

Study number:

Visit moment:



Informal caregiver questionnaire

The following questionnaire is about your experiences as an informal caregiver. With the help of this data, we can assess the burden on informal caregivers.

Please answer each question by ticking the answer that most applies to you. If you are unsure how to answer the question, please give the best possible answer.

Date of completion of this questionnaire - -

1. What is your age?

..... years

2. What is your gender?

- Male
- Female

3. What is your marital status?

- Married
- Living with partner
- Divorced (not living together)
- Widowed (not living together)
- Single/unmarried

4. What is your relationship with your loved one?

I am a...

- Husband/wife/partner
- Sister (in law), brother (in law)
- Daughter (in law), son (in law)
- Other, namely

5. Do you live with your loved one?
- Yes
 - No
6. What is your highest level of education?
- Primary school (primary education, special education)
 - Lower vocational education (e.g. LTS, LHNO, LEAO, household school)
 - Secondary general education (e.g. VMBO, ULO, MULO, MAVO)
 - Secondary vocational education (e.g. MTS, MEAO, MHNO)
 - Secondary general education (e.g. HBS, MMS, HAVO, VWO, gymnasium)
 - Higher vocational education (e.g. HTS, HEAO, HHNO)
 - Scientific education (university)
 - Other, namely:
7. Are you in paid employment?
- No
 - Yes, I work fulltime
 - Yes, I work parttime, namely hours per week
8. Were you involved in the decision making process regarding the start of and type of dialysis?
- Yes
 - No
9. How long have you been providing him/her with informal care?
- Less than a month, namely weeks
 - Less than a year, namely months
 - More than a year, namely years
10. On how many days do you usually provide informal care for him/her?
- 1 day
 - 2 days
 - 3 days
 - 4 days
 - 5 days
 - 6 days
 - 7 days

11. How much time did you spend assisting with household tasks during the past week that, in normal health, he/she would have done by himself/herself or would not have been necessary?

For example, preparing food and drinks, cleaning the house, washing, ironing and sewing clothes, taking care of (grand)children, getting groceries, or small jobs in the house or garden.

... hours per week

12. How much time did you spend caring for him/her during the past week?

This includes personal care (dressing, washing, combing, shaving) and help with going to the toilet, moving around the house, eating, drinking, and administering medication.

.... hours per week

13. How much time did you spend on practical support for him/her during the past week that, in normal health, he/she would have done him/herself or would not have needed?

For example, moving around outside the house (support in walking or using a wheelchair), making trips and visits to family or friends, contacts with health services (e.g. to the family doctor, hospital, therapy), arranging help, aids and/or home adaptations, and dealing with financial and administrative matters.

... hours per week

14. If applicable: Assistance in carrying out home dialysis.

.... hours per week

15. Can he/she stay alone?

- No, he/she needs constant supervision
 Yes, but he/she can be left alone for an hour at most
 Yes, he/she can easily be left alone for a few hours (or more)

16. Does he/she also receive help from professional caregivers at home (e.g. home care)?

- No
 No, not yet, he/she is on a waiting list for professional help at home for number of hours per week
 Yes, for number of hours in the past week

17. Does he/she need more professional help than he/she is currently receiving?

- No
 Yes, and this help has been requested
 Yes, and this help has not been requested

18. Does he/she receive help from other informal caregivers besides you?

- No, I am the only informal caregiver
- Yes, from other informal caregivers,
Altogether for (number) hours in the past week
They perform the following tasks:

Providing informal care can take up a lot of time. The next three questions are about giving up activities because of informal care.

19. Did you quit or reduce paid work to be able to provide informal care to him/her?

- No, I did not do any paid work
- No, I still do the same amount of paid work
- Yes, I do less paid work, namely (number) hours per week less, since (year)

20. Did you quit or reduce unpaid work to be able to provide informal care to him/her?

- No, I did not do any unpaid work
- No, I still do the same amount of unpaid work
- Yes, I do less unpaid work, namely (number) hours per week less, since (year)

21. Did you give up any leisure time or hobbies to be able to provide informal care for him/her?

- No, I did not have any hobbies or leisure time
- No, I still spend as much time on my hobbies or leisure time
- Yes, namely (number) hours per week less, since (year)

22. If applicable: Travelling time from you to your loved one to provide informal care.

.... hours per week

23. If applicable: Bringing/picking up of your loved one to centre dialysis.

.... hours per week

24. Do you also take care of other people in your environment?

- No
- Yes, for people (only fill in the number of people you take care of)
Altogether for (number) hours in the past week

25. Where were your parents born?

Please tick 1 to 2 boxes. We would like to know where your parents were born, because cultural factors may play a role in the provision of informal care to your loved one.

- Netherlands
- Somewhere else in Europe
- Turkey
- Morocco
- North Africa (e.g. Egypt)
- Central and South Africa
- Middle East
- Asia (e.g. China)
- South-East Asia (e.g. Indonesia, Vietnam)
- South Asia (e.g. India, Pakistan)
- North America
- Central and South America
- Netherlands Antilles and the Caribbean
- Suriname (Hindustani)
- Suriname (Creole)
- Australia and New Zealand
- I don't know

The questionnaire continues on the next page.

Positive experiences of informal caregivers

1. I enjoy the happy moments I have with my loved one
 - Agree
 - Neither agree nor disagree
 - Disagree
2. Caring for my loved one makes me feel good
 - Agree
 - Neither agree nor disagree
 - Disagree
3. I get a lot of appreciation for the help I provide
 - Agree
 - Neither agree nor disagree
 - Disagree
4. During the period that I have been providing care, my loved one and I have grown closer
 - Agree
 - Neither agree nor disagree
 - Disagree
5. As a result of providing care, I have learned to be happy about little things
 - Agree
 - Neither agree nor disagree
 - Disagree
6. As a result of providing care, I have learned new things myself
 - Agree
 - Neither agree nor disagree
 - Disagree
7. As a result of providing care, I have met new people
 - Agree
 - Neither agree nor disagree
 - Disagree
8. Helping has made my relationship with my family and friends closer
 - Agree
 - Neither agree nor disagree
 - Disagree

The questionnaire continues on the next page.

EDIZ+

Below are some questions about the influence that providing informal care has had on your other obligations and on your leisure time. The intention is that you indicate to what extent each of these questions applies to you.

1. Did you do work or other activities less carefully than you are used to because you were so busy helping?
 Yes
 Not too bad
 No
2. Did it take you longer than usual to manage your household?
 Yes
 Not too bad
 No
3. Were you too tired to do anything in your leisure time?
 Yes
 Not too bad
 No
4. Did you get sick or overworked because you had too many obligations at the same time during the period you helped?
 Yes
 Not too bad
 No
5. Did you regularly run out of time during that period?
 Yes
 Not too bad
 No

The following statements are about how you might experience giving help. Think about the moment in the past 12 months when the need for help was the greatest. The intention is to indicate for each of these statements to what extent it applies to you.

6. Overall, I felt very pressured by the situation of the person I care for
 Agree
 Neither agree nor disagree
 Disagree
7. My independence was compromised
 Agree
 Neither agree nor disagree
 Disagree

8. The help for the person I cared for fell too much on my shoulders
- Agree
 - Neither agree nor disagree
 - Disagree
9. Combining the responsibility for the person I care for and the responsibility for my work and/or family was not easy
- Agree
 - Neither agree nor disagree
 - Disagree
10. I always had to be there for the person I was caring for
- Agree
 - Neither agree nor disagree
 - Disagree
11. My involvement with the person I cared for made me feel very attached to them
- Agree
 - Neither agree nor disagree
 - Disagree
12. My involvement with the person I cared for caused me conflicts at home and/or at work
- Agree
 - Neither agree nor disagree
 - Disagree
13. The situation of the person I was caring for never left my mind
- Agree
 - Neither agree nor disagree
 - Disagree
14. I never felt free of responsibilities
- Agree
 - Neither agree nor disagree
 - Disagree

Now a final question about your health

15. Has your health improved or deteriorated as a result of giving help?
- Improved
 - Remained the same
 - Deteriorated

The questionnaire continues on the next page.

SF-12

With regard to your health, we would like to summarise a few things. These questions will help keep track of how you are feeling and how well you are able to carry out your usual activities. For each question, please tick the answer that most closely matches your opinion.

1. *In general, would you say your health is:*

- Excellent
 Very good
 Good
 Fair
 Poor

2. *The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?*

- | | Yes, limited a lot | Yes, limited a little | No, not limited at all |
|--|--------------------------|--------------------------|--------------------------|
| a. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, swimming, or cycling | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Climbing <u>several</u> flights of stairs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

3. *During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?*

- | | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Accomplished less than you would like | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Were limited in the kind of work or other activities | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

4. *During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?*

- | | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Accomplished less than you would like | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Did work or activities less carefully than usual | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

5. *During the past weeks, how much did pain interfere with your normal work (including work outside the home and housework)?*

Not at all
A little bit
Moderately
Quite a bit
Extremely

6. *These questions are about how you have been feeling during the past 4 weeks. For each question, please tick the one answer that comes closest to how you have been feeling. How much of the time during the past 4 weeks.*

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Did you have a lot of energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Have you felt down-hearted and blue?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. *During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?*

All of the time
Most of the time
Some of the time
A little of the time
None of the time

The questionnaire continues on the next page.

CES-D

Below is a list of some ways you may have felt or behaved. Please indicate how often you have felt this way during the last week by circling the appropriate number.

	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me	0	1	2	3
2. I did not feel like eating; my appetite was poor	0	1	2	3
3. I felt that I could not shake off the blues even with help from my family or friends	0	1	2	3
4. I felt I was just as good as other people	0	1	2	3
5. I had trouble keeping my mind on what I was doing	0	1	2	3
6. I felt depressed	0	1	2	3
7. I felt that everything I did was an effort	0	1	2	3
8. I felt hopeful about the future	0	1	2	3
9. I thought my life had been a failure	0	1	2	3
10. I felt fearful	0	1	2	3
11. My sleep was restless	0	1	2	3
12. I was happy	0	1	2	3
13. I talked less than usual	0	1	2	3
14. I felt lonely	0	1	2	3
15. People were unfriendly	0	1	2	3
16. I enjoyed life	0	1	2	3
17. I had crying spells	0	1	2	3
18. I felt sad	0	1	2	3
19. I felt that people dislike me	0	1	2	3
20. I could not get "going"	0	1	2	3

EQ-5D-5L

Under each heading, please tick one box that best describes your health TODAY.

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

SELF-CARE

- I have no problems with washing or dressing myself
- I have slight problems with washing or dressing myself
- I have moderate problems with washing or dressing myself
- I have severe problems with 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 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

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

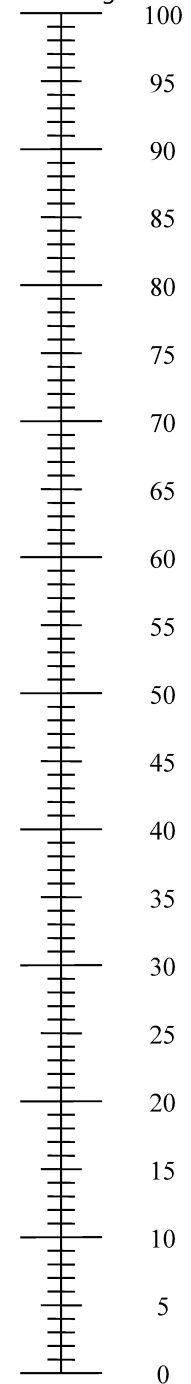
ANXIETY/DEPRESSION

- 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

- We want to know how good or bad your health is TODAY.
- This scale runs from 0 to 100.
- 100 stands for the best health you can imagine.
0 stands for the worst health you can imagine.
- Mark an X on the scale to indicate your health TODAY.
- Write down the number where you placed the X in the box below.

YOUR HEALTH TODAY =

The best health
you can imagine



The worst health
you can imagine

The questionnaire continues on the next page.

Support questions

Do you receive support for the things that you find a burden?

- Yes
- No

Would you like more support for the things that you find a burden?

- Yes
- No

What support would help you care for your loved one?

- Understanding your loved one's disease
- Managing the symptoms of your loved one (including giving medication)
- Help with daily care of your loved one (e.g. dressing, washing, toileting)
- Knowing who to contact if you are worried about your loved one (e.g. at night, during dialysis)
- Material help, such as a parking card
- Financial support
- More knowledge about which agencies to contact for care-related issues
- Support in talking about the disease with your loved one
- More knowledge about what to expect in the near future with regards to care
- More cooperation and coordination with care professionals

Are you sufficiently involved in the treatment of your loved one?

- Yes
- No

What do you need yourself to function well? Do you need more support with/for:

- Having time for yourself (e.g. through care to get away once in a while)
- Your own financial, legal, and/or work-related matters (e.g. more support from your supervisor, insight into the right to certain allowances)
- Dealing with your own feelings and concerns (e.g. through peer contact, contact with social workers)
- Taking care of your own health (physical problems)
- Your philosophy of life or spirituality
- Practical help at home (e.g. help with shopping, housework, cooking)
- Being relieved during the night

Something else, namely:

This is the end of the questionnaire. Thank you for filling it in!