



(For research team) WP5 midpoint group B. Participant code: \_\_\_\_\_

## WP5: Mid-point Questionnaire – Group B

## RHAPSODY

**(Research to Assess Policies and Strategies for Dementia in the Young)**

The questionnaire is anonymous. Please answer as honestly and accurately as you can. The information you provide will be treated with respect (as explained in the information sheet provided).

The information you provide is important and appreciated.

For dates, please use the form      /  /   /   /  /   /   /  /  .

DD    MM    YYYY

For example: July 13, 1952: \_1\_/\_3\_/\_ \_0\_/\_7\_/\_ \_1\_/\_9\_/\_5\_/\_2\_/\_  
DD MM YYYY

Date :     |\_|\_| |\_|\_| |2|0|1|6|  
                    DD    MM    YYYY

Participant Code: |\_|\_|\_|\_|

Researcher (Surname, first name): \_\_\_\_\_

## 1. Background Information Questionnaire (ENG)

This questionnaire asks about you, the person you care for, and the services that are available.

**There is no right or wrong answer – we are interested in your experience.**

Please read each question and respond by putting an “X” in the box which corresponds best to your answer. If you make a mistake please draw a line through the incorrect information then write the correct information above or check the correct box.

### Section A : Caregiving experience

1	During the last 6 weeks, have you used the internet to get information or advice, relating to the illness of the PwYOD? (E.g. about managing symptoms, medical information, accessing practical help, etc.)	No <input type="checkbox"/> Yes <input type="checkbox"/>  If yes, please indicate roughly how much time you have spent in the last 6 weeks - Less than 1 hour <input type="checkbox"/> Less than 5 hours <input type="checkbox"/> Less than 10 hours <input type="checkbox"/> 10 hours or more <input type="checkbox"/>
2	<b>Over the last 4 weeks</b> , about how many days away from your caring responsibilities have you had? (Please add half days together to give a total number of days.)	<input type="checkbox"/> < 5 days <input type="checkbox"/> 5 -10 days <input type="checkbox"/> > 10 days
3	Roughly how long can you leave the person you care for at home alone?	<input type="checkbox"/> Not at all <input type="checkbox"/> Up to 1 hour <input type="checkbox"/> Up to a ½ day <input type="checkbox"/> A whole day <input type="checkbox"/> A whole day and night
4	Do you know who to contact with questions about treatment or care of the person with dementia?	<input type="checkbox"/> Yes <input type="checkbox"/> No

## 2. Coping with Caregiving Questionnaire

**How well informed do you feel about coping with early onset dementia?**

To understand your experience of living with someone with young onset dementia, it is important to us to know how well informed you feel about ways of caring and coping. **Please read each item below, and tick the box that best indicates how well informed you feel today about the topic.**

	Topic	Very poorly informed 1	Poorly informed 2	Moderately informed 3	Quite well informed 4	Very well informed 5	Not Applicable to my situation 9
1	Symptoms of young onset dementia						
2	Dementia treatments (drugs and/or therapies)						
3	Differences between dementia in younger and older people						
4	The different ways dementia affects individuals	Data not used					
5	How to help with memory problems						
6	How to help with language problems						
7	How to help with orientation problems						
8	How to help with depression and anxiety						
9	How to help with agitation and anger						
10	How to cope with changes in your relationship						
11	How to cope with your own emotions (anger, grief, guilt)						
12	Finding out about legal and financial matters						
13	Where to find out about community support						
14	How to ask others for practical help						
15	When respite or residential care may help						
16	How talking to others about dementia may help						
17	How to relax and find time to look after yourself						

### 3. Revised Scale for Caregiving Self-Efficacy

We are interested in how confident you are that you can keep up your own activities and also respond to caregiving situations. Please think carefully about the questions asked below and be as frank and honest as you can about what you really think you can do. Please think about each item and state how confident you are that you could do each item.

Rate your degree of confidence from 0 to 100 using the scale below.

0	10	20	30	40	50	60	70	80	90	100
Cannot do					Moderately					Certain
at all					certain can do					can do

For example, a rating of 20% confidence means that it is unlikely, but not totally out of the question for you to be able to perform the activity. A rating of 100% means that you are absolutely certain that you could perform the activity whenever you wished. A 50 confidence rating means that if you gave it your best effort, chances are about 50-50 that you could perform the activity. You can use any score between 0 and 100 (10, 20, 30, etc.) to express your confidence.

--- Please make all your ratings based on what you could do **TODAY**, as the person you are **NOW** rather than on the person you used to be, or the person you would like to be. Rate how you think you would do as you are **TODAY**. ---

#### PRACTICE RATING

To familiarize you with the rating form, please complete this practice item first.

0	10	20	30	40	50	60	70	80	90	100
Cannot do					Moderately					Certain
at all					certain can do					can do

If you were asked to lift objects of different weights right now, how confident are you that you can:

#### Physical Strength

- |   |                          |
|---|--------------------------|
| 1. Lift a 10 pound 5 kilogram (kg) object | Certainty (0-100) _____% |
| 2. Lift a 20 pound 10 kg object           | Certainty (0-100) _____% |
| 3. Lift a 50 pound 20 kg object           | Certainty (0-100) _____% |
| 4. Lift a 100 pound 45 kg object          | Certainty (0-100) _____% |

As a guide, a typical bag of sugar weighs just over 2 pounds (1 kilogram), so a 10 pound object would be similar to a shopping bag holding 4 bags of sugar.

For the questions below, please rate **how confident you are that you can do the following activities**. If a question is *absolutely* not applicable to your situation, write N/A.

0	10	20	30	40	50	60	70	80	90	100
Cannot do at all					Moderately certain can do					Certain can do

## Self-Efficacy for Obtaining Respite

5. How confident are you that you can ask a friend/family member to stay with the person with young onset dementia (YOD) for a day when you need to see the doctor yourself?

*Certainty (0-100)* \_\_\_\_\_%

6. How confident are you that you can ask a friend/family member to stay with the person with YOD for a day when you have errands to be done?

*Certainty (0-100)* \_\_\_\_\_%

7. How confident are you that you can ask a friend or family member to do errands for you?

*Certainty (0-100)* \_\_\_\_\_%

8. How confident are you that you can ask a friend/family member to stay with the person with YOD for a day when you feel the need for a break?

*Certainty (0-100)* \_\_\_\_\_%

9. How confident are you that you can ask a friend/family member to stay with the person with YOD for a week?

*Certainty (0-100)* \_\_\_\_\_%

0	10	20	30	40	50	60	70	80	90	100
Cannot do at all					Moderately certain can do					Certain can do

## Self-Efficacy for Responding to Disruptive Patient Behaviors

10. When the person with YOD forgets their daily routine and asks when lunch is right after they have eaten, how confident are you that you can answer him/her without raising your voice?

*Certainty (0-100)* \_\_\_\_\_%

11. When you get angry because the person with YOD repeats the same question over and over, how confident are you that you can say things to yourself that calm you down?

*Certainty (0-100)* \_\_\_\_\_%

12. When the person with YOD complains to you about how you're treating him/her, how confident are you that you can respond without arguing back? (e.g., reassure or distract him/her?)

*Certainty (0-100)* \_\_\_\_\_%

13. When the person with YOD asks you 4 times in the first one hour after lunch when lunch is, how confident are you that you can answer him/her without raising your voice?

*Certainty (0-100)* \_\_\_\_\_%

14. When the person with YOD interrupts you for the fourth time while you're making dinner, how confident are you that you can respond without raising your voice?

*Certainty (0-100)* \_\_\_\_\_%

*All cares sometimes have negative thoughts about their situation. Some thoughts may be brief and easy to get rid of. Other times, thoughts may be hard to put out of your mind, just like a silly tune is sometimes hard to get out of your mind. We would like to know how well you can turn off any of the following thoughts. Use the same confidence rating. Don't be concerned about how often the thoughts come up. We want you to rank your confidence that you can turn off or get rid of each type of thought when it does come up."*

***If you have absolutely never had the thoughts in one of the items, put "N/A" (not applicable) on the line for rating confidence.***

0	10	20	30	40	50	60	70	80	90	100
Cannot do at all					Moderately certain can do					Certain can do

## **Self-Efficacy for Controlling Upsetting Thoughts about Caregiving**

15. How confident are you that you can control thinking about unpleasant aspects of taking care of the person with YOD?

*Certainty (0-100)* \_\_\_\_\_%

16. How confident are you that you can control thinking how unfair it is that you have to put up with this situation (taking care of the person with YOD)?

*Certainty (0-100)* \_\_\_\_\_%

17. How confident are you that you can control thinking about what a good life you had before the person with YOD illness and how much you've lost?

*Certainty (0-100)* \_\_\_\_\_%

18. How confident are you that you can control thinking about what you are missing or giving up because of the person with YOD?

*Certainty (0-100)* \_\_\_\_\_%

19. How confident are you that you can control worrying about future problems that might come up with the person with YOD?

*Certainty (0-100)* \_\_\_\_\_%

## 4. Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate by circling how often you felt or thought a certain way.

In the last month, how often...	Never 0	Almost Never 1	Sometimes 2	Fairly Often 3	Very Often 4
1. ... have you been upset because of something that happened unexpectedly?					
2. ... have you felt that you were unable to control the important things in your life?					
3. ... have you felt nervous and "stressed"?					
4. ... have you felt confident about your ability to handle your personal problems?					
5. ... have you felt that things were going your way?					
6. ... have you found that you could not cope with all the things that you had to do?					
7. ... have you been able to control irritations in your life?					
8. ... have you felt that you were on top of things?					
9. ... have you been angered because of things that were outside of your control?					
10. ... have you felt difficulties were piling up so high that you could not overcome them?					



## 5. E5-EQ-DL Health Questionnaire

Under each heading, please tick the 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 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 ☐

### 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 ☐

## 6. Burden Scale for Family Care-givers, short version (BSFC-s)

We are asking you for information about your present situation. The present situation comprises your caregiving deduced from the illness of your family member (or friend).

The following statements often refer to the type of your assistance. This may be any kind of support up to nursing care.

Please draw an "X" for the best description of your present situation. Please answer every question!

	strongly agree	agree	disagree	strongly disagree
1. My life satisfaction has suffered because of the care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I often feel physically exhausted.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. From time to time I wish I could "run away" from the situation I am in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Sometimes I don't really feel like "myself" as before.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Since I have been a caregiver my financial situation has decreased.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My health is affected by the care situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. The care takes a lot of my own strength.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I feel torn between the demands of my environment (such as family) and the demands of the care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I am worried about my future because of the care I give.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. My relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## 7. Revised Memory and Behaviour Checklist

**Instructions:** The following is a list of problems patients sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened? Use the following scales for the frequency of the problem and your reaction to it. Please read the descriptions of the ratings carefully.

Frequency ratings:

0 = never occurred  
1 = not in the past week  
2 = 1 to 2 times in the past week  
3 = 3 to 6 times in the past week  
4 = daily or more often  
9 = don't know / not applicable

Reaction ratings:

0 = not at all  
1 = a little  
2 = moderately  
3 = very much  
4 = extremely  
9 = don't know / not applicable

Please answer all the questions below. Please circle a number from 0-9 for both frequency and reaction.

		Frequency	Reaction (how much it bothered you)
1	Asking the same question over and over.	0 1 2 3 4 9	0 1 2 3 4 9
2	Trouble remembering recent events (i.e. items in newspaper or on TV).	0 1 2 3 4 9	0 1 2 3 4 9
3	Trouble remembering significant past events.	0 1 2 3 4 9	0 1 2 3 4 9
4	Losing or misplacing things.	0 1 2 3 4 9	0 1 2 3 4 9
5	Forgetting what day it is.	0 1 2 3 4 9	0 1 2 3 4 9
6	Starting, but not finishing, things.	0 1 2 3 4 9	0 1 2 3 4 9
7	Difficulty concentrating on a task.	0 1 2 3 4 9	0 1 2 3 4 9
8	Destroying property.	0 1 2 3 4 9	0 1 2 3 4 9
9	Doing things that embarrass you.	0 1 2 3 4 9	0 1 2 3 4 9
10	Waking up other family members up at night.	0 1 2 3 4 9	0 1 2 3 4 9
11	Talking loudly and rapidly.	0 1 2 3 4 9	0 1 2 3 4 9
12	Appears anxious or worried.	0 1 2 3 4 9	0 1 2 3 4 9

Frequency ratings:

0 = never occurred  
1 = not in the past week  
2 = 1 to 2 times in the past week  
3 = 3 to 6 times in the past week  
4 = daily or more often  
9 = don't know / not applicable

Reaction ratings:

0 = not at all  
1 = a little  
2 = moderately  
3 = very much  
4 = extremely  
9 = don't know / not applicable

13	Engaging in behavior that is potentially dangerous to self or others.	0 1 2 3 4 9	0 1 2 3 4 9
14	Threats to hurt oneself.	0 1 2 3 4 9	0 1 2 3 4 9
15	Threats to hurt others.	0 1 2 3 4 9	0 1 2 3 4 9
16	Aggressive to others verbally.	0 1 2 3 4 9	0 1 2 3 4 9
17	Appears sad or depressed.	0 1 2 3 4 9	0 1 2 3 4 9
18	Expressing feelings of hopelessness or sadness about the future (e.g. "Nothing worthwhile ever happens" / "I never do anything right")	0 1 2 3 4 9	0 1 2 3 4 9
19	Crying and tearfulness.	0 1 2 3 4 9	0 1 2 3 4 9
20	Commenting about death of self or others (e.g. "Life isn't worth living")	0 1 2 3 4 9	0 1 2 3 4 9
21	Talking about feeling lonely.	0 1 2 3 4 9	0 1 2 3 4 9
22	Comments about feeling worthless or being a burden to others.	0 1 2 3 4 9	0 1 2 3 4 9
23	Comments about feeling like a failure, or about not having any worthwhile accomplishments in life.	0 1 2 3 4 9	0 1 2 3 4 9
24	Arguing, irritability and/or complaining.	0 1 2 3 4 9	0 1 2 3 4 9