2017

TOPICS-MDS

QUESTIONNAIRE

Care receiver, baseline

Your experiences as a care receiver are valuable

You receive care. This list contains questions about what this care means for you as a care receiver. Your answers will be used in research to improve care for the elderly. The more information there is about care for elderly people, the more this can be taken into consideration. For example, when changing the facilities, regulations or legislation for care and wellbeing. Therefore, your experiences are also valuable for other elderly people.

Instructions for this questionnaire

- Completing this questionnaire will take approximately half an hour.
- Read each question through completely before selecting an answer.
- If you find it difficult to understand or answer the questions, ask your partner, a family member or a friend to help you.
- Some questions may appear to be ‘repeated’, but please answer all questions. They are intended to view your situation again from a different angle.
- When you are done, please check that you have not forgotten any questions.

Date of birth, gender and postal code

Please fill in your details below:

Date of birth:

Day	Month	Year

Gender: ☐ Male ☐ Female

Postal code
(four numbers):

Personal information

1 In which country were you born?

- ☐ The Netherlands
- ☐ Another country:

2 In which country was your father born?

- ☐ The Netherlands
- ☐ Another country:

3 In which country was your mother born?

- ☐ The Netherlands
- ☐ Another country:

4 What is the highest level of education that you have completed?

- ☐ Fewer than 6 classes of primary school
- ☐ 6 Primary school classes / lom-school / mlk-school
- ☐ More than primary school / primary school with uncompleted further education
- ☐ (Pre-)vocational secondary education (Ambachtsschool, vmbo)
- ☐ Secondary vocational education (Mulo / mms / mavo / mbo)
- ☐ University entrance level (Hbs / gymnasium / atheneum)
- ☐ University / tertiary education / higher professional education (hbo)

5 What is your marital status?

- ☐ Married
- ☐ Unmarried, no partner
- ☐ Long-term cohabitation, unmarried
- ☐ Divorced
- ☐ Widow / widower / partner deceased

6 Do you have children?

- ☐ No
- ☐ Yes

Living situation

7 What is your living situation?

- ☐ Independent, alone
- ☐ Independent, with others (partner, children, etc.)
- ☐ Care facility (nursing home / residential care centre)
- ☐ Another, namely

Health and disease

The following questions are about your health.

8 On a scale of 0 to 10: how do you rate your health in general? 0 indicates 'completely unhealthy' and 10 'completely healthy'.

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Under each heading, please tick the ONE box that best describes your health **TODAY**.

9 Mobility

- ☐ I have no problems in walking about
- ☐ I have slight problems in walking about
- ☐ I have moderate problems in walking about
- ☐ I have severe problems in walking about
- ☐ I am unable to walk about

10 Self-care

- ☐ I have no problems washing or dressing myself
- ☐ I have slight problems washing or dressing myself
- ☐ I have moderate problems washing or dressing myself
- ☐ I have severe problems washing or dressing myself
- ☐ I am unable to wash or dress myself

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

- ☐ I have no problems doing my usual activities
- ☐ I have slight problems doing my usual activities
- ☐ I have moderate problems doing my usual activities
- ☐ I have severe problems doing my usual activities
- ☐ I am unable to do my usual activities

12 Pain / discomfort

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

13 Anxiety / depression

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

14 Do you have complaints about your memory?

- ☐ No
- ☐ Yes

15 Did you consult a doctor about your memory problems?

- ☐ No
- ☐ Yes

16 Did you fall in the past 12 months?

- ☐ No
- ☐ Yes

The following questions are about the diseases and conditions that you have or have had.

17 Do you have or have you had one or more of the following diseases and conditions in the **past 12 months**? Tick "no" or "yes" for all diseases and conditions mentioned.

	No	**Yes**
Diabetes	☐	☐
Stroke, cerebral haemorrhage (bleed in the brain), cerebral infarction (blocked blood vessel in the brain) or TIA	☐	☐
Heart failure, myocardial infarction (heart attack) or other heart condition	☐	☐
A type of cancer (malignant disease), namely …	☐	☐
Asthma, chronic bronchitis, pulmonary emphysema or COPD	☐	☐
Involuntary urinary loss (incontinence)	☐	☐
Wearing of the joints (arthrosis, osteoarthritis / degenerative arthritis)	☐	☐
Chronic joint inflammation (arthritis)	☐	☐
Loss of bone tissue (osteoporosis)	☐	☐
Hip fracture or other bone fractures	☐	☐
Dizziness	☐	☐
Neurological disease (Parkinson's disease, multiple sclerosis, epilepsy)	☐	☐
Depression	☐	☐
Anxiety / panic disorder	☐	☐
Dementia	☐	☐
Hearing problems (despite hearing aid)	☐	☐
Problems with vision (despite glasses / contact lenses)	☐	☐

Tasks and activities of daily life

18 The following questions refer to daily activities which should be performed frequently, such as walking a flight of stairs or cooking. In each question it is asked whether you are able to perform the activity **at this moment**. It is not intended to assess whether you are actually performing the activities, but if you can do them if necessary.

Can you, fully independently, …				
	Yes, I can do it fully independently			**No, I cannot do it fully independently, I can only do it with someone's help**
	…without any difficulty	**…but with some difficulty**	**…but with great difficulty**	
… dress yourself?	☐	☐	☐	☐
… stand up from sitting in a chair ?	☐	☐	☐	☐
… wash and dry your whole body?	☐	☐	☐	☐
… go up and down the stairs?	☐	☐	☐	☐
… walk outdoors (if necessary with a cane or wheel rollator)?	☐	☐	☐	☐
… take care of your feet and toenails?	☐	☐	☐	☐
… do “light” household activities (for example, dusting and tidying up)?	☐	☐	☐	☐
… do the shopping?	☐	☐	☐	☐
… take your medicines?	☐	☐	☐	☐
… use your own or public transportation?	☐	☐	☐	☐

Mouth care

19 Do you experience complaints with your mouth, jaws or temples?

	No	Yes
I experience pain	☐	☐
I have chewing complaints	☐	☐
I have dry mouth complaints	☐	☐
Ik have swallowing complaints	☐	☐

How you are feeling

20 The following questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks** have you…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
… been a very nervous person?	☐	☐	☐	☐	☐	☐
… felt calm and peaceful?	☐	☐	☐	☐	☐	☐
… felt downhearted and blue?	☐	☐	☐	☐	☐	☐
... been a happy person?	☐	☐	☐	☐	☐	☐
… felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐

Social activities

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
21 **During the past 4 weeks**, how much of the time has **your physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?	☐	☐	☐	☐	☐

Quality of life

22 The following question is about your 'quality of life'. This refers to what you think about your life. For example, whether you are satisfied with your life, whether you have enjoyment in your life and whether your life gives you satisfaction.

On a scale of 0 to 10: how do you rate your life at this moment? 0 indicates 'completely unsatisfied' and 10 'completely satisfied'.

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Your care use

23 Have you been admitted to the hospital **in the past 12 months**? You had to stay overnight, for example because you had surgery and could not go home the same day.

☐ No

☐ Yes, namely ☐ times in total in the past 12 months

Did you tick "Yes"? Please answer the following question. If not, go to question 25.

24 How many days did you stay in hospital in total? If you stayed in hospital more than once in the **past 12 months**, then please sum up the number of days you stayed during each of the admissions.

☐ days in total in the past 12 months

25 Have you visited the emergency department of a hospital for yourself in the **past 12 months**? Other names for emergency department are: emergency room (ER), emergency ward, accident & emergency department (A&E) or casualty department.

☐ No

☐ Yes, namely ☐ times in total in the past 12 months

26 Have you visited an out-of-office hours GP service or had a visit from a general practitioner in the **evening, night or on the weekend** for yourself in the **past 12 months**?

☐ No

☐ Yes, namely ☐ times in total in the past 12 months

27 How many appointments (office hours and house calls) have you had with a general practitioner for yourself in the **past 12 months**?

☐ Not a single appointment

☐ One or more appointments, namely ☐ times in total in the past 12 months

28 Did you receive home care in the **past 12 months**?

☐ No

☐ Yes

Have you ticked “Yes”? Please answer questions 29 to 31. If not, continue with question 32.

29 What type of home care did you receive in the **past 12 months**? You can tick more than 1 answer.

- ☐ Help with household chores (for example: vacuuming, making the bed, grocery shopping)
- ☐ Personal care (for example: help with bathing/showering or dressing)
- ☐ Nursing care (for example: changing dressings, administering medications, measuring blood pressure)

30 How many weeks did you receive this home care? Please, sum up all weeks in the **past 12 months**. Please note: a period of 12 months concerns 52 weeks.

Help with household chores: ☐ weeks in the past 12 months

Personal care: ☐ weeks in the past 12 months

Nursing care: ☐ weeks in the past 12 months

31 How many hours of home care did you receive during these weeks on average?

Help with household chores: on average ☐ hours per week

Personal care: on average ☐ hours per week

Nursing care: on average ☐ hours per week

32 In the **past 12 months**, did you have to stay overnight somewhere else than your own home because of your health? For example, in a nursing home, residential care center, psychiatric hospital or rehabilitation center?

- ☐ No
- ☐ Yes, namely ☐ times in total in the past 12 months

Have you ticked “Yes”? Please answer the following question. If not, go to question 34.

33 How long did you stay in this care facility? If you stayed more than once in a care facility in the **past 12 months**, please sum up the number of days of all stays together.

[ ] days in total in the past 12 months

34 In the **past 12 months**, did you stay somewhere else than your own home during the day for treatment? So, you did not stay overnight. For example, you went to day care or day treatment.

☐ No

☐ Yes, namely [ ] times per week in the past 12 months

35 Because of your health problems, did you receive help from your family or friends in the **past week** with household chores such as preparing food, cleaning your house, doing the laundry, ironing or mending your cloths, grocery shopping or do odd jobs in and around the house?

☐ No

☐ Yes, namely [ ] hours in the past week

36 Because of your health problems, did you receive help from your family or friends in the **past week** with personal care (dressing, washing your body, combing your hair, shaving), toileting, transferring in the house, eating, drinken or taking medications?

☐ No

☐ Yes, namely [ ] hours in the past week

37 Because of your health problems, did you receive help from your family or friends in the **past week** with getting around outside the house, making trips, visiting family or friends, dealings with health care (attending your visits to the GP, hospital or treatment), arranging for help, aids or home adjustments, or arranging your finances or paper work?

☐ No

☐ Yes, namely [ ] hours in the past week

Closure

38 Has somebody helped you to complete this questionnaire?

- ☐ No, I completed the list alone
- ☐ Yes, somebody helped me to complete the list

39 If yes, what did the help consist of?

- ☐ Someone else has written down the answers, I have chosen the answers myself
- ☐ Someone else helped me to choose and write down the answers
- ☐ Someone else has chosen and written down the answers for me

If you have any comments, please write them down in the space below:

This is the end of the questionnaire. Thank you very much for completing the questionnaire.