

Carer completed forms:

- EQ-5D-3L
- Satisfaction with carer support (Likert scale)
- Zarit Burden Interview
- DEMQoL



Participant ID:

Date:

Health Questionnaire

English version for the UK

(Validated for Ireland)

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

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

Self-Care

- I have no problems with self-care ☐
- I have some problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

Usual Activities (e.g. work, study, housework, family or leisure activities)

- I have no problems with performing my usual activities ☐
- I have some problems with performing my usual activities ☐
- I am unable to perform my usual activities ☐

Pain / Discomfort

- I have no pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have extreme pain or discomfort ☐

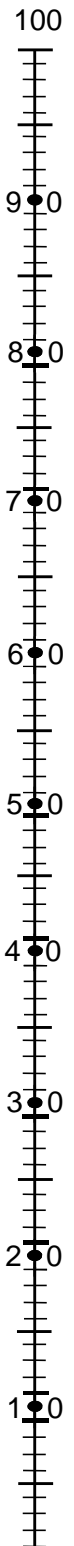
Anxiety / Depression

- I am not anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am extremely anxious or depressed ☐

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

**Your own health
state today**



ID

Date

Satisfaction with Support

How satisfied are you with your overall support?

1 = Very satisfied

2 = satisfied

3 = neutral

4 = dissatisfied

5 = very dissatisfied

Participant ID:

Date:

The Zarit Burden Interview

Circle the response that best describes how you feel.

	<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Quite frequently</i>	<i>Nearly always</i>
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Instructions for caregiver: The questions above reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There are no right or wrong answers.

Scoring instructions: Add the scores for the 22 questions. The total score ranges from 0 to 88. A high score correlates with higher level of burden.

DEMQOL - Carer (version 4)

Instructions: *Read each of the following questions (in bold) verbatim and show the respondent the response card.*

I would like to ask you about _____ (your relative's) life, as you are the person who knows him/her best. There are no right or wrong answers. Just give the answer that best describes how _____ (your relative) has felt in the last week. If possible try and give the answer that you think _____ (your relative) would give. Don't worry if some questions appear not to apply to _____ (your relative). We have to ask the same questions of everybody.

Before we start we'll do a practise question; that's one that doesn't count. (Show the response card and ask respondent to say or point to the answer). In the last week how much has _____ (your relative) enjoyed watching television?

a lot quite a bit a little not at all

*Follow up with a prompt question: **Why is that?** or **Tell me a bit more about that.***

For all of the questions I'm going to ask you, 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

- | | | | | |
|---|----------------------------------|-----------------------------------|--------------------------------|----------------------------------|
| 1. cheerful? ** | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 2. worried or anxious? | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 3. frustrated? | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 4. full of energy? ** | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 5. sad? | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 6. content? ** | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 7. distressed? | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 8. lively? ** | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 9. irritable? | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 10. fed-up | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 11. that he/she has things to look forward to? ** | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| | <input type="radio"/> 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.....

- | | | | | |
|--|----------------------------------|-----------------------------------|--------------------------------|----------------------------------|
| 12. his/her memory in general? | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 13. forgetting things that happened a long time ago? | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| | <input type="radio"/> not at all | | | |
| 14. forgetting things that happened recently? | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| | <input type="radio"/> not at all | | | |
| 15. forgetting people's names? | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 16. forgetting where he/she is? | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |
| 17. forgetting what day it is? | <input type="radio"/> a lot | <input type="radio"/> quite a bit | <input type="radio"/> a little | <input type="radio"/> not at all |

- | | | | | |
|-------------------------------------|----------------|----------------------|-------------------|---------------------|
| 18. his/her thoughts being muddled? | F a lot | F quite a bit | F a little | F not at all |
| 19. difficulty making decisions? | F a lot | F quite a bit | F a little | F not at all |
| 20. making him/herself understood? | F a lot | F quite a bit | F a little | F not at all |

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

- | | | | |
|---|---------------------|----------------------|---------------------|
| 21. keeping him/herself clean (eg washing and bathing)? | F a lot | F quite a bit | F a little |
| | F not at all | | |
| 22. keeping him/herself looking nice? | F a lot | F quite a bit | F a little |
| | | | F not at all |
| 23. getting what he/she wants from the shops? | F a lot | F quite a bit | F a little |
| | F not at all | | |
| 24. using money to pay for things? | F a lot | F quite a bit | F a little |
| | | | F not at all |
| 25. looking after his/her finances? | F a lot | F quite a bit | F a little |
| | | | F not at all |
| 26. things taking longer than they used to? | F a lot | F quite a bit | F a little |
| | | | F not at all |
| 27. getting in touch with people? | F a lot | F quite a bit | F a little |
| | | | F not at all |
| 28. not having enough company? | F a lot | F quite a bit | F a little |
| | | | F not at all |
| 29. not being able to help other people? | F a lot | F quite a bit | F a little |
| | | | F not at all |
| 30. not playing a useful part in things? | F a lot | F quite a bit | F a little |
| | | | F not at all |
| 31. his/her physical health? | F a lot | F quite a bit | F a little |
| | | | F 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? ** | F very good | F good | F fair | F poor |
|---|--------------------|---------------|---------------|---------------|

** items that need to be reversed before scoring

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a lot quite a bit a little not at all