

Questionnaire Number (the same as at first interview):

QUESTNUM

Country Code:

F2CTRY

EUROFAMCARE

Follow-Up

FOR INTERVIEWER: For not contacted Respondents please fill up the Annex 1.

F1NAME	Name of interviewer:	_____	?
F1INTN	Number of Interviewer	_____	
F7DOI F7MOI F7YOI	Date of Interview: (DD / MM / YYYY)	<input type="text"/> / <input type="text"/> / <input type="text"/>	?
F3ADM	Mode of administration		
		Postal •	
		Phone ,	
		Postal supplemented with phone <i>f</i>	
		Face to face "	
F3OTHE	Other, what:	...	

Codes and variables which have to be turned into national versions are written in orange! Also the reference to pages may have changed if your national service lists are very long.



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): QUESTNUM

EUROFAMCARE

1	Are you still providing more than 4 hours of care/support per week for <i>the same ELDER</i>?	Yes ●	If yes , go to question no 4
		No €	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 ● F3REAA1	professional carer ● F3REAA2	nursing home ● F3REAA3	others ● F3REAA4
F3REASB	b) ELDER died...			
	...at home ●	...in a nursing home ,	...in hospital <i>f</i>	...else where "
F3SP EC	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:				
F97Q OL1	Excellent ●	Very good ,	Good <i>f</i>	Fair "	Poor ...

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
F98Q OL2	5 ... I have felt cheerful and in good spirits	...	"	<i>f</i>	,	●	€
F99Q OL3	6 ... I have felt calm and relaxed	...	"	<i>f</i>	,	●	€
F100 QOL4	7 ... I have felt active and vigorous	...	"	<i>f</i>	,	●	€
F101 QOL5	8 ... I woke up feeling fresh and rested	...	"	<i>f</i>	,	●	€
F102 QOL6	9 ... My daily life has been filled with things that interest me	...	"	<i>f</i>	,	●	€

10 Overall, how would you rate your quality of life in the last two weeks?

F103
QOL7

Very poor	Poor	Neither good nor poor	Good	Very good
...	"	f	,	•

11 Generally speaking, who do you consider should be responsible for the care and support for the elderly?

F11E
XPEC

Family should have full responsibility	•
Family should have main responsibility, state/society/public authority contribute	,
State/society/public authority should have main responsibility, family contribute	f
State/society/public authority should have full responsibility	"
It is difficult to say	...

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?

F12H
OUR

	?	Hours per week
--	---	----------------

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?
(In the case you don't give support and care to others, please write "0" into the box)

F14H
OURO

	?	Hours per week
--	---	----------------

14 Where do you and ELDER live?

F21C
OHAB

In the same household	•
In different households but the same building	,
Within walking distance	f
Within 10 minutes drive / bus or train journey	"
Within 30 minutes drive / bus or train journey	...
Within 1 hours drive / bus or train journey	†
Over 1 hours drive / bus or train journey	‡

15 Where does ELDER usually live now?

F22H
OME

At home	•
In a care home	,
In sheltered housing	f
Other, specify below...	"
Specification of other:	?

F22O
THE

16 Are you currently employed or on a job?

F175E
MPL

€ No continue below in white section • Yes continue below in grey section

F180
WOR1

Because of caring for ELDER you can not work at all •

Because of caring for ELDER you had to give up your job during the last 12 months ,

You stopped work not because of caring for ELDER, but for another reason f

How many hours per week were you working before you had to give up/stop work?

? hours

Please continue with question no. 17

F180H
OUR

How many hours do you work in an average week?

F175HOUR ? hours

All in all the number of your working hours per week is unchanged, - despite caring for ELDER •

Because of caring for ELDER you had to reduce your working hours ,

You had to reduce your working hours not because of caring for ELDER, but for another reason f

If you had to reduce your working hours, by how many per week?

F178HOUR ? hours

And what difference has this made to your net income per month?

F178INC ? Euros/Pounds/Zlotys/Crowns

Please continue with question no. 17

17 Has caring for ELDER caused any other restrictions to your working life or career?

F181W
OR1

I can/could not develop my professional career or studies Yes • No €

F181W
OR2

I can/could work only occasionally Yes • No €

18 If you needed a break from your caring role is there someone who would look after ELDER for you?

F69B
REAK

Yes, I could find someone quite easily •
Yes, I could find someone, but with some difficulty ,
No, there is no one f

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
F43IA DL1	Housework (clean floors etc.)	€	•	,
F44IA DL2	Prepare their own meals (cleaning vegetables, cooking etc.)	€	•	,
F45IA DL3	Go shopping	€	•	,
F46IA DL4	Handle their own money	€	•	,
F47IA DL5	Use the telephone (incl. dialing a number)	€	•	,
F48IA DL6	Take their own medicines	€	•	,
F49M OB	Walk outside	€	•	,
F51BA R2	Manage stairs	€	•	,
F533B AR4	Use the toilet (or commode)	€	•	,
F54BA R5	Use the bath or shower	€	•	,
F55BA R6	Keep up their personal appearance (brush hair, shave, make up etc.)	€	•	,
F56BA R7	Dress themselves	€	•	,
F57BA R8	Feed themselves	€	•	,
20	Get around indoors	Unable (has to be moved in a wheelchair or has to be carried) In a wheelchair without help or walking with major physical help Walking with some help (guided or supervised) Without help (may use any aid, e.g. stick)	€ • , <i>f</i>	
F50BA R1				
21	Move themselves from bed to chair, if next to each other	Unable, no sitting balance Major help needed (1 or 2 people, physical) Minor help needed (verbal or physical) Without help	€ • , <i>f</i>	
F52BA R3				
22	Does ELDER have accidents with their bladder? (incontinence of urine)	Yes, frequent accidents (once a day or more, or needs a catheter) Yes, occasional accidents (less than once a day) No accidents (continent)	€ • ,	
F58BA R9				

23 F59BA R10	Does ELDER have accidents with their bowels? (incontinence of faeces)	Once a week or more or needs of enema	€
		Less than once a week	•
		No accidents (continent)	,

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 F35M EM1	Has ELDER any memory problems? (Such as having difficulty in remembering what day it is, or recognising friends or neighbours)	€ No	à Go to question 27
		• Yes	à Continue in grey section (question 25)
25 F36M EM2	IF 'YES', has the doctor given you any cause of ELDER's memory problems?	€ No	à Go to question 27
		• Yes	à please specify below:
26 F37M EM3 F37S PEC	Please, specify 'other' here:	Dementia	• Other ,
		?	

27	How frequently – if at all – does ELDER demonstrate at present any of these behaviours?	Most of the time	Some-times	Rarely	Never
F39B EHP1	Wander in or outside the home environment or behaving in a way that endangers their safety?	f	,	•	€
F40B EHP2	Have difficulty holding normal conversation, have no insight into their problems, or become uncooperative with your requests	f	,	•	€
F41B EHP3	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)	f	,	•	€

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	Sometimes	Never	Not relevant
F82C OP1	Do you feel you cope well as a caregiver?	"	<i>f</i>	,	•	<input type="checkbox"/>
F83C OP2	Do you find caregiving too demanding?	"	<i>f</i>	,	•	<input type="checkbox"/>
F84C OP3	Does caregiving cause difficulties in your relationships with friends?	"	<i>f</i>	,	•	<input type="checkbox"/>
F85C OP4	Does caregiving have a negative effect on your physical health?	"	<i>f</i>	,	•	<input type="checkbox"/>
F86C OP5	Does caregiving cause difficulties in your relationship with your family?	"	<i>f</i>	,	•	<input type="checkbox"/>
F87C OP6	Does caregiving cause you financial difficulties?	"	<i>f</i>	,	•	<input type="checkbox"/>
F88C OP7	Do you feel trapped in your role as a caregiver?	"	<i>f</i>	,	•	<input type="checkbox"/>
F89C OP8	Do you feel well supported by your friends and / or neighbours?	"	<i>f</i>	,	•	<input type="checkbox"/>
F90C OP9	Do you find caregiving worthwhile?	"	<i>f</i>	,	•	<input type="checkbox"/>
F91C OP10	Do you feel well supported by your family?	"	<i>f</i>	,	•	<input type="checkbox"/>
F92C OP11	Do you have a good relationship with the person you care for?	"	<i>f</i>	,	•	<input type="checkbox"/>
F93C OP12	Do you feel well supported by health and social services? (for example, public, private, voluntary)	"	<i>f</i>	,	•	<input type="checkbox"/>
F94C OP13	Do you feel that anyone appreciates you as a caregiver?	"	<i>f</i>	,	•	<input type="checkbox"/>
F95C OP14	Does caregiving have a negative effect on your emotional well-being?	"	<i>f</i>	,	•	<input type="checkbox"/>
F96C OP15	Overall, do you feel well supported in your role of caregiver?	"	<i>f</i>	,	•	<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?					
	...A	...B	...C	Number	Unit	per Day	per Week	per Month	in 6 months
Medical services:				?					
A01	FSE§§01...	General Practitioner	•		visits	•	,	<i>f</i>	"
A02	FSE§§02...	Neurologist	•		visits	•	,	<i>f</i>	"
A03	FSE§§03...	Other specialist	•		visits	•	,	<i>f</i>	"
A04	FSE§§04...	General Hospital	•		days	• , <i>f</i> "			
A05	FSE§§05...	Geriatric Hospital	•		days	• , <i>f</i> "			
A06	FSE§§06...	...	•		...	•	,	<i>f</i>	"
A07	FSE§§07...	...	•		...	•	,	<i>f</i>	"
Care services:				?					
A08	FSE§§08...	1 st service	•		visits	•	,	<i>f</i>	"
A09	FSE§§09...	2 nd service	•		hours	•	,	<i>f</i>	"
A10	FSE§§10...	3 rd service	•		days	•	,	<i>f</i>	"
A11	FSE§§11...	4 th service	•		contacts	•	,	<i>f</i>	"
A12	FSE§§12...	5 th service	•		measures	•	,	<i>f</i>	"
A13	FSE§§13...	...	•		...	•	,	<i>f</i>	"
A14	FSE§§14...	...	•		...	•	,	<i>f</i>	"
Therapists:				?					
A15	FSE§§15...	1 st service	•		visits	•	,	<i>f</i>	"
A16	FSE§§16...	2 nd service	•		visits	•	,	<i>f</i>	"
A17	FSE§§17...	3 rd service	•		visits	•	,	<i>f</i>	"
A18	FSE§§18...	4 th service	•		visits	•	,	<i>f</i>	"
A19	FSE§§19...	5 th service	•		visits	•	,	<i>f</i>	"
A20	FSE§§20...	6 th service	•		visits	•	,	<i>f</i>	"
A21	FSE§§21...	7 th service	•		visits	•	,	<i>f</i>	"
Home and living support:				?					
A22	FSE§§22...	1 st service	•		visits	•	,	<i>f</i>	"
A23	FSE§§23...	2 nd service	•		visits	•	,	<i>f</i>	"
A24	FSE§§24...	3 rd service	•		visits	•	,	<i>f</i>	"
A25	FSE§§25...	4 th service	•		visits	•	,	<i>f</i>	"

A26	FSE§§26...	5 th service	•		visits	•	,	<i>f</i>	"
A27	FSE§§27...	6 th service	•		visits	•	,	<i>f</i>	"
A28	FSE§§28...	7 th service	•		visits	•	,	<i>f</i>	"
Counselling:					?				
A29	FSE§§29...	1 st service	•		visits	•	,	<i>f</i>	"
A30	FSE§§30...	2 nd service	•		visits	•	,	<i>f</i>	"
A31	FSE§§31...	3 rd service	•		visits	•	,	<i>f</i>	"
A32	FSE§§32...	4 th service	•		visits	•	,	<i>f</i>	"
A33	FSE§§33...	5 th service	•		visits	•	,	<i>f</i>	"
A34	FSE§§34...	6 th service	•		visits	•	,	<i>f</i>	"
A35	FSE§§35...	7 th service	•		visits	•	,	<i>f</i>	"
Other services:					?				
A36	FSE§§36...	1 st service	•		visits	•	,	<i>f</i>	"
A37	FSE§§37...	2 nd service	•		visits	•	,	<i>f</i>	"
A38	FSE§§38...	3 rd service	•		visits	•	,	<i>f</i>	"
A39	FSE§§39...	4 th service	•		visits	•	,	<i>f</i>	"
A40	FSE§§40...	5 th service	•		visits	•	,	<i>f</i>	"
A41	FSE§§41...	6 th service	•		visits	•	,	<i>f</i>	"
A42	FSE§§42...	7 th service	•		visits	•	,	<i>f</i>	"

30 Which of the services ELDER is/was using in the last 6 months is/was *most helpful* for you?
FSEH 1 (Please write the name of the service (e.g. "speech therapist" or "meals on wheels") or the equivalent number of the service from the services list in question 29 (e.g. "A07" or "A34"))

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

? ?

FSEH 2 **The second most helpful?**

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

? ?

FSEH 3 **The third most helpful?**

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

? ?

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:

FSEN H1	Name (term) of the service	?	Or the number of the service from the list:	?
FSEN H2	Name (term) of the service	?	Or the number of the service from the list:	?
FSEN H3	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				How often did YOU use this service on average?				
	...A		...B	Unit	per Day	per Week	per Month	in 6 months	
			?						
B01	FSC§§01...	1 st services	•		visits	•	,	f	"
B02	FSC§§02...	2 nd service	•		visits	•	,	f	"
B03	FSC§§03...	3 rd service	•		visits	•	,	f	"
B04	FSC§§04...	4 th service	•		visits	•	,	f	"
B05	FSC§§05...	5 th service	•		visits	•	,	f	"
B06	FSC§§06...	...	•		...	•	,	f	"
B07	FSC§§07...	...	•		...	•	,	f	"
B08	FSC§§08...	...	•		...	•	,	f	"
B09	FSC§§09...	...	•		...	•	,	f	"
B10	FSC§§10...	...	•		...	•	,	f	"
B11	FSC§§11...	...	•		...	•	,	f	"
B12	FSC§§12...	...	•		...	•	,	f	"
B13	FSC§§13...	...	•		...	•	,	f	"
B14	FSC§§14...	...	•		...	•	,	f	"
B15	FSC§§15...	...	•		...	•	,	f	"

33 FSCCH 1	Which of the services YOU are/were using in the last 6 months is/was <i>most helpful</i> 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: ?
FSCCH 2	The second most helpful?		
	Name (term) of the service	?	Or the number of the service from the list: ?
FSCCH 3	The third most helpful?		
	Name (term) of the service	?	Or the number of the service from the list: ?

34 FSCCN H1	If you should find that one or more of the services YOU are/were using is/was <i>not helpful</i> for YOU, please feel free to write it down:		
	Name (term) of the service	?	Or the number of the service from the list: ?
FSCCN H2	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
FALS \$1	Allowance from national list	•	€
FALS \$2	Allowance from national list	•	€
FALS \$3	Allowance from national list	•	€
FALS \$4	Allowance from national list	•	€
FAL TOT	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 F157 FUT1	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	•
	Yes, and I would consider increasing the care I give for a limited time	,
	Yes, I am prepared to continue to provide care if the situation remains the same	f
	Yes, I am prepared to continue to provide care to Elder but only if I have some more support (from services, family, friends etc.)	"
	No, I am not prepared to continue to provide care to Elder, no matter what extra support I receive	...

36 F68 OTH F68S PEC	Are there any significant changes in the last year that affected your life that we have not covered?	Yes •	No €
	If yes, please specify ?		
<hr/>			
<hr/>			
<hr/>			

PLACE for national questions

Further remarks

37 FFIN SPEC	Do you have any comments, suggestions, experiences or ideas you want to express and let other people know? Please feel free and very welcome to write it down here. Any statement is appreciated!
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Thank you! Please write the usual text here!