

# Caring for Others

If you look after a family member, partner or friend in need of support or services because of their age, physical or learning disability or illness, including mental illness, we would like you to complete this questionnaire. You do not have to answer all of the questions; if you don't want to answer a question, or don't know the answer, then move on to the next question.

## Section 1: About the person you care for

The questions in this section ask about the person you care for, by which we mean the person you look after or help, and your experience of support and services.

If you care for more than one person, please answer **only** in relation to the person you spend the most time helping. If you spend an equal amount of time caring for two or more people, please answer in relation to the person who lives with you. If you live with two or more people that you spend an equal amount of time caring for, please choose **one** person to answer about.

1. How old is the person you care for? \_\_\_\_\_ years

(If you don't know the exact age, please give an approximate one – the person cared for should be aged 18 or over)

**2. Does the person you care for have....?**

***Please tick [✓] all that apply***

- |                          |                                     |       |
|--------------------------|-------------------------------------|-------|
| <input type="checkbox"/> | Dementia                            | a (1) |
| <input type="checkbox"/> | A physical disability               | b (1) |
| <input type="checkbox"/> | Sight or hearing loss               | c (1) |
| <input type="checkbox"/> | A mental health problem             | d (1) |
| <input type="checkbox"/> | Problems connected to ageing        | e (1) |
| <input type="checkbox"/> | A learning disability or difficulty | f (1) |
| <input type="checkbox"/> | Long-standing illness               | g (1) |
| <input type="checkbox"/> | Terminal illness                    | h (1) |
| <input type="checkbox"/> | Alcohol or drug dependency          | i (1) |

**3. Where does the person you care for usually live?**

***Please tick [✓] one box***

- |                          |                |   |
|--------------------------|----------------|---|
| <input type="checkbox"/> | With me        | 1 |
| <input type="checkbox"/> | Somewhere else | 2 |

**4. Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?**

*Please tick (✓) one box*

- |                          |  |   |
|--------------------------|--|---|
| <input type="checkbox"/> | We haven't received any support or services from Social Services in the last 12 months | 1 |
| <input type="checkbox"/> | I am extremely satisfied   | 2 |
| <input type="checkbox"/> | I am very satisfied  | 3 |
| <input type="checkbox"/> | I am quite satisfied   | 4 |
| <input type="checkbox"/> | I am neither satisfied nor dissatisfied  | 5 |
| <input type="checkbox"/> | I am quite dissatisfied  | 6 |
| <input type="checkbox"/> | I am very dissatisfied   | 7 |
| <input type="checkbox"/> | I am extremely dissatisfied  | 8 |

**5. Has the person you care for used any of the support or services listed below in the last 12 months?**

**They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.**

*Please tick (✓) one box per row*

	<b>Yes</b>		<b>No</b>		<b>Don't know</b>	
a. Support or services allowing you to take a break from caring at short notice or in an emergency	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3
b. Support or services allowing you to take a break from caring for more than 24 hours	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3
c. Support or services to allow you to have a rest from caring for between 1 and 24 hours (eg. a sitting service)	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3
d. Personal assistant	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3
e. Home care/home help	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3
f. Day centre or day activities	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3
g. Lunch club	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3
h. Meals Services	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3
i. Equipment or adaptation to their home (such as a wheelchair or handrails)	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3
j. Telecare Alarm	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3
k. They are permanently resident in a care home	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3

**Section 2: About your needs and experiences of support**

The questions in this section ask about the support and services that **you** use as a carer. They may be arranged by you or by Social Services. They may be provided by a voluntary organisation, a private agency or Social Services.

**6. Have you used any of the support or services listed below, to help you as a carer over the last 12 months?**

**They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services. Please do not include any unpaid help from family and friends.**

*Please tick (✓) one box per row*

	<b>Yes</b>	<b>No</b>	<b>Don't know</b>
a. Information and advice	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
b. Support from carers groups or someone to talk to in confidence	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
c. Training for carers	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
d. Support to keep you in employment	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

**Section 3: The impact of caring and your quality of life**

Some of the questions in this section look at the impact of caring on particular aspects of your life, while others ask about the quality of different parts of your life more generally.

**7. Which of the following statements best describes how you spend your time?**

**When you are thinking about what you do with your time, please include anything you value or enjoy, including formal employment, voluntary or unpaid work, caring for others and leisure activities.**

*Please tick [✓] one box*

- |                          |  |   |
|--------------------------|--|---|
| <input type="checkbox"/> | I'm able to spend my time as I want, doing things I value or enjoy   | 1 |
| <input type="checkbox"/> | I do some of the things I value or enjoy with my time but not enough | 2 |
| <input type="checkbox"/> | I don't do anything I value or enjoy with my time                    | 3 |

**8. Which of the following statements best describes how much control you have over your daily life?**

*Please tick [✓] one box*

- |                          |   |   |
|--------------------------|---|---|
| <input type="checkbox"/> | I have as much control over my daily life as I want   | 1 |
| <input type="checkbox"/> | I have some control over my daily life but not enough | 2 |
| <input type="checkbox"/> | I have no control over my daily life                  | 3 |

**9. Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation?**

*Please tick [✓] one box*

- |                          |   |   |
|--------------------------|---|---|
| <input type="checkbox"/> | I look after myself                             | 1 |
| <input type="checkbox"/> | Sometimes I can't look after myself well enough | 2 |
| <input type="checkbox"/> | I feel I am neglecting myself                   | 3 |

**10. Thinking about your personal safety, which of the statements best describes your present situation?**

By 'personal safety' we mean feeling safe from fear of abuse, being attacked or other physical harm.

*Please tick [✓] one box*

- |                          |   |   |
|--------------------------|---|---|
| <input type="checkbox"/> | I have no worries about my personal safety      | 1 |
| <input type="checkbox"/> | I have some worries about my personal safety    | 2 |
| <input type="checkbox"/> | I am extremely worried about my personal safety | 3 |

**11. Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?**

*Please tick [✓] one box*

- |                          |   |   |
|--------------------------|---|---|
| <input type="checkbox"/> | I have as much social contact as I want with people I like          | 1 |
| <input type="checkbox"/> | I have some social contact with people but not enough               | 2 |
| <input type="checkbox"/> | I have little social contact with people and feel socially isolated | 3 |

**12. Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?**

*Please tick [✓] one box*

- |                          |   |   |
|--------------------------|---|---|
| <input type="checkbox"/> | I feel I have encouragement and support                     | 1 |
| <input type="checkbox"/> | I feel I have some encouragement and support but not enough | 2 |
| <input type="checkbox"/> | I feel I have no encouragement and support                  | 3 |



**13. Thinking about the other people you have caring responsibilities for, which of the following best describes your current situation? Please exclude the person you spend most time helping.**

*Please tick [✓] one box*

- |                          |  |   |
|--------------------------|--|---|
| <input type="checkbox"/> | I don't have caring responsibilities for anyone else | 1 |
| <input type="checkbox"/> | I always have enough time to care for them           | 2 |
| <input type="checkbox"/> | I sometimes have enough time to care for them        | 3 |
| <input type="checkbox"/> | I never have enough time to care for them            | 4 |

**14. In the last 12 months, has your health been affected by your caring role in any of the ways listed below?**

*Please tick [✓] all that apply*

- |                          |                                    |       |
|--------------------------|------------------------------------|-------|
| <input type="checkbox"/> | Feeling tired                      | a (1) |
| <input type="checkbox"/> | Feeling depressed                  | b (1) |
| <input type="checkbox"/> | Loss of appetite                   | c (1) |
| <input type="checkbox"/> | Disturbed sleep                    | d (1) |
| <input type="checkbox"/> | General feeling of stress          | e (1) |
| <input type="checkbox"/> | Physical strain (e.g. back)        | f (1) |
| <input type="checkbox"/> | Short tempered/ irritable          | g (1) |
| <input type="checkbox"/> | Had to see own GP                  | h (1) |
| <input type="checkbox"/> | Developed my own health conditions | i (1) |
| <input type="checkbox"/> | Made an existing condition worse   | j (1) |
| <input type="checkbox"/> | Other                              | k (1) |
| <input type="checkbox"/> | No, none of these                  | l (1) |

**15. In the last 12 months, has caring caused you any financial difficulties?**

*Please tick [✓] one box*

- |                          |                     |   |
|--------------------------|---------------------|---|
| <input type="checkbox"/> | No, not at all      | 1 |
| <input type="checkbox"/> | Yes, to some extent | 2 |
| <input type="checkbox"/> | Yes, a lot          | 3 |

**Section 4: Information and advice quality**

The next questions ask for your views about the quality of information and advice.

- 16. In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits? Please include information and advice from different sources, such as voluntary organisations and private agencies as well as Social Services.**

*Please tick (✓) one box*

- |                          |  |   |
|--------------------------|--|---|
| <input type="checkbox"/> | I have not tried to find information or advice in the last 12 months | 1 |
| <input type="checkbox"/> | Very easy to find  | 2 |
| <input type="checkbox"/> | Fairly easy to find  | 3 |
| <input type="checkbox"/> | Fairly difficult to find   | 4 |
| <input type="checkbox"/> | Very difficult to find   | 5 |

If you found it difficult to find information and advice, please tell us why and what we can do to make it easier for you

**17. In the last 12 months, how helpful has the information and advice you have received been? Please include information and advice from different organisations, such as voluntary organisations and private agencies as well as Social Services.**

*Please tick (✓) one box*

- |                          |   |   |
|--------------------------|---|---|
| <input type="checkbox"/> | I have not received any information or advice in the last 12 months | 1 |
| <input type="checkbox"/> | Very helpful  | 2 |
| <input type="checkbox"/> | Quite helpful   | 3 |
| <input type="checkbox"/> | Quite unhelpful   | 4 |
| <input type="checkbox"/> | Very unhelpful  | 5 |

If you found the information and advice you received unhelpful, please tell us why and what we can do to make it more helpful for you

**Section 5: Arrangement of support and services in the last 12 months**

The next question is about organising the support and services for you and the person you care for.

**18. In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?**

*Please tick (✓) one box*

- |                          |  |   |
|--------------------------|--|---|
| <input type="checkbox"/> | There have been no discussions that I am aware of, in the last 12 months | 1 |
| <input type="checkbox"/> | I always felt involved or consulted                                      | 2 |
| <input type="checkbox"/> | I usually felt involved or consulted                                     | 3 |
| <input type="checkbox"/> | I sometimes felt involved or consulted                                   | 4 |
| <input type="checkbox"/> | I never felt involved or consulted                                       | 5 |

## Section 6: About yourself

The next group of questions helps us to get a better picture of the types of carers who took part in this survey.

### 19. In addition to your caring role, please tell us which of the following also applies to you?

*Please tick [✓] all that apply*

- |                          |   |       |
|--------------------------|---|-------|
| <input type="checkbox"/> | Retired                                       | a (1) |
| <input type="checkbox"/> | Employed full-time                            | b (1) |
| <input type="checkbox"/> | Employed part-time (working 30 hours or less) | c (1) |
| <input type="checkbox"/> | Self-employed full-time                       | d (1) |
| <input type="checkbox"/> | Self-employed part-time                       | e (1) |
| <input type="checkbox"/> | Not in paid work                              | f (1) |
| <input type="checkbox"/> | Doing voluntary work                          | g (1) |
| <input type="checkbox"/> | Other   | h (1) |

**20. Thinking about combining your paid work and caring responsibilities, which of the following statements best describes your current situation?**

*Please tick [✓] one box*

**Not in paid work**

- |                          |   |   |
|--------------------------|---|---|
| <input type="checkbox"/> | I am not in paid employment because of my caring responsibilities | 1 |
| <input type="checkbox"/> | I am not in paid employment for other reasons (e.g. Retired)      | 2 |

**In paid employment**

- |                          |   |   |
|--------------------------|---|---|
| <input type="checkbox"/> | I am in paid employment and I feel supported by my employer                               | 3 |
| <input type="checkbox"/> | I am in paid employment but I don't feel supported by my employer                         | 4 |
| <input type="checkbox"/> | I do not need any support from my employer to combine my work and caring responsibilities | 5 |

**Self-employed**

- |                          |   |   |
|--------------------------|---|---|
| <input type="checkbox"/> | I am self-employed and I am able to balance my work and caring Responsibilities   | 6 |
| <input type="checkbox"/> | I am self-employed but I am unable to balance my work and caring Responsibilities | 7 |

**21. About how long have you been looking after or helping the person you care for?**

***Please tick [✓] one box***

- |                          |                                      |   |
|--------------------------|--------------------------------------|---|
| <input type="checkbox"/> | Less than 6 months                   | 1 |
| <input type="checkbox"/> | Over 6 months but less than a year   | 2 |
| <input type="checkbox"/> | Over 1 year but less than 3 years    | 3 |
| <input type="checkbox"/> | Over 3 years but less than 5 years   | 4 |
| <input type="checkbox"/> | Over 5 years but less than 10 years  | 5 |
| <input type="checkbox"/> | Over 10 years but less than 15 years | 6 |
| <input type="checkbox"/> | Over 15 years but less than 20 years | 7 |
| <input type="checkbox"/> | 20 years or more                     | 8 |



**22. About how long do you spend each week looking after or helping the person you care for?**

***Please tick [✓] one box***

- |                          |                                    |    |
|--------------------------|------------------------------------|----|
| <input type="checkbox"/> | 0-9 hours per week                 | 1  |
| <input type="checkbox"/> | 10-19 hours per week               | 2  |
| <input type="checkbox"/> | 20-34 hours per week               | 3  |
| <input type="checkbox"/> | 35-49 hours per week               | 4  |
| <input type="checkbox"/> | 50-74 hours per week               | 5  |
| <input type="checkbox"/> | 75-99 hours per week               | 6  |
| <input type="checkbox"/> | 100 or more hours per week         | 7  |
| <input type="checkbox"/> | Varies – Under 20 hours per week   | 8  |
| <input type="checkbox"/> | Varies – 20 hours or more per week | 9  |
| <input type="checkbox"/> | Other                              | 10 |

If other please specify:

**23. Over the last 12 months, what kinds of things did you usually do for the person you care for?**

***Please tick [✓] all that apply***

- |                          |  |       |
|--------------------------|--|-------|
| <input type="checkbox"/> | Personal care?<br>(Things like dressing, bathing, washing, shaving, cutting nails, feeding, using the toilet)  | a (1) |
| <input type="checkbox"/> | Physical help?<br>(Such as helping with walking, getting up and down stairs, getting into and out of bed)  | b (1) |
| <input type="checkbox"/> | Helping with dealing with care services and benefits?<br>(Things like making appointments and phone calls, filling in forms)   | c (1) |
| <input type="checkbox"/> | Helping with paperwork or financial matters?<br>(Such as writing letters, sending cards, filling in forms, dealing with bills, banking)                                      | d (1) |
| <input type="checkbox"/> | Other practical help?<br>(Things like preparing meals, doing his/her shopping, laundry, housework, gardening, decorating, household repairs, taking to doctor's or hospital) | e (1) |
| <input type="checkbox"/> | Keeping him/her company?<br>(Things like visiting, sitting with, reading to, talking to, playing cards or games)   | f (1) |
| <input type="checkbox"/> | Taking him/her out?<br>(Such as taking out for a walk or drive, taking to see friends or relatives)  | g (1) |
| <input type="checkbox"/> | Giving medicines?<br>(Things like making sure he/she takes pills, giving injections, changing dressings)   | h (1) |
| <input type="checkbox"/> | Keeping an eye on him/her to see he/she is all right?  | i (1) |
| <input type="checkbox"/> | Giving emotional support?  | j (1) |
| <input type="checkbox"/> | Other help?  | k (1) |

**24. Do you have any of the following?**

***Please tick [✓] all that apply***

- |                          |                                     |       |
|--------------------------|-------------------------------------|-------|
| <input type="checkbox"/> | A physical impairment or disability | a (1) |
| <input type="checkbox"/> | Sight or hearing loss               | b (1) |
| <input type="checkbox"/> | A mental health problem or illness  | c (1) |
| <input type="checkbox"/> | A learning disability or difficulty | d (1) |
| <input type="checkbox"/> | A long-standing illness             | e (1) |
| <input type="checkbox"/> | Other                               | f (1) |
| <input type="checkbox"/> | None of the above                   | g (1) |

**25. How old are you? \_\_\_\_\_ years**

**26. Are you male or female?**

***Please tick [✓] one box***

- |                          |        |   |
|--------------------------|--------|---|
| <input type="checkbox"/> | Male   | 1 |
| <input type="checkbox"/> | Female | 2 |

**27. How many children aged 18 or under do you have parental responsibility for?**

- |                          |    |   |
|--------------------------|----|---|
| <input type="checkbox"/> | 0  | 1 |
| <input type="checkbox"/> | 1  | 2 |
| <input type="checkbox"/> | 2  | 3 |
| <input type="checkbox"/> | 3  | 4 |
| <input type="checkbox"/> | 4+ | 5 |

**28. To which of these groups do you consider you belong?**

*Please tick (✓) one box*

**White**

- |                          |   |   |
|--------------------------|---|---|
| <input type="checkbox"/> | English / Welsh / Scottish / Northern Irish / British | 1 |
| <input type="checkbox"/> | Irish   | 2 |
| <input type="checkbox"/> | Gypsy or Irish Traveller                              | 3 |
| <input type="checkbox"/> | Any other White background                            | 4 |

**Mixed / multiple ethnic groups**

- |                          |                                       |   |
|--------------------------|---------------------------------------|---|
| <input type="checkbox"/> | White and Black Caribbean             | 5 |
| <input type="checkbox"/> | White and Black African               | 6 |
| <input type="checkbox"/> | White and Asian                       | 7 |
| <input type="checkbox"/> | Any other Mixed / Multiple background | 8 |

*List continued on next page*

### **Asian / Asian British**

<input type="checkbox"/>	Indian	9
<input type="checkbox"/>	Pakistani	10
<input type="checkbox"/>	Bangladeshi	11
<input type="checkbox"/>	Chinese	12
<input type="checkbox"/>	Any other Asian background	13

### **Black / African / Caribbean / Black British**

<input type="checkbox"/>	African	14
<input type="checkbox"/>	Caribbean	15
<input type="checkbox"/>	Any other Black / African / Caribbean background	16

### **Other ethnic group**

<input type="checkbox"/>	Arab	17
<input type="checkbox"/>	Any other background	18
<input type="checkbox"/>	Prefer not to say	19

**29. Did someone help you to complete this questionnaire?**

***Please tick [✓] one box***

Yes

1

No

2

### Section 7: The Pandemic

So far you have been asked for your experiences of the past 12 months only. The following four questions cover your experiences across the **whole of the pandemic**, i.e., since March 2020.

30. **Thinking about your experiences during the Coronavirus (COVID-19) pandemic, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services?**

*Please tick (✓) one box*

- |                          |   |   |
|--------------------------|---|---|
| <input type="checkbox"/> | We didn't receive any support or services from Social Services during the Coronavirus (COVID-19) pandemic | 1 |
| <input type="checkbox"/> | I am extremely satisfied  | 2 |
| <input type="checkbox"/> | I am very satisfied   | 3 |
| <input type="checkbox"/> | I am quite satisfied  | 4 |
| <input type="checkbox"/> | I am neither satisfied nor dissatisfied   | 5 |
| <input type="checkbox"/> | I am quite dissatisfied   | 6 |
| <input type="checkbox"/> | I am very dissatisfied  | 7 |
| <input type="checkbox"/> | I am extremely dissatisfied   | 8 |

**31. Thinking about how much social contact you had with people you like during the Coronavirus (COVID-19) pandemic, which of the following statements best describes your social situation during this time?**

***Please tick [✓] one box***

- |                          |  |   |
|--------------------------|--|---|
| <input type="checkbox"/> | I had as much social contact as I want with people I like          | 1 |
| <input type="checkbox"/> | I had some social contact with people but not enough               | 2 |
| <input type="checkbox"/> | I had little social contact with people and felt socially isolated | 3 |

**32. Thinking about your personal safety during the Coronavirus (COVID-19) pandemic, which of the statements best describes how you felt during this time?**

*By 'personal safety' we mean feeling safe from fear of abuse, being attacked or other physical harm. We do not mean feeling safe from fear of contracting coronavirus.*

***Please tick [✓] one box***

- |                          |  |   |
|--------------------------|--|---|
| <input type="checkbox"/> | I had no worries about my personal safety        | 1 |
| <input type="checkbox"/> | I had some worries about my personal safety      | 2 |
| <input type="checkbox"/> | I was extremely worried about my personal safety | 3 |



**33. Thinking about your experiences during the Coronavirus (COVID-19) pandemic, did you feel you were involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?**

**Please tick (✓) one box**

- |                          |  |   |
|--------------------------|--|---|
| <input type="checkbox"/> | There were no discussions that I am aware of, during the Coronavirus (COVID-19) pandemic | 1 |
| <input type="checkbox"/> | I always felt involved or consulted  | 2 |
| <input type="checkbox"/> | I usually felt involved or consulted   | 3 |
| <input type="checkbox"/> | I sometimes felt involved or consulted   | 4 |
| <input type="checkbox"/> | I never felt involved or consulted   | 5 |

**Section 8: Comments**

The next group of questions allow you to provide additional information on your experiences.

- 34. Please use the space provided below to describe any other experiences you would like to tell us about, or to write any other comments you would like to make?**

**35. We may be asking some people to take part in follow-up research for this study in the next year or so.**

**Would you be happy to be invited to take part in more research?**

*Note that even if you say “yes” there will be no obligation to take part in the future.*

**Please tick (✓) one box**

Yes, I have written my name, address and phone number in the space below

No

**If you would be happy to be contacted for this purpose please provide your contact details here:**

Name: Address:  Telephone number: Email address (optional):
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If you would like to access a copy of the national report for the survey, this will be published in the summer and is available on the NHS Digital webpage: <http://bit.ly/adult-carers-survey>

**Please tick (✓) this box if you would like to receive a copy of the nationally released report for the survey**

**Thank you for helping us by filling in this questionnaire.  
Please post it back to us in the envelope provided.  
You do not need to put a stamp on the envelope.**

**For your views to count please return this form by 1<sup>st</sup> November 2021**