

8. SERVICES FOR CARERS

The next questions ask about any contact you may have with services that are meant to support you in your role as a carer for a person with dementia.

8.1. Admiral Nurses provide specialist support to carers of people with dementia (*the information sheet enclosed describes the Admiral Nurse service*).

Have you ever used an Admiral Nurse service?

- Yes —————>Go to next Question 8.2 (below).
- No —————>Go to Question 8.8 (on page 20).
- Don't know —————>Go to Question 8.8 (on page 20).

8.2. How long ago did you first use the Admiral Nursing service?

- Less than a month ago
- Between 1 and 2 months ago
- Between 3 and 6 months ago
- Between 7 and 12 months ago
- Between 1 and 2 years ago
- Between 2 and 5 years ago
- More than 5 years ago
- Don't know

8.3. When were you last in contact with the Admiral Nursing service?

- Up to 6 months ago
- Between 7 and 12 months ago
- Between 1 and 2 years ago
- Between 2 and 5 years ago
- More than 5 years ago
- Don't know

8.4. What kind of contacts have you had with the Admiral Nurse service?

Please tick ALL that apply.

- Face-to-face visits
- Telephone contact
- Email contact
- Support group meetings
- Other (*please provide details*) _____

8.5. Have you used the Admiral Nursing service in the last four weeks?

- Yes —————▶ **Go to next Question 8.6 (below).**
- No —————▶ **Go to Question 8.8 (on page 20).**

8.6. Thinking about the last four weeks only, how many times have you been in contact with the Admiral Nurse service? We are interested here in each type of contact you have had. *Please write in the number below.*

	Number of times I have had this sort of contact in the last four weeks
Face-to-face visits	
Telephone contact	
Email contact	
Support group meetings	
Other (<i>please provide details below</i>):	

8.7. What type of support do you feel you get or got from the Admiral Nurse service? Please tick ALL that apply.

- Emotional and social support (including discussion with you about YOUR problems and concerns)
- Information, advice and knowledge
- Practical help (including referral to, and liaison with, other services)
- Educating and supporting other professionals that you are in contact with
- Assessing your needs
- Recommendations about medication for the person you care for
- Clinical examination of the person you care for
- Going to support groups and training for carers that the Admiral Nurse service organises
- Other (*please provide details*):

8.8. There are other sorts of services that are set-up specially to support carers. This next few questions are about some of these. We will be asking about other types of services later on. Please tick below to show the services for carers you have used OR have never used.
Please choose one answer for each type of service.

	I have used this sort of service	I have never used this sort of service
Short breaks/respice when the person you care for is looked after away from home	<input type="radio"/>	<input type="radio"/>
Someone to sit with the person you care for or take them out during the day while you do other things	<input type="radio"/>	<input type="radio"/>
A night-time sitting service at home to help you get a full night's sleep	<input type="radio"/>	<input type="radio"/>
A carers' advice service	<input type="radio"/>	<input type="radio"/>
A support group for carers	<input type="radio"/>	<input type="radio"/>

If you have used NONE of these services, please go to Question 9.1. (on page 25).

If you have used ANY of these services, please go to the next Question 8.9.

8.10. The next few questions are about your use of carers' services in the last four weeks only, and whether you paid anything for them.

How many times have you used these services in the last four weeks?

	Not at all	Number of times
Short breaks/respite when the person you care for is looked after away from home	<input type="radio"/>	
Someone to sit with the person you care for or take them out during the day while you do other things	<input type="radio"/>	
A night-time sitting service at home to help you get a full night's sleep	<input type="radio"/>	
A carers' advice service	<input type="radio"/>	
A support group for carers	<input type="radio"/>	

If you have used ANY of these services in the last four weeks, please go to Question 8.11 (on page 23).

If you have used NONE of these services in the last four weeks, please go to Question 9.1 (on page 25).

8.11. Do you or the person you care for pay anything for this service?

	I pay for this service	The person I care for pays for this service	We both pay something towards this service	Neither of us pays anything for this service	Not applicable – service not used in past four weeks
Short breaks/respite when the person you care for is looked after away from home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to sit with the person you care for or take them out during the day while you do other things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A night-time sitting service at home to help you get a full night's sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A carers' advice service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A support group for carers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you or the person you care for DO PAY for any service listed above, please go to the next Question 8.12 (on page 24).

If you or the person you care for DO NOT PAY for any service listed above, please go to Question 9.1. (on page 25).

8.12. This question asks how much you or the person you care for pays for the service each time you use it.

	Not applicable – service not used/not paid for in last four weeks	How much (to the nearest £) do you pay for this service each time you use it?
Short breaks/respite when the person you care for is looked after away from home	<input type="radio"/>	
Someone to sit with the person you care for or take them out during the day while you do other things	<input type="radio"/>	
A night-time sitting service at home to help you get a full night's sleep	<input type="radio"/>	
A carers' advice service	<input type="radio"/>	
A support group for carers	<input type="radio"/>	

9. HEALTH SERVICES THAT YOU USE

Now we are moving on to ask about health services that you may use. First we ask about health services that YOU have used for yourself in the last four weeks.

9.1. In the last four weeks how many times have you used ANY of the following hospital services for yourself? If you have not used the service please tick NONE.

	Number of times I have used this service in the last four weeks	
	None	Number of times
Outpatient appointment	<input type="radio"/>	
Planned hospital admission without staying overnight	<input type="radio"/>	
Planned hospital admission with an overnight stay	<input type="radio"/>	
Unplanned or emergency hospital admission	<input type="radio"/>	
Any other hospital appointment	<input type="radio"/>	

9.2. In the last four weeks, how many times have you used ANY of these other health services? If you have not used the service please tick NONE.

	Number of times I have used this service in the last four weeks	
	None	Number of times
A GP, either at the health centre or at home	<input type="radio"/>	
A practice or district nurse	<input type="radio"/>	
A nurse specialist (other than an Admiral Nurse)	<input type="radio"/>	
A therapist (including occupation therapist, physiotherapist, speech therapist)	<input type="radio"/>	

10. HEALTH SERVICES THAT THE PERSON YOU CARE FOR USES

Now we would like to ask you about any health services the person you care for has used in the last four weeks.

10.1. In the last four weeks, how many times has the person you care for used ANY of the following hospital services? If the person you care for has NOT USED the service, please tick NONE.

	Number of times the person you care for used this service in the last four weeks		
	None	Number of times	Don't know
Outpatient appointment	<input type="radio"/>		<input type="radio"/>
Planned hospital admission without staying overnight	<input type="radio"/>		<input type="radio"/>
Planned hospital admission with an overnight stay	<input type="radio"/>		<input type="radio"/>
Unplanned or emergency hospital admission	<input type="radio"/>		<input type="radio"/>
Any other hospital appointment	<input type="radio"/>		<input type="radio"/>

10.2. In the last four weeks, how many times has the person you care for used ANY of these other health care services? If the person you care for has NOT USED the service, please tick NONE.

	Number of times the person you care for used this service in the last four weeks		
	None	Number of times	Don't know
A GP, either at the health centre or at home	<input type="radio"/>		<input type="radio"/>
A practice or district nurse	<input type="radio"/>		<input type="radio"/>
A nurse specialist (other than an Admiral Nurse)	<input type="radio"/>		<input type="radio"/>
A therapist (including occupational therapist, physiotherapist, speech therapist)	<input type="radio"/>		<input type="radio"/>

The next questions are about any other services that the person you care for may have used in the last four weeks. If the person you care for has NOT USED the service, please tick NONE.

10.3. In the last four weeks, how many times has the person you care for used ANY of the services below?

	Number of times the person you care for used this service in the last four weeks		
	None	Number of times	Don't know
Day care centre	<input type="radio"/>		<input type="radio"/>
Other type of day care service	<input type="radio"/>		<input type="radio"/>
Home care	<input type="radio"/>		<input type="radio"/>
Meals (for example, via meals on wheels, luncheon club, etc.)	<input type="radio"/>		<input type="radio"/>
Appointment with someone from social services	<input type="radio"/>		<input type="radio"/>
Memory café	<input type="radio"/>		<input type="radio"/>

If the person you care for has used ANY of these services in the last four weeks, please go to the next Question 10.4 (on page 28).

If the person you care for has used NONE of these services in the last four weeks, please go to Question 10.6 (on page 29).

10.4. Do you or the person you care for pay anything for this service?

	I pay for the service	The person I care for pays for the service	We both pay something towards the service	Neither of us pays anything for the service	Not applicable – service not used in past four weeks
Day care centre	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Home care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Meals (for example, via meals on wheels, luncheon club, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appointment with someone from social services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Memory café	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other type of day care service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you or the person you care for pay for ANY service listed above please go to the next Question 10.5.

If you or the person you care for DO NOT PAY for any services listed above, please go to Question 10.6. (on page 29).

10.5. This question asks how much you or the person you care for pays for the service each time you or he/she uses it.

	Not applicable – service not used/paid for in past four weeks	How much (to the nearest £) is paid for this service each time it is used?
Day care centre	<input type="radio"/>	
Home care	<input type="radio"/>	
Meals (for example, via meals on wheels, luncheon club, etc.)	<input type="radio"/>	
Appointment with someone from social services	<input type="radio"/>	
Memory café	<input type="radio"/>	
Other type of day care service	<input type="radio"/>	

10.6. Are there any other health or care services that you or the person you care for have used in the last four weeks?

Yes

No

10.7. Please write in below the other services you have used in the last four weeks.

1. _____

2. _____

3. _____

11. HOUSEHOLD INCOME

We are interested in whether carers' finances influence what services they use and how much they may pay for them. So the next few questions are about your household finances and how you feel you are getting on financially.

This information, like all the personal details you have supplied, is **CONFIDENTIAL** and will not be shared with anyone outside the research team. But if you do not want to answer these questions just tick 'Rather not say'.

11.1. We would like you to think about **ALL** the money that comes into your household - including wages, pensions, savings, benefits from all household members and before any deductions, such as tax or national insurance.

We just need a rough estimate - please don't worry if you are not sure of the exact amount.

You can give your answer as a weekly, or a monthly or an annual estimate by following the instructions here:

- Income each week \longrightarrow Go to next Question 11.2 (below).
- Income each month \longrightarrow Go to Question 11.3 (on page 31).
- Income each year \longrightarrow Go to Question 11.4 (on page 32).
- Rather not say \longrightarrow Go to Question 11.5 (on page 33).

INCOME EACH WEEK

11.2. Thinking about **ALL** the money that comes into your household - including wages, pensions, savings, benefits from all household members and before any deductions, such as tax or national insurance - which amount is closest to your **TOTAL** household income per week?

Please tick ONE only.

- up to £290 a week
- £291 - £385
- £386 - £480
- £481 - £580
- £581 - £675
- £676 - £770
- £771 or more a week

Please go to Question 11.5 (on page 33).

INCOME EACH MONTH

11.3. Thinking about ALL the money that comes into your household - including wages, pensions, savings, benefits from all household members and before any deductions, such as tax or national insurance - which amount is closest to your TOTAL household income per month?

Please tick ONE only.

- up to £1250 a month
- £1251-£1670
- £1671-£2085
- £2086-£2500
- £2501-£2920
- £2921-£3335
- £3336 or more a month

Please go to Question 11.5 (on page 33).

INCOME EACH YEAR

11.4. Thinking about ALL the money that comes into your household - including wages, pensions, savings, benefits from all household members and before any deductions, such as tax or national insurance - which amount is closest to your TOTAL household income per year?

Please tick ONE only.

- up to £15,000 a year
- £15,000 to £19,999
- £20,000 to £24,999
- £25,000 to £29,999
- £30,000 to £34,999
- £35,000 to £39,999
- £40,000 or more a year

11.5. Which of the statements below best sums up how your household is getting on financially nowadays?

- I/We manage very well
- I/We manage quite well
- I/We get by OK
- I/We have some financial difficulties
- I/We have severe financial difficulties
- Don't know
- Rather not say

12. FINAL SECTION

12.1. We need to be sure that we have covered the right areas in our survey and we can do this if we know what the first half of your postcode is.

Please write in the first half of your postcode in the box below – for example, if your postcode is YO10 5DD, you would only need to write YO10.

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ANY FURTHER COMMENTS

12.2. If you would like to provide more information or comment on any aspect of this questionnaire, please write your comments in the box below:

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We would like to acknowledge the time you have taken in helping us with this research, with a small gift of £10. We are also keen to share the results of our research with people who have taken part. These will be available in the late summer next year 2017. If you would like us to send the gift and/or the summary of our findings please tick below and provide your email address or postal address. We will not use your address for any other purposes and will remove it from our records once we have sent you the gift and/or the summary.

I would like to be sent a £10 gift —————→ **Go to next Question 12.3 (below).**

I would like to be sent a summary of the findings in summer 2017 —————→
Go to next Question 12.3 (below).

I do not want a gift or a summary.

12.3. Please write your email address or postal address in capital letters below.

Email address _____

Postal address _____

If completing this survey has raised any issues that you would like to talk over with someone, we have given details of sources of support on the enclosed information sheet.

Thank you for completing this survey. The information will be very useful in helping us to understand what support is available to people who support someone with dementia. You cannot be identified from the information you have provided. The questionnaire will be treated confidentially and kept secure. If you have any questions, please email [REDACTED] or [REDACTED] or telephone [REDACTED] and ask to speak to Kate or Fiona.

Please check you are happy with your answers, then return the questionnaire in the pre-paid envelope enclosed. You do not need a stamp.

Thank you for completing this questionnaire

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EQ-5D: Copyright © EuroQol Research Foundation. EQ-5D™ is a trade mark of the EuroQol Research Foundation. Self-efficacy for Managing Dementia scale: Copyright © 2002 Fortinsky *et al.* Survey of carers in households 2009/10: Copyright © 2010, The Health and Social Care Information Centre. All Rights Reserved (Question: 'What kinds of things do you usually do for him/her over and above what you would normally do for someone?').