

# Carer Well-Being & Support

## A questionnaire for carers of people with a mental health problem or dementia

Before you start filling this questionnaire in, there are a few things you should know.

- ❖ This questionnaire is for you as a carer to talk about your own circumstances and needs, and not those of the person you care for. We recognise that carers' needs are closely linked with the needs of the person they care for, but this questionnaire has been designed to find out about YOUR circumstances and YOUR needs.
- ❖ It can be filled in by anyone who has a role in caring for someone with a mental health problem or dementia. You don't have to be a person's main carer or live at the same address as them.
- ❖ Please try to answer every question; there are no wrong or right answers.
- ❖ We recognise that some carers may be caring for more than one person. For each question, **choose one answer** that best reflects your caring responsibilities as a whole.
- ❖ The first section of the questionnaire asks about how you have been over the past 4 weeks. We recognise that this may have been an unusual time for you. However, we would like you to respond about your well-being in the last 4 weeks specifically. If you would like to tell us why this has been an unusual time, there is space to do so in the section about your needs, on page 7.

# A. Well-Being

The questions in Part A are about aspects of **your general well-being**. All of the questions are about how you have been over the past four weeks.

We recognise that some carers may be caring for more than one person. For each question, **tick one box on each line** that best reflects your caring responsibilities as a whole.

Please write today's date: \_\_\_\_\_

## Your role as a carer

The first set of questions asks about your **role as a carer**. (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
1. not having enough time to yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. having to put the needs of the person you care for ahead of your own needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. not being able to take a break from caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. not being able to plan for the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your relationship with the person you care for

The next questions are about your **relationship with the person you care for**. (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
6. strains in your relationship with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. the person you care for being too dependent on you <u>at the moment</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. the person you care for becoming too dependent on you <u>in the future</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. the person you care for saying things that upset you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. feeling irritable with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. reaching 'breaking point', where you feel you can't carry on with things as they are?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your relationships with family and friends

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
12. strains in your relationships with family and friends, because of your caring responsibilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. "drifting apart" from family and friends, because your caring responsibilities limit the time available to keep in contact with them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. feeling isolated and lonely because of the situation you are in?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. not getting the support you need from family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your financial situation

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
16. your own financial situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. the financial situation of the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. having to cover extra costs of caring (e.g. extra help in the home, trips to hospital)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your physical health

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
19. your own physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. your caring role making your physical health worse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your emotional well-being

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
21. being unable to cope with the "constant anxiety" of caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. feeling depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. being unable to see anything positive in your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. lack of sleep brought about through worry or stress?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. lack of sleep caused by the person you care for keeping you awake at night?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. feeling so exhausted that you can't function properly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Stigma and discrimination

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
27. people treating you differently because of the illness/condition of the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your own safety

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about the person you care for...	A lot	Quite a bit	Moderately	A little	Not at all
28. accidentally doing something that puts you at risk (e.g. leaving the gas on)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. being aggressive or threatening towards you (e.g. verbal threats, sexual aggression, physical intimidation)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## The safety of the person you care for

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about the person you care for...	A lot	Quite a bit	Moderately	A little	Not at all
30. harming themselves?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. getting themselves into dangerous situations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. relapsing or deteriorating, such that it puts their safety at risk?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## B. Support

The questions in Part B ask **how satisfied** you are, in general, with the **support you may receive** to help you in your role as a carer. Support may be provided by people working in the voluntary, private or statutory sectors, such as GPs, social workers, housing support workers, community psychiatric nurses, care workers, psychologists, psychiatrists, and carer support services or groups run by the voluntary sector.

Please tick the box on each line that best reflects your level of satisfaction with **the support you receive as a whole**.

### Information and advice for carers

The next questions ask about how satisfied you are with **information and advice** for carers. (Please tick one box on each line.)

<u>In general, how satisfied</u> are you...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
1. that you have enough information about the condition/illness of the person you care for to enable you to feel confident in caring for them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. that you have enough information about how their condition/illness is likely to develop in the longer-term?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. that you can get whatever information you need when you need it (e.g. through your doctor or on your own)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. with how easy it is to understand the information you have?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. with the amount of advice available to you (e.g. from healthcare workers or other carers)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. that you are clear about who to go to for the information and advice you need?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. that you are clear about who to contact if there is an emergency and you need help right away?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. that you are clear about who to call if you have a routine inquiry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your involvement in treatment and care planning

(Please tick one box on each line.)

<u>In general, how satisfied</u> are you with...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
9. your involvement in important decisions (e.g. medication, hospitalisation)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. your ability to influence important decisions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Support from medical and/or care staff

The following questions ask about **the support you may receive from medical and/or care staff** - that is, the people providing treatment and care for the person you care for (e.g. GPs, social workers, housing support workers, community psychiatric nurses, workers from the voluntary sector, psychologists and psychiatrists). (Please tick one box on each line.)

In general, <b>how satisfied</b> are you with...	Very satisfied	Somewhat satisfied	Somewhat Dissatisfied	Very dissatisfied
11. how easy it is to get help and support from staff for the <i>person you care for</i> (e.g. to prevent relapse)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. how easy it is to get help and support from staff for <i>yourself</i> (e.g. advice on how to deal with certain behaviours)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. the quality of help and support from staff for the <i>person you care for</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. your relationships with key staff who support the <i>person you care for</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. how well the staff you have contact with are communicating with each other (i.e. that they share important information)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. how seriously staff take what you say to them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. the level of understanding staff have of what it must be like to be in your situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## C. Your Needs

The questions in Part C are about **your needs for support** to help you in your role as a carer

### 1. Would you like more support to help you in your role as a carer?

No, not at all

Yes, a little

Yes, a lot

### 2. What types of additional support would you most like to receive?

### 3. Is there anything else that's important to your well-being that you'd like help with or would like to change?

## D. Background Information

The following information will help us to understand your caring situation better and interpret your answers more effectively.

### About you

**1. Your date of birth?** \_\_\_\_\_

**2. Your gender?** Female   
Male

**3. Your ethnic background?**

*White:* British   
Irish   
Other White background

please state \_\_\_\_\_

*Mixed:* White and Black Caribbean   
White and Black African   
White and Asian   
Other Mixed background

please state \_\_\_\_\_

*Asian or Asian British:*

Indian   
Pakistani   
Bangladeshi   
Other Asian background

please state \_\_\_\_\_

*Black or Black British:*

Caribbean   
African   
Other Black background

please state \_\_\_\_\_

*Chinese or other ethnic group:*

Chinese   
Other

please state \_\_\_\_\_

**4. Your environment (the area you live in)?**

Rural   
Semi-urban   
Urban

**5. Your employment status?**

Employed full-time   
Employed part-time   
Self-employed   
Unemployed   
Retired   
Student   
Unable to work due to caring responsibilities   
Unable to work due to ill-health /disability   
Other (please specify)

**6. In what year did you first start caring for someone with a mental health problem/dementia?** (If you don't remember the exact year, please give an estimate of the year you started caring.)

\_\_\_\_\_

\_\_\_\_\_

**7. Please estimate as best you can how many hours you spent last week looking after someone with a mental health problem/dementia?**

\_\_\_\_\_

\_\_\_\_\_

**Was this:**

More hours than usual?   
About the same number of hours as usual?   
Fewer hours than usual?

**8. How many people with a mental health problem/dementia do you currently care for?**

1 person   
2 persons   
3 + persons



## About the Person or Persons You Care For

This next section asks about the person or persons you care for with a mental health problem or dementia. Please respond about the person you care for using the first column of boxes ('Person 1'). If you care for more than one person with a mental health problem or dementia, please tick relevant boxes in the other two columns (Persons 2 & 3). There is space at the end of the questionnaire if you would like to tell us about any further caring responsibilities you may have.

### 9. Who do you care for?

	Person 1	Person 2	Person 3
My <b>son/daughter</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>partner/spouse</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>brother/sister</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>parent</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>friend</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Other</b> (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

### 10. What is their illness/condition?

	Person 1	Person 2	Person 3
Dementia (e.g. Alzheimer's Disease)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychosis/schizophrenia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bi-polar disorder/manic depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other mental health problem (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

### 11. Do you live with each other at the moment?

	Person 1	Person 2	Person 3
Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Some of the time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
↳ <b>If no, where are they currently living?</b>			
Own/rented accommodation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supported accommodation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With other family member/friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

**12. Which of the following statements best describes your role as a carer at the moment?**

	Person 1	Person 2	Person 3
I am the <b>only</b> caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I <b>share</b> caring responsibilities with others, but <b>I</b> am the <b>main</b> caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I <b>share</b> caring responsibilities with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I share caring responsibilities, but <b>someone else</b> is the <b>main</b> caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

## Taking a Break

**13. Which of the following types of support, if any, do you use to allow you to take a break from caring?** (Tick more than one box if required.)

Friends/family providing temporary care	<input type="checkbox"/>	Other respite care (please specify below)	<input type="checkbox"/>
Paid carers coming into the home	<input type="checkbox"/>	_____	
Paid carers providing care away from the home (e.g. care home)	<input type="checkbox"/>	_____	
Supported activities out of the home, for the person you care for	<input type="checkbox"/>	I'm unable to take a break from caring	<input type="checkbox"/>
Supported breaks for you and the person you care for, away from the home	<input type="checkbox"/>	I do not need support to take a break from caring	<input type="checkbox"/>
		I do not need to take a break from caring	<input type="checkbox"/>