

Thank you for completing this questionnaire.

Any information that you give us will be treated in strict confidence and the answers will be stored without your name and address so that you cannot be identified personally.

Please complete the questionnaire using ballpoint pen.

We will send you another, shorter, questionnaire to complete in three months time.

If you have any questions or problems completing this questionnaire please contact the study researcher, Dr Judi Edmans on [REDACTED].

A. There are four sets of questions we would like you to answer over the next 8 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. 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?.....

6. How many hours per day, on average, do you give physical care to the person in this study?

.....

7. How many hours per day, on average, do you need to give supervision to the person in this study?

.....

8. Does the person you care for have any unpaid carers (apart from yourself)?

Please tick one box

Yes.....

No.....

B. 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. 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.....

C. This set of questions are general questions about how YOUR health is at the moment. Please indicate which statement best describes your own health state TODAY by placing a tick in ONE box for EACH SECTION.

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.....

D. This set of questions relate to YOUR quality of life. Please circle the number that best describes YOU at the present time (today) – 1 means you have a low quality of life and 10 that you have a high quality of life. You can choose any number in between on this scale that best suits your circumstances.

1. Emotional Quality of Life

Please rate your emotional quality of life on a scale from zero to ten.

Zero applies to someone who is depressed, anxious, insecure, alienated, and lonely.

Ten applies to someone who is emotionally comfortable with self, others, and environment.

0 1 2 3 4 5 6 7 8 9 10

2. Social Quality of Life

Please rate your social quality of life on a scale from zero to ten.

Zero applies to someone whose social relationships are unsatisfactory, of poor quality, or few; help from family and friends is not even available occasionally.

Ten applies to someone whose social relationships are very satisfactory and extensive; at least one person would assist him or her indefinitely.

0 1 2 3 4 5 6 7 8 9 10

3. Financial Quality of Life

Please rate your financial quality of life on a scale from zero to ten.

Zero describes someone who constantly is worried about medical costs and present and future living expenses.

Ten describes someone who feels confident of his or her financial status now and in the future.

0 1 2 3 4 5 6 7 8 9 10

4. Physical Quality of Life

Please rate your physical quality of life on a scale from zero to ten.

Zero describes someone who has no energy or is physically ill and feels unable to maintain normal activities.

Ten describes someone who is energetic, in good physical health, and is maintaining normal activity levels.

0 1 2 3 4 5 6 7 8 9 10

Thank you for taking the time to complete the questionnaire.

Please return the questionnaire in the pre-paid envelope enclosed.

Please tick this box if you would like us to send you a
summary of the findings of this study (this will be in about
two years time)