

# APPENDIX

**Appendix 1**

# CARER QUESTIONNAIRES

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**PILOT QUESTIONNAIRE**  
**PERSONAL DETAILS**

Are you male or female?

Male	<input type="checkbox"/>
Female	<input type="checkbox"/>

Please indicate your age category

Less than 60	<input type="checkbox"/>
60 to 64	<input type="checkbox"/>
65 to 69	<input type="checkbox"/>
70 to 74	<input type="checkbox"/>
75 to 79	<input type="checkbox"/>
80 to 84	<input type="checkbox"/>
85 to 89	<input type="checkbox"/>
90 or older	<input type="checkbox"/>

What is your relationship to the person for whom you care?

Partner/spouse	<input type="checkbox"/>
Son/daughter	<input type="checkbox"/>
Parent	<input type="checkbox"/>
Other relative	<input type="checkbox"/>
Friend	<input type="checkbox"/>
Other	<input type="checkbox"/>

Do you live in the same house?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

What is your marital status?

Single	<input type="checkbox"/>
Married	<input type="checkbox"/>
Widowed	<input type="checkbox"/>
Divorced	<input type="checkbox"/>
Separated	<input type="checkbox"/>
Other	<input type="checkbox"/>

**THE IMPACT OF CARING**

What effect has caring had on the following areas of your life?

Area of life	Much worse	Worse	No change	Better	Much better
Physical health					
Emotional health					
Household routine					
Leisure & social life					
Finances					

**FOCUS ON FINANCES**

Do you feel that your financial situation has affected your caring role in any way?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Possibly	<input type="checkbox"/>

Do you have debt problems?

Never	<input type="checkbox"/>
Sometimes	<input type="checkbox"/>
Always	<input type="checkbox"/>

If you do have financial problems, do they cause you worry, anger or distress?

None	<input type="checkbox"/>
Some	<input type="checkbox"/>
Severe	<input type="checkbox"/>
Not applicable	<input type="checkbox"/>

Do you think that these problems are anything to do with caring?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Possibly	<input type="checkbox"/>
Not applicable	<input type="checkbox"/>

## **SOURCES OF SUPPORT**

Do you get support in caring from other household members?

Never	<input type="checkbox"/>
Sometimes	<input type="checkbox"/>
Regularly	<input type="checkbox"/>
Not applicable	<input type="checkbox"/>

Do you get support in caring from friends, relatives or neighbours who aren't part of your household?

Never	<input type="checkbox"/>
Sometimes	<input type="checkbox"/>
Regularly	<input type="checkbox"/>

Do you get help in caring from formal sources (eg. carers benefits, domiciliary help, respite care)?

Never	<input type="checkbox"/>
Sometimes	<input type="checkbox"/>
Regularly	<input type="checkbox"/>

Thank you for your help

**MAIN QUESTIONNAIRE**  
**PERSONAL DETAILS**

1. Gender?

Male	<input type="checkbox"/>
female	<input type="checkbox"/>

2. What is your date of birth? \_\_\_\_\_

3. What is your relationship to the person for whom you care?

Partner/spouse	<input type="checkbox"/>
Son/daughter	<input type="checkbox"/>
Parent	<input type="checkbox"/>
Other relative	<input type="checkbox"/>
Friend	<input type="checkbox"/>
Other	<input type="checkbox"/>

4. Do you live in the same house?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

5. What is your marital status?

Single	<input type="checkbox"/>
Married	<input type="checkbox"/>
Widowed	<input type="checkbox"/>
Divorced	<input type="checkbox"/>
Separated	<input type="checkbox"/>
Other	<input type="checkbox"/>

6. What is your current or most recent occupation? (please state) \_\_\_\_\_

7. Are you currently retired?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

8. What is your ethnic origin? (please state) \_\_\_\_\_

9. Is the house you live in

Owned	<input type="checkbox"/>
Council	<input type="checkbox"/>
Housing association	<input type="checkbox"/>
Privately rented	<input type="checkbox"/>
Other	<input type="checkbox"/>

How long have you been living in this property? (please state) \_\_\_\_\_

### **DETAILS OF CARING ROLE**

I would like to talk to you about your caring role and how it affects your day to day life

10. Is there a name which you use to describe (names) disability/illness?

11.

12. Can you tell me something about the way in which the illness/disability has developed?

13. Can you tell me something about how the disability/illness effects your everyday life and has this changed as you have got older?

14. How would you describe the nature of your relationship between yourself and (name)

15. Does (name) do anything for you and, if so, what?

16. How long have you been caring for and what led you begin to care for (name)

17. Does your caring role conflict with any other role which you have to perform?

18. On average, how many hours do you spend caring each week?

Under 10 hours	<input type="checkbox"/>
10 to 35 hours	<input type="checkbox"/>
Over 35 hours	<input type="checkbox"/>

19. Does your caring role regularly include the provision of personal care such as washing, dressing and feeding?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

20. What influence has caring had on the following areas of your life?

Area of life	Much worse	Worse	No change	Better	Much better
Physical health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Household routine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure & social life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

21. How do you feel about your caring role?

Very dissatisfied	<input type="checkbox"/>
Dissatisfied	<input type="checkbox"/>
Variable	<input type="checkbox"/>
Satisfied	<input type="checkbox"/>
Very satisfied	<input type="checkbox"/>



**MATERIAL CIRCUMSTANCES**

I now want to talk to you about your financial situation and explore possible ways in which your access to money and material goods has affected your caring role.

22. What is your household income and the sources of this income for yourself and (name)?

Sources of income	Carer	Care recipient	Household
Earnings			
State pension			
AA/DLA			
Income support			
Private pension			
Other (specify)			
Total			

23. Do you and the person you care for have combined savings in excess of £3000?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

I'd like to talk to you now about how you organise this income.

24. Do you have complete control over your own money or is (name) or someone else involved?

25. Do you control (name's) money or do they assume some responsibility?

26. Can you explain how each person's money is used and what their money is spent on?

27. How do you decide how the money is spent day to day (eg food shopping)

28. How do you decide how money is spent on large purchases (eg buying furniture)

29. Has the way in which you organise money changed in recent years due to such things as widowhood, retirement, since the assumption of caring responsibilities (eg has there been a role reversal or have earlier patterns been maintained)

I now want to ask you about how adequate your income is

30. Do you ever have problems in making ends meet?

Never	<input type="checkbox"/>
Sometimes	<input type="checkbox"/>
Always	<input type="checkbox"/>

31. Do you feel that your household income is adequate in meeting yours and (name's) needs and have you had to sacrifice anything to manage (eg. food, holidays, transport, clothing, entertainment)

32. Do you feel that your housing and household goods are adequate in meeting yours and (name's) needs?

33. Do you think that you have suffered financially as a result of caring and, if so, in what areas? (eg lost earnings, pension rights, services, home adaptations)

34. Do you feel that your financial situation has influenced your caring role in any way?

### **FORMAL AND INFORMAL SUPPORT**

This final section of the interview will be concerned with formal and informal support which you and (name) receive.

35. I will now read out a list of possible sources of formal support that you or the person for whom you care receive or has received in the past, can you tell me if you have ever received these services and, if so, what help it is or has been to you (please tick)

Service type	Never received	Currently received	Received in the past		Helpful	No Difference	Not helpful
Home carer							
Community nurse							
Social worker							
Day centre/day hospital							
Hospital/home respite care							
Carer support group							
Other							

36. Do you pay for any of these services and, if so, which ones?

37. Do you have regular access to informal support from friends, relatives and neighbours to help you in your caring role and if so, what kind of help is provided and how often?

By relatives

By friends or neighbours

38. Would you like more help from these sources?

39. Do you have relatives living locally?

40. Is there any support or care either formal or informal that you feel that you need or would like but don't have at the moment?

Thank you for your help

Would you be willing to take part in a follow-up interview?

# QUESTIONNAIRE FOR FOLLOWUP INTERVIEWS

## BIOGRAPHICAL APPROACHES

Can you describe to me the process by which you became a carer

How has your life changed since our last meeting with regard to the following areas:

- Caring role
- Informal support
- Formal support
- Material circumstances

## **THE CARING EXPERIENCE**

Research tends to focus on the negative aspects of caring but my previous interviews revealed that carers gained many satisfactions from their role. What for you are the satisfactions and dissatisfactions of your role:

- Satisfactions
- Dissatisfactions

## **INFORMAL SUPPORT**

Help from friends, neighbours and relatives has been found to be an important source of support to informal carers

Who is your main source of informal support (if any)

Relatives	<input type="checkbox"/>
Neighbours	<input type="checkbox"/>
Friends	<input type="checkbox"/>
Other	<input type="checkbox"/>

What sort of help do they provide

Housework	<input type="checkbox"/>
Personal care	<input type="checkbox"/>
Shopping	<input type="checkbox"/>
Managing finances	<input type="checkbox"/>
Providing transport	<input type="checkbox"/>
Other	<input type="checkbox"/>

Would you like more help from these sources

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

Do you give informal carers anything in return for the help they provide

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

### FORMAL SUPPORT

Most carers seen in my initial interviews were in receipt of some form of formal support, this section will further explore your attitudes to this help

Home carers	<input type="checkbox"/>
Respite care	<input type="checkbox"/>
Day care	<input type="checkbox"/>
Community nurse	<input type="checkbox"/>
Voluntary sitter	<input type="checkbox"/>
Carer support group	<input type="checkbox"/>
Other	<input type="checkbox"/>

Would you like more formal help

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

What other support would help you in your caring task

Nothing	<input type="checkbox"/>
Better housing	<input type="checkbox"/>
Home adaptations/equipment	<input type="checkbox"/>
More money	<input type="checkbox"/>
More practical support	<input type="checkbox"/>
More social/psychological support	<input type="checkbox"/>
Other	<input type="checkbox"/>

Have you experienced any problems in gaining access to formal support

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

## MOBILITY

From previous interviews it was found that many carers were prevented from going out regularly due to such things as mobility problems and caring responsibilities.

How often were you able to leave the house in the last month

Never	<input type="checkbox"/>
One to five times	<input type="checkbox"/>
Six to ten times	<input type="checkbox"/>
More than ten times	<input type="checkbox"/>

Where do you go

Shops	<input type="checkbox"/>
Visiting friends/relatives	<input type="checkbox"/>
Social activities	<input type="checkbox"/>
Health related visits (eg. GP)	<input type="checkbox"/>
Other	<input type="checkbox"/>

How are these outings facilitated

Bus	<input type="checkbox"/>
Car	<input type="checkbox"/>
On foot	<input type="checkbox"/>
Others provide transport	<input type="checkbox"/>
Other	<input type="checkbox"/>

Would you like to go out more often

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

If 'yes' what is preventing you from doing this

Own disability	<input type="checkbox"/>
Care recipient's disability	<input type="checkbox"/>
Lack of transport	<input type="checkbox"/>
Don't want to go out alone	<input type="checkbox"/>
Can't afford it	<input type="checkbox"/>
Other	<input type="checkbox"/>

## MATERIAL CIRCUMSTANCES

Previous interviews with carers revealed a good deal of concern for financial issues such as levels of pension provision, this section will further address these concerns.

How would you describe your financial position

Very comfortable	<input type="checkbox"/>
Comfortable	<input type="checkbox"/>
I have to be careful but I get by	<input type="checkbox"/>
I have trouble in making ends meet	<input type="checkbox"/>
Things are very difficult	<input type="checkbox"/>

What do you feel are the main problems faced by older people in general and yourself in particular

	Older people in general	Yourself
Health	<input type="checkbox"/>	<input type="checkbox"/>
Loneliness	<input type="checkbox"/>	<input type="checkbox"/>
Finances	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>

What social class do you feel that you belong to

Middle class	<input type="checkbox"/>
Working class	<input type="checkbox"/>
Other	<input type="checkbox"/>

## FINANCIAL MANAGEMENT

All of the carers seen in my initial interviews exercised a cautious approach to money management, this section will explore these management strategies further

If your household income includes Attendance Allowance or Disability Living Allowance, what is it spent on

Caring issues	<input type="checkbox"/>
General household spending	<input type="checkbox"/>
Other	<input type="checkbox"/>

Do you have any of the following

Bank account	<input type="checkbox"/>
Cheque book	<input type="checkbox"/>
Credit card	<input type="checkbox"/>
Cash card	<input type="checkbox"/>

How are your bills paid

In cash	<input type="checkbox"/>
By cheque	<input type="checkbox"/>
By direct debit	<input type="checkbox"/>
By stamps	<input type="checkbox"/>
Other	<input type="checkbox"/>

What are your main sources of economy, if any

Housing	<input type="checkbox"/>
Transport	<input type="checkbox"/>
Care services	<input type="checkbox"/>
Food	<input type="checkbox"/>
Social life	<input type="checkbox"/>
Other	<input type="checkbox"/>

Research has identified four main categories of household income allocation:

- The whole wage system in which one household member, usually the wife, is responsible for all the financial affairs of the household
- The allowance system in which one household member, usually the husband, gives his wife a set amount of housekeeping money
- The pooling system in which adult household members contribute their earnings to a common pool to which there is common access
- The independent management system in which adult household members keep their incomes separate and each are responsible for paying for specific household items.



Which of these systems have you adopted before retirement, after retirement and now and can you explain why you have adopted these systems

Type of household income allocation	Pre retirement	Post retirement	Now
Whole wage system			
Allowance system			
Pooling system			
Independent management system			
Other			

Ask carers if they would be willing to take part in a focus group

**APPENDIX 2**  
**PROFILE OF RESPONDENTS**

NAME	AGE	CARED-FOR PERSON	ETHNIC ORIGIN	WEEKLY HOUSEHOLD INCOME (£)	CAR OWNER	HOUSING STATUS	SOURCE
Mr Davis	60	Mother	WB	250-299	Yes	Owner	VO
Mr Millet	60	Daughter	WB	250-299	Yes	Owner	VO
Mrs Halsey	62	Husband	WB	150-199	No	Council	SSD
Mrs Hudson	64	Son	WB	250-299	Yes	Owner	PC
Miss Howard	65	Mother	WB	200-249	Yes	Owner	VO
Mrs Flude	68	Husband	WB	200-249	Yes	Owner	VO
Mrs Reid	68	Husband	WB	250-299	No	Council	Advert
Mr Cicourel	69	Wife	Italian	200-249	Yes	Owner	Advert
Mrs Lipset	69	Husband	WB	150-199	No	Owner	VO
Mrs Harris	70	Husband	WB	200-249	No	Council	SSD
Mrs Hacker	72	Son	WB	200-249	No	Owner	PC
Mrs Gibbons	73	Husband	WB	150-199	Yes	Owner	SSD
Mrs Bell	75	Husband	WB	150-199	No	Council	SSD
Mr Carson	78	Wife	WB	150-199	No	Council	SSD
Mr Hall	78	Wife	WB	Unknown	No	Council	SSD
Mr Hart	78	Wife	WB	100-149	No	Council	SSD
MrMacLellan	78	Wife	WB	150-199	Yes	Council	SSD
Mrs Phillips	79	Husband	WB	150-199	No	Council	SSD
Mrs Williams	79	Husband	WB	150-199	No	Council	SSD
Mrs Field	82	Husband	WB	200-249	Yes	Owner	SSD
Mrs Kincaid	83	Son	WB	350-399	No	Owner	SSD
Mrs Roach	84	Husband	WB	150-199	No	Owner	SSD
Mrs Taylor	84	Husband	WB	200-249	No	Council	SSD
Mr Tumin	84	Wife	WB	150-199	No	Council	SSD
Mr Denis	85	Wife	Jamaican	200-249	No	Council	SSD
Mr Wilson	85	Wife	WB	150-199	No	Council	SSD
Mr Lane	86	Wife	WB	150-199	No	Owner	SSD
Mrs Lane	86	Husband	WB	150-199	No	Owner	SSD
Mr Caplow	87	Wife	WB	100-149	No	Council	SSD
Mrs Coates	88	Husband	WB	Unknown	No	Owner	SSD
Mr Hunter	89	Wife	WB	150-199	Yes	Owner	SSD
Mr Tunstall	91	Wife	WB	250-299	No	Council	PC
Mr Taylor	92	Wife	WB	200-249	No	Council	SSD
Mr Dale	94	Son	WB	300-349	Yes	Owner	SSD

WB – White British; Source (how initial contact was made): SSD – social services dept home care service; PC – personal contact; VO – voluntary organisation.

All respondents' names have been changed to preserve their anonymity

## **MR DAVIS**

Mr Davis was 60 years old and had been looking after his 94-year-old mother with whom he lived for about 15 years since she first became physically frail. He acquired the role of co-resident carer by default having moved in with his parents 25 years ago following his divorce. Although he did not perform personal care he felt that he cared on a 24-hour basis having gradually taken over things like shopping, cooking and housework but he says that he did not have trouble in adapting to this role. He felt that his life had been very much adversely affected as a result of poor relationship with his mother. For example, although she spent most of her time sitting in her bedroom, he said that his mother rarely let him out of the house and if she couldn't find him she began to wander. Shortly after moving in with his parents he also had a nervous breakdown causing him to lose his job as an insurance manager and he never worked since. He was now largely dependent for his own income on a small pension from his last job. This was supplemented by his mother's income of Attendance Allowance and a State Pension. He had assumed total control over his and his mother's income and the house had been transferred to him. Indeed it was for financial reasons that Mr Davis remained a carer for so long for he said that he would be unable to run the house, a large old terraced house in Heeley, on his income alone. Thus he said that some years ago he had considered permanent residential care for his mother but if he had gone ahead with this he would have lost his mother's share of the household income. However, in spite of this he had now got his mother's name down (against her will) for permanent residential care and had resigned himself to the fact that he would have to sell the house once this was arranged.

In the meantime, Mr Davis was well supported by formal provision with his mother being visited by home carers morning and evening seven days a week for which he paid £8.25 a week. She also had a rolling programme of respite care for two weeks every five weeks for which he paid a subsidised weekly fee of £73. This support was arranged by his Social Worker but Mr Davis did not feel that his Social Worker was able to alleviate his fundamental and subjectively derived dissatisfaction with his current role. Mr Davis did not belong to a Carers Support Group as he said his mother didn't let him out so he would not be able to attend their meetings. Neither did Mr Davis have any informal support although he had two daughters but they did not live locally (Oakham and Leeds) and he preferred not to involve them. He was similarly reluctant to ask for help from neighbours. Follow-up enquiries revealed that since the initial interview, Mr Davis' mother had been admitted to permanent care and Mr Davis has sold the house and moved elsewhere.

## **MR MILLET**

Mr Millet was aged 60 and retired 13 years ago from his job as a steelworker. He had been the co-resident carer of his daughter who has learning disabilities for all of her life. He felt that in some ways his caring role had got harder than it was before he retired as the fact that he was on lots of committees meant that he had little time and also because the older his daughter got, the more words she learnt, making it difficult for him to understand what she was saying as she had a speech impairment. He also felt that his declining level of fitness over the years had detrimentally affected his role. Her major care need was for help and supervision with day-to-day matters such as money management, cooking etc. At £260 a week his household income was less than it was before he retired but he says it was enough for them to manage on. Indeed he said that he was economical with his money. For example, he had a camper van so he didn't have to pay for accommodation

when they went on holiday. His daughter attended a social services day centre every weekday but he was concerned about what will happen to her and where she will live when he was no longer able to look after her. For he said that she would not be allocated a place in a council home until he died.

### **MRS HALSEY**

Mrs Halsey was 62 and had looked after her 65-year-old husband since he had a stroke in 1991, which left him paralysed down one side, he also had angina and was catheterised. Since the onset of her husband's illness, Mrs Halsey had assumed responsibility for his care, which included personal care tasks such as feeding. This assumption had been a gradual process as her husband's illness had progressively worsened. Before the onset of his stroke, Mr Halsey who was made redundant from his job, as a steelworker in 1982 would assist his wife in household tasks, however, she now had to perform these tasks alone. As a consequence of these increased responsibilities, Mrs Halsey, who was herself epileptic, felt that caring had damaged her physical and mental health. Mrs Halsey moved from a first floor maisonette in Lowedges where she had been since 1963 to a ground floor flat in Batemoor in 1991 due to her husband's mobility problems. The flat now had many adaptations to accommodate her husband's disability which were supplied free of charge. She was reluctant to move, not only because she left her old neighbours behind but also because her current accommodation is much smaller than her old maisonette meaning that she had to get rid of a lot of furniture. She felt that this cautious approach to money was characteristic of her generation. Mrs Halsey was supported in her role by home carers who visited morning and evening, seven days a week to get her husband up and put him to bed. She paid £16.50 a week for this service. Mr Halsey also went out on Monday for physiotherapy, went to a community centre on Friday and visited a day centre on Wednesday. He was also occasionally visited by a shower nurse and sometimes had respite at a local home. Mrs Halsey's daughter who lived locally also gave her regular practical help with such things as shopping and transportation. Mrs Halsey was available for a follow-up interview which revealed that while her home circumstances had remained largely unchanged, her health had significantly deteriorated and she now felt unable to leave the house and was reliant on an oxygen max 24 hours a day. She had also given up smoking on medical advice, an achievement of which she was very proud.

### **MRS HUDSON**

She was in her sixties and had been caring for her severely autistic son, David, for all his life, 42 years, providing all care. David was also partially mobile which meant that she had to supervise him and was unable to leave him alone for any significant length of time. This problem was exacerbated by David's epilepsy and aggressive and excitable behaviour, which found difficult to cope with. Although she regarded herself as being in generally good health she felt that the physical demands of caring have become harder to cope with, as she got older. She also felt that her mental health had suffered as a result of the stressful nature of caring. In spite of this she appeared to feel generally positive about her role, which she regarded as being freely chosen, having regularly turned down the opportunity of having him admitted into permanent care. She felt herself to be reasonably well off, receiving £158 a week in benefits including income support and DLA for David as well as her own state pension and a widows pension. Until her retirement she also received carers benefit. In spite of this she felt that she had suffered financially as a result of caring, which had prevented her from accumulating her own occupational pension. In addition, she expressed

concern over recent threats over David's benefits, which due to new social Security may be suspended if he stayed in respite care for too long. She also felt that means tested benefits and services unfairly penalised people such as herself who were reasonably well off. She found her car to be particularly useful as well as a second hand stair lift, which she bought for £1,200 after unsuccessfully trying to obtain one from the social services. She was well supported by informal and formal sources; her two daughters provide help on a regular basis while a neighbour was available in emergencies. He also regularly received respite care in a local hospital as well as attending a day centre there, both of which were provided free of charge. She also recently joined a carers support group attached to the hospital. She felt that she was being increasingly pressured to admit David to permanent care, however she still preferred to look after him herself and will continue to do so for as long as she is able feeling that the care she provided was better from him than that provided by the formal sector. While she was happy with the support she received she did express a few minor complaints such as poor bowel management and the lack of structure and discipline provided in respite care making her caring task more difficult when he returned home.

### **MISS HOWARD**

Miss Howard was a retired teacher of 65 and had been looking after her 93-year-old mother who was physically frail and had had dementia for the past 3 years. She assumed this role after the sudden death of her father and prior to this she had been involved in the extra resident care of both her parents. She did not feel that her health has suffered as a result of caring, for although she had migraines she said that she had always suffered from these. However, she did feel that it was a strain looking after her mother and facing the conflict between on one hand respecting her independence and on the other ensuring her safety. She also felt that her social life had greatly suffered in view of the fact that she had to look after her mother 24 hours a day. The joint weekly income of Miss Howard and her mother was around £200 and included her mother's attendance allowance and widows pension and her own state and occupational pensions. Miss Howard also had savings and owned her own house in another part of Sheffield, which she intended to keep. The only formal support received by Miss Howard was a voluntary sitter from a sitting service who stayed for two hours a week free of charge. Miss Howard was not a member of a carer support group and would not consider respite care or permanent residential care for her mother. However, Miss Howard did have several home aids and adaptations such as a wheelchair provided by the NHS and a bath chair which she bought herself. She was also supported by a neighbour and by her sister who lives in Hull but who visited about every two weeks. In spite of this apparent self-sufficiency, like many carers, Miss Howard felt that the formal support provided to people such as herself was inadequate, especially when compared to the support given to other carers such as the mothers of children.

### **MRS FLUDE**

Mrs Flude was 68 and had been looking after her 73-year-old husband, a retired chartered accountant, for around 6 years since he developed multi-infarct dementia. During this time her husband's illness had progressively worsened and he was now totally immobile as well as having a variety of other physical problems such as incontinence and thrombosis. Due to this progressive deterioration, Mrs Flude thought that her caring role had got harder over the years and she now felt that she was involved in caring on a 24-hour basis. She felt that this strain was worsened by the fact

that there was no prospect of her husband's condition improving as well as by the fact that she had to perform many personal care tasks which she found particularly difficult and tiring. As a consequence of these strains, her physical and mental health as well as her social life had been significantly harmed by caring. Financial concerns played an important role in shaping her caring responsibilities, thus she described how she was initially deterred from having her husband admitted into residential care due to the fact that she would have lost his pension and attendance allowance, money that she needed to maintain the relatively large home. Indeed, similar financial concerns prevented her from leaving her husband earlier in her marriage. Mrs Flude and her husband lived in their own house in Dore having moved from a larger house in Fulwood following her husband's retirement. Mrs Flude said that they had to downsize her housing due to financial difficulties incurred by her husband earlier in their marriage. This downsizing helped her to release capital to help to supplement their post retirement income, which was now around £200 a week and included her husband's attendance allowance and occupational pension and both their state pensions. She maintained that this downsizing was very difficult to come to terms with due to feelings of relative deprivation and although apparently relatively affluent she had problems in managing the house on the limited income.

Mrs Flude had varying experiences of formal support. On the initial onset of her husband's illness she had great difficulty in accessing any sort of support due to the failure of her GP to provide her husband with a diagnosis or to refer her to a social worker. Consequently, she was ignorant and confused as to what support would be available to her. When she was eventually allocated a social worker following her husband's hospital admission, she found her to be insensitive maintaining that she would

have to sell her house in order to pay for her husband's care. However, she was much happier with her current social worker who had helped her to access her current support. Her current help included home carers from Medicare who visited three times a day for a charge of £16.50 a week, day care at Cheshire Homes three times a week and respite care which is provided free of charge due to the fact that Mr Flude had been assessed as having particular health needs. Prior to this assessment she had to pay around £250 per week for her husband's respite care. She had also got many home aids and adaptations, for example she paid to have a stair lift fitted and had a bed and hoist provided by the health service. So while she was now generally happy with the formal support received, she felt that she had to fight for it and she often found the constant visits of carers to be something of an intrusion. Moreover, while she was aware of non-statutory organisations such as voluntary sitting services she rarely used them, as the sitters could not stay long enough for her to go out for any significant length of time. Similarly she did not belong to a carers support group because she said she did not have time to attend the meetings. However Mrs Flude was quite well supported by informal sources with her son and daughter living in Totley and Dore respectively and providing practical help on a regular basis. She also received occasional help from her brother in Chester and her cousin in Dartmouth.

## **MRS REID**

Mrs Reid was in her late sixties and had been involved in the co-resident care of her husband Brian for the past three and a half years. Brian had suffered from anxiety and depression since the death of his previous wife twelve years ago and, a result of this, Mrs Reid's caring role involved largely the provision of emotional support as well as assisting with household tasks such as shopping.

Consequently, unlike many co-resident carers Mrs Reid had a relatively low objective level of 'burden' in that she did not provide personal care such as washing and dressing and provided care for less than 35 hours a week. Neither did she become a carer by default in that she actively chose to perform such a role when she gave up her flat to move in with Brian. In spite of her relatively low level of caring responsibility, Mrs Reid felt that caring had had a negative impact on her physical and mental health, often getting tired, stressed and worried. Like her health, Mrs Reid felt that her finances had been adversely affected by caring. This was because, due to concerns about her own material security and independence, should her relationship with Brian break up, she took on another council flat of her own in December 1997. Although she spent very little time there, travelling between this flat and Brian's house in Netheredge. In this respect Mrs Reid felt that not only had caring affected her material well-being but her desire to be materially independent had influenced her caring role, making it more 'costly'. In spite of the financial costs incurred by Mrs Reid in her caring, she didn't feel that she had problems in making ends meet, with both herself and Brian being in receipt of occupational and state pensions, while Mrs Reid also received disability living allowance, due to her mobility problems. Mrs Reid maintained that they managed their separate incomes largely independently although they did take joint responsibility for food expenditure. While Mrs Reid was generally satisfied about her own financial position she felt that Brian's house in Netheredge was far too large for him and a drain on his resources due to its high maintenance costs. However, she said that he refused to sell it due to sentimental attachments.

Both Brian and Mrs Reid, who came from Barnsley but had lived in Sheffield since 1980, had their own children from previous marriages. Mrs Reid said that all of her three children, two of whom lived locally, would be available for emotional or practical support if she needed it, although she didn't at present. Neither Brian nor Mrs Reid needed or were in receipt of formal provision from the Health and Social Services although Mrs Reid was a member of a carer support group, which she joined only a few months ago. While she originally joined in her capacity as former carer of her disabled daughter she later realised that she was currently acting as a carer for Brian. Consequently she felt that her membership of the group had helped to enhance her awareness of her caring role and she was now a volunteer on the carer help line at the carers centre. It had also provided her with support and friendship, as such, she maintained, unusually, that her leisure and social life had actually improved as a result of becoming a carer.

#### **MR CICOUREL**

Mr Cicourel was a 69-year-old man who had been involved in caring for his 59-year-old wife since she first contracted MS 20 years ago. Since then her condition had progressively worsened and she was now totally bedridden requiring all forms of care and was unable to be left alone for any significant length of time. The progressive nature of her illness meant that demands on him had become ever greater and he now said that he took each day as it came feeling unable to plan for the future or even to contemplate it. However, in some ways he felt that his role had got easier with age as he no longer had to juggle caring responsibilities with his job as a bus driver or with childcare. In spite of his burdens Mr Cicourel was broadly accepting of his role with his sense of duty and obligation preventing him from pursuing the possibility of long term care for her. As a consequence of this sense of duty, he believed that caring had a positive impact on his mental health feeling that if he did not perform this role he would be plagued with worry and guilt. He felt that

he had suffered financially as a result of caring as he took early retirement 12 years ago to accommodate his responsibilities.

His current income was £200 a week, which incorporated his own state and occupational pension and his wife's DLA. However, he did not feel that he had problems in making ends meet having changed his life style to accommodate his reduced income, for example he had not replaced his car for nine years or been on holiday for five years. Like Mrs Hudson he resented the fact that means tested services charge people like himself who were relatively well off and he was unwilling to pay for home sitters, as he did not feel able to afford it. He felt that caring had harmed his social life and his only informal support was from his son who lived locally. His daughter lived in another town and was therefore unable to help. He did not want to join carers support group, as he would not be able to attend the meetings. His main source of formal support was from a team of district nurses who visited his wife every morning, seven days a week. His only complaint with this service was the lack of continuity of care when regular nurses were replaced with staff who were unfamiliar with his wife. He was less happy with respite care, which until recently his wife received at a local hospital maintaining that the standard of care it provided was inadequate. Consequently he now preferred to look after his wife at home and refused to consider the option of permanent care for her. He was seen for a follow up interview and his wife had died.

#### **MRS LIPSET**

Mrs Lipset was in her late sixties and had been involved in the co-resident care of her 72 year old husband, Cyril, for the past 36 years since he became ill with syphilis based dementia, a condition about which she was very ashamed and embarrassed. Since then his condition had progressively worsened and he now needed all forms of domestic, personal and physical care. For example, he was incontinent and therefore needed regular changing. He also needed to be supervised due to his confusion and his tendency to wander. In spite of the demands of her role Mrs Lipset didn't feel that her physical health had suffered as a result of it, for while she had experienced ill health herself in the past few years such as pneumonia and back trouble, she felt that these were unrelated to caring. However, she did feel that other areas of her life had suffered including household routine, leisure and social life and mental health, finding her husband's tendency to wander particularly stressful. Thus she recounted several stories of her husband going missing in various parts of the country and having to be tracked down by the Police. However, in spite of these stresses, Mrs Lipset was broadly accepting her role which she regarded as being freely chosen and which she would continue to perform for as long as she felt able to do so.

Although Mrs Lipset did not feel she has suffered financially directly as a result of caring, she did maintain she had lost out financially as a result of the ill health of her husband who had been unable to work and had been reliant on benefits since the onset of his illness in 1962. As a result of this Mrs Lipset became the main breadwinner through her job as a bookkeeper with its flexible hours enabling her to perform her caring tasks. Thus Mrs Lipset was able to recall the days of National Assistance and Means Testing and thought that financial support for people in her position have improved since then. For example, she remembered how, in the early 1960s, their house was repossessed due to her husband's unemployment, for in those days Social Security would not meet the mortgage interest payments of claimants as they do now. They had lived in council



accommodation ever since, having lived in their three bed roomed council house in Totley since 1974 but have now bought it. When he initially became ill Cyril received non-contributory sick pay and he currently received a weekly pension and Disability Living Allowance totalling £138.79 per week. Mrs Lipset also received a small State Pension of £41.55 and due to her husband's illness she took sole responsibility for managing their joint income. As such, she felt that she was a good manager of money and that, while their income was not great, it is adequate for meeting their modest needs.

During the years she had been caring for her husband they had many dealings with formal provision. When he first became ill in the 1960s her husband spent some time as an in-patient at Middlewood Psychiatric Hospital and also went in occasionally for respite care and to have his medication stabilised. Mrs Lipset was not entirely happy with the care provided by the hospital feeling that Cyril was often poorly supervised and that the standards of physical care were inadequate at times. For example, she remembered how he often went missing from the ward and tried to walk back home to Totley. On another occasion he went missing on a hospital holiday in Blackpool and the Police had to find him. Some years later when the hospital began to close down, hospital wards were replaced by semi-independent houses in order to minimise the impact of institutionalisation on patients. However, Cyril was too dependent to cope in these houses but he was also too young to be eligible for more sheltered provision for older people. Thus as Mrs Lipset observed, he spent some years in limbo as there was no provision appropriate to his needs. When Cyril eventually became old enough, he began to receive respite care and day care in old peoples' homes. However, again these were not entirely appropriate to his needs as his confusion meant that the staff were often unable to cope with his behaviour. Moreover, as many Day Centres did not provide transport it was difficult for her husband to attend as they did not have a car and lived on the outskirts of Sheffield.

It was not until 3 years ago that Mrs Lipset and her husband received adequate support when Cyril began to attend a Day Centre attached to an EMI council home where he went from Monday to Friday, transport was provided and apart from a charge for meals, the service was free. He also went into the home for respite care for which Mrs Lipset paid a subsidised rate of £66.50 a week and Mrs Lipset herself attended the carer support group meetings held at the home every month. Due to the council's policy of privatisation which is in itself is a product of developments in welfare pluralism and the purchase provider split arising from this, the home was threatened with closure last year but this threat was successfully resisted by the campaigning of staff and carers. In addition to the service provided by the home, Mrs Lipset and her husband also had a social worker and continence nurse who kept them supplied with pads. Their only source of informal support was from their son, their only child who lived locally who provided material and practical help such as transportation in his car when needed. Mrs Lipset said she also gets a lot of enjoyment from her dog and her regular aromatherapy sessions.

## **MRS HARRIS**

Mrs Harris was seventy and had been looking after her husband who was also seventy since he had a stroke three years ago, he also had angina. This involved constant supervision and help with personal care but Mr Harris who herself had osteoporosis and arthritis did not feel that she had any problems in adapting to this role. Mrs Harris had worked as a lab technician while her husband was an air force as an air force fighter pilot and had worked all over the world in this capacity. They

moved to Sheffield from Dorset 5 years ago to be near their son and daughter who both lived locally (significantly they have an upsized perception of locality perceiving Oughtibridge and Mansfield as being local). Since returning to Sheffield they had lived in a council bungalow in High Green and did not possess a car. Their total household income was £226 per week, which included two state pensions and attendance allowance. Mrs Harris said that she had always controlled and managed this income and continued to do so and she said that it was adequate to their needs –they both, by their own admission, drank and smoked quite heavily, in spite of their ill health. Their daughter, who worked for the DSS in Leeds, provided help with shopping and pension collection and their neighbours also helped with occasional household tasks such as changing light bulbs. Social services had fitted various aids and adaptations in their bungalow and also provided home helps each day both morning and evening.

### **MRS HACKER**

Mrs Hacker was a widow in her early 70s and had been involved in the co-resident care of her 44-year-old son, Andrew, for all of his life. Since the death of her husband, a police constable, 25 years ago she had performed this task alone. Andrew had cerebral palsy, which severely restricted his mobility, which meant he could not be left alone due to his high risk of falling and sustaining injury. This problem was exacerbated by arthritis in his hands, which limited his manual dexterity. As a consequence of these disabilities Mrs Hacker had to supervise Andrew and provide him with assistance in personal care tasks. In spite of the demanding and sustained nature of her caring role Mrs Hacker was quite adamant that she did not regard it as a burden thus she felt that no areas of her life had been adversely affected as a consequence of her caring and got irritated at the way people expressed sympathy to her because of her situation. While she acknowledged that she was in poor health having had liver, bowel, bladder and heart problems she maintained that these problems were totally unrelated to her caring. Moreover, while she felt that her caring had become progressively harder to perform, she felt this was because of the progressive decline in her sons condition rather than as a result of her own poor health. Indeed, it was clear from the interview that she gained a lot of pleasure from his company. Mrs Hacker maintained that her material circumstances had in no way affected her caring role and that her income was entirely adequate for, as she said ‘*What you’ve never had you never miss*’. This income included her state pension, a police widows pension and disability living allowance for Andrew. She shared control of this income with her son. Mrs Hacker felt that she had actually benefited financially from her caring role as her son had helped her find a job. Neither were now working for she was retired and his arthritis prevented him from continuing. Although Mrs Hacker had lived in the same area all her life she had very few sources of informal support. Her only living relative was her sister who had Parkinson’s disease. Moreover, she said that her neighbours on her estate kept very much to themselves. However, Andrew attended a social services resource centre for two days a week where he received aromatherapy, physiotherapy and regularly used a council Dial a Ride service. Mrs Hacker also received respite for three and half hours every three weeks from a Sitting Scheme which she received free of charge. While Mrs Hacker was happy with the formal support received Andrew was more critical, feeling that provision for disabled people was often ageist in that it focussed on the needs of young people and old people but not people of his own age. He also disliked mixing only with other disabled people and refused to go on holidays catering for the physically disabled.

## **MRS GIBBONS**

Mrs Gibbons was 73 and had been looking after her 77-year-old husband since he had a stroke two years ago. She lived with her husband in an owner-occupied modern terraced house where they had been for the past 35 years. She was a highly involved carer performing personal care tasks such as washing and dressing for her husband but she was able to leave him alone in the house for short periods. She felt that caring had a negative impact on her health, household routine, leisure and social life but nevertheless felt generally satisfied with her role. During their working lives Mr Gibbons worked as a commercial manager and Mrs Gibbons did office work. Their combined income was £170 per week and incorporated a state and occupational pension and attendance allowance for Mr Gibbons and a small state pension for Mrs Gibbons. They had no significant savings and while they did not have health problems neither were they well off. For example, although they owned a car it needed repairing and Mrs Gibbons was unable to afford this. Although Mrs Gibbons had lived in the same house for 35 years, it was an ageing neighbourhood and, she claimed, neighbours were too old to provide any help. The help, which she received from relatives was also limited. Her sister died recently and her son, who lived in Dronfield, was unable to provide much support due to work responsibilities. However, her brother and sister in law, who lived in Mosborough, did visit regularly. Home carers visited in the morning seven days a week and a stair lift was fitted and paid for by Social Services.

## **MRS BELL**

Mrs Bell was 75 years old and looked after her 85-year-old husband who had dementia. She felt that her caring role had become more demanding in the last 12 months since her husband's confusion worsened following an episode of bronchial pneumonia. During their 50 years of marriage Mrs Bell had not worked while her husband had been employed in the air force as an accountant and as a businessman. Mrs Bell felt herself to be in generally good health but said that she got tired and depressed as a result of caring and as she was unable to leave her husband unattended. She felt that caring had also affected her social life. Mrs Bell and her husband lived in a ground floor council flat in Jordanthorpe where they moved 5 years ago due to problems in negotiating stairs in their previous home. Their household income was around £160 and incorporated a state pension for herself and her husband and attendance allowance. He did the finances up until a year ago but now Mrs Bell had taken over this role and she felt that they could manage on the income, which they received. Their major source of formal support was from home carers who visited morning and evening 7 days a week to assist in the washing and dressing of Mr Bell. Another visited for one and a half hours each Wednesday to allow Mrs Bell to go shopping. While Mrs Bell found this service useful, she would have liked someone to stop longer as she was constantly clock watching when she went out. A voluntary sitter from the Alzheimer's Disease Society also visited once a week. Mrs Bell refused respite care for her husband as she felt that it would do him more harm than good by exacerbating his confusion. Although she was familiar with her neighbours they did not provide her with any significant help in her role. Moreover, although her son and daughter lived quite nearby in Pennistone and Breystone, they both had busy lives with work and family responsibilities and were therefore unable to provide Mrs Bell with much informal support. Of most help in this respect was her daughter's mother in law.

## **MR CARSON**

Mr Carson was 78 and looked after his 77-year-old wife since she developed dementia two years ago. Due to her confusion, he was unable to leave his wife alone for any significant period and felt that his health had suffered as a result of this. He did not feel that he had any great problem in adapting to his caring role as he said that this had been a gradual process progressively taking over housework tasks following his retirement. Their total weekly income was £160 and incorporated two state pensions and attendance allowance. He said that he used the attendance allowance to pay his daughter who gave up her job so that she could provide daily assistance in the care of her mother. Although they had lived in the same council terrace for 49 years, they had little contact with neighbours and did not ask them for help. However, support was received from home carers who visit twice-daily 7 days a week.

## **MR HALL**

Mr Hall was 78 and had looked after his 77-year-old wife for around 20 years since she had a nervous breakdown. She now apparently rarely left the house due to her nerves and this isolation was exacerbated by her mobility problems due to ulcerated legs. Mr Hall was also in poor health with mobility problems of his own, however, unlike his wife he did go out regularly with the aid of his invalid scooter. Mr Hall was a former builder while Mrs Hall was a housewife. Their household income consisted of two state pensions, attendance allowance and disability living allowance and apparently they had always shared responsibility for the management of this income. They had lived in the same council house for 27 years and while they were on good terms with some of the neighbours, who often provided help in an emergency, like several of the council tenants seen they had problems with the disruptive and antisocial behaviour of some of the other neighbours. They complained to the council about this and after a five-year battle, were successful in getting their unwanted neighbours evicted. Due to their mobility problems they had paid to have a stair lift fitted in their house. Mr Hall also drove a disabled scooter, which he found invaluable for transporting himself around the city, especially since he was able to take his scooter on the city's trams. Mr and Mrs Hall were supported by home carers who visited once a day and by their sons and daughter who all lived nearby and helped out with shopping and heavy housework. Mr and Mrs Hall were seen for a follow-up interview, which revealed that their situation had remained largely unchanged.

## **MR HART**

Mr Hart was 78 and had been looking after his wife who was 84 for two years since she had a stroke and she was now wheelchair bound and incontinent. Mr Hart was a retired steel worker and he and his wife had lived in a council terrace for 30 years. Prior to his caring role Mr Hart had never performed housework or cooking, however, he said that he had few problems in managing as he was very well supported by his three children all of whom lived locally. They visited around 3 times a day and provided help with the practicalities of caring such as housework, cooking and shopping. He also said that their neighbours would provide help in an emergency. In addition, home carers visited 3 times a day, 7 days a week and Mrs Hart attended a day hospital once a week for company and rehabilitation which was provided free of charge. Mr Hart did not receive an occupational pension, only a state pension, while his wife who worked as a cleaner and shop assistant, received a partial state pension and attendance allowance. Their household income of approximately £115 was

also supplemented by income support and they said that they could manage on this income. They had never been car owners.

## **MR MACLELLAN**

Mr MacLellan was 78 years old and had been looking after his wife for around 20 years since she developed Parkinson's disease and he took early retirement from his job as a builder at the age of 63 in order to accommodate this caring role. He now felt that he cared on a 24-hour basis, providing his wife with personal care such as feeding and dressing. He also performed domestic tasks such as washing, housework and shopping. Moreover, due to his wife's risk of falling, he could not leave her alone for any significant length of time. Indeed, she recently had several falls, breaking her shoulder and hip thus further restricting her self caring abilities and mobility and making Mr MacLellan's caring role harder. Mr MacLellan had various health problems including a history of heart attacks and angina. However, Mr MacLellan was generally satisfied with his role and didn't feel that his physical health had been directly impeded as a result of caring, although his mental well being, social life and finances had been adversely affected. For example, his social and leisure activities were restricted as he was unable to leave his wife unattended but he was quite accepting of this as he said that he didn't want to go out without his wife anyway. Mr MacLellan and his wife lived in a one bed roomed council flat in Batemoor for which they paid a subsidised rent of £13 a week. They moved there several years ago after selling their previous house where his wife was unable to manage the stairs. Mr MacLellan said that the proceeds from their former house had now been largely spent on cars and other expenses and he now had only around £300 in savings. Their total household income was around £150 a week including a state pension for himself and his wife and £50 in attendance allowance. He chose not to apply for income support to supplement this income as he felt that he could manage without it. He had assumed total responsibility for managing and controlling this income since the onset of his wife's illness. Although their income was small he felt that it was adequate to their needs for he said that they never went anywhere so they don't need much.

Their major source of formal support was from home carers who visited morning and evening 7 days a week to assist in the dressing and undressing of his wife. He paid £34 per month for this service, which he saved up for with weekly stamps. He felt that not only did they provide practical help for his wife but they were also an important source of surveillance for them both. His wife was also supported by a community nurse who visited once a week to administer an enema. His wife also occasionally received respite care in local residential and nursing homes for which Mr MacLellan had paid a subsidised fee of around £150 a week. However, he would not wish for his wife to be permanently admitted to such care as he felt they were better off staying together. Like all the other carers interviewed on the Jordanthorpe estate, Mr MacLellan was not a member of a carer support group as he said he didn't have time to attend their meetings. Although Mr MacLellan had three children, two of whom live in Sheffield, he said that they were unable to provide much support due to the fact that they had their own problems such as ill health and work responsibilities. His major source of informal support was from a neighbour who sat with his wife while her husband and Mr MacLellan went to a pub on Saturday afternoon. However, apart from this Mr MacLellan had little contact with neighbours in the locality. The follow up interview revealed little change in Mr MacLellan's situation.

## **MRS PHILLIPS**

Mrs Phillips was 79 and had looked after her 80-year-old husband on a full time basis for the past two years since he was diagnosed as having emphysema. However, she felt that the assumption of caring responsibilities had been an insidious process, which had gradually crept up on her in the last 9 years. Due to Mrs Phillips unwillingness to leave her husband unattended, due to his risk of having a heart attack, she felt that her social life and leisure had greatly suffered as a result of her caring role and she was now rarely able to leave the house, unlike previously when she had always been very active, working at Middlewood hospital and more recently as a home warden. Mrs Phillips was herself in generally good health, apart from suffering from bronchitis, which she did not attribute to her caring role. As with the majority of carers interviewed, she would not consider residential care for her husband, although she said that she sometimes jokes that she'll put him in a home. Mrs and Mrs Phillips had lived in their rented warden controlled bungalow for the past eight years having moved from another rented house nearby due to Mr Phillips mobility problems. Like Mr Denis and Mr Hall, Mrs Phillips had problems with her neighbours experiencing violence and harrassment from local children. She was supported in her role by her daughter who lived locally and helped with shopping, daily visits by home carers and a crossroads sitter who visits two nights a week so that Mrs Phillips could play bingo, her only form of social life. As they only had £2000 in savings this service was provided free of charge. Contact was made with Mrs Phillips a year after her initial interview, during this time her husband had died and she felt that it would be too upsetting for her to take part in a follow up interview.

## **MRS WILLIAMS**

Mrs Williams was 79 and had been looking after her husband who is 84 since he had a stroke 4 years ago. He was also an insulin controlled diabetic and because of this she was unable to leave him unattended for long periods. She felt that her household routine and leisure and social life had suffered as a result of being a carer because she was no longer able to do the things that she used to. Their total household income was £191 and incorporated two state pensions, attendance allowance and £27 per week occupational pension from Mr Williams' former job as a tool warehouseman. She felt that this was adequate to their needs as she said that they were '*brought up to be frugal*' and were simply carrying on that way. Throughout their marriage Mrs Williams had always assumed full responsibility for the management and control of the money giving her husband a small spending money allowance. Due to Mr Williams' impaired mobility, getting out was a problem and this was exacerbated by the fact that they did not own a car, having sold their last car following retirement, as they could not afford to run it. However, they were fortunate in that their council terrace where they had lived for the past 11 years was in the Uppertorpe area and therefore within easy reach of the tram network. Unlike buses Mr Williams was able to board these trams as they had an access ramp for wheelchairs. This enabled them to travel to places like Meadowhall. Their son lived in Derby and is unable to provide much practical help although he did ring every day and their next-door neighbour sometimes provided help but only in an emergency. Mr Williams also received support from home carers who visited twice-daily 7 days a week and he sometimes went into respite care.

## **MRS FIELD**

Mrs Field was 82 and for the past 10 years had been involved in the co-resident care of her 87 year old husband who, although he had never been diagnosed as such, appeared to be suffering from dementia. She was a highly involved carer performing many personal caring tasks. For example, her husband was doubly incontinent and she therefore had to regularly toilet him and change his incontinence pads, a job which she found particularly unpleasant. She was also unable to leave her husband unattended due to his confusion and subsequent tendency to wander. She felt that her caring role had got harder over the years due to the progressive decline in her husband's health. She also felt that her own mental and physical health had suffered as a result of caring, feeling that the heart attack that she had in 1997 was partly due to the strains of her role. Mrs Field was less certain about the impact of caring on her social life, for while she did not go out as much as she used to this is probably due to her age and mobility problems rather than the result of caring or financial constraint. She also felt that her household routine had been largely unaffected by caring for she maintained that her husband had never helped her with housework, nor had he ever cooked throughout their married life. Similarly, she had always been responsible for household finances including the payment of bills.

The joint household income of Mrs Field and her husband was £200 and included attendance allowance and a state pension for herself and her husband. They also received interest from their significant savings and a small income from the lease of an office building, which they owned in Sheffield. They both worked during their marriage, he as a solicitor and her as a schoolteacher, neither had an occupational pension. Despite their relatively low income, Mrs Field claimed that she did not have any problems in meeting financial commitments and running their very large detached house in Fulwood. They had lived in this house for 50 years and while she recognised that it was far too big for them, she said that she had got used to the space and because of this would be reluctant to move due to the relative deprivation she would feel. She would only do so if her husband went into a home, an option which would only be pursued if she was no longer able to look after him. Due to the fact that Mr and Mrs Field had lived in the same house for so long they were well known to many of the neighbours who were willing to provide help in an emergency and she was visited once a week by one neighbour for a chat. However, she claimed that she was not as friendly with the neighbours as in the past when there used to be regular 'drinks parties' in the vicinity and many of her old neighbours had either died or moved away while newer residents were often out all day at work. Mrs Field's 3 children lived in London, Oxford and Bristol, but they did provide her with some social and financial support. For example, she recently went on holiday to Spain with one of her daughters. Her grandson also provided her with practical help such as changing light bulbs and she spoke to her sister who lived in Froggatt regularly on the phone. More regular and practical support was provided by her gardener's wife who had been given free use of Mrs Fields' car in return for the provision of twice-weekly chauffeuring duties. Mrs Field was unable to drive due to a wrist injury. In spite of this regular support provided by her gardener's wife, Mrs Field claimed to feel emotionally closer to her children and sister thus revealing a lack of congruence between 'exchange' and 'affect', the two most common ways of measuring informal networks. In addition to her informal support, Mr Field was supported by home carers from Monday to Friday, day care twice a week and respite care for one week in every six weeks. Mrs Field was not in a carer support group because she couldn't get to meetings.

**MRS KINCAID**

Mrs Kincaid was 83 and lived with her 47-year-old son. As Mrs Kincaid appeared to be slightly confused, it was clear that theirs was a reciprocal caring relationship, with her son who was entirely self-caring, apparently doing most of the housework and shopping. They had been in their current owned semi for 6 years having moved from a council house on the Manor estate. She said that she had little contact with her new neighbours, unlike her own neighbours who she said were very friendly and supportive. However, she said that there was less crime and violence in her new neighbourhood and because of this her other two sons who also lived in Sheffield were more willing to visit her with their children. Mrs Kincaid received attendance allowance and a state pension while her sons full time earnings brought their total household income to around £350 a week. The responsibility for the management of this income was apparently shared – she paid household bills and he paid for large purchases such as the freezer. Although Mrs Kincaid had two other sons she said that they did not provide any practical help. Formal support included an Age Concern day centre, a united reform luncheon club, a private cleaner and home carers with whom Mrs Kincaid was not happy as she said that they stole her clothes. However, she said that she was afraid to complain due to her apparent fear of reprisals.

### **MRS ROACH**

Mrs Roach was 84 and had been involved in the co-resident care of her 85-year-old husband since he developed kidney problems 25 years ago. She was highly involved, performing personal tasks such as dressing and while she was able to leave him alone she would only do so for short periods when she went to the shops. Thus, she said that she didn't like leaving him and neither did he like to be left alone. She felt that her caring role had got harder over the years due to the impact of ageing on both of them. Like her health, she felt that her leisure and social life had been harmed by caring as she now rarely goes out. On the other hand, she said that she didn't want to go out anyway, recounting her fear of crime and black people and her feelings that Sheffield was not as safe and clean as it used to be. Mr and Mrs Roach had lived in their owner/occupied bungalow since they moved from Manchester back to their native Sheffield 20 years ago. Due to Mr Roach's ill health their ambition to retire to Torquay had to be abandoned. Their joint household income was around £160 and incorporated two state pensions, attendance allowance and an occupational pension from Mr Roach's former employment as a railway inspector, Mrs Roach was herself a housewife during their marriage although they have no children. Prior to the onset of Mr Roach's ill health he took charge of the household income, giving his wife a housekeeping allowance but now Mrs Roach had to assume full responsibility for financial matters and she had not found this easy. In spite of being a carer for 25 years, Mr Roach had only been receiving attendance allowance for the past 8 months due to Mrs Roach's long standing reluctance to apply for it as she said that she wished to remain independent. Mrs Roach had a sister living nearby who visited every Saturday but who was unable to provide much support due to her own health problems. She also had two brothers who lived in Wincobank and Stannington, however, she regarded them as living too far away to be of much assistance thus revealing a parochial perception of locality. Neither, she says, were her neighbours much practical help as they were too old. It was her niece who lived in Dronfield who was her main source of support and she paid her to take her shopping every Friday and do her washing. Home carers visited every morning, 7 days a week having started two years ago when Mrs Roach was hospitalised with pneumonia. She refused to consider the option of permanent or respite care for her husband even though he was apparently willing to enter such care.



## **MR AND MRS TAYLOR**

Mr and Mrs Taylor were aged 92 and 84 respectively and regarded themselves as being involved in a two-way caring relationship. Both had mobility and sight problems, while Mrs Taylor had angina and Mr Taylor had ear nose and throat problems. In accordance with their reciprocal caring relationship, they shared household tasks, with Mrs Taylor doing the cooking while Mr Taylor went to the shops and collected their pensions. They lived in a ground floor council flat in Batemoor where they moved 13 years ago due to Mrs Taylor's problems in negotiating the stairs in their former rented house. They paid a subsidised rent for this flat and their weekly household income was around £200 including two state pensions, income support and attendance allowance for Mrs Taylor. Mrs Taylor, who worked for 17 years following the death of her first husband in 1958, also got a small widows pension. However, Mr Taylor, a former steelworker, did not get an occupational pension. Throughout their marriage they had shared responsibility for the control and management of household income with Mrs Taylor taking charge of housekeeping expenditure, while Mr Taylor paid the bills and generally 'worried' about money. Although they had been living in the same flat for 13 years, Mr and Mrs Taylor did not find their neighbours to be particularly supportive, for although most were also retired, they tended to keep themselves to themselves. Although they got no practical help from their neighbours, Mrs Taylor's daughter from her previous marriage who lived in Dore usually took them out in her car on Thursday nights. Their major source of formal support was from a social services home carer who visited on Mondays, Tuesdays, Thursdays and Fridays to do housework and shopping for a weekly charge of £8.25. In view of their mobility problems they felt that their major unmet need was their lack of adequate transportation.

## **MR TUMIN**

Mr Tumin was an 84-year-old man who had been looking after his 81-year-old wife Edna since she first became ill 3 years ago. Since then his wife's condition had become progressively worse, suffering from a variety of problems including vertigo, hardening arteries, occasional confusion and minor strokes. Consequently, Mr Tumin provided his wife with all forms of domestic, personal and physical care and due to her impaired mobility and susceptibility to collapsing, he was unable to leave her unattended for over an hour. Mr Tumin himself also had health problems including arthritis and since he had a hip replacement he had to walk with a stick. However, he did not feel that his physical health had suffered as a result of caring; unlike his emotional health which he felt had suffered slightly as a result of the demands of his role. In spite of these demands he didn't think that his household routine had been adversely impacted, there had simply been a role reversal with him taking over the household tasks such as hoovering and shopping which his wife used to perform. Neither did he feel that his leisure and social life had changed greatly for he said that since he retired 20 years ago, this had become fairly limited anyway and that he was still able to go out for an hour or so each evening. Subjectively, Mr Tumin felt satisfied with his role which he saw as a way of returning the help and support that his wife provided him with throughout their marriage. As such, he did not contemplate the idea of having his wife admitted to permanent care as long as he was able to look after her himself.

Like their household routine, there was also a role reversal in the way in which household income was managed since Edna became ill. Thus Mr Tumin described how, throughout their married life, his wife had been responsible for paying all the household bills from the housekeeping allowance,

which he gave her but he had now assumed responsibility for this. He said that this was quite a challenge as their income was not great. Thus his wife who originally worked in service but who was a housewife throughout their married life received a state pension and attendance allowance. Mr Tumin also got a state pension and an occupational pension of approximately one pound a week from his former job as a coachbuilder. Since they turned 80, they also began to receive an extra 25 pence a week each on their state pensions! From their total weekly household income of £160, Mr Tumin paid three pounds a week for a special telephone and about £5 per week in subsidised rent on their three bed roomed council house in Heeley which they had lived in for over 20 years. He also had to pay for the extra electricity used by his wife's stair lift and around £70 a week for his wife's respite care. As a consequence of this, Mr Tumin felt that he had suffered financially as a result of caring. However, like all the other carers interviewed, he felt that they could manage on the income they had.

Mr Tumin first came into contact with formal provision in June 1997 when he had to go into hospital for an operation and needed support for his wife while he was away. This led him to be allocated a social worker. In subsequent years, Mr Tumin and his wife had received increased amounts of support and she was currently receiving respite care for one week in every five. Mr Tumin was initially reluctant to accept this arrangement but finally agreed after persuasion from his social worker. Both were now happy with the respite care provided, for Mr Tumin felt that not only did it give him a break but it also allowed his wife to experience a change of environment and to meet new people. When Edna was at home, domiciliary support was provided with a home carer coming in the morning and in the evening, a stair lift had also been installed by the social services. Mr and Mrs Tumin had no children and their informal support came from their niece who lived in Killamarsh and provided them with practical help such as clothes washing.

## **MR DENIS**

Mr Denis was 85 and had looked after his 72-year-old wife for around 10 years since she became frail and immobile as a result of an undiagnosed illness, which could have been a stroke. He and his wife emigrated from Jamaica 36 years previously, aiming to improve their job prospects, leaving behind him all his friends and family including a son, his only child from a previous relationship. Mr Denis was a highly involved and apparently devoted carer, performing personal care for his wife in spite of his own health problems, which included arthritis of the spine. Since arriving in Sheffield, Mr Denis and his wife had lived in rented accommodation and had been tenants of their current second floor council flat in Broomhall for 20 years. Due to their mobility problems and the fact that their block of flats did not have a working lift, Mr Denis' current household income was around £200 a week and included attendance allowance, two state pensions and income support. Mr Denis was very satisfied with this income and said that he was better off now than he was before retirement. Thus although he and his wife worked full time since arriving in Sheffield, they were always in poorly paid jobs and had never been able to save any money or afford a car. In spite of this Mr Denis said that he had never regretted coming to Sheffield and was very grateful to the government for the financial help which they now provided him with. Mr Denis' only support in his role was from formal sources, being visited by home carers once a day, seven days a week. They provided his wife with assistance in personal care and they used to provide assistance with cooking and shopping, however, this service had been stopped as they were unable to provide a diet which

was compatible with and Mrs Denis' ethnically specific dietary preferences. Mr Denis was on poor terms with his neighbours who he never spoke to due to their noisy and anti-social behaviour.

### **MR WILSON**

Mr Wilson was 85 and looked after his wife who is 90. He retired from his job as a furnace man in 1978 while his wife who was trained, as a nurse had not worked since they married 65 years ago. Mrs Wilson had a variety of physical problems and went into hospital in February 1998 to have a catheter fitted. After her discharge she spent 4 weeks in a nursing home to recuperate and continued to improve since she returned home. Due to his wife's impaired mobility, Mr Wilson had gradually taken responsibility for most household tasks since his retirement such as shopping and cooking. However, he did not find it hard to adapt to this as he said that he had always been a good shopper. Although Mr Wilson saw himself as caring on a 24-hour basis, he said that he was able to leave his wife alone and continued to enjoy an active leisure and social life going to painting classes in the winter and bowling in the summer. Since his wife was discharged from hospital she had received attendance allowance. Consequently Mr Wilson felt that in some respects his caring role had been accompanied by an improvement in household finances. Mr Wilson felt generally satisfied with his role and its only negative impact had been on his physical health, for he said that he had lost weight as a result of the physical strains of caring.

Mr Wilson and his wife had lived in a council house in Jordanthorpe for 36 years. Several adaptations had been fitted in order to accommodate his wife's disability such as a stair lift which the council provided free of charge. Their weekly household income was around £150 and included £8 income support, the lowest rate of attendance allowance and a state pension for himself and his wife. In their younger days Mrs Wilson was *'in charge of the purse strings'* and would control and manage all household income, giving her husband a small allowance from this. Mr Wilson had now assumed this responsibility by carefully managing their limited income. For example, he saved for the home carers they received with a weekly stamp and paid for the special phone every quarter. The attendance allowance was kept separately and paid for things like the extra heating bills incurred as a result of his wife's disability. Like all the other carers interviewed Mr Wilson felt that their income was adequate in meeting their needs for as he said *'young people want things now but we had to save up in our day'*. Their major source of formal support was from home carers who visited for 10 minutes every morning and evening to help Mrs Wilson dress and undress and to empty her catheter bag. The charge for this was £8.25 per week. A community nurse also visited every 8 to 10 weeks to change Mrs Wilson's catheter. A cleaner from Age Concern visited for 2 hours every fortnight to do heavy housework for which the charge was £11. Pre-cooked meals were provided regularly by the council, which Mr Wilson stored in a specially provided freezer and cooked in a steam cooker which was also council provided. While they had little contact with neighbours, their daughter, who lived in Dronfield, helped with cleaning and heavy shopping while their son, who lived in Clay Cross, helped with decorating. Mr Wilson said that he would like more help with gardening.

### **MR AND MRS LANE**

Like many older couples, Mr & Mrs Lane who were both 86, felt that they were involved in a reciprocal caring relationship with both having health problems and mobility impairments. This

reciprocity in caring started 2 years ago after Mr Lane had a heart attack. Prior to that he was the main carer of his wife who had been ill since 1995 due to an operation on her knee, which had become infected. Both were satisfied with the role and felt that it had not adversely effected their lives except their finances, having paid £2,000 to have a stair lift fitted. They said that they now shared household tasks with Mr Lewis washing up while Mrs Lewis dusted. They also shared the management of household income although throughout most of their marriage Mr Lewis held financial control giving his wife a housekeeping allowance. Their combined household income was around £160 per week and was made up of an occupational pension from Mr Lanes' former job as a steel worker; two state pensions and attendance allowance and they felt that this was adequate to their needs. They had transferred the ownership of their house to their son because of the help he provided them with. Although they had lived in this house for 60 years, they had little contact with their neighbours who were mainly younger people who go to work. All their older neighbours had either died or moved away. Indeed they felt that their isolation and inability to go out due to their disabilities was their biggest problem. Thus Mrs Lane said that she hadn't been into town for 5 years and was therefore unable to buy her own clothes unless through catalogue purchases. Their son lived locally in High Green and provided them with assistance with shopping and gardening and also took them for a drive twice a week. They had never owned a car themselves. They were also supported by home carers who visited 7 days a week.

#### **MR CAPLOW**

Mr Caplow was 87 and has looked after his wife who was also 87 since she first became ill with diverticulitis and heart problems at the age of 75. This assumption had been a gradual process as her illness had progressed and her disability was now such that, although she was mobile, she had only left their flat once in the past 6 years. Mr Caplow who himself suffered from thyroid problems now felt that he looked after his wife on a 24 hour basis, providing personal care and also performing all household tasks such as cleaning and cooking. He did not feel that he had difficulty in adapting to this traditionally female role and neither did he feel that his mental or physical health had suffered as a result of caring. However, he did think that his leisure and social life had suffered, for apart from playing snooker occasionally he rarely went out. Mr Caplow and his wife moved from their rented house in Norton Hammer to their flat in Batemoor 23 years ago, shortly after he was made redundant from his job as a railway shunter at the age of 59. Their joint weekly income was about £142 and incorporated his own state pension and occupational pension and his wife's smaller state pension and attendance allowance. During most of their marriage he said that his wife who never worked would assume responsibility for the control and management of household income and he used to hand over his earnings to her from which she gave him an allowance – the 'whole wage system'. However, due to her illness he had now taken over the household finances, which he felt were adequate in meeting their needs. Indeed, he didn't feel that his financial situation had deteriorated since he left his last job for which he was poorly paid. The only formal support received by Mr Caplow was a home carer who did his shopping once a week and while he had four children living locally, he didn't like to make too many demands on them. Mr Caplow took part in a follow-up interview, which revealed that his wife had recently died.

#### **MRS COATES**

Mrs Coates was 88 and had been looking after her 85-year-old husband for 10 years since he had a heart attack. He now had impaired mobility and needed assistance with personal care. Mrs Coates who also had mobility problems, did not feel that her life had suffered in any way as a result of caring. Mr Coates was Polish and came to Sheffield after the war to work as a steel grinder, while Mrs Coates helped to run the sweet shop which she took over from her parents. Neither had an occupational pension, their income being made up of attendance allowance and two state pensions. Mrs Coates managed this money, a role which she had always performed due to her husband's unfamiliarity with British currency. She felt that they could manage on this income for, as Mrs Coates said, they never went anywhere, not only because disability precluded this but also because they didn't want to. Indeed, they sold their car some years ago because they felt that they no longer needed it. Mrs Coates said that she gave her own state pension to her son in return for the help he provides - he paid their gardener and did their shopping. Until recently he used to travel from London to visit them on alternate weekends but Mrs Coates had now told him to cut down on his visits as she thought it was becoming too much for him due to his own ill health. She said that her neighbour now did her weekly shopping and would also help her out in an emergency. However, although she had lived in the same house for 37 years she had little contact with other neighbours and while she also had a sister and cousin living in Fulwood she rarely saw them due to their own health problems, although she did speak to her sister on the phone quite regularly. Mr Coates was supported by home carers who visited twice a day, six days a week and although they paid to have a stair lift fitted they chose to confine themselves largely to living downstairs.

#### **MR HUNTER**

Mr Hunter was 89 and looked after his 90-year-old wife who developed dementia a few months ago. Due to her confusion he was unable to leave her unattended for any significant length of time. He also helped his wife to get dressed and go to the toilet as well as taking over responsibility for the performance of housework which his wife performed totally unaided until the age of 85. In some respects he had found this to be a difficult readjustment, although he said that he now had no particular problems with his new role being in relatively good health himself. He and his wife lived in a large detached bungalow in Grenoside, which he had built before his retirement as a family butcher; they had been there for 39 years. In spite of their apparent affluence, Mr and Mrs Hunter did not receive an occupational or personal pension for as Mr Hunter said, these were not widely available during their own working lives and their total weekly income was around £150 a week. Mr Hunter owned a car but did not drive it as he said that he no longer felt safe on the roads and he was thinking of replacing it with an invalid scooter. Mr and Mrs Hunter had a son and daughter living locally who were very supportive, providing help with shopping, pension collection and bringing over 2 meals a day. They were also well supported by their neighbours being well supported in the community due to their former occupation. Their formal support consisted of daily visits by home carers. During the initial interview Mr Hunter was also trying to persuade his wife to attend a day centre once a week so that he could have a rest but on the follow up interview, Mrs Hunter had been admitted into permanent nursing home care, as Mr Hunter felt no longer able to cope with the care of his wife. He had also sold his car.

#### **MR TUNSTALL**

Mr Tunstall was 91 and had looked after his 90-year-old wife who was blind and had arthritis of the spine, for about 20 years. Like many co-resident carers his assumption of caring responsibilities had been a gradual and insidious process as his wife's disability had progressed and he now assumed responsibility for household tasks. In spite of the fact that he suffered from poor health himself he did not feel that this had been a result of caring. However, he did feel that his social life had suffered not simply due to his caring role but also due to the increase in his wife's disability, which had accompanied this role. During their 68 years of marriage Mrs Tunstall was a housewife and Mr Tunstall worked for the Council for 45 years most recently as an accountant. Following his retirement from the Council at the age of 60 he worked part time for a Post Master in Meadow Head until he reached the statutory retirement age of 65. They now had quite a good weekly income of £287, which included his occupational pension and state pension and his wife's state pension and attendance allowance. He also had substantial savings in several building society accounts some of which were derived from the sale of his former house in 1975; he now lived in a first floor council flat in Batemoor. On the whole Mr Tunstall felt that their income was adequate for their needs and he said that he had always been careful with money. Although he had a bank account, like most of the carers in the sample he disliked credit and debt. Due to his wife's disabilities he had now assumed responsibility for all household expenditure, this contrasted with the pattern of money management earlier in their marriage when his wife took charge of house keeping spending through an allowance that he gave her every week. In spite of his age, the only formal support received by Mr Tunstall was a district nurse who visited his wife every two weeks and a cleaner who he employed himself for about an hour a week. He was also considering respite care for his wife who had had several hospital admissions in recent months and while he was generally happy with the care she received in hospital, he felt she was discharged before she was fully recovered, thus precipitating the need for a rapid re-admission. Although Mr and Mrs Tunstall had no children, they had a nephew who visited at least once a week to help out but like most of the carers interviewed he did not like to impose upon them too much. A follow-up interview was not carried out with Mr Tunstall, as he was not contactable. A neighbour, Mr Caplow, was subsequently able to tell me that since his previous interview his wife had been admitted to a home and Mr Tunstall had died suddenly shortly afterwards while walking to the shops.

#### **MR DALE**

Mr Dale was 94 and had been the main carer of his son who had cerebral palsy since his wife died 13 years ago. However, he did not regard himself as a carer and maintained that his son and himself looked after each other. Thus his son did his 'leg work' around the house while Mr Dale took charge of his son's finances and generally kept an eye on him. Due to the mutually supportive nature of their relationship, Mr Dale thought that his life had actually improved as a result of becoming a carer and did not feel that he would be able to cope at home without his son's assistance. Although Mr Dale had his leg amputated at the age of 13 following an accident at work and now walked with a stick, he continued to run a car and had recently bought a new one. Unusually for this sample of respondents, he also owned a mobile phone and various financial accessories such as a credit card. Moreover, in spite of his impaired mobility he maintained quite an active social life and was a member of various clubs and societies. Their total household income was around £300 per week and incorporated disability living allowance (£33) mobility allowance (£13) and income support (£107) for his son and a state pension (£67) occupational pension and attendance allowance (£32) for Mr Dale. Mr Dale, who previously worked as a Coal Board manager was initially reluctant to apply

for attendance allowance as he said it undermined his wish to be independent. Although Mr Dale had lived in the same owner/occupied semi for 60 years he had little contact with neighbours and they would only provide help in an emergency. However, his daughter who lived in Solihull, was very supportive and visited them regularly as well as providing 'respite' care. Prior to Mrs Dale's death Mr Dale's son attended a training centre during the week, however Mr Dale later withdrew him from attending preferring to 'train him' at home. He also received home carers once a day 5 days a week.