Chapter 6

Elderly people in residential care: informal care

This study examined choice, participation and satisfaction of elderly people ‘at the margin’ of community and residential care. The previous chapters have discussed the extent to which frail elderly people living in the community participated in decisions about their care. The following chapters examine how elderly people who have ‘crossed the margin’ and entered residential care participated in decisions about their care.

We were particularly interested in examining how the decision to move into residential care was made and how much choice elderly people themselves had in the decision about whether to enter residential care and where to go. We wanted to explore how elderly people made choices between entering local authority and private homes and to what extent they thought they had had any choice. We were also interested in hearing the views of their informal carers, both on the care they had provided when the elderly person lived in the community and the extent to which this had affected their lives or contributed to the elderly person’s move into care.

The elderly people we interviewed in residential care were all selected because they had recently entered residential care. We wanted to ensure that the move had been a relatively recent event so that people’s memories were still relatively fresh about what had happened around the time of the move into residential care. We therefore interviewed elderly people who had moved into the selected homes within the previous twelve months.

We interviewed 103 elderly people living in residential care, 31 in the London borough, 36 in the southern county and 36 in the northern county. The samples were split between those who had moved into a local authority home (52 people in 19 homes) and those who had moved into a private home (51 people in 24 homes). The appendices give details of the methods used for sampling the residential homes and the elderly people interviewed within the selected homes. We interviewed 22 men and 88 women.

As with the community sample, we started by establishing with whom the elderly people had lived and how they were supported in the community by family and friends. We then examined how they were supported by formal
services. The care provided by informal and formal sources gave a framework to the decision to move into care, as discussed in Chapter 8.

The residential sample, like the community sample, was drawn from the over-75s and once again there was a high proportion of very elderly people. Around half the elderly people we interviewed in residential care were 85 or over. A fifth were 90 or more. This meant that the residential care sample as a whole was older than the community sample. But there were differences within the residential sample. The local authority residents were older than the private residents – 52 per cent of the local authority residents were 85 or over compared with 43 per cent of the private residents.

**With whom the elderly people had lived**

Again, it might be assumed that these very elderly people would have been living with others but, like the community sample, a high proportion had been living alone. Tables 6.1 and 6.2 show that, of the 103 elderly people we interviewed, 74 (72 per cent) had been living alone before they went into residential care, ten had been living with an elderly spouse (one couple’s son had been living with them) and 19 had lived with someone other than their spouse, in almost all cases with sons or daughters.

<table>
<thead>
<tr>
<th>Table 6.1</th>
<th>Size of previous household of elderly people living in residential care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
</tr>
<tr>
<td>Lived alone</td>
<td>72</td>
</tr>
<tr>
<td>With one person</td>
<td>14</td>
</tr>
<tr>
<td>With two people</td>
<td>9</td>
</tr>
<tr>
<td>With three people</td>
<td>3</td>
</tr>
<tr>
<td>With four people</td>
<td>–</td>
</tr>
<tr>
<td>With five people</td>
<td>2</td>
</tr>
</tbody>
</table>

*Base: all elderly people in residential care (103) Local authority homes (52) Private homes (51)*

The residential sample was older than the community sample, the proportion of residents who had been living alone was higher than we found among our community sample (72 per cent compared with 62 per cent). There were also fewer elderly couples than we found in our community sample. Twenty-two per cent of the elderly people we interviewed in the community lived with their spouse, compared with 10 per cent of our residential sample. This was usually because the elderly people in residential care had ‘lost’ their partner and may well have been a contributory factor to their entering residential care, particularly if their spouse had been a ‘carer’.
Residents of private homes were more likely to have been living alone before they entered residential care than those in local authority homes (80 per cent compared with 63 per cent).

The 19 elderly people who had lived with someone other than their spouse had all lived with other relatives, apart from one elderly man who had been living in private rented accommodation with a resident landlady. Eleven had lived with a daughter and, in eight of these cases, with a son-in-law. Seven had lived with a son and, in five cases, a daughter-in-law. In five of the 19 cases, grandchildren had also been living in the household.

### Table 6.2  With whom the elderly people in residential care had been living

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Local authority homes</th>
<th>Private homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lived alone</td>
<td>72</td>
<td>63</td>
<td>80</td>
</tr>
<tr>
<td>Spouse only</td>
<td>9</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td>Daughter only</td>
<td>3</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Son only</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Landlady only</td>
<td>1</td>
<td>–</td>
<td>2</td>
</tr>
<tr>
<td>Spouse and son</td>
<td>1</td>
<td>2</td>
<td>–</td>
</tr>
<tr>
<td>Daughter and son-in-law</td>
<td>5</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Son and daughter-in-law</td>
<td>3</td>
<td>6</td>
<td>–</td>
</tr>
<tr>
<td>Daughter, son-in-law and grandchildren</td>
<td>3</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Son, daughter-in-law and grandchildren</td>
<td>2</td>
<td>4</td>
<td>–</td>
</tr>
</tbody>
</table>

Base: all elderly people in residential care (103) (52) (51)

Elderly people in residential care: informal care

Of the 29 elderly people who had lived with others, 23 said they had received help from other members of the household and this was confirmed by their carers. Two of the others had lived with equally elderly wives, who were very physically or mentally disabled and who were unable to care for themselves, let alone help the elderly person. With the others, there was some evidence that the elderly person may have underestimated the amount of care they had received. This lack of appreciation may have contributed to their move into residential care as, in all these cases, the elderly people entered residential care as a result of pressure on the carer.

The 23 elderly people who said they had received help from other members of the household had generally received help from their spouse or child. Daughters and daughters-in-law were more likely than male relatives and
grandchildren to have given help. This was confirmed by the carers we interviewed. Most help seems to have been provided by one main carer.

Help from members of the household was most likely to be of a functional nature. Almost all the elderly people who said they received help said resident carers had helped with the shopping, cleaning and cooking, whilst around three-quarters said their relatives had done their laundry. As many as half these people said that all the necessary functional tasks were taken care of by their carers. This level of help was confirmed by the carers we spoke to. We interviewed 18 resident carers, all of whom helped the elderly person with functional tasks – 16 of the 18 said they did everything for the elderly person in the way of functional tasks.

Eight of the 29 elderly people living with others said they had also received help of a personal nature, usually with washing themselves or in getting up or going to bed, but some had received help bathing, dressing and going to the lavatory. Four elderly people said that their resident carers had helped them with all their personal functions. Again, it appears that some of the elderly people may have underestimated how much help they received from their carers. Eleven of the 18 resident carers we spoke to said they had also helped the elderly person with personal tasks, including four who said they did everything personally for their elderly relative. Help of a personal nature was most likely to be provided by a spouse or daughter.

The elderly people living with others received a good deal of help from their resident carers, usually with normal day-to-day functional tasks. More than a quarter said they had received both functional and personal help, including four who said their carers had done everything for them. Residents who had lived with their elderly spouse, who accounted for a third of those who had been living with others (and 10 per cent of our total residential sample) were particularly likely to have received a good deal of help from them. Resident daughters and daughters-in-law also provided a good deal of help, usually with very little help from other members of the household. Sons tended to provide functional help only, and sons-in-law were said to provide very little direct help.

The elderly people in residential care were most likely to have received only functional help from the people they lived with. Comparing the elderly people living in residential care with those we interviewed in the community, we found that the elderly people in the community were more likely to have received help of a personal nature, as well as functional or practical help, than those living in residential care, and respondents living in the community were more likely to say that the relatives they lived with did ‘everything’ for them.

Nine out of ten of the elderly people who lived with others said they had had other close relatives, apart from those sharing the same household. As with Clare Wenger’s study on the supportive networks of elderly people (Wenger, 1984), the interpretation of ‘close relative’ was left to the respondent and is, therefore, to some extent a subjective, rather than an objective, response. Like our community sample, however, virtually none of the residents said they had received help from these other relatives. This was confirmed by the 18 resident
carers we spoke to, most of whom said that other relatives offered no help but, if they did, it was irregular and only functional.

**Elderly people who had lived alone**

Who had helped the 74 elderly people who had lived alone, one in ten of whom had no kin at all? Just over half of those who had close relatives said they had not received help from them. It was noticeable that the residential sample was less likely than the community sample who lived alone to say they had received help from relatives.

Less than half of those who had lived alone, therefore, said they had received help from relatives. This proportion may seem rather low and, from our analyses, it appeared that many of them probably received rather more help from relatives than they claimed. Over 80 per cent of the related carers we interviewed said that they had helped the elderly person regularly. Even allowing for the fact that some elderly people did not have a carer, it still seems likely that relatives gave more help than the elderly people indicated, albeit mainly of a functional nature.

As expected, children were most likely to help parents living alone, with daughters slightly more likely to provide help than sons. Daughters-in-law also played a key part in caring for their spouse’s parent. Sons-in-law, on the other hand, were less likely to provide much help and elderly people were more likely to refer to help from other female relatives, particularly nieces, as well as sisters.

Help given by relatives to elderly people living alone was almost exclusively help with shopping or collecting their pensions or various odd jobs or providing them with transport. Very few said their relatives had helped with the cleaning, cooking or laundry, and it is probable that this assistance was often provided by a home help in these cases. Only a very small proportion of those who lived alone said that relatives had helped them with tasks of a personal nature.

This situation was more or less confirmed by the relatives we spoke to, although they appeared to be offering more help with laundry and help of a personal nature than the elderly people had indicated.

Once again, the elderly people living alone in the community were rather more likely to have received help of a personal nature than those who had lived alone before moving into residential care.

**Family network**

Two-thirds of the residential sample had living children but a third were childless, either because they had never had children or because they had no surviving children. This figure is comparable to that found by Mark Abrams in four urban areas in England (Abrams, 1978) but is substantially higher than that for our community sample. Around a fifth of the elderly people we interviewed in the community were childless compared with a third of the residential sample. Both samples were drawn from the same geographic areas.

The elderly people in residential care had rather small families and Table 6.3 shows that most of those who had children had only one or two.
T able 6.3 Number of living children of elderly people in residential care

<table>
<thead>
<tr>
<th>No of children</th>
<th>Local authority homes</th>
<th>Private homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>None ever</td>
<td>28</td>
<td>31</td>
</tr>
<tr>
<td>None living</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>One living</td>
<td>33</td>
<td>35</td>
</tr>
<tr>
<td>Two living</td>
<td>26</td>
<td>23</td>
</tr>
<tr>
<td>Three living</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Four living</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Five living</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Six living</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>More than six living</td>
<td>1</td>
<td>–</td>
</tr>
</tbody>
</table>

Base: all elderly people in residential care (103) (52) (51)

Table 6.4 Family network of elderly people in residential care

<table>
<thead>
<tr>
<th></th>
<th>Local authority homes</th>
<th>Private homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living spouse/no children</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Living spouse and children</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Living children/no spouse</td>
<td>60</td>
<td>58</td>
</tr>
<tr>
<td>Other relatives (no living spouse or children)</td>
<td>23</td>
<td>21</td>
</tr>
<tr>
<td>No kin at all</td>
<td>7</td>
<td>8</td>
</tr>
</tbody>
</table>

Base: all elderly people in residential care (103) (52) (51)

Ill family network of the elderly residents. One in ten had a living spouse immediately before moving into residential care and two-thirds had living children. A small proportion (7 per cent) had both a living spouse and living children.

Some indication of the relative isolation of these elderly people living in residential care is shown by the fact that almost one third (30 per cent) did not have a living husband, wife or children. Most of these people referred to other ‘close’ relatives, such as siblings, nephews, nieces and cousins but 7 per cent said they had no kin at all. There was little difference in the family networks of
The total family network mentioned by the elderly people in residential care was relatively small. Apart from the 7 per cent who had no relatives at all, a further two-thirds of the residents only mentioned between one and five close relatives, including over a quarter who only referred to one or two people. Only a quarter of the residents had larger family networks comprising six or more relatives.

The family networks of those living in residential care were smaller than those in the community. Elderly people living in the community were more likely to have had a living spouse and were more likely to have had living children. But having a large family is not much use in terms of daily care if they all live a long way away. We asked the elderly people in residential care where their relatives lived so that we could see how readily available they might have been to help.

As we have seen, a quarter of the elderly people actually lived with a member of their own family before they went into residential care. A further third had had a member of their family living near them, in the same town or locality, while around one sixth had relatives in the same authority. Three-quarters of the residents, therefore, had either lived with relatives or had relatives living nearby, including almost two-thirds whose children lived with them or nearby.

The nearest relative of 10 per cent of the elderly people lived some considerable distance away in another part of Great Britain, while a handful of residents only had relatives abroad. Around one in six people, therefore, either had no kin or had relatives living at a considerable distance, either abroad or in this country. In these cases, friends or neighbours often helped the elderly person.

There were four main patterns of support from relatives. Firstly, there were those elderly people who lived with others. These people generally received a good deal of help from their resident carers and this help was likely to have been both functional and personal. Secondly, there were those people who had lived alone, with close relatives nearby helping them with functional tasks such as shopping, collecting their pension, transport and other odd jobs. Thirdly, there were those who lived alone who had not received help from their relatives, usually because they lived too far away to help practically. And fourthly, a small proportion had no kin at all.

**Help from friends and neighbours**

A third of the elderly people said they had received help from friends or neighbours when they lived in the community, usually of a functional nature. Friends and neighbours were most likely to help the elderly person with their shopping, with odd jobs or by picking up their pension. Around a fifth of those who had help from friends and neighbours, however, said that the help had been with the cooking and with the laundry. Residents of local authority homes were rather more likely than private home residents to have received help from friends and neighbours.
Friends and neighbours also played a key role by simply ‘keeping an eye’ on the elderly person, by visiting the elderly person socially and providing company, as well as checking that the elderly person was well and did not require medical or social help. Only five residents said that friends or neighbours had helped them with personal tasks, such as help in getting up or going to bed, help with washing or bathing or going to the lavatory.

Ten of the 56 informal carers we interviewed were friends or neighbours of the elderly person. In most of these cases, the elderly person either had no close family at all or their family was living abroad or a considerable distance away from them. These friends and neighbours all said they regularly provided help for the elderly person, usually with shopping, laundry, cooking and transport as well as other odd jobs. But, as indicated by the elderly people themselves, friends and neighbours rarely offer help of a personal nature.

Main informal carer
To help us identify who had been the elderly person’s main informal carer, and to find out whom the elderly person had relied on when they lived at home, we asked the elderly people who they considered had helped them most.

Children were the main providers of informal care when the residential sample had lived in the community. A quarter of the residents said that their daughter had helped them most and around one in ten cited their son as their main source of help. But 6 per cent referred to their son and daughter-in-law equally and a small proportion gave credit to their daughter-in-law alone, which meant that a fifth of the elderly people referred to their son and/or daughter-in-law as their main carer.

All those who had been living with their spouse before moving into residential care – around 10 per cent of the residential sample – said that their partner had helped them most.

Where the elderly person did not have children or where their children were living some distance away, friends and neighbours seem to have stepped in to fill the gap. More than one in ten people said that when they lived at home, a friend or neighbour had helped them most.

But as many as a quarter of our sample (25 per cent) could not identify anyone from family, friends or neighbours as the person who had helped them most at home. This was either because they were independent and were managing themselves or because they felt their home help or home carer had helped them most. Private residents were four times as likely as local authority residents to say that they did not have an informal carer (41 per cent compared with 10 per cent) and often said that they managed alone.

Informal carers interviewed
Among elderly people living in the community, where possible, we identified and interviewed as ‘the carer’ the person who was giving most practical or emotional support to the elderly person.
With our residential sample, however, we wanted to interview the person who had been most involved in the move into residential care. In some cases, this person had helped the elderly person very little when they lived in the community, becoming actively involved only around the time of the move into residential care. For this reason, the informal carers of the elderly people in residential care who were interviewed tended to be family members rather than friends or neighbours. They were sometimes, but by no means always, a rather different kind of informal carer from the carers of those living in the community. Fewer spouses were interviewed as the carers of those in residential care and this may well be because the loss of a spouse, particularly one who was a ‘carer’, was a contributory factor to entering residential care.

We interviewed a total of 74 carers, 73 of whom had been involved in the move into care of the elderly people we interviewed. The remaining carer had been caring for his elderly mother whom it was not possible to interview because of her mental frailty. Like the community sample, the sample of carers of those in residential care had to be treated separately from the sample of elderly people in residential care.

We achieved interviews with the carers of two-thirds of the elderly people interviewed in the London area and southern county, and as many as 80 per cent of those interviewed in the northern county, where the elderly people were more likely to have children and generally had bigger families.

We were more likely to identify and interview a carer for our local authority sample than we were for our private sample. We achieved interviews with the carers of 81 per cent of local authority residents, but only 63 per cent of our private residents.

There were three main reasons why we did not always interview an informal carer. Firstly, and most important, some people simply did not have an informal carer. These people accounted for just over 10 per cent of our total residential sample and were most likely to have moved into a private home. We could not identify an informal carer for as many as one in five of the private residents. In the remaining cases, we were unable to interview the informal carer, either because they lived too far away or because they were in hospital, or because either the informal carer or the elderly person refused an interview.

Who were the informal carers?
There were two main types of informal carers. Firstly, there were carers who were living with the elderly person. They were spouses or children, had generally been living and caring for the elderly person for some considerable time and were responsible for personal and functional tasks. These carers received very little help from other relatives or from friends or neighbours.

Secondly, there was a large group of carers who were supporting the elderly people within the latter’s own home but did not live with them. They may also have been children, but also included more distant relatives as well as friends and neighbours. These carers generally provided functional help and were more likely to receive help from other relatives or from friends and neighbours.
Relationship of carers to elderly people

Table 6.5 shows that one third of the carers we interviewed were daughters, 26 per cent were sons and 9 per cent were daughters-in-law. The fact that 60 per cent of our sample of carers were children of the elderly people in residential care reflects the fact that most care was provided by children and that the children were likely to be involved in the decision and arrangements to move into care. It was also noticeable that a larger proportion of sons were interviewed as part of our residential sample than were interviewed as part of our community sample. This reflected the fact that sons tended to step in when major, life decisions were being made, often with financial implications, but were less likely to be actively involved in the practical aspects of caring for an elderly relative.

We also interviewed a small number of spouses. Ten of the elderly people had been living with their spouse immediately before coming into care. In four cases, the couple had moved into residential care together and in six cases, the carer had remained in the community. We were able to interview only four of these spouses (three wives and one husband). Three of them were living in the community and one was living with her husband in a local authority home. We were unable to interview the other six spouses as two had died since the the elderly person had moved into residential care, one was ill in hospital, one was suffering from senile dementia, one was not considered to be a carer and we were advised not to interview the remaining spouse because of tension between her and her husband.

Table 6.5  Relationship of carer to elderly people in residential care

<table>
<thead>
<tr>
<th>Base: all informal carers</th>
<th>Local authority homes</th>
<th>Private homes</th>
<th>London area</th>
<th>Southern area</th>
<th>Northern area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>5</td>
<td>5</td>
<td>6</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Daughter</td>
<td>34</td>
<td>29</td>
<td>41</td>
<td>25</td>
<td>32</td>
</tr>
<tr>
<td>Son</td>
<td>26</td>
<td>24</td>
<td>28</td>
<td>35</td>
<td>32</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>9</td>
<td>14</td>
<td>3</td>
<td>15</td>
<td>4</td>
</tr>
<tr>
<td>Niece</td>
<td>9</td>
<td>10</td>
<td>9</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Friend</td>
<td>9</td>
<td>14</td>
<td>3</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Neighbour</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Step-son</td>
<td>1</td>
<td>–</td>
<td>3</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Second cousin</td>
<td>1</td>
<td>–</td>
<td>3</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

Base: all informal carers of elderly people in residential care (74) (42) (32) (20) (25) (29)
Almost half the carers in the northern authority were daughters, while in the southern area, the carers were likely to be sons, daughters or friends. In the London authority, sons and daughters-in-law were the main carers. The remainder of the carers were more distant relatives, including nieces, step-sons and cousins, while friends and neighbours accounted for around 10 per cent of our carers’ sample.

**Sex of carers**
Almost three-quarters of the carers interviewed were women, although over a third of the carers of those in private homes were men, reflecting the involvement of sons at the time of admission to residential care, especially where there were financial implications.

**Resident and non-resident carers**
A quarter of the carers we interviewed (18) had lived with the elderly person. As might be expected, the resident carers were spouses (4) or children, especially daughters (8), but also included two sons and four daughters-in-law. These carers had generally been living with the elderly person for many years, with eight of them saying the elderly person had been living with them for more than ten years, and a further five saying that they had always lived with them. This latter group included the four spouses we interviewed. Eight of the resident carers were over 60 years old, including five who were over 70. This obviously reflects the spouses included in our sample, but also indicates that some of the children who had lived with and cared for the elderly people had been pensioners themselves.

The majority of the carers, therefore, had not been living with the elderly person. Carers in the northern authority were least likely to have lived with the elderly person. The majority of the non-resident carers, however, lived very near the elderly person, two-thirds of them within five miles of the elderly person’s home, mostly not more than one mile away. As many as two-thirds of the non-resident carers in the southern authority lived less than a mile away from the elderly person.

The carers of the local authority residents we interviewed had lived nearer the elderly person than the carers of the private residents. Half of the local authority carers we spoke to had lived within a mile of the elderly person, compared with a third of the private carers. This is at least partly due to the fact that a greater proportion of friends and neighbours were interviewed as ‘the carer’ of local authority residents. The private carers, however, by no means lived a considerable distance away. Two-thirds had lived within ten miles of the elderly person. Most of the rest had lived within 10 and 20 miles of the elderly person and in the couple of cases where the distance was much greater, the elderly person had received help from another relative or from social services.
Duration of caring
Caring for the elderly person had been a longstanding responsibility for most of the carers. Almost half said they had been looking after the elderly person for more than five years, including almost a fifth who had been caring for more than ten years. Some people had been caring for as long as 20 or 30 years and only around 10 per cent had been caring for less than one year. The resident carers had generally been caring longer than non-resident carers.

Many of the carers, however, had difficulty saying just how long they had been caring since the caring role had developed gradually over a period of time, as in the case of this son who had cared for his elderly mother in the London area: ‘About twenty years. But it’s difficult to say when "looking after" began. It just developed...’

The burden of caring had frequently becoming more intense in the last few years before admission to residential care. This daughter described how caring for her mother had intensified: ‘It’s been a gradual thing. It got worse over the last two years. I had been looking after her for 18 years. She had her own room and I cooked for her, but it got so that I had to dress her and bath her and be here constantly by the end of the time...’

Feelings about caring
Virtually all the carers had been happy to take on the caring role. Janet Finch has documented the reasons why people care (Finch, 1989), and our carers, particularly the children of the elderly people, demonstrated the same mixture of duty, obligation and responsibility: ‘I felt perfectly happy to look after her. She had been a good mother and I accepted it as a daughter’s job...’

Sons were particularly likely to feel duty-bound to help their elderly parents, like this son caring for his mother in the southern area: ‘We didn’t mind, but you can’t say it’s not a duty...She’s my mother. It was my duty in a way I suppose...’

For many of the caring relatives, the caring role came naturally and many, like this daughter, felt that they wanted to reciprocate the care and help that their parents had given them when they were younger: ‘It just came naturally. She had looked after me, it was my turn to look after her...’

More distant relatives and to some extent friends and neighbours were more likely to have felt they had no choice but to care, generally because there were no (other) relatives. This young woman explained how she had started caring for her elderly neighbour: ‘I felt I had to do it. When she came out of hospital, there was no-one else. The ambulance men brought her home and put her in bed and left her. I had to do everything. They knew she had no family. She’d filled in a form and said "only a neighbour"...’

More than one in ten carers commented that supporting the elderly person had not taken much time to start with and had been no bother at all. Some of these carers, however, particularly the resident carers, had clearly never envisaged just how much they would end up doing or that they would be caring for so long, as this daughter who had lived with her mother in the London area...
explained: ‘To start with, she was looking after herself and then it grew on me. There was a gradual decline. It never entered my head that when I started looking after her how long it might last. For the last fifteen years, she had given up doing anything for herself. I’ve done most of her shopping and cooking for nearly 30 years...’

Only a small proportion of the carers admitted to any reluctance to take on the caring role, and even in these cases, their sense of responsibility won. This son described how he felt when he first started caring for his elderly mother: ‘I got mildly irritated. I thought, "I can’t turn my back on her – Honour thy Mother and Father". But I always felt it was a tie...’

Around a quarter of the carers had felt under pressure to take on the caring role. Again, this sense of pressure had usually come from the carer’s own sense of responsibility, with three-quarters of those who felt under pressure commenting that they had felt it was their duty or obligation. Again, sons were most likely to feel a sense of duty: ‘I felt under pressure to care for her, but only through what one thinks of his mother. A sense of duty...’

This son similarly experienced feelings of duty and obligation: ‘Pressure may be the wrong word but I certainly felt a moral obligation. It was the natural, logical thing to do. We thought about it over a period of time. After her cancer operation four years ago, the thoughts started then of having her live with us...’

Around a fifth of those who had felt pressure to take on the caring role said that the pressure had come from the elderly person themselves, while a similar proportion felt they had had no choice as there was no-one else who could, or would, do it. The niece of an elderly woman living in a private home in the London area described the pressure she had been under: ‘It was pressure from her. But no-one else wanted to know anyway. They thought she was a cantankerous old woman! She was, but we got on...’

**Help given by informal carers**

Nine out of ten of all the carers said they had helped the elderly person regularly. Although we selected the carers of the residential sample in a slightly different way from the community sample, it was clear that many of these carers had still had a heavy caring role. It also reinforced the evidence provided by the elderly people that when they had a carer, they tended to receive a lot of help from that person. Carers of residents in local authority homes were rather more likely than those of private residents to have provided regular help (98 per cent compared with 81 per cent), probably because they lived nearer the elderly person than the carers of private residents.

All the resident carers helped the elderly person with functional tasks and virtually all said they carried out all the necessary household tasks, such as shopping, cleaning, cooking and laundry, as they presumably would have done had the elderly person not been living there. They were also likely to have helped the elderly person with personal tasks. Around two-thirds of the resident carers said they also helped the elderly person with their personal care and as many as
a quarter said they had done everything for the elderly person in terms of both functional and personal help.

Help from non-resident carers was more likely to be confined to tasks of a functional kind. All of them provided functional help, especially shopping, laundry, collecting the elderly person’s pension and managing their finances, and three-quarters of them said they provided functional help only. Only a quarter of the non-resident carers (compared with two-thirds of the resident carers) said they had helped the elderly person with personal tasks, such as washing and dressing.

Reflecting the picture painted by the elderly people themselves, the carers of those in residential care were more likely than carers in the community to have provided functional help only. Carers of people living in the community were more likely to be providing both functional and personal help, and were more likely to be doing ‘everything’ for the elderly people.

Support from other close relatives
In many cases, particularly among resident carers, the carers bore the main responsibility for looking after the elderly person alone. Resident carers may have received some help from other members of the household, usually from their own spouse, but were unlikely to have done so from other family members. Sixteen of the 18 resident carers said the elderly person had other close relatives, but most of these (10) received no help or support from them. Those who did receive help from other close relatives only did so occasionally or in an emergency and help was generally of a functional nature.

The non-resident carers were more likely to receive at least some help from other members of the family, mainly from their own spouses as well as from siblings and from friends or neighbours. This help again tended to be of a functional nature.

The carers we interviewed reinforced the impression given by the elderly people that help from other relatives was limited or non-existent.

Carers’ assessment of support from other members of the family
It is perhaps not surprising that only half the respondents felt they had had enough support from family members. There was little difference between resident and non-resident carers, but sons seemed to have received more support from relatives than daughters did. A fifth of the carers commented that there were no other members of the family, but as many as a third said they had relatives who had not been as supportive as they might have been. Daughters-in-law and nieces were more likely to say they had not received enough support from other family members.

Of these 22 cases where the carer felt they had had insufficient family support, a quarter had not received help because other relatives had not lived locally. In the majority of cases, however, relatives seem to have been reluctant to help. A third of these respondents said they would have liked other relatives
to have helped them more or to have shared the responsibility of caring, like this daughter-in-law in the northern area:

I’d have liked everyone concerned to have got together and talked but they never did...I felt if we all got together for a few hours and discussed his needs and who could do what...It wouldn’t alter the situation but everyone would feel easier. Say there’s a crisis and I’d arranged to do something, I’ll still be the one who’s expected to cope. I’m not blaming anyone, but I’m handier, across the road. If I’m not careful, I can feel resentful...

Around a quarter of these carers said that other members of the family had not helped at all. This niece had clearly felt isolated in her caring role: ‘No-one else wanted to know. She’d upset everyone. My brother just set up this trust fund and that’s it. He said "over to you". No-one else helps...’

It seemed that in many cases, the responsibility for caring had fallen onto one person, with other relatives drawing back and thus increasing the burden on the carer. Another niece in the London area described how other relatives had failed to help her: ‘There are about 15 others as closely related as me but none of them ever take her out or visit her or ever did. I don’t mind at all but I’d have liked a break...’

Support from friends and neighbours
Non-resident carers had clearly relied on friends and neighbours of the elderly person for support. Three-quarters of them said the elderly person had also received help from friends or neighbours, mainly of a functional nature, including half who said the elderly person had been helped regularly. This confirmed the situation presented by the elderly people themselves. Neighbours were particularly likely to keep an eye on the elderly person between visits from the relatives. Resident carers, on the other hand, were again left to care alone, and less than a fifth said they had received help from friends and neighbours.

Effects of caring on the carers
The burden of caring is well documented but we were particularly interested in exploring whether the strain of caring and a breakdown in the caring relationship was one of the reasons why elderly people move into residential care. Like the carers of elderly people living in the community, we asked the carers of those who had moved into a home a series of questions about how they had coped with their caring role and how they felt they could have been helped.

People’s lives had been affected by their caring role to varying degrees, often depending on how involved they had been and their age. The lives of those who had been living with their elderly relative were more likely to have been considerably affected. The main effect was to restrict the carer’s lives. Almost two-thirds of the resident carers said that living with and caring for their relative had resulted in a loss of freedom. Many of the non-resident carers also referred to the restrictions on their lives. This son had lived with and cared for his 80 year
old mother for two years before she moved into a local authority home: ‘God! It was much more restricted, much more so than with kids. It was the planning. We couldn’t go away impromptu on holiday. It all had to be planned, worked out to the finest detail. If I was going out, I had to plan all her meals, where, when, how. All she could do was tea and toast...’

Overall, nearly half of all these carers said they had lost their freedom, compared with just over a third of the carers in the community. This provided some evidence that carers of those in residential care felt that their lives had been more affected by their caring role than did those who were continuing to care in the community.

Some carers clearly felt quite bitter about the way in which their life had been affected, like this daughter in the London area who had shared her home with her mother for thirty years: ‘I’ve lost my freedom. I’ve been questioned every time I’ve been out or come in. I’ve never been able to come in to my own front door without going into her room...’

This son had lived with his mother for thirty years, before she entered a private home at the age of 94: ‘Having an old person at home, your life has got to be built around them. It became a millstone at the end...’

The family lives of a third of the resident carers had also been affected by having an elderly relative live in the household. Daughters-in-law, who were likely to have taken on the caring role out of a sense of duty to their husbands, were particularly likely to say that caring had resulted in friction in their marriage or in neglect of their own family.

A woman who lived with her incontinent mother-in-law for two years before she moved into a local authority home described the effect on her marriage: ‘My life was ruined. We couldn’t go out. It was like having a child. If we went out, it was “How long will you be?” It was coming between my husband and myself and we’ve been married for thirty years...’

Other relatives, like this son, also described the effect that caring had had on their married life: ‘My life changed. I became ratty, I fell out with my wife. My father-in-law had cancer and that took a lot of time as well. I know it sounds foolish but it all becomes too much. You give up your hobbies and pursuits and you end up doing it all. You’re left so tired you neglect your own things...’

Daughters-in-law were also particularly likely to say that caring had resulted in neglect of their own family and that caring for an in-law had been at the expense of caring for their children – ‘Quite considerably. It was a lot of extra physical work. She was incontinent and she could get nasty. I had to keep telling the children to be quiet. It affected the family considerably. She was very demanding. It pushed the children out. They used to go out because nanny smelt and didn’t want noise...’ – or at the expense of caring for their own parents: ‘Everybody else had to go to the wall, including my own mother...’

Some carers spent a considerable amount of time helping the elderly person and led very busy lives, juggling their own family life, holding down a job and caring. This daughter-in-law had lived with her mother-in-law all her married life – 26 years. As well as caring for her mother-in-law, she was working
part-time and had raised two children: ‘Towards the end a great deal. It did take
time and it did put on a strain. She did get very demanding and would bang on
the ceiling. Family life was very difficult. We couldn’t go away or entertain...’

Some carers, particularly those who were elderly themselves, had found
caring very tiring. Two women who had looked after their physically and
mentally ill husbands commented that caring had quite simply worn them out.
In both these cases, the husband had moved into a residential home, while the
wife remained in the community.

People who had not been living with the elderly person often said that for a
lot of the time they were worried about the elderly person, in case they had fallen
or were not well. This worry often lay heavily on their minds and was in itself a
considerable pressure on them. Combined with the worry, some had felt guilty
when they were not visiting their elderly relative.

Friends and neighbours, who were generally doing less than family members,
were most likely to say that their life had not been affected at all.

Only a small proportion of the carers said they had actually given up work
in order to care for their relative (5 per cent), but as many as a quarter had changed
their working pattern in some way because of their caring role. These were more
likely to have been resident carers than non-resident carers, and daughters rather
than sons. Most frequently, carers had lost time from work or had had to take
time off, but others had reduced the number of hours they worked by moving
from full-time work to part-time or had changed their hours to fit in with caring.
But some carers said they had gone out of their way not to let caring affect their
work as they had relied on this to provide some sort of outlet or respite from
caring.

Respite care
Virtually all of the carers considered that it was a good idea for elderly people
to go for day care. Three-quarters of them felt that the company and conversation
offered by day care was the main advantage to the elderly people themselves:
‘Social really – this is the main thing. They need company. When they get stuck
at home on their own, they get blinkered and never speak to anyone and then
their health goes down and they just give up...’

Many other advantages were cited, however, including the change of
scenery, which was mentioned by a quarter of our sample, giving the elderly
person an extra interest and something to look forward to, and the provision of
stimulation. Other advantages included the chance to have a meal and a bath, the
opportunity to participate in activities and go on outings, keeping them mobile
and the opportunity to see trained people and doctors.

But more carers were interested in what day care did for them. Two-thirds
of all carers felt that the main advantage of day care was to give carers some
respite from caring. Resident carers were particularly likely to refer to the
advantages of day care; virtually all referred to the respite offered by this service.
This daughter, who had been living with and caring for her mother for 30 years,
recognised the need for respite care. She herself, however, had been unable to
reap the benefits of day care as her mother suffered from deafness and would not
attend a day centre: ‘Give them a break. Old people become very trying. My
doctor was very sympathetic. I’ve never been able to do anything right for my
mother. She would go for me. She’s very demanding. She always criticised us.
My doctor said it’s very common between mother and daughter...’

Around a fifth of all carers felt that day care gave people a sense of security,
knowing that the elderly person was safe and being cared for and therefore
relieving them of some of the worry brought on by caring for an elderly relative:
‘If they’re working, they wouldn’t need to worry about them in the daytime. And
if they were at home, they’d get a break...’

Resident carers also said that day care for elderly people offered carers more
freedom, allowing them to go out. Non-resident carers, on the other hand, whose
elderly relative usually lived alone, also referred to the company which day care
offered elderly people and said that carers would feel happier knowing that they
were receiving a meal and a bath.

Similarly, nearly 90 per cent of carers considered that it was an advantage
for elderly people to be able to go for a short-stay in a residential home. Almost
half the carers said that a short-stay would give the elderly person an opportunity
to see for themselves what residential care was really like: ‘It gets them to realise
that residential homes are not the type of home they used to be 30 years ago.
They can see what it’s really like, that it’s not a workhouse, that they’re not locked
up...’

A third of the carers thought that short-stay care would provide elderly people
with company and conversation, while others said it would give the elderly
person a holiday or break, it would be a change of scenery and that the elderly
person would be safe and well looked after.

The main advantage of short-stay care to the carers was thought to be the
respite it gave them. Around two-thirds cited relief as an advantage of this type
of care: ‘It’s a break for the relatives. There’s a lot of worry. It’s a good thing.
Relatives that care for old people have a lot on their plate. Some elderly people
can be real tyrants, real tigers. They never thank you and they’ll tell you off. It’s
a blessing when they go away...’

This son had lived with his mother for almost two years without the benefit
of short-stay care. It was only after she entered residential care that he realised
the strain that caring had been and recognised the advantages of respite care:
‘Gives them a break. Time to take breath. We don’t know we’re born. We don’t
know how we did it. We don’t row any more...’

A third of the resident carers also said that short-stay care for elderly people
allowed their carers to go away on holiday.

The non-resident carers, on the other hand, who often felt worried about the
safety of the elderly person, stressed the peace of mind they would have, knowing
the elderly person was being cared for: ‘Oh relief, to my husband more than me.
It’s the worry all the time that gets you, fear of something happening. It gives
you a bit of a breathing space...’
Carers’ assessment of professional support

But if only half the carers felt they had had enough support from other members of the family, did they feel they had been supported by the professionals? As many as two-thirds of the respondents felt they had received enough support from professionals but there were significant differences of opinion between carers of people who had entered local authority and those who had entered private homes.

Carers of private residents were less likely to feel they had received adequate support from professionals. More than a third of the private carers felt they had not had enough support from the professionals compared with a quarter of the local authority carers.

There were also differences between the three areas. While the majority of carers in the London and southern authorities felt satisfied with the support received from professionals, almost half of those in the northern area claimed they had not received enough support.

There was also a noticeable difference between the views of carers in the community and carers of those in residential care. Almost a third of the people who had cared for someone who had moved into residential care said they had not had enough support from the professionals, compared with a fifth of those caring in the community.

What were the problems encountered by the carers of those in residential care? A quarter of the carers who felt they had not received enough support commented that the elderly person’s GP had not called regularly and felt the GP should have visited more frequently: ‘We would have liked the doctor to call and see her more often. She was on loads of drugs and he just gave her a repeat prescription...’ This son similarly criticised the GP: ‘Definitely not. The doctor should have called more regularly. Someone should have noticed the pressure my mother was under...’ Even some carers who were generally satisfied with the professionals criticised the GP for not visiting.

A further quarter of dissatisfied respondents felt that the elderly person had not received enough home help. Carers in the northern authority were particularly dissatisfied with the provision of home helps: ‘More home help time and for her to do more. Even if she had cleaned right through just once a month. All she did really was light the fire...’ Others were unable to get a home help at all: ‘I could have done with the home help but it was refused. I suppose I should have pushed for it...’

Other carers, like this daughter who was living with her elderly mother, said they would have liked to have received more help from the social services department: ‘Someone to help generally. It was the lifting I couldn’t do. Someone to take her out in the wheelchair. It got that I couldn’t manage it. And someone to bath her...’

Other criticisms related to infrequent visits by social workers as well as the lack of information about services and benefits available to elderly people and their informal carers: ‘One thing you don’t get as a carer – nobody gives you any information on what can be done...’
Main needs of carers

Finally, we asked the respondents whether they felt that carers who are looking after elderly people need more help themselves. As many as three-quarters of the sample agreed that more help was needed, a view held by four-fifths of the resident carers. This compares with around two-thirds of resident carers in the community and again gives some indication that stress on the carer was a contributory factor in the elderly person’s move into residential care.

What sort of help did these carers require? Reflecting the pressure and lack of freedom felt by many carers, respite was the main request by carers. The form of this respite, however, varied. Almost a quarter only wanted relief occasionally, but around half as many felt there was a need for regular and frequent breaks: ‘A break and support. It’s a 24 hour day job. There’s pressure on you all the time, even if she’s not with you. You still think about them all the time...’

This daughter had been living with and caring for her mother for 13 years: ‘You need a break. It just goes on and on and there’s no changing it. You know that it’s not going to change...There comes a time when you just need a break, just for two weeks. You’d know that it was there...’

Resident carers in particular felt a need for respite care at home, in the form of a sitting service: ‘If somebody would come to sit with her for three or four hours so that I wouldn’t have been a nervous wreck when I picked my son up every day and had to leave her...’

Around one in ten commented that carers need more information about available services and benefits. This daughter commented on the lack of information in the northern area: ‘Guidance... what help is available and can be given to carers, what services are available...’ And this son complained about the problem of knowing what was available in the southern area. ‘There’s no coordinator to say “you can get this” or “try that”. You just blunder along doing your best...’

A similar proportion simply said that they would have liked someone to talk to: ‘I’d have liked someone there I could have talked to when things got rough, when the pressure was building up. I’d phone the DCO but I couldn’t always get him. Like the time when she said she’d take all her tablets. I came back here crying and phoned the DCO. Luckily he was there. He came in 15 minutes and I was crying and we went next door and she was crying. He was the only one I could turn to...’ Only one carer had been in touch with a carers’ support group, a potential source of information and moral support.

A wide range of other means of help was suggested, including more home help, more financial support and the need to share the caring role.

As with the carers of those living in the community, the need for practical assistance and respite from the caring role was apparent from the interviews with carers of those living in residential care. But had these carers received this support? And if they had not, had this contributed to the elderly person’s move into residential care? The formal care offered to the elderly residents, and their carers, when they lived in the community will be discussed in the next chapter.
Elderly people in residential care: informal care