Study ID ....

A. There are seven sets of questions we would like you to answer over the next 27 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).. ☐

[ ]

C. 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** (less than 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** (less than 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** (less than 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	**Yes** ☐ **No** ☐

failure or a bad person? Or say he/she wishes to die or harm him/herself?	
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** (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** (less than 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** (less than 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** (less than 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** (less than 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	**Yes** ☐ **No** ☐

easily? Or impatient? Do his/her moods change quickly? Does he/she get bad tempered? Or angry or argumentative?	
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** (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** (less than 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** (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) ☐

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** (less than 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) ☐

D. DEMQOL Quality of Life

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* **everyday life**. 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	A lot □	Quite a bit □	A little □	Not at □

	/herself looking nice?				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 than they used to?	A lot □	Quite a bit □	A little □	Not at all □
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	A lot □	Quite a bit □	A little □	Not at □

	able to help other people?				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 asked 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 □

E. Questions about the effect of health problems on the everyday life of the person you care for.

I am going to ask some questions about how health problems affect the person you care for's everyday life.
I want to know about:

- what they do in practice,
- any kind of help they usually have available,
- how they compare with other people of their age and background.

[London Handicap Scale; mobility]

1. How well is the person you care for able to go where they want to go, using any help or means of transport they usually have available? Exclude journeys to hospital.

		Please tick one box	
A	Can he/she go everywhere they want to, no matter how far away?	Yes, Level 1	☐
	If no,		
B	Does he/she get out of the house?	Yes, Level 2	☐
		No, Level 3	☐

[Physical independence]

2. How well is the person you care for able to look after themself? Include things like shopping, housework, cooking, getting to the toilet and getting dressed.

		Please tick one box	
A	Does he/she do almost everything to look after them self that someone like they would be expected to do? He/she needs no more than a little help now and again.	Yes, Level 1	☐
	If no,		
B	Does he/she need help to be available all the time? They cannot be left alone safely.	No, Level 2	☐
		Yes, Level 3	☐

[Occupation].

3. Next, I am interested in work and leisure activities, which includes any paid work, housework, gardening, visiting people, hobbies, watching TV; anything the person you care for does to occupy their time.

		Please tick one box	
A	Does he/she do everything they want or need to do, that someone like he/she would be able to do?	Yes, Level 1	☐
	If no,		
B	Are there are times, when he/she would like to be occupied, that he/she do nothing?	No, Level 2	☐
		Yes, Level 3	☐

[Social integration].

4. Next, I want to know if their health stops them getting on with people, including family, friends, and people they might meet during a normal day.			
		Please tick one box	
A	Does he/she get on well with people, see everyone they want to see, and meet new people? If no,	Yes, Level 1	☐
B	Does he/she find it difficult to get on with people who they don't know well? Maybe they see no-one except close family or the people who look after them.	No, Level 2	☐
		Yes, Level 3	☐

[Awareness]

5. Next, awareness of their surroundings. Assume they are using their usual glasses or hearing aid			
		Please tick one box	
A	Does he/she see, hear, speak and think clearly, and have a good memory? If no, ask question B	Yes, Level 1	☐
B	Does he/she have problems with hearing, speaking, seeing or memory, which makes life difficult most of the time?	No, Level 2	☐
		Yes, Level 3	☐

[Economic self sufficiency]

6. Finally, affording things they need.			
		Please tick one box	
A	Can he/she afford everything they need, including anything they need to buy because of ill-health or disability? If no, ask question B	Yes, Level 1	☐
B	Does he/she find it difficult to afford their most basic needs? They cannot afford things They need because of ill health.	No, Level 2	☐
		Yes, Level 3	☐

The next few questions about YOU the carer or family members.

F. 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……….………….. ☐

G. 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……………	☐

Part Two: Carer Schedule

All the questions below relate only to the last three months.

A. CARER'S EMPLOYMENT

1.	Are you:	In paid employment	☐
		Retired	☐
		Housewife / husband	☐
		Unemployed / Student	☐
		Full time carer of children	☐
		Full time carer of an adult	☐
		Home Maker	☐
		Semi retired	☐

2.	Have you cut down on paid work in order to provide care for the person in this study.	No	☐
		Reduced hours	☐
		Given up work	☐
	By how many hours per week? *(Only if reduced hours or given up work)*	☐☐	

Only complete if in "Paid Employment"			
3.	What was your most recent job (State main type if more than one)	Manager / administrator	☐
		Professional	☐
		Associate professional	☐
		Clerical worker / Secretary	☐
		Skilled labourer	☐
		Services / Sales	☐
		Factory worker	☐
		Other: ______________________	☐

Only complete if in "Paid Employment"		
4.	Total number of paid hours per week *(Round to the nearest whole number)*	☐☐

B. TIME SPENT WITH PARTICIPANT BY PRINCIPAL CARER *(i.e. Informant)*

5. Do you consider yourself to be a carer of the person in this study?	Yes	☐
	No....................	☐
	Lives in care home................	☐

6a.	Do you normally live with the participant	No	☐
		Yes	☐

6b	***If Yes:*** On a typical day, how much of the time can you leave the participant at home alone?	Not at all	☐
		Less than 1 hour	☐
		1-3 hours	☐
		3-6 hours	☐
		6-12 hours	☐
		Overnight	☐

7.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)	

C. TIME SPENT WITH PARTICIPANT BY OTHER INFORMAL CARERS

8.	Do any other people (eg friends and relatives) regularly provide help for the participant	No	☐
		Yes	☐
8b.	***If Yes:*** In an average/typical week, what is the total number of hours these people spend caring for the participant? *(Round to the nearest whole number)*	☐☐	

9a.	Have any friends or relatives taken time off paid work (over the past three months) to help with care giving?	No	☐
		Yes	☐
9b.	***If Yes:*** Estimate the total number of days taken off work? *(Round to the nearest whole number)*	☐☐	