



WP5: Final Questionnaire – Group B

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

The information you provide is important and appreciated.

For example: July 13, 1952: _1_/_3_/_0_/_7_/_1_/_9_/_5_/_2_/_
DD MM YYYY

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.

Section A : Caregiving experience

1	Over the last 4 weeks , 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
2	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
3	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						
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	Data not used					
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 at all					Moderately certain can do					Certain 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 at all					Moderately certain can do					Certain 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 caregivers 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 people with dementia 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

8. Programme Content

**A. The following questions are about the content and format of the program.
Please circle the appropriate response for each question.**

1. Overall I would rate the quality of the programme as

<i>Poor</i>	<i>Fair</i>	<i>Good</i>	<i>Very good</i>	<i>Excellent</i>
1	2	3	4	5

2. I would recommend this programme to others

<i>Strongly disagree</i>	<i>Disagree</i>	<i>Neutral</i>	<i>Agree</i>	<i>Strongly agree</i>
1	2	3	4	5

3. The content of modules was easy to understand

<i>Strongly disagree</i>	<i>Disagree</i>	<i>Neutral</i>	<i>Agree</i>	<i>Strongly agree</i>
1	2	3	4	5

4. I received relevant information

<i>Strongly disagree</i>	<i>Disagree</i>	<i>Neutral</i>	<i>Agree</i>	<i>Strongly agree</i>
1	2	3	4	5

5. I feel able to put what learned from the programme to use day-to-day

<i>Strongly disagree</i>	<i>Disagree</i>	<i>Neutral</i>	<i>Agree</i>	<i>Strongly agree</i>
1	2	3	4	5

6. It was difficult to find the time to use the programme

<i>Strongly disagree</i>	<i>Disagree</i>	<i>Neutral</i>	<i>Agree</i>	<i>Strongly agree</i>
1	2	3	4	5

7. I found communicating with other carers on the forum helpful

<i>Strongly disagree</i>	<i>Disagree</i>	<i>Neutral</i>	<i>Agree</i>	<i>Strongly agree</i>
1	2	3	4	5

8. I received support from other carers via the forum

<i>Strongly disagree</i>	<i>Disagree</i>	<i>Neutral</i>	<i>Agree</i>	<i>Strongly agree</i>
1	2	3	4	5

9. It was helpful to hear the experiences and suggestions of other carers on the forum

<i>Strongly disagree</i>	<i>Disagree</i>	<i>Neutral</i>	<i>Agree</i>	<i>Strongly agree</i>
1	2	3	4	5

10. The information in the programme was :

<i>Far too general</i>	--	<i>Just Right</i>	--	<i>Far too detailed</i>
1	2	3	4	5

11. I found the number of individual modules :

<i>Not enough</i>	--	<i>Just right</i>	--	<i>Too many</i>
1	2	3	4	5

12. I found the duration of individual modules :

<i>Far too short</i>	--	<i>Just right</i>	--	<i>Far too long</i>
1	2	3	4	5

13. The overall length of the programme was :

<i>Far too short</i>	--	<i>Just right</i>	--	<i>Far too long</i>
1	2	3	4	5

B. Please provide a rating to indicate how helpful you found each part of the program. If you did not use one of the parts below, please write 'NA' instead.

1. What is Young Onset Dementia?

<i>Totally unhelpful</i>	<i>Unhelpful</i>	<i>Neutral</i>	<i>Helpful</i>	<i>Very helpful</i>
1	2	3	4	5

2. A medical perspective on Young Onset Dementia

<i>Totally unhelpful</i>	<i>Unhelpful</i>	<i>Neutral</i>	<i>Helpful</i>	<i>Very helpful</i>
1	2	3	4	5

3. Frequent problems and solutions

<i>Totally unhelpful</i>	<i>Unhelpful</i>	<i>Neutral</i>	<i>Helpful</i>	<i>Very helpful</i>
1	2	3	4	5

4. Dealing with challenging behaviours

<i>Totally unhelpful</i>	<i>Unhelpful</i>	<i>Neutral</i>	<i>Helpful</i>	<i>Very helpful</i>
1	2	3	4	5

5. Family issues

<i>Totally unhelpful</i>	<i>Unhelpful</i>	<i>Neutral</i>	<i>Helpful</i>	<i>Very helpful</i>
1	2	3	4	5

6. How to get help

<i>Totally unhelpful</i>	<i>Unhelpful</i>	<i>Neutral</i>	<i>Helpful</i>	<i>Very helpful</i>
1	2	3	4	5

7. Looking after yourself

<i>Totally unhelpful</i>	<i>Unhelpful</i>	<i>Neutral</i>	<i>Helpful</i>	<i>Very helpful</i>
1	2	3	4	5

C. For each statement below, please tick the box that best represents how you feel now, since using the online resource.

	<i>Knowledge, skills, coping</i>	<i>Strongly Disagree 1</i>	<i>Slightly Disagree 2</i>	<i>Neutral 3</i>	<i>Slightly Agree 4</i>	<i>Strongly Agree 5</i>
1.	I have a better understanding of the reactions and behaviour of the person I care for.					
2.	I am able to communicate and interact better with the person I care for.					
3.	I do more varied activities with the person I care for.					
4.	My ideas about the disease have changed.					
5.	I feel I can manage everyday situations more easily					
6.	I feel more able to cope in my caring role					

<i>Stress and mood</i>		<i>Strongly Disagree 1</i>	<i>Slightly Disagree 2</i>	<i>Neutral 3</i>	<i>Slightly Agree 4</i>	<i>Strongly Agree 5</i>
7.	I get less easily annoyed or irritated with the person I care for					
8.	I feel less nervous/ anxious.					
9.	My general health has improved.					
10.	My mood has improved					
11.	I experience less conflict with the person I care for					
<i>Self-care / getting help</i>		<i>Strongly Disagree 1</i>	<i>Slightly Disagree 2</i>	<i>Neutral 3</i>	<i>Slightly Agree 4</i>	<i>Strongly Agree 5</i>
12.	I accept help from others with my caring responsibilities more easily.					
13.	I can ask for help from friends and family more easily					
14.	I managed to find more time to do things that I like.					
15.	I now feel less guilt about doing things for myself					
16.	The programme has helped me to take more care of myself					
17.	I am now more conscious of my own needs					

9. Programme Technology

The following questions are about how you found using the programme TECHNOLOGY, rather than the information provided in the presentations and videos.

Perceived Usefulness

1. *Using the programme enables me to manage better in my role as a carer*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

2. *Using the programme makes me more constructive in my role as a carer*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

3. *Using the programme makes me more effective in my role as a carer*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

4. *I find the programme to be useful in my role as a carer*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

Perceived Ease of Use

5. *Interacting (using) the programme is clear and understandable*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

6. *Interacting with the programme does not require a lot of mental effort*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

7. *I find the programme easy to use*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

8. *I find it easy to get the programme to do what I want it to do.*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

Computer self-efficacy

9. *I was able to use the programme with no one around to tell me what to do as I go*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

10. *I was able to use the programme using just the built-in help facility for assistance*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

11. *I was able to use the programme if someone showed me how to do it first*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

12. *I was able to use the programme as I have used similar programmes before this one to do a similar activity.*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

Behavioural Intention

13. *If I can have access to the programme in future, I intend to use it*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

14. *If I had access to the programme, I predict that I would use it*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

15. *If the programme were available in the next 6 months, I would plan to use it.*

Strongly Disagree			Neutral (neither agree nor disagree)			Strongly Agree
1	2	3	4	5	6	7

For Researcher use only (not for eCRF)

11. Qualitative Feedback

Opening statement.

We would be grateful for your honest feedback about the program and your experience of using it.

Optional prompt for encouraging comments from participants who have not used the program extensively, without actually indicating to them that we are aware of low use.

Were there any challenges to using the program?

- i. During the pilot, have you found information in the online resource that answered queries you would otherwise have taken to a health and social care professional? Yes/ No
If Yes, please tell us what information you used and how it helped you.
- ii. In the future, can you envisage using the online resources to answer some queries instead of contacting a health and social care professional? Yes / No.
If Yes, please tell us how the online resource may help you.
- iii. What were the most helpful/preferred aspects of the programme?
- iv. What were the least helpful/weaker aspects of the programme?
- v. Do you have any suggestions to improve the programme?
- vi. Did you experience technological problems? If yes, please describe
- vii. If the Rhapsody programme was made available to purchase, would you consider buying it?
Yes ☐ No ☐
If you answered YES:
What would be an appropriate price?
Less than £10 ☐ £10-20 ☐ More than £20 ☐
Which form of payment would you prefer, in order to access the programme?
One-off payment ☐ Subscription based payment (i.e. monthly fee) ☐