, in terms of numbers of patients admitted, length of hospital stay and budget allocations. This management applied to the Health Service worker groups, but not to the social work group, who were also the smallest work unit within the hospital.

My own thoughts and conclusions in response to the question, and application to hospital organisational reality, as it is described above, are these.

In the context of power relations within the hospital, the Social Work Unit was seen as an uncertain entity in terms of its function. In that sense, it was vulnerable to domination by other groups who had the option to co-operate, pressure, derogate or exclude it at their own convenience or on the basis of their own judgement.

The ideas of care in the community, which were being promoted in health were very much linked to the community as the best place for patients to go on discharge, and in other workers' experiences the social workers' most frequent tasks were those of providing community based services on discharge. The patients who needed to be discharged and could not return to the community therefore, came to be seen as needing social work referrals. Through these connections, the inappropriate referrals to social workers were made, including patients with complex health and social care needs, and patients who needed ongoing health care provision. This simplistic rationalisation is only a

partial explanation, but it is sensible in the absence of other facts.
There were no formal mechanisms within the hospital operational procedures to tell nurses about health care resources outside the hospital , except for other hospitals, and community nursing services. The staff did not know what range of resources the social workers could access, but since they worked with a community focus, it would be a logical action to refer any sort of patient who was deemed to need to be discharged. It was only when the social workers refused to act on the health care need related referrals, that the absence of policy, procedure and guidance for health care staff about health care needs became an issue, and a potential source of conflict. It is a precarious business within an organisation to approach the most dominant worker groups and explain to them that they are apparently trying to delegate responsibility for their work to the wrong people.

The assumption that social workers were responsible for health care needs has some parallels with assumptions about informal carers, and their responsibility for patients' health care needs. But, if health care responsibility for patients is not formally stated, how would the worker groups know?

The gap between dominant management thinking and interface working reality is shown to be very wide by the examples of patients with complex and continuing health care needs. Taking the issue further upwards into power structures, it can be seen that those who were responsible for policy and funding in health had not assessed these needs for care, and neither health or social care policy makers had foreseen the eventualities.

Later on, in the mid 1990's, complex needs and continuing care issues became the subjects of intense debate and controversy among policy makers and planners, but at the time when this research was conducted, it was interface workers who were struggling with the issues.

However, when the research findings, including these issues, were brought to the Multi-disciplinary Management Forum, the hospital managers reinforced their decision making about patients who had complex and continuing heath care needs, and kept them in hospital. They were included in the monitoring of blocked beds, and some stayed on the acute wards for many months.

Collaborative working was discussed at the beginning of

this section of Chapter 6, in relation to theoretical perspectives and its relevance within organisations. Clearly, when complex and controversial situations arise, collaboration is needed and can be used to find answers to one-at-a-time or collective situations.
If it is a tool which can creatively progress the aims of an organisation it becomes an essential component to take the organisation forward. Since all organisations have to respond to change and adapt to their environments, demands and pressures, they need collaborative mechanisms which are part of the infrastructure of systems, worker groups and the management tasks.
If however, the situation is that of one organisation being linked to another, as Health and Social Services are, with separate management structures, funding and very different work foci, collaborative working and the actual structuring of collaboration appears to be very complicated.

Joint planning, which was established in the 1970's as a mechanism to enable Health and Social Services to collaborate and work together effectively did not succeed in its aims. Joint funding mechanisms have not succeeded either, and agreements about shared funding of services or even projects has been fraught with risks to budgets and services in one organisation or the other.

Joint initiatives between the organisations have so far been developed at senior management levels, with intentions of meeting needs in the community for different service user groups. This has been a top-down management approach which has not included bottom-up interface perspectives.

The situation in hospital is different, in part because no senior Social Services managers are actively engaged within hospital settings, and also because those patients whose needs are greatest within those settings are already the responsibility of the Health Service.

The understanding which is needed about patients who are assessed and known mostly by interface practitioner workers, or first line managers, requires fine detail and a comprehensive knowledge of both health and social need to inform it.

Like any other well informed understanding, collective examples are needed for comparison and examination to unpick the complexity and interrelatedness of health and social care need.

6.10 Management, mapping and measuring.

Management tasks in hospital involve planning for services which will meet patient needs for Health care within a given catchment area, budgetting for those needs, and estimating the types and costs of resources which will be required within the hospital.

Staffing measurements for wards with specific numbers of beds enable managers to allocate appropriate numbers and grades of staff to undertake work tasks which are required for patient care, and which cover the ancillary work which is associated with health care processes.

A hospital can be mapped in terms of its patient intake and output, the numbers of operations completed and so on. When waiting lists grow because there are not enough resources and funds to meet health care needs in hospital, managers can measure the shortfall in services and make a case of need for more resources.

These mapping and measuring devices, which are key tools for managers, enable those with power and authority to determine work priorities and make the least damaging reductions to services, and to make the best effective use of scarce resources.

The same management devices do not apply to the Social Work structures for social care in hospital settings. Management is provided at a low level of authority and power, and work outputs from hospital teams are shown, in Nottinghamshire at least, as a statistical percentage of client referrals recieved by the whole of the County Social Services during one year periods. This is a central departmental measurement, and does not inform managers about actual demand for services in any particular hospital, or the types of services which will be needed in the Area Social Services provider teams to respond to client/patient need.

The actual workloads of interface staff have not been properly measured by demand on the time for services that individual hospitals require, and their tasks have not been determined by appropriate staffing grades.

In Chapter 4, the referrals to the Social Work staff were shown to be high in volume, demand by patient need was affected by the fast hospital throughput of patients, and staff had to work overtime without payment to cope with the work.

The absence of mapping and measuring the Social Work task left workers in a position whereby they could be exploited. No acknowlegment was given to the the fact that as the hospital admission rates were rising by 5%

each year so the referral rate to the Social Workers was rising by the same percentage. No guidance from senior managers was given about ways of coping with the annual increases, except that work should be prioritised.

There are ways in which workloads and volume of referrals can be addressed. These were found by accident through the reseach findings which were meant to show client social care needs for services as patients were discharged from hospital.

Figure 14, which showed the hospital as a change system in terms of inputs and outputs of patients and needs can also be interpreted as a map of hospital activity.

Further information is provided by Table 65 which shows the social care needs of clients by complexity of task.

This table indicates that different levels of skills and workers could be more effectively deployed to share the work depending on complexity.

The two tables provided the first indictors that an equation could be built up to calculate how much work was being generated, and how many workers would be needed to complete it at Mansfield General Hospital.

Other facts were found to be needed to complete the equation. These had to account for the number of days that individual cases were open to workers and most importantly what size of caseload any worker could reasonably be expected to manage at any one time.

In order to find these facts the actual number of caseload days was manually counted for the one year of research. This was done by taking the allocation and closure dates for each case, and thereby finding how many days each case was open. The total number of days duration for all cases came to 10687 for the one year period.

A work study of four social worker caseloads was set up for a one month period to find the size of caseload that any one person could manage at any one time, given the mixed caseload which was evident in an acute general hospital. It was found by observing how the workers responded to uncontrolled demand by referral that having different numbers of cases open on one day affected their work performance, ability to manage their workload and to complete their work on time.

When they each had 20 open cases to work with, they were able to cope. Although they felt a moderate degree of pressure they did not feel that stress was disabling them, in fact them reported a sense of achievement by getting this amount of work done during the day.

If they had a caseload of 15 open cases they felt that their work was slack, but that they had time to plan their work better and to particpate more effectively and thoughtfully with other staff.
The situation was different when caseloads reached 25. At this point the workers felt stressed and seriously under pressure. They could not complete their work in order to meet discharge requirements, the amount of messages left for them by telephone began to pile up and they began to feel muddled. They began to forget arrangements and could not complete their records on time, so important details were held in their heads and not available for reference by anyone else.

The maximum and minimum caseloads that workers could reasonably be expected to manage effectively were set at 20 and 15 open cases. This was to become a workload management device for the future in order to reduce stress, for maximum work quality and effectiveness, and for workers to be able to overview their work performance by means of a simple measure.

A third factor for the equation had to be found which would tell us the average size of the caseload that the Mansfield Hospital Social Workers had actually carried during the research period.

This was done by finding the number of work days that a Social Worker was available during the year. This meant excluding bank hoildays, weekends, annual leave and potential periods of sickness. The available number of work days per Social worker on this basis was 220, therefore the number of worker days at Mansfield General Hospital was 440 for the period of research.

The factors for the equation were finally found as follows:

Total no. of days for open cases	10687 = a
No. of Social Work days available	440 = b
Average no. of cases in workload	? = c
No. of cases completed	1233 = d
Average length of time cases were open	? = e

Equation: $a \div b = c$ or $10687 \div 440 = 24.3$

The average size of caseload for the workers showed that they were working at a high level of stress, and there had been potential throughout the year of research for inaccuracies to have occurred in casework. Also, their own working practices and difficulties would have caused unpredictability, muddles and inadequate communication with other staff.

A checking measurement of how long on average each case was open was applied to see if there was a similarity with the average length of time that patients who were referred to Social Workers stayed in hospital, which was 10 days.

Here the equation is $a \div d = e$

or, $10687 \div 1233 = 8.6$ days.

This check proves a high degree of accuracy, because social work referrals took 1.5 days for processing from the time of ward referral to becoming an open case to social workers.

If the equation is developed it can be used to show how many Social work days are needed for a lower average caseload of 20 which is more realistic.

This would be $a \div c = d$ or $10687 \div 20 = 534.4$ and means that there was a shortfall of at least 94 Social Workers days at the hospital. Another half time post was required to make the task properly manageable, and given the number of tasks shown by complexity that worker should have been a Social Work Assistant who could take on the simpler cases of client need.

This equation could be used as a formula in any hospital setting even if the type of work was different, by finding the relevant numerical factors for the equation. It is a particularly useful tool for measuring work with a high volume and fast turnover.

Hospital Social Work managers should be able use tools of measuring and mapping in order to appraise and evaluate work performance, not only for the health and benefit of their workers, but particularly for the best outcomes for clients who are people in need.
The absence of such tools which underpin evaluation have left Social Workers in health care setting in a marginalised position and have been another factor of inequality for clients who also have health care needs.

*The workload equation was not planned originally as part of this research. It was one of the evolved outcomes of the action research process, and was made possible by the quantitative and qualitative methodology which enabled the research team to reflect creatively on their findings and practice.

A final point needs to made about management thinking and understanding about the tasks of its organisation.
If organisations are to work co-operatively, collaboratively and to communicate effectively then managers need to understand the theories which underpin these processes. If two powerful organisations are to work together in this way, and are interdependent on each other because of related inputs and outputs which

affect them both, then it is logical for managers to work together at understanding how their organisational processes are linked, overlap and separate at the boundaries of each. Managers too must keep their boundaries permeable and be open to explorations of power and culture, as Loxley's theoretical framework for collaboration demonstrated earlier. There is no point in trying to do these things at the bottom least powerful levels if the top levels have a different agenda based on competition and power retention.

Management training is another issue. In any given organisation a theoretical understanding is needed about the nature and usefulness of its outcomes, or products. When these outcomes are human beings, and the organisational aims are to meet human needs, then all theoretical perspectives of human need should be integral to training processes.

At this time, Maslow's theory of human need is used for professional training, and Bradshaw's theory of need is used for Business Planning training for managers.

The latter is useful for professionals, or experts or managers because it allows them to set desirable standards and to alter their eligibility criteria accordingly. It would seem to be necessary, in the light of findings from this research to use a theory such as Doyal and Gough's theory of human need because it addresses the interrelatedness of health and social need, and just as important, relates to equity, equality and social justice. This theory of need opens the door for reasons to measure need and unmet need, and to understand the holism of need as it can affect each one of us. The theory validates the place of altruism in the context of human care-giving, and progresses understanding about the reasons for linking formal and informal care on a continuum of care needs meeting processes.

6.11. Revisiting the aims of research into Client/patient need.

The last section of Chapter 6 revisits the aims of this thesis, which were stated in the preface in the form of four questions.

Each of these is restated, with a summarised response in order to conclude the work.

1.
Are patient/client needs identified and met by Health and Social Services professionals?

Client/patient need is not always identified by Health Service professionals, either from a Health or Social Care perspective. Screening projects have shown that almost twice the number of patients referred by ward staff to hospital social workers have needs for support and information which are not met through the usual doctor/nurse referral route. Although these appear to be lower levels of need, and not necessarily life threatening, they would improve the quality of life of patients and their families if they were identified within the acute hospital setting.

The majority of need for routine Social Service provision appears to be identified and referred by Health professionals in an appropriate way. A proportion of need for domiciliary help is likely to be missed because patients do not ask for it, and some patients are discharged from hospital before assessment of need can be completed, leaving their needs unmet. The acute hospital setting is different from a patient's home environment, and thus assessment of need is to some extent hypothetical. Whilst in hospital some patients may not think that they need services, and subsequently discover, when they are discharged, that they cannot cope. In these instances their needs cannot be identified within the acute hospital episode and need a community based response instead.

Patients with complex needs require a complex service response. Whether or not these needs can be met depends on the availability of specialist resource provision by both Health and Social Services. Professional awareness appears to be led by knowledge of available resources, and patients are referred for these accordingly. A recurring problem is that both Health and Social Services professionals are not always aware of resources which link need to support or treatment facilities, therefore needs are not met.

Those patients with the highest levels of need and who are most at risk because of continuing illness, approaching death, and severe levels of disability are also shown to have the highest level and most alarming instances of unmet need.

The key problem is that a continuum of health care provision from acute hospital, to continuing health care, rehabilitation, convalescence and soundly constructed community based care packages is not in operation for these patients. Disputes about whether different aspects of care provision are the responsibility of Health or Social Services compounds the complex care issue, leaving patients at risk of not receiving services from either. The consequence of these situations is that those patients with the highest levels of need are also those whose needs are most likely to be unmet.

2.
Are formal and informal care structures linked together effectively to provide a safe and adequate transition from hospital to home?

Formal and informal care structures are not actually linked at all. In structure and operation they are very different. Their one common factor is that they are both variable in terms of availability, competence and adequacy when meeting the care needs of patients who return to the community.

The structures of formal and informal care are adjacent and separate. Communication between the two, which might be considered as a link depends on the ability of individuals within each to ask for, give and receive information which then becomes a basis for the assessment of need. When communication is too brief, obstructed, constrained or does not happen, adequate amounts of information cannot be used for thorough and comprehensive assessment of need.

The individuals who belong to each of the structures need to have a working knowledge of each other's roles, resposibilities, purpose and capacities. Without such knowledge, co-operation and role sharing are impossible.

The need for each to understand how the other structure functions is equally important. Responsibility for this has to belong to the formal sector, and to be acquired through education and training which is drawn from theory, research and experience.

Otherwise, prejudice, assumptions and out of date practice prevent the real and contemporary needs of patients/clients and carers from being addressed by appropriate, efficient and equality based professional practice.

The likelihood that some patients will be discharged unsafely from hospital continues to exist.

3.
Do informal care structures meet care needs in the community as they are expected to, and is there a valid role and need for volunteers in the existing structures of care?

Most care needs are met by families, friends and to a lesser extent by neighbours in the community. Families are the main infrastructure for the survival of individuals, and all members participate to a greater or lesser degree, depending on age, gender, and intergenerational ties. There are a minority of exceptions, where dysfunctional behaviour and relationships, and abuse interrupts the care processes in families.

Informal care structures do not always exist from birth to death. Older people who have outlived their relatives and partners are at risk when they are left alone, ill, and unable to actively participate in other social networks.

Some younger people, whose behaviour, mental illness or disability prevents them from functioning integrally with the informal care structures of families, friends or very close social groups, are equally at risk of being 'remaindered', as are older people with no carers.

Gender related roles are a key issue in the 'caring' functions in informal networks. Women in families provide more care than men, but a smaller proportion of men do shoulder an equal burden of care.

The presence of volunteers provides a special element of caring, which is part has to be attributed to altruism, and probably also relates in part to a collective unconscious drive to protect and ensure not only the survival of non-related others, but to uphold the dignity and standards of life which most people want for themselves.

Volunteers, by degree of what they give and do, can ensure the safety and care of vulnerable people in times of risk, isolation and distress. They can fill the role of absent family members when they are most needed, helping to restore confidence, self-esteem and physical well-being, following hospitalisation in this case. They can also become a link between formal and informal care structures because their services are not constrained by prescriptiveness and budgets.

They can humanise and sensitise formal care structures, and provide information about service deficiencies and unmet need.

4.
Is a seamless pattern of care possible?

It is clear from the findings of this research that a seamless pattern of care does not actually exist, and many reasons prevent it from occurring at the interfaces of Health, Social Services and the community.
The aim to achieve seamless care must be held as a key focus for public sector providers, so that the debate can continue, and improvements to systems, practice and understanding need can be made.

In all of these areas, client/patient and carer need has to be put at the centre of concern. Otherwise the individual is displaced by other motives and aims which leave 'need' unmet.

6.12 Overview of the research methodology.

The research work at Mansfield General Hospital was ambitious in that an attempt was make to see the hospital as a whole process of meeting patient/client care needs, and had no funding to provide any resources extra to day-to-day working practices. The research process was conducted by a research team, who were members of the Social Work Unit at the hospital. As a group of workers, who were not employed by Health, they were a minority of professionals within the hospital setting.

Their own ideology had been formed through their own experiences in relation to the majority, who were health care professionals. Their role within the hospital was a reactive one, and their working practices depended very much on how the majority working groups related to them, and recognized that patients needed their services. They were a working group with an unclear identity , and their professional interventions were not measured or evaluated. They were on a middle ground between Health and Social Services in a structural sense, working with one and employed by the other.

As such, and because they were front-line workers, they were subjected to attitudes which each organisation had about the other and at times, professional loyalties were severely tested.

The undertaking of research which would possibly expose difficulties, resource problems and inadequacies in services in both Health and Social Services presented a risk to them, and they stood to be criticized on its outcomes when they were made public.

The other point about their unclear professional identity is this. If their own organisation, Social Services, did not affirm and confirm their role, how could other groups of workers in Health be clear about it either? The reality of their role in hospital was embedded in custom and practice, and the respect they earned through co-operative and collaborative working. This had to be maintained throughout the research period or their identity would have been further threatened.

When the research period began, the processes for gathering qualitative and quantitative data were clearly established, and it was acknowledged that these would entail more documentation on a daily basis, and more time in meetings to gather qualitative research evidence.

At first, when enthusiasm was high to undertake the research work, the three co-action researchers and myself found that we were able to follow the processes. The data collection forms for quantitative evidence were completed, and we were able to use our meeting times to discuss and focus an interprofessional working. When pressure of work began to build up during the winter months, the workers sometimes forgot to enter their quantitative data, and I had to spend more of my time to check for information as I closed the casework. It became clear that each of the social workers had different approaches to their work, and no doubt these differences have affected the outcomes of the research in ways which I have not perceived.

As I was an 'insider' researcher and had to complete my own work while the research was in progress, I too was affected by changes in work pressure and the attitudes of other Health and Social Services staff. I acknowledge that the ways in which I worked within the hospital environment and my own attitudes, defences and anxieties will have been expressed unconsciously through my perceptions and interpretations, and are reflected in my analysis of the research findings.

When work stress was high, the workers began to lose their ownership of the research. The discussions about research issues became brief and on some occasions did not happen because of work constraints.

The qualitative elements of research were not followed as thoroughly as I would have wished, and therefore the qualitative analysis which would have added depth to the findings is missing from the thesis.

More qualitative research evidence could have been found by involving other professionals more constructively in discussions, focus groups, by recording conversations and by setting out themes in a more organised way as they emerged. I feel that interpretation of the themes which were identified was limited.

On reflection, I would have liked to have used interviews with patients, carers and volunteers after hospital discharges to make their views more representative in the data.

My own weakness in undertaking this research was that I had only a minimum of knowledge of research methodolgy, only basic skills for using computer software, and little experience of statistical analysis. There are many ways, therefore, in which this thesis could have been better presented.

Having reflected on the weaknesses of the research, I feel very satisfied about the outcomes of the research process. The aims for undertaking the research initially were not to write a thesis, but to improve the working practices which were used for assessment of and planning for the meeting of client/patient need, and for the needs of carers at Mansfield General Hospital. These aims were achieved at both interface and management levels within the hospital. Presentations of data findings from the research were accepted by Health care workers and managers, and used to improve documentation on the wards, the Patient Booklet, and most importantly were used by a Discharge Working Group when a hospital discharge policy was drawn up.

When the hospital closed and became integrated with Kings Mill Hospital in 1992, the original staff were still in contact in their new environment, and the collaborative practices which we had developed gradually became adopted by Kings Mill staff.

Health care managers supported an application for permanent funding for the Discharge Scheme, and a second worker was funded by Health. The volunteer group rose to 35, and three people from other cultures were recruited.

The aims of action research , as I understand them, are to empower people, to enable them to access services which they have rights to receive, and to seek equity and equality for disadvantaged groups of people. I consider that these aims have been achieved as far as possible through this action research, with all its limits and constraints.

New knowledge has emerged especially in relation to those people whose health and social needs were greatest. Before the research data was collated, no-one knew about the numbers of people without carers or about the interdependent couples and the outcomes of their hospitalization. It was very painful to reflect on their situations and human loss collectively.

We did not know what happened to carers of people who were dying until the volunteers told us, and we did not know what the issues which we identified about complex care and continuing health care needs would lead to in the future.

Ann Loxley (1991) refers to 'a shadow of the future' in her book 'Collaboration in Health and Welfare'. She suggests that collaborative working will lead to future constructive action through a framework of trust and understanding, providing that it becomes part of the infrastructure of an organisation. I would like to conclude by saying that this has been the case, as a long term outcome of the collaboration which was established during the original research period. It applies now at Kings Mill Hospital in the form of a collaborative working model for patients with complex and continuing health and social care needs, whereby the patients, their carers, nurses, social workers, therapists and specialist workers meet together in Case Conference to make a case for appropriate funding for the care package of the patient's choice.

APPENDICES

APPENDIX 1

Informal Carers - Pts referred to Social Workers

Total patients - 935=100%   Men 346=37%   Women - 589=63%

Carer(s)	Men	Living alone	Women	Living alone	Total Pts	Total Living alone	%
No carers	29	19	31	23	60	42	6
Parents and sister	1	-	-	-	1	-	-
Son(s)	26	10	75	46	101	56	11
Daughter(s)	45	29	121	90	166	119	18
Step-son	-	-	1	1	1	1	-
Mother	1	-	2	-	3	-	-
Father	1	-	-	-	1	-	-
Maternal grandmother	-	-	1	-	1	-	-
Parents	13	-	10	-	23	-	2
Foster parents	1	-	1	-	2	-	-
Father and sister	1	1	-	-	1	1	-
Child	-	-	1	-	1	-	-
Boyfriend	-	-	1	1	1	1	-
Husband	-	-	59	-	59	-	6
Wife	75	-	-	-	75	-	8
Mother & neighbour	1	-	-	-	1	-	
Brother	4	4	2	2	6	6	>1

Sister	3	3	18	15	21	18	2
Parents and Army	2	-	-	-	2	-	
Nephew	3	3	4	4	7	7	>1
Niece	2	2	8	7	10	9	>1
Cousin	1	1	1	1	2	2	
Cohabitee	-	-	1	-	1	-	
Consort/friend	-	-	1	-	1	-	
Girlfriend	1	-	-	-	1	-	
Grandson	-	-	1	1	1	1	
Grandaughter	-	-	2	2	2	2	
Son, daughter, friend and neighbour	1	1	-	-	1	1	
Son, landlady and friend	1	-	-	-	1	-	
Son, grandaughter and grandson	1	1	-	-	1	1	
Son and daughter	13	6	39	24	52	30	6
Son, daughter and husband	9	-	12	-	21	-	2
Son and husband	-	-	23	-	23	-	2
Son and grandson	-	-	2	-	2	-	
Son and grandaughter	-	-	3	1	3	1	
Son and wife	10	-	-	-	10	-	1
Son and sister	-	-	3	3	3	3	
Son and sister-in-law	-	-	1	1	1	1	
Son and brother	-	-	1	1	1	1	
Son, daughter, grandson and							

grandaughter	-	-	1	1	1	1	
Son, daughter and sister	-	-	1	1	1	1	
Son, daughter and friend	-	-	1	1	1	1	
Son, daughter and neighbour	2	-	1	1	3	1	
Son, daughter and grandson	-	-	2	-	2	-	
Son, husband and neighbour	-	-	1	-	1	-	
Son, duaghter and neighbour	-	-	1	1	1	1	
Son, daughter, grandson, grandaughter and husband	-	-	1	-	1	-	
Son, nephew and neighbour	-	-	1	1	1	1	
Son, aunt and uncle	1	1	-	-	1	1	
Son, neighbour and warden	-	-	1	1	1	1	
Son and friend	3	3	2	2	5	5	>1
Son and warden	-	-	1	1	1	1	
Son and neighbour	1	1	9	9	10	10	1
Daughter and brother	3	-	-	-	3	-	
Daughter and wife	26	-	-	-	26	-	2
Daughter and grandson	-	-	3	1	3	1	
Daughter and sister	1	-	3	3	4	3	
Daughter and grandaughter	-	-	8	7	8	7	>1
Daughter and husband	-	-	33	-	33	-	4

Husband and grandson	-	-	2	-	2	-
Husband and sister-in-law	-	-	1	-	1	-
Husband and niece	-	-	1	-	1	-
Husband and mother	-	-	1	-	1	-
Husband and brother-in-law	-	-	1	-	1	-
Husband, nephew and neighbour	-	-	1	-	1	-
Husband, mother and friend	-	-	1	-	1	-
Husband and friend	-	-	1	-	1	-
Husband, wife and neighbour	1	-	3	-	4	-
Wife and sister	1	-	-	-	1	-
Wife and sister-in-law	1	-	-	-	1	-
Wife, grandaughter and grandson	1	-	-	-	1	-
Daughter-in-law and neighbour	1	1	-	-	1	1
Brother and niece	-	-	1	1	1	1
Brother and friend	-	-	1	1	1	1
Brother and neighbour	3	2	1	1	4	3
Brother and sister	2	1	-	-	2	1
Sister and aunt	1	1	-	-	1	1
Sister, niece and nephew	-	-	1	1	1	1
Sister and niece	-	-	2	2	2	2
Sister and neighbour	-	-	1	1	1	1

Daughter, grandaughter and husband	-	-	1	-	1	-	
Daughter, sister and friend	-	-	1	1	1	1	
Son, daughter, grandson grandaughter and neighbour	1	1	-	-	1	1	
Daughter, sister, friend and lodger	-	-	1	-	1	-	
Daughter, grandson friend and neighbour	-	-	1	1	1	1	
Daughter, husband, wife and neighbour	2	-	1	-	3	-	
Daughter, sister-in-law, and nephew	-	-	1	1	1	1	
Daughter, wife and sister	1	-	-	-	1	-	
Daughter, friend and neighbour	2	2	2	2	4	4	
Daughter and friend	-	-	5	4	5	4	
Daughter and neighbour	3	3	5	5	8	8	>1
Daughter and hostel warden	-	-	1	-	1	-	
Daughter, wife and grandson	1	-	-	-	1	-	
Daughter and mother-in-law	1	1	-	-	1	1	
Daughter, nephew and warden	1	1	-	-	1	1	
Daughter, friend and lodger	1	-	-	-	1	-	
Husband and sister	-	-	1	-	1	-	

Sister, friend and neighbour	1	1	1	1	2	2
Sister and mother	1	-	1	-	2	-
Sister and brother-in-law	-	-	1	1	1	1
Sister and step-brother	1	1	-	-	1	1
Sister, sister-in-law and neighbour	1	1	-	-	1	1
Grandaughter and neighbour	-	-	1	1	1	1
Nephew and niece	1	1	-	-	1	1
Nephew and niece-in-law	1	1	1	1	2	2
Nephew and friend	-	-	2	2	2	2
Nephew and neighbour	-	-	1	1	1	1
Nephew and cousin	1	1	-	-	1	1
Nephew, friend and neighbour	1	1	-	-	1	1
Niece and warden	-	-	1	1	1	1
Niece and neighbour	-	-	1	1	1	1
Niece and friend	-	-	1	1	1	1
Niece, son-in-law and friend	1	-	-	-	1	-
Cousin and neighbour	1	1	1	1	2	2
Cousin's husband	-	-	1	-	1	-
Cousin and friend	1	1	-	-	1	1
Uncle, friend and neighbour	-	-	1	1	1	1
Friend(s)	9	8	12	12	21	20

Friends and neighbours	4	4	4	4	8	8	
Friend and landlady	1	-	-	-	1	-	
Neighbours	9	9	20	20	29	29	
Neighbour and god-daughter	-	-	1	1	1	1	
Neighbour and private help	-	-	1	1	1	1	
Other lodgers	1	-	-	-	1	-	
Neighbour and warden	2	2	-	-	2	2	
Paid helper	-	-	2	2	2	2	
Warden	2	2	-	-	2	2	
Volunteer	-	-	1	1	1	1	
Landlady	1	-	-	-	1	-	
Total patients	**346**	**130**	**589**	**328**	**935**	**458**	**49**

935 pts = 100%
346 men = 100%
589 women = 63%
458 living alone = 49%

Men 346 = 100% Living alone 130 = 38% (14% of all pts)
Women 589 = 100% Living alone 328 = 56% (35% of all pts)

Fig 7 'Informal carers for patients referred to the social worker' shows that patients were being cared for mostly by members of their families, spouses if they were married, sons, daughters and other kin either singularly or in combination, and that a small number had non-kin as their carers. An equally small number had somehow become 'remaindered', and had no carers.

CHAPTER 2.

App. A.

S.W.R.	D.S.R.

FORM 1 - REFERRAL TO DISCHARGE SCHEME

SOCIAL WORKER:

DATE:

PROV. DISCHARGE DATE:

WARD:

CLIENT'S NAME:

D.O.B.:

AGE:

SEX: M ☐ F ☐

ADDRESS:

STATUS: M ☐ S ☐ W ☐ D ☐

TEL NO:

NAME OF G.P.:

TEL NO:

REASON FOR ADMISSION:

S.W.D. OPEN ☐ CLOSED ☐

LIVING ALONE: Yes ☐ No ☐ WITH SOMEONE - WHO? PLEASE SPECIFY:

Son	Daughter	Wife	Husband	G. Son	G. daughter	Other

EXISTING FORMAL CARE

CIAL SERVICES	M	T	W	T	F	S	S
Home Help							
M.O.W.							
Day Centre							
Day Care Pt. III							
Phased							

HEALTH SERVICE	M	T	W	T	F	S	S
District Nurse							
Bath Att.							
Day Hospital							
Respite							

EXISTING INFORMAL CARE

SOCIAL ORGANISATIONS	M	T	W	T	F	S	S
Lunch Club							
Church							
O.A.P. Club							
Other Orgn							

	M	T	W	T	F	S	S
Private help							

SOCIAL WORK TASKS

	New	Reinstate
Welfare Rights		
Domiciliary Services		
M.O.W.		
O.T. Aids		
Housing		
Family problems.		
Help with dependent		
Residential care		
Other (specify)		
Discharge Scheme		

SOCIAL WORKER COMMENTS:

HOUSING

Owner Occupier		Bungalow	
Private tenant		House	
Council		G. floor flat	
L. Coal Board		Upstairs flat	
Lodgings		Warden	
A.P.H., L.A.		Other:	
Private res. home			

Heating

Gas fire		Elec. fire	
Central Heat.		Coal	

Bathroom

Upstairs ☐ Downstairs ☐ None ☐

Toilet

Upstairs		Downstairs	
Outside		Commode	

Is your bed? Upstairs ☐ Downstairs ☐

App. B.

MANSFIELD GENERAL HOSPITAL

Request for:

SOCIAL WORK

Date of Referral

Ward/Dept.

Consultant

G.P.

Admission date:

Expected date of discharge:

Name

Address

D.o.B.

Sex

M/S/W/Sep/D

Diagnosis

Reason for Referral:

1. General assessment of need ☐
2. Advice & support to patient/family ☐
3. Counselling re bereavement and/or loss for patient and family ☐
4. Home Help and/or M.O.W. - New referral/recommencement of existing services (Delete as appropriate) ☐
5. Financial difficulties ☐
6. Housing/Accommodation ☐
7. Other (please specify) ☐

Degree of Urgency

- Very (Within 24 hours) ☐
- Moderately (Within 2/3 days) ☐
- Non-Urgent ☐

Referral requested by

- Medical Staff ☐
- Nursing Staff ☐
- Patient ☐
- Relative/Friend ☐

Does patient know of referral to Social Worker Yes/No

Signed...

Status ....

App. C.

HOSPITAL DISCHARGE SCHEME

PATIENT'S CONSENT FOR VOLUNTEER SUPPORT

I____
of____

give consent for a volunteer from the Discharge Scheme to visit me at home following my discharge from hospital.

Patient's signature__________________________
* Carer's signature__________________________
Screener's signature__________________________

Date__________________________

* when applicable

App D.

S.W.R.	D.S.R.

FORM 3 - VOLUNTEER REPORT

Please complete and return weekly to Discharge Scheme office.

VOLUNTEER'S NAME:

CLIENT'S NAME:

TASKS	M	T	W	T	F	S	S	COMMENTS	
Shopping									
Laundry									
Pension									
Cleaning									
Meals									
Firelighting									
Dressing									
Washing									
Toilet									
Pet									
Transport									
Prescription									
Getting up									
Putting to bed									
Other									
TOTAL TIME EACH DAY								WEEKLY TOTAL IN HOURS	

PLEASE COMMENT WHEREVER POSSIBLE

1. Attitude and response of client towards you?

2. Did the client have any emotional problems not identified earlier?

3. Was family (if any) supportive?

4. Were there any problems around your withdrawal from client?

5. Were you able to manage the set tasks?

6. Were there tasks not previously identified?

7. Did any problems arise?

8. Did you feel your help was beneficial and effective?

9. Was the formal care from Social Services/Domiciliary Services/Health Service effective?

10. Does being a volunteer present difficulties to you?

11. How can we improve our service to the client and our support to you?

DISCHARGE SCREENING

S.W.R. ☐ D.S.R. ☐

App. E

WARD: D.O.A.: D.O.D.:

NAME: AGE: SEX: M ☐ F ☐

ADDRESS:

TEL NO:

NAME OF SCREENER: DATE OF REFERRAL DATE OF SCREENING

PATIENT'S NEED FOR HELP WITH:	Prior to Admission	On Discharge
Shopping		
Laundry		
Pension		
Cleaning		
Meals		
Firelighting		
Dressing		
Washing		
Toilet		
Pet		
Transport		
Prescription		
Getting up.		
Going to bed		

INFORMAL CARERS	M	T	W	T	F	S	S
Son							
Daughter							
D/in/Law							
S/in/Law							
Father							
Mother							
Husband							
Wife							
G. son							
G. daughter							
Friend							
Nephew							
Niece							
Neighbour							

Comments:

MAIN CARER

Name:

Address:

Tel. No.

LOCATION OF KEY:-

Name:

Address:

Tel. No.

NEXT OF KIN

Name:

Address:

Tel. No.

HEALTH SERVICE AIDS

	Prior to Admission	On Discharge		Prior to Admission	On Discharge
Commode			Ripple bed		
Air Ring			Bedpan		
Pillows			Urinal		
Sheepskin			Back rest		
			Other.		

O.T. AIDS/EQUIPMENT

	Prior to Admission	On Discharge		Prior to Admission	On Dischage
Bed			Wheelchair		
Hoist			Walking aid		
Cot sides			Bath		
Table			Shower		
Eating			Stairs, gate, rail		
Drinking			Ramp		
Chair			Household equip.		
Dressing			Other (specify)		

FORM 2 (continued)

OCCUPATION: ____________________

RETIRED ☐

EARLY RETIREMENT

REDUNDANCY ☐ ILL HEALTH ☐ DEPENDANT ☐ OTHER ☐

PERSONAL DISABILITIES

Dentures Yes | No

Eyesight Good | Poor

Hearing Good | Poor

Special Diet Yes | No

Spectacles Yes | No

Hearing Aid Yes | No

Mobility Good | Poor

HOUSING DIFFICULTIES Yes ☐ No ☐

Specify:

EMOTIONAL DIFFICULTIES Yes ☐ No ☐

Specify:

MENTAL ILLNESS: Yes ☐ No ☐

Specify:

COMMUNICATION DIFFICULTIES: Yes ☐ No ☐

Specify:

MEDICATION: Yes ☐ No ☐

Specify:

WELFARE RIGHTS Yes ☐ No ☐

RECOMMENDED VOLUNTEER TASKS:-

VOLUNTEERS:

Name:

Address:

Tel. No.:

DAYS & TIMES REQUIRED

	M	T	W	T	F	S	S
Week 1							
Week 2							
Week 3							

Further comments:-

FOR OFFICE USE:

Has patient been informed of Scheme?

Has he/she given consent?

Has volunteer been contacted?

Has information been sent?

Have relevant agencies been notified? ←

Has discharge date been confirmed?

SERVICES	COMMENTS
WARDEN	
HOME HELP	
M.O.W.	
DIST. NURSE	
MACMILLAN NURSE	
O.T. AIDS	
DAY CENTRE/HOSP.	

Signed: .... Date: ....

CHAPTER 4.

APPENDIX 1

Informal Carers - Pts referred to Social Workers

Total patients - 935=100% Men 346=37% Women - 589=63%

Carer(s)	Men	Living alone	Women	Living alone	Total Pts	Total Living alone	%
No carers	29	19	31	23	60	42	6
Parents and sister	1	-	-	-	1	-	-
Son(s)	26	10	75	46	101	56	11
Daughter(s)	45	29	121	90	166	119	18
Step-son	-	-	1	1	1	1	-
Mother	1	-	2	-	3	-	-
Father	1	-	-	-	1	-	-
Maternal grandmother	-	-	1	-	1	-	-
Parents	13	-	10	-	23	-	2
Foster parents	1	-	1	-	2	-	-
Father and sister	1	1	-	-	1	1	-
Child	-	-	1	-	1	-	-
Boyfriend	-	-	1	1	1	1	-
Husband	-	-	59	-	59	-	6
Wife	75	-	-	-	75	-	8
Mother & neighbour	1	-	-	-	1	-	
Brother	4	4	2	2	6	6	>1
Sister	3	3	18	15	21	18	2
Parents and Army	2	-	-	-	2	-	
Nephew	3	3	4	4	7	7	>1
Niece	2	2	8	7	10	9	>1
Cousin	1	1	1	1	2	2	
Cohabitee	-	-	1	-	1	-	
Consort/friend	-	-	1	-	1	-	
Girlfriend	1	-	-	-	1	-	
Grandson	-	-	1	1	1	1	
Grandaughter	-	-	2	2	2	2	
Son, daughter, friend and neighbour	1	1	-	-	1	1	
Son, landlady and friend	1	-	-	-	1	-	
Son, grandaughter and grandson	1	1	-	-	1	1	
Son and daughter	13	6	39	24	52	30	6
Son, daughter and husband	9	-	12	-	21	-	2
Son and husband	-	-	23	-	23	-	2
Son and grandson	-	-	2	-	2	-	
Son and grandaughter	-	-	3	1	3	1	

Son and wife	10	-	-	-	10	-	1
Son and sister	-	-	3	3	3	3	
Son and sister-son-in-law	-	-	1	1	1	1	
Son and brother	-	-	1	1	1	1	
Son, daughter, grandson and grandaughter	-	-	1	1	1	1	
Son, daughter and sister	-	-	1	1	1	1	
Son, daughter and friend	-	-	1	1	1	1	
Son, daughter and neighbour	2	-	1	1	3	1	
Son, daughter and grandson	-	-	2	-	2	-	
Son, husband and neighbour	-	-	1	-	1	-	
Son, duaghter and neighbour	-	-	1	1	1	1	
Son, daughter, grandson, grandaughter and husband	-	-	1	-	1	-	
Son, nephew and neighbour	-	-	1	1	1	1	
Son, aunt and uncle	1	1	-	-	1	1	
Son, neighbour and warden	-	-	1	1	1	1	
Son and friend	3	3	2	2	5	5	>1
Son and warden	-	-	1	1	1	1	
Son and neighbour	1	1	9	9	10	10	1
Daughter and brother	3	-	-	-	3	-	
Daughter and wife	26	-	-	-	26	-	2
Daughter and grandson	-	-	3	1	3	1	
Daughter and sister	1	-	3	3	4	3	
Daughter and grandaughter	-	-	8	7	8	7	>1
Daughter and husband	-	-	33	-	33	-	4
Daughter, grandaughter and husband	-	-	1	-	1	-	
Daughter, sister and friend	-	-	1	1	1	1	
Son, daughter, grandson grandaughter and neighbour	1	1	-	-	1	1	
Daughter, sister, friend and lodger	-	-	1	-	1	-	
Daughter, grandson friend and neighbour	-	-	1	1	1	1	

Daughter, husband, wife and neighbour	2	-	1	-	3	-
Daughter, sister-in-law, and nephew	-	-	1	1	1	1
Daughter, wife and sister	1	-	-	-	1	-
Daughter, friend and neighbour	2	2	2	2	4	4
Daughter and friend	-	-	5	4	5	4
Daughter and neighbour	3	3	5	5	8	8 >1
Daughter and hostel warden	-	-	1	-	1	-
Daughter, wife and grandson	1	-	-	-	1	-
Daughter and mother-in-law	1	1	-	-	1	1
Daughter, nephew and warden	1	1	-	-	1	1
Daughter, friend and lodger	1	-	-	-	1	-
Husband and sister	-	-	1	-	1	-
Husband and grandson	-	-	2	-	2	-
Husband and sister-in-law	-	-	1	-	1	-
Husband and niece	-	-	1	-	1	-
Husband and mother	-	-	1	-	1	-
Husband and brother-in-law	-	-	1	-	1	-
Husband, nephew and neighbour	-	-	1	-	1	-
Husband, mother and friend	-	-	1	-	1	-
Husband and friend	-	-	1	-	1	-
Husband, wife and neighbour	1	-	3	-	4	-
Wife and sister	1	-	-	-	1	-
Wife and sister-in-law	1	-	-	-	1	-
Wife, grandaughter and grandson	1	-	-	-	1	-
Daughter-in-law and neighbour	1	1	-	-	1	1
Brother and niece	-	-	1	1	1	1
Brother and friend	-	-	1	1	1	1
Brother and neighbour	3	2	1	1	4	3
Brother and sister	2	1	-	-	2	1
Sister and aunt	1	1	-	-	1	1
Sister, niece and nephew	-	-	1	1	1	1

Sister and niece	-	-	2	2	2	2	
Sister and neighbour	-	-	1	1	1	1	
Sister, friend and neighbour	1	1	1	1	2	2	
Sister and mother	1	-	1	-	2	-	
Sister and brother-in-law	-	-	1	1	1	1	
Sister and step-brother	1	1	-	-	1	1	
Sister, sister-in-law and neighbour	1	1	-	-	1	1	
Grandaughter and neighbour	-	-	1	1	1	1	
Nephew and niece	1	1	-	-	1	1	
Nephew and niece-in-law	1	1	1	1	2	2	
Nephew and friend	-	-	2	2	2	2	
Nephew and neighbour	-	-	1	1	1	1	
Nephew and cousin	1	1	-	-	1	1	
Nephew, friend and Neighbour	1	1	-	-	1	1	
Niece and warden	-	-	1	1	1	1	
Niece and neighbour	-	-	1	1	1	1	
Niece and friend	-	-	1	1	1	1	
Niece, son-in-law and friend	1	-	-	-	1	-	
Cousin and neighbour	1	1	1	1	2	2	
Cousin's husband	-	-	1	-	1	-	
Cousin and friend	1	1	-	-	1	1	
Uncle, friend and neighbour	-	-	1	1	1	1	
Friend(s)	9	8	12	12	21	20	
Friends and neighbours	4	4	4	4	8	8	
Friend and landlady	1	-	-	-	1	-	
Neighbours	9	9	20	20	29	29	
Neighbour and god-daughter	-	-	1	1	1	1	
Neighbour and private help	-	-	1	1	1	1	
Other lodgers	1	-	-	-	1	-	
Neighbour and warden	2	2	-	-	2	2	
Paid helper	-	-	2	2	2	2	
Warden	2	2	-	-	2	2	
Volunteer	-	-	1	1	1	1	
Landlady	1	-	-	-	1	-	
Total patients	**346**	**130**	**589**	**328**	**935**	**458**	**49**

935 pts = 100%
346 men = 100%
589 women = 63%
458 living alone = 49%

Men 346 = 100% Living alone 130 = 38% (14% of all pts)
Women 589 = 100% Living alone 328 = 56% (35% of all pts)

App.1 'Informal carers for patients referred to the social worker' shows that patients were being cared for mostly by members of their families, spouses if they were married, sons, daughters and other kin either singularly or in combination, and that a small number had non-kin as their carers. An equally small number had somehow become 'remaindered', and had no carers.

APPENDIX 2

23 women without carers who lived alone

1. Patient -65, gall bladder problem and previous self harm
This woman had just lost her husband, and needed bereavement counselling. she convalesced with relatives some distance away from Mansfield, who could not give her day to day support

2. Patient -65, self harm
This was a single woman, living alone with a history of mental illness and self harm. The Mental Health Team and CPN in the community were responsible for all her care and support.

3. Patient 65-69, cancer
This woman had no carers and died in hospital

4. Patient 70-74, hypertension and myocardial infarction
Patient was housebound at home. She had no family and paid for private help. She refused all other services.

5. Patient 70-74, cancer
This patient was widowed and completely alone. She needed advice about mastectomy services, and provision of services for laundry, shopping and firelighting

6. Patient 75-79, fractured femur, arthritis.
A divorced woman with no family who was chronically physically handicapped. she needed an Orange Car Badge application form and DIAL information

7. Patient 75-79, cancer and heart disease
This was a single woman who decided she could not carry on caring for herself any longer. She asked the social worker to admit her to a nursing home as no rélatives were available to help

8. Patient 75-79, fractured femur, heart disease
This woman was registered handicapped, lived alone, and was a widow. She did not want to leave hospital. She had an antipathy towards her son-in-law and this obstructed the possibility of her daughter being able to care for her. The couple were going away on holiday anyway, and did not want to cancel. In hospital, the patient caused a dispute between the nursing staff and management, and the social worker was asked to 'come and sort it out'. The patient refused services at home, but after a full assessment was discharged safely

9. Patient 75-79, falls and neurological disease
A widow who lived alone. All her family lived in Kent and she relied on Social Services for domiciliary care. She was housebound

10. Patient 80-84, accident, 'other' illness
This widow had no family. She was eventually transferred to the geriatric hospital for medium stream rehabilitation

11. Patient 80-84, breast cancer
This widow had no informal carers or relatives prior to admission but she had been quite independent. Once in hospital, her health declined rapidly, and she was transferred to the geriatric hospital for terminal care

12. Patient 80-84, bowel problems and epilepsy
A widow who had been active and self caring before admission. she needed services on discharge from hospital, but had no family to help

13. Patient 80-84, fractured femur
This single woman had come for a holiday with her sister's family in Mansfield. She had her own flat in Norwich with no relatives nearby. She was able to go back to her sister's relatives to convalesce before she finally went home two months late, with help from Social Services in Norwich.

14. Patient 80-84, bowel problems.
This widow had no carers, but her warden had called daily to monitor her situation. She was transferred to the geriatric hospital for longer term care.

15. Patient 80-84, fracture and dementia
This widow was totally dependent on an area based social worker and domiciliary services in the community. she was transferred to the geriatric hospital

16. Patient 80-84, fracture, thrombosis and gout
This woman was also a widow, and all her family lived far away. she was, on admission, totally dependent on an area based domiciliary services assistant and home help. She had no access to any other carers.

17. Patient 85-89, heart disease, circulatory disease
A widow who lived alone in a warden aided bungalow. there were no family to help her. On discharge she needed a community care assistant daily to help her dress, provide meals, social contact, OT aids and day centre

18. Patient 85-89, thrombosis
A widow, completely on her own. On discharge she needed an increase of her domiciliary services.

19. Patient 85-89, mobility problems and falls
This widowed lady was entirely dependent on an area based social worker who was talking to her about a permanent Part 111 placement. She had recently had short term care in Part 111, but had resisted long term care. she went to Part 111 on discharge

20. Patient 85-89, bowel disease
This widow was deaf, and registered partially sighted. She had no relatives, and organising self care for her colostomy presented a lot of difficulties. She also needed a Welfare Rights review. She was transferred to the geriatric hospital for longer term care and rehabilitation

21. Patient 85-89, poor mobility and falls
This widow lived alone, and although she had sons who lived nearby, neither they nor their families were supportive. The area social worker offered her a Part 111 place but she refused. she accepted short term care occasionally, and had a community care assistant twice daily or more. she went home to try again

22. Patient 85-89, breast cancer
This widow had a family who lived miles away and could not help her. The social worker applied for an NSCR grant for her prothesis and special clothing, because these were not available on prescription. she was discharge and able to cope alone with services

23. Patient 90+, poor mobility and falls
This very elderly widow lived in warden aided accommodation, had no carers, and was in very poor health. She showed little prospect of improving, and was transferred to the geriatric hospital for longer term care

APPENDIX 3

Patients whose sons and daughters lived far away from Mansfield

1. Male aged 25
His entire family lived in Liverpool, and he had no-one to care for him at all.

2. Male aged 43
His family 'lived away'. He said he had a fiancee in Aylesbury, but she did not appear. He had no other carers.

3. Males aged 65
He lived with his wife who had a history of psychiatric illness, and also cared for her elderly mother. His only son lived in Brighton and could not help.

4. Male aged 74
His son lived in Oxford and his daughter in Worcester. She came to Mansfield for hour days when he was discharged, to care for him and his dependent wife who had Alzheimers disease.

5. Males aged 75
His daughter lived in Norfolk, and his son was in Woodhall Spa. A neighbour was his carer.

6. Male aged 81
He had a son living in Ravenshead, and daughter in Calverton. His son travelled to support him

7. Male aged 81
His nephew lived in Long Eaton and contacted him daily by telephone. A friend and neighbour cared for him at home

8. Male aged 81
His sister-in-law lived with her family in Melton Mowbray. Neighbours were carers.

9. Male aged 82
His only son lived in Scotland, and had no contact with his father. He had no carers, and was transferred to the geriatric hospital

10. Males aged 84
His only son lived in Torquay. A friend cared for him

11. Female aged 61
Her son lived in Scotland and could not help. A neighbour cared for her dog whilst she was in hospital

12. Female aged 61
Patient was homeless, having separated from her husband. She went to live with her daughter in Derby

13. Female aged 61
Her daughter lived in Retford, so her sister and friend were her carers

14. Female aged 68
Although her son lived with her, he was not her carer. Her sister and neighbours cared for her, and her two daughters, who lived in Sheffield, were not available

15. Female aged 68
Her only son lived in Chesterfield, and her sister in Mansfield Woodhouse looked after her

16. Female aged 69
Only son in London. Her neighbour cared for her

17. Female aged 69
Two daughters lived in Langwith, one in Devon. The daughter from Devon came to stay with her mother for four days

18. Female aged 69
Patient's only daughter lived in Manchester. Neighbours cared for her

19. Female aged 72
Her son and family lived in Duffield, and had fallen out with her. Her neighbours were her carers

20. Female age 72
Her brother lived in Derby and called weekly. This patient was being financially exploited by a male 'friend' and a distant nephew eventually obtained Power of Attourney for her affairs

21. Female aged 75
Daughter lived 'away' but called weekly. A friend was caring for her

22. Female aged 75
Her son lived locally but was not supportive. Her daughter lived in Suffolk with her disabled husband and would have helped if she could. She had no other carers. This patient relied on Social Services support.

23. Female aged 78
Patient's son lived in Nottingham, and his wife travelled to help her

24. Female aged 78
She had a son in Japan, and one in Norwich. The son and his wife from Norwich cared as much as they could at that distance, but the Housing Warden cared on a daily basis.

25. Female aged 81
This patient may have had relatives in Germany, but they were not in contact. A neighbour was her carer before admission

26. Female aged 85
Her niece travelled from Matlock weekly to care for her, and two other elderly sisters also helped.

27. Female aged 86
She had a daughter 'somewhere' who was not involved with her, and a son in Paplewick who was not in touch either. She had no carers, and was very depressed

28. Female aged 88
Her only daughter lived in Bristol, and her son was in Lancashire. Her neighbour was her only carer

APPENDIX 4

A summary of Social Work Tasks in Adult Care

1) Welfare Rights and Finances

Advice about all types of DSS benefits: application or appeal:negotiation with DSS offices and Welfare Rights officers: charitable grants such as N.S.C.R.: funding from hospital social work budgets: housing benefit: finding money for special diets and equipment: advising patients about debts and household bills: transport and hospital fares.

2) Domicilary Services, Meals on Wheels and Day Centre

Referrals for home help and meals on wheels: reinstatement of service on discharge, or increase : negotiation of dates for service commencement when discharges were premature or delayed: arranging for cleaning or clearance of properties which had been damage ie by fire, or needed an environmental health officer for infestation: inviting domiciliarly service officer to a home assessment prior to discharge: enabling patients to pay for private services when Social Services would not, or could not, undertake the task: arranging domicillary help for dependent relatives whilst patient/carers were in hospital: arrangement for special diet provision: arranging day centre provision.

3) Occupational Therapy and Aids to Daily Living

Making referrals to OT's for ward assessments, sometimes direct sometimes via ward staff: care planning with OT's, helping to acquire special equipment: accompanying OT on home assessments: working with area OT's, arranging home loan deliveries: referring for hospital loans equipment ie hospital beds: liaising with physiotherapists and care planning: getting beds downstairs:repair of equipment .

4) Housing

Requests for rehousing and negotiating with medical staff or gp's to provide a recommendation for housing points: updating information with housing re patients' needs: getting repairs done : supporting patients who wanted to move from one housing area to another to be near relatives: negotiating alternative care facilities when patients were temporarily homeless (ie after a fire); accommodation for homeless patients: lodging/landlord problems: decoration and gardening. Advising patients who wanted to sell their houses and move to council or housing association properties.

5) Family Problems

Family disputes about care arrangemnts: arguments about neglect: counselling stressed carers: dealing with situations of elder abuse or exploitation: advising about wills, property and money: ensuring safe care packages in spite of carers: making care arrangemnts with families who lived far away: Court of Protection: Power of Attourney: referral to Carers' Groups: supporting carers who refused to have patients home, or were unable to cope. Liaison with hospital and community staff about special needs - diet and feeding: fear of terminal illness: patients taking discharge against medical advice: relatives arguing and complaining about each other: ill health of carers. Itinerant patients. Monitoring fraught family situations after discharge.

6) Helping with dependents

Providing services for dependent left at home: home visits to assess situation: liaising with area social workers and OT: arranging alternative care - Part 111 private care, hospital re-admission: helping family to cope: arranging hospital visits for disabled dependents: reducing patient's anxiety and preventing premature self discharge or refusal of treatment: acting on patient's behalf in the carer's interests: care of pets.

7) Residential Care

Assessment of need for residential care - Part 111 permanent, short-term or phased care: financial assessments: Part 111 panel presentation: residential home visit: placement: review: transport: helping patients and relatives to put affairs in order: settling disputes about assessment with residential care staff for frail , sick or dying applicants: negotiating with area social services for other home choices: emergency arrangements for patients in Accident and Emergency: day care: residential homes: advising and informing families about private care, finances and allowances: counselling patients and families: making arrangements with medical staff to deal with delayed admissions, changes in patient's health, need for nursing home care.

8) Other Work

Non-accidental injury - children. Involvement of specialist workers - physical disability, mental health, sensory impairment. Counselling for the bereaved and dying. advice re funeral and post death arrangements. Development group work; rehabilitation systems development; work-load management and evaluation; integration of voluntary organisations in service delivery; education for medical and nursing staff; attending courses, conferences and workshops; practice supervision with students; developing SSD and NHS relationships; compiling resource information for staff and patients.

CHAPTER 6

NORTH NOTTINGHAMSHIRE HEALTH AUTHORITY
King's Mill Hospital

If any one, or a number, of the following criteria apply, record in patient's notes stating reason for, and what action you have taken.

HEALTH & SOCIAL SERVICES

"AT RISK" ASSESSMENT GUIDELINES

CODE NO.	GUIDELINES
1	If score 10 and above, this is significant
2	Consider existing and new disabilities Psychological refers to anxiety about treatment, depression, confusion, clinical signs of psychiatric disorder
3	Consider planning and suitability of discharge following previous admission, e.g. *elderly patient readmitted with a broken femur* *following surgery and discharged home with inadequate help*
4	Repeated in-patient stays, but no specific health reason identified
5	Refers to :- * inability to take medication either self-inflicted or unable to understand or cope with treatment * discharged following previous admission, against medical advice * ignored advice given by health care staff
6	Remember to include private arrangements and voluntary help, such as from a neighbour, as well as statutory services. Don't forget to refer to Social Work Department a.s.a.p.
7	No family, friends or neighbours able or willing to provide care and support after discharge
8	Carers who are ill, frail or elderly, or stating that they do not want the patient to go home. Family arguments and breakdown
9	Remember to ask patient, relative or friend as soon as possible, If patient is a carer, determine if this presents a problem on discharge. *Consider child-care arrangements*
10	This criteria is dependent upon health and social circumstances
11	Relevance - assess on admission - **ALWAYS** refer to Social Worker
12	Patient malnourished, very dirty, bruised or injured by carers on admission, *especially* unexplained injury
13	Base this criteria on average stay for diagnosis/ operation Consider any other factors which may affect length of stay. The longer a patient is in hospital, the more difficulty will present on discharge

+++
MWsac Mar'93

NORTH NOTTINGHAMSHIRE HEALTH AUTHORITY

HEALTH & SOCIAL SERVICES "AT RISK" ASSESSMENT

PATIENT's NAME:	*D o B:*
CONSULTANT :	*WARD:*

TO BE RECORDED ON ADMISSION

1 Waterlow Scale on every patient on admission [ ]

2 Functional Disability

(a) *Physical* [ ]

(b) *Psychological* [ ]

3 Previous admission within last two (2) weeks [ ]

4 Non-specific re-admission [ ]

5 Previous non-compliance with health care [ ]

6 Already receiving Home Care Support [ ]

7 No family carers [ ]

8 Carers ill, in dispute, or verbalising an inability to cope [ ]

9 Patient is a carer for dependent person at home [ ]

10 Accommodation / housing problems [ ]

11 Request for residential care [ ]

12 Patient neglected and/or abused [ ]

13 Potential long period of hospitalisation [ ]

Signed: .... *Date:* ....*199.*

NORTH NOTTINGHAMSHIRE HEALTH AUTHORITY

King's Mill Hospital

"AT RISK" ASSESSMENT

1 HEALTH

(a) Waterlow Scale on every patient on admission ☐

(b) Re-admission ☐

(c) Long period of hospitalisation ☐

(d) Previous non-compliance with health care ☐

2 SOCIAL

(a) *FORMAL* - already having statutory services ☐

(b) *INFORMAL* - NO formal carers - or carers ill, or someone dependent on them ☐

- Patient or carer verbalising an inability to cope ☐

- Functional disability ☐

- Mental incapacity ☐

- Accommodation difficulties ☐

+++
NNHA/DG/Acute Services
October 1992

WATERLOW SCALE. BOLSOVER WARD TISSUE ASSESSMENT

RING SCORES IN TABLE, ADD TOTAL. SEVERAL SCORES PER CATEGORY CAN BE USED

BUILD / WEIGHT FOR HEIGHT

AVERAGE	0
ABOVE AVERAGE	1
OBESE	2
BELOW AVERAGE	3

SKIN TYPE VISUAL RISK AREAS

HEALTHY	0
TISSUE PAPER	1
DRY	1
OEDEMATOUS	1
CLAMMY (TEMP^)	1
DISCOLOURED	2
BROKEN / SPOT	3

SEX AGE

MALE	1
FEMALE	2
14 - 49	1
50 - 64	2
65 - 74	3
75 - 80	4
81 +	5

CONTINENCE

COMPLETE/ CATHETERISED	0
OCCASION INCONT	1
CATH/INCONTINENT OF FAECES	2
DOUBLY INCONTINENT	3

MOBILITY

FULLY	0
RESTLESS	1
APATHETIC	2
RESTRICTED	3
INERT/TRACTION	4
CHAIRBOUND	5

APPETITE

AVERAGE	0
POOR	1
N.G. TUBE FLUIDS ONLY	2
NBM/ANOREXIC	3

SPECIAL RISKS

TISSUE MALNUTRITION

eg. TERMINAL CACHEXIA	8
CARDIAC FAILURE PERIPHERAL	5
VASCULAR DISEASE	5
ANAEMIA	2
SMOKING	1

NEUROLOICAL DEFICIT

eg. DIABETES, M.S., CVA, MOTOR / SENSORY PARAPGIA	4-6

MAJOR SURGERY / TRAUMA

ORTHOPEADIC BELOW WAIST, SPINAL	5
ON TABLE 2 HOURS	5

MEDICATION

STEROIDS CYTOTOXICS HIGH DOSE ANTI-INFLAMMATORY	5

SCORE	10+ AT RISK	20 + VERY HIGH RISK

NAME.. DATE..........................

WATERLOW SCALE................

DATE	WATERLOW SCALE	COMMENTS

Name:
Hospital No:
Score on Admission:
Date of Admission:
Action Taken:
Signature of Nurse:

Reassesment.

Date.	Score.	Action Taken.	Signature.

Action Taken -
i.e. Pressure area care.
Pressure relieving aids.

Adapted from BRADEN Risk Assesment Calculator.

BRADEN 1987

Sensory perception	Completely limited	1	Very limited	2	Slightly limited	3	No impairment	4
Moisture	Constantly moist	1	Very moist	2	Occasionally moist	3	Rarely moist	4
Activity	Bedfast	1	Chairfast	2	Walks occasionally	3	Walks frequently	4
Mobility	Completely limited	1	Very limited	2	Slightly limited	3	No limitation	4
Nutrition	Very poor	1	Probably inadequate	2	Adeaquate	3	Excellent	4
Friction and shear	Problem	1	Potential problem	2	No apparent problem	3		

Scores equal to or below 16 = AT RISK

BARTEL ASSESSMENT for...

ACTIVITIES OF DAILY LIVING

Chart to record what the patient (or client) actually DOES do in daily life, not what he/she can do.

The score reflects the degree of INDEPENDENCE from help provided by another person:
- if supervision is required, the patient is NOT independent,
- if aids and devices are used but no help is required, the patient IS independent.

Please record the main source of information as shown.

BOWELS:
2 completely continent, can self-administer suppositories or laxative.
1 occasional accident (less than once a week), or aid from someone else (eg. enema).
0 any worse grade of incontinence.

BLADDER:
2 completely dry (for a week or more) and able to manage any device (eg. catheter and bag) without help
1 occasional accident (less than once a day), or needs help with device.
0 any worse grade of incontinence.

FEEDING:
2 able to use any device, cut up food, use condiments, spread butter etc. by self, & in reasonable time.
1 needs some help eg. cutting/spreading, but feeds self.
0 needs more help than this, ie. to be fed.

GROOMING:
1 independent with washing hands and face, combing hair, shaving & teeth.
0 needs the help of another with any of these activities.

DRESSING:
2 able to select and put on all clothes (which may be adapted) fasten all zips, buttons, laces without help.
1 needs some help, but can do at least half.
0 needs more help than the above.

TRANSFER:
3 needs no help, (including locking own wheelchair).
2 needs minor help, verbal or physical = can transfer with one person alone with ease (eg. with spouse).
1 needs major help = two people or one strong or trained person, but can sit unaided.
0 can't sit, or needs complete lift by two people/hoist.

TOILET USE:
2 able to get on/off unaided, handle clothes, wipe self, flush toilet or empty commode (which may be sited nearby, but not moved for the subject by someone else)
1 able to manage with minor help in balancing, handling clothes or toilet paper, this help must be MINIMAL.
0 needs more assistance than above.

WALKING:
3 may use aid, (not wheelchair) speed not important, but must be able to manage around own house/flat (or ward)
2 needs supervision, verbal or physical, including help standing up, or help onto a Zimmer frame (or other aid), or distance inadequate.
1 independent in wheelchair and able to negotiate corners unaided.
0 immobile.

STAIRS:
2 independent up and down, and can carry walking aid if necessary.
1 needs verbal or physical supervision, or help carrying aid.
0 unable, unsafe or needs lift.

BATHING:
1 able to get in and out of bath or shower, clean self all over, may use any aids, or just have a standup wash (all over) if can manage everything.
0 unable to wash all over completely independently.

* Information from Therapist implies direct testing and observation of patient.

sjw/bar16.doc/16.5.90

Name:
Address:

Hosp. No.:

Date of Assessment	/ / /	/ / /	/ / /	/ / /	/ / /
INFORMATION FROM P = patient / client R = relative or carer N = nurse T = therapist *					
BOWELS 2 continent 1 occasional accidents 0 incontinent					
BLADDER 2 continent 1 occasional accidents 0 incontinent					
FEEDING 2 independent 1 needs some help 0 dependent					
GROOMING face/hair/teeth/shaving 1 independent 0 needs help					
DRESSING 2 independent 1 can do half 0 dependent					
TRANSFER 3 independent 2 minor help 1 major help (can sit) 0 unable					
TOILET USE 2 independent 1 needs some help 0 dependent					
WALKING 3 independent 2 walks with one 1 wheelchair independent 0 unable					
STAIRS 2 independent 1 needs help 0 unable					
BATHING 1 independent 0 dependent					
Total Score					

NORTH NOTTINGHAMSHIRE HEALTH AUTHORITY

SUMMARY OF COMPLAINTS RECEIVED FOR THE MONTH PERIOD ENDING 199
RELATING TO PATIENTS OF UNIT
WHO ARE RESIDENTS OF NORTH NOTTINGHAMSHIRE

TE CEIVED	CATEGORY OF COMPLAINT	SPECIALTY	MAIN ISSUES RAISED BY COMPLAINANT	FINDINGS ON INVESTIGATION	ACTION TAKEN	ORIGINATOR OF COMPLAINT	TIME TAKEN TO ACKNOWLEDGE (IN DAYS)	DAT CLOSE

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