Study ID ……

A. There are five sets of questions we would like you to answer over the next 11 pages.

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. What is your age?
……

4. Do you live with the the person in this study?

Please tick one box

Yes…… ☐
No…… ☐

5. Are you

Please tick one box

in regular paid employment?…… ☐
unemployed?…… ☐
a student?…… ☐
retired?…… ☐
Full time carer ☐

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.

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

2. Hallucinations: does the person have hallucinations, such as false visions or voices?	Yes ☐ No ☐
If yes, how often do these problems occur?	Occasionally (<once a week) ☐ Often (about once a week) ☐ Frequent (several times a week but less than every day) ☐ Very frequent (once a day or more) ☐
And how severe are the problems?	Mild (hallucinations present but seem harmless and produce little distress) ☐ Moderate (hallucinations are distressing and disruptive) ☐ Marked (hallucinations are very disruptive & are a major source of disturbed behaviour) ☐

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?	Yes ☐ No ☐
If yes, how often do these problems occur?	Occasionally (<once a week) ☐ Often (about once a week) ☐ Frequent (several times a week but less than every day) ☐ Very frequent (once a day or more) ☐
And how severe are the problems?	Mild (behaviour is disruptive but can be managed with distraction or reassurance) ☐ Moderate (behaviour is disruptive and difficult to distract or control) ☐ Marked (agitation is very disruptive and a major source of difficulty; there may be a threat of personal harm) ☐

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?	Yes ☐ No ☐
If yes, how often do these problems occur?	Occasionally (<once a week) ☐ Often (about once a week) ☐ Frequent (several times a week but less than every day) ☐ Very frequent (once a day or more) ☐
And how severe are the problems?	Mild (depression is distressing but usually responds to distraction or reassurance) ☐ Moderate (depression is distressing, depressive thoughts are spontaneously spoken by the subject and difficult to alleviate) ☐ Marked (depression is very distressing, & a major source of suffering for the subject) ☐

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

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?	Yes ☐ No ☐
If yes, how often do these problems occur	Occasionally (<once a week) ☐ Often (about once a week) ☐ Frequent (several times a week but less than every day) ☐ Very frequent (once a day or more) ☐
And how severe are the problems?	Mild (elation is noticeable by friends and family but is not disruptive) ☐ Moderate (elation is noticeably abnormal) ☐ Marked (elation is very pronounced; subject is euphoric and finds everything to be funny) ☐

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?	Yes ☐ No ☐
If yes, how often do these problems occur?	Occasionally (<once a week) ☐ Often (about once a week) ☐ Frequent (several times a week but less than every day) ☐ Very frequent (once a day or more) ☐
And how severe are the problems?	Mild (apathy is noticeable but produces little interference with daily life; only slightly different from usual behaviour; subject responds to suggestions to do things) ☐ Moderate (apathy is very evident; may be overcome with coaxing and encouragement; responds spontaneously only to powerful events such as family visits) ☐ Marked (apathy is very evident and usually fails to respond to any encouragement or external events) ☐

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?	Yes ☐ No ☐
If yes, how often do these problems occur?	Occasionally (<once a week) ☐ Often (about once a week) ☐ Frequent (several times a week but less than every day) ☐ Very frequent (once a day or more) ☐
And how severe are the problems?	Mild (behaviour is noticeable but usually responds to distraction or reassurance) ☐ Moderate (behaviour is very evident and difficult to overcome by carer) ☐ Marked (behaviour usually fails to respond to any intervention by carer and is a source of embarrassment or social distress) ☐

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?	Yes ☐ No ☐
If yes, how often do these problems occur?	Occasionally (<once a week) ☐ Often (about once a week) ☐ Frequent (several times a week but less than every day) ☐ Very frequent (once a day or more) ☐
And how severe are the problems?	Mild (irritability or moodiness is noticeable but usually responds to distraction or reassurance) ☐ Moderate (irritability or moodiness is very evident and difficult to overcome by carer) ☐ Marked (irritability or moodiness is very evident, usually fails to respond to any intervention by carer and they are a major source of distress) ☐

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?	Yes ☐ No ☐
If yes, how often do these problems occur	Occasionally (<once a week) ☐ Often (about once a week) ☐ Frequent (several times a week but less than every day) ☐ Very frequent (once a day or more) ☐
And how severe are the problems?	Mild (behaviour is noticeable but produces little interference with daily life) ☐ Moderate (behaviour is very evident but can be overcome by carer) ☐ Marked (behaviour is very evident and usually fails to respond to any intervention by carer & is a major source of distress) ☐

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 (<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) ☐

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

C. DEMQOL Quality of Life (use response set card)

For these questions, I want you to think about the last week.
First I'm going to ask you about *(your relative's)* **feelings**. In the last week, would you say that (*your relative) has felt…..*

Have they felt…

1.	Cheerful?**	A lot □	Quite a bit □	A little □	Not at all □
2.	Worried or anxious?	A lot □	Quite a bit □	A little □	Not at all □
3.	Frustrated?	A lot □	Quite a bit □	A little □	Not at all □
4.	Full of energy?**	A lot □	Quite a bit □	A little □	Not at all □
5.	Sad?	A lot □	Quite a bit □	A little □	Not at all □
6.	Content?	A lot □	Quite a bit □	A little □	Not at all □
7.	Distressed?	A lot □	Quite a bit □	A little □	Not at all □
8.	Lively?	A lot □	Quite a bit □	A little □	Not at all □
9.	Irritable?	A lot □	Quite a bit □	A little □	Not at all □
10.	Fed-up?	A lot □	Quite a bit □	A little □	Not at all □
11.	That he/she has things to look forward to? **	A lot □	Quite a bit □	A little □	Not at all □

Next, I'm going to ask you about (*your relative's)* **memory**.
In the last week, **how worried** would you say (*your relative)* has been about …..

How worried have they been about…

12.	His/her memory in general?	A lot □	Quite a bit □	A little □	Not at all □
13.	Forgetting things that happened a long time ago?	A lot □	Quite a bit □	A little □	Not at all □
14.	Forgetting things that happened recently?	A lot □	Quite a bit □	A little □	Not at all □
15.	Forgetting people's names?	A lot □	Quite a bit □	A little □	Not at all □
16.	Forgetting where he/she is?	A lot □	Quite a bit □	A little □	Not at all □
17.	Forgetting what day it is?	A lot □	Quite a bit □	A little □	Not at all □
18.	His/her thoughts being muddled?	A lot □	Quite a bit □	A little □	Not at all □
19.	Difficulty making decisions	A lot □	Quite a bit □	A little □	Not at all □
20.	Making him/herself understood?	A lot □	Quite a bit □	A little □	Not at all □

Now, I'm going to ask you about your (*relative's)* <u>everyday life.</u> In the last week, how worried would you say *(your relative)* has been about ….

How worried have they been about…

21.	Keeping him/herself clean (eg. Washing and bathing)?	A lot □	Quite a bit □	A little □	Not at all □
22.	Keeping him/herself looking nice?	A lot □	Quite a bit □	A little □	Not at all □
23.	Getting what he/she wants from the shops?	A lot □	Quite a bit □	A little □	Not at all □
24.	Using money to pay for things?	A lot □	Quite a bit □	A little □	Not at all □
25.	Looking after finances?	A lot □	Quite a bit □	A little □	Not at all □
26.	Things taking longer	A lot □	Quite a bit □	A □	Not at all □

	than they used to?			little	
27.	Getting in touch with people?	A lot □	Quite a bit □	A little □	Not at all □
28.	Not having enough company?	A lot □	Quite a bit □	A little □	Not at all □
29.	Not being able to help other people?	A lot □	Quite a bit □	A little □	Not at all □
30.	Not playing a useful part in things?	A lot □	Quite a bit □	A little □	Not at all □
31.	His/her physical health?	A lot □	Quite a bit □	A little □	Not at all □

We've already talked about lots of things, (*your relative's)* feelings, memory and everyday life. Thinking about all of these things in the last week, how would you say *(your relative)* would rate

32.	His/her quality of life overall? **	Very good □	Good □	Fair □	Poor □

** items that need to be reversed before scoring.

D. Next 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.

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……..…..…..… ☐

E. This set of questions about how YOUR health is at the moment. Which statement best describes your own health state today?

1. Mobility

Please tick one box

I am confined to bed……..…..…… ☐
I have some problems in walking about…..…… ☐
I have no problems walking about……..…… ☐

2. Self care

Please tick one box

I am unable to wash or dress myself…….. ☐
I have some problems in washing or dressing…… ☐
I have no-problems with looking after myself…..…… ☐

3. Usual activities (e.g. housework, leisure, family)

Please tick one box

I am unable to perform my usual activities.…… ☐
I have some problems performing my usual activities..…… ☐
I have no problems performing my usual activities..…… ☐

4. Pain / Discomfort

Please tick one box

I have no pain or discomfort……..…… ☐
I have moderate pain or discomfort……..…..… ☐
I have extreme pain or discomfort……..…..… ☐

5. Anxiety / Depression

Please tick one box

I am not anxious or depressed……..…… ☐
I am moderately anxious or depressed……..…… ☐
I am extremely anxious or depressed……..…..… ☐

F. 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…….……..……..	☐
Rather more than usual…..……..……	☐
Much more than usual……..…..……..	☐

11. Been thinking of yourself as a worthless person?

Please tick one box

Not at all……	☐
No more than usual…….……..	☐
Rather more than usual…..…..…….	☐
Much more than usual…..…..……..	☐

12. Been feeling reasonably happy all things considered?

Please tick one box

More so than usual…….……	☐
About same as usual…..…..…..…….	☐
Less so than usual…….…..…….	☐
Much less than usual…..…..…..…….	☐

The end - thank you