
7 Information for Carers: The Views of Carers of People Living in the Community

Many people who are eligible for residential care are looked after in the community by relatives, friends and neighbours, all of whom act as carers. These people are likely to play a significant role in any consideration of residential care. They may collect information about the options available; they may help the person concerned to consider the different options; in many cases they may themselves be instrumental in taking the decision about the course of action to take.

It is, therefore, important to consider the needs and role of carers in the overall provision of information about residential care. On the one hand they will have significant information needs themselves. On the other, they will act as a source of information for the person being cared for.

To learn more about their needs and their role in providing information we conducted in-depth interviews with a total of 35 carers. In 13 of the cases the person cared for had been admitted to a residential home. The remaining 22 carers were still looking after someone at home. For them, residential care was one of the possible future options open to the person for whom they were caring. We interviewed these carers to try to discover what their information needs were and how they obtained information about residential and other services. This section contains the findings from these interviews.

The carers were identified in three geographical areas through contacts with a local authority social services department, through the Carers' National Association and two of its branches and through Contact a Family.

Fourteen of the carers were looking after elderly people, most of whom had some degree of mental infirmity. Six carers were looking after young people with learning difficulties. In the remaining two cases the people cared for were in their late fifties. One had multiple sclerosis, the other had suffered a stroke.

The period during which the person had been acting as a carer varied from one month to 21 years. On average people had been acting as carers for six and a half years.

Information needs

Carers need a great deal of information on a wide range of topics. We tried to focus on their need for information about residential care. In our preparatory work we had assumed that, in order to make informed choices about whether or not to use residential care, people would need information about the different alternatives to

residential care; about the facilities available; about the sort of life that the person would lead in the home; and about the financial and other material implications of residential care. The pattern of information needs which emerged from the interviews was rather different.

We asked all the carers whether or not they had tried to find out about residential care. Eight of the 22 said that they had. Taking this group first, we asked them what they had wanted to know about. The range of information sought was wide. One carer, for example, responded:

I wanted to know if the staff have got to be kind, friendly and caring. The place has got to look clean; the dining room has to be friendly and clean looking. I wanted to know about the money aspects. I think I wanted to know if he would get a room to himself; what the bed was like; whether he would have a commode; how far was it to the toilet?

One other carer wanted simply to find those homes which she could eliminate. Overall, however, it was possible to group the information needed into a number of categories.

What most people had wanted to know about, however, were matters which can broadly be described under the heading 'quality of life'. This includes the elusive concept which is best described as the atmosphere of the home - the answer to underlying questions like 'is this the right sort of place for them?' 'will they feel comfortable here?'. The carers used a range of different words and phrases to describe it - happiness, kindness, how the old people seemed. It is a difficult concept to put into words, but there was a clear need for information about the atmosphere in the home. Closely related to this is the need for information about cleanliness, the standard of care that the person could expect and the type of room they would get.

People wanted to know about the administrative or procedural aspects of the home. One mentioned the home's acceptance criteria, others wanted to know if the residents were able to go out by themselves or in a group. Two carers wanted to know whether the people they cared for would have a room of their own, and if not, what sort of privacy they would get. Three carers were interested in the eating arrangements and the quality of the food.

Carers were also interested in the staff working in the homes. One wanted to know about the attitudes of the staff, another simply said that they were interested in the quality of the staff.

Financial aspects of residential care were important for a number of the carers. Three said they wanted to know about the fees, another was more interested in the money that would be given to the resident.

Finally two carers mentioned the general facilities in the home and the home's location.

In summary, then, carers who had obtained information about residential care were interested in the atmosphere or quality of life in the home; the administrative and procedural arrangements; the staff; the financial aspects; and general matters such as the facilities in the home and its location.

A rather fuller picture emerged when we asked all 22 of the carers in our sample what sort of things they thought people and their carers most wanted to know about when they were contemplating residential care.

Again, the quality of life was thought to be the highest priority. Nine of the 22 carers actually mentioned the quality of life and the quality of care as matters they thought people would be interested in. Four mentioned medical attention and a further three referred to the appropriateness of the home for the person's particular illness. Other topics mentioned were the atmosphere in the home; the use of drugs; the kind of residents; and the home's ethos.

The next largest group of concerns was focussed on the facilities and activities in the homes. Eight carers thought that people would want to know about activities and outings, four made specific mention of facilities and four carers felt that people would want to know about the mental activity which a resident could expect - in one case, where the carer was thinking in terms of young people with learning difficulties, there was a reference to schooling. Food was also mentioned as a matter for concern.

A considerable number of the carers felt that people would want to know about the staff in the home. They identified concrete issues such as the qualifications of the staff, the ratio of staff to residents and the sex of the staff. They also mentioned less easily measured aspects such as the attitude of the staff and the kind of staff.

Information about administrative and procedural matters did not feature so prominently among the total sample. Carers did, however, identify a number of aspects which they felt people would want information about. These included whether or not a person would have their own room; whether they could retain their own possessions; what the regulations were; when the people had to get up in the morning; the extent of any waiting list; the arrangements for holidays and for visiting; and generally the degree of freedom which a person could expect.

Relatively low on the list of priorities came the financial arrangements. Here most of the respondents identified the costs of the care as the thing which people would want information about. They also mentioned sources of financial assistance and the arrangements for providing the resident with personal spending money.

Four of the carers identified the physical environment and the location of the home as important topics. A further two said that they felt people would want to know about arrangements for the carers. One identified the need to support the carer's decision and another, the arrangements for contacting the carer if the resident was in distress.

This provides quite a full catalogue of topics about which, it was thought, people contemplating residential care would want information. In some cases it would be relatively easy to collect and present the information: the ratio of staff to residents or the fees charged, for example, are quite straightforward and information can be provided in an objective way. Other matters, however, call for a much more subjective judgement and in these areas the nature and form of the information collected will depend much more on individual requirements.

It is interesting to compare the information which carers thought to be important with our initial assessment of information needs. We thought that people faced with a decision about residential care would need information about the alternatives to residential care; the range of residential facilities available; the sort of life that residents would lead; and the financial and other material implications of the move into a residential home.

None of the carers made any reference to the need to know what the alternatives to residential care were. It might be reasonable to assume that the carers themselves felt that they were aware of the alternatives. They were after all people who had been caring for someone for an average of six and a half years.

It was perhaps more surprising that the carers did not identify a need to find out information about the range of residential facilities that were available. The information needs identified by the carers were concerned almost exclusively with the process of evaluating homes once they had been identified. No-one perceived that people would need first of all to identify what homes were available.

Nearly all the attention was focussed on the group of information needs which we had identified as 'the sort of life that residents would lead'.

Carers also identified the need for information about the financial and other material implications of the move into residential care.

Sources of information

We wanted to find out which sources of information carers in the community chose when looking for information about residential care. We also, however, felt that it was important to know something about the sources that carers used to obtain information about other services available to them as carers.

We therefore began by asking them what were the main ways in which they found out about services available to people being cared for at home and their carers. We then asked about respite care and whether or not they had obtained any information about it. Lastly we asked them about residential care. First, we concentrated on those who had considered residential care, asking them how they had gone about collecting the information. We then asked all the carers how they would go about trying to find out about residential care, what they felt would be the best way for someone in their position to be given information, and finally, where they would advise a friend to go looking for information.

Information about services generally

The carers in our sample made use of a wide range of community services. Most common were those which involve getting the person cared for out of the home for short periods. These services range from lunch clubs to respite care in residential homes. Other services, such as meals-on-wheels and home helps, come into the person's home. There is also a wide range of community health workers who visit and deliver their services within the home. These include community nurses, community psychiatric nurses, occupational therapists, district nurses and home care assistants. Carers and the people they care for also receive medical services from hospitals and specialist clinics. Young people with learning difficulties call upon

school and educational services. Finally, there are specialist services provided by voluntary associations such as RADAR, Age Concern and the Red Cross. All of these were being used by one or more of the carers in our sample.

In many cases the carer was being supported by more than one service. One carer described the help she received in this way:

The home care girl from social services gets him up, washes him and does anything else that's needed. In fact she does three times the amount of work she is supposed to. A care assistant comes to put him to bed. From the doctor we get the district nurse and an auxiliary nurse to give him a shower once a week. Then a home help comes in for two hours a week because I'm asthmatic.

In contrast, one carer when asked about the support services she received replied:

None. My father will not go anywhere.

The range of sources of information was as wide as the range of services provided. During the interviews it became apparent that social workers play a key role in providing carers with information about the services available. They were mentioned as an information source by eight of the carers and a further two spoke of the social services department:

The only person likely to give information was the social worker. Anything new, she'd say 'this is what we're doing' so I could follow it up.

Another carer was less complimentary:

I got passed from one social worker to another until I got lost.

Of broadly equal significance to social workers were hospitals and specialist medical staff. Six carers mentioned hospitals as sources of information. Three others were more specific, referring to hospital consultants, hospital social workers and nursing staff:

The hospital social worker was helpful - had bright ideas about ways of looking after him.

In contrast, one carer was critical of the lack of information provided by the hospital:

Nobody explained anything, for example, that incontinence pads were available. Nobody explains or tells you at the hospital before you come home - you learn by trial and error.

Other, community-based health workers were also important. Here, though, the range was wider. It included district nurses, physiotherapists, community mental health teams, health visitors, community psychiatric nurses, community nurses, occupational therapists and domiciliary nurses:

The community psychiatric nurse came to see me and explained the attendance allowance and the difference between the two hospitals.

General practitioners were mentioned as a source of information by only one carer, although another referred to a GP-practice sister. Generally, however, doctors were not seen as a good information providers:

Quite candidly, I did not get a lot of help from doctors. I can't understand why he never says 'Can you manage?'. It would help. He just sees the sick person not the carer.

Institutions were important sources of information, particularly for those with learning difficulties. Schools and a pre-school counsellor were referred to by four carers. Others referred to adult training centres, day centres and the staff of residential homes. One carer said that a pre-school counsellor was the main source of their information, another said:

Everything I learned came through the schools.

Voluntary bodies had been used by six of the carers. Two were related to particular diseases - Alzheimer's Disease Society and the Multiple Sclerosis Society. Also mentioned were the Carers' National Association, carers groups and the Citizen's Advice Bureaux.

Finally, one carer said that they had obtained information from friends while another had got information from newspapers, both local and national.

In some cases contacts were made by chance or through the carer's own informal networks. One said:

I heard about Carers standing in a bus queue and overheard a conversation - I butted in and they sent me all the gen.

Another made the comment:

I have got a good friend in the doctor's surgery so I get her to ask if there is anything I need.

Most of the carers were able to cite more than one source of information and often it was apparent that one contact had led on to another:

The district nurse arranged for the social worker to call. The social worker then arranged for the occupational therapist to come for aids.

Frequently, the pressures on the carers make it difficult for them to develop a systematic approach to the business of collecting information:

I've fallen into things because looking after ____ is so difficult. I've not had time to reflect. You just need sleep and help to carry on. It's easier to carry on than to think about asking for help. You know your own case best and you don't like to have to keep explaining things to different people.

The overall picture which emerged was one in which carers had received bits of information from different sources at different times. It did not seem that these, when added together, provided the carer with all the information they required, in fact some commented on their incomplete information:

I never had a social worker. If I wanted to know anything I would ring ____ [the carers' support worker]. You have got to find it all out. You've got to ring round and round. I've had very little information. He was discharged and we were in limbo land except for the occupational therapist.

Information about respite care

A significant proportion of the carers had used respite care at some stage - 15 out of the 22 in our sample. It had not always been a success:

Mother wouldn't settle and I had to come back after two days holiday and take her home.

In other cases the person being cared for refused to go:

The doctor was very insistent about respite care but there's no way he's going to go.

The main source of information about respite care was the social worker. Eight of the 22 carers had been given information by their social worker and people generally seemed pleased with the information they received, indeed all eight stated that the social worker was the best source of information.

Three carers had been told about respite care by their doctors, although interestingly no-one later mentioned doctors as a good information source. Perhaps because in one case:

The doctor told me about respite care - said get in touch with the social worker if you need to.

In situations like this it is quite likely that information received from the person who can actually arrange the service will carry more weight.

Community health workers also gave information about respite care - they were referred to by four of the carers. The staff in residential homes were also mentioned as were schools and teachers.

Six of the carers had received leaflets about respite care. These came from the institutions offering the care, from social services departments and from voluntary organisations. Only two of the four carers found the leaflets useful. One said:

It's a start, but the information was not specific to the different areas.

Another carer said:

I mostly knew it already. But for someone who didn't it would be very helpful.

Information about residential care

To obtain a full impression of the sources of information that people might turn to when considering residential care we asked a range of questions. We began by asking whether the carers had ever tried to find out, or had talked to anyone, about residential care. We asked those who had what they had done. For those who had not explored residential care as an option, we asked them where they would look for information if the need arose. We then tried to get people thinking more widely, outside the context of their own situation. To do this we asked them what they would advise a friend who wanted to know about residential care. Finally, we asked them what they thought was the best way of providing information about residential care to people in their position.

The overall picture which emerges is that people try to acquire information about residential care from a wide range of sources that do not differ greatly from the sources used to gather information about other services. Social workers and social services departments are both used as major information sources and perceived by many to be the most appropriate places to go. In contrast doctors and general practitioners are not much used but there seems to be a feeling that they could play an important role. Health workers, whether based in the community or in hospitals are quite important, but given the general state of health of the people concerned, they were not mentioned as frequently as they might have been. Voluntary organisations, self-help and contacts with friends and other carers were seen to be important.

Thirteen of the 22 carers we interviewed said that they had not tried to find out about residential care. They had, for one reason or another, rejected it as a possibility. For some it was simply a case of putting off the decision until later:

I wouldn't want to think about it before I had to.

When ____ comes into his teens I'll be looking around for something more permanent. I'll want to make sure that ____ is set up for when we are older.

One person had tried residential care and, on the basis of the experience, had rejected it:

I always thought what was on offer was not going to be good enough. I found somewhere with the help of social services but ____ was so badly injured by the other residents that we realised that we could never put him into residential care.

Mostly, though, people had simply rejected it as a possibility:

In no shape or form will I think about it.

I have never thought about it. Sometimes I've been that desperate but it's disloyal to want to put him away.

We asked these carers what they would do if the time ever came when they needed to consider residential care. Over half of the 13 carers said that they would turn to a social worker or go to the social services department. One carer said that they would telephone the social services and ask to speak to the divisional director.

Two people said they would approach their GP and two others said that they would make contact with residential homes. Another referred to the hospital:

I would go to the hospital first because they have got all the information and lists.

Others said they would contact occupational therapists and the Carers' National Association. Two people said they would approach other carers. One because she was a member of a self-help group, the other simply said:

I would go to another carer - one who has been caring for a long time.

When we asked the carers who had already tried to find out about residential care we were able to identify a rather wider range of sources. Social workers and the

social services departments were still mentioned more frequently than any other information source.

Half the carers said that they went direct to the homes. In one case this was because the person cared for already visited the home for respite care. In another case the carer rang around a number of homes having first obtained a list from the social services department.

The other sources of information were each mentioned by only one carer. They were: the hospital, the hospital social worker, the school, the day care centre, the church, friends and other carers and the community health council. This last source of information seemed to have been particularly effective:

The community health council had a list and some small pieces about each home. It is very useful and I've been through it and weeded out some, for example, those that won't take confused people.

In some cases the carer had been made to confront the issue of residential care:

I have looked into it and looked at a home. My aim is to keep ____ at home. Basically I want her to die here. Officers at ____ [a residential home used for day care] said 'You ought to be thinking about residential care.' But I won't.

It came to the point when the doctor talked to me about it. They said 'You won't cope with the next stage.' I said 'You teach me and I'll cope.' So I won't have it.

In other cases the process seemed much more random:

I looked in the Yellow Pages and relied on word-of-mouth.

About half of the carers had been given leaflets of some kind.

We wanted to get the carers to think a little more widely, in case there were factors particular to their circumstances which constrained their choice of information sources. To achieve this we asked them what course of action they would recommend to a friend who needed information about residential care.

Again the social workers and social services department were clearly the preferred source of information:

I had a neighbour who did ask and I told them to get in touch with a social worker who will get the ball rolling.

Go to the social services. They will put you on the right road.

Five people said that they would recommend going to a GP:

Initially go to the GP - they should tell you. Some practices have lots of information. Our GPs reside in the same place as district nurses, so they are on the spot.

District nurses and community psychiatric nurses were mentioned by two carers:

Try the community psychiatric nurse if you can't go straight through like we can because we are in touch with the hospital. And keep pestering and don't give up.

Two carers recommended the Carers' National Association, commenting that it is very supportive. Other sources mentioned included schools, Citizens Advice Bureaux, the Member of Parliament - as a last resort - and the Yellow Pages.

A number of the carers said that they would stress the fact that it was necessary to do much of the work yourself:

It's up to you to do the finding out.

Go round and inspect - you've got to take the initiative.

Finally we asked all the carers what they thought was the best way for people in their position to get information about the services available to them. This question produced a slightly broader range of information sources. The social workers and social services departments still came out ahead of the rest:

The best way is through the social work department. A designated person should be available in the social work department who you can ring up and ask.

Social workers should be the centre of information.

People also felt that general practitioners and other doctors should play a more significant information role:

Either a GP or the neurologist - they could give you something to read and then you'd go to the GP more armed and start to discuss with more knowledge about what's there.

The doctor's surgery should be the place, definitely. I asked one of the doctors if they told carers to apply for attendance allowance and he said no. People are familiar with the doctor and that should be where they can get a leaflet - it would be easy for them to hand it out.

Hospitals and community health workers were the next most frequently mentioned potential sources of information, followed by day centres, the Citizens Advice Bureaux, carers themselves and the Carers' National Association. One carer referred to an information pack which their local social services department had produced for carers. They felt that the pack was very useful and said:

The best way is with information packs. In some way we need leaflets. Information is there if you can get it. If it is all together in a pack it's easy and you can go from there.

Throughout there is a heavy reliance on oral information. Carers were given relatively little information in printed form. When they were it was perceived to be useful.

Key issues

The role of the carer

The carer plays a dominant role in seeking information, in processing it and in making any decision at the end of the day. Very few of the carers talked about discussing the matter with the person being cared for, or presenting them with the information.

The strain under which carers operate

Many of the carers are working under conditions of considerable strain. As one put it:

I've not had time to reflect. You just need sleep and help to carry on. It's easier to carry on than to think about asking for help.

Yet many of the carers felt that they had to take the initiative and to seek out the information for themselves. The carer should not be expected to collect all the information. Instead greater efforts should be made towards ensuring that information is delivered to the carers.

Emotional feelings associated with residential care

It became clear that for many of the carers, even to consider residential care is tantamount to an admission of defeat. Such attitudes are likely to inhibit carers from collecting information until a point is reached when the range of options is so reduced that residential care is inevitable. Any information delivery system should be so designed that it takes these emotional feelings into account.

The role of voluntary organisations

Voluntary bodies play an important role in meeting the information needs. At a local level, however, much of the information produced by national bodies can only be of limited relevance as it is necessary to frame the information so that it has general applicability. Such nationally-produced information should be supplemented by information which is relevant to the particular local circumstances.

Information packs

One of the social services departments mentioned by carers in our sample had produced a carers support information pack. This was very well received and highly thought of. Such information packs provide an excellent means of communicating information to the people who need it. The printed information, however, will almost certainly need to be supplemented by information given orally by social workers and others.

Oral information

Most of the information given to the carers was communicated orally. Some leaflets were made available, but their distribution was relatively limited.

Information and service delivery

Information given by people who had some control over the delivery of a service seems to have carried greater weight with the carers. This is perhaps not surprising, but it should be borne in mind when considering the best ways of ensuring that information is given to the carers.