

Study ID

A. There are four sets of questions we would like you to answer over the next 19 pages. Please read the instructions for each set of questions.

Today's date:.....

1. What is your name?.....

2. What is your relationship to the person in this study?

Please tick one box

Husband/wife/partner.....

Brother/sister.....

Son/daughter.....

Another relative (please specify in the box below).....

A friend.....

A paid carer.....

Any other (please specify in the box below).....

3. Are you

Please tick one box

in regular paid employment?.....

unemployed?.....

a student?.....

retired?.....

Full time carer of children?.....

Full time carer of an adult?.....

homemaker?

semi-retired.....

4. Do you consider yourself to be a carer of the person in this study?	Yes	<input type="checkbox"/>
	No.....	<input type="checkbox"/>
	Lives in care home	<input type="checkbox"/>

5. Over the past 4 weeks, how many hours per week, on average, did you give care to the person in this study?	Hours per week
Physical (washing, dressing, feeding)	
Domestic (Cleaning, laundry, shopping)	
Company (visiting, telephoning)	
Dealing with finances	
Household Maintenance (repairs, gardening)	

6a	Do you normally live with the participant	No	<input type="checkbox"/>
		Yes	<input type="checkbox"/>
6b	<i>If Yes:</i> On a typical day, how much of the time can you leave the participant at home alone?	Not at all	<input type="checkbox"/>
		Less than 1 hour	<input type="checkbox"/>
		1-3 hours	<input type="checkbox"/>
		3-6 hours	<input type="checkbox"/>
		6-12 hours	<input type="checkbox"/>
		Overnight	<input type="checkbox"/>

7. Does the person you care for have any unpaid carers (apart from yourself)?	
	<i>Please tick one box</i>
	Yes..... <input type="checkbox"/>
	No..... <input type="checkbox"/>

B. I am going to ask about different types of behaviour. We would like to know if any of these apply to the person you care for OVER THE LAST FEW WEEKS. Please answer ALL the questions by putting a tick in the box which you think most clearly applies to them. If things have changed over that time, respond for the last week.

<p>1. Delusions: does the person have beliefs that you know are not true?</p>	<p style="text-align: right;">Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur?</p>	<p>Occasionally (less than once a week) <input type="checkbox"/></p> <p style="text-align: center;">Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p> <p style="text-align: center;">Very frequent (once a day or more) <input type="checkbox"/></p>
<p>And how severe are the problems?</p>	<p>Mild (beliefs present but seem harmless and produce little distress) <input type="checkbox"/></p> <p style="text-align: center;">Moderate (beliefs are distressing and disruptive) <input type="checkbox"/></p> <p>Marked (beliefs are very disruptive & are a major source of disturbed behaviour) <input type="checkbox"/></p>

<p>2. Hallucinations: does the person have hallucinations, such as false visions or voices?</p>	<p style="text-align: right;">Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur?</p>	<p>Occasionally (less than once a week) <input type="checkbox"/></p> <p style="text-align: center;">Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p>

	<p>Very frequent (once a day or more) <input type="checkbox"/></p>
<p>And how severe are the problems?</p>	<p>Mild (hallucinations present but seem harmless and produce little distress) <input type="checkbox"/></p> <p>Moderate (hallucinations are distressing and disruptive) <input type="checkbox"/></p> <p>Marked (hallucinations are very disruptive & are a major source of disturbed behaviour) <input type="checkbox"/></p>

<p>3. Agitation and Aggression: does the person have periods when he/she is agitated or aggressive? Or refuses to co-operate? Or won't let people help him/her with washing or dressing? Or shout or swear?</p>	<p style="text-align: right;">Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur?</p>	<p>Occasionally (less than once a week) <input type="checkbox"/></p> <p>Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p> <p>Very frequent (once a day or more) <input type="checkbox"/></p>
<p>And how severe are the problems?</p>	<p>Mild (behaviour is disruptive but can be managed with distraction or reassurance) <input type="checkbox"/></p> <p>Moderate (behaviour is disruptive and difficult to distract or control) <input type="checkbox"/></p> <p>Marked (agitation is very disruptive and a major source of difficulty; there may be a</p>

threat of personal harm)

<p>4. Depression: does the person seem sad or depressed? Does he or she say that he or she feels sad or depressed? Or a burden, a failure or a bad person? Or say he/she wishes to die or harm him/herself?</p>	<p style="text-align: right;">Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur?</p>	<p>Occasionally (less than once a week) <input type="checkbox"/></p> <p style="text-align: center;">Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p> <p>Very frequent (once a day or more) <input type="checkbox"/></p>
<p>And how severe are the problems?</p>	<p>Mild (depression is distressing but usually responds to distraction or reassurance) <input type="checkbox"/></p> <p style="text-align: center;">Moderate (depression is distressing, depressive thoughts are spontaneously spoken by the subject and difficult to alleviate) <input type="checkbox"/></p> <p>Marked (depression is very distressing, & a major source of suffering for the subject) <input type="checkbox"/></p>

<p>5. Anxiety: Is the person nervous, anxious, worried or frightened? Is he/she shaky, tense or fidgety? Is he/she</p>	<p style="text-align: right;">Yes <input type="checkbox"/> No <input type="checkbox"/></p>
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<p>afraid to be in particular places or apart from familiar people?</p>	
<p>If yes, how often do these problems occur?</p>	<p>Occasionally (less than once a week) <input type="checkbox"/></p> <p>Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p> <p>Very frequent (once a day or more) <input type="checkbox"/></p>
<p>And how severe are the problems?</p>	<p>Mild (anxiety is distressing but usually responds to distraction or reassurance) <input type="checkbox"/></p> <p>Moderate (anxiety is distressing, anxiety symptoms are spontaneously voiced by the subject and difficult to alleviate) <input type="checkbox"/></p> <p>Marked (anxiety is very distressing & a major source of suffering for the subject) <input type="checkbox"/></p>

<p>6. Elation: does the person seem abnormally cheerful or happy for no reason? Does he/she find things funny that others don't? Or tell silly jokes, or play tricks or pranks? Or boast about abilities or wealth?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur</p>	<p>Occasionally (less than once a week) <input type="checkbox"/></p> <p>Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p>

	<p>Very frequent (once a day or more) <input type="checkbox"/></p> <p>Mild (elation is noticeable by friends and family but is not disruptive) <input type="checkbox"/></p> <p>Moderate (elation is noticeably abnormal) <input type="checkbox"/></p> <p>Marked (elation is very pronounced; subject is euphoric and finds everything to be funny) <input type="checkbox"/></p>
And how severe are the problems?	

<p>7. Apathy and indifference: has the person lost interest in the world around him/her? Does he or she seem less interested in his/her usual activities and in other people? Or become less likely to start a conversation? Or seems not to have any motivation or not to care about things any more?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur?</p>	<p>Occasionally (less than once a week) <input type="checkbox"/></p> <p>Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p> <p>Very frequent (once a day or more) <input type="checkbox"/></p>
And how severe are the problems?	<p>Mild (apathy is noticeable but produces little interference with daily life; only slightly different from usual behaviour; subject responds to suggestions to do things) <input type="checkbox"/></p>

	<p>Moderate (apathy is very evident; may be overcome with coaxing and encouragement; responds spontaneously only to powerful events such as family visits) <input type="checkbox"/></p> <p>Marked (apathy is very evident and usually fails to respond to any encouragement or external events) <input type="checkbox"/></p>
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<p>8. Disinhibition: does the person seem to act impulsively without thinking about the consequences? Does he/she talk to strangers as if he or she knows them? Or say or do things that are rude or embarrassing? Or hurt people's feelings?</p>	<p style="text-align: right;">Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur?</p>	<p>Occasionally (less than once a week) <input type="checkbox"/></p> <p>Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p> <p>Very frequent (once a day or more) <input type="checkbox"/></p>
<p>And how severe are the problems?</p>	<p>Mild (behaviour is noticeable but usually responds to distraction or reassurance) <input type="checkbox"/></p> <p>Moderate (behaviour is very evident and difficult to overcome by carer) <input type="checkbox"/></p> <p>Marked (behaviour usually fails to respond to any intervention by carer and is a source of embarrassment or social distress) <input type="checkbox"/></p>

<p>9. Irritability and temper: does the person get irritated easily? Or impatient? Do his/her moods change quickly? Does he/she get bad tempered? Or angry or argumentative?</p>	<p style="text-align: right;">Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur?</p>	<p>Occasionally (less than once a week) <input type="checkbox"/></p> <p style="padding-left: 100px;">Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p> <p>Very frequent (once a day or more) <input type="checkbox"/></p>
<p>And how severe are the problems?</p>	<p>Mild (irritability or moodiness is noticeable but usually responds to distraction or reassurance) <input type="checkbox"/></p> <p>Moderate (irritability or moodiness is very evident and difficult to overcome by carer) <input type="checkbox"/></p> <p>Marked (irritability or moodiness is very evident, usually fails to respond to any intervention by carer and they are a major source of distress) <input type="checkbox"/></p>

<p>10. Motor behaviour: does the person pace around or wander? Or engage in repetitive activities, such as opening cupboards or drawers, or picking at things, or winding threads?</p>	<p style="text-align: center;">Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur</p>	<p>Occasionally (less than once a week) <input type="checkbox"/></p> <p style="text-align: center;">Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p> <p>Very frequent (once a day or more) <input type="checkbox"/></p>
<p>And how severe are the problems?</p>	<p>Mild (behaviour is noticeable but produces little interference with daily life) <input type="checkbox"/></p> <p>Moderate (behaviour is very evident but can be overcome by carer) <input type="checkbox"/></p> <p>Marked (behaviour is very evident and usually fails to respond to any intervention by carer & is a major source of distress) <input type="checkbox"/></p>

11. Sleep: Does the person have difficulty sleeping? Is he or she up at night (not including getting up once or twice to the toilet)? Does he/she get up at night thinking it is day? Is he /she sleepy during the day?

Yes **No**

If yes, how often do these problems occur

Occasionally (less than once a week)
Often (about once a week)
Frequent (several times a week but less than every day)
Very frequent (every night)

And how severe are the problems?

Mild (night time behaviours occur but are not particularly disruptive)
Moderate (night time behaviours occur and disturb the subject and the sleep of the carer; more than one type of night time behaviour may be present)
Marked (night time behaviour occurs; several types of night time behaviour may be present; the subject is very distressed during the night and the sleep of the carer very disturbed)

<p>12. Appetite: Has the person's appetite or eating habits changed? Has he/she lost or gained weight, or changed the foods he/she likes?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur</p>	<p>Occasionally (less than once a week) <input type="checkbox"/></p> <p>Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p> <p>Very frequent (once a day or more) <input type="checkbox"/></p>
<p>And how severe are the problems?</p>	<p>Mild (change in appetite or eating habits is present but has not led to change in weight & is not disturbing) <input type="checkbox"/></p> <p>Moderate (change in appetite or eating habits <i>is</i> present & cause minor change in weight) <input type="checkbox"/></p> <p>Marked (obvious changes in appetite or eating habits are present and cause weight change; is embarrassing or otherwise disturbs the subject) <input type="checkbox"/></p>

THE NEXT FEW PAGES OF QUESTIONS ARE ABOUT YOU THE CARER OR FAMILY MEMBER.

C. There is a list below of things which other people have found to be difficult when helping someone who has an illness. We would like to know if any of these apply to you OVER THE LAST FEW WEEKS. Please answer ALL the questions by putting a tick in the box which you think most clearly applies to you.

1. Sleep is disturbed (for example: because the person you care for is in and out of bed or wanders around at night)

Please tick one box

Yes.....

No.....

2. It is inconvenient (for example: because helping takes so much time or it's a long drive over to help)

Please tick one box

Yes.....

No.....

3. It is a physical strain (for example: because of lifting in and out of a chair; effort or concentration is required)

Please tick one box

Yes.....

No.....

4. It is confining (for example: helping restricts free time or cannot go visiting)

Please tick one box

Yes.....

No.....

5. There have been family adjustments (for example: because helping has disrupted my routine; there has been no privacy)

Please tick one box

Yes.....

No.....

6. There have been changes in personal plans (for example: I had to turn down a job; could not go on vacation/holiday)

Please tick one box

Yes.....

No.....

7. There have been other demands on my time (for example: from other family members)

Please tick one box

Yes.....

No.....

8. There have been emotional adjustments (for example: because of severe arguments)

Please tick one box

Yes.....

No.....

9. Some behaviour is upsetting (for example: because of incontinence; the person you care for has trouble remembering things; or the person you care for accuses people of taking things)

Please tick one box

Yes.....

No.....

10. It is upsetting to find the person you care for has changed so much from his/her former self (for example: he/she is a different person than he/she used to be)

Please tick one box

Yes.....

No.....

11. There have been work adjustments (for example: because of having to take time off)

Please tick one box

Yes.....

No.....

12. It is a financial strain

Please tick one box

Yes.....

No.....

13. Feeling completely overwhelmed (for example: because of worry about the person you care for; concerns about how you will manage)

Please tick one box

Yes.....

No.....

D. We should like to know if you have had any medical complaints and how your health has been in general, OVER THE LAST FEW WEEKS. Please answer ALL the questions by putting a tick in the box which you think most clearly applies to you. Remember that we want to know about present and recent complaints, not those you had in the past.

Have you recently.....

1. Been able to concentrate on whatever you're doing?

Please tick one box

- Better than usual.....
- Same as usual.....
- Less than usual.....
- Much less than usual.....

2. Lost much sleep over worry?

Please tick one box

- Not at all.....
- No more than usual.....
- Rather more than usual.....
- Much more than usual.....

3. Felt that you were playing a useful part in things?

Please tick one box

- More so than usual.....
- Same as usual.....
- Less useful than usual.....
- Much less useful.....

4. Felt capable of making decisions about things?

Please tick one box

- More so than usual.....
- Same as usual.....
- Less so than usual.....
- Much less than usual.....

5. Felt constantly under strain?

Please tick one box

- Not at all.....
- No more than usual.....
- Rather more than usual.....
- Much more than usual.....

6. Felt that you couldn't overcome your difficulties?

Please tick one box

- Not at all.....
- No more than usual.....
- Rather more than usual.....
- Much more than usual.....

7. Been able to enjoy your normal day-to-day activities?

Please tick one box

- More so than usual.....
- Same as usual.....
- Less so than usual.....
- Much less than usual.....

8. Been able to face up to your problems?

*Please tick one
box*

- More so than usual.....
- Same as usual.....
- Less so than usual.....
- Much less able.....

9. Been feeling unhappy and depressed?

Please tick one box

- Not at all.....
- No more than usual.....
- Rather more than usual.....
- Much more than usual.....

10. Been losing confidence in yourself?

Please tick one box

- Not at all.....

No more than usual.....	<input type="checkbox"/>
Rather more than usual.....	<input type="checkbox"/>
Much more than usual.....	<input type="checkbox"/>

11. Been thinking of yourself as a worthless person?
Please tick one box

Not at all.....	<input type="checkbox"/>
No more than usual.....	<input type="checkbox"/>
Rather more than usual.....	<input type="checkbox"/>
Much more than usual.....	<input type="checkbox"/>

12. Been feeling reasonably happy all things considered?
Please tick one box

More so than usual.....	<input type="checkbox"/>
About same as usual.....	<input type="checkbox"/>
Less so than usual.....	<input type="checkbox"/>
Much less than usual.....	<input type="checkbox"/>

Thank you for taking the time to complete the questionnaire