
3 Information for Elderly People Moving into Residential Care: The Views of Heads of Homes

This account of the information needs of elderly people moving into residential care, and of the current patterns of information provision, is based on in-depth interviews with seven heads of homes for elderly people. Four homes were in the voluntary sector, three were private residential care homes.

We explore what heads of homes thought about the ways in which elderly people and their relatives and carers find out about residential care, and about the quality of this information. We then consider heads of homes' views on how much professional workers know about residential care provision, and how they acquire and transmit this information. Finally, we outline their views on the role of written information and of alternative means of imparting information.

Finding out about residential care : elderly people and their relatives

Overall, there was a general feeling amongst heads of homes that information was not readily available to those who needed it, at a time when they were facing a major change in their lives. Carers, relatives and the elderly people themselves frequently have very incomplete information about residential care in general, about the options available to them and about how to make a decision. People get information from many different sources, not all of them reliable. There is no obvious place to go for information and advice:

There's no system and its very unclear where to go. It depends on luck and who you happen to know.

People find out about residential care provision in all sorts of roundabout ways and may contact a range of different professionals and agencies for help. People who are expected to be able to provide information about the existing provision include professionals whom they already know, such as district nurses and psychiatric nurses; recognised sources of general information such as advice centres and voluntary agencies; local community groups and organisations such as churches or religious groups. A hospital social worker will be involved if a person is moving straight from hospital. Friends and neighbours are important sources of information and advice.

Several of the heads of homes suggested enquirers should contact Counsel and Care for the Elderly, a specialist advice agency, for further information, but individuals do not always know where to refer enquirers for more reliable information if they cannot provide it themselves.

Many people get lists of homes from the local authority social services department but this is inadequate as it does not give enough information or opinions and guidance on individual homes:

The local authority sends out an alphabetical typed list of all the residential homes in the Borough. There's 80 on the list but they get no further help as they're not allowed to say anything about any particular ones.

Once they start looking they get it [the information], but it's very difficult. After all, an independent body can only list places - it can't say if they're good or bad. It's the same with schools, you just have to suss them out.

When it comes to approaching an individual home, people rely heavily on recommendations from friends, relatives of residents and local contacts such as the church. One head of home described the ways in which people hear about the home:

We get lots of recommendations. People mention us to churches and we get lots from the church. Locally lots of social workers know us. Counsel and Care for the Elderly put people on to us. Social workers sometimes come and ask for information. We did a PR thing some time ago to all the doctors in the London area. Sometimes from organisations for retired people who might help with funding. Or other homes without suitable vacancies might recommend us.

If people get information about residential care in haphazard ways, this is little different from their access to information about services for people in the community. Heads of homes think that elderly people and their carers and relatives themselves expect to obtain information about community services from many different sources, including the social services, doctors, libraries and advice and voluntary agencies.

Their access to information depends crucially on how mobile and active they are, whether they can get to sources of information, and whether they have a contact or a way into 'the system'. Where they are housebound and have to rely on a contact such as a GP or social worker, much depends on how well informed that person is. One contact can open up access to all sorts of information and services:

I knew a number of carers who struggled on with no help, but once they got a tap in, they might get quite a lot of help, depending on the area.

The GP and other health services are potentially very useful ways of getting information about community services to people, most of whose needs arise from health problems. Even people who are not able to get out and about much will usually be in a GPs' waiting room or outpatients' clinic at some time. So, although social services are the main providers of care services for people in the community, it is important that people can get access to these through their contact with the health service.

According to heads of homes, it is a mixture of accident, circumstances and previous experience which determines who people contact for information, if anyone, and how successful they are. If there is no widely understood or accessible system of getting information about services for people in the community, they are likely to start from a position of inadequate understanding of services or of where to start looking for help, when it comes to finding information about residential care.

People can be quite easily deterred from seeking help if they receive an initially unhelpful response:

Local authorities vary a lot. People only need one off-putting experience.....then many people feel there's no point in going through with it. They get curt or rude responses, or the phones don't get answered, and people don't try again. Then they're no longer Part III-able and they have no choices.

In this situation, heads of homes thought that some people are more likely to obtain information than others. Those who are most energetic or determined may be more successful, and others are effectively denied access to information:

Most people who are able to look after themselves get the information all right.

Some poor things on their own may not have any contact with a social worker or a relative to help them.

While access to a well-informed and helpful professional is of vital importance, it is important to recognise that many admissions to the homes were made without any professional intermediary being involved, so the elderly persons or their relatives did not get access to information and advice that way:

Very often a social worker isn't involved. I've never dealt with a social worker. The hospital social worker may refer someone here and then wash their hands of it. The bulk come from the hospital social worker so they should be better informed. You think they would be desperate to find out.

Nevertheless, people do often go to social workers, doctors and other professionals for help. The professionals themselves, however, get their information in various, haphazard ways which depend on them being in the right place at the right time, and are consequently not always reliable sources of information:

It's pathetic really, extremely limited. Normally the social worker and the GP are the only people they contact. I don't know why but social workers seem so limited. This home has been here for fifty years but hospital social workers, especially, don't seem to know we exist.

I was the first one (private home) in the Borough, so it's all done by personal recommendations now. Also, local GPs might come to sign a death certificate so they know when we have a vacancy.

One head of home, who had previously worked in a day centre, had first hand experience of trying to collect this sort of information:

We had a very hard job to find out what was available so relatives could make a choice. We never found the information anywhere. We wanted information about where the homes were, the sort of residents, prices, policies and activities. I realised then how difficult it was and it's much harder for the carers.

Heads of homes thought that the lack of information is particularly dangerous because it allows all sorts of misconceptions about residential care to go unchallenged. People have outdated ideas about residential care and impressions they have picked up through television and the media. They expect to lose all their

independence and individuality and are afraid to complain about anything they don't like.

They have an idea of a Dickensian workhouse, always asking about rules and visiting hours. Their generation saw the hospital as the workhouse. Horror stories go about.

Finding out about residential care : professionals

Professional workers may not always be involved in decisions about moving into residential care but it is clear that many different professionals - in the social services, in the health service, in the voluntary sector - as well as many informal advisers are expected to be able to provide information. It is crucial, therefore, that they themselves are well informed or at least know where to send people for help. However, there do not seem to be any systems or structures in place to ensure that these professionals are fully informed or can confidently suggest other sources of local advice. Heads of homes said that professionals rely heavily on informal and haphazard ways of acquiring information, building up their own local knowledge and sometimes contacting national agencies for information.

I used to think social workers knew all the answers, but I had to give them answers and suggestions. They ring Counsel and Care for the Elderly and ask their colleagues. As far as I can work out these are their main means.

Asking your colleagues and building up your own local knowledge are always important means of getting information, but not entirely reliable:

Social workers who work in an area for a long time pick things up but there's a high staff turnover and you can't rely on that.

Moreover, local knowledge and personal stores of information are difficult to organise and make accessible to other people. It was widely felt that the agencies and departments involved were not good at communicating information to one another.

Information is sparse but could be found. It could be made better. I find lots of departments don't pass information on to another. Possibly it's the time factor.

The Council are aware of us, some of the nursing home beds are allocated to the Council. But I've lived in this borough for twelve years, worked as a geriatric nurse, but I'd never heard of this home till I applied for this post.

Social workers, of course, have access to the lists of private and voluntary sector homes registered with the local authority but this only gives very basic information, and is inadequate for families and professionals alike. It does not include information about vacancies or recommendations. One of the heads of homes felt that there was plenty of opportunity for the local authority to capture and use this information, but went on to point out that social workers are not allowed to supplement the list by recommending a particular private home.

Social Services come round all the time - and it will be more often, they tell me, after the Griffiths report - so they must know. But they're not allowed to recommend anywhere, though sometimes they might say 'try those first'.

The view was also expressed that some social workers are not interested in finding out about residential care outside the local authority's own provision. Doctors and GPs are often expected to be able to provide information but their access and information resources are even more limited. They pick up some information if they visit patients in elderly people's homes but this is very limited, localised information.

Some of the homes were trying to provide more information about their facilities to professionals, usually by sending out brochures and leaflets. However, they were unsure about the success of this strategy. It was difficult to know who to send it to and to get the right information across:

We did one big mail out last year when applications fell very low - sent it out to GPs and social services departments for quite a distance around London. It was quite successful and led to more referrals, though they may not be the proper ones.

People like us find it very difficult to find out what services there are - what are the different departments, the heads of departments etc. Believe me I've tried and the whole thing is a mire of misinformation....I've mailed out 100 solicitors, GPs, hairdressers, dentists, accountants - 100 of everything I can think of, as a way of trying to find grannies.

Another head of home was firmly set against advertising, feeling that it gave misleading information and that people should rely instead on their own judgement in assessing places.

It's a puzzle to me how lots of the places get filled. There's lots of new people in the business for funny reasons, they have very little interest in caring. How do they get filled?

Another option for owners of residential homes trying to provide information about their facilities is to use one of several national agencies that specialise in collecting and providing information about residential care homes. Several mentioned Counsel and Care for the Elderly as a source of information and referrals, but only one mentioned two other agencies - Gracelink and the National Bed Line - saying that although they subscribed, they had never received any referrals that way.

In the view of heads of homes, then, for professionals there are many obstacles to becoming well informed about residential care and being able to pass this on to clients and enquirers. There is no clear agreement about the allocation of responsibility for either disseminating and updating information within and between agencies or for passing it on to the public. They lack the time, and sometimes the motivation, to individually seek out the information that is required. In these circumstances too much depends on the individual:

A lot is up to the individual social worker and how much time and interest he or she has in the individual client.

The role of written information and visits

All the homes had some written information, usually a booklet or brochure, about their facilities. In all of the homes the same information was intended for professionals, elderly people and carers. One of the booklets was quite out of date about its policy and approach.

The information was generally used to give to anyone who made enquiries or visited the home, and sometimes for publicity and advertising. The booklets were not seen as the major source of information for people enquiring about the home, and one owner thought it was of no value at all:

I haven't got a brochure but I have got a little leaflet which I produced under pressure from the Council. I can't see the point of a brochure, but they said just write down your aims and objectives. It's ridiculous.

Visits to homes were by far the most important and valuable ways of getting information about what residential homes were like. All of the owners encouraged elderly people and their families to come and look around and talk to the staff:

Quite frankly, if you want to know what a home is like, go and spend a day there. Every day has the same routine, with different distractions for staff and residents.

One of the best ways of getting information is chatting to residents on a visit, especially if they come for a day and it happens naturally.

These invitations were usually taken up by enquirers but one owner commented that people sometimes snap up vacancies over the phone, without having visited the home. It is important to realise that the visit is an important source of information for the staff as well. They use it to judge whether the elderly person would fit in and to assess their degree of disability. This can impede the exchange of information - families will sometimes exaggerate or understate the extent of the disability in order to make their relative fit the criteria for admission.

Admissions sometimes happen in a hurry and this prevents the proper exchange of information. Homes find themselves under pressure from hospitals to accept new residents:

We have a lot of problems with our contractual beds with the health authority. The consultants dispute our process for assessments, visit and choice. We insist the head of home must decide, and people should be given the choice.

They never understand why someone can't come straight into a vacancy. They should get the information earlier and understand the process for assessment.

Trial periods of staying in the home were also encouraged, where possible, and these should be as long as possible. A day or even a week are not long enough to settle in and decide whether or not you like the home. Stays in the home also helped people to feel more in control of the decision:

Sometimes, when people aren't sure, we suggest they come in for a short stay, if we have a vacancy. Usually it works and it's good because they don't feel they have been forced into it, but have made up their own minds.

They should try and spend a day in a few homes, and ideally spend a month in a home before they settle anything.

What do people need to know, and want to know, about residential care?

There is a wide range of things that people need to know about. Medical arrangements and nursing care are very important, particularly what happens if the

resident becomes seriously ill, and whether it is possible to continue to be registered with the previous GP. Food and meals, as the focus of the day, are very important, as are the daily routine, single rooms and the possibility of bringing your own furniture and possessions. People want to know about services such as hairdressing, chiropody, library service, activities and outings, the qualifications and experience of the staff.

The head of home is generally an important source of information and advice for prospective residents and their families, and not only of information about the particular home but about residential care in general. They vary in the extent to which they provide information and referrals to enquirers who are not suitable for their home but they clearly form an important part of this very loose and fragmented network of information providers, particularly for people who approach the home without seeking information anywhere else first. Many people arrive at the home ill equipped to begin finding the information they need and have to be guided by the staff:

I start off by saying 'Do you want to know the rules - there aren't any'. That surprises people and lightens the atmosphere. I might get one or two questions but it's never sufficient. I have to lead people into it.

They may lack even the most basic understanding to help them to begin to seek information:

The most important thing is getting it right, but people don't even know the difference between a residential and a nursing home. The hospitals might say the person doesn't need nursing care, but they may still need nursing home care. People don't ask about this.

Sometimes the heads of homes find that people do not want to receive information, for various reasons;

They usually don't know what questions to ask and they're not always 100% in agreement with coming - they may have agreed under pressure or come from hospital.

Families ask the same sort of things. Some ask a lot of questions, some don't care.

Some local authorities provide lists or checklists of questions to help people find out information:

They all come with the same list of questions from the social services that tells them to talk to the residents, note the smell, ask about meals, arrangements for visits, for doing the washing, is there a hairdresser, what time do they go to bed and so on.

The financial implications of moving into residential care are an important area of information need. It is a complex area of social security regulations and local authority policy of which people have little or no knowledge when they are considering residential care or even at the time when they approach the homes themselves, and it is an area which continues to worry elderly people who foresee their money running out.

Quite often people don't have a clue when they come to us. Many don't realise about attendance allowance, and the GP doesn't always know. Some social workers do - it depends on how long they've been in the job. People who do know maybe go to the Post Office or the DSS. But elderly people on their own don't know where to start, or haven't got the energy to start.

They should be realistic and well-informed on the financial side - that's the one thing that worries elderly people.

The homes usually refer people to the DSS or Counsel and Care for the Elderly for help but also spend time and effort themselves explaining the situation and helping with form filling. One pointed out that they are not allowed to give actual financial advice.

The heads of homes felt that, above all, people need personal contact and advice as well as straightforward information. Moving into residential care can be a traumatic and upsetting time and information often gets forgotten or is not absorbed and has to be repeated.

The urgency with which people are often trying to find a suitable residential care home often gets in the way of full information gathering and exchange. Decisions may be put off to the last minute because they are so upsetting to everyone involved, and this in turn reduces the options to what is available at the time:

People should be encouraged to plan ahead so that they can make choices. It should be talked about as easily as insurance. We still get a lot of relatives feeling guilty - we have to get away from that.

Because it's such a major decision it shouldn't be rushed. You need to see if they can absorb the information. It might be given to them but afterwards you find they haven't absorbed it. We have a problem - filling beds to balance the books, and giving time to new residents to make decisions. If we could encourage them to get information at an earlier stage we'd be in a better position.

Improving the provision of information

Heads of homes recognised the difficulties of trying to meet the range of information needs about residential care. Some felt that any initiative had to start by challenging people's attitudes and preconceptions about residential care:

There is a need for a high profile agency across the country. A PR exercise like for AIDS would get the message across to people about where to go - provided the information was good when they got there, people would get the message. But money needs to be spent.

We need a nationwide campaign to change people's views - over a long period of time.

The issues about the provision of written information were familiar to the heads of homes. Leaflets could be posted to pensioners or made available in all sorts of public places - doctors' surgeries, hospitals, DSS, tube stations, post offices, day centres - but none of them would be read unless people were interested. As people tend not to plan ahead for moves into residential care there is little value in the widespread dissemination of leaflets, in the hope that they will be picked up by someone who needs it.

GPs and doctors are likely to be the most effective way of getting information to most people, although they are not seen as being very well informed at present. Potential residents and carers tend to feel comfortable asking them and the doctor is often a respected source of advice:

I think doctors, GPs. It's a traditional form of authority, still a highly respected member of the community. It doesn't matter if he's good or bad, he might have been their doctor for forty years and they think he's good.

Key issues

Independence and objectivity of the information

The requirements for local authorities to be objective in their provision of information about private and voluntary sector homes can be seen actually to restrict people's access to information, as the information is reduced to a simple, factual list. However, this objectivity is lost when individual professionals respond to people's needs for advice and recommendations by making suggestions that are based on their own information, which is personal, subjective and incomplete.

It is not yet clear whether the new 'arms-length' inspection units for residential care will be better placed to provide objective, independent and more detailed information than the present system. There may be a role here for voluntary organisations or independent organisations to compile authoritative information that can secure the confidence of the public and homeowners.

Responsibility for giving information

It is widely accepted that people turn to professionals with whom they are in contact for information but there appears to be a lack of clarity about the responsibility of various professionals to provide information. The extent to which they do so seems to reflect their personal inclination and interpretation of their job, rather than a task and responsibility that is formally recognised as part of their role. Heads of homes are themselves important sources of information but have no statutory or professional requirement to ensure they are well-informed about local and national provision and policy.

It has to be recognised that the various professionals and agencies concerned have many responsibilities to fulfil and that some of these may come into conflict with the provision of full information to their client, particularly with the need to allow plenty of time for the information to be absorbed and considered. Hospital staff in particular are often under great pressure to move patients out of hospital as quickly as possible. The responsibility for providing information, and how this should be done, probably needs to be made more explicit.

In a system where individuals and families can independently make the decision that an elderly person should move into residential care, without any contact or consultation with advisers, there is always the potential for ill-informed decisions to be made. Should there be a requirement or mechanism to ensure that people in this position are given the opportunity for access to formal information and advice?

Ensuring the communicators are well-informed

In circumstances where people rely heavily on information from a wide range of individuals and professionals it is essential to ensure that these communicators are well informed. It appears that very little exists in the way of structures and procedures to ensure that professionals in the community, homes and hospitals are given this support.

It would be extremely difficult and expensive, and probably impractical, to ensure that all potential communicators and advisers are fully informed. To ensure that the information is given as accurately and fully as possible it may be necessary to place restrictions on who is allowed to give information. This requires sensitive questions of the allocation of responsibility and professional status to be addressed, and it may be necessary to introduce some training for some staff. There are indications that many professionals would be relieved to know there was a reliable source of information they could use or to whom they could refer people.

Making sure the communicators are well informed means deciding who is responsible for gathering, updating and disseminating the information. Additional resources may be required. Inter-agency communication is essential, particularly between local authorities and health authorities.

Oral and printed information

All the homes provided some sort of printed leaflet, but the priority that was given to ensuring they contained full and accurate information varied considerably. There was a lack of clarity about the precise objectives of the written information and the same leaflets were used for different purposes, including advertising, informing enquirers and informing residents. The access to printed information other than about individual homes was very limited.

There is a heavy reliance on oral communication. This fulfils the need for personal contact, repetition and discussion, advice and recommendation, and helping to explore what the enquirer needs to know. However, this can only happen when the informant has the time and knowledge to do it. The potential for inaccurate information to be given is considerable as there is no easy way of checking that what is being said is correct.

There is probably a need for more general printed information about aspects of residential care that can reinforce oral communication, not necessarily replace it, and for guidance to homes on the sort of printed material they should be producing.

Timeliness and planning

There is little opportunity to inform people over the period of time leading up to the admission to residential care, because of a general reluctance to look ahead to this possibility. Information provision has to be compressed into a short, busy and anxious time, when choices and options are constrained by lack of vacancies. This suggests the need to look at ways of overcoming people's fear and reluctance to consider residential care until it becomes a necessity.

National and local information

Apart from those people who contact national voluntary agencies such as Counsel and Care for the Elderly, or local branches of national organisations such as Age Concern or Citizens Advice Bureaux, most people are reliant on locally compiled sources of information. Yet clearly there is a need for information that is national in its remit, such as information about paying for residential care and information about the contractual and legal aspects of moving into a home. Such information is needed alongside information about local policy and provision.

It should be possible to look at the division of responsibility for national and local information. Local agencies and advisers should concentrate on compiling local information, while more general information is more efficiently produced at a national level.

Who is the information for?

Implicit in the views expressed by the heads of homes is a possible conflict of interest between professionals and families on the one hand and the elderly person on the other. The heads of homes speak, on the whole, about providing information to families and carers, not to the prospective resident. This is because the elderly person is not seen to be physically or mentally fit enough to take a very active part in the decision, or to want to do so. But the possibility of the families and the elderly people having different needs and interests has to be recognised. We need to consider how the information can best be communicated to the potential residents themselves.