

EUROFAMCARE

Follow-Up

In reference to our previous agreement we have the pleasure of contacting you after 12 months from the initial questionnaire study to talk about your further experiences concerning your role as Elder's Caregiver.

First of all we will look at whether you are still in your role as a caregiver or whether you are not:

- If you have stopped caring for your family member for any reason we mention below, then we kindly ask you to answer the following questions 1 to 11 only. We would be very happy if you could also take the opportunity to answer the very last question of the questionnaire where you can comment on your situation as a family carer personally or in general in any way you like.
- If you are still caring for your family member we kindly ask you to complete the whole questionnaire except the questions 2 and 3.

Before we start with the questions we would like to explain how to administer this questionnaire. For most of the questions different answer categories are provided: often just "yes" or "no":

Yes <input type="checkbox"/>	No <input type="checkbox"/>
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Or sometimes little scales, for **example**:

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In general you are asked to tick **only one box** per question, for **example**:

Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
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If you wish to change an answer you have already ticked, please do it as follows:

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

When you see the writing symbol ? then you are asked to write text or numbers into the relevant field, for **example**:

On average, how many hours a week do you give care and support to ELDER?	28 ?	Hours per week
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The character of several questions is rather private and personal. This is related to the characteristics of family care as a private and personal issue. Please understand that this information may help to better understand the situation of family carers in our and other countries, in order to improve the situation of family carers now and in the future. Your answers will be treated very confidentially. Your contribution will remain anonym. Your personal data will never be given to third parties nor will it be linked to the answers you have given in this questionnaire. All aspects of data protection and security, as defined by law, will strictly be observed.



Questionnaire Number (the same as at first interview):

EUROFAMCARE

1	Are you still providing more than 4 hours of care/support per week for <i>the same</i> ELDER?	Yes <input type="checkbox"/>	If yes , go to question no 4
		No <input type="checkbox"/>	If no , go to question no 2

2 When did you stop/reduce caring for ELDER, how many months ago?	?	months
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3	What is the reason you are no longer providing more than 4 hours of care and support to ELDER? <i>(Tick appropriate response, more than one response may be possible)</i>			
	a) ELDER still needs more than four hours of care and support, but somebody else is providing that amount of care and support. (If ELDER has died, please tick the last carer, if it was not you.):			
	other family member <input type="checkbox"/>	professional carer <input type="checkbox"/>	nursing home <input type="checkbox"/>	others <input type="checkbox"/>
	b) ELDER died...			
	...at home <input type="checkbox"/>	...in a nursing home <input type="checkbox"/>	...in hospital <input type="checkbox"/>	...else where <input type="checkbox"/>
	c) If there is another reason, please specify: <i>(e.g. ELDER is not in need of care anymore; you had become ill etc.)</i>			?

4	In general, would you say your health is:				
	Excellent <input type="checkbox"/>	Very good <input type="checkbox"/>	Good <input type="checkbox"/>	Fair <input type="checkbox"/>	Poor <input type="checkbox"/>

We are interested in how you view your quality of life.

	Over the last two weeks...	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
5	... I have felt cheerful and in good spirits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	... I have felt calm and relaxed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	... I have felt active and vigorous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	... I woke up feeling fresh and rested	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	... My daily life has been filled with things that interest me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10	Overall, how would you rate your quality of life in the last two weeks?				
	Very poor	Poor	Neither good nor poor	Good	Very good
	m	m	m	m	m

11	Generally speaking, who do you consider should be responsible for the care and support for the elderly?	Family should have full responsibility	m
		Family should have main responsibility, state/society/public authority contribute	m
		State/society/public authority should have main responsibility, family contribute	m
		State/society/public authority should have full responsibility	m
		It is difficult to say	m

For those who have stopped caring for ELDER for more than four hours the questionnaire ends here. On [page 13](#) (question 37) you will have the possibility to give further remarks.

We kindly ask all others to answer the following questions concerning your situation as a family carer.

12	On average, how many hours a week do you give care and support to ELDER?	?	Hours per week
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13	In total, how many hours a week do you give care and support to people (both elderly and non elderly) other than ELDER, if any? <i>(In the case you don't give support and care to others, please write "0" into the box)</i>	?	Hours per week
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14	Where do you and ELDER live?	In the same household	m
		In different households but the same building	m
		Within walking distance	m
		Within 10 minutes drive / bus or train journey	m
		Within 30 minutes drive / bus or train journey	m
		Within 1 hours drive / bus or train journey	m
		Over 1 hours drive / bus or train journey	m

15	Where does ELDER usually live now?	At home	m
		In a care home	m
		In sheltered housing	m
		Other, specify below...	m
		Specification of other:	?

16 Are you currently employed or on a job?	
<p>m No <i>continue below in white section</i> â</p>	<p>m Yes <i>continue below in grey section</i> â</p>
<p><i>Because of caring for ELDER you can not work at all</i> m</p>	<p>How many hours do you work in an average week?</p> <p style="text-align: right;"> <input type="text" value="?"/> hours </p>
<p><i>Because of caring for ELDER you had to give up your job during the last 12 months</i> m</p>	<p>All in all the number of your working hours per week is <i>unchanged</i>, - despite caring for ELDER m</p>
<p>You stopped work <i>not because</i> of caring for ELDER, but for <i>another</i> reason m</p>	<p><i>Because of caring for ELDER you had to reduce your working hours</i> m</p> <p>You had to reduce your working hours <i>not</i> because of caring for ELDER, but for <i>another</i> reason m</p>
<p>How many hours per week were you working before you had to give up/stop work?</p> <p style="text-align: right;"> <input type="text" value="?"/> hours </p>	<p>If you had to reduce your working hours, by how many per week?</p> <p style="text-align: right;"> <input type="text" value="?"/> hours </p>
<p><i>Please continue with question no. 17</i></p>	<p>And what difference has this made to your net income per month?</p> <p style="text-align: right;"> <input type="text" value="?"/> Euros/Pounds/Zlotys/Crowns </p> <p><i>Please continue with question no. 17</i></p>

17 Has caring for ELDER caused <i>any other restrictions</i> to your working life or career?	
I can/could not develop my professional career or studies	Yes m No m
I can/could work only occasionally	Yes m No m

18 If you needed a break from your caring role is there someone who would look after ELDER for you?	
Yes, I could find someone quite easily	m
Yes, I could find someone, but with some difficulty	m
No, there is no one	m

The next questions refer to ELDER's situation. They are about activities that we all need to do as part of our daily lives.

Please decide for each activity whether ELDER is **completely unable** or needs **some help** or can carry out the activity **without help**.

19		Unable	With some Help	Without Help
	Housework (clean floors etc.)	m	m	m
	Prepare their own meals (cleaning vegetables, cooking etc.)	m	m	m
	Go shopping	m	m	m
	Handle their own money	m	m	m
	Use the telephone (incl. dialing a number)	m	m	m
	Take their own medicines	m	m	m
	Walk outside	m	m	m
	Manage stairs	m	m	m
	Use the toilet (or commode)	m	m	m
	Use the bath or shower	m	m	m
	Keep up their personal appearance (brush hair, shave, make up etc.)	m	m	m
	Dress themselves	m	m	m
	Feed themselves	m	m	m
20	Get around indoors	Unable (has to be moved in a wheelchair or has to be carried)		m
		In a wheelchair without help or walking with major physical help		m
		Walking with some help (guided or supervised)		m
		Without help (may use any aid, e.g. stick)		m
21	Move themselves from bed to chair, if next to each other	Unable, no sitting balance		m
		Major help needed (1 or 2 people, physical)		m
		Minor help needed (verbal or physical)		m
		Without help		m
22	Does ELDER have accidents with their bladder? (incontinence of urine)	Yes, frequent accidents (once a day or more, or needs a catheter)		m
		Yes, occasional accidents (less than once a day)		m
		No accidents (continent)		m
23	Does ELDER have accidents with their bowels? (incontinence of faeces)	Once a week or more or needs of enema		m
		Less than once a week		m
		No accidents (continent)		m

Some of the most stressful situations for carers are related to problems which affect the memory and behaviour of the person they care for. The next questions relate to this issue.

24	Has ELDER any memory problems? (Such as having difficulty in remembering what day it is, or recognising friends or neighbours)	<input type="checkbox"/> No	à	Go to question 27	
		<input type="checkbox"/> Yes	à	Continue in grey section (question 25)	
25	IF 'YES', has the doctor given you any cause of ELDER's memory problems?	<input type="checkbox"/> No	à	Go to question 27	
		<input type="checkbox"/> Yes	à	please specify below:	
26		Dementia	<input type="checkbox"/>	Other	<input type="checkbox"/>
	Please, specify 'other' here:				?

27	How frequently – if at all – does ELDER demonstrate at present any of these behaviours?	Most of the time	Sometimes	Rarely	Never
	Wander in or outside the home environment or behaving in a way that endangers their safety?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Have difficulty holding normal conversation, have no insight into their problems, or become uncooperative with your requests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Do they behave in ways that you find upsetting? (For example constantly asking questions, following you around, repeat what has been said shout and scream for no particular reason or inappropriately dress or undress)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

A year after our previous study we look at the support that is available to you as a carer. You may have the feeling that some questions do not suit your personal situation at the moment (e.g.; “relationship with your family” – if there are no other family members then this question would be not relevant). In this case you may tick the box on the right.

28	Always	Often	Some-times	Never	Not relevant
Do you feel you cope well as a caregiver?	m	m	m	m	<input type="checkbox"/>
Do you find caregiving too demanding?	m	m	m	m	<input type="checkbox"/>
Does caregiving cause difficulties in your relationships with friends?	m	m	m	m	<input checked="" type="checkbox"/>
Does caregiving have a negative effect on your physical health?	m	m	m	m	<input type="checkbox"/>
Does caregiving cause difficulties in your relationship with your family?	m	m	m	m	<input checked="" type="checkbox"/>
Does caregiving cause you financial difficulties?	m	m	m	m	<input type="checkbox"/>
Do you feel trapped in your role as a caregiver?	m	m	m	m	<input type="checkbox"/>
Do you feel well supported by your friends and / or neighbours?	m	m	m	m	<input checked="" type="checkbox"/>
Do you find caregiving worthwhile?	m	m	m	m	<input type="checkbox"/>
Do you feel well supported by your family?	m	m	m	m	<input checked="" type="checkbox"/>
Do you have a good relationship with the person you care for?	m	m	m	m	<input type="checkbox"/>
Do you feel well supported by health and social services? (for example, public, private, voluntary)	m	m	m	m	<input checked="" type="checkbox"/>
Do you feel that anyone appreciates you as a caregiver?	m	m	m	m	<input type="checkbox"/>
Does caregiving have a negative effect on your emotional well-being?	m	m	m	m	<input type="checkbox"/>
Overall, do you feel well supported in your role of caregiver?	m	m	m	m	<input type="checkbox"/>

As you know, we are interested in the use of services (medical, care, social, counselling) by YOU and ELDER a year after our previous study. Therefore we will take the two tables in the questions 29 and 32. It might be that you were/are using only one or a few of these services, maybe you even did not use any of them. The lists contain quite a lot of very specific services addressing special needs which may not be relevant for your ELDER and/or yourself. The table in question 29 shows different services for social and physical supply for elder people. After each table you can decide if and which service has been helpful for ELDER or YOU and which one not.

These services address the needs of **elderly people**.

We ask you to look at the different dimensions and to tick those services ELDER has used in the last six months. For those services ELDER has actually used, please enter how many of the given units were used per day/week/month or in the last 6 months. It is very important that you also tick the time category (per day, per week etc.) when there are different alternatives offered.

29	What service has ELDER used in the last 6 months? Tick at appropriate boxes			How often did ELDER use this service on average?					
				Number	Unit	per Day	per Week	per Month	in 6 months
	...A	...B	...C						
Medical services:				?					
A01	General Practitioner	m		visits	m	m	m	m	m
A02	Neurologist	m		visits	m	m	m	m	m
A03	Other specialist	m		visits	m	m	m	m	m
A04	General Hospital	m		days	m	m	m	m	m
A05	Geriatric Hospital	m		days	m	m	m	m	m
A06	...	m		...	m	m	m	m	m
A07	...	m		...	m	m	m	m	m
Care services:				?					
A08	1 st service	m		visits	m	m	m	m	m
A09	2 nd service	m		hours	m	m	m	m	m
A10	3 rd service	m		days	m	m	m	m	m
A11	4 th service	m		contacts	m	m	m	m	m
A12	5 th service	m		measures	m	m	m	m	m
A13	...	m		...	m	m	m	m	m
A14	...	m		...	m	m	m	m	m
Therapists:				?					
A15	1 st service	m		visits	m	m	m	m	m
A16	2 nd service	m		visits	m	m	m	m	m
A17	3 rd service	m		visits	m	m	m	m	m
A18	4 th service	m		visits	m	m	m	m	m
A19	5 th service	m		visits	m	m	m	m	m
A20	6 th service	m		visits	m	m	m	m	m
A21	7 th service	m		visits	m	m	m	m	m
Home and living support:				?					
A22	1 st service	m		visits	m	m	m	m	m
A23	2 nd service	m		visits	m	m	m	m	m
A24	3 rd service	m		visits	m	m	m	m	m
A25	4 th service	m		visits	m	m	m	m	m

31 If you find that one or more of the services ELDER is/was using is/was *not helpful* for you please feel free to write it down:

Name (term) of the service	?	Or the number of the service from the list:	?
Name (term) of the service	?	Or the number of the service from the list:	?
Name (term) of the service	?	Or the number of the service from the list:	?

The next table in question 32 contains different services for advice and support for carers.

These services address the needs of **family carers**.

Here we ask you again to have a look at the different dimensions and to tick those services YOU have used in the last six months. For those services YOU have actually used, please enter how many of the given units were used per day/week/month or in the last 6 months. It is very important that you also tick the time category (per day, per week etc.) when there are different alternatives offered.

32 What services have YOU used in the last 6 months? Tick at appropriate boxes

What services have YOU used in the last 6 months? Tick at appropriate boxes				How often did YOU use this service on average?					
	...A	...B	Unit	per Day	per Week	per Month	in 6 months		
		?							
B01	1 st services	m	visits	m	m	m	m		
B02	2 nd service	m	visits	m	m	m	m		
B03	3 rd service	m	visits	m	m	m	m		
B04	4 th service	m	visits	m	m	m	m		
B05	5 th service	m	visits	m	m	m	m		
B06	...	m	...	m	m	m	m		
B07	...	m	...	m	m	m	m		
B08	...	m	...	m	m	m	m		
B09	...	m	...	m	m	m	m		
B10	...	m	...	m	m	m	m		
B11	...	m	...	m	m	m	m		
B12	...	m	...	m	m	m	m		
B13	...	m	...	m	m	m	m		
B14	...	m	...	m	m	m	m		
B15	...	m	...	m	m	m	m		

33 Which of the services YOU are/were using in the last 6 months is/was *most helpful* for you?
(Please write the name of the service (e.g. "self help group" or "home visits") or the equivalent number of the service from the services list in question 32 ((e.g. "B07" or "B14"))

Name (term) of the service	?	Or the number of the service from the list:	?
The second most helpful?			
Name (term) of the service	?	Or the number of the service from the list:	?
The third most helpful?			
Name (term) of the service	?	Or the number of the service from the list:	?

34 If you should find that one or more of the services YOU are/were using is/was *not helpful* for YOU, please feel free to write it down:

Name (term) of the service	?	Or the number of the service from the list:	?
Name (term) of the service	?	Or the number of the service from the list:	?
Name (term) of the service	?	Or the number of the service from the list:	?

Optional:

34 a Do you or ELDER receive any financial support, or allowances listed below because of your caring situation? [tick appropriate]

	YES	NO
Allowance from national list	m	m
Allowance from national list	m	m
Allowance from national list	m	m
Allowance from national list	m	m
Total amount of allowances for ELDER and YOU per month:	?	Euros/Pounds/Zlotys/Crowns

We would like to ask you about caring for ELDER in the future.

35 In the next year, are you willingly continue to provide care to ELDER?

Yes, and I would even consider increasing the care I give if necessary	m
Yes, and I would consider increasing the care I give for a limited time	m
Yes, I am prepared to continue to provide care if the situation remains the same	m
Yes, I am prepared to continue to provide care to Elder but only if I have some more support (from services, family, friends etc.)	m
No, I am not prepared to continue to provide care to Elder, no matter what extra support I receive	m

