

# Dementia Quality of Life Scale for Older Family Carers (DQoL-OC<sup>©</sup>) – 22 items

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Thank you for taking the time to fill in this questionnaire. The questionnaire has four sections. The first section will ask for some factual information. The next three will ask about different aspects of your role as a carer, how satisfied you are, and how you feel about various aspects of your life.

**Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that seems most appropriate (this is often your initial response).

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# Section 1

This section asks for information **about yourself and the care you provide**. Please answer all the questions, and do not spend too much time on any one item.

a)	What is your date of birth?	...../...../..... day month year
b)	What is your gender?	<input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> I prefer not to say
c)	What is your ethnic group?	<input type="checkbox"/> White <input type="checkbox"/> Afro-Caribbean <input type="checkbox"/> Asian <input type="checkbox"/> Arab <input type="checkbox"/> Other ethnic group: _____ <input type="checkbox"/> I prefer not to say
d)	What is the highest qualification you hold?	<input type="checkbox"/> No qualifications <input type="checkbox"/> Vocational <input type="checkbox"/> GCSE <input type="checkbox"/> A level <input type="checkbox"/> Diploma <input type="checkbox"/> University degree <input type="checkbox"/> Postgraduate degree <input type="checkbox"/> Other:
e)	Are you currently and regularly providing care for MORE THAN ONE PERSON in a non-formal caring capacity? (including children or grandchildren)	<input type="checkbox"/> No <input type="checkbox"/> Yes
f)	Do you live with the family member you care for?	<input type="checkbox"/> No <input type="checkbox"/> Yes
g)	What is your relationship with the family member you care for?	<input type="checkbox"/> Spouse <input type="checkbox"/> Son or daughter <input type="checkbox"/> Sibling <input type="checkbox"/> Other:
h)	Approximately how long have you been caring for your family member?	<input type="checkbox"/> Less than 1 year <input type="checkbox"/> 1 to 3 years <input type="checkbox"/> 4 to 6 years <input type="checkbox"/> 7 to 10 years <input type="checkbox"/> More than 10 years

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i)	On average, how many HOURS PER DAY do you care for your family member? ('care' means anything that you need to do for your family member because he/she is not able to do this on their own anymore)	<input type="checkbox"/> Less than 3 hours <input type="checkbox"/> 3 to 6 hours <input type="checkbox"/> 6 to 12 hours <input type="checkbox"/> More than 12 hours
j)	On average, how many DAYS PER WEEK do you care for your family member?	<input type="checkbox"/> 1 day <input type="checkbox"/> 2 to 3 days <input type="checkbox"/> 4 to 5 days <input type="checkbox"/> 6 to 7 days
k)	How would you describe your family member's dementia symptoms at this moment? (e.g. regarding memory loss, difficulty in communicating, inability to reason, disorientation)	<input type="checkbox"/> Totally uncontrolled <input type="checkbox"/> Mostly uncontrolled <input type="checkbox"/> Partially (un)controlled <input type="checkbox"/> Mostly controlled <input type="checkbox"/> Totally controlled
l)	How would you describe the stage of your family member's dementia at the moment?	<input type="checkbox"/> Initial stage <input type="checkbox"/> Moderate stage <input type="checkbox"/> Advanced stage

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## Section 2

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### Instructions

We want to know how you feel about your role as a carer, your health, and your quality of life at this moment in time. Please keep in mind your values, hopes, pleasures, and concerns, and circle the number that most accurately represents your situation.

### Example

Thinking about your role as a carer, a question might ask:

	Always	Frequently	Occasionally	Rarely	Never
How often does the caring negatively affect your relationships with family or/and friends?	1	2	3	4	5

In this question, you should circle the number that BEST FITS how often the caring negatively affects your relationships with family or/and friends. So you would circle the number that corresponds to the option “Occasionally” if caregiving occasionally affects negatively your relationships with family or/and friends, as follows:

	Always	Frequently	Occasionally	Rarely	Never
How often does the caring negatively affect your relationships with family or/and friends?	1	2	3	4	5

Please read each question, assess your feelings, and circle the number on the questionnaire for each question that gives the best answer for you at this moment in time.

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## The Dementia Quality of Life Scale for Older Family Carers (DQoL-OC)

This first set of questions asks for information about different aspects associated with your role as a carer of a family member with dementia. Please circle the number that best describes your role as a carer.

	Questions	Always	Frequently	Occasionally	Rarely	Never
1	How often does the caring negatively affect your relationships with family or/and friends?	1	2	3	4	5
2	How often is your financial situation affected by the demands of caring?	1	2	3	4	5
3	How often do you experience a conflict of interest between what you want and what your family member wants?	1	2	3	4	5
4	How often have you had to change your own life and interests to fit around your family member's needs?	1	2	3	4	5
5	How often is caring physically hard on you?	1	2	3	4	5
6	How often do you feel burdened by the care demands?	1	2	3	4	5

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This next set of questions asks how you feel about different aspects of your life. Please choose the option that best describes how you have felt about each area of your life as a carer.

	Questions	Very frequently	Frequently	Occasionally	Rarely	Never
7	I feel worried about my health	1	2	3	4	5
8	I feel exhausted	1	2	3	4	5
9	I feel as if my family member has changed from who she/he used to be and this affects me negatively	1	2	3	4	5
10	I feel worried about the future	1	2	3	4	5
11	I feel I have no choice in being a carer	1	2	3	4	5
12	I feel that I have lost control over the everyday events and decisions in my life	1	2	3	4	5
13	I feel that I have given up things that I enjoy because my family member needs me	1	2	3	4	5
14	I feel as if the boundaries between my own life and my caring role have become blurred	1	2	3	4	5
15	I feel sad or depressed	1	2	3	4	5
16	I feel isolated	1	2	3	4	5
17	I feel guilty	1	2	3	4	5

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The next set of questions asks **how satisfied you are with different aspects of your life as a carer**. Please **choose the option that best describes your situation**. “Very satisfied” (number 5) means the highest satisfaction possible and “Very dissatisfied” (number 1) means the lowest satisfaction possible.

		<b>Very dissatisfied</b>	<b>Dissatisfied</b>	<b>Neither satisfied nor dissatisfied</b>	<b>Satisfied</b>	<b>Very satisfied</b>
<b>18</b>	How satisfied are you with how much confidence you feel with your caring role?	1	2	3	4	5
<b>19</b>	How satisfied are you with how well you can cope with your caring situation?	1	2	3	4	5
<b>20</b>	How satisfied are you with the relationship with the family member you care for?	1	2	3	4	5
<b>21</b>	How satisfied are you with how well you can sleep?	1	2	3	4	5
<b>22</b>	How satisfied are you with your overall quality of life?	1	2	3	4	5

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**And finally, please tell us:**

**1. What do you think would most help to improve your quality of life as a carer?**

**2. Is there anything else that is related to your quality of life that you feel hasn't been covered in this questionnaire.**

**Thank you for your time.**

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