

This part of the questionnaire is about you and the person you care for. It helps us to understand people's answers if we know a bit about them, and it also tells us if there are any groups of people who have not had their voices heard.

You do not have to answer the questions about your personal details if you would prefer not to – you can just tick 'prefer not to say' and move on to the next question.

## 1. ABOUT THE PERSON YOU CARE FOR

### 1.1. Who is it that you look after or help?

- Spouse/partner
- Parent
- Parent-in-law
- Grandparent
- Other relative
- Friend or neighbour
- Other (*please provide details*) \_\_\_\_\_
- Prefer not to say

### 1.2. What is his/her sex?

- Male
- Female
- Prefer not to say

### 1.3. Which of the following age bands does s/he fit into?

- Under 45 years of age
- 45-54
- 55-64
- 65-74
- 75-84
- 85-94
- 95 and over
- Prefer not to say

**1.4. Which of these groups does the person you care for belong to?**

*Choose one option that best describes his or her ethnic group or background.*

- White
- Mixed/Multiple ethnic groups
- Asian/Asian British
- Black/African/Caribbean/Black British
- Other ethnic group
- Prefer not to say

**1.5. How long have you been aware of his or her dementia symptoms?**

- Under 1 year
- 1-5 years
- 6-10 years
- 11 years or more

**1.6. Has the person you care for been formally diagnosed with dementia, for example after tests or a brain scan?**

- Yes
- No
- Don't know

**1.7. What type of dementia does the person you care for have?**

*Please tick ALL that apply.*

- Alzheimer's Disease
- Vascular dementia
- Dementia with Lewy Bodies
- Fronto-temporal dementia
- Other type (*please provide details*) \_\_\_\_\_
- Don't know

**1.8. How severe would YOU say his/her dementia is?**

- Mild
- Moderate
- Severe

## 2. THE NEXT FEW QUESTIONS ARE ABOUT YOU

### 2.1. What is your sex?

- Male
- Female
- Prefer not to say

### 2.2. Which of the following age bands do you fit into?

- Under 16 years of age
- 16-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-69
- 70-74
- 75 or over
- Prefer not to say

### 2.3. Which of these groups do you consider you belong to?

- White
- Mixed/Multiple ethnic groups
- Asian/Asian British
- Black/African/Caribbean/Black British
- Other ethnic group
- Prefer not to say

**2.4. What level of qualification do you have? Please tick the highest that applies.**

- Secondary school and equivalent qualifications (*for example, School Certificate, O-Level, CSE, GCSE, NVQ Levels 1 to 3, OND/ONC, Traditional or Modern Apprenticeship, City and Guilds, RSA*)
- Over 16 qualifications (*for example, AS-Level, A-Level, Scottish 6th Year Certificate, Higher School Certificate, Access qualification*)
- College level qualifications (*for example, NVQ Levels 4 & 5, Foundation degree, RSA higher, HMC/HND, BTEC higher, nursing qualification below degree level, other higher education below degree level*)
- Bachelor's level qualifications (*for example, University/CNAA Bachelor degree, teaching qualification*)
- Master's level qualification and above (*for example, Higher degree, Doctorate*)
- None of these
- Prefer not to say

**2.5. Which of these statements describe your work situation?**

*Please tick ALL that apply to you currently.*

- I am in full-time paid work
- I am in part-time paid work
- I look after the home full-time
- I am fully retired from paid work
- I have a long-term illness or disability that prevents me from having paid work
- I am currently unemployed
- I am in full-time education
- I am in part-time education
- Other (*please provide details*) \_\_\_\_\_
- Prefer not to say

### 3. ABOUT CARING FOR THE PERSON WITH DEMENTIA

#### 3.1. How long have you been caring for the person that you support?

*(that is, doing things for him/her over and above what you would normally do)*

- Less than 6 months
- Between 6 months and 1 year
- Between 1 and 3 years
- Between 3 and 5 years
- Between 5 and 10 years
- Between 10 and 15 years
- 15 years or more

#### 3.2. Apart from any people paid to provide care, such as nurses or care workers, is there anyone else who regularly also looks after the person you care for – for example, another member of your household, another member of your family, a relative or a friend?

- Yes —————→ Go to next Question 3.3 (below).
- No —————→ Go to Question 3.4 (below).
- Don't know —————→ Go to Question 3.4 (below).

#### 3.3. Do any of these people (including anyone in your household) spend more time than you do looking after the person you care for?

- Yes
- No
- Other person spends equal time
- Don't know

#### 3.4. If you needed a break for a couple of days, is there someone you could rely on to look after the person you care for?

- Yes —————→ Go to next Question 3.5 (on page 8).
- No —————→ Go to Question 3.6 (on page 8).

**3.5. Who are you able to rely on if you want a break for a couple of days?**

- Relative, friend or neighbour
- Service arranged with the NHS, local authority or charity/voluntary organisation
- Paid helper
- Other (*please provide details*) \_\_\_\_\_

**TYPE OF SUPPORT PROVIDED**

**3.6. What kind of things do you usually do for the person you care for?**

*Please tick ALL that apply.*

- Helping with personal care, such as dressing, bathing, washing, shaving, cutting nails, feeding, and using the toilet
- Physical help, such as walking, getting up and down stairs, and getting into and out of bed
- Helping with dealing with care services and benefits, such as making appointments and telephone calls, and filling in forms
- Helping with other paperwork or financial matters, such as writing letters, sending cards, filling in forms, dealing with bills and banking
- Other practical help, such as preparing the meals, doing his/her shopping, laundry, housework, gardening, decorating, household repairs, and taking to a doctor's or hospital appointment
- Keeping him/her company, such as visiting, sitting with, reading to, talking to, and playing cards or games
- Taking him/her out, such as taking out for a walk or drive, and taking to see friends or relatives
- Giving medicines, such as making sure he/she takes tablets, giving injections and changing dressings
- Keeping an eye on him/her to see if he/she is alright
- Any other help not included above? (*please provide details below*):

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**If you have ticked TWO OR MORE answers above, please go to the next Question 3.7.**

**If you have ticked ONE answer above, please go to Question 3.8 (on page 10).**



**3.8. Thinking about the last 24 hours, how much time in TOTAL did you spend caring?** Don't worry if this was not a usual sort of day for you; we are interested in what you actually did yesterday.

**Total number of hours spent caring yesterday**

**hours**

## THE IMPACT OF CARING

We are interested in the impact that getting or not getting support has on carers' quality of life and health. The next section has questions that are used regularly in research to measure these sorts of effects.

### 4. THE NEXT SEVEN QUESTIONS ASK YOU ABOUT YOUR QUALITY OF LIFE AS A CARER

**4.1. Which of the following statements best describes how you spend your time?** When you are thinking about how you spend your time, please include anything you value or enjoy, including leisure activities, formal employment, voluntary or unpaid work, and caring for others. *Please tick ONE only.*

- I'm able to spend my time as I want, doing things I value or enjoy
- I'm able to do enough of the things I value or enjoy with my time
- I do some of the things I value or enjoy with my time, but not enough
- I don't do anything I value or enjoy with my time

**4.2. Which of the following statements best describes how much control you have over your daily life?** *Please tick ONE only.*

- I have as much control over my daily life as I want
- I have adequate control over my daily life
- I have some control over my daily life, but not enough
- I have no control over my daily life



**4.3. Thinking about how well you look after yourself - such as, getting enough sleep or eating well - which statement best describes your present situation?**

*Please tick ONE only.*

- I look after myself as well as I want
- I look after myself well enough
- Sometimes I can't look after myself well enough
- I feel I am neglecting myself

**4.4. Which of the following statements best describes how safe you feel? By 'feeling safe' we mean feeling safe from fear of abuse, being attacked or other physical harm, such as accidents, which are a result of your caring role.**

*Please tick ONE only.*

- I feel as safe as I want
- Generally I feel adequately safe, but not as safe as I would like
- I feel less than adequately safe
- I don't feel at all safe

**4.5. Thinking about how much contact you have with people you like, which of the following statements best describes your social situation? *Please tick ONE only.***

- I have as much social contact as I want with people I like
- I have adequate social contact with people
- I have some social contact with people, but not enough
- I have little social contact with people and feel socially isolated

**4.6. Thinking about the space and time you have to be yourself in your daily life, which of the following statements best describes your present situation? *Please tick ONE only.***

- I have all the space and time I need to be myself
- I have adequate space and time to be myself
- I have some of the space and time I need to be myself, but not enough
- I don't have any space or time to be myself

**4.7. Thinking about feeling supported and encouraged in your caring role, which of the following statements best describes your present situation?** This question is asking about feeling supported and encouraged, rather than how you are supported and encouraged by particular people or organisations.

*Please tick ONE only.*

- I feel I have the encouragement and support I want
- I feel I have adequate encouragement and support
- I feel I have some encouragement and support, but not enough
- I feel I have no encouragement and support