

Participant ID:

Date:

C-DEMQOL

A measure of carer quality of life

PURPOSE

This questionnaire is designed to find out about your life and experiences of being a carer of a person with dementia.

INSTRUCTIONS

Please think of how things have been and how you have felt **in your caring role in the past 4 weeks**. Of course, there might have been good and bad days, but we want to capture a snapshot of how you have felt on a typical day during the past month. For each question, choose **one option** that best describes how you feel and mark it by putting a cross in the box, as shown

Here is an example question:

My own physical health in the past 4 weeks has been...

- very good
- mostly good
- satisfactory
- quite poor
- very poor

Please remember:

- There are no right or wrong answers, so please be as open as you can, and try to answer all the questions to the best of your judgement.
- If you feel that a question **does not apply** to you or to the person you care for, write "N/A" (stands for Not Applicable) next to the question.

CARER RESPONSIBILITIES AND PERSONAL NEEDS

First, we would like to know how you feel about your **caring responsibilities**, which may include managing medications, providing help with washing and dressing, medical visits or social outings, and also anything you need to do if the person with dementia is in a care home.

We would also like to know how your caring responsibilities affect your **ability to have time for yourself**, and doing the things that you enjoy or want to do, in particular activities that are **important to your quality of life**.

1. Carrying out my caring tasks and responsibilities takes up...

- very little of my energy
- some of my energy
- a considerable amount of my energy
- most of my energy
- all of my energy

2. Being a carer for the person with dementia takes up...

- very little of my time
- some of my time
- a considerable amount of my time
- most of my time
- all of my time

3. Meeting my own needs (for doing things I enjoy) whilst also caring has been...

- not a problem for me
- quite easy
- a problem at times
- quite difficult
- very difficult

4. Thinking of my ability to do things I enjoy, I have felt...

- free to do them when I want
- restricted in a little way by my caring duties
- restricted to some extent by my caring duties
- restricted a lot by my caring duties
- unable to do them due to my caring duties

5. In terms of freedom to do things I enjoy, my caring responsibilities have had...

- no impact on my freedom
- little impact on my freedom
- some impact on my freedom
- a significant impact on my freedom
- restricted my freedom completely

6. Thinking of my ability to do activities I enjoy whilst also caring, I feel that...

- all of my needs are met
- most of my needs are met
- some of my needs are met
- only a few of my needs are met
- none of my needs are met

CARER WELLBEING

Next, we would like to find out about **your wellbeing** and how this has been affected by your caring role. Think of how you have felt in the **past 4 weeks**.

7. I consider the emotional demands that caring places on me...

- very light
- quite light
- moderate
- quite heavy
- very heavy

8. In terms of my wellbeing, meeting the demands of caring has been...

- not at all stressful
- a little stressful
- quite stressful
- stressful
- very stressful

9. I have been having emotional problems (such as feeling sad, stressed or anxious) ...

- none of the time
- a little of the time
- some of the time
- most of the time
- all of the time

10. Whenever I need to get away from the person I care for, I feel...

- not at all guilty
- a little guilty
- quite guilty
- guilty
- very guilty

11. Thinking of changes in the person I care for due to dementia (such as changes in ability, memory, or behaviour), I find them...

- not at all upsetting
- a little upsetting
- quite upsetting
- upsetting
- very upsetting

12. Thinking of the physical and emotional demands of caring, I feel that they have...

- no impact on my health
- little impact on my health
- some impact on my health
- a significant impact on my health
- a very significant impact on my health

CARER ROLE

Now we would like to know how you feel about **being a carer** for a person living with dementia. This includes how you feel about your **relationship with the person you care for**, and your feelings about him or her.

13. Considering all the demands that caring places on me, I feel that overall I have...

- coped very well
- coped quite well
- coped OK
- coped quite poorly
- coped very poorly

14. When thinking of my present role as a carer for a person with dementia, I feel...

- not at all resentful
- a little resentful
- quite resentful
- resentful
- very resentful

15. Since the person I care for developed dementia, our relationship has...

- improved a lot
- improved a little
- not changed
- deteriorated a little
- deteriorated a lot

16. My relationship with the person I care for in the past 4 weeks has been...

- very good
- quite good
- fair
- quite poor
- very poor

17. I feel appreciated by the person I care for...

- always or almost always
- often
- sometimes
- once in a while
- never

18. I feel frustration toward the person I care for...

- none of the time
- a little of the time
- some of the time
- most of the time
- all of the time

FEELINGS ABOUT FUTURE

Now we would like to know how you feel about your **own future as a carer**, and the future for **the person you care for**. Again, think of how you have felt in the **past 4 weeks**.

19. When thinking about meeting the future care needs of the person with dementia, I...

- feel relaxed
- have only a few worries
- have some worries
- have significant worries
- worry a lot

20. I worry about how I will be able to cope emotionally as the dementia gets worse in the future...

- none of the time
- a little of the time
- some of the time
- most of the time
- all of the time

21. I worry about what may happen to the person I care for in the future...

- none of the time
- a little of the time
- some of the time
- most of the time
- all of the time

22. I anticipate that trying to meet the needs of the person with dementia in the future will be...

- not at all difficult
- a little difficult
- quite difficult
- difficult
- extremely difficult

23. When thinking of making important caring decisions in the future, I ...

- feel relaxed
- have only a few worries
- have some worries
- have significant worries
- worry a lot

24. When thinking about the future impact of caring on my finances, I ...

- feel relaxed
- have only a few worries
- have some worries
- have significant worries
- worry a lot

CARER SUPPORT

Lastly, we would like to know how you feel about the **help and support** that you may need as a carer. This includes the help and support given by **family and friends**, as well as any **professional support** provided by health and social services, or other groups or organisations. Of course, some members of your family may help a lot and some not at all. The same may be true for your friendship group or other groups. However, we want to capture how you feel about the help provided by these groups **on balance**, perhaps considering only the help from members who you **expect to help**.

25. Overall, my **needs for support** have been met...

- completely
- considerably
- to some extent
- a little
- not at all

26. The level of **professional support** offered or provided to me has met my expectations...

- completely
- considerably
- to some extent
- a little
- not at all

27. I feel supported by **professionals** (for example, doctors, social workers, care workers)...

- completely
- considerably
- to some extent
- a little
- not at all

28. I feel supported by **family members**...

- completely
- considerably
- to some extent
- a little
- not at all

29. I feel supported by my **friends**...

- completely
- considerably
- to some extent
- a little
- not at all

30. I feel supported by **community groups** (for example, charities, faith groups)...

- completely
- considerably
- to some extent
- a little
- not at all