
6 Information for Carers: The Views of Carers of People who now Live in Residential Care

Many of the people who face the prospect of residential care are looked after by carers in the community. The carers are most usually relatives, although neighbours and friends often take on significant caring responsibilities.

The carers are, we felt, likely to make an important contribution towards the choice of residential care, either assisting the person concerned with the consideration of alternatives or, in many cases, playing an active part in the decision itself. If this is so, carers have significant information needs which should be taken into account. Accordingly, we have tried to explore the nature of these information needs and the ways in which the carers had set out to meet them.

To do this we carried out in-depth interviews with 35 carers, 13 of whom had been caring for people who had recently moved into residential homes. The carers were selected in three geographical areas through contacts with a social services department and through the Carers National Association and two of its local groups. An approach was also made to Contact a Family who put us in touch with a further selection of carers.

This section presents the findings from the 13 interviews with carers of people who had moved into residential homes. At the time of the interview, nine of the people were living in homes run by local authorities, the remaining four being in private homes.

One of the carers had looked after a person with a severe physical handicap while the remainder had been caring for elderly people. The majority of the elderly people were mentally infirm and in most cases this was complicated by additional physical illnesses or disabilities.

In 12 out of the 13 cases the move into a residential home had been precipitated by a health problem. In two instances the health problem was compounded by other problems with housing or a reduction in the availability of carer support. But it was a breakdown in health which caused most carers we interviewed to begin contemplating residential care seriously.

In some cases the deterioration in health was gradual, leading to a point when residential care seemed the only option:

She was living alone in a flat. We began to realise that she was not looking after herself. It suddenly caught up with us when we found two drawers full of unanswered bills and letters. The home help organiser suggested one day a week at a day centre and a home

carer to cook lunch two days a week. Later she got a nurse to help with bathing then she needed more help. We arranged for sheltered accommodation but she wouldn't go. Eventually we had an indirect comment from her doctor that she was ready for a Part 3 residential home.

More usually, however, the decision to explore residential care came as a result of a sudden illness or an accident:

She had Alzheimer's disease. She was going down very slowly then she developed breast cancer.

Often this was compounded by other changes in circumstances or the pressures of increased strain on the carer:

She had a broken femur which wouldn't mend. She came home from hospital and it broke again. Our relationship became awful and the doctor said 'She will destroy you. You should see a social worker.' So I did. Someone from the care attendant scheme came for a few weeks but Mother didn't like it so it stopped.

In one case it was a change in the carer's circumstances alone which triggered the move:

When Mum died I couldn't cope on my own.

In one other case the carer had been forced to look for alternative accommodation because the person for whom they cared was given notice to leave the home in which she had been living:

It started nine years ago. She had a series of heavy falls and said that she wanted to be looked after. She stayed at ____ for eight years but her health went down and she needed round the clock attention. Then we were told that she was under a month's notice. It hit us like a bomb. We looked at several homes that had a bad feel then moved her into a private home for four months but we couldn't cope with the fees. We applied to the social services department, went to see the home and liked it.

It seems therefore, that the decision to choose residential care is seldom straightforward and in the overwhelming majority of cases it was the carer who took the prime responsibility for making the decision. In many cases, though, the carer was assisted in the decision making by someone pointing out the inevitability of the situation:

I went to the doctor to ask for respite care. They put me in touch with Age Concern. She then went to the Age Concern lunch club and the welfare lady came and said it would come to the point where they couldn't manage and we should start thinking about residential care.

In other cases the carer felt that the decision had been made jointly:

The decision was taken by me and the social worker, plus the hospital pushing.

In most instances, however, it was necessary for the carer to take the initiative:

I asked for help because I felt that I couldn't go on any longer.

I took the decision. I couldn't relax and I felt hopeless and depressed. They took her calliper away for modification and she was without it for a month. Someone - the social worker - mentioned residential care and a nice place in _____. The social worker gave me a list and started to talk about fees. I found out that the social services would help. So I phoned around and found that there was only one vacancy.

In one case the carer was presented with a fait accompli:

It was complicated. The doctor said that he should go into _____ for three weeks every three months and that he shouldn't occupy a hospital bed. They tried to push him onto me. The social worker kept coming out and putting my back up by asking personal questions. A doctor from _____ came out and a woman. Then, first I know he's been put into a home.

In this case the carer was a neighbour, and thus her right to make a decision on behalf of the person cared for must be questioned. Yet there seems to have been an expectation that she would provide caring services and, in view of this, she should perhaps have been more closely involved in the decision about residential care.

Clearly, the circumstances at the time when residential care becomes a possibility are complicated. They may be precipitated by an accident or an illness but this is likely to be the culmination of a longer term decline in the physical and mental faculties of the person concerned. When it becomes necessary to consider the residential care option the onus for the decision is placed firmly on the carer. They may be led up to the decision point and given support and encouragement but, at the end of the day, the decision rests with the carer.

The information needs

Carers need significant amounts of information in order to make decisions about whether or not to opt for residential care. They will first need information about all the different options open to them. They should be aware of the alternative ways in which the problem that they and the person cared for face could be overcome. It may well be that, having assessed each of the options, they conclude that residential care is the only viable possibility. But to do this they first must know enough about each of the options.

Having decided that residential care is the preferred option, the carer then needs information about the different residential care facilities that are available. Here the concept of 'availability' can vary according to the urgency of the need for residential care. As we have seen, many of the admissions are made in response to a sudden deterioration in the condition of the person being cared for. In such circumstances 'availability' may mean only those homes which currently have vacancies. In other cases there may be less pressure to find a place quickly and then 'availability' may mean all the homes within a defined geographical area, regardless of whether or not they have a vacancy.

The carer will also need to consider the financial and other material implications of the move to residential care. These can be complicated. If, for example, the carer lives in a home which is owned or rented by the person being cared for, a move into a residential home could have major financial and housing implications. Similarly, the move to care in a home would result in the loss of benefits which may have been

playing an important role in contributing to the household budget. These issues need to be explored in some detail if adverse consequences of the move are to be taken into account.

On a less specific, but no less important, level, the carer will need to know what sort of life the person will lead once they have entered the home. They will need to be reassured that the person will have an acceptable level of care and attention, that they will live in a congenial and stimulating environment. In short, the carer will need to feel that the person they are caring for will feel comfortable and content in their new home.

In addition to these basic information needs, the people we interviewed indicated that they required an extensive additional range of information, much of which was determined by the particular circumstances of the person they cared for. One carer, for example, was particularly concerned to discover the homes' policies on drug regimes:

I needed to know about the use of drugs. I don't agree with keeping people quiet, so the home must have a policy not to use sedatives.

Others had particular queries about the facilities available: would there be a telephone in the room; could they have breakfast in bed; how much wardrobe space would they get; what kinds of entertainment and stimulus were provided? One other carer who had considered private homes wanted to know which homes were run by their owners and which were run by managers and owned by companies, believing that the latter were mainly motivated by profit.

In short, carers had extensive information needs. We asked the carers we interviewed whether or not they felt that they had enough information when they took the decision to opt for residential care. The majority felt that they had enough information at the time. However, a significant minority, about one third, felt that they lacked sufficient information. In two cases the carer felt that they needed information to provide support during the period leading up to the decision:

I think some more positive information from the social worker would have been useful. I always felt that I was dumping him.

I think it would have been useful to have someone say 'this is the way; this is what you can expect' and for them to be interested. It would have been nice to have someone suggesting where to try - a social worker perhaps, but we tried and they are a law unto themselves.

Another felt that she lacked information about the activities in the home and about what the person she cared for would do during the day:

I felt I needed more information about what care was available - what they do with them. She's so much better now but there's no activity. She could do more now she's better. They look after her healthwise, but they just sit. There's no stimulation.

One carer wanted the information to be better organised, possibly to facilitate comparison between homes:

Perhaps if the information had been broken down into headings like: room; activities provided; costs; financial help available, etc.

Sources of information

We asked each of the carers whether they had received information from a range of professionals and others with whom we thought they might have come into contact. In each case we asked whether they had received information about the alternatives, the availability of facilities, the financial implications and the quality of life in the home. We then asked them if they had approached any other individuals or organisations for information. We asked them to say which was the most useful source of information and to suggest the best way for information to be given to others in their position. Finally, we asked them what sources of information they would recommend to a friend who was caring for someone who might need residential care.

Social workers

All but one of the people being cared for were visited by a social worker. In all but one of these cases the social worker gave the carer information about residential care.

In about half the cases the social worker provided information about the alternative ways of overcoming the problem without resorting to residential care. In one case the carer had considered and rejected the alternatives:

I knew about services but it was obvious that I had to think about residential care.

In another case the carer tried one of the other options suggested and only considered residential care when the first alternative failed:

The social worker suggested the care attendant scheme but it was not successful because Mother didn't like the girls.

In some cases where the social worker had not given information about alternatives, it appeared that circumstances were such that the information would have been superfluous:

There was not a lot of choice because she was too far gone to manage.

In nearly all cases the social worker had given the carers information about the homes that were available. Often this was simply a list of the local homes, sometimes supported by a leaflet or two about particular homes. In one case the social worker began to take things further, then the case was transferred to another social worker and the impetus was lost:

One did get us information and got as far as visiting. Then the social worker left and Mum was not taken in for assessment. Trying to find information was like going up a blind alley. We kept changing social workers, some of whom thought I shouldn't be considering the private sector.

In one case the social worker failed to provide information about the homes available and the carer had to investigate for themselves, eventually obtaining a list direct from the social services department.

In about half the cases, social workers provided some information about the quality of life in the homes, although in no case did this seem to be extensive.

In nearly all instances the social worker provided information about the financial implications of the move into residential care. In one case the carer was referred on to the local office of the Department of Social Security.

On the whole people found the information the social workers gave them useful. In several cases the carers were very pleased:

_____ [the social worker] was first class. She was very thoughtful and patient and made suggestions about sheltered accommodation, etc.

He was generally very good and helpful and talked about what was available.

You hear all sorts of things about social workers but _____ helped me with income support - filled in all the forms for me.

Others had a less satisfactory experience. One woman who was caring for a neighbour who was mentally infirm said:

The social worker didn't give me any information. She only wanted the private details such as why a single woman had a male person in the house.

Another found that the social worker was ...

... not particularly useful. They just led to traumas with the social worker saying different things at different times. They kept changing the social worker - some were helpful, some were hostile. They want you to keep on.

Another carer looking after a neighbour felt that the social worker did not really give any useful information:

I would have liked to know a lot more. Where she is she doesn't do anything. I'd like to know how things are run, and about money. Had I been a relative - I'm only a neighbour - it would have been nice to have had more information about the daily life she would lead. People - social workers - are so busy and they are happy if a neighbour is willing to do things because it takes a job off them.

In contrast, someone looking after an elderly, physically handicapped woman said:

I don't know who else could do it. They were useful. I was very thankful for the social worker.

It seems, therefore, that social workers do play an important role in providing information about residential care and when things go well, the information they give is felt to be very useful. In a significant minority of cases, however, carers felt either that the social worker had not given enough information, or that the information given was not useful. To an extent this might be determined by circumstances and personalities.

Hospitals

In view of the health problems experienced by the people who went into residential care, it might be expected that hospital staff would act as a source of information for carers.

Nine of the people being cared for in our sample had spent time in hospital before going to live in the home. One had been in and out of hospital over a period of 26 years, others had been for much shorter periods. Experience of hospital care, however, was a common characteristic of most of the people.

We interviewed only a small number of carers and our sample cannot in any way be said to be representative. However, on the basis of our interviews it does seem that hospital social workers are failing to make any significant contribution towards meeting the information needs of carers. For many people who look after a frail and sick person, a social worker attached to a hospital may well seem to be an obvious source of information and assistance, particularly as several of the individuals concerned were moved almost straight from the hospital to the residential home.

Only a small minority of carers - two out of the 13 - said that they had received any information from the hospital social worker. As one respondent put it:

The hospital social worker was sweet, but she didn't know anything.

In one case the information related to other ways of coping with the problem and the hospital social worker also gave information about the facilities available, although the carer commented:

The hospital social worker gave me a list - threw it at me - and I wrote to some homes. The information I got was sparse. They don't know about private homes.

In the other case the information seemed to consist of the hospital social worker attempting to persuade the carer to take back the person cared for even though the carer felt that she could no longer cope.

General practitioners

The other health-related professional who might seem an obvious source of information is the person's general practitioner. The picture which emerged indicated that doctors gave moral support but very little useful information:

The GP was not very helpful. They said keep going and if you can't, come back and we'll think again.

He was wholehearted in supporting the idea that she should go in but he didn't give any information.

In one other case, the general practitioner seems to have circumvented the carer:

The social worker got in touch with the GP and he agreed to _____ going into residential care. But he didn't speak to me about it.

None of the carers indicated that the general practitioners involved provided any information on our key indicators - alternatives to care, financial implications, local availability of facilities and the quality of life in the home.

Health visitors, district nurses, occupational therapists, etc.

About half the people being cared for had received visits from a health visitor, a district nurse or from someone like a community occupational therapist. In about half of these cases the carer had received information about residential care. In other words, three of our carers received information from this source. As one of the carers put it when talking about visits from a district nurse:

You don't know anything to start with so you begin with them and ask sensible questions.

These sensible questions elicited information about the range of homes available. In another case a district nurse helped a carer to make a successful claim for attendance allowance.

Two of the three carers who had received information said that they found it useful although the range of information provided seems to have been very limited.

Residential homes

Over half of the carers had some form of contact with other residential homes before the person they cared for moved into residential care. In four cases the home had been used for respite care and in one other for day care. These experiences gave the carer a basis for judging the type of care that might be expected with a permanent stay. In one case the carer had actually arranged a trial stay of six weeks and this served the same purpose.

Five of the carers made visits to the homes to look at the facilities for themselves. During these visits they were given information by the staff. Mostly this came from the person in charge of the home, although in one case the carer said that they had got information from:

Really anyone who was around - nobody in particular.

The information which the carers received seemed to be fairly general. Three out of the five, for example, said that they received no information about the financial implications. Yet most thought that the information gathered during the visit was useful:

Yes, it was useful. If you don't know anything, what you learn by going around and ringing up is useful. But you must do it for yourself.

Fairly useful, but we'd got the experience from ___ so we knew what to look for. She did talk as we went around.

Again, this seems to be a long way from the systematic provision or collection of information which could later be used to evaluate options and make choices.

Day centres and lunch clubs

Seven of the 13 people being cared for had gone to a day centre or a lunch club. As these often seemed to be used as an option before full residential care was required, they might be thought to be a good place to provide information about the residential care option. In fact none of the carers gathered any useful information from this source.

Home helps

A similar picture emerged with the home help service. Four of the 13 people being cared for received some form of home help service but in no case did the home help provide any information about residential care.

Other organisations

We asked the carers if they had approached any other organisations for information. Three said that they had done so. One had picked up information through membership of the Alzheimer's Disease Society. Another had obtained a list of homes from Age Concern. The third had approached Counsel and Care for the Elderly and had received a detailed letter about inspection and a recommendation to approach the local social services department. In this case the carer was trying to find out information about the availability of care in the private sector. All three carers felt that they had been successful in obtaining information from the organisations concerned.

Other people

We also asked if the carers had approached any other people, as distinct from organisations, for information. Four had done so. One had approached people she had met at meetings of the Alzheimer's Disease Society and the Carers' National Association. Others had approached friends and relatives. In at least two cases the carer mainly seemed to need the opportunity to talk generally:

I did talk to the home help because, quite frankly, I felt guilty and even now I feel guilty. I should try to soldier on.

I talked to my sister and one of my aunties - that's all. Until you've been involved you don't know.

The most useful information source

We asked the carers who had given them most information and who had given them the most useful information. Social workers came out a long way ahead on both counts. Over half the carers named the social worker as the person who provided most information and six out of 13 said that their information was the most useful.

Other people referred to were the head of a private care agency, the head of a residential home and, as the carer put it, 'ultimately, the hospital social worker.'

When we asked the carers about what they thought would be the best way for people in their position to get information, a rather different position emerged. Three people were clear that they thought it should be the social worker:

I think the social worker. Get in touch and keep asking questions you want answers to and don't give up until you're satisfied.

I think the social worker. She knows about people at home. I feel she is well equipped to give people information. The social worker would sit and let me talk - not just five minutes - she sat for one hour and let me talk.

Ideally there should be someone from the social services department who follows your case from beginning to end and from whom you can get guidance - ask questions until you're settled. That would take the uncertainty out of it and you'd go back to the same person and they'd know what you were talking about.

Another three, however, were equally clear that the general practitioner was the best person:

The GP is the only one in touch with everyone - the consultants, community psychiatric nurses and the district nurses. The GP is or should be the best, but isn't.

I would think the doctor's surgery, definitely. They can direct people to where they can find the information. It's the key rather than social workers. People know their doctors and they must get to know about the homes - some of them are doctor to the home and go regularly anyway.

The way through could be through the GP or the health visitor. But there is only a restricted amount of visiting because of the cuts. The GP holds the key.

One other person felt that the best way would be to give the information through voluntary organisations like the Carers' National Association and Counsel and Care for the Elderly.

These views reflect how people feel the system should be. We also asked them, based on their experience, where they would recommend a friend in a similar position to go. In response to this question only one person said that they would recommend the friend to go to the general practitioner. In contrast, seven said that they would recommend going first to a social worker. Three thought that it would be necessary to make direct approaches to the homes. One of these recommended trying to arrange respite or short-term care as it was the only way to try out a home.

An element of self-help was felt to be necessary. The key here was to get a list of homes and then start making your own contacts. One said:

Start with the social services list. They're not marked in any way - you can't tell the good ones from the bad. When you 'phone you find they won't take epileptics or very severely disturbed, etc. and they might not have a vacancy even if they do. You have to do it all yourself.

The general picture which seems to emerge is one in which carers have to rely to a great extent on their own resources to collect the information to enable them to make choices about residential care - choices that are made on behalf of other people. Social workers play an important role in helping them to gather the information they need but even so, there are major gaps. As a result, in many cases, decisions are made on the basis of insufficient information.

Key issues

The role of social workers

Clearly social workers play a key role in supporting carers with information. Particular problems seem to arise when there is a change in the social worker and a consequent break in continuity. There also seems to be some confusion about the role of the social worker in giving information about private sector homes, although, presumably this will be clarified as the new community care arrangements become better established.

More difficult to accommodate is the problem of personality clashes. Much of the information is transmitted orally and consequently the relationship between the giver and the receiver of information is very important. Personality clashes can never be completely avoided, but perhaps there should be some recognition of the fact that they do occur and a mechanism for replacing one social worker with another when they do. Certainly in cases where there is a strong relationship between the carer and the social worker the flow of information seems to be more effective.

The carer's relationship to the person being cared for

In most of the cases we interviewed, the carer was related to the person being cared for. In such cases the carer is in a reasonably strong position when it comes to making decisions on behalf of the other person. It is less straightforward when the person is being cared for by a neighbour. The carer may have developed a long and lasting relationship with the person cared for, and yet they can be excluded from the decision about residential care.

Information about benefits and financial implications

A move into residential care can have significant financial consequences for some carers. Any information system designed to provide information about residential care should be able to meet the need for information on benefits and on the financial implications of residential care.

Urgency

Many of the admissions were made with a considerable degree of urgency in response to an accident or to a sudden deterioration in a person's health. Any information system, therefore, should be able to accommodate the need to assemble a large amount of information in a short space of time.

Availability of facilities

One carer made the point that choice is only a reality if there is a surplus of provision. In theory day care and respite care is available, but it is not a viable alternative if there are no vacant places available. Thus it is of limited value providing someone with information about a facility to which they cannot gain access. Equally, it is debatable whether or not information about a facility should be withheld from a person on the grounds that demand already exceeds supply.

Feelings of guilt

It is apparent that many of the carers experienced feelings of guilt at having placed the person they were caring for in a residential home. Information about residential care and the alternatives to it may help to overcome these guilt feelings.