When I Went Home . . .

When I Went Home...

a study of patients discharged from hospital

Pat Gay
Jill Pitkeathley

King Edward's Hospital Fund for London

When I Went Home . . .

King Edward's Hospital Fund for London

King Edward's Hospital Fund for London is an independent charity founded in 1897 and incorporated by Act of Parliament. It seeks to encourage good practice and innovation in health care through research, experiment, education and direct grants. For information, write to the Secretary, King Edward's Hospital Fund for London, 14 Palace Court, London W2 4HT.

When I Went Home...

a study of patients discharged from hospital

by

Pat Gay and Jill Pitkeathley

King Edward's Hospital Fund for London

Produced by Pitman Medical Publishing Co Ltd, Tunbridge Wells, Kent

Printed and bound in England by The Pitman Press, Bath

ISBN 0 900889 72 1

Distributed for the King's Fund by
Pitman Medical Publishing Co Ltd

King's Fund Publishing Office
126 Albert Street, London NW1 7NF

Acknowledgments

The study was supported by grants from the clinical research fund of the Oxford Regional Health Authority and from King Edward's Hospital Fund for London. Our thanks to them and to the many people who gave help and advice in the preparation and conduct of the study. Among these were the staff in the department of applied statistics, University of Reading; Dr Lex Barr, Oxford RHA; Dr Muir Gray, community physician, Oxfordshire; the assessment panel of the clinical research fund, Oxford RHA; voluntary service colleagues, and medical, nursing and ancillary staff of the hospitals concerned.

We wish most of all to thank the patients themselves for receiving us so cordially into their homes and for giving our questions their considered attention.

PG and JP
1978

The Authors

Pat Gay	is voluntary services organiser with Henley Hospital and Peppard Hospital, Oxfordshire. She has worked for the Government Social Survey and is a graduate of the Open University.
Jill Pitkeathley	is voluntary services coordinator with general hospitals in West Berkshire. She was formerly a social worker and is a graduate of Bristol University.

Contents

Prelude

Throughout the country about 100 000 patients are discharged from hospital every week. This is an account, mostly in their own words, of how 257 patients got on when they went home.

Our interest in discharged patients came originally from the experiences of one of us (PG) during a study of medium-term and long-term sickness carried out by the Office of Population Censuses and Surveys for the Department of Health and Social Security. That study was not directed toward gathering information about how discharged patients managed when they got home, but many of the people interviewed had been recently discharged and some of them spoke informally about the problems they were encountering. Provision of any kind seemed patchy. A few had everything the statutory services could provide, but most were managing with the help of family, friends or neighbours, or were coping on their own as best they could.

We began to look further into the sorts of difficulties they reported, and it seemed to us that this might be an important area in which volunteers could help. Our concern with the work of volunteers is of long standing and arises naturally enough from our work as voluntary help coordinators in the National Health Service.

Hospitals have long recognised the contribution which volunteers can make to the care of patients, and more recently social service departments, councils of voluntary service and other coordinating bodies have begun to use volunteers in community work. But little attention has been specifically devoted to the possible role of volunteers in the care of patients after their discharge home. There is no recognisable group in the community to take over where the hospital care ends. A ward sister described the problem thus.

> 'I know when I ask a patient "Have you got someone to come in?" or "Will you be all right at home?" that they are loaded questions. I know she is longing to get home and is bound to answer "Yes". I worry about it but I need the bed for the next patient. What I want is someone I could ring up—just tip them the wink that Mrs S is coming home. Just someone like a neighbour who would keep an eye on her. If I could do that I'd feel released.'

Our first specific experience of bringing discharged patients and volunteers together was setting up a day centre in conjunction with a hospital community ward. So successful was this, both for the patients and for the volunteers, who derived a great deal of satisfaction from it, that it led us to believe there might be other services that volunteers could provide for discharged patients.

We began to seek further information about what could be done, and indeed what was perhaps being done elsewhere. A survey of the literature revealed that while work of a similar nature had been attempted, there seemed to be no information about what patients themselves thought of the idea. So we decided to ask them.

Talking to our patients was a happy experience for us. No one refused to see us and we were warmly received by the vast majority. They gave us their time, attention and opinions, freely and seriously, and supplied all the information we sought. Some of them invited us to come and see them again, others gave us keepsakes of our visits.

During eight months of interviewing, we collected recipes, lettuce plants, knitting patterns, children's drawings, a fossil—'for you dear, as a souvenir'—and even a water colour shyly given as an example of a newly discovered talent by a man over 70. And we established, we believe, that there is indeed a role for volunteers with newly discharged patients. We hope this account will show what is needed, what can be done and how it can be arranged.

A note on method and sample

Questionnaire

The aim was to construct questions which could provide the most information about how patients manage after discharge, and about the potential opportunities for volunteers. Our schedule contained few questions which could be precoded Yes or No. We felt it would be more satisfactory to use open questions so that our results could be reported mainly in the patients' own words.

The questionnaire finally emerged after six drafts, each of which was discussed and criticised by doctors, nurses, social workers and many others, and tried out in pilot studies with a small number of people. We were aware that our close involvement with the volunteer movement could lead us to subjective assessment and we took pains to consult as many people as possible to avoid bias.

Sample

The total number of patients interviewed was 257: 217 from four general hospitals and 40 from a psychiatric hospital. In the four general hospitals, names were drawn from the lists of discharged patients once weekly, on a different day each week. We excluded certain groups: maternity cases, children under 16, patients who had been in hospital less than four days and those living more than 40 miles from the hospital who had been admitted mainly as emergency cases. The children, we felt, would have someone at home to care for them, and, bearing in mind the hospitals' policy of open visiting, their discharge would have been foreseen and discussed jointly by their parents and the staff.

We gave more thought to the maternity cases. A new baby is likely to cause a good deal of disruption in the house, and we were aware of the possible isolation felt by new mothers and the problems of postnatal depression. But our overall impression was that, for most, the arrival of a baby is a happy event and new mothers tend to receive a lot of help from family and friends. This being so, it was less likely that they would need additional help from a volunteer.

Of the remainder, every seventh name was drawn.

We were not able to draw a random sample of the psychiatric patients. The consultant psychiatrists felt it was vital to get the patients' consent first, and we agreed. We contacted 40 patients in the acute wards who were about to be discharged and asked each one for permission to visit at home. Permission was readily given by all of them.

Of the total number of patients, 146 were women and 111 men. There were 33 between the ages of 16 and 35, 109 between 36 and 65, and 115 over 65. The age distribution of the psychiatric patients had a variation; 11 were between 16 and 35, 21 in the middle range and only eight were over 65. This was because they came from the acute wards where patients tend to be younger than those in the long-stay wards.

The social classes of the patients, coded by occupation of the head of the household in accordance with usual practice, were

A–B	professional and higher managerial	23
C	lower managerial and clerical	100
D	skilled manual workers	43
E	unskilled and those whose sole income was the state pension	91

We found that 98 people had lived in the area for more than 20 years and 147 had a relative living within two miles. These factors might have a bearing on the extent of neighbourly help that could be expected, and on the amount of knowledge about local community services.

Interviewing

We saw the patients at home two or three weeks after their discharge. No previous appointments were made with patients from the general hospitals. Anyone not at home after three calls was deleted from the list. On the doorstep we would explain why we had come and ask if we could carry out an interview. Often we were invited in before we had a chance to explain ourselves, and at the beginning we were surprised by the warmth of the welcome. Later we came to expect it and were never disappointed. The same is true of the psychiatric patients, who knew we were coming.

Reporting

The questions themselves are used as headings in our report, though not necessarily in the same order as in the questionnaire, and the patients' responses form the major part of the text. In addition, we include seven case studies.

A full report on methodology, with the questionnaire form and all statistical information, is available on loan or for perusal at the King's Fund Centre library for research workers and other specialist readers.*

Confidentiality

No names or numbers were recorded and the used questionnaires have been destroyed in the presence of witnesses. The identifying letters in the case studies and elsewhere in the report bear no relation to the patients' own names. Where circumstance might make them identifiable, minor details have been changed.

---

*King's Fund Centre, 126 Albert Street, London NW1 7NF. A condensed version, *The community care of discharged hospital patients,* has been published in the *Health and Social Service Journal,* 7 April 1978.[5]

Questions and answers

What was the matter with you?

The purpose of this first question was not to elicit medical information but to open the discussion. As it turned out, the patients varied greatly in their knowledge of what had been the matter with them. Some were able to give the correct terminology to their illness, many could not and 44 of them simply did not know what had been the matter with them. Such replies as 'I had an operation, I don't know what for, but I have 14 stitches' from a 79-year-old retired farmer, were common. A housewife of 47 years reported 'a stroke, diabetes, gangrene and an amputated leg'.

A 90-year-old woman said she was 'took bad at home, giddy because I was losing weight and went into a skellington (*sic*). When the doctor at the hospital saw me, he laughed and asked me if I thought I was slimming like them teenagers who get nervorsy (*sic*)'.

A 70-year-old bookie, who obviously didn't miss a trick in his business, could only say, 'I don't know but I was filling up with water like a hot-water bottle'.

The question was omitted in interviews with psychiatric patients because the consultants thought no useful purpose would be served by getting what might be garbled accounts of their diagnoses.

The reasons patients gave for their hospitalisation were broken down into four categories—surgical 112, medical 80, accident and emergency 25, and psychiatric 40. There was virtue in breaking down a sample of this size into four simple categories since the figures for each would be large enough for conclusions to be drawn. In the context of the need for community care, the actual illness was of less importance than discovering the length of the recovery period and the degree of immobilisation. Also, however vague the description of the illness, it could be confidently assigned to one of these categories.

How long were you in hospital?

The duration of the stay in hospital was a factor likely to affect the patient's overall circumstances when he went home. A long stay could be expected to have an adverse effect because of the degree of institutionalisation which could have occurred. Of the total sample, 66 were in hospital between four and ten days, 90 stayed between 11 and 21 days, and the remaining 101 for more than three weeks. These figures denote a longer stay than the national average of under nine days, but may be accounted for by our exclusion of patients staying less than four days. Their inclusion would have reduced the average considerably.

A different picture emerged from the psychiatric sample, where only two were in hospital for ten days or less, 17 for between 11 and 21 days, and 21 for more than three weeks.

The patients made little comment on the length of their stay. Most seem to regard hospital treatment as a scarce commodity; they were well aware that others were waiting for the beds and, apart from the discharge procedures which are reported later, they seemed to be generally satisfied.

Do you suffer from any long-standing illness, disability or infirmity?

This question was asked because such illness could account for any abnormally long recovery period and might influence the need for care and the number of activities the patient could pursue on his own. Nearly a quarter (60 people) of the sample, suffered from some kind of long-standing illness; arthritis and bronchial conditions were most frequently mentioned.

Who looked after you when you came out?

Subsidiary questions were 'Does he/she normally live here?' and 'Why did you decide to go to . . . ?' if the patient went somewhere other than home.

The amended main question for psychiatric patients was 'Did you need looking after?'

Our results showed that 133 of the patients interviewed were cared for by their spouses, 12 by neighbours and 90 by someone else such as a married child or a niece or nephew living near by.

Twenty-two people had no one to look after them, either because they lived alone or had only a young family at home. Ten of them were from the psychiatric hospital, and loneliness certainly seemed to be a factor in how well or badly they were coping.

> 'I'd be all right if there was someone to talk to.'
>
> 'You don't always want to talk to the neighbours.'
>
> 'Sometimes I go two or three days only talking to the cat.'

Even with a husband and family, some of the women felt lonely.

Mrs B lived with her husband and two teenage children in a pleasant house on the outskirts of the town. She appeared to be well enough off materially but said that she had been suffering from depression off and on for a number of years, but had not previously had anything severe enough to need hospital treatment. She described her problems.

> 'I must have something to do and someone to talk to. I just can't sit around. I'm very lonely because the children have got out of hand and no one seems to want to know me. I see nobody and not having a job I don't get to know anyone. It's a lack—I did have a friend here but she has moved and now I have no one.'

Her husband, who had a managerial job, she described as being 'worn out by my illness; he looked like a ghost when I came out of hospital and is still feeling the effects'.

In their book, *Social Origins of Depression,* Brown and Harris list among the 'vulnerability factors' which cause a temporary mild depression to slide into a severe condition, the absence of any close confiding relationship with another person.[3] Mrs B's experience would seem to illustrate this.

She was 42, in the middle category of age groups and was looked after by her husband on discharge. In this age group of 109 people, as could be expected, 73 were looked after by their spouse. But no fewer than 70 of the 115 people over 65 either looked after themselves or were looked after by someone outside their household. This would seem to confirm that special attention needs to be given to the discharge arrangements for patients over 65.

What can result from a failure to do so is brought out by the case of Mr C who, as it happened, was interviewed the day before his seventy-fifth birthday. He was a retired cycle-mechanic, a man of high intelligence with a gift for music. He had been in hospital for five weeks after a collapsed lung and pneumonia. He had no one to look after him at home because his wife had been taken ill while he was away and was herself in hospital at the time. He was sure his wife's illness had been brought on by her struggle to look after him before he was admitted and, while he was in hospital, by going to visit him on her bike. (She was 74 years old.) In reply to 'Who looked after you?' he said 'Nobody. It was cold and I had to do everything; there was no one to switch on the heat or anything before my arrival but I managed somehow.'

Predictably, he was not back to normal and while he managed to go out of the house, he was not strong enough to do the shopping or to go visiting. He had had home help, a health visitor and meals-on-wheels. But his case illustrates very well how a volunteer could help. No one of any age, let alone a man in his seventies, should be discharged to a cold and empty house.

The length of time the patient had lived in the area had only slight bearing on who looked after him on discharge. Of the 68 people who had lived in the same area for less than seven years, only one had to rely on a neighbour and seven had no one; whereas in the group who had lived there more than 20 years (98 people) the corresponding numbers were six and eight. This pattern was not significantly different between the general and psychiatric samples. However, it should be borne in mind that this might not be the case in an area with a more rapidly changing population.

It is sometimes assumed that people are unwilling to care for sick relatives but the overall impression from this study was that this is emphatically not so. Typical remarks were 'I had no problems really because my married daughter came over every day', or 'My daughter-in-law couldn't do enough for me, she is more like a daughter to me'.

Is there anyone keeping an eye on your progress?

Hospital patients normally receive a good deal of attention from both staff and fellow patients, and to a greater or lesser extent they experience a sense of loss when they go home. A consequent decline in morale is not unusual. Our question was worded thus since it is expressive of concern without interference, and respondents readily appreciated being asked. Over two-thirds of the patients (167) felt that someone was keeping an eye on their progress and all but 13 mentioned a professional—general practitioner, district nurse or, much less often, a social worker. The family and neighbours were not regarded as the appropriate performers of this function. As might be expected, the extent of contact with professionals was related to age and to the length of stay in hospital. Nearly half of the over-65 group, but only four of the 33 patients in the 16–35 age group had a professional keeping an eye on them. Of the 101 patients who had been in hospital more than three weeks, 34 had a professional in this role; but of the 66 whose stay was less than ten days, it was only 14.

One aspect of the monitoring of recovery was whether the patient perceived it as being regular. It was so perceived by about half of those who thought someone was keeping an eye on them. Patients often mentioned their GP in answer to this question, only to say later that they had not been in contact with him. It is possible that some of them felt that the GP knew about them and their condition even if they had not actually seen him. To what extent their belief was justified by the facts is impossible to say. It is enough to report that some GPs told us they did not get reports on their patients from the hospital.

> 'If a typist isn't available on the ward or it's a Friday afternoon, it's as likely as not that the first time we know about the discharge is when the patient arrives at the surgery. It could be days or months later.'

One doctor told of his embarrassment. 'I saw a woman in the street and asked her how her husband was getting on in hospital. "Oh doctor," was the reply, "didn't you know he died there?"

Are you back to normal now?

'Can you do all or most of the things you could do before you went into hospital?' From these questions we obtained the patient's own assessment of his condition after discharge. The main purpose was to get some idea of how much effort from volunteers might be required. Interviewed two or three weeks after discharge, 180 of the 257 patients reported that they were not back to normal. Of the 40 psychiatric patients, 18 regarded themselves as not back to normal. Perhaps surprisingly, there appeared to be no connection between the time it took for people to feel they had returned to normal and the length of hospital stay, and there was only a slight variation between those who had and had not a long-standing illness. People seemed to regard their other illnesses as 'normal' for them.

The patients were asked a number of subsidiary questions here—ability to get out of the house, back at work, shopping, visits to friends, social events and so on. These questions were designed both to establish the criteria of normality and to assess which specific tasks volunteers might usefully perform. For example, if a patient reported that he could not go shopping, he was asked who was doing it for him.

Have you heard of the following services?

(Home help, district nurse, health visitor, social worker, meals-on-wheels, citizens' advice bureaux)

Subsidiary questions asked whether help was needed; if provided, how soon started; was it satisfactory? These questions tested the patient's knowledge of what help was available, the use made of them and, if volunteers were needed, how they could mesh in with what was provided and avoid wasteful duplication or usurping of statutory function. Nearly all the patients knew of these services though there was a good deal of confusion about the distinction between the district nurse, health visitor and social worker. 'The lady from the welfare' was their usual term for such callers—even the interviewers!

Of the total number interviewed, 89 had received help from one or other of the services. This is not to say that the other 168 had needed help and did not get it. Some people commented that they had been offered a home help, for example, but had felt they did not need one. Thirty-two of the 67 who lived alone, and 64 of the 115 people over 65 had received help. The level of satisfaction of those who received help was very high. Such comments as 'the nurse is marvellous—I look forward to her coming' express the general feeling. However, there was dissatisfaction, mainly about the delay in starting these services. 'The dreaded 48 hours' immediately following discharge is something we heard again and again.

> 'I was told dressings would have to be attended to but no one called. I phoned the hospital but they said no arrangements had been made. They said it wasn't necessary now, but I insisted and 11 days later the nurse called for the first time.'
>
> 'I rang the doctor to ask if nurse could bath me but he didn't know I was home.'
>
> 'I wish I knew when the nurse was coming again.'
>
> 'I wish the help could have started sooner—I was all weekend on my own.'
>
> 'Meals-on-wheels hasn't restarted. No one knows I'm here.'

Have you yourself been in contact with your GP since your discharge?

It is well established that the most important link between home and hospital is, or should be, the GP. In answer to this question, 180 reported that they had been in contact with their GP, including 34 of the psychiatric patients. The psychiatric hospital never gave the patients more than a few days' supply of drugs. There was a double purpose in this: to avoid overdoses and to ensure that the GP was contacted. It should be made clear, though, that 'contact' was not necessarily taken to mean a visit to or by the doctor. In general, those patients who would have liked to have seen the doctor and had not done so did not regard it as his fault.

> 'It was the hospital to blame, they hadn't told him. I'm sure he'd call if he knew.'
>
> 'The GP asked us to let him know when I was discharged as the hospital never tells him anything.'
>
> 'My doctor doesn't know I've been in—I wish someone would tell him.'
>
> 'I wrote to him [GP] about a home help and he hasn't even written back.'

On the whole, patients expressed satisfaction with their GP, and appreciated what he did for them. They stressed their unwillingness to 'bother' him unless absolutely necessary. But when the contact breaks down it can cause great hardship, as the case of Mrs D shows. This 64-year-old woman had broken her leg by falling off her bicycle. She had been in hospital for eight weeks and at the time of the interview, two weeks after discharge, was unable to get about very well. She could not get out on her own and had not been shopping or visiting, and she had not had a call from her GP. She was much less able to cope than she had expected and needed reassurance and advice. As she had no telephone she had written to the doctor a day or two after discharge asking for a visit but 'from that day to this I have neither seen nor heard from him'. Consequently, there had been no contact with the health visitor or community nurse. 'I don't call out the doctor unnecessarily, in fact it's a good few years since I've seen him, so why doesn't he come?' The pain-killing tablets prescribed on discharge had run out and she felt helpless in the face of what she saw as a mysterious discrimination against her. 'I can't think what I've done to deserve this. I sit here by the window every day expecting to see him come in, but he hasn't come yet.'

Mrs D sums up what can happen better than any statistical table.

The patients were also asked the reasons for contacting the GP. These came into three categories: 84 for medical reasons—that is, because some aspect of their recovery or general health was worrying them; 50 for tablets or other prescriptions and 47 for a national insurance certificate. This last group had no other reason for seeing the GP and often commented that it seemed a waste of time. 'Why doesn't the hospital give you your certificate and then you wouldn't have to bother doctor?' Some patients commented that this used to be done 'in the old days', and no one knew why the practice had stopped.

Would you say there had been any effect on your family? For example, did anyone have to come over specially or stay off work to help you out?

The answers indicated the degree of disruption to family life and the use that could be made of volunteers.

Some disruption was reported by 99 patients, mainly those in the older age groups; 40 aged 36–65 years and 35 aged over 65. The degree was highly variable, from ‘My daughter couldn’t get her own housework done’, to more extreme cases.

Mr E had set up a building and decorating business in the previous year and was just starting to do well. His wife, who had had a hysterectomy, was 42 and had been in hospital for 12 days. Since returning home she had been very ill and was not well enough to be interviewed on the day. Her husband told of the difficulties in spite of prompt attention by the community services. The home help, community nurse and health visitor had all been active and the husband was very satisfied with what they were doing.

There were four sons, aged between 4 and 18, living at home: the youngest was autistic and attended a special playgroup in the morning. He required a great deal of attention and his father had to return home from work at frequent intervals throughout the afternoon. This, and anxiety about his wife, meant that he was shuttling between home and work all day with a consequent heavy drain on his energy, and he suspected he was losing business. He said that if a volunteer could check up a couple of times during the morning and help to get the children ready for school he’d feel safe to stay at work for half the day until the little lad returned home at 1 o’clock. This man was bearing a good deal of stress, some of which could have been alleviated by a little more help.

As this case shows, the patient is not the only one under strain. Quite frequently a member of the family was present during the interview and when this question was asked it seemed to be the signal for them to express their own feelings.

> ‘I’ve been looking after her now for nine long years. I gave up my job to do it.’

> ‘Our lives haven’t been the same since she went in [the psychiatric hospital] for the first time.’

Sometimes a relative would accompany us back to the car after the interview and would express fears for the future.

> 'I need a break so badly—how can I ever get one?'
>
> 'How will I manage when she gets worse?'
>
> 'When he dies, whatever shall I do?'

Half of the psychiatric group reported family disruption: a higher proportion than that of the total group, which was 39 per cent. One explanation could be that just over half the psychiatric patients had spent more than three weeks in hospital. Another could be that more of them were in the middle age group which could be expected to include larger numbers with growing families. The most likely explanation may be the nature of the illness. Families of psychiatric patients can have a very difficult time when the patient returns home, as these comments of a wife, made in a sudden outburst outside the front door at the end of the interview, illustrate.

The patient had been in and out of hospital several times in the past ten years. He was in a very negative frame of mind and very difficult for his wife to cope with.

> 'Can't *you* do something about him? It's a bloody disgrace that they can't do better than this. I don't know what to do, he won't help himself and everyone does their best for him. Him being like this has made life hell for me and our girl. I don't know what to do.'

If you had to give advice to someone coming out of hospital, what would you tell them?

In the pilot of this survey, this question was answered mainly in medical terms with such replies as 'Do what the doctor tells you' predominating. But we wanted to compose a comprehensive picture of what it was like for the patient 'out there' which would include his interactions, his feelings, his rate of recovery, his morale—all expressed in his own terms. We had to devise a question which would not be value-laden and would at the same time prevent the patient from giving an unconsidered 'Yes' reply to save himself the trouble of thinking, or to please the interviewer. By first describing something of the voluntary help we had in mind and then asking 'might you have found this useful?', the question became both interesting and impartial enough to ensure a thought-out reply. Difficulties might have been expected, perhaps, because people were being asked to conceptualise. As it turned out, we had no difficulty. The question came about mid-point in the interview and by that time a very easy, tension-free relationship had been established in almost every case.

Supposing you hadn't had . . . to help you when you came home and there was a voluntary group in your area who were there specially to help discharged patients, might that have been useful? In what ways?

These reframed questions gave us quantifiable answers, and provided abundant practical points which could be taken up. The results indicated that 215 thought that a voluntary group, or a 'volunteer network' as we began to call it, would be useful or very useful, and 42 thought it would not. The latter gave reasons such as 'I wouldn't want strangers around' or 'I don't want to bother anyone'.

The patient's feelings about the value of the volunteer network appeared to be very little affected by the home circumstances. Of those who thought it would be useful or very useful, 180 had their spouses to look after them. Seventy-two of the 90 who had reported that no one was 'keeping an eye', and 132 of the 154 who felt that a professional was keeping an eye, said they would have found the volunteer network useful or very useful. An odd result on the face of it but possibly a volunteer network, being outside that of the family and neighbours, was perceived as being more like the statutory services. Of those who thought it would be useful or very useful, 72 were already receiving services such as meals-on-wheels or home helps.

The respondents' answers were more or less the same whether they felt they were back to normal or had another illness.

What could volunteers do?

If the respondent decided in favour of a volunteer network, the idea was explored in greater detail. Shopping, transport and chatting were likely to be mentioned more than others, and these answers are shown in the table.

Total mentioning	*Shopping*	*Transport*	*Chatting*	*Other*
All patients	141	57	103	84
Psychiatric patients	6	5	18	17

Note: These replies were multicoded so they add up to a number greater than the sample.

The 'other' category featured surprisingly strongly. It included collecting prescriptions, helping to get the children ready for school, cooking light meals at midday and, unexpectedly, talking to the patient's husband or wife, and giving support to the family.

> 'You'd need a service like that otherwise you'd have to stop longer in hospital.'
>
> 'To give advice and find things out . . . '
>
> 'Help first thing in the morning; I was crying because I couldn't make a cup of tea.'
>
> 'Someone coming in regularly for a chat would be the best help of all.'
>
> 'Someone to help my wife with me.'
>
> 'Someone to go to the pub with.'*
>
> 'I wish there was someone to sit with me so my daughter can go out.'
>
> 'They spent so much putting him in there in that awful ward— it's quite unnecessary. If I could have a break two or three times a week for a little while, that's all I need.'
>
> 'The social worker said we need a humidifier but we've heard nothing. A volunteer could chase up things like that. It's a worry as my wife is crippled with arthritis.'
>
> 'If I had someone to calm me down I'd be OK.'
>
> 'She's a trial to me. I don't usually talk to no one about it.'

---

*This from a young psychiatric patient who couldn't face going out by himself but desperately wanted to mix with others.

Some patients said that they would have found it helpful to talk to someone else who had been through the same experience. Mr F, a 58 year old, had been in hospital for a colostomy operation. He was looked after by his wife and two sons and received weekly visits from the district nurse. Though not in need of any practical help, he felt he would like to talk to someone who had had the same operation to ask 'Silly things like do you tell your workmates about the bag and what about when you're away on holiday, that sort of thing'.

The variety of things that volunteers could do was extraordinary as the following two cases show.

Mrs G, a delightful old lady of 94, was a retired cook. She lived alone in the same tiny house she'd lived in for 70 years. Her nearest relative, a nephew, lived 50 miles away. When the interviewer called, the door was on the latch and she was delighted to have a visitor.

She had been in hospital for two weeks with what she described as 'heart trouble', and had looked after herself on discharge helped by 'my wonderful neighbours and friends'. Her GP was actually waiting at home for her when she arrived in the ambulance. She thought the reason for this was that she had discharged herself though the ward sister had been against it and had rung the GP 'to get him to tell me off'. But he had said he would be there when she arrived home to see her safely in. When asked what advice she'd give to someone coming out of hospital she replied 'Discharge yourself—you'd go mad in there'.

She had been receiving visits from the home help and the district nurse before going to hospital and these started again immediately she was discharged. She thought the district nurse was 'wonderful', but was less happy about the home help. 'She don't sweep under things the way you would yourself.'

This old lady's lively mind quickly took to the idea of voluntary help. She wanted no help with the shopping—her neighbours did it—but would have loved 'a little drive sometimes, to see the primroses'. Although well supported by her neighbours, she remarked that they were all elderly. 'Don't think me mad but I'd like someone young like you to visit me—not old fogies all the time.'

Throughout the interview she kept running out to the kitchen to see that her sausages for dinner were not burning although she liked them 'a bit on the black side'. As the interviewer was leaving, she said 'Here open this bottle of Guinness for me will you. Now, if you hadn't come, I'd have had to do without—now that's another thing a volunteer could do for me.'

Mr H was 60 years old and had spent 11 days in the psychiatric hospital, his first admission. When the interviewer saw him in hospital before he was discharged he said he had just lost his wife and he would tell all about it when she went to visit him. And he did. The interviewer expected to hear a tale of sorrowful bereavement. It was not. His story is an example of how a life can be completely submerged by a long drawn out illness in a spouse, and the folly of being determined to carry on bravely by oneself regardless of the cost.

The arthritis that had crippled his wife for ten years had forced a pattern of day-to-day existence which had resulted in a gradual, almost total, social isolation. 'I used to play the saxophone regularly in a jazz band in the town—Friday nights for practice and Saturdays for functions. Of course, that was the first thing to go—I couldn't continue when there was such a lot of trouble at home. I was also in the firm's darts team and often went to the pub with a group of friends. By the end I wasn't seeing anyone, friends and neighbours just dropped off coming and my son was the only person we saw from one week's end to another.' He spoke with great bitterness.

At about the time of his wife's death, Mr H was 60 and retired from his job as an accounts clerk. At one blow, therefore, he was cut off from the social life at work and the need for constant attention to his wife was removed.

Mr H answered negatively to the idea of a volunteer network, and then went on to point out precisely those things a volunteer could do to help him. (The expression of diametrically opposite views in the same interview are not uncommon and make the point about the dubious nature of information that is based solely on answers to Yes/No questionnaires.)

This man was not on anyone's list for follow-up after discharge, yet it was clear that without help he would not easily find his way back into the world of normal social relationships. The saxophone was now his sole companion. 'I've started practising again in the spare room and I can play as well as ever I could.' He went to fetch his saxophone and began to play the sweet heady sounds of the jazz he loved. He enquired whether there might be a jazz group somewhere that he might join. 'They might not want an old hand like me, but you can see I can play as well as any youngster. I love the music but it must be played in company.' Laying his instrument to one side he went on to explore the possibility of going to the pub again, but shied away from the notion. 'I wouldn't know anyone and you get out of the way of talking to strangers.'

He was clearly seeking a way out of his isolation. Here is an excellent example of what a volunteer could do; tracking down a jazz group who might take him on, and accompany him to the pub. The seeds of recovery were there but they could not germinate or flourish without the intervention of a willing befriender.

Money

Patients were asked if money had been a worry. Only 55 said that it had. Difficulties came when their spouses had to stay off work, with a consequent drop in income if they were hourly paid or if the patient's recovery took a long time or there was permanent disability. As well as decreased income, causing families to modify their life styles—'taking it very steady with the housekeeping', 'absolutely no luxuries'—there was sometimes an additional problem in the strain this caused to the relationships. We report two cases.

Mr I had undergone abdominal surgery and was far from fully recovered when he was interviewed. He required special foods and hygiene routines, both costly, and the family, even at that early stage, had had to draw on their savings. Mrs I had given up her part-time job to look after her husband and the loss of her earnings had left a large gap in their combined income because he was receiving only his national insurance benefits.

He was very low. He saw his prospects as poor since he would not be able to go back to heavy lorry-loading which had been his job. Mrs I said 'I'm worried sick. You know it's not easy to get part-time work with all the unemployment but I couldn't go on with no one to look after him in the mornings when I was out. If I could have had someone reliable who would look in during the mornings I would have felt OK to continue.'

Mr I added, 'I don't know what's hit us; we used to have a nice sum between us but now with both wages gone I feel very worried about the present and daren't think much beyond the next day. I didn't want my wife to give up her bit of money but I can't see what else she could have done.'

Their plight was encountered to a lesser extent in other cases.

Mrs J faced great difficulties about money. Her employers had given her notice when she went into the psychiatric hospital. She had been in for only three weeks and had relied on her wages to support her two teenage sons. Her divorced husband had been constantly in arrears with his maintenance payments; these had now ceased altogether because he had moved away from the area and Mrs J could not trace him. She found providing food and clothing for her sons 'a nightmare'. The social security allowance for clothes and shoes did not match the needs of her youngsters whose growth rate was more rapid than the rules allowed. She showed the interviewer the pieces of cornflake packet she had used to lengthen the life of their shoes. She was in perpetual conflict with the social security office and altogether had little to be cheerful about. Her plight was so complicated that a volunteer would not have been able to help much in a practical way. Nevertheless, as a befriender a volunteer could have been very valuable.

Reference was frequently made to the costs of having someone in hospital, in visiting and taking sweets and other treats.

> 'It costs a lot to visit on them buses.'
>
> 'You have to buy flowers and chocolates and that.'

One 78 year old had had to use all his cash and old age pensioner concessionary tickets to visit his wife, and had been left a 'bit short'.

How have you been getting on for transport?

This is where volunteers can be extremely useful, and the intention of the question was to assess the need rather than to measure the level of satisfaction with hospital transport or the ambulance service. Inevitably, however, the endless hours of waiting for official transport were reported.

> 'Why on earth do they sometimes come at 9 am and other times not until 11.30?'

> 'I sit here waiting for hours, not daring to settle to anything in case the ambulance turns up.'

Though individual incidents were reported with irritation, the general impression was one of tolerance. The remark, 'They can't help it; they're so busy' was commonplace.

Eight of the 77 people who felt they had got back to normal life could only get out of the house if taken, and 40 of the 180 who were not back to normal were similarly placed. The immediate family took a large share of the responsibility for transport.

> 'My son comes every Sunday regular to take me out.'

> 'If we want to go out anywhere or want anything fetching we only have to phone my sister or my nephew.'

However, there were some like the man who had not been 'farther than the village' for 20 years except for the trip to hospital itself.

> 'I really enjoyed that drive you know–you may think it's queer to say you enjoyed being taken to hospital but I saw all the new road works and that.'

Mrs K would 'love a drive occasionally to see the river'. And Mrs L, like several others, suggested she would be only too willing to pay for the petrol if someone would take her to the chiropodist.

Mainly, though, the need for transport was of a social kind, like Mrs G and her 'little trip out into the country'.

It is difficult, given the complexity of the present systems of reimbursing volunteer drivers and the regulations governing the provision of transport, to see how this need could be adequately met. Providing transport which is not strictly necessary for treatment or recovery, but which can improve the quality of life for patients, ex-patients and their relatives, is something which volunteers can do particularly well.

There is unlikely to be any shortage of volunteers for this. The newly retired in particular are very keen and for them it has a twofold advantage—it keeps them active and can help towards the cost of keeping a car on the road. It would be a pity if administrative difficulties prevented this contribution by volunteers. It should not be impossible for some kind of joint financing system for volunteer transport to be agreed between health and social services, possibly with a standard national mileage rate. Journeys which were considered to be medically or socially necessary, which could not be provided by the statutory services, could be funded in this way, always with the approval of these statutory services to avoid over-provision.

Just *because* a service is provided cheaply by volunteers, it should not be used to excess or without regard to real need.

Many of those who organise volunteer transport will find John's (a volunteer driver) experience uncomfortably familiar.

> 'I went to pick him up like I was asked and I had such a shock when I saw him. The social worker had told me he wasn't very agile but I swear he was nippier than I am! And do you know there was a bus stop right outside his house which would have taken him right to the hospital. And to crown it all, he asked me if I could take him to visit his wife again in the evening as his son—who had a car mind you—wanted to go to the pictures.'

Happily, though, Marion's experience will be equally familiar.

'She's such a dear old soul and so devoted to her husband. You know, she was paying for a taxi to come home from the hospital before the social worker asked me to help. I really think she sees me as her friend now I've taken her a few times. He's not well at all and if anything happens to him I hope to go on visiting her if I can help.'

Discharge procedures

It was not our intention to test the respondents' level of satisfaction with the care they received in hospital. On the whole they appeared to be happy about their stay. Our schedules were full of comments like 'Those nurses couldn't do enough for me' and 'I can't speak too highly of the way they treated me'. The patients were often very anxious that we should report favourably their impression of their stay. One man said 'Now write it down on your form—the health service is wonderful'.

One question though, 'Who told the family you were due to come out of hospital?', prompted many adverse comments from the patients and their relatives about two large district general hospitals. Discharge procedures from the other hospitals were found to be satisfactory. Of 124 patients discharged from acute hospitals, 45 were dissatisfied.

> 'They only gave me an hour's notice.'
>
> 'One day they said I'd be in another week, then they said I could go that day.'
>
> 'It was all a bit rushed—do they always do that?'

> 'You'd think they could organise it a bit better.'

> 'I had the shock of my life when he rang to say he was coming home.'

> 'I had no time to get anything ready it was all so sudden.'

The patients were more tolerant if they felt they were fit for discharge.

> 'Well, they are under a lot of pressure.'

> 'You can't really blame them, they needed my bed.'

When they felt they had been discharged before they were fit, however, the sentiments were often quite different.

> 'They should do something about that hospital. They said transport would be available and it wasn't. He walked home with his plaster on and collapsed half-way here.'

> 'They left me at my gate in a snowstorm.'

> 'They discharged me too early and the wound broke open. Now I have to go to outpatients every day for dressings.'

> 'I had an infection when they discharged me and they wouldn't believe me; I was in terrible pain.'

> 'I was discharged with a water infection. I wanted to ring up my own doctor but they said I must wait until I was actually home.'

> 'My son was discharged with a severe infection and had to be readmitted.'

The interviewers, with their lack of medical training, often found themselves in difficult situations.

> 'Would you have a look at this wound? There seems to be some funny stuff coming out of it and I don't know what to do.'

If patients are discharged suddenly it is extremely difficult to mobilise the required services. Mrs K illustrates this problem well.

Mrs K was interviewed to accompanying cries of her toddler and three-month-old baby. By coincidence another discharged patient was visiting her and she remarked that she had made quite a few friends while she was in hospital.

She was 25 years old and had been admitted for an appendicectomy though she was subsequently found to be suffering from an infection of the uterus. She was less concerned with this than with the suddenness of her discharge.

> 'It was unbelievable really. I was given one hour's notice. I didn't know where my husband was and I couldn't get hold of anyone to come and fetch me. They asked me if I needed transport and I said I did. Well, then they said you had to give 24 hours' notice if you wanted transport. I can laugh about it now but it wasn't funny then I can tell you. They kept telling me they needed my bed immediately, until I felt guilty for being there. Anyway, my mother-in-law called to see me as luck would have it so she was able to take me home. But I'd seen this lady—I'm not sure who it was—would it be a social worker? Well, she said I'd need a home help but of course being shunted out so quickly there wasn't time to arrange it. It's no good having one now I've been here two weeks—it was the first few days I needed it. God knows how they ever get it organised when they shove you out with an hour's notice like that.'

There is no doubt that staff, particularly in acute hospitals, are under considerable pressure to discharge patients. 'They needed the bed' is only too true. It seems, though, that their anxiety 'to keep the assembly line moving', as one patient put it, may lead the hospital staff to be over-optimistic in their assessment of what it would be like for the patient at home.

> 'I don't think anyone knew I was alone before they discharged me. Why don't they tell you things and follow things up?'

We are not suggesting that patients are unfairly pressured into going home but rather that they and the staff collude in 'painting a rosy picture about going home' as one young woman said.

Mrs L, who had had a hysterectomy, described her feelings as the consultant began his rounds and she knew he might say she could go home.

> 'You watch them getting nearer to you and you feel all excited. It's silly really but you're like a kid—you're so excited that you may be going out. Then when he asks you if you feel well enough to go home—well what do you say? You're not going to turn down the chance, so even if you are a bit tired and nervous about coping, of course you say "Yes". Anyway, you know they need the bed. Then there's your husband—how would he feel if you said you wanted to stay in a bit longer? Anyway, I certainly came out too soon—I was really jiggered and, of course, when you come home you do start doing things even though they've told you to take it easy.'

The possible offence to relatives if you don't appear to be eager to come home was mentioned by other patients.

> 'I knew my daughter-in-law would think I was being funny if I said I didn't want to go to her place, but to stay in the ward.'

> 'They [her family] kept asking me when I would be coming home so in the end I said I'd be OK to go.'

The patient and his family may gloss over possible problems at home and the staff may too easily accept their assessment if they need the bed for another patient.

A staff nurse said, 'Actually you only see the patient in bed—you don't think of them in their kitchen or driving or anything else.'

The question about going home is all too often phrased, 'You're OK to go home, aren't you?' What answer can the patient give other than 'Yes please'? In fairness, it should be said that the patients' reactions we are reporting here are not usually known to hospital staff. The staff nurse continued, 'The last we see of them is when they go out of the ward. How are we supposed to know what happens to them then?'

None of the people concerned with these decisions—least of all the patient himself—may be fully aware of their implications. The patient may be sitting by his bed, with a smile on his face, but when he gets home can feel quite different. A young woman told us, 'I'd only been in a short time—well two weeks—and the night I went home I suddenly felt absolutely terrified about how I'd cope. It was as though I'd been so sheltered and cocooned and I suddenly felt—God, I'm on my own—and I wept and wept.'

Voluntary organisations

Voluntary organisations may seem a far cry from the young woman who suddenly realised how vulnerable she was when she got home. But they are linked with her in that they comprise one of the resources which can come to the aid of someone in her position if they are properly activated. The phrase 'It's terribly hit and miss' was one frequently used by the representatives of voluntary organisations to whom we talked. These included the Red Cross, Age Concern, Women's Royal Voluntary Service, Councils of Voluntary Service and several organisers of good-neighbour schemes.

The overall picture to emerge was that these organisations and groups were asked for help by the hospitals in three distinct sets of circumstances. First, when a patient they were already assisting went into hospital.

> 'If one of our handicapped people that we are visiting is admitted, that's OK. Our welfare officer will know all about it and she'll probably get to know the ward sister while the patient is in. Then they'll get together about the discharge.'

> 'When meals-on-wheels is already going in, of course, we soon hear about the admission.'

These links between hospital and voluntary organisations were summed up by one organiser.

> 'When we are all working together for the patient it really feels good. You feel that we [the voluntary organisation] are part of the team caring for that patient and that's marvellous.'

The second set of circumstances was where the ward sister or the medical social worker (MSW) had a well established connection with a particular voluntary organisation.

> 'We only seem to get referrals from certain social workers. I don't know why that is. Anyway how is it decided which patients see the social worker?'

> 'Miss . . . [an MSW], now she thinks in terms of voluntary organisations. She thinks of us as another resource she's got to call on. But it's difficult to keep track of these social workers. Either they are not available or they seem to leave the area so quickly.'

> 'Now the social workers are all so young and there is all this "generic" business, they don't seem to have all the wrinkles about what's available in the area. In . . . there are some old hands about, and all the voluntary agencies seem to be well established. As a result, the system seems to work. All the hospital staff and the social workers know that you ring Age Concern for this patient, Red Cross for that, and so on. But where they are all new, somehow they don't seem to build up all the little bits and pieces of knowledge that mean you know who to contact.'

The organiser of a good-neighbour scheme expressed the feelings of many of the organisations.

> 'We've tried endlessly to get the hospital just to let us know about people being discharged to this area. But basically it comes back to the ward sister, and she simply can't be expected to look through all her lists on the off chance that the patient lives in this little bit of town. So it's bound to be hit and miss. Quite frankly, it's largely a matter of chance whether we get to hear about them or not. It's people who know people really.'

The third set of circumstances is the crisis—what many people called 'the Friday afternoon syndrome'.

> 'The time they ring us is really when they can't find anyone else. If they want to discharge someone just before the weekend, and social services, the home helps and everyone else have gone home, they scratch their heads and suddenly think "Ah yes, the voluntaries".'

> 'If they ring me, they know I'll always get someone to go round. That dreaded 48 hours after discharge is crucial and it's simply no use waiting until Monday.'

> 'I do think the hospital rings here sometimes in a bit of a panic and I've learned to make absolutely sure they've got their facts right. We have had cases of being asked to go and see old Mr Bloggs when he's discharged and when we get there we find his daughter organising everything. And relatives can be very upset if you say you thought the old boy needed help from us.'

Understandably, there was a certain amount of resentment among the voluntary organisations at being used by the hospitals in this way.

> 'They wouldn't dream of keeping us informed or treating us as equals, but when they do ask, you know you'd better move or there'll be trouble.'

But it was much more common to hear remarks like

> 'They [the hospitals] are a bit cavalier in their attitude to us and treat us as though we are there just for their convenience on a Friday afternoon, but really that is what we are there for isn't it?'

> 'Like it or not, we have just got to realise that statutory services simply do take the weekend off, and that in any case it can take them up to ten days to get their services organised, whereas we can operate immediately.'

> 'We are so much more flexible than the hospitals or social services are able to be. We have lots of strings to our bow—we know more about the area or that this particular place will supply such-and-such a piece of equipment. The hospitals have to work so narrowly and fit people into what they are able to provide, whereas a voluntary organisation can look first at the patient and see what his needs are.'

There was a good deal of tolerance among the voluntary organisations for the lack of consideration sometimes shown them by hospital staff.

> 'We would dearly love a proper procedure about being informed of the discharges, and I really think it would save everyone's time, but the wards are so busy what can you expect?'

> 'They never think of us unless it's a crisis and then they want help yesterday, but when you think of the pressure they are under its quite understandable.'

> 'After all, what are we there for if it's not to fill gaps?'

Several of the organisations had had the experience of being asked to provide a visitor or some sort of support for a patient who, in in their view, should not have been discharged. In some cases they had been able to get the patient readmitted by contacting the general practitioner. In one case, the discharge had been delayed because a WRVS member had insisted that she could not get the arrangements made in time. In general, though, the organisations did what the hospitals asked them to do. As one representative put it, 'We really set ourselves higher standards and expectations than the professional services'.

Why is it that, in the face of these high standards and the often instant response to requests for help, the hospital authorities did not make more use of the voluntary organisations at the time of discharge? There seemed to be two main reasons.

The first was a lack of confidence in the organisations.

> 'Direct referral by the hospitals doesn't exist because they don't really have any confidence in us. There were lots of good reasons for this in the past—you know the old Lady Bountiful thing. And I'm not saying that doesn't happen sometimes. I know one old boy who's been taken under the wing of a certain WI group. They're killing him with kindness. He's so dependent he'll never live alone again. But really that's a rare case. The hospitals simply haven't caught up with the new image of voluntary organisations.'

> 'If we are acting as agents for the statutory services, we've simply got to provide a good service. We can provide a different type of caring; we are more flexible and you can rely on us to act professionally, if that doesn't sound daft.'

The fact that the workers in the statutory services who *did* refer to the voluntary agencies were those who had established good relationships with them, and who knew the sort of services they could provide, certainly seemed to bear out the above comments.

The second reason seemed to be simply a lack of knowledge about what the voluntary organisations could provide.

> 'They just don't know about us and we are always too busy actually doing the job to go out and bang the drum about what we do. For instance, I was once asked to take some pyjamas down to an old chap who'd just been admitted and the sister on the ward said she didn't know we provided clothing and could she ask us in future. I was delighted but then that sister left and we've never been asked again. I suppose I should go and say to the staff "Hey, do you know we can provide clothing", but when all is said and done we are volunteers and our time is limited.'

One good-neighbour scheme organiser said she had tried to publicise the scheme in her area and in the local hospitals but had found no one read the leaflets or cards.

> 'I long for the day when we are as well known as the CABs*, then no one will say to me "I would have asked you for help but I didn't know about you".'

Besides being too busy doing the job to publicise themselves, the voluntary organisations often expressed the fear that if they made their services too widely known they would be inundated with requests for help which they would be unable to meet.

> 'I'm terrified of building up people's hopes and giving hospitals the idea that they can simply ring us up and we'll fix everything. Because if they did that on any big scale we just couldn't cope and then you could be sure the hospitals would say "There you are. We knew the voluntary organisations were unreliable".'

---

* Citizens' advice bureaux.

Some of the voluntary organisations were fatalistic about their future role in the care of discharged patients.

> 'I can't see it'll ever be any better. They'll never think of us except in a crisis.'

Others took a different view. When discussing Friday afternoon discharges an official of the voluntary agency said 'I'm tired of hearing that "they" should invent a proper system for dealing with these cases and that all the care stops at the hospital gate. Let's just remember it's a two-sided gate. Why is the onus always on the hospital? Surely we should offer some suggestions as to how a system could work? It *can* work because I know of places where ward staff, social workers and the voluntary people all get together for a sort of case conference before discharge. We should really go and tell the hospitals precisely what we can offer and introduce ourselves so they know they can trust us.'

People agreed that any system for notifying voluntary organisations about a discharge must be simple. They felt that no ward sister should have to work her way through long lists of good-neighbour organisers or welfare workers. The idea of some kind of co-ordinator for each area emerged strongly.

> 'Maybe the ward sister would need to have six names for different parts of the county. She would simply ring the appropriate one and this person could then mobilise her forces, using all her local knowledge.'

They were anxious to point out that the actual numbers were likely to be very small—a fact borne out by our findings that most patients were well cared for by their families—and that, for this very reason, a foolproof referral system ought to be possible.

> 'It should be like a chain of interlocking wheels, when one moves they all move.'

Informal volunteers

Twelve of our patients reported that it was their neighbours who mainly looked after them on discharge, and that they would have been unable to manage without their help. This informal volunteering, unorganised and unsung, is something which everybody knows about, but the factors which determine its existence in a particular locality, the extent to which it operates and the quality of the care it provides are very difficult to pin down precisely.

We are not referring here to the part played by families or the interest taken by friends, but to those relationships of neighbourliness which come from living side-by-side. This, not the ties of kinship or friendship, is the distinguishing characteristic. Obviously there is some overlapping, relatives may be close neighbours, and contact may be retained with one-time neighbours after they have left the district.

A return home from hospital is an event which could be expected to bring out feelings of helpfulness in neighbours, and it would be counter-productive to suggest, let alone provide, an organised volunteer network where the informal volunteers are already coping. But we thought it important to try to get at least a 'feel' of what was happening among our patients and their neighbours, based upon what we were told during interviews with the patients and with some of the organisers of good-neighbour schemes and the local clergy.

We started with some loosely defined concepts, one of which was the effect of social class. The case of Jane would suggest that, among other things, this is one factor.

Jane, aged 31, was discharged after surgery to the prosperous middle-class area where she now lives and where, as she put it, 'most of the wives are graduates'. Before her marriage Jane had been a teacher, and until two years ago she lived in a small semi-detached house in a predominantly working-class area of the town. During that time she had given birth to her daughter in hospital, and her experience on returning home was very different from her latest experience.

> 'When I came out of hospital after Diana was born no one spoke to me. I was so lonely and suffering from postnatal depression although I didn't realise it at the time. I couldn't understand why the neighbours didn't call because if I pushed the baby out in the pram they did stop and speak to me. I realise now they were probably scared of me because they saw me as belonging to a different social class and talking posh. I got very down and felt very near to hitting the baby lots of times. I told my doctor and he sent the health visitor to see me every day. She was very good, but looking back it was such a waste of her time—I didn't need a health visitor, I needed a good neighbour.
>
> 'Anyway, in the end I did knock on my neighbour's door and ask if she could advise me about the baby's cradle cap which I just couldn't get rid of. Once that was done she was in like a shot—never off my doorstep in fact. It seemed that I had to give her permission to call by asking for help. She enjoyed the company, and the feeling of being useful.

> 'Of course this time [of discharge] it's been very different. The women here can't do enough. In fact, sometimes I feel guilty because they do so much unasked. I said as much to one of them the other day and she said I should remember that she needed to be needed.'

Another concept we looked at was the tradition of good neighbourliness.

Joanna was 75 and had spent two weeks in hospital with a chest infection. She had lived for the past 11 years in one of the council's bungalows for old people. Her son lived within two miles but she said that she couldn't expect him to be with her 'running errands, like, when he had his work to think of'. The neighbours were 'very good all around and I don't know what I'd have done without them. They have been shopping and at first one of them came in to make me bed up in the living room.'

Joanna had lived in the area since her marriage more than 50 years ago. When she had moved to the bungalow, all the neighbours 'in my little bit' (probably the half dozen houses on either side) had come in to see her. 'They'd been friendly with the last person who was here and I suppose they came in automatic, like. Of course, I do me bit, and if I can help anyone else I do when I'm fit.' She made another important point. 'They're all retired round here so we have time for each other. It's not like where my son lives; there they're all out at work, the wives as well.'

Although this was a relatively new development of the local council, which dated back 15 or so years, there was already a strong feeling of neighbourliness among the tenants.

This lady had plenty of support from her neighbours, which was important to her ability to cope with her return home from hospital as well as the daily business of living.

Tradition, however, may well work in the opposite direction. In an area where people 'keep themselves to themselves', anyone coming out of hospital cannot expect the help that Joanna found so valuable.

A vicar whose parish included a street in a lower-middle-class area, was puzzled that he couldn't get any kind of volunteer service or good-neighbour scheme going at all. He discovered that the streets were full of widows and, at first, he could not understand why they did not help each other. He thought that the explanation lay in the social history of the street. The houses belonged to the railway and all the families had moved in in the 1920s and 30s when railway workers felt themselves to be socially superior to the people around them because they were in work while the others were unemployed. The young wives were proud of their social status and did not 'neighbour' either among themselves or with other wives. The families have duly grown up and moved away, the railwaymen have died and the widows are now left, *still* not helping each other.

The vicar found that they would accept help from outsiders—*provided* they came from far enough away not to be considered neighbours and *provided* no group activities were involved. This looked like an example of an area where a volunteer network would be likely to be especially well received.

Common characteristics, such as age, education, occupation, attitudes and aspirations, make for homogeneity in a group and this, in time, has a bearing upon the kind of neighbourliness it develops.

George was a middle-range civil servant who had undergone surgery of varying intensity over the past ten years or so. He was 51 years old, married to a rather neurotic wife; they had no children and had lived in their prosperous middle-class area, a few streets away from Jane, for some years. He described how helpful 'informal volunteers' had been.

> 'A few years ago I came out of hospital after major surgery in Portsmouth. It took a long time to recover even though that operation wasn't as big as the one I've just had. Having people interested in you acts like a tonic. That time no one outside the family cared a damn whether I lived or died. It makes a difference to the way you recover, and how quickly, if you feel outsiders care. Somehow you make an effort. I know it sounds funny, but you make an effort so when they come in to ask how you are for the sixth or seventh time you say "Yes, I'm getting on famously" even if you don't feel up to much. And saying that makes you feel just a tiny bit better somehow.'

Mr M's experience was quite the opposite. He and his wife lived in the same area as Jane and George. 'We lived next door to the same two couples for 38 years. Then when they died and young families moved in it was all different. They are very nice but we haven't anything in common.' It is interesting to note that when Mr M had his stroke the neighbours came to his aid instantly and with great effect, picking him up and making arrangements for his transfer to hospital. Even so, Mrs M did not feel she was really involved with them.

Another common interest may be found where the identity of an area is under threat from redevelopment. The vicar in another area of the town, once a prosperous artisan quarter, but now ripped apart to make way for 'improvements', said, 'I run a community good-neighbour scheme in four small streets. No one in this community wants help from any organisation; we help each other. They will neither give nor accept help from outside these streets. This is an area of small respectable houses–they still sand their steps. And they guard their status and self-sufficiency in the face of the advancing bulldozers. You can see that anyone coming home from hospital would practically have a reception committee awaiting the ambulance. No need for a volunteer network here—definitely not.'

We suggest there are two factors which tend to go against the development of informal help. One is the incidence of women of all ages going out to work. Joanna mentioned this in contrasting her own neighbourhood with that where her son lived. Mrs N, a 34-year-old who was far from well after a gall bladder operation, also made the same point. 'You don't see anyone when you are at work all day [as she was before the operation], so you don't get to know the neighbours much.' She hadn't called on anyone to help. 'They're tired when they get in in the evenings and want to put their feet up and you can't ask them to do things for you.' Her widowed father lived on a council housing estate just across the park from her and he called in twice a day to do any small chore and 'to see I'm all right while my husband is at work. Strictly between ourselves, I think he enjoys being important to me again.'

This leads to the second factor, the proximity of members of the family. It was almost universally expressed thus. 'You don't interfere when the family comes over so often to help. They go to a lot of trouble driving over after work and at weekends and it doesn't do to intrude.'

We began to see the informal network as a pyramid—the nuclear family, which makes the biggest contribution, forming the base, the extended family above it, friends forming the next layer, and neighbours at the tip.

Our evidence makes possible only the broadest of generalisations about an area. Each small section has its own characteristics. It is essential for anyone thinking of forming a volunteer network for discharged patients to have a thorough grasp of the dynamics of each neighbourhood.

Psychiatric patients

Our findings showed that psychiatric patients have special problems after discharge. They are likely to be more of a social than a practical nature, though not exclusively so.

All but two of the psychiatric patients had been in hospital for more than ten days, and just over half for more than three weeks, the average length of stay being six weeks. Thus, the hospital had become a temporary home for most of the patients, and this had a bearing on how they coped on discharge.

The three admission wards were separated. One consisted of a suite of very large rooms on the first floor of the main building which had been 'purpose-built', grimly, about 100 years ago. The second was a single-storey building three minutes' walk away from the main building, set in extensive grounds and gardens. The third was also separately sited—a rather beautiful modern building dating from the middle 1950s, which had won a prize for architectural merit. Each catered for between 20 and 30 patients.

All the wards gave the impression of pleasant informality. Most of the staff did not wear a uniform and to the casual observer it was not immediately obvious who was staff and who was patient.

The accommodation was similar, although the fittings and general appearance differed considerably between the main building and the wards in the garden. Each had two sitting rooms with television, a games room and a quiet room. In the two 'garden' wards the sitting rooms were small enough to give a sense of intimacy but obviously large enough to hold 20 or so patients should they all decide to use them at once.

The sleeping quarters in the 'garden' wards were separate dormitories; some were four-bedded rooms with adequate space between the beds and with a locker for personal possessions and either an individual wardrobe or space in a large fitment outside.

In the main building, the rooms were very big, with high ceilings as its age would suggest, and the dormitories were large with the beds closer together than anyone would consider ideal. The lockers and wardrobes tended to be scattered around.

The dining areas in all the wards had small tables and there always seemed to be a lot of activity with the patients in the kitchens. Each ward had three or four baths and accompanying lavatories. There were also treatment and recovery rooms, single side rooms and the usual run of ancillary rooms and staff offices. Everyone appeared to move around more or less at will, although it was evident that the more disturbed were closely but unobtrusively watched over by the staff. On a typical late afternoon, there would be groups playing games, individual patients entertaining their visitors, others in the kitchen making tea, some watching television, reading magazines or just sitting.

The mode of treatment differed between the main building, where the medical model was mainly in operation, and the garden wards which were run as therapeutic communities.

On admission, a patient had a settling-in period of a couple of days while the staff observed him and devised an appropriate scheme of treatment. He would get up at around 7.30 am, make his bed and be ready for breakfast at 8. This was followed immediately by any required medication and the daily community meeting at which general information was exchanged, personal matters discussed and the washing-up rota announced for the day. This was drawn up by the staff so that everybody took a turn, and was the source of subtle bargaining and a certain amount of backsliding by those who regarded it as an unacceptable chore. By 9.30 most patients were on their way to another building for keep fit or occupational therapy. Referrals to the latter were made by the doctor in charge of the case at the Monday review meeting, and what the patient actually did during these sessions was tailored as far as possible to meet his individual needs. If ECT had been prescribed, this was generally administered between 10 am and noon when the ward was relatively empty.

Lunch, at 12.15, came from the central kitchens in accordance with the choices ticked off on a menu list by the patients on the previous day. There followed an hour's quiet period, with the staff occupied in handing over to the next shift.

In the afternoon, some patients returned to occupational therapy, or drama, and some had group therapy sessions run by the nurses.

After tea, at 4.30, and medicines, the washing-up rota came into operation again; until supper, patients would watch television, play table tennis or visit the local pub or cinema.

Life was, therefore, structured, but there would be wide variation depending on the severity of the illness. As patients got better, personal decisions on spending their time increased, and the general aim was to prepare the patient for life outside. In this connection, we may mention the volunteer home economics teacher who came in twice a week to instruct four men in the basics of cooking so that looking after themselves would not present too much of a problem when they were discharged.

Landmarks on the way to recovery were, first, a day at home and then weekend leave. The patients regarded weekend leave with a mixture of joy and trepidation, and their families would have had the opportunity to discuss it beforehand with the staff and to report on it afterwards.

One of the patients told us 'It's like a holiday camp in there and going home is a return to a highly uncomfortable reality'. But another had hated being in and hoped she would never have to return. Her story raises other issues, and shows how volunteers can help.

Mrs A, aged 46, had spent six weeks in the hospital. Going to 'that place' had been the worst thing that had ever happened to her. She had 'just collapsed' after several months of depression. Her general practitioner was called and he asked her whether she would like to go to the hospital for a rest. She agreed because she 'just wanted a bit of peace', but she did not realise the place the doctor mentioned was in fact a unit in the psychiatric hospital. 'If I'd known, I'd never have agreed.'

She now felt quite recovered from her breakdown and able to cope with the help of tablets. She felt, though, that being in a mental hospital was going to 'blight the rest of my life'. Her former employers had asked her to leave because they said they had rearranged the working pattern while she had been away. However, when her husband told the firm he was going to consult a solicitor about the matter, they had hastily given her several hundred pounds 'compensation'.

Mr A had stayed at home for the first week after his wife's discharge but had then returned to work. Their son was living away from home but they had an 18-year-old daughter who was doing her 'A' levels. Mrs A had asked her daughter to tell her friends she had been in hospital for a hysterectomy, so they would not know she had been a mental patient. She had been to her GP once for a certificate and a prescription. She had wanted to spend time talking to him but 'the surgery was full, so what can you do?' She was going for an interview for a job the next morning and she spent some time talking about it. Afterwards she said she felt she would have liked a volunteer to do what I'd done—'Just to sit and listen to me going on about the job'. She felt, though, that she would be very wary if the volunteer tried to persuade her to go to any of 'those clubs for ex-patients'. 'I don't want to be an ex-patient—I want to forget I've ever been in there.'

This case demonstrates the importance of our making the first contact in the hospital. Mrs A could accept a listening ear, even though she had been unable to accept the fact of being a patient in a psychiatric hospital.

There is a vast gulf between hospital, where the range of decisions the individual is called upon to make is limited and the support of staff and fellow patients very considerable, and home where decisions of one sort or another have to be made all the time. A charge nurse said, 'There is always sadness on both sides at the parting of the ways when a patient goes home from the intimate, congenial atmosphere here to who knows what private hell.'

Clearly, the psychiatric patients are extremely vulnerable at the point of discharge. Since the completion of our survey, a social work department has been established at the hospital and the number of community nurses increased from five to 12. However, more than 600 patients are discharged each year and these represent only 40 per cent of the total number with whom these nurses have to deal, the rest being referred to them by GPs direct. Because the statutory services remain over-stretched, it may be that volunteers have a particular part to play here. We propose a model of volunteer intervention.

A psychiatric model

The need for this began to emerge from the beginning of our survey.

The consultants expressed the view that their patients would be unwilling to see us after they had been discharged because they would wish to forget they had ever been in hospital. In practice, we found the opposite. Each patient we had arranged to see was not only willing to see us, but waiting, often with the kettle already on! They talked freely and at length—often more than two hours—and it was obvious from what they told us that they were by no means friendless and isolated. However, they felt that it would place too great a burden on friendships if they tried to impart the sort of rambling confidences they seemed able to disclose in the course of our interviews. We felt that it was our first meeting with them in hospital, to make a firm appointment to call, which was of the utmost importance in establishing the relationship upon which it was possible to build during the interview.

This led us to the proposition that very many patients discharged from psychiatric hospitals would greatly benefit from a one-to-one relationship with a suitable volunteer. Our long experience of volunteers leaves us in no doubt that suitable people would be available who would regard participation in such a scheme as a challenge to their ability and imagination.

It would be necessary to proceed with caution in initiating such a project, and, of course, it would be up to the patient to opt out if and when he chose.

In general, it appeared from the people we saw that they needed the support of someone outside the circle of family, friends and workmates, who had time for them and upon whom they could depend for help to face a variety of what, in normal circumstances, would be ordinary, simple matters. For example, at least two people needed someone to help in changing or getting jobs: they could not face what they perceived as the ordeal of going to the job centre on their own. Besides the need for assistance with specific tasks, there was an overall requirement for someone to offer support and encouragement at the point where the cushioning of the hospital was relinquished for the less predictable world outside.

Crucial to the operation of the scheme would be the volunteer's first contact with the patient in the hospital immediately before discharge.

Our findings indicate that help with shopping, going out, a sense of a link with the hospital and the nurses, and general befriending are likely to be the most frequent forms of volunteer intervention.

The volunteers would have to be chosen with care, and sensitivity would be needed to match the individual patient with the individual volunteer. It would be equally important to prepare the volunteer for working with the patient. The intention would not be to produce a set of mini-professionals, but to provide a kind of 'strength through ordinariness' so that the patient has someone to turn to if the going gets tough.

The scheme would need to be studied and evaluated. We would envisage a simple first measurement: at the end of six months, the patient, volunteer and a member of the patient's family would be asked to rate the patient's recovery on a simple five-point-scale—much better, better, no better, no worse and worse. In addition, the doctor in charge of the case would be asked to record an estimate, rated on a similar scale, of how he expects the patient to progress over the period. This would, as it were, set the objective.

The volunteer's effectiveness could also be measured in a similar way, with the patient, a family member and the volunteer asking whether the intervention had been very useful, useful or not useful.

The research team would support the volunteer by ensuring close and continuous contact with the volunteer group.

If our proposed model did no more than lengthen the periods the patients spent at home, that would be a considerable achievement, for 29 of our 40 patients had been admitted to hospital two or more times. One member of staff, in discussing our proposal said, 'We bring patients into hospital, we relieve them of the necessity to contend with immediate problems while treating them with drugs or ECT, and when they're feeling well again and able to cope they are discharged to precisely the same circumstances that caused the breakdown in the first place. Should we wonder that they keep coming back?'

General conclusions and recommendations

We are well aware of the shortcomings inherent in a survey of the kind we have conducted. Imprecise as it may be, however, it can be very effective in getting to the heart of feelings as well as the more concrete evidence. The use of open questions often enabled us to get the flavour of situations which gave more cogent information than statistical data could convey on their own. It was with the limitations of this method firmly in mind that we reached our conclusions. What we found can best be interpreted if it is considered on both macro and micro levels. This small sample revealed things about the wider society which influenced the patterns of care that patients received when they returned home from hospital.

Extending the extended family

Our findings showed that most discharged patients were adequately, even well, cared for by some member of their family. Harris states in his discussion of the extended family, '. . . in the last twenty years or so sociologists have re-discovered the existence of links between nuclear families which were previously thought to have atrophied in urban industrial societies. Hence a great deal of bringing patients' relatives in for visits. He agreed to try this and was soon in great demand by the local organisers and volunteer bureaux. He was almost always available and eager to do most driving jobs. At first he needed a lot of support and reassurance; as one organiser put it, 'I felt he was haunting me for a while'. Now he is much more confident and can cope with quite demanding jobs, such as taking relatives to visit a dying patient. It is now more than a year since he was discharged and this is his longest period 'outside' since his divorce.

He feels his voluntary work has given him 'something to get up for in the morning'. The organiser of volunteers puts it another way. 'We are definitely keeping him out of hospital; we are his therapy, but so what—look at all he is giving back.'

Frank would seem to be a success story. It does not always work out so happily. The case of Margie is one that didn't.

She was 63, discharged from the psychiatric hospital after an illness precipitated by the sudden death of her husband. The marriage had been close and happy and she was completely unable to reconcile herself to the sudden loss of her husband.

After discharge she had become obsessively attached to a young mother who lived opposite in the cul-de-sac, and so bad had her interfering become that, in desperation, the health visitor had asked the organiser of the local day centre to take Margie on as a helper. Furious at what she saw as a conspiracy, Margie made excuses about helping and (in the end) reluctantly said she could only give an hour or so as she had to be home because of the dog. However, as time went on, she spent more time at the day centre and was willing to help with anything that needed doing. Margie, who had very rigid standards of conduct, became more and more pleased to be involved with the busy centre where there were many lively volunteers and a happy atmosphere.

For a full year she devoted her energies at home to making toys and knitting for the day centre bazaar, and she seemed cheerful and enjoyed a joke with everyone. The one hour she had grudgingly promised turned into six.

Everything seemed to be going well and most people had forgotten why she had originally been referred to the day centre, when one day Margie failed to turn up. Thinking that as she lived on her own she might not be well and in need of help, one of the other volunteers called in to see what the matter was. She found Margie sobbing like an abandoned child, clutching the photograph of her dead husband and saying that all she wanted in life was to have her husband alive again. In spite of repeated attempts by all her day centre friends, Margie remained in her depression, and although she occasionally made the effort, volunteering had been only partially successful as therapy.

What might have been perceived by the outsider as acts of kindness by Frank and Margie were, in fact, necessary for the maintenance of their own emotional stability. Margie had to give up volunteering, but the help she gave was valued even though it lasted only for a short while. Many people can be helped to achieve a sense of wholeness if they are given the opportunity to give to the community.

A volunteer network

In the surveyed area at least, our findings indicate that neither the voluntary organisations nor well disposed individuals know where help is needed or where to go to offer it. In background and need, volunteers are as diverse as the community itself. There is no shortage of goodwill, but to be of use it must be matched to proven need.

time has been spent in refuting the proposition that in such societies the nuclear family is isolated.'[8]

From our sample, it was clear that the extended family is indeed alive and well, and active in maintaining the welfare of its members. Since the extended family lived mainly in separate nuclear units within easy reach of each other, we named it 'the spread-out extended family'. It was characterised by interactions which were relatively easy, frequent and apparently harmonious. In most cases the absence of economic hardship, and the widespread possession of telephones and cars, facilitated constant communication between and within generations. Many older patients reported, for example, that married sons or daughters would come over by car on Friday evenings to shop for them in the supermarkets, and younger patients often mentioned the help they had from parents in child-minding and help around the house.

The area is favoured economically, socially and geographically. The standards of housing, comfort and personal care were high. It is interesting to speculate on who cares for discharged patients in less-favoured areas and where the spread-out extended family is not so commonly found.

Where the family and neighbourly care did not operate, the answer to our original question 'Is there a need for voluntary care in the community for discharged patients?' was an emphatic 'Yes'—particularly during the first 48 hours after discharge.

At present, the formal arrangements and final responsibility for the care of discharged patients in the community are in the hands of the statutory services—which constitutes the 'first line' of care. Another resource is the informal network of caring by family and neighbours. For those to whom this is either not available or insufficiently so, we conclude that the statutory services should be more ready to regard the voluntary sector as an extra resource. More thought and effort should be directed toward harnessing the store of goodwill in the community, either by drawing on what already exists, such as the voluntary organisations and the informal care by families and neighbours, or by introducing a volunteer network as a complementary provision.

Volunteering—a two-way process

The use and encouragement of the 'caring elements' of the community would enable the statutory and voluntary services to be deployed more economically, but, in our view, of much greater importance would be the contribution to the emotional health of the community. Emotional needs are fulfilled in close relationships with families, among intimate friends and through work, but for some people this is not enough. They seek greater fulfilment by involving themselves in caring relationships in the wider community. There is much satisfaction to be gained from doing something for others which is not, as it were, laid down in the rubrics of family lore.

Those engaged in organising voluntary work are well aware of its potential as therapy for those involved in it. Many people are able to help themselves through difficult emotional periods by offering help to others.

The case of Frank is a very good example. He was interviewed two weeks after his discharge from the psychiatric hospital. He had been a patient three times before and talked for a long time about how lonely he was. He was in his late fifties, had been divorced for some years and his two children lived abroad. He was interested in the sort of work volunteers did in his area and he was given the address and telephone number of the local volunteer bureau. Some weeks later he was, by chance, encountered again in the office of the voluntary help organiser at a general hospital, offering his services as a volunteer. It was suggested to him that since he enjoyed driving he could be very useful to the hospital

We recommend the establishing of a volunteer network which would operate where neighbours or family were not available. This means recruiting a team of volunteers whose specific task would be to take on a patient on discharge and follow him through until his recovery. Their efforts would be directed at whatever help was needed in individual cases—shopping, for example, should never be a job for the home help (unless she is doing it in her own time). We believe the idea would have a broad appeal to voluntary workers because it would offer variety both of job and people, would be fulfilling a real need, would be mostly short term and would provide the immense satisfaction of seeing a task through from beginning to end. For example, volunteers with school-age children would be particularly attracted to an opportunity of this kind because it could be fitted into term time and in the children's absence during the day.

We are strongly of the opinion that any such network should be linked to existing ventures like the good-neighbour schemes so that the organisers can ensure that efficient use is made of the new resource.

In places which already have a good-neighbour scheme, its organiser could compile a register of volunteers to look after discharged patients.

If the hospital, and its wards, had a list of streets in the towns and villages of its catchment area and the telephone numbers of the organisers of good-neighbour schemes, all that would be needed is a telephone call to 'tip the wink' about the discharge.

Good-neighbour schemes vary: they flourish in some areas and never get off the ground in others. So, setting up the links and keeping them going may not be all that simple.

Matching the provision to the need

Hospitals sometimes seem to have to fit the patients into what they can provide or arrange instead of the other way round. A volunteer network would seek to provide the individual patient with what he needs.

A social worker told us, 'If I have to contact the voluntary people I feel I've failed somehow'. In our view this sentiment is misguided. Whichever contact is most appropriate to a given patient should be the one to be used, regardless of whether it is statutory or voluntary. Many social workers tend to define problems and, therefore, seek solutions in terms of statutory provision. For example, an elderly widower being discharged home may be offered meals-on-wheels because this is the standard method of ensuring that people living on their own get some cooked meals. It is likely that the old man would need company as much as his food, and a volunteer who could do his shopping and get him a meal and have a gossip would be providing both. Meals-on-wheels only means eating in solitude and this is sure to emphasise rather than relieve loneliness. It is, similarly, a waste of resources to provide a home help when a befriender is what is needed, as the case of Mrs Q illustrates.

She was a 29-year-old mother with a two-year-old daughter and had been in the psychiatric hospital for six weeks. She was very anxious about how she would cope at home. The toddler was feeling insecure and given to tantrums, which added considerably to Mrs Q's anxiety. Since she had only recently moved house she did not know anyone on the estate, which was still under construction and, consequently, raw and unfriendly in appearance. Mrs Q thought she was back to normal though she admitted leaning heavily on her husband and found great difficulty in going out with the little girl or to do the shopping. Not surprisingly, she was much in favour of a volunteer network.

> 'You definitely need a back-up. You come out physically tired, which people don't realise about mental illness, and you're out of the way of things and very vulnerable. You get upset over really small things. Basically you need someone to chat to, someone to be with you when you're shopping. You need reassurance above all.'

The hospital had arranged a home help who had taken on a befriending role as she had a child of the same age. The house itself was small and easy to run so the amount of housework was minimal. A volunteer could have met Mrs Q's needs, allowing the home help to be deployed elsewhere.

Organising

Our experience shows that you have to start in the place where the discharge is made, that is in the hospital ward, and by whoever is senior in charge on the day. Bearing in mind the ward sister we quoted in the prelude who talked about loaded questions (You're all right to go home, aren't you?), it would be better if she could rephrase her question to give the patient a chance to say 'No'.

We acknowledge the heavy burden already carried by nurses but, though at first sight it may seem to be adding to their work to suggest they do more, it should be remembered that some of the benefits of inpatient care can be lost if the discharge is not handled adequately. We should reiterate here that, in our experience, only a few patients are likely to be involved.

It may well be that where a number of discharged patients and the local circumstances warrant it—for example, where care by families, friends and neighbours is not so much in evidence—consideration should be given to the appointment of a discharged patients' coordinator, with which some hospitals are already experimenting.

Such a post could be jointly funded by the health service and the social services. The coordinator would have overall responsibility for meshing together statutory services and voluntary services, as well as for establishing new ones like the volunteer network. He/she could be based in the hospital itself or in some other agency such as a voluntary organisation.

Another way of using the community resources would be through the volunteer bureaux, now well established in many places. Volunteer bureaux and councils of voluntary service are well placed to set up and support a volunteer network. They are in contact with both the potential helpers and those who wish to be helped. They are also in a position to compile a register of discharged patients' volunteers, particularly as many of the people who offer help through the bureaux are prepared for short-term assignments rather than for a long commitment to an institution such as a hospital. It is unreasonable to expect a volunteer bureau which is run by unpaid staff, and therefore probably open only during restricted hours, to be the kind of clearing house we are suggesting, since one of the prime requirements is instant action for the discharged patient who requires help.

There are staff in hospital who have contacts in the community, the most obvious being the medical social worker who would have knowledge of the local area. However, the medical social worker in many hospitals is able to see only a few patients and her main concern is with statutory provision. It may be unreasonable to expect her to involve herself too far in extra arrangements.

Many hospitals now have a voluntary services coordinator (VSC) who has links with the voluntary organisations, the informal sector and with well disposed individuals. She will be working closely with all these and will have a good deal of knowledge about what they can offer. The VSC should be a bridge between the hospital and the community: what more apt place to bridge than at the point of discharge? It is important to point out that most VSCs are already fully, not to say over-, committed and this extra area of work would mean extra hours, a rearrangement of the work and perhaps more staff. However, some VSCs already see it as part of their function to act as coordinators for discharged patients and others are beginning to expand their area of interest in this direction.

Of the possible alternatives we have outlined, the discharged patients' coordinator (DPC) commends itself most strongly to us, both because he/she could be regarded as a specialist in matching the needs of the discharged patients to what is available, and also to develop less easily identifiable services. There is another equally important reason. The DPC would be favourably placed to undertake the important task of helping hospital staff to understand that some patients need help, often of a very simple kind, on their return home. It is of no use whatever having the community geared and ready to help, if the hospitals are unaware of what is there. The job of making sure that hospital staff know what is available tends to be neglected because no one perceives it as his clear function to do this. The appointment of a coordinator would remedy this. It is worth recalling here that the people we spoke to in the voluntary organisations felt that in general the hospitals did not know what even the well established organisations had to offer.

It is difficult, if not impossible, to set out a precise model for establishing a volunteer network. The experience of some voluntary groups shows that much depends upon local conditions and needs, and upon what is already provided.

We would therefore say to all those concerned with discharge arrangements, look about you, because there are almost certainly additional resources available to you.

Seven case studies and a final comment

We bring our report to a close with short selected case studies, in the hope that the reader may share the privilege of interviewing seven of our patients at home. And we end with the verbatim outburst of one of our respondents which, though somewhat incoherent in some places, seems to sum up all that we discovered, all that we propose and the problems that need to be considered in setting up and operating a volunteer network for discharged hospital patients.

Case study 1

Mr P was a retired postman, 67 years old, who lived on his own in a council maisonette. He had been there for three years although he had lived in the area for over 40 years.

He had what he described as 'a heart condition' which had increased in gravity over eight years and his hospital admission had been for pneumonia. He had spent a week in hospital and three weeks as a preconvalescent patient. He had a daughter but they had quarrelled a year ago, and she had not been in touch.

The various community services were well aware of his condition and the home help, the district nurse and the meals-on-wheels were all in evidence. But the hospital's contact with the GP left much to be desired. Two weeks after discharge 'the doctor has not had the report. There were some x-rays and a cardiogram which should have been sent on but they haven't come through. He doesn't know exactly what's going on with me.' Nevertheless, Mr P was very satisfied with the help he had received from the statutory services.

The question about the volunteer network evoked a strongly positive reply. 'Someone to chat to would be best of all.'

Being a pensioner, he was not affected by a fall in income, and fellow-postmen dropped in for a chat when they had any letters for him. He was able to get out of the house, though he lived half way up a very steep hill, and he managed his own shopping since his neighbour could not help because she was out at work all day. 'It won't be so good in bad weather though, because I have to walk so slowly. A bit of help at those times would be just the job.'

His answer about how he managed about transport makes amusing reading. 'If I can't get to the bus stop to get on the bus, my niece's husband is a bus driver and he'll alter the route a bit to pick me up—but he can't always if he's on late shift.'

Case study 2

Mrs Q was 30 and would have been pretty if it had not been for the lines of tension and anxiety on her face. She was a 'regular customer', as she put it, at the local hospital. They had removed 'a lump' in her breast and she was admitted every six weeks for radiotherapy. She usually stayed five days.

'I'll talk to anyone; I want the company' was her greeting, and she invited me into the kitchen where she made the tea. Her husband was a sales representative and they had lived in the area for less than two years. She was quite able to go out if driven but her neighbour was doing the shopping for her. 'I like her to do it because it's an excuse to have someone call each day.' She was very depressed and felt strongly the need for company and someone to talk to. As she was fairly new to the area, and had few friends, her need for company was beginning to put a strain on the marriage. 'You see, I keep wanting him to stay at home to be with me and he gets fed up. Anyway he's got to think of the job. He can't keep telling them his wife is ill.' She felt that if her husband knew she had 'someone like these volunteers' to pop in to see her, he would be reassured.

'Also, I don't want to go on about my troubles, but could you meet someone before you go into hospital who has had the same operation, so they could tell you all about it?'

Case study 3

Mr R was a retired farm worker of 73. He had moved into the area the previous year to live with his son, daughter-in-law and two grandchildren. The small council house was sparsely furnished and the breakfast dishes were still on the table at midday. Mr R had not got around to clearing them away. 'I don't generally do it till just before they come home. Then I quick scoot around.'

He had been in hospital for 17 days with what he described as 'lung trouble'. He was so breathless he could scarcely talk. Yet he did the family shopping on his bike. He was alone all day and got his 'bit of dinner' for himself. That day it was to be sausage and egg and he offered to cook me some. It was not every day he had a 'bit of stuff' calling on him. There was no one keeping an eye on him, 'and what's more, I don't want no one' he assured me vehemently. His daughter-in-law got on his nerves. She was always worrying about him being alone and because he wouldn't stop smoking. He had been in touch with his doctor, at the daughter-in-law's insistence, because of his persistent cough. He was very upset when I refused a cigarette and gave me a long lecture, punctuated by coughing fits, about how smoking keeps you fit by 'keeping germs at bay'.

When asked who told the family he was coming home from hospital, he replied 'No one, I just gave them a surprise—I just turned up. You should have seen their faces.'

This independent old man was not in the least interested in the idea of a volunteer calling on him. 'I'm not helpless. I can manage. I'm fine on my own and I don't want no one.'

Case study 4

We have said that the extended family is alive and well and living in this area. Mrs S is a typical example of many of the discharged patients we encountered, where everything went smoothly and where the family coped.

She was 50 years old, married to a fitter. She had been in hospital for nine days for a hysterectomy. She had lived in the same council house with her husband, son and daughter for 12 years. Her married son lived nearby and it was her daughter-in-law who had mainly looked after her on her discharge from hospital. She came in every morning after she had taken her younger child to nursery school, did the housework and shopping and prepared a snack for lunch. Later in the day she returned to cook the evening meal.

Surrounded as she was by her family, Mrs S was still able to speculate about the need for volunteers. 'Well, if I hadn't had my daughter-in-law, I'd have been in a mess. I'd need someone to pop in. It's not easy for my daughter-in-law really, with two young kiddies. It would be nice for her if someone else could do the shopping.'

Case study 5

Sometimes other members of the family were very keen to tell us what they thought and we quite often had to listen to the views of a husband or wife before we actually got to the patient. Mr T was one of these. He was also one of the very few who complained about the treatment in hospital and insisted on telling about this before I began the interview with his wife.

> 'The general condition was terrible on the ward where my wife was. Once she had to wait half an hour for a bedpan. The social worker was very helpful but we didn't see her before the discharge as it was all so sudden. I really should have made a complaint but I didn't know who to contact.'

Mrs T was 73 and had been in hospital for seven weeks after fracturing her hip. She and her husband had lived in this small terraced house since they were married some 50 years ago. Mr T was 80, a retired engineer. He was looking after her alone and did all the shopping and cooking as they didn't like to bother the neighbours and their only child lived some miles away. The district nurse called 'occasionally' and they liked her very much. But they would have preferred her to have started coming immediately after discharge instead of five days after. They contacted their own doctor on the advice of a friend, and were very surprised to know that he had not even been told of the admission. They described the discharge as 'very unexpected' but they were both so delighted she was coming home that they did not mind too much at the time. Mrs T had to return to outpatients once a week and was taken by ambulance, which she described as 'long-winded but OK'.

They both felt they would have liked voluntary help because they would prefer a stranger to 'these neighbours who only want to know your business'. They would have liked someone to help with shopping or 'a new face to chat to. After 50 years you are a bit bored with the same one all day!'

Case study 6

The road to the top in any profession is generally believed to be a difficult one for the person concerned, but what is perhaps not so well recognised is that his family may find the going hard as well.

Mrs U, who was 35, had married at 18 and had seen her husband progress from leaving school with two 'O' levels, through evening classes in engineering, to become technical director and a board member of one of the largest companies in the country, all by the age of 34. Because of her husband's career, the family had moved house frequently and they had been at the present address for only six months. She knew very few people nearby and had no friends to chat to about anything.

She had been in the psychiatric hospital for three months, the fourth in a series of admissions since a postnatal depression six years earlier. At the time of the interview she did not regard herself as back to normal and she talked about the post discharge period, of which she had considerable past experience, like this.

> 'I think you have to realise you've been ill. If you've had pneumonia or something like that it's easy enough but the problem is, I feel ashamed. You do odd things in this kind of illness. You have to have a period of convalescence. Above all you

want someone to talk to—that would help. I don't feel the need of a group because I want to be treated as normal and not confined to social contacts with other patients or ex-patients.'

Case study 7

This man of 77, a gentle individual who was quietly delighted to be visited, lived in a small terraced house, and had broken his leg by falling from top to bottom of the staircase. He had been in one hospital for three weeks and had had seven weeks of preconvalescence in another.

Though he lived alone and it was winter time, he had been discharged home. He couldn't manage, and a married couple, who knew him through his church, had taken him into their family and were prepared to look after him for 'a month or two'. It became too difficult for them because they had young children. Nothing whatsoever had been done to help him by the statutory authorities.

His friend told us that he had had no visits from the district nurse or social worker, and their request for a visit by the GP had been ignored. When interviewed, he was out of the tablets the hospital had given him, and he didn't know what to do next.

To those in the social services it may seem an easy matter for patients to make their difficulties known. But this old man's friend was not on the phone and had to go out to a box (she was recovering from flu at the time) in very cold wet weather. She did not know whom to contact, and when she found out they were not available. Three weeks had gone by and neither his urgent short-term welfare nor any attempt at a permanent solution to his long-term problems had been initiated. He needed a rail to the staircase in his house as a very minimum requirement for returning there, but nothing had been done.

He felt the volunteer network would be very useful. He had no relatives to call upon. He wanted help with shopping and 'a bit of help in the mornings lighting fires'. 'I couldn't even make myself a cup of tea. I'm not self-pitying but before these friends took me in I used to cry and men are not supposed to cry and I haven't cried many times in my life.'

A final comment

'Twenty years ago I had a breakdown and if I'd had the sort of help you're talking about I wouldn't have been struggling along for 20 years. I'm weary of schemes never coming to anything. I hope you don't think I'm being cynical. I don't hold much for it—I'm against prejudice and many things. Up and down like a thermometer. Very tired about so-called schemes and I don't care any more. No way of people being rehabilitated. I'm sure there has been a bad effect on my family, it depresses me and is bound to affect choice. Choice in the sense that they have to take my illness into account.

'I went when I was younger and a founder member of the . . . [a national association for patients] to visit other sufferers and in every case they were crying out for help which we couldn't give. Couldn't give it because we didn't know enough about the things they were asking. They wanted advice which I couldn't give. There's been a waste of 20 years' life if I'd had support at the beginning. At my age you know yourself and your illness better than the doctors. You have the choice to reject help if you want to but you need someone to chat to, not just friends because you will lose them if they get bored with you. I feel strongly that the sort of help you're talking about could make a lot of difference in many cases, not in every case though.

'If what I've told you makes any sense and perhaps helps someone then I'll feel that perhaps 20 years hasn't been entirely wasted.'

Select bibliography

---

1 AGE CONCERN (LIVERPOOL). *Going home?: the care of elderly patients after discharge from hospital.* Report on the continuing care project of Age Concern Liverpool. (Chairman, Peter W.G. Urquhart.) Liverpool, Age Concern, 1975. pp. v 74.

2 AMERICAN HOSPITAL ASSOCIATION. *The volunteer in long-term care.* Chicago, A.H.A., 1968. pp. 52.

3 BROWN, George W. *and* HARRIS, Tirril. *Social origins of depression.* London, Tavistock Publications, 1978. pp. 450.

4 *Care for the elderly: a collection of reports on a series of twelve conferences held at the Hospital Centre between June–December 1970.* London, King's Fund Hospital Centre, 1971. pp. 74.

5 GAY, P. *and* PITKEATHLEY, J. *The community care of discharged hospital patients. Health and Social Service Journal.* 7 April, 1978. pp. C9–C16. Centre eight pages.

6 GREAT BRITAIN. DEPARTMENT OF HEALTH AND SOCIAL SECURITY. *Better services for the mentally ill.* London, H.M. Stationery Office, 1975. pp. viii 91. *Cmnd. 6233.*

7 GREAT BRITAIN. DEPARTMENT OF HEALTH AND SOCIAL SECURITY *and* WELSH OFFICE. *Better services for the mentally handicapped.* London, H.M. Stationery Office, 1971. pp. iv 67. *Cmnd. 4683.*

8 HARRIS, C.C. *The family.* London, Allen and Unwin, 1969. pp. viii 212.

9 HIRST, Jean. *Elderly patients discharged home from hospital: report on a study 1974–75.* Oxford, Radcliffe Infirmary, Department of Social Work, 1975. pp. 77 plus tables.

10 HOCKEY, Lisbeth. *Care in the balance: a study of collaboration between hospital and community services.* London, Queen's Institute of District Nursing, 1968. pp. 163.

11 *Home from hospital. Practice Team,* no. 13. June 1972. pp. 3–5.

12 KURTZ, Harold P. *and* BURROWS, Margaret. *Effective use of volunteers in hospitals, homes and agencies.* Springfield, Illinois, Charles C Thomas, 1971. pp. 119.

13 LINDARS, M.E. *and others. Needs of the elderly in Reading: a report to the medical officer of health 1971,* by M.E. Lindars, S.B.J. Macfarlane *and* D.F. Rowlands. Reading, County Borough of Reading, Department of Health Services *and* University of Reading Department of Applied Statistics, Operational Research Unit, 1971. pp. 39 plus appendices.

14 *Rehabilitation services for mental deficiency.* Meeting at the Scottish Hospital Centre on Friday, 27th November, 1970. *in Centrepiece: collected conference reports 1970.* Edinburgh, Scottish Hospital Centre, 1970. pp. 7.0–7.13.

15 SKEET, Muriel *and* CROUT, Elizabeth. *Health needs help: results of a study into the role and preparation of volunteers working within the reorganised National Health Service.* London, Blackwell Scientific Publications, 1977. pp. viii 79.

16 STEVENS, Pamela F. *Discharge from hospital: the problem of adjustment. Nursing Times.* 9 May, 1974. pp. 700–702.

Index

When I Went Home . . .

How do patients manage when they get home from hospital? What help do they need? And who helps them? Pat Gay and Jill Pitkeathley, two voluntary help coordinators, listened to some 250 patients describe their experiences and problems and in this book they report, largely in the patients' own words, what happens. Volunteers are well integrated in the hospital service itself and many work alongside the community health and social services, sometimes as members of the big voluntary organisations and sometimes in the smaller neighbourhood groups. But the authors point out 'there is no recognisable group in the community to take over where the hospital care ends' especially for those patients with no family or friends nearby or those not already known to the community services or voluntary organisations, who 'dread the 48 hours' after discharge from hospital. This book explains what help is needed and how it can be arranged.

When I Went Home . . . is the natural sequel to Winifred Raphael's surveys of patients' views of hospital life.

Patients and Their Hospitals—report on patients' views of general hospitals
ISBN 0 900889 64 0

Psychiatric Hospitals Viewed By Their Patients—report of life in nine large psychiatric hospitals
ISBN 0 900889 65 9

Just An Ordinary Patient—a preliminary survey of opinions on psychiatric units in general hospitals
ISBN 0 900889 46 2

'. . . thoughtful persons over at Tavistock Square should consider striking a special medal for a woman who didn't go anywhere near the Annual Representative Meeting, but whose endeavours, indirectly and unintentionally, can have done the medical cause nothing but good. She is Mrs Winifred Raphael, tireless investigator for the King's Fund . . .'
World Medicine

FROM ALL BOOKSELLERS
Full list from the King's Fund Publishing Office,
126 Albert Street London NW1 7NF

0 900889 72 1