Elderly people in the community: informal care
Chapter 2

Elderly people in the community: informal care

The elderly people we interviewed who were still living in the community had been selected as being at the margin of community and residential care, in that they fulfilled the criteria for selection we had agreed with the local authorities. It was clear that some were more at risk than others at the time that we interviewed them, but we wanted to assess the ways in which people who did not wish to enter residential care were being helped to stay in the community. We wanted to look at the support elderly people were being offered in the community both from formal and informal sources, and we were particularly interested in the ways in which the elderly people were able to participate in decisions made about their care and how they exercised choice in the services they received.

We started by establishing with whom the elderly people lived and went on to examine how they were supported in the community by family and friends. The importance of the informal network in providing care for elderly people cannot be underestimated, and successive studies have indicated that most elderly people can only continue to live in the community because of the care provided by informal carers (Green, 1988; Parker, 1990).

With whom the elderly people were living

We interviewed 100 elderly people living in the community, 30 in the London borough, 34 in the southern county and 36 in the northern county. Even though we sampled only among the over-75s, we found that nearly 40 per cent of the elderly people were 85 or over (see Appendix). It might be assumed that a high proportion of such an elderly sample would be living with others, but as Tables 2.1 and 2.2 show, 62 per cent of the total sample were living alone, and most of the rest (22 per cent) were living with an equally elderly spouse. (In only one case was anyone else living with these elderly couples.) Only 16 per cent of those interviewed were living with anyone other than a spouse, and, of these, two were living with elderly sisters and one with an elderly friend. Therefore, only 13 per cent of elderly people could be said to live with a younger ‘carer’ or carers.
In the London borough, 80 per cent of those interviewed were living alone, and only one elderly person was living with relatives other than a spouse. In the northern area, 58 per cent lived alone, there were 12 elderly couples and only three elderly people living with other relatives, while in the southern area, 50 per cent lived alone, there were eight elderly couples and nine elderly people living with younger relatives.

Table 2.1  Size of household of elderly people living in the community

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>London area</th>
<th>Southern area</th>
<th>Northern area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living alone</td>
<td>62</td>
<td>80</td>
<td>50</td>
<td>58</td>
</tr>
<tr>
<td>With one person</td>
<td>28</td>
<td>17</td>
<td>29</td>
<td>36</td>
</tr>
<tr>
<td>With two people</td>
<td>8</td>
<td>3</td>
<td>18</td>
<td>3</td>
</tr>
<tr>
<td>With three people</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>With four people</td>
<td>1</td>
<td>–</td>
<td>3</td>
<td>–</td>
</tr>
<tr>
<td>With five people</td>
<td>1</td>
<td>–</td>
<td>–</td>
<td>3</td>
</tr>
</tbody>
</table>

**Base:** all elderly people in the community (100) (30) (34) (36)

Table 2.2  With whom the elderly people in the community were living

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>London area</th>
<th>Southern area</th>
<th>Northern area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living alone</td>
<td>62</td>
<td>80</td>
<td>50</td>
<td>58</td>
</tr>
<tr>
<td>Spouse only</td>
<td>21</td>
<td>17</td>
<td>18</td>
<td>28</td>
</tr>
<tr>
<td>Daughter only</td>
<td>2</td>
<td>–</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Son only</td>
<td>2</td>
<td>–</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Sister only</td>
<td>2</td>
<td>–</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Friend only</td>
<td>1</td>
<td>–</td>
<td>3</td>
<td>–</td>
</tr>
<tr>
<td>Spouse and nephew</td>
<td>1</td>
<td>–</td>
<td>–</td>
<td>3</td>
</tr>
<tr>
<td>Daughter and son-in-law</td>
<td>4</td>
<td>3</td>
<td>9</td>
<td>–</td>
</tr>
<tr>
<td>Son and daughter-in-law</td>
<td>3</td>
<td>–</td>
<td>9</td>
<td>–</td>
</tr>
<tr>
<td>Daughter, son-in-law and (2) grandchildren</td>
<td>1</td>
<td>–</td>
<td>–</td>
<td>3</td>
</tr>
<tr>
<td>Son, daughter-in-law and (3) grandchildren</td>
<td>1</td>
<td>–</td>
<td>3</td>
<td>–</td>
</tr>
</tbody>
</table>

**Base:** all elderly people in the community (100) (30) (34) (36)
The elderly people living with others usually lived with only one other person, so that any caring clearly devolved on the shoulders of that person. Seven of them lived with a son or daughter and their respective spouses only, while two lived with a son or daughter, their spouses and grandchildren. One elderly person lived with her own spouse and a nephew.

Table 2.3 With whom elderly people in the community were living by age of elderly person

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>75-79</th>
<th>80-84</th>
<th>85+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alone</td>
<td>62</td>
<td>52</td>
<td>61</td>
<td>71</td>
</tr>
<tr>
<td>With spouse</td>
<td>22</td>
<td>31</td>
<td>21</td>
<td>16</td>
</tr>
<tr>
<td>With others</td>
<td>16</td>
<td>17</td>
<td>18</td>
<td>13</td>
</tr>
</tbody>
</table>

Base: all elderly people in the community (100) (29) (33) (38)

It might have been thought that the very elderly people would not be living alone, but this was by no means true, as Table 2.3 shows. Only just over half of those aged 75-79 were living alone, compared with 61 per cent of the 80-84 year-olds, 70 per cent of those aged 85-89 and six of the seven 90-94-year-olds. In some ways this is not surprising, in that the younger age-groups were less likely to be widowed, but in other respects, it shows the great vulnerability of some of the elderly people we interviewed in the community. Some of them, as we shall see, were very tough and independent, but they were very old, and not all of them had extensive informal care networks.

Table 2.4 With whom elderly people in the community were living by sex of elderly person

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alone</td>
<td>62</td>
<td>44</td>
<td>68</td>
</tr>
<tr>
<td>With spouse</td>
<td>22</td>
<td>41</td>
<td>15</td>
</tr>
<tr>
<td>With others</td>
<td>16</td>
<td>15</td>
<td>16</td>
</tr>
</tbody>
</table>

Base: all elderly people in the community (100) (27) (73)

We interviewed 73 women and 27 men and, as Table 2.4 shows, women were more likely to be living alone than men, who were more likely to be living with a spouse. Nevertheless there were a number of very elderly men living on their own, and some of them caused their carers great concern.
Informal help and care
We wanted to know to what extent the elderly people received help and care from their informal network, both from those living with them, from relatives not living with them, and from friends and neighbours. Of the 38 elderly people living with others, all but four said they received help from the people they lived with. These four were all looking after equally elderly spouses, who were more disabled than they were and were usually suffering from dementia. Three of them were men looking after very disabled wives. They were interviewed in the ‘elderly people’ sample, but they could all have been classified as carers, as indeed could some of the other elderly people interviewed who were living with very frail spouses. This study certainly underlined the fact that carers can be very elderly themselves, and that caring for the carers does not only mean supporting middle-aged daughters. There was no question that in some cases elderly couples were supporting each other, and if one of them died or became ill, there would have been little alternative to residential care for the survivor.

Help from members of the household
We looked first at those living with other people – the elderly couples and those living with younger relatives. We divided the kind of help they received into ‘functional’ tasks, such as shopping, cleaning, cooking, laundry, transport and so on, and ‘personal’ tasks, such as help with dressing, washing, getting to bed and so on.

Two-thirds of those living with a spouse said their husbands or wives helped them with both functional and personal tasks, while two-thirds of those living with others said they were helped with only functional tasks. However, over a quarter of those living with a spouse said that their spouse helped them with ‘everything’, both functional and personal, and nearly one fifth of those living with other relatives said the same. The numbers were, of course, small, but underline the findings that, even among those living with others, there were some very independent elderly people who required little help or care. However, there were also some very frail people who relied totally on their resident carers.

Those who received help from the people they lived with usually mentioned everyone who lived in the house as offering some help, but most of the personal care given came from a spouse or a female member of the household, as might be expected.

Help from other relatives
But what about other relatives? After all, the majority of those living with others were living with an elderly spouse. We were interested to know to what extent other relatives were helping them, and, of course, if elderly people were living with sons and daughters we wanted to know to what extent they undertook the main responsibility for caring for their parents. We also wanted to know what kind of help those living alone received from relatives. At the same time, we
were interested in establishing what kind of family network these elderly people had.

We therefore asked those living alone whether they had any close relatives, and those living with others whether they had any other close relatives. We included spouses, children, grandchildren, siblings, nieces and nephews among the close relatives, but some of the elderly people included great-grandchildren while one or two mentioned cousins or more remote relatives.

Almost all of those living alone said they had close relatives, although two elderly people living alone said they had no close relatives at all. Among those living with a spouse, all but two said they had other close relatives, while among those living with other relatives, all but three said they had other close relatives.

The question of whether these relatives helped the elderly people was another matter. Well over half of those living alone or living with a spouse said they were helped by other relatives, but only two of those already living with other relatives said that anyone else helped.

The extent of help from relatives, according to the elderly people, needs to be put into perspective. What was surprising among those living alone, perhaps, was that over 40 per cent of those who had relatives said they received no help from them, not even of a functional nature. Often these elderly people had no children, and, even if they had other ‘close’ relatives, they received no help from them, sometimes because they themselves were very independent, and sometimes because the relatives lived at a distance. But often it appeared that no help was expected or given from relatives more distant than children.

The same was true of those living with a spouse. Often they had no children, and, even if they were not particularly independent, the more distant relatives were unlikely to provide any help. There was no doubt that those living with relatives other than a spouse were unlikely to receive much help from other members of the family, according to the elderly person, and this view was borne out by the carers. It is probable that the elderly people we interviewed, all of whom were known to social services departments, might have had rather fewer available close relatives to help them than those who were not known to social services, but the sample of elderly people in residential care, not all of whom were known to social services, had even smaller networks of close relatives. The evidence tends to confirm the pattern observed in other studies indicating that relatives other than spouses and children rarely give care of a ‘personal’ nature to elderly people, and that most of the care is provided by one person.

If the elderly people received help from relatives other than those with whom they were living, it was most likely to be functional help. Only one elderly person, who was living alone, said she received help with ‘everything’ from a relative, and five, again living alone, said they received both functional and personal help. However, the functional help was sometimes very intensive and clearly helped to keep the elderly person in community. In other cases, the family was keeping a close eye on the elderly person, although it was doubtful whether more intensive care would be available, as this elderly man, living with his wife, explained: ‘Our daughter comes over every three weeks and does the garden. She brings us things
from Sainsbury’s, she shops, she does the garden. Our son can’t help us manually. He’s on a life pill. Our daughter and son keep in touch every day to see what they can do to help. He phones every day so that everything’s not put on to her. Our son-in-law decorated this room…’

It was unusual for relatives more distant than sons and daughters and their spouses to provide any care, but with some of these very isolated elderly people, other relatives occasionally played a role, not always to the taste of the elderly person, as an elderly woman living alone in the London area commented: ‘I have a cousin – we’ve never been close. He lives in Leeds. He doesn’t come often. He writes every week. Once I lost my pension book. Now he keeps it and sends me money. It annoys me – he’s bossy. I like to be independent. He lives in Leeds. We didn’t know each other very well…’

Help from friends and neighbours

Much interest has been shown in the extent to which elderly people are helped or can be helped by friends and neighbours. There has been discussion of the extent to which care in the community can or should be offered by the ‘community’, and government papers during the 1980s were strong in their exhortations for the community to care. ‘Care in the community must increasingly mean care by the community…’ (DHSS 1981)

But how far is this realistic? Many commentators and researchers have suggested that care in the community is usually care by a close female relative, especially if any care of a personal nature is required (Finch and Groves, 1983; Qureshi and Walker, 1989). The elderly people in our community sample suggested that this was a fair assessment of their situation. Only 27 per cent of them said that they had any regular help from friends and neighbours, accounting for one third of those who lived alone, just over a quarter of those living with a spouse, and none of those who lived with other relatives or friends.

The help offered by neighbours was overwhelmingly of a practical nature, with most of it being help with shopping, although one third of those who were helped by neighbours mentioned that they did odd jobs and gardening. A handful of neighbours helped with laundry, transport and paying bills, but essentially this kind of help was very limited. Only one person had help from a neighbour with cleaning or making beds, and only one elderly person mentioned help with personal care. Some neighbours clearly kept an eye on the elderly people and came to visit, but it should be stressed that the help offered by neighbours to these frail elderly people was usually limited to the kind of help which might be offered by younger, fitter neighbours to each other. There was little evidence of care in the community being undertaken by friends and neighbours. Even if some of the elderly people were underestimating the amount of help they were getting from the ‘community’, there was little indication that this kind of care can be relied upon to any extent to help maintain elderly people in the community when they need care of a more intensive nature.
Family network
It has sometimes been asserted that the family is beginning to cease to care, although research in recent years challenges the view that there was once a ‘golden age’ of family care, in which all elderly people were taken into the bosom of a warm and caring family network (Wall, 1984; Qureshi and Walker, 1989). It is quite clear that ‘caring’ for elderly people is – and was – most likely to be undertaken by their children. But Mark Abrams (1978) found that 30 per cent of elderly people interviewed had never had children or had no living children. Subsequent research has shown that absence of children can often lead to entry to residential care.

Table 2.5  Number of children of elderly people in the community

<table>
<thead>
<tr>
<th>No of children</th>
<th>Total</th>
<th>London area</th>
<th>Southern area</th>
<th>Northern area</th>
</tr>
</thead>
<tbody>
<tr>
<td>None ever</td>
<td>20</td>
<td>20</td>
<td>32</td>
<td>8</td>
</tr>
<tr>
<td>None living</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>–</td>
</tr>
<tr>
<td>One living</td>
<td>36</td>
<td>43</td>
<td>32</td>
<td>33</td>
</tr>
<tr>
<td>Two living</td>
<td>21</td>
<td>13</td>
<td>24</td>
<td>25</td>
</tr>
<tr>
<td>Three living</td>
<td>9</td>
<td>13</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Four living</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Five living</td>
<td>2</td>
<td>–</td>
<td>–</td>
<td>6</td>
</tr>
<tr>
<td>Six living</td>
<td>3</td>
<td>–</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>More than six living</td>
<td>2</td>
<td>3</td>
<td>–</td>
<td>3</td>
</tr>
</tbody>
</table>

Base: all elderly people in the community (100) (30) (34) (36)

As Table 2.5 shows, 22 per cent of those interviewed had never had children or had no living children, representing 29 per cent of the men and 21 per cent of the women. There were marked differences between the districts, with just under a quarter of those in the London area having no children, compared with as many as 35 per cent of those in the southern county, but less than 10 per cent in the northern area. There were no striking differences between those living alone, with a spouse or with other relatives.

But those with children had not had large families on the whole. Nearly 60 per cent of the sample had only one or two children, and only 12 per cent had four or more. Again, there were geographical differences. In all three areas, around 60 per cent had only one or two children, but big families were a marked feature of the northern area, where nearly a quarter had four or more living...
children, compared with 6 per cent of those interviewed in both the London and southern areas.

Table 2.6  Family network of elderly people in the community

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>London area</th>
<th>Southern area</th>
<th>Northern area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living spouse/no children</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Living spouse and children</td>
<td>19</td>
<td>13</td>
<td>15</td>
<td>28</td>
</tr>
<tr>
<td>Living children/no spouse</td>
<td>59</td>
<td>63</td>
<td>50</td>
<td>64</td>
</tr>
<tr>
<td>Other relatives (no living spouse or children)</td>
<td>15</td>
<td>20</td>
<td>23</td>
<td>3</td>
</tr>
<tr>
<td>No kin at all</td>
<td>3</td>
<td>--</td>
<td>9</td>
<td>–</td>
</tr>
</tbody>
</table>

Base: all elderly people in the community (100) (30) (34) (36)

Given that little help was expected or received from relatives more distant than children or spouses, some analysis of the family networks of the elderly people is of crucial importance. Table 2.6 shows that 23 per cent of the elderly people had a living spouse, of whom 4 per cent had a spouse and no children while 19 per cent had a spouse and children. The largest group of elderly people – 59 per cent – had a child or children but no spouse. This meant that 82 per cent of the elderly people had either a spouse or living children or both, leaving 18 per cent of elderly people with neither spouse nor children. Of this group, 15 per cent had other relatives, but 3 per cent had no kin at all.

The elderly people in the community were rather more likely than those who had entered residential care to have had a spouse and/or children (82 per cent compared with 73 per cent), but nearly one fifth of our community sample did not have a close family member who might be called upon to take on a caring role.

We asked the elderly people about their relatives in some detail. Apart from the three who had no kin at all, a further 13 per cent could mention only one relative and 12 per cent had only two relatives. Among the 13 who mentioned only one relative, five were more distant than a spouse or child.

The elderly people did not have big family networks on the whole, with 37 per cent mentioning three or four relatives, 10 per cent mentioning five relatives, 20 per cent mentioning between six and ten relatives and 5 per cent indicating that they had eleven or more relatives. It is probable that a few nieces, nephews and cousins were not mentioned by elderly people. Those who were mentioned usually appeared to have played some kind of role in the elderly person’s life or were mentioned because they were the only kin the elderly people had.

But having relatives certainly did not mean that they might take on an active caring role even if they lived in the same neighbourhood. Even having children
was no guarantee that they would provide care, particularly if they lived at a distance. We made an analysis of where the elderly person’s nearest relative lived, and made a further analysis of where their nearest child lived, if they had any children.

37 per cent of the elderly people lived with at least one relative. A further 40 per cent had at least one relative living in the same town or area. 12 per cent had a relative living at a distance but in surrounding areas, while nearly ten per cent said their nearest relative lived some distance away or abroad. (Three per cent had no relatives at all.)

13 per cent of the elderly people lived with a son or daughter, while 48 per cent had at least one child living in the same town or area. In 7 per cent of cases the nearest child lived at a distance but in a surrounding area, while 11 per cent of elderly people said their nearest child lived a long way away or abroad. 22 per cent of the elderly people, of course, had no children.

In over one fifth of cases, the elderly person’s nearest relative lived at a distance or they had no kin at all. Given the importance of sons and daughters in taking on the caring role when their parents get older, and particularly when one of them dies, it was very important to note that 40 per cent of the elderly people had no son or daughter living in the area or neighbourhood in which they were living. It was little wonder that some of the non-resident carers were worried about what would happen to the elderly person if they became frailer and more dependent. Informal care on an intensive basis was clearly not readily available for a sizeable minority of the elderly people we interviewed, unless they could move to live with a son or daughter who lived in another area or unless such caring was available from a more distant relative who lived nearer. There was little likelihood of that happening on a large scale, even if the availability had been greater.

**Informal carers in the community**

We wanted to identify and interview the elderly people’s carers in the community. We were aware that we would not be able to achieve this aim in every case, partly because some of the elderly people were very independent and could not identify anyone as a carer and partly because some of the elderly people or carers might not wish us to interview them. It is also not always easy to identify who the carer actually is, as the social workers we interviewed confirmed. In some cases, it is quite obvious, but in other cases it is much more difficult to establish who is the carer or even if there is anyone who could be called an informal carer.

We started by asking the elderly person to identify the person in their informal network who helped them most to manage at home. We had been talking to them about relatives and friends and relations and hoped that this would lead them to mention someone from this network. In spite of this, a few elderly people insisted that a professional, usually a home help, was their main informal carer.
In all cases where the elderly person named a professional and could not name an informal source, we treated this as no informal carer named at this stage.

We found, perhaps not surprisingly, that over a third (34 per cent) of the elderly people could not name an informal source who helped them most to manage at home. (As many as 52 per cent of those living alone could not name anyone.) 17 per cent of the total mentioned a spouse and 25 per cent mentioned a daughter. 14 per cent mentioned their son or daughter-in-law or both son and daughter-in-law. Of the remaining 10 per cent, 6 per cent mentioned friends or neighbours, 3 per cent a sister or niece, and 1 per cent mentioned her daughter, son and neighbour. It can be seen that the vast majority of elderly people who could name an informal carer spoke of a spouse or child.

We did not always interview this person, since in some cases the carer refused to be interviewed or the elderly person refused on their behalf, and in some cases this person could not really be called a carer, since they had very little contact with the elderly person.

We then had the problem of trying to identify a carer for the elderly people who said that nobody within their informal network helped them. Looking at those who said they had no informal carer (34 people), we could not identify anyone who could be interviewed in nearly half the cases. In six cases we interviewed a professional who appeared to be caring informally as well as formally. In a further twelve cases we identified a carer, and managed to interview six of them.

We finally achieved interviews with 72 informal carers. 69 of these were caring for elderly people we interviewed, while three of them, all in the London borough, were caring for the three elderly people whom it was not possible to interview because of mental or physical frailty. It can be seen that the sample of carers had to be treated separately from the sample of elderly people. We achieved interviews with the carers of over three-quarters of the elderly people interviewed in both the southern and northern areas, but with only 50 per cent of those interviewed in the London area, although we interviewed a further three carers in that area. There were a number of reasons for this difference between the areas, but probably the most important was that a higher proportion of elderly people in London were living alone and said they had no carer.

Among the carers we interviewed, 31 (43 per cent) were living with the elderly people and 41 (57 per cent) were not living with them. This meant that the carers’ sample tended to slightly over-represent resident carers when compared with our sample of elderly people. (38 per cent of the elderly people were living with others and 62 per cent were living alone.) We interviewed 18 carers in the London area, five of whom were living with the elderly person; 26 in the southern county, 14 of whom were living with the elderly person; and 28 in the northern county, 12 of whom were living with the elderly person.

Who were the informal carers?
We found that the elderly people living in the community had rather different types of carer from those living in residential care. Table 2.7 shows that 24 per
cent of the carers interviewed were the spouses of the elderly people (13 per cent husbands and 11 per cent wives), compared with only 5 per cent of the carers of the elderly people interviewed in residential care. This is not surprising, but it underlines again how the death of a partner can precipitate the move into residential care.

Table 2.7  Relationship of carer to elderly person in the community

<table>
<thead>
<tr>
<th></th>
<th>Total (Nos)</th>
<th>London area</th>
<th>Southern area</th>
<th>Northern area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>24 (17)</td>
<td>23</td>
<td>19</td>
<td>29</td>
</tr>
<tr>
<td>Daughter</td>
<td>40 (29)</td>
<td>34</td>
<td>31</td>
<td>54</td>
</tr>
<tr>
<td>Son</td>
<td>10 (7)</td>
<td>17</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>8 (6)</td>
<td>6</td>
<td>15</td>
<td>3</td>
</tr>
<tr>
<td>Professional</td>
<td>8 (6)</td>
<td>11</td>
<td>15</td>
<td>–</td>
</tr>
<tr>
<td>Other relative (female)</td>
<td>4 (3)</td>
<td>–</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Friend/neighbour</td>
<td>4 (3)</td>
<td>6</td>
<td>8</td>
<td>–</td>
</tr>
<tr>
<td>Other relative (male)</td>
<td>1 (1)</td>
<td>6</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Total: all informal carers of elderly people in the community</td>
<td>(72)</td>
<td>(18)</td>
<td>(26)</td>
<td>(28)</td>
</tr>
</tbody>
</table>

40 per cent of the informal carers interviewed were daughters, 8 per cent were daughters-in-law and 10 per cent were sons. A further 4 per cent were sisters or nieces and one carer (1 per cent) was a nephew. In 4 per cent of cases we interviewed a friend or neighbour and in 8 per cent of cases we interviewed a professional, usually a home help, but including a BUPA nurse and a voluntary helper. Again, the pattern emerged of most of the informal care being undertaken by very close members of the family, usually spouses or children.

There were some geographical differences, with rather more elderly spouses and daughters being interviewed in the northern area than in the other two areas, and more non-family members being interviewed in the southern area and London.

Comparing the sample with the sample of carers of elderly people in residential care it can be seen that a rather higher proportion of sons were interviewed in the latter sample. This is almost certainly due to the fact that sons tended to become involved more with elderly people when the decision to enter residential care was taken. They tended to assume more responsibility at the death of their father or mother, who might previously have been caring for an elderly person or whose death precipitated a move out of the community, and they often became more involved when financial matters were being discussed.
Three-quarters of the carers interviewed were women, although over a third of those interviewed in the northern area were men, reflecting the rather higher number of elderly husbands caring for wives interviewed in that area.

Table 2.8  Age of carers of elderly people in the community

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>London area</th>
<th>Southern area</th>
<th>Northern area</th>
</tr>
</thead>
<tbody>
<tr>
<td>35-49</td>
<td>24</td>
<td>22</td>
<td>39</td>
<td>11</td>
</tr>
<tr>
<td>50-59</td>
<td>30</td>
<td>39</td>
<td>19</td>
<td>35</td>
</tr>
<tr>
<td>60-69</td>
<td>23</td>
<td>17</td>
<td>23</td>
<td>25</td>
</tr>
<tr>
<td>70-79</td>
<td>13</td>
<td>11</td>
<td>15</td>
<td>11</td>
</tr>
<tr>
<td>80+</td>
<td>11</td>
<td>11</td>
<td>4</td>
<td>18</td>
</tr>
</tbody>
</table>

Base: all informal carers of elderly people in the community (72) (18) (26) (28)

One of the main points of interest in Table 2.8 showing the age of the carers is the fact that nearly half of them were over the age of 60 (46 per cent). But what is even more striking is that a quarter of those interviewed were over 70 and indeed 11 per cent were over 80. This proportion was actually higher in the northern area where nearly one fifth of the carers were over 80. The ages of the carers are, of course, related to the type of person interviewed as the carer, but what this table reinforces is that carers are by no means a homogeneous group of people for whom certain kinds of services or support can be supplied across the board. In addition, the question asked so often of social workers of ‘who is the client – the cared-for or the carer?’ becomes somewhat academic in so many cases where it is quite difficult to sort out who is the elderly client. We found that with some of these elderly couples it was almost a matter of chance whom we interviewed as the elderly person and whom we interviewed as the carer. The implications for the formal services are far-reaching.

Duration of caring
The willingness to care for an elderly person is often related to how long the carer thinks the caring is going to continue. There is evidence that people may take on the caring role with the assumption that it might not last for long. It is certainly apparent that caring can be very wearing if it continues for a long time with no end in sight, and that caring for elderly people appears to be different from caring for younger handicapped people, for example, in that there is often a gradual decline in the person being cared for, often with a strain on any affectionate relationship which may have existed before. Where there have been no strong
ties of love and affection, the duration of caring may put severe strains on the relationship.

It is often assumed that elderly people tend to move into the home of one of their children and that the greatest burden on carers comes about as a result of sons and daughters looking after their mothers or fathers in their homes. This undoubtedly occurs, but it was not reflected in our sample to any great extent. There are a number of reasons for this. One was the way in which we drew our sample, which was taken from those known to social services departments. Elderly people who are known to social services departments usually only become known when they need services. There is a probability that those living alone or with an elderly spouse may well be seen to need services before those living with their children. However, the burden being borne by some of the carers who were living with elderly people was acute, as was apparent in interviews, and serves to underline the fact that many such situations become known to the statutory services only when a breakdown in the informal relationship is near and may not easily be averted.

Of the 31 carers living with the elderly people, over half were spouses and three were children or siblings who had always lived with the elderly person. A quarter of the rest had lived with the elderly person for less than five years, while the others had lived with the elderly person for more than five years, two of them for more than ten years.

The elderly people who had not been living with the carers for a long time had more usually moved in with the carer rather than the other way round, and a typical story was that told by a daughter-in-law: ‘He was on his own in a large old house that was falling down around his ears. There was no heating or hot water. There was a big rambling garden. He couldn’t manage. I was trying to spend more time there than it was worth. There was no money to put the place right. It was either with us or go into a home...’

But in two cases the elderly person and carer had moved in together and two carers had moved in with the elderly person, as this step-daughter illustrated: ‘Mum got bad. She was taken ill. I came for two weeks and have stayed for two years...’

The precipitating factor in causing the elderly person to start living with the carer was usually illness or frailty on the part of the elderly person. We were interested to know what the carer felt about the move to begin with, and then what they felt about it now. It must be remembered that we were only talking about 12 people who were in this situation. Most of them said they felt quite happy about living with the elderly person to begin with. There was a sense of relief on the part of some of them that there were no more worries or telephone calls and less travelling, but one or two expressed doubt about whether it had been a good idea from the beginning and one daughter said she had no choice.

Certainly there was evidence that some carers had started off well but were now regretting their decision, like this daughter-in-law: ‘I wasn’t bothered at the beginning because I thought it would be easier than my husband going over there. But then there were difficulties. I got high blood pressure and the doctor was
unsympathetic. He (father-in-law) threatened me with a knife. I didn’t realise he needed watching. You can’t trust him...

We asked all the carers how long they had been looking after the elderly person. Table 2.9 shows the differences between the resident and non-resident carers.

Table 2.9 Length of time carer had been looking after elderly person in the community

<table>
<thead>
<tr>
<th></th>
<th>Total carers</th>
<th>Resident carers</th>
<th>Non-resident carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 1 year</td>
<td>10</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>1 &lt; 2 years</td>
<td>15</td>
<td>6</td>
<td>22</td>
</tr>
<tr>
<td>2 &lt; 5 years</td>
<td>29</td>
<td>32</td>
<td>27</td>
</tr>
<tr>
<td>5 &lt; 10 years</td>
<td>21</td>
<td>23</td>
<td>20</td>
</tr>
<tr>
<td>10 years or more</td>
<td>25</td>
<td>32</td>
<td>20</td>
</tr>
</tbody>
</table>

Base: all informal carers of elderly people in the community (72) (31) (41)

Nearly half the carers said they had been looking after the elderly person for more than five years, and a quarter had been looking after them for more than ten years. But these proportions should be treated with some caution, since nearly three-quarters of the husbands and wives said they had been looking after their spouse for more than five years, and it was sometimes difficult to disentangle what they meant by ‘looking after’, although we had drawn a clear distinction between living with someone and looking after them.

However, looking at Table 2.9, it can be seen that it was not only those living with the elderly people who had been looking after them for some years, since 40 per cent of the non-resident carers said they had been caring for more than five years. Indeed around 40 per cent of the daughters interviewed said they had been looking after their mothers or fathers for more than five years. There can be no doubt that the strain was beginning to tell on some of the carers.

Reasons for caring

There is usually a point at which carers can say that they started to look after someone or ‘care’ for them. Table 2.10 shows that the main reason given by the carer for starting to look after the elderly person was a physical illness or a fall or fracture. Over a third of the carers gave this as their main reason. Perhaps not surprisingly it was mentioned by more resident than non-resident carers. Bereavement was the second main reason, mentioned by over a quarter of the non-resident carers compared with only a tenth of the resident carers. Disability was mentioned more by resident than non-resident carers, while mental frailty
or confusion were mentioned by one in ten of both types of carers. Practical considerations such as financial or accommodation problems or the illness of the existing carer accounted for over 10 per cent of the non-resident carers’ main reasons, while age and deterioration had led to similar proportions of both resident and non-resident carers starting to look after the elderly person. Finally, in 4 per cent of cases, all wives of elderly men, the carers said they were not really ‘looking after’ the elderly people, and in a further 4 per cent of cases, the carer was a professional who regarded the caring as part of her job.

Table 2.10  Main reason for carer starting to look after elderly person in the community

<table>
<thead>
<tr>
<th></th>
<th>Total carers</th>
<th>Resident carers</th>
<th>Non-resident carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness of elderly person</td>
<td>34</td>
<td>37</td>
<td>28</td>
</tr>
<tr>
<td>Bereavement</td>
<td>19</td>
<td>10</td>
<td>27</td>
</tr>
<tr>
<td>Disability</td>
<td>13</td>
<td>19</td>
<td>7</td>
</tr>
<tr>
<td>Mental frailty/confusion</td>
<td>10</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Practical*</td>
<td>9</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Age/deterioration</td>
<td>8</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>Professional</td>
<td>4</td>
<td>–</td>
<td>7</td>
</tr>
<tr>
<td>Married</td>
<td>4</td>
<td>10</td>
<td>–</td>
</tr>
</tbody>
</table>

Base: all informal carers of elderly people in the community  (72) (31) (41)

* Includes financial and accommodation difficulties, illness of elderly person’s spouse etc.

But the reasons for starting to look after the elderly person were by no means as clear-cut as the analysis above might suggest. As well as giving one main reason, most carers gave a number of other reasons, and often included most of the categories given above. The most common reasons included a combination of the elderly person’s inability to look after themselves, mainly because of physical illness, age and disability, often exacerbated by bereavement and the loss of a supporting spouse. The difficulty of ascribing a ‘main reason’ to the start of a caring relationship is graphically illustrated by this daughter, describing how she started looking after her mother:

My father died. But it was an ongoing thing... They moved to Bournemouth, then to Sussex and then to Eastbourne. I’ve always been back and forth every week, every fortnight. It’s part of my nature – the caring role. But I’m getting too tired now. The plan was for my mother and father to come here. I bought this house with that intention. Ten days before they came, my father died. My mother came and turned this place
into a turmoil. It didn’t work out at all. She didn’t like it. She didn’t want to come into the country. She moved to sheltered housing in 1985. It wouldn’t have worked. She needs 24 hour care. We can’t do it. She’s deteriorating and so are we...

Feelings about caring
We asked the carers how they had felt about looking after the elderly person to begin with and how they felt about it now. We also asked them whether they had felt under any pressure to start looking after the elderly person. There is evidence that carers, particularly relatives other than spouses, take on the caring role quite happily, without fully realising what they are letting themselves in for, either in terms of the duration of the caring or of the potential wear and tear on them and their families as the elderly person becomes more dependent. We were particularly interested to know what the other members of their families had felt about the situation, both at the beginning and now, since there is so much evidence that carers may feel themselves torn in all directions by their caring role.

In around half the cases, the carers said they took on the role happily or that they wanted to care because they felt it was a reciprocal role. There were interesting variations on this. A typical comment from a child was given by this daughter living with her mother: ‘She’s always stood by me, so it was my job to stand by her – to repay her for all she’s done for me...’ But sometimes the reciprocity was more complicated, as this husband explained: ‘I was only too pleased to look after her. She married me when I was almost a down-and-out. She brought me to my senses and this is my way of paying her back for all her help and support...’

In around a fifth of cases, the caring started with little thought to the future, and many regarded it as a matter of course: ‘I didn’t mind. She is my mother. We had a family meeting and it was decided that I do it. The rest of the family visit regularly...’ But in nearly one fifth of cases, there was a sense that the caring was regarded as a duty or that there was no option or that it was something which had to be done by an only child, as this daughter explained: ‘It was a bit aggravating. But one did it out of duty. I’d retired. If you were able to talk to my friends they’d say I’ve done too much. But you can only do how you feel. I’m like that...’

But there were rumblings even at this early stage that the caring role was assumed only reluctantly, and over one fifth of the resident carers said they had not realised when they took on the caring how much was entailed or the extent to which their lives would be affected. It should be noted that half the elderly wives who were caring for their husbands made this comment, one of many indications that life was becoming very difficult for some of the very elderly carers we interviewed.

Less than one fifth (18 per cent) of carers said they had felt under pressure to start looking after the elderly person at the beginning. But there was quite a marked difference between the resident and non-resident carers, with hardly any
of those living with elderly people feeling under any pressure at the beginning, compared with over quarter of the non-resident carers. There was also a difference according to the relationship of the carer to the elderly person, with nearly 30 per cent of the daughters feeling under pressure, compared with only around one in ten of the spouses. The main sources of pressure were felt to be from the elderly people themselves and from a sense of personal duty. In very few cases were other relatives felt to be putting any pressure on carers to take on the role.

But where there was a feeling of pressure to care it was often exacerbated by a feeling that there was no alternative, as this elderly wife explained: ‘I felt under pressure from everyone, because I got no help from any social services, a social worker or anyone. They come and see you – they write everything down and think, because you’re not on the floor, you’ve got enough money to help yourself...’

The majority of carers who did not feel under any pressure to begin with often spoke of the feelings of reciprocity heard so often in these interviews, as this daughter explained: ‘No – he’s my dad. He looked after me when I was little. I think it goes in a circle. I may moan and groan, but there’s no way I’d have him anywhere but with me. He can be very difficult, certainly...’

We asked the carers how they felt about looking after the elderly person now. There was no doubt that fewer carers were as sanguine about the caring role as they had been when they had taken it on, although nearly a third of the respondents still said that they felt quite happy about their role, with roughly equal proportions of resident and non-resident carers agreeing on this. It was, however, noticeable that the elderly husbands were considerably happier about caring than the elderly wives were. Not one wife felt happy about the role, while nearly half the husbands did. It is possible that they might have been doing rather less than some of the elderly wives, but there was no doubt that some of them were looking after very disabled wives.

Around 10 per cent of carers, all non-resident carers, said that they did not mind the caring because it was not much bother. And around one in ten said they continued to care out of a sense of duty or because there was no-one else to do it.

But there were indications that the strain of caring was beginning to take its toll on carers, with one fifth saying that they were finding the caring very tiring and that it was getting them down, and around 10 per cent saying that they were finding it very difficult because they were ill or getting older themselves. Around a fifth of the carers complained about their lack of freedom and the time and commitment involved in looking after the elderly person, often combined with a feeling of pressure and being relied upon to a much greater extent than before. There were expressions of anger and frustration, and, in some cases, it was clear that the informal caring relationship was about to collapse.

Some of the elderly wives were at the end of their tether, it appeared, but they coped in various ways, like this woman in the London area – ‘I get very tired but I’d never stop looking after him till I dropped. I’d never let him suffer
or go without. I have bronchitis but I have to keep on so I can look after him...’ – but an elderly woman in the same area indicated that the strain was beginning to tell – ‘It’s really beginning to get me down. I get no help, no days off at all and he never speaks...’

The elderly husbands often appeared to be better able to cope, like this elderly man in the northern area: ‘It is a little harder now. I have been diagnosed as diabetic so I have to be careful of my diet and things like that. I don’t have the energy I had a few years ago, but I still enjoy looking after her. It’s called love...’

There was little doubt that an important factor in the willingness to continue to care was the nature of the relationship beforehand. Elderly spouses were often caring for very disabled and frail husbands and wives. Some of the carers were caring for elderly parents who were themselves caring for spouses suffering from dementia. Some of these carers were desperate with worry about both parents, like this daughter: ‘I worry a lot that he’ll die – have a fall or something – and she’ll be left in the house on her own. She’s a completely senile old woman...’

The loss of freedom and sense of responsibility were felt very acutely by some of the sons and daughters, many of whom were in their sixties and had hoped for a more relaxing life than they were experiencing, like this daughter – ‘It’s obviously altered what I hoped would be four or five years of a carefree retirement. It’s always there. I’ve lost my freedom... I’m more free and easy now she’s not living here, but I can’t move out. I can’t go away without extensive plans. She’s disoriented out of her environment, so I can’t move her or take her out and about...’ – and this son whose mother had moved in with him and his wife at his retirement – ‘It’s knocked the ground from under our feet. We had so many plans – walking here, travelling round the world. All that’s gone. We’ve lost our freedom...’

In some cases, the carers were literally at the end of their willingness to care, as a daughter illustrated: ‘I don’t feel I want to do it any more. I’ve brought up four kids on my own and for the first time I want freedom. It just finished me when I went to New Zealand to see my daughter and my mum broke her arm and nobody would have her over Christmas. I cut my trip to my daughter short by seven weeks and came home...’

The pressure to care had certainly increased. Nearly 40 per cent of the carers felt under pressure to care at the time we interviewed them compared with less than a fifth who had felt under pressure at the beginning. Again, the elderly husbands were the least likely to feel under pressure, but half the wives and daughters-in-law felt under considerable pressure, as did over 40 per cent of the daughters.

The sense of duty and pressure from the elderly person were still the most common sources of pressure on carers. The sense of a lack of alternatives was very strong among some of the carers, adding to the pressure, as this elderly wife explained: ‘I feel under pressure from the family, from him, from everyone. Who else will do it? If I fall ill, God knows what will happen...’
Help given by informal carers related to where they lived

Ninety-five per cent of the carers said they helped the elderly people regularly, 4 per cent said they helped sometimes and 1 per cent helped in an emergency. All the resident carers said they helped the elderly person regularly, compared with 90 per cent of the non-resident carers. There was little difference between the areas.

Around 50 per cent of the carers said they gave functional help only, while the other half said they gave both functional and personal help to the elderly people. Perhaps not surprisingly, the help offered by resident carers was more personal than that offered by non-resident carers. Three-quarters of the resident carers said they helped the elderly people with both functional and personal tasks, compared with one third of the non-resident carers, meaning that one quarter of the resident carers and more than two-thirds of the non-resident carers helped the elderly person only with functional tasks. There was virtually no difference between the areas: the most important factor in the provision of personal care appeared to be whether the carer lived with the elderly person or not.

Over 40 per cent of the resident carers said they did everything for the elderly person, compared with only 3 per cent of the non-resident carers.

The findings were slightly at odds with the assessments given by the elderly people, although it is difficult to compare the two samples directly, since we interviewed only carers of people who had carers. However, elderly people as a whole tended to suggest that they were more independent of personal help from relatives than the carers suggested. Similarly, the finding among the elderly people living alone which suggested that nearly half of them received very little help, even of a functional nature, from relatives with whom they were not living, does not really coincide with the reported activities of the non-resident carers we interviewed.

There was almost certainly an under-reporting by the elderly people of help from their relatives and carers, although there was probably some over-reporting of help by the carers. However, there are interesting implications in this slight discrepancy, since professionals or others making an assessment of an elderly person’s needs should be sensitive to the possibility that elderly people may not be as independent as they sometimes make out.

We asked the 41 non-resident carers how far away they lived from the elderly people, how they got to the elderly people, how long it took them and how often they went. The intensity and availability of informal caring was crucial in keeping many of these elderly people in the community, but the strain on the non-resident carers of keeping the caring going was clearly beginning to show in some cases.

One third of the non-resident carers lived within half a mile of the elderly people, a further third lived within a radius of five miles, nearly one fifth lived between five and ten miles away, while one fifth lived more than ten miles away from the elderly people. There were no marked area differences, although the carers in the southern area tended to live rather nearer the elderly people than those in other areas. It must be rather difficult to offer intensive care to someone if you live more than ten miles away from them.
Over 50 per cent of the carers said they usually went by car to visit the elderly person, over a quarter walked, 10 per cent used public transport and 7 per cent cycled. Over three-quarters of the carers in the London area usually went by car, while two-fifths of the southern county carers walked.

Nearly 60 per cent of the carers had a journey of less than fifteen minutes to get to the elderly person, although there were marked area differences, with much shorter travelling times reported in the southern area on the whole. One-sixth of the carers had a journey of over an hour to get to the elderly person, and it was not surprising that the nature of their ‘caring’ was different from that of many of those who lived nearer the elderly person they were looking after.

Over one-fifth of the carers said they visited the elderly person more than once a day and a further 10 per cent said they visited on a daily basis. Over a half visited more than once a week, while 7 per cent said they visited on a weekly basis. Five per cent visited every ten days or so, while 2 per cent visited once a fortnight.

The most intensive visiting was found in the southern area, with half the carers visiting at least once a day and the other half visiting more than once a week. On the other hand, nearly one third of the carers in the London area and one in six of the northern carers visited only once a week or less frequently.

There was clearly a very wide spread of caring among the non-resident carers, with some offering very intensive personal and functional care every day, while others offered less intensive ongoing care usually of a more functional nature, and others did not do much more than keep a caring eye on the elderly person while providing functional help as needed. A wide range of carers and caring functions was seen quite distinctly even in this small sample of non-resident carers. The resident carers were different again, and this analysis of tasks and proximity to the elderly people reinforces yet again the dangers of assuming that carers can be regarded as anything like a homogeneous group.

**Reaction from other members of the carers’ household**

One quarter of the resident carers were living with someone in addition to the elderly person and three-quarters of the non-resident carers were living in households with other people. The vast majority of carers living with others said that other members of the household had not minded or had welcomed their decision to look after the elderly people to start with. In some cases the feeling was less positive. As one daughter put it: ‘They didn’t mind how much I did as long as they didn’t have to have my parents to live here with us...’

The few neighbours who had taken on the caring role reported that other members of their family had welcomed the caring at the beginning: ‘They didn’t mind at all. They helped me. The girls sit with her and take food to her. They go in and take food – cake, jelly, trifle. Little things – leftovers. She was still able to do things then. They were great. My husband would fix the leaks in the bathroom...’

But the honeymoon period had not always lasted long, and although over half the respondents said the other members of the household were still quite
happy about the caring, nearly one third said that their spouse was unhappy now about the time they spent with the elderly person or felt that the carer was being expected to do too much.

Resentment from other members of the household was rather stronger when the elderly people were actually living with them, but some carers could cope as long as their spouse remained supportive, as this daughter said: ‘My husband wouldn’t have it any other way. He just says, "It’s one of those things." He’s that sort of person. He takes everything in his stride. My children were very good to start with but they get a bit impatient now...’

Some of the carers’ husbands and wives were particularly supportive – ‘My husband thinks as much of my mother as I do...’ – while others were said to understand the pressure to care – ‘They support me in every way they can. They know I want to look after her...’

But there were certainly indications that families would only take a certain amount, and this was not perhaps surprising, as this daughter explained: ‘We’ve had them every Christmas since my daughter started school. She’s 21 now. It’s ghastly when they come – terrible. My mother is dirty and violent. If they had to live with us my family would break up. They know I have to give a lot of time to Mum and Dad and accept it. They go round themselves sometimes. My daughter went last week and gardened. But they’ve all got their own jobs and their own lives. My husband gets fed up because he has to visit his old mother and he feels we have to give all the attention to my parents...’

**Other close relatives**

There were 15 cases where people other than the carer were living with the elderly people. There were 11 cases in which the resident carer reported other people living with them and the elderly person – members of the family in each case – and four cases where the carer was non-resident but the elderly person was living with someone else (in three cases with a spouse and in one case with a friend). We asked the carer whether these other members of the elderly person’s household helped them at all, and, if they helped regularly, what they did.

In most cases, whether the carer was resident or non-resident, the other members of the household offered regular help to the elderly person, most frequently of a practical or functional kind. They were often the sons or sons-in-law of the elderly person and were helping their wives with the caring.

We asked the carers whether the elderly person had other close relatives, and if so, whether they helped them regularly, sometimes or only in an emergency. As the elderly people had indicated, nearly 90 per cent were said to have other close relatives, and in 63 per cent of these cases, the carer said at least one of them offered some kind of help. But it should be noted that this accounted for only just over half the carers, leaving a fairly high proportion who were getting no help with the elderly people either from members of their own household or from other relatives.

What did these other relatives do? The help was almost entirely of a functional nature – shopping, laundry, odd jobs or gardening – and only one carer
said that other relatives outside the household offered any personal care to the elderly person. When other members of the family helped, the carer said it was regular help in over half the cases, usually from the elderly person’s son, daughter or daughter-in-law. In some cases, the help was given willingly, but negotiation was often necessary: ‘My brother doesn’t do anything. My sister has mum every other weekend if nothing crops up, and for a week if I can wangle it. For two days out of fourteen she has her...’

In some cases, help from close relatives was thought to be difficult to arrange because of their other commitments, sometimes down through the generations, as this elderly man pointed out – ‘My daughter who lives alone looks after her grandchildren while their mother works...’ – while in other cases the help was much more spasmodic – ‘My brother occasionally calls in and does a bit of shopping, if he remembers...’

**Carers’ assessment of support from other members of the family**

Just under half the carers thought they had enough support from other members of the family, while just under 30 per cent thought they had not had enough support. In around one fifth of the cases the question was not considered relevant since the elderly person had no relatives or ‘other’ relatives who were in a position to help. This proportion was also found among the sample of carers of elderly people in residential care. The question of whether other relatives could relieve the carer of any burden of caring is academic in such cases, and should not be forgotten when the picture of informal care in the community is being put together.

Among those who said they had help and support from other members of the family, a few had a lot of help and others said they only had to ask for help and it would be forthcoming. These carers were found among resident and non-resident carers and among all types of carer in each of the areas. Elderly spouses tended to say that other members of the family did what they could or were too far away to help. There was evidence of some close-knit families in which everyone would lend some kind of a hand, as this daughter living with her mother illustrated: ‘My daughters are very good. My sister comes when I telephone her. Men are not suitable for this sort of thing, and anyway, her dignity would not allow her to have men look after her...’

But there was evidence of resentment of the lack of help offered by other relatives, particularly among resident carers, of whom over a third thought they did not receive enough help from other relatives, compared with under a quarter of the non-resident carers. The main complaint, unique to elderly spouses and daughters, was that other members of the family did not visit, as this elderly wife said: ‘It would help just to come and see him. I get so tired of it all. I think that I can’t carry on. It’s all wrong. All his brothers and sisters do not want to know...’

Among some of these carers the psychological burden of being the only social contact of the elderly people was often as wearing as the actual physical caring, as this daughter-in-law explained: ‘We get no help from my husband’s
brother. Once we had to pay his petrol to get him up here to see her, and he’s only been three times in two years. The district nurse is very caring – about me as well as her...’

The picture from the carers was again one of most of the care for the elderly person fixed firmly on the shoulders of one member of the family, with the help and support of their own spouse in a number of cases. Certainly, any personal care was undertaken by one person in the vast majority of cases, and in many of these instances, the personal care given was quite considerable (see Qureshi and Walker, 1989). It should be noted that in many of the cases where considerable personal care was given there was no other potential carer. The family networks of many of these elderly people were so small that there was not really a choice of carer. Either one person took on the responsibility or the informal care would not be available at all.

Support from friends and neighbours
Help from friends and neighbours was rather less frequently mentioned than help from relatives, and two-thirds of the carers said the elderly person received no help from friends and neighbours, confirming the evidence from the elderly people themselves. But 15 per cent of carers said the elderly people received regular help from this source, with one fifth of the non-resident carers mentioning it. It was almost invariably functional help, but in some cases it was clearly of crucial importance in maintaining the elderly person at home, as this daughter-in-law explained: ‘There’s a chap upstairs. He’s a companion to her. And she has a sister that lives opposite, but they fall out regularly. She is elderly too, so she can’t help. The next door neighbour but one switches on the calor gas and switches it off. He changes her gas bottle which saves us rushing over there...’

But some of the elderly people had no help from friends and neighbours, and the very isolated lives that some of them lived were often related to the way they had always lived, as this daughter noted: ‘She is a person who has never allowed anyone into her house. She did not like people and always wanted to be on her own – and now she is on her own. A neighbour used to call, but she took the key back off her and now she doesn’t come at all...’

Effects of caring on the carers
The importance of informal carers in keeping elderly people living in the community is obvious. But the stresses and strains of caring are also obvious, and, in comparing elderly people living in the community with those living in residential care, we wanted to examine some of the reasons for entering residential care. We had thought that one of the main reasons would be the fact that, for some reason or another, the informal caring in the community had broken down. We therefore asked the carers a series of questions about how far their lives had been affected by looking after the elderly person, whether they thought they had had enough support from members of the family and professionals, and whether they needed more support and help themselves.
There were undoubtedly differences in the effect upon the samples of carers in the community and carers of people who had entered residential care. Around a quarter of the carers in the community said their lives had not been affected at all and a further 13 per cent said they had been affected very little. On the other hand, just over one third said they had suffered from a loss of their freedom, with a rather higher proportion of resident carers than non-resident carers complaining about this. But this should be compared with nearly two-thirds of the resident carers of elderly people in residential care who said they had lost their freedom. There was clear evidence that these carers on the whole felt their lives had been much more affected by looking after the elderly people than the carers in the community did, as is shown in Chapter 6.

This was not to say that the carers of elderly people in the community were unaffected by the caring, and some were clearly nearing the end of their tether. As with the carers of those in residential care, the loss of freedom was the most trying factor, and this was often combined with worry, fatigue and lack of time. The loss of freedom was felt most acutely by sons and daughters-in-law and elderly sisters, but daughters and wives also complained. Again, the elderly husbands were the least likely to complain.

In some cases, the loss of freedom was made more difficult to bear because of the carer’s expectations of an increase in freedom at retirement. A daughter commented: ‘I have not been able to do what I wanted. I have to think and I don’t have as much freedom as I had at the office. It’s dampened my retirement a bit. I thought that it would be nice and easy...’ Her views were echoed by a daughter-in-law: ‘My life has been turned upside down. What I expected to do when I retired has not happened...’

Neither of these carers was living with the elderly person. For those who were, the loss of freedom was often more trying, as this daughter-in-law explained: ‘We’ve become extremely tied when he’s here. We can’t leave him and we can’t take him and leave him in the car. Our social life is restricted to when he’s out...’

Sometimes the loss of freedom and the constant demands had an effect on all aspects of the carers’ lives, as this daughter pointed out: ‘Our lives have been considerably affected. We plan things a lot more and think about things. If we want to go out it has to be the right weekend. She’s with us all the time, but we have the evening to ourselves, when we get her upstairs. Your freedom goes. When we have a row, we have to do it quietly – it’s not like having a child. When we do have a row we have to tone it down. We have to plan when we’re going to have a row, or when we’re going to make the bed squeak...There are times when I wish I’d never said "Yes" and I feel like packing my bags...’

Caring for the elderly people often made the carers alter their lifestyles and this could have enormous effects on their lives and their marriages, as a resident daughter-in-law said: ‘I had to give up work, and that was traumatic after forty-one years...Now I have much less income and feel tied to the home. I have threatened to leave six times in the last two years. It does put pressure on your marriage. We have disagreements on how she should be looked after...’
And for those who were not living with the elderly people, the strain could be as great, as this son explained: ‘I feel obliged to try and visit her three or four times a week, even when I’m in pain myself. I feel as if I have to be there constantly, in case the warden calls me to say that she wants me...’

This constant pressure on non-resident carers could affect marriages too, as a daughter explained – ‘My life has been interrupted. It’s tiring, running backwards and forwards. My husband is at home and he misses me. He doesn’t see too much of me...’ – and her views were echoed by a neighbour carer – ‘It does cause some arguments between a husband and wife if one has to go in the middle of a meal to see her...’

The effects on the carers’ working lives were quite striking. Seventeen per cent of the sample of carers in the community said they had given up work to look after the elderly person, representing nearly 30 per cent of the resident carers compared with only 7 per cent of the non-resident carers. The people who had given up work were mainly husbands, wives, daughters and daughters-in-law. Often the elderly spouses had given up jobs they had only held in retirement, but some of the younger women had felt the loss of their jobs very keenly, as this daughter explained: ‘I gave up my job bringing in £200 plus expenses, and now I’m down to my pension. I went on to freelance, but I couldn’t plan tours and teaching. I can’t give my mind to my job if I’m uncertain...’

A further 15 per cent of the carers, mainly daughters and daughters-in-law had changed their working patterns because of the elderly person, usually by cutting down on their hours or changing their jobs to be nearer the elderly person. There can be no doubt that younger generations of women, who may not feel as duty bound to help elderly relatives and who may have more responsible jobs than many of the women we interviewed, may be less prepared to make the sacrifices some of the carers in our sample had done. They certainly felt they had made sacrifices, and most of them did not feel happy about it, as this daughter said: ‘I feel as though I’ve aged twenty years – and, in a word, agitated all the time...’

Considerably more of the carers of elderly people in the community had given up work than had carers of elderly people in residential care. But this could have been explained by the rather high proportion of elderly spouses among the carers in the community compared with the residential care sample. On the other hand, rather fewer carers in the community had changed their working patterns than we found among the carers of the residential sample. It could well be that the increasing demands of these elderly people combined with an increasing restriction of working and social life had taken an increasing toll on the tolerance of the carers and had contributed to the decision for the elderly person to enter residential care. The outlet, status and money offered by work should not be underestimated.

But, as we have seen, over a third of the carers of elderly people in the community felt the caring role had made little or no difference to their lives. They were found among resident and non-resident carers in almost equal proportions, but perhaps the last word should remain with the elderly husbands, most of whom
said their lives had not been affected, and two of whom said specifically that they enjoyed their caring role. This elderly husband in the northern area explained his reasons: ‘My life has not been affected. We have lived together for years and known each other since I was 17. She is part of my life...’ And another in the same region stressed the reciprocal nature of caring which was so apparent in some of these relationships – ‘I feel that I have a chance to repay her for all she has done for me in the past. If I was ill and she was not, she would have done the same for me...’

**Carers’ assessment of professional support**

Nearly 80 per cent of carers said they had had enough support from professionals, representing roughly equal proportions in each area and identical proportions of resident and non-resident carers. The proportion was higher than was found among carers of elderly people in residential care, where two-thirds said they had had enough professional support.

The elderly husbands felt most satisfied with the support they had received from professionals, while the sons and daughters were the least satisfied, but, even so, over 70 per cent of them thought they had had enough support. Social workers, home help organisers and doctors came in for special praise, and some carers were clearly receiving considerable moral and practical support, like this daughter living with her elderly father – ‘I don’t know what else they could do. I think the social worker has been marvellous, and helped a great deal...’ – and her view was supported in another area by another daughter – ‘They have done everything in their power to help me...’

However, some of those who felt they had had enough support had reservations about GPs, the main complaint being that the doctor did not ‘check up’ on the elderly person regularly, as this daughter-in-law explained: ‘I would have thought that a doctor or a health visitor – someone from the practice – might just call in at times to see how we are managing. We are doing as well as might be expected but they don’t know this. There’s not much back-up from the practice, and some practices do much more. I ring up for a monthly prescription but no-one questions it. I have reduced his medication, in fact...’

Of those who thought they did not have enough professional support, the most common complaints also centred round GPs. Elderly people’s daughters were the most likely to express concern about GPs, ranging from pleas for more regular supervision of the elderly people’s health and well-being through to proper diagnosis and treatment, as this daughter said: ‘More would be done for her, say, if it was the Queen. I have never known what is wrong with her, and things have got worse and she is getting deaf now. But she has never been examined thoroughly by a doctor...’

It has been recognised for years that one of the main needs of carers is proper information on the health of the elderly person they are looking after, so that they know how to look after them, what to expect in terms of deterioration of health, what they can expect the elderly person to be able to do – a matter of diagnosis and prognosis. The role of the GP in this respect is crucial, and there was certainly
evidence that some GPs could do more to support carers, although it should be stressed that some carers cited very supportive doctors.

Carers often feel themselves to be in a kind of limbo, with no-one to help them assess the present, let alone the future. Some of them certainly seemed to have had difficulty getting into ‘the system’ to gain access to services, both for the elderly people and themselves. It sometimes took a long time, as this daughter in the southern county explained: ‘At the beginning we were very naive. It’s taken us five years to get where we are now. We need people we can always contact. They may not be in the social worker’s department, but we could phone her. We need more help and support. The doctor is good and pops in when he is nearby...’

If elderly people are to remain living in the community, the extent and quality of professional support given to them is obviously a major factor, but it is quite clear that carers too need professional help and support, and we were interested to know what they had found most helpful. The carers gave a wide range of replies, but it was striking that by far the most helpful service was found to be the home help or home care service, cited by nearly 40 per cent of the carers overall, while a further 6 per cent cited the domiciliary care or home help organiser. Husbands and sons mentioned the home help service more often than other relatives and non-resident carers mentioned it more often than resident carers. The social worker was found to be the most helpful ‘service’ by nearly one fifth of respondents, rather more often by resident carers. Apart from these, no other service or professional was mentioned by more than 10 per cent of carers, with GPs and district nurses cited by just under 10 per cent each. Day care, short-stay care, health visitors, sitters, occupational therapists, night nurses, chiropodists all received one or more mentions, but so did aids and equipment.

The help supplied by the home help service or by the district nurse or bath nurse was usually of a practical kind, but it also offered support to the carer. The carers who mentioned GPs or social workers often saw them in two roles – as facilitators of other services and as suppliers of moral or emotional support. This daughter had nothing but praise for the GP – ‘The doctor is always good and kind. He does all he can to help and advise...’ – while this elderly wife felt the same about the social worker – ‘She comes, and you can talk and ask...’ The personality of the person concerned was often more important than their status, as this non-resident carer in the southern area explained about the social worker: ‘He’s quiet and unassuming, and not dynamic. But he cares, though. He’s organised all the help and services, like home care. If he says he’ll do something, he has done it. The home care people are very good...’

**Main needs of carers**

We asked carers whether they thought that people looking after elderly people themselves needed more help than they were receiving, and if so, what was the main thing they needed. Nearly 70 per cent thought carers did need more help, 10 per cent thought they did not, but over a fifth said they did not know or could
not really comment. Carers in the London borough were more likely than those in the other two areas to think they needed more help.

Around two-thirds of the resident carers thought carers needed more help, compared with nearly three-quarters of the non-resident carers. There was an interesting difference between the carers in the community and those where the elderly person was in residential care, where over 80 per cent of resident carers thought that carers needed more help, again an indication that the stress of caring had helped to contribute to the elderly person entering residential care.

What did the carers think they needed? The main needs were for relief and respite from caring, a common theme in research on carers’ needs and an issue highlighted by carers’ organisations. A sitting service was cited specifically by one fifth of those who thought carers needed more help, reflecting the views expressed by carers of elderly people in residential care.

The need for respite was widespread. A daughter-in-law summarised the feelings of many: ‘You need to have a break. You can’t keep it up twenty-four hours a day, seven days a week...’ The unremitting nature of caring was emphasised time and again. This daughter did not live with her mother but was in constant attendance: ‘I need a break. Not just a holiday which is two weeks a year, but two days a week. That would be someone else coming to look after her two days a week, and I would not have to see her at all for two days a week...’

But respite alone was not thought to be enough. Money was thought to be the most important requirement by over 10 per cent of carers: ‘We get an attendance allowance of £22 a week. If we didn’t have her here to stay, she’d go into a state-run home. I don’t know what it costs, but it’s a damn sight more than £22 a week. Someone prepared to look after a disabled, elderly person should get more for it. It’s trying to hold down a job, run a home whilst looking after an elderly person. The rewards are not great, compared to what you’re saving the government...’

Elderly spouses were particularly likely to mention money, like this wife in the London borough: ‘Attendance allowance would help. There are things I could get him which he can’t afford. Maybe I could have paid someone to sit with him or get him some little luxuries...’

More support and information were thought necessary by some carers. A son looking after his mother in London summed it up: ‘We need to know more information, such as what is available to call on. In another borough when mother was sick we got no help at all. At 80 there should be a booklet – or maybe at 75 – something written down by the DSS – ”A beginner’s guide to looking after your old mum” – from the doctor maybe...’

It was thought social services could offer more information, as this neighbour in the London area explained: ‘Carers need the support of social services. There’s all sorts of equipment you can get. If only they would tell the carers what is around and not just the old person...’ And her view was echoed by a son in the northern area: ‘They need support, help and understanding from the social services and everyone else. Perhaps offering help and telling you what help is there without you having to ask...’
A daughter-in-law thought one of the main needs of carers was liaison between the various professionals concerned, and her recommendation was the only one which implied the need for some kind of ‘care manager’: ‘When I was ill I went to my doctor, but it was hard for my doctor from a different practice to get my father-in-law into a short-stay. It was hard work for the doctor, because the professionals are too isolated from each other – they’re in their own corners. One person should have the major responsibility for the old person – plus the carer – but there’s no liaison, and there’s not much in the social services office itself. If our social worker is away sick then we could be in trouble. It’s not only our experience – other people have had this problem...’

The need for ongoing support from professionals was implicit in many of the remarks by carers. Much interest has been generated in carers’ support groups in recent years, although social workers in all three areas expressed reservations about their effectiveness or suitability for all carers. Only one person in the whole sample had been to a carers’ group in the southern county. She had attended it twice, had found it very interesting but difficult to get to.

The 99 per cent of carers who had not been to a carers’ group expressed little or no interest in such a group. The few in each area who commented on such a possibility were lukewarm or indifferent, saying that they were too infrequent, too far away or too restricted in the topics they covered. A daughter living with her mother summed up the views of a number of carers: ‘I have thought of it, but I am too tired to go out, and I would like to talk about something different when I do...’

There was no doubt that carers’ groups were considered marginal to the needs of carers who were much more interested in good professional help and support, combined with help and support from their families. The need for practical assistance, with respite from the caring role, permeated these interviews with carers, and it is this which helped them maintain the elderly people they were looking after in the community. The formal care offered in the community will be discussed in the next chapter.