Interview information

Carer study number   ED_RT☐☐_C☐☐☐

General practice ref number   ED_RT☐☐_T☐

Interviewer (tick)   I T-B ☐   PJ ☐   JW ☐   TG ☐   Other ☐

Interview date   ☐☐ ☐☐ ☐☐☐☐

Interview time   **1**   Baseline   **2**   Follow-up

Location of interview with carer

1   Patient's home   **2**   Carer's home   **3**   GP surgery

4   Hospital   **5**   Residential home   **6**   Nursing home

7   Day centre   **8**   Carer's workplace

9   Other………………………………

10   Patient and Carer's home

Interview start time   ☐☐☐☐   Interview end time   ☐☐☐☐

Introduction

Thank you for seeing me today.

Points to cover with carer pre interview:

1. **I'll just go over what the study is about again. We plan to talk to families who are registered with twenty GP practices in the area, all with a relative with memory problems (or who have been diagnosed with dementia). This involves asking about the time you first became concerned something was wrong with your relative, about when and how the diagnosis was made, and what's happened since.**

2. **A lot of the questions are about any contact you have had with your GP practice……We ask these questions because we are working with some of practices to try and improve their service to people with these problems. Then we plan to talk to the families again to see if they have noticed any difference.**

3. **As we said in the letter…..**

> **Your involvement is VOLUNTARY**
>
> **Information is kept confidential, and nothing will be passed on to the practice. So no one at the practice will know what you have said and there will be no detrimental effect on the care you or your relative gets from the doctor.**
>
> **Please say if I ask a question you don't understand or feel unhappy about: I'll try to explain why we are asking it, but we can always skip a question if you are still not happy with it.**
>
> **Please let me know if you would like to take a break or continue the interview at another time.**

4. Any questions or things not understood?   **Yes ☐ No ☐ Can we start?**

I'd like to start by asking you some background questions about you and your family. This will help us understand the differences between people in the study.

1a). Could you tell me how you are related to (name)?

Carer is :	Wife	1	Son	5
	Husband	2	Other relative ………………	6
	Daughter	3	Other (specify ………………)	7
	Daughter-in-law	4		

b). Record carer gender   Male   1   Female   2

c). Record patient gender   Male   1   Female   2

2 a). Could you tell me whether you are:

Married/Co-habiting	1	Divorced	4
Single	2	Separated	5
Widowed	3		

b). Is your (relative):

Widowed	1	Divorced	4
Married/Co-habiting	2	Separated	5
Single	3		

3 a). Do you have any children under 18 living at home?   RECORD NUMBER ……….

b). Are you responsible for looking after anyone else other than (your relative)(and your children)?

Yes (details …………………………………) 1   No   2   NA   99

4. Are you:

Working full time (30hrs/wk or more)	1	Family commitments/homemaker	5
Part time (29 hrs/wk or less)	2	Retired (when …………………………)	6
Unemployed	3	Studying/training	7
Unable to work for health reasons	4	Other (specify) …………………………	8

5 a). Could you tell me your date of birth?   ……………

b). How old were you when you finished education?   ……………

c). Did you do any further studies after you left school?   ………….……………….

d).How old was your relative when they finished school?   ………………………… DK   88

e). And did your relative go into further education? …………….…………… DK 88

6 a). To which of these ethnic groups do you consider you belong?

	Carer	Relative		Carer	Relative
White UK	1	1	Indian	7	7
White Irish	2	2	Pakistani	8	8
White other ………………..	3	3	Bangladeshi	9	9
Black - Caribbean	4	4	Chinese	10	10
Black - African	5	5	Asian other ……………	11	11
Black - Other	6	6	Any other ethnic group	12	12
			Refused to say	13	13

b). And your (relative)?(CODE ABOVE)

7 a). Does your (relative) live in her own home?   Yes   1   No   2

IF NO: b). How long is it since she left her own home?   ……. yrs …....mths

DK   88   NA   99

c). Who does your relative live with? (RECORD ALL HOUSHOLD MEMBERS)

……………………………………………………………………………………………………

……………………………………………………………………………………………………

…………………………………………………………………………………………….NA 99

IF LIVES WITH CARER: GO TO Q8

IF NOT WITH CARER:

d). In an average week, how many times do you see your relative?   ☐☐

   How long, on average, do you stay each visit?   ☐☐☐mins

e). In an average week, how many times do you talk on the phone?   ☐☐

    How long, on average, do you spend on each call?   ☐☐☐mins

NA   99

8 a). Does anyone else – family, friends or neighbours – give your relative any help?

Yes   1   No   2   DK   88   NA   99

IF NO: GO TO Q9

b). **IF YES**: Who? ……………………………………………………………………..

……..………………………………………………………………………………………

……………………………………………………………………….**NA 99**….

c). After you, who helps the most? ………………………………………………….…..

…………………………………………………………………………………………

……………………………………………………………………… **NA 99**…

These next questions are about how it first became noticed (your relative) might be having problems with their memory or getting confused:

9 a). First, can I just check, has (your relative) been with the same doctors' practice since the time these problems   were first noticed?   **Yes   1   No   2   DK   88**

b). And with same GP?

Yes, same GP throughout	**1**	**Same practice, any GP**	**2**
Same practice, changed GP	**3**	**No, changed practice**	**4**
Can't remember	**77**	**Don't know**	**88**

IF CHANGED:

c). Why did (your relative) change GP/Practice?

When moved address	**1**
Other	**2**
Can't remember	**77**
DK	**88**
NA	**99**

d). When did (your relative) change practice?

Before diagnosis of d. made	**1**
After diagnosis made	**2**
Other	3
Can't remember	**77**
DK	88
NA	**99**

IF CHANGED PRACTICE AFTER DIAGNOSIS- GO TO Q23

10 a). Can you tell me how long ago it was first noticed that something was wrong?

☐☐☐mths ago   Can't remember   77   DK   88

 b). Who noticed it?

Main Carer	**1**	GP	**4**	
Other Relative	**2**	Nurse	**5**	
Friend/Neighbour	**3**	Social Services	**6**	
Other (who) …………………	**7**			

 c). What was it that was noticed? …………………………………………………………………..
  ……
  ……

 d). What did you think was causing it?

Dementia   **1**   **Age**   **2**

Other   **3** GO TO (e)   **Can't remember**   **77**   **Don't know**   **88**

IF OTHER:

 e). (Detail) …………………………………………………………………………………………
  ………………………………………………………………………………………… **NA 99**

11 a). Was anyone at the practice contacted about it when you first noticed it?

Yes   1   **No   2**   IF NO: GO to 11(f)

Can't Remember   77   DK   88

IF YES:

 b). Who contacted them?

Interviewee	**1**	Social Services	**5**
Other Relative	**2**	Other (who) …………………	**6**
Friend	**3**	Can't remember	**77**
Neighbour	**4**	DK	**88**
NA	**99**		

 c). Who was contacted?

GP	1	Practice nurse	2
Other………..	3	Other nurse	4

Can't Remember   77   DK   88

NA   99

d). What did she say? …………………………………………………………………………………

 …………………………………………………………………………………………………..

Can't remember 77   **DK   88**   **NA   99**

e). What did she do?

……………………………………………………………………………………….…..

 ………………………………………………………………………………………………

Can't remember 77   **DK   88**   **NA   99**

IF NO:

f). How long was it after you noticed something was wrong before someone talked to the GP about it?

☐☐☐**mths later**   **Can't remember 77**   **DK   88   NA   99**

g). Who contacted the GP at this time?

Interviewee	**1**	Social Services	**5**
Other Relative	**2**	Other (who)…………………	**6**
Friend	**3**	Can't remember	**77**
Neighbour	**4**	DK	**88**
NA	**99**		

h). What did she say?

…………………………………….…………………………………………………

 …………………………………………………………………………………………………..

 …………………………………………………………………………………………………..

Can't remember 77   **DK   88**   **NA   99**

i). What did she do?

……………………………………………………………………………………….

 …………………………………………………………………………………………………..

 …………………………………………………………………………………………………..

Can't remember 77   **DK   88**   **NA   99**

12 a). What did you think of the way the GP responded to the concern about (your relative)? (CARD A)

Very poor   1   Poor   2   Fair   3

Good   4   **Very good**   5   **Excellent**   6

Can't say   77   **NA**   99

b). Why do you say that? ………………………………………………………………………………..

  ………

  ………

c). What did you think of the way the practice team as a whole responded? (CARD A)

Very poor   1   **Poor**   2   **Fair**   3

Good   4   **Very good**   5   **Excellent**   6

Can't say   77   **NA**   99

d). Why do you say that?

………………………………………………………………………………………

…….

………

13 a). How long was it after it was noticed something was wrong before Social Services /The Council were contacted?

☐☐☐**mths later**

Straight away   1   **Already in contact**   2   **Not contacted 3**

Can't remember   77   **DK**   88

IF NOT CONTACTED: GO TO Q14

IF CONTACTED:

b). Did anyone contact them for you?

Yes   1   No   2   Can't remember 77   DK   88   NA   99

IF NO: GO TO 13d

IF YES:

c). Who contacted Social Services?

GP   1   Practice nurse   2   Other nurse   3

other(who) ………..…….   4   Can't remember   77   DK   88
NA   99

d). What did Social Services say when they were contacted about your relative?

……
………………………………………………………………………………………………… **NA 99**

e). What did they do?

……………………………………………………………………………………….................................

 …………………………………………………………………………………………………… **NA 99**

f). What did you think of Social Services' response? (CARD A)

Very poor   **1**   **Poor**   **2**   **Fair**   **3**

Good   **4**   **Very good**   **5**   **Excellent**   **6**

Can't say   **77**   **NA**   **99**

 g). Why do you say that?

………………………………………………………………………………………………………..
…………..………………………………………………………………………….………………… **NA 99**

These next questions are about what was done to establish what was wrong:

14 a). What was done by the GP to establish what was wrong?

GP did something   **1**   **GP did something- DK what**   **2**
GP did nothing   **3**   **DK if GP did anything**   **88**

CODE BELOW

b). Did anyone else do anything to establish what was wrong?

Yes   **1**   **No**   **2**   **Can't remember**   **77**   **DK**   **88**   **NA**   **99**

IF YES, 1:

CODE BELOW (PROMPT)

	Done By GP	Done by other (who)	Done but DK by who	Not done	Can't remember
Took a blood sample	1	2 ……………	3	77	88
Took a urine sample	1	2 ……………	3	77	88
Took blood pressure	1	2 ……………	3	77	88
Did a physical examination	1	2 ……………	3	77	88
Arranged a brain scan	1	2 ……………	3	77	88
Tested your relative's memory	1	2 ……………	3	77	88
Prescribed medicine for depression	1	2 ……………	3	77	88
Referred to a specialist/hospital/unit	1	2 ……………	3	77	88
Told you about help and support organisations, i.e. the Alzheimer's Society?	1	2 ……………	3	77	88
Other …………………………	1	2 ……………	3	77	88

15 a). All in all, how would you rate the way the problem was investigated? (CARD A)

Very poor   **1**   **Poor**   **2**   **Fair**   **3**

Good   **4**   **Very good**   **5**   **Excellent**   **6**

Can't say   **77**   **NA**   **99**

b). Why do you say that?

……………………………………………………………………………………………………….

………………………………………………………………………………………… **NA 99**

Now I'd like to ask about how you were told what the problem was:

16 a). Can you remember who first gave you a diagnosis for your relative's problem?

GP	**1** GO TO (c)
Other prof (title …..……………)	**2** GO TO (d)
Not given by anyone	**3** GO TO (b)
Other (…..……………)	**4**
Can't remember	**77**
DK	**88**

IF 3 (Not given): CHECK

 b). So how did you find out what the problem was?

……

……

……

IF CLEAR NO DISCLOSURE OCCURRED, SKIP TO Q18

IF GP:

 c). Which GP was that? ………………………………………..   **NA   99**

d). How long ago was that?   □□□**mths**   **Can't remember 77**   **NA   99**

e). What was the diagnosis you were given? (What did you find out the diagnosis to be?)

AD	**1**	**Senile dementia 3**	**Mixed type**	**5**	**DK**	**88**
Vascular	2	Dementia 4	Other ……………… 6		NA	99

f). Apart from the diagnosis, were you told (did you find out) anything else at that time?

	Yes	No	Can't rem.	DK	NA
Course, prognosis	1	2	77	88	99
Tranqu/sedative medication	1	2	77	88	99
Available services	1	2	77	88	99
Prim care team support	1	2	77	88	99
Anti-dem medication	1	2	77	88	99
Carer support	1	2	77	88	99
Cause	1	2	77	88	99
Other ………………..	1	2	77	88	99
Other ………………..	1	2	77	88	99

17 a). All in all, how would you rate the way you were told (found out about) the diagnosis? (CARD A)

Very poor	1	Poor	2	Fair	3
Good	4	Very good	5	Excellent	6
Can't say	77	NA	99		

b). Why do you say that?

……

……

………………………………………………………………………………………………… **NA 99**

IF NO DISCLOSURE OCCURRED, SKIP TO Q18

The next questions are about how things are now. The first ones are about your relative's <u>usual doctor</u>. If you don't feel she has a usual doctor just think about the doctor in the practice who you feel knows your relative best. IF NONE OF THE DOCTORS KNOWS BEST ASK ABOUT THE DOCTORS AT THE PRACTICE IN GENERAL.

18 a). In the last 12 months, how many different doctors from the practice has she seen? …………

     DK   88

b). IF DOESN'T SEE OWN OR SAME GP CONSISTENTLY: Can you tell me why not?

………………………………………………………………………………………………………..

……………………………………………………………………………………………**NA 99**

c). Are you with the same practice yourself?   **Yes   1**   **No   2**

19. In the **past 12 months**, how many times have you seen a doctor from the practice about your relative?

☐☐☐ **times**   **Don't know   88**

20. In the **past 12 months**, has your relative seen a doctor from the practice on her own?

Yes 1 No 2   **Don't know   88**

IF YES:

b). How many times?   ☐☐☐ **times**   **Don't know   88   NA   99**

21. Overall, how satisfied are you with the? (CARD D)

	Very Satis-fied	Satis-fied	Dis-satis-fied	Very Dissat-isfied	No Contact	Can't Say	DK
a). Doctor's care for your relative?	1	2	3	4	5	77	88
b). Help the Doctor gives you to care for your relative?	1	2	3	4	5	77	88

22.	Def. not	Prob. not	Prob. yes	Def. yes	Not Sure		DK
Would you **recommend** your relative's usual doctor to someone else looking after someone with dementia? (CARD F)	1	2	3	4	5		88

I'd like to ask now about the practice as a whole – nurses, receptionists and so on who work with the GPs.

23 a). Can I just check: have you talked to any of these people at your relative's practice about her care?

FOR EACH SEEN:
 b). How helpful did you find the? (Card E)

	Seen	Not seen	Very Helpful	Quite helpful	Neither helpful	Notvery helpful	Notatall	Madethings worse	Does not apply
Practice nurse	1	2	1	2	3	4	5	6	99
Practice manager	1	2	1	2	3	4	5	6	99
Community nurse	1	2	1	2	3	4	5	6	99
Health Visitor	1	2	1	2	3	4	5	6	99
CPN	1	2	1	2	3	4	5	6	99
Nurse (unspecific)	1	2	1	2	3	4	5	6	99
Receptionist	1	2	1	2	3	4	5	6	99
Other……………	1	2	1	2	3	4	5	6	99

24. Would you recommend your relative's practice as a whole to someone else looking after a person with dementia? (CARD F)

1	2	3	4	5	88
Definitely Not	Probably Not	Probably Yes	Definitely Yes	Not Sure	DK

These next questions are about what your relative can and can't do for herself, and whether they get or want extra help, advice or information. The help might be from your GP or someone else at the practice, from social services, from a voluntary agency or just someone that you know. For each sort,

I'd like you to tell me how helpful it's been for you, using this scale, with 1 for very helpful to 6 for makes things worse. (CARD E)

25 a). First, is she able to manage her own personal care by herself – washing and dressing?

	1	2	88	
	Yes	No	DK	IF YES: GO TO Q26

IF NO:

b). Does she get any help with that?

	1	2	88	99	
	Yes	No	DK	NA	IF NO: GO TO

Q25f

IF YES AT (b):

c). Who from? (identify prof if possible)

…………………………………………………………………… **NA 99**

IF NOT FAMILY MEMBERS:

d). How helpful would you say that was? (CARD E)

Very helpful	Quite helpful	Neither helpful	Not very helpful	Not at all helpful	Makes things worse	NA
1	2	3	4	5	6	99

e). Do you feel this is enough help?

	1	2	88	99
	Yes	No	DK	NA

IF NO AT (b):

f). Do you feel she needs help with that?

	1	2	88	99
	Yes	No	DK	NA

26 a). Is she able to manage her medication by herself ?

	1	2	88	
	Yes	No	DK	IF YES: GO TO Q27

IF NO:

b). Does she get any help with that?

	1	2	88	99

	Yes	No	DK	NA	IF NO: GO TO

Q26f

IF YES AT (b):

c). Who from? (identify prof if possible)

……………………………………………………………….. **NA 99**

IF NOT FAMILY MEMBERS (**CARD E**)

d). How helpful would you say that was?

Very helpful	Quite helpful	Neither helpful	Not very helpful	Not at all helpful	Makes things worse	NA
1	2	3	4	5	6	99

e). Do you feel this is enough help?

1	2	88	99
Yes	No	DK	NA

IF NO AT (b):

f). Do you feel she needs help with that ?

1	2	88	99
Yes	No	DK	NA

27 a). Is she able to prepare her food by herself?

1	2	88	
Yes	No	DK	IF YES: GO TO Q28

IF NO:

b). Does she get any help with that?

1	2	88	99	
Yes	No	DK	NA	IF NO: GO TO

Q27f

IF YES AT (b):

c). Who from? (identify prof if possible)

………………………………………………………………… **NA 99**

IF NOT FAMILY MEMBERS:

d). How helpful would you say that was? (CARD E)

Very helpful	Quite helpful	Neither helpful	Not very helpful	Not at all helpful	Makes things worse	NA
1	2	3	4	5	6	99

e). Do you feel this is enough help?

1	2	88	99
Yes	No	DK	NA

IF NO AT (b):

f). Do you feel she needs help with that?

1	2	88	99
Yes	No	DK	NA

28 a). Is she able to get around the house safely by herself?

1	2	88	
Yes	No	DK	IF YES: GO TO Q29

IF NO:

b). Does she get any help with that?

1	2	88	99	
Yes	No	DK	NA	IF NO: GO TO

Q28f

IF YES AT (b):

c). Who from? (identify prof if possible)

……………………………………………………………………NA 99

IF NOT FAMILY MEMBERS:

d). How helpful would you say that was? (CARD E)

Very helpful	Quite helpful	Neither helpful	Not very helpful	Not at all helpful	Makes things worse	NA
1	2	3	4	5	6	99

e.) Do you feel this is enough help?   **1**   **2**   **88**   **99**

                                              Yes   **No**   **DK**   **NA**

IF NO AT (b):

f). Do you feel she needs help with that?   **1**   **2**   **88**   **99**

                                                Yes   **No**   **DK**   **NA**

29 a). Is she able to go to the toilet by herself? (ie. stay continent) (toileting problems) (any accidents?)

                     1   **2**   **88**

                     Yes   **No**   **DK**   IF YES: GO TO Q30

IF NO:

b). Does she get any help with that?

                     1   **2**   **88**   **99**

                     Yes   **No**   **DK**   **NA**   IF NO: GO TO Q29f

IF YES AT (b):

c). Who from? (identify prof if possible)

…………………………………………………………….. **NA 99**

IF NOT FAMILY MEMBERS:

d). How helpful would you say that was? (CARD E)

Very helpful	**Quite helpful**	**Neither helpful**	**Not very helpful**	**Not at all helpful**	**Makes things worse**	**NA**
1	2	3	4	5	6	99

e). Do you feel this is enough help?   **1**   **2**   **88**   **99**

                                                Yes   **No**   **DK**   **NA**

IF NO AT (b):

f). Do you feel she needs help with that?   **1**   **2**   **88**   **99**

 Yes   **No**   **DK**   **NA**

30 a). Is she able to do the shopping for herself?

 1   **2**   **88**

 Yes   **No**   **DK**   IF YES: GO TO Q31

IF NO:

 b). Does she get any help with that?

 1   **2**   **88**   **99**

 Yes   **No**   **DK**   **NA**   IF NO: GO

TO Q30f

IF YES AT (b):

 c). Who from? (identify prof if possible)

……………………………………………………………………. **NA 99**

IF NOT FAMILY MEMBERS:

 d). How helpful would you say that was? (CARD E)

Very helpful	**Quite helpful**	**Neither helpful**	**Not very helpful**	**Not at all helpful**	**Makes things worse**	**NA**
1	2	3	4	5	6	99

 e). Do you feel this is enough help?   **1**   **2**   **88**   **99**

 Yes   **No**   **DK**   **NA**

IF NO AT (b):

 f). Do you feel she needs help with that?   **1**   **2**   **88**   **99**

 Yes   **No**   **DK**   **NA**

31 a). Is she able to get around outside the house?

1	**2**	**88**	
Yes	**No**	**DK**	IF YES: GO TO Q32

IF NO:

b). Does she get any help with that?

1	**2**	**88**	**99**	
Yes	**No**	**DK**	**NA**	IF NO: GO

TO Q31f

IF YES AT (b):

c). Who from? (identify prof if possible)

………………………………………………………….…… **NA 99**

IF NOT FAMILY MEMBERS:

d). How helpful would you say that was? (CARD E)

Very helpful	**Quite helpful**	**Neither helpful**	**Not very helpful**	**Not at all helpful**	**Makes things worse**	**NA**
1	2	3	4	5	6	99

e). Do you feel this is enough help?	**1**	**2**	**88**	**99**
	Yes	No	DK	NA

IF NO AT (b):

f). Do you feel she needs help with that?	**1**	**2**	**88**	**99**
	Yes	No	DK	NA

32 a). Is she able to do the housework?

1	**2**	**88**	
Yes	**No**	**DK**	IF YES: GO TO Q33

IF NO:

b). Does she get any help with that?

1	**2**	**88**	**99**

	Yes	No	DK	NA	IF NO: GO

TO Q32f

IF YES AT (b):

c). Who from? (identify prof if possible)

………………………………………………………………… **NA 99**

IF NOT FAMILY MEMBERS:

d). How helpful would you say that was? (CARD E)

Very helpful	Quite helpful	Neither helpful	Not very helpful	Not at all helpful	Makes things worse	NA
1	2	3	4	5	6	99

e). Do you feel this is enough help?	**1**	**2**	**88**	**99**
	Yes	No	DK	NA

IF NO AT (b):

f). Do you feel she needs help with that?	**1**	**2**	**88**	**99**
	Yes	No	DK	NA

33. Is she able to manage her money and bills?

1	**2**	**88**	
Yes	No	DK	IF YES: GO TO Q34

IF NO:

b). Does she get any help with that?

1	**2**	**88**	**99**	
Yes	No	DK	NA	IF NO: GO

TO Q33f

IF YES AT (b):

c). Who from? (identify prof if possible)

…………………………………………………………………. **NA 99**

IF NOT FAMILY MEMBERS:

d). How helpful would you say that was? (CARD E)

Very helpful	Quite helpful	Neither helpful	Not very helpful	Not at all helpful	Makes things worse	NA
1	2	3	4	5	6	99

e). Do you feel this is enough help?	**1**	**2**	**88**	**99**
	Yes	No	DK	NA

IF NO AT (b):

f). Do you feel she needs help with that?	1	2	**88**	**99**
	Yes	No	DK	NA

34 a). Does she ever become aggressive verbally? (eg. threatening to harm you, swearing)

1	**2**	**88**	
Yes	No	DK	IF NO: GO TO Q35

IF YES:

b). Do you get any advice on how to manage that?

1	**2**	**88**	**99**	
Yes	No	DK	NA	IF NO: GO TO Q34f

IF YES AT (b):

c). Who from? (identify prof if possible)

…………………………………………………………………… **NA 99**

IF NOT FAMILY MEMBERS:

d). How helpful would you say that was? (CARD E)

Very helpful	Quite helpful	Neither helpful	Not very helpful	Not at all helpful	Makes things worse	NA
1	2	3	4	5	6	99

e). Do you feel that you get enough advice?	.1	**2**	**88**	**99**
	Yes	No	DK	NA

IF NO AT (b):

f). Do you feel you need more advice?   1   2   88   99

                                               Yes   No   DK   NA

35 a). Does she ever become aggressive physically? (eg. hitting out, spitting, kicking)

                    1   2   88

                    Yes   No   DK   IF NO: GO TO Q36

IF YES:

b). Do you get any advice on how to manage that?

                    1   2   88   99

                    Yes   No   DK   NA   IF NO: GO

TO Q35f

IF YES AT (b):

c). Who from? (identify prof if possible)

…………………………………………………………………. **NA 99**

IF NOT FAMILY MEMBERS:

d). How helpful would you say that was? (CARD E)

Very	**Quite**	**Neither**	**Not very**	**Not at all**	**Makes things**	**NA**
helpful	**helpful**	**helpful**	**helpful**	**helpful**	**worse**	
1	2	3	4	5	6	99

e). Do you feel that you get enough advice?   1   2   88   99

                                                Yes   No   DK   NA

IF NO AT (b):

f). Do you feel you need more advice?   1   2   88   99

                                               Yes   No   DK   NA

36 a). So, can I just check what help **from outside the family** your relative is getting at the moment?

(circle all services/ sources of help named by carer in list below)

		Yes	No
1	District nurse/Health visitor	1	2
2	Community Psychiatric Nurse	1	2
3	Memory clinic	1	2
4	Social Services worker	1	2
5	Befriending service	1	2

6	Support group	1	2	
7	Residential/nursing home respite care	1	2	
8	Sitting service	1	2	Hrs/week ☐☐☐ **NA 99**
9	Meals on Wheels	1	2	Hrs/week ☐☐☐ **NA 99**
10	Home care	1	2	Hrs/week ☐☐☐ **NA 99**
11	Day Care	1	2	Hrs/week ☐☐☐ **NA 99**
12	Lunch club	1	2	Hrs/week ☐☐☐ **NA 99**
13	Privately funded carer	1	2	Hrs/week ☐☐☐ **NA 99**

37. Is there anyone else who helps your relative that I haven't already mentioned?

| **1** | **2** | **88** | |
| **YES** | **NO** | **DK** | IF NO: GO TO Q38 |

IFYES:

Who?

………

 ………………………………………………………………………………………………….**NA 99**

Now I'd like to ask about different issues or questions that might have come up in relation to your relative's care. Can you tell me for each one if its something that's come up for you – by that I mean you might have worried about it or got advice or help about it from someone.

38 a). Have you had any advice about what to tell your relative (about their diagnosis)?

| **1** | **2** | **88** | |
| **Yes** | **No** | **DK** | IF NO: GO TO Q38f |

IF YES:

 b). Who from? (identify prof if possible)

………………………………………………………………… **NA 99**

 c). What advice?

………………………………………………………………….…………… **NA 99**

IF NOT FAMILY MEMBERS:

 d). How helpful would you say that was? (CARD E)

| **Very helpful** | **Quite helpful** | **Neither helpful** | **Not very helpful** | **Not at all helpful** | **Makes things worse** | **NA** |

1	2	3	4	5	6	99

e). Do you feel that you got enough advice?

1	**2**	**88**	**99**
Yes	**No**	**DK**	**NA**

IF NO AT (a):

f). Do you feel you needed advice about that?

1	**2**	**88**	**99**
Yes	**No**	**DK**	**NA**

39 a). Have you had any advice about how to keep your relative as independent as possible?

1	**2**	**88**	
Yes	**No**	**DK**	IF NO: GO TO Q39f

IF YES:

b). Who from? (identify prof if possible) ………………………………………………………….………

NA 99

c). What advice?

…………………………………………………………………………………………. **NA 99**

IF NOT FROM FAMILY MEMBERS:

d). How helpful would you say that was?   (CARD E)

Very helpful	**Quite helpful**	**Neither helpful**	**Not very helpful**	**Not at all helpful**	**Makes things worse**	**NA**
1	2	3	4	5	6	99

e). Do you feel that you got enough advice?

1	**2**	**88**	**99**
Yes	**No**	**DK**	**NA**

IF NO AT (a):

f). Do you feel you needed advice about that?

1	**2**	**88**	**99**
Yes	**No**	**DK**	**NA**

40 a). Have you had any advice about equipment and adaptations for the home?

1	**2**	**88**	
Yes	**No**	**DK**	IF NO: GO TO Q40f

IF YES:

b). Who from? (identify prof if possible)

……………………………………………………………… **NA 99**

c). What advice?

…………………………………………………………………………….. **NA 99**

IF NOT FROM FAMILY MEMBERS:

d). How helpful would you say that was?   (CARD E)

Very helpful	**Quite helpful**	**Neither helpful**	**Not very helpful**	**Not at all helpful**	**Makes things worse**	**NA**
1	2	3	4	5	6	99

e). Do you feel that you got enough advice?	1	2	88	99
	Yes	No	DK	NA

IF NO AT (a):

f). Do you feel you needed advice about that?	1	2	88	99
	Yes	No	DK	NA

41 a). Have you had any advice about your relative driving?

1	2	88	99	
Yes	No	DK	NA	IF NO: GO

TO Q41f

IF YES:

b). Who from? (identify prof if possible)

………………………………………………………… **NA 99**

c). What advice?

…………………………………………………………………………. **NA 99**

IF NOT FROM FAMILY MEMBERS:

d). How helpful would you say that was?   (CARD E)

Very helpful	**Quite helpful**	**Neither helpful**	**Not very helpful**	**Not at all helpful**	**Makes things worse**	**NA**
1	2	3	4	5	6	99

e). Do you feel that you got enough advice?	1	2	88	99

	Yes	No	DK	NA

IF NO AT (a):

f). Do you feel you needed advice about that?   1   2   88   99

	Yes	No	DK	NA

42 a). Have you had any advice about pensions and 'social security benefits' and grants?

	1	2	88	
	Yes	No	DK	IF NO: GO TO Q42f

IF YES:

b). Who from? (identify prof if possible) …………………………………………………………..
NA 99

c). What advice?

………………………………………………………………………………………… **NA 99**

IF NOT FROM FAMILY MEMBERS:

d). How helpful would you say that was?   (CARD E)

Very helpful	Quite helpful	Neither helpful	Not very helpful	Not at all helpful	Makes things worse	NA
1	2	3	4	5	6	99

e). Do you feel that you got enough advice?   1   2   88   99

	Yes	No	DK	NA

IF NO AT (a):

f). Do you feel you needed advice about that?   1   2   88   99

	Yes	No	DK	NA

43 a). Have you had any advice about costs of services?

	1	2	88	
	Yes	No	DK	IF NO: GO TO Q43f

IF YES:

b). Who from? (identify prof if possible) …………………………………………………………..
NA 99

c). What advice?

………………………………………………………………………………………… **NA 99**

IF NOT FROM FAMILY MEMBERS:

d). How helpful would you say that was?   (CARD E)

Very helpful	Quite helpful	Neither helpful	Not very helpful	Not at all helpful	Makes things worse	NA
1	2	3	4	5	6	99

e). Do you feel that you got enough advice?	1	2	88	99
	Yes	No	DK	NA

IF NO AT (a):

f). Do you feel you needed advice about that?	1	2	88	99
	Yes	No	DK	NA

44 a). Have you had any advice about legal aspects like Enduring Power of Attorney (prompt regarding making decisions about future care and wishes and note specifics)?

1	2	88	
Yes	No	DK	IF NO: GO TO Q44f

IF YES:

b). Who from? (identify prof if possible) …………………………………………………………..
NA 99

c). What advice?
…………………………………………………………………………………………… **NA 99**

IF NOT FROM FAMILY MEMBERS

d). How helpful would you say that was?   (CARD E)

Very helpful	Quite helpful	Neither helpful	Not very helpful	Not at all helpful	Makes things worse	NA
1	2	3	4	5	6	99

e). Do you feel that you got enough advice?	1	2	88	99
	Yes	No	DK	NA

IF NO AT (a):

f). Do you feel you needed advice about that?	1	2	88	99
	Yes	No	DK	NA

45 a). Have you had any advice about day care?

	1	2	88	
	Yes	**No**	**DK**	IF NO: GO TO Q45f

IF YES:

b). Who from? (identify prof if possible) …………………………………………………………….
NA 99

c). What advice? ……………………………………………………………………………………...
NA 99

IF NOT FROM FAMILY MEMBERS:

d). How helpful would you say that was?   (CARD E)

Very helpful	**Quite helpful**	**Neither helpful**	**Not very helpful**	**Not at all helpful**	**Makes things worse**	**NA**
1	2	3	4	5	6	99

e). Do you feel that you got enough advice?	**1**	**2**	**88**	**99**
	Yes	**No**	**DK**	**NA**

IF NO AT (a):

f). Do you feel you needed advice about that?	**1**	**2**	**88**	**99**
	Yes	**No**	**DK**	**NA**

46 a). Have you had any advice about how to get a break?

	1	2	88	
	Yes	**No**	**DK**	IF NO: GO TO Q46f

IF YES

b). Who from? (identify prof if possible) …………………………………………………………..
NA 99

c). What advice? …………………………………………………………………………………....
NA 99

IF NOT FROM FAMILY MEMBERS:

d). How helpful would you say that was?   (CARD E)

Very helpful	**Quite helpful**	**Neither helpful**	**Not very helpful**	**Not at all helpful**	**Makes things worse**	**NA**

1	2	3	4	5	6	99

e). Do you feel that you got enough advice?	**1**	**2**	**88**	**99**
	Yes	**No**	**DK**	**NA**

IF NO AT (a):

f). Do you feel you needed advice about that?	**1**	**2**	**88**	**99**
	Yes	**No**	**DK**	**NA**

Now I'd like to ask you a few questions about your own needs as a carer.

47 a). Has anyone asked you how you were doing in the care of your relative?

Yes 1   No 2   DK 88   IF NO: GO TO 47d

IF YES:

b). Who? …………………….……………………………………………………………………..
NA 99

c). How helpful would you say that was? (CARD E)

Very helpful	Quite helpful	Neither helpful	Not very helpful	Not at all helpful	Makes things worse	NA
1	2	3	4	5	6	99

IF NO:

d). Would you have liked to be asked how you were doing?	**1**	**2**	**88**	**99**
	Yes	**No**	**DK**	**NA**

48 a). Has anyone given you a chance to talk about your fears or anxieties about your relative?

Yes 1   No 2   DK 88   IF NO: GO TO 48d

IF YES:

b). Who? …………………….…………………………………………………………………….
NA 99

c). How helpful would you say that was? (CARD E)

Very helpful	Quite helpful	Neither helpful	Not very helpful	Not at all helpful	Makes things worse	NA

1	2	3	4	5	6	99

IF NO:

d). Have you wanted a chance to do that?

	1	**2**	**88**	**99**
	Yes	**No**	**DK**	**NA**

49 a). Has anyone given you a chance to talk about what to expect in the future care of your relative?

Yes **1**   **No** **2**   **DK** **88**   IF NO: GO TO 49d

IF YES:

b). Who? …………………………..…………………………………………………………………..
NA 99

c). How helpful would you say that was? (CARD E)

Very helpful	**Quite helpful**	**Neither helpful**	**Not very helpful**	**Not at all helpful**	**Makes things worse**	**NA**
1	2	3	4	5	6	99

IF NO:

d). Do you feel you needed to talk about that?

	1	**2**	**88**	**99**
	Yes	**No**	**DK**	**NA**

50 a). Has anyone given you any reference materials containing information or advice about dementia, such as books, leaflets, information sheets, videos?

Yes **1**   **No** **2**   **DK** **88**   IF NO: GO TO 50e

IF YES:

b). What were you given?

…………………………………………………………………………………… **NA 99**

c). Who gave that to you?

…………………………………………………………………………………… **NA 99**

d). How helpful would you say that was? (CARD E)

Very helpful	**Quite helpful**	**Neither helpful**	**Not very helpful**	**Not at all helpful**	**Makes things worse**	**NA**

1	2	3	4	5	6	99

IF NO:

e). Do you feel you needed things like that	1	2	88	99
	Yes	**No**	**DK**	**NA**

Finally, one or two more background questions

51. How is your health in general?

  Would you say it was**:** (CARD A)

Very poor	**1**	**Poor**	**2**	**Fair**	**3**
Good	**4**	**Very good**	**5**	**Excellent**	**6**
Can't say	**77**	**NA**	**99**		

52. Have you had any **long-standing illness, disability or infirmity**? By long-standing I mean anything that has troubled you over a period of time or that is likely to affect you over a period of time.

Yes (specify)   1   No   2   Can't say   77

……………………………………………………………………………………………………

……………………………………………………………………………………………………

 ………………………………………………………………………………… **NA 99**

53. Is your accommodation:

1)	**Owner-occupied?**
2)	**Rented from local authority/housing association?**
3)	**Rented from a private landlord?**
4)	**Or is it under other arrangements?**
	If so, please describe:

…………………………………..

          ……………………………………………………………

54 a). Is there a car or van <u>normally</u> available for use by you?   **Yes   1   No   2**

 b). If yes, how many are normally available?   **One   1   Two or more   2   NA   99**

55. I'd like to end by asking you a question about the future.

a). What do you feel your relative needs to give her the best possible life in, say, 12 months time?

…………………………………………………………………………………………………..

…………………………………………………………………………………………………..

…………………………………………………………………………………………………..

…………………………………………………………………………………………………..

b). And what about for yourself: what do you think would help you over the next 12 months ?

…………………………………………………………………………………………………..

…………………………………………………………………………………………………..

…………………………………………………………………………………………………..

…………………………………………………………………………………………………..

56. What advice would you give to someone else who has started caring for their relative?

…………………………………………………………………………………………………..

…………………………………………………………………………………………………..

…………………………………………………………………………………………………..

…………………………………………………………………………………………………..

…………………………………………………………………………………………………..

I've finished, thank you very much for all your help. I would like to come back in a year's time and talk to you again, to see how things have changed. Do you think that would be OK? I'll contact you again nearer the time. (Check morale)

Again, thank you very much for your help.

Interview end time   ☐☐☐