



NIA/NINR

Resources for Enhancing Alzheimer's Caregiver Health

Baseline Battery (BA)

Completion Log		
	Person	Date
Data collected		____/____/____
Data entered		____/____/____
System ID		
Data verified		____/____/____
Data cleaned		____/____/____
Data transferred		____/____/____
Subject ID		



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Baseline Introduction

Thank you for participating in the REACH II project. Your assistance will help us to learn more about how to help people like yourself, who are taking care of a family member at home, to effectively manage their day-to-day lives. The questions that I will ask you take about two hours. I will be asking a variety of questions about (CR) as well as yourself. They include general background information, questions about your health, activities, and your attitudes or opinions.

All of the information that you give me will be kept strictly confidential. At any time, if you are uncomfortable answering any questions in the survey, you can refuse to answer the questions. You are also free to stop the interview at any time. However, you should know that your answers are very important to us. The completion of the interview is important for scientific purposes.

For most of the questions I will be asking you, there are no right or wrong answers. We are simply interested in your opinions and feelings. If you do not understand any of the questions, you should feel free to ask me to repeat or clarify them. Finally, if you would like to take a break at any time during the session, just let me know.

INTERVIEW COVER PAGE (BA)

1. Which interview is taking place?

0 () Baseline

1 () 6 month follow-up →

1.1 Specify type:

0 () Core follow-up

1 () Placement

2 () Bereavement

2 () Discontinued

2. Date interview started: / /
MM DD YYYY

3. Date interview completed: / /
MM DD YYYY

4. Interviewer's name: _____
Last, First

5. REACH certification number: _____

Baseline battery only:

6. Has the caregiver (CG) given consent to participate in the study? 0 () No 1 () Yes

Baseline battery only:

7. Has the care recipient (CR) given consent to participate in the study or has proxy consent been obtained? 0 () No 1 () Yes

For reporting to Principal Investigator only:

8. Were any of the following acute baseline alerts reported during the interview? (check all that apply):

() No () Yes

CG CES-D score greater than or equal to 15

(baseline: see p. 56, #15; follow-up: see p. 53, #15; placement: see p. 17, # 15; bereavement: see p. 13, #15)

() No () Yes

CR has threatened to hurt him/herself 3 or more times in the past week

(baseline: see p. 41, # 32; follow-up: see p. 38, #32)

() No () Yes

CR has commented about the death of him/herself or others 3 or more times in the past week

(baseline: see p. 41, # 33; follow-up: see p. 38, #33)

() No () Yes

CR has access to a gun

(baseline: see p. 73, # 52; follow-up: see p. 70, #52)

() No () Yes

CR drives

(baseline: see p. 73, # 53; follow-up: see p. 70, #53)

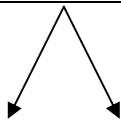
If any of the acute screening items have been indicated, please notify the Principal Investigator or appropriate site personnel immediately.

MMSE

My name is _____ and I am from _____ (name of institution). We are here to ask your (caregiver relationship or name) some questions. Could we ask you some questions? Would that be ok?

Does the care recipient appear to understand what you are asking him/her to do?

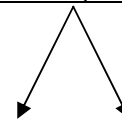
*Yes, capable of giving consent,
Is the care recipient willing to
answer the questions?*



*If yes
& consent given,
proceed with
MMSE*

*If no
& consent
not given, do not
proceed with MMSE*

*No, not capable of giving consent,
Proxy consent in effect
Is the care recipient willing to
answer the questions?*



*If yes proxy
consent,
proceed with
MMSE*

*If no proxy consent,
do not
proceed with
MMSE*

ORIENTATION

1. **Please tell me today's date.**
 - 1.1 **Can you tell me what month it is?** _____
 - 1.2 **Can you tell me what date it is?** _____
 - 1.3 **Can you tell me what year it is?** _____
 - 1.4 **Can you tell me what day it is?** _____
 - 1.5 **Can you tell me what season it is?** _____

Score _____ (Maximum score = 5)

2. **Can you tell me what building we are in right now?**
 - 2.1 **Building** _____
 - 2.2 **Floor** _____
 - 2.3 **City** _____
 - 2.4 **County** _____
 - 2.5 **State** _____

Score _____ (Maximum score = 5)

REGISTRATION

3. ***I'm going to name three objects, and I'd like you to repeat them after me, ok?*** (Name three objects, allotting one second to say each.)

APPLE ... TABLE ... PENNY

Give 1 point for each correct answer on the first trial only. Repeat the objects until the participant can name them all - maximum of 6 trials. Stop after 6 unsuccessful trials and enter a 7 for number of trials to indicate that they never learned the succession.

3.1 Number of trials _____

Score _____ (Maximum score = 3)

ATTENTION AND CALCULATION

4. ***I'm going to ask you to do some subtraction. Think of the number 7. I want you to subtract 7 from 100. Now subtract 7 from that and keep going until I stop you.*** (Enter numbers given by respondent below.)

100,

- 4.1 _____
 4.2 _____
 4.3 _____
 4.4 _____
 4.5 _____ (Stop)

Score _____ (Maximum score = 5) *

5. ***I want you to spell a word forward and then backward. The word is 'WORLD.'***

5.1 ***Spell it forward.*** _____
 (If incorrect, then correct the participant and allow him/her to respell it until he/she spells it correctly.)

5.2 ***Spell it backward.*** _____
 (Write exact letters given by respondent in blanks.)

Score _____ (Maximum score = 5) *

RECALL

6. ***Do you remember a few minutes ago I had you repeat some words after me? Can you tell me what they were?*** (Give 1 point for each correct answer)

Score _____ (Maximum score = 3)

LANGUAGE

7. **Please name these for me.** (Show the participant a wooden pencil and a watch, preferably worn on the wrist. Score 1 point for each correct answer.)

Score _____ (Maximum score = 2)

8. **I'm going to read a sentence and I want you to repeat it after me. Say exactly what I say, ok?**

NO IFS, ANDS, OR BUTS.

Score _____ (Maximum score = 1;
Score 1 point only if every word is repeated correctly.)

9. **Now I'm going to ask you to do something for me. I'm only going to say it once, so listen carefully.**

**Take this paper in your right hand;
Fold the paper in half with both hands;
and put the paper in your lap.**

Score _____ (Maximum score = 3;
Score 1 point for each stage.)

10. **Read this card, and do what the card tells you to do.** (Show the card (RC 2) with close your eyes on it. One prompt allowed after initial instructions. Score 1 point.)

Score _____ (Maximum score = 1)

11. **Now please write a sentence for me on this blank piece of paper.** (Do not dictate a sentence or provide a subject; it must be written spontaneously. Prompt as often as you like. The sentence must contain a subject and verb and be sensible. Correct grammar and punctuation not necessary. Score 1 point.)

Score _____ (Maximum score = 1)

12. **Please copy this design exactly as it is for me.** (Hold the card (RC 3) with the design on it in front of the participant; do not let the participant trace the design. All 10 angles must be present and 2 must intersect to score 1 point. Tremor and rotation are ignored.)

Score _____ (Maximum score = 1)

13. Total score _____

14. Is the MMSE Total Score = 0?

0 () No

1 () Yes

15. Does (CR) spend at least 22 hours a day in a bed or chair?

0 () No

1 () Yes

15.1 Has this occurred for at least 4 of the past 7 days?

0 () No

1 () Yes

16. Is the MMSE Total Score greater than 23?

0 () No

1 () Yes

16.1 Was an MD diagnosis of dementia obtained?

0 () No

1 () Yes

17. *Did the participant exhibit any signs of illiteracy or physical impairments that would hinder performance on any of the items in this test?*

0 () No

1 () Yes

17.1 Specify: _____

Question 18 is only asked at the baseline interview. It should be skipped for all other interviews.

18. *Is the respondent eligible to participate in the REACH project?*

0 () No (*MMSE = 0 and participant bedbound*) or (*MMSE over 23 and no MD diagnosis of dementia*)

1 () Yes

WRITE A SENTENCE:

MMSE

Subject ID

COPY THE DESIGN:

PERSONAL APPEARANCE

While administering the MMSE, please observe the following aspects of the CR's personal appearance.

	No	Yes	N/A	Unknown	Refused
1. <i>Hand and nails clean</i> No dirt or foreign matter is visible under or on fingernails, on palms or back of hands, or fingers.	0 ()	1 ()	-2 ()	-3 ()	-4 ()
2. <i>Nails clipped</i> Fingernails are of approximately the same length. Edges of nails are smooth.	0 ()	1 ()	-2 ()	-3 ()	-4 ()
3. <i>Hair clean and combed</i> Hair is free of lint, foreign materials, and excessive natural oil (unapplied). Exceptions: Dry scalp, dandruff, barrettes, hair bands, wigs, hair pieces or extensions, hair dresses.	0 ()	1 ()	-2 ()	-3 ()	-4 ()
4. <i>Face clean</i> No dirt or food is visible on face. There is no more than one piece of lint or "dust" on face. Exceptions: Do not score mucus in or on the nose in this category.	0 ()	1 ()	-2 ()	-3 ()	-4 ()
5. <i>Clean shaven</i> No beard, beard "shadow" or "patches" (uneven shaving) visible. Exceptions: Score N/A if the participant is female, or a male whose beard or mustache appears "planned".	0 ()	1 ()	-2 ()	-3 ()	-4 ()
6. <i>Shoes on</i> (including slippers) Shoes or slippers must be on both feet	0 ()	1 ()	-2 ()	-3 ()	-4 ()
7. <i>Shoes tied</i> Laces pass through every eyelet to the tops of both shoes, and are tied in bows. Exceptions: Score N/A if shoes do not require laces.	0 ()	1 ()	-2 ()	-3 ()	-4 ()
8. <i>Dressed in clothing</i> Person is dressed in a dress, or top and pants (i.e., shirts, sweatshirt or blouse, and pants or sweatpants). Score N/A if in night clothes before noon.	0 ()	1 ()	-2 ()	-3 ()	-4 ()
9. <i>Clothing is dry</i> No wet spots are visible in crotch of pants or on front or back of dress or skirt.	0 ()	1 ()	-2 ()	-3 ()	-4 ()

Personal Appearance

Subject ID

	No	Yes	N/A	Unknown	Refused
10. <i>Clothing untorn</i> There are no tears, rips, holes, or fabric pulls on clothing or shoes. Pant legs are not frayed.	0 ()	1 ()	-2 ()	-3 ()	-4 ()
11. <i>Clothing unstained</i> No dirt or stains are visible on clothing. Exceptions: Do not score stains on shoes.	0 ()	1 ()	-2 ()	-3 ()	-4 ()
12. <i>Not physically restrained</i>	0 ()	1 ()	-2 ()	-3 ()	-4 ()
13. <i>No indications of injury</i> (bruises, cuts, bites, abrasions, skin rashes or open sores.	0 ()	1 ()	-2 ()	-3 ()	-4 ()

CAREGIVER/CARE RECIPIENT SOCIODEMOGRAPHIC INFORMATION

To begin the interview, I would like to ask you to read some things for me. This will help me better understand how to present material to you throughout the interview. Don't worry about how well you are able to read. Our goal is to assist you in the best way and that means understanding how I should present things to you.

INTERVIEWER ANSWERS FOLLOWING 3 LITERACY QUESTIONS:

1. (RC4)	Caregiver read the set of words.				
	None 0 ()	Some 1 ()	All 2 ()	Unknown -3 ()	Refused -4 ()
2. (RC4)	Caregiver read CTIS screens.				
	None 0 ()	Some 1 ()	All 2 ()	Unknown -3 ()	Refused -4 ()
3. (RC4)	Caregiver read sentences.				
	None 0 ()	Some 1 ()	All 2 ()	Unknown -3 ()	Refused -4 ()

Thank you. Now I would like to obtain some general information about you and (CR).

4. (RC5)	What is your marital status? What is (CR)'s marital status?	Caregiver	Care Recipient
	Never married	0 ()	0 ()
	Married, or living as married	1 ()	1 ()
	Widowed, not currently married	2 ()	2 ()
	Divorced, not currently married	3 ()	3 ()
	Separated	4 ()	4 ()
		Unknown -3 ()	-3 ()
		Refused -4 ()	-4 ()

Caregiver

Care Recipient

5. **How many years of formal education did you (CG) complete? How many years of formal education did (CR) complete?**
(RC6)

No formal education	0 ()	0 ()
Grade 1	1 ()	1 ()
Grade 2	2 ()	2 ()
Grade 3	3 ()	3 ()
Grade 4	4 ()	4 ()
Grade 5	5 ()	5 ()
Grade 6	6 ()	6 ()
Grade 7	7 ()	7 ()
Grade 8	8 ()	8 ()
Grade 9	9 ()	9 ()
Grade 10	10 ()	10 ()
Grade 11	11 ()	11 ()
Grade 12/High School Diploma/GED	12 ()	12 ()
Vocational/training school after high school	13 ()	13 ()
Some college/associate degree	14 ()	14 ()
College graduate (4 or 5 year program)	15 ()	15 ()
Master's degree (or other post-graduate training)	16 ()	16 ()
Doctoral degree (PhD, MD, EdD, DVM, DDS, JD etc)	17 ()	17 ()
Unknown	-3 ()	-3 ()
Refused	-4 ()	-4 ()

6. **Would you describe yourself as Hispanic or Latino/a? Would (CR) describe himself/herself as Hispanic or Latino/a?**
(RC1)

No	0 ()	0 ()
Yes	1 ()	1 ()

6.1 **If Yes, Specify origin:**
(RC7)

Cuban	1 ()	1 ()
Mexican	2 ()	2 ()
Puerto Rican	3 ()	3 ()
Other	4 ()	4 ()

6.1.1 If other, specify : _____

Unknown	-3 ()	-3 ()
Refused	-4 ()	-4 ()

Caregiver

Care Recipient

7. *How would you describe your primary racial group?*
(RC8) *How would (CR) describe his/her primary racial group?*

No primary group 0 ()

0 ()

7.1 If no primary group, specify :	_____	_____
------------------------------------	-------	-------

- | | | |
|--|--------------|--------------|
| White, Caucasian | 1 () | 1 () |
| Black, African-American | 2 () | 2 () |
| American Indian or Alaska native | 3 () | 3 () |
| Asian | 4 () | 4 () |
| Native Hawaiian or other Pacific Islander | 5 () | 5 () |
| Other | 6 () | 6 () |

7.2 If other, specify :	_____	_____
-------------------------	-------	-------

- | | | |
|----------------|--------|--------|
| <i>Unknown</i> | -3 () | -3 () |
| <i>Refused</i> | -4 () | -4 () |

8. *In which country where you born? In which country was (CR) born?*
(RC9)

- | | | |
|----------------------|--------------|--------------|
| United States | 1 () | 1 () |
| Canada | 2 () | 2 () |
| Cuba | 3 () | 3 () |
| Mexico | 4 () | 4 () |
| Other | 5 () | 5 () |

8.1 If other, specify :	_____	_____
-------------------------	-------	-------

- | | | |
|----------------|--------|--------|
| <i>Unknown</i> | -3 () | -3 () |
| <i>Refused</i> | -4 () | -4 () |

9. *How many years have you lived in the United States?* ___ Years
How many years has (CR) lived in the United States? ___ Years

10. **What is your current employment status?**
(RC10)

- 1 () **Employed at a job for pay, full-time**
- 2 () **Employed at a job for pay, part-time**
- 3 () **Homemaker, not currently working for pay**
- 4 () **Not currently employed, retired**
- 5 () **Not currently employed, not retired**
- 3 () Unknown
- 4 () Refused

10.1 **Are you employed outside of the home?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

10.2 **How many hours per week do you work at your paid job?** ____ : ____
hours minutes

10.3 **Have you had to reduce the number of hours that you work in an average week in order to provide care to (CR)?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

10.3.1 **How many hours have you had to reduce per week?** ____ : ____
hours minutes

10.4 **Did you stop working because of (CR's) need for care?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

10.4.1 **Why?**
(RC11)

- 1 () You anticipated having to care for (CR)
- 2 () To provide additional care for (CR)
- 3 () Other

↓

10.4.1.1 **Specify** _____

11. **Other than problems with memory or confusion, how would you rate the physical health of (CR)?**
(RC12)

- 1 () **Poor**
- 2 () **Fair**
- 3 () **Good**
- 4 () **Very good**
- 5 () **Excellent**
- 3 () *Unknown*
- 4 () *Refused*

Next, I would like to ask you about your household income. Some people may not be comfortable answering this question, but I want to assure you that your responses will be kept strictly confidential. This information is very important to the project because it helps us understand how caregiving affects people with different incomes.

12. **Which category on this card [give respondent card] best describes your yearly household income before taxes? Do not give me the dollar amount, just give me the category. Include all income received from employment, social security, support from children or other family, welfare, Aid to Families with Dependent Children (AFDC), bank interest, retirement accounts, rental property, investments, etc.**
(RC13)

- 0 () **Less than \$5000**
- 1 () **\$5000 - \$9,999**
- 2 () **\$10,000 - \$14,999**
- 3 () **\$15,000 - \$19,999**
- 4 () **\$20,000 - \$29,999**
- 5 () **\$30,000 - \$39,999**
- 6 () **\$40,000 - \$49,999**
- 7 () **\$50,000 - \$59,999**
- 8 () **\$60,000 - \$69,999**
- 9 () **\$70,000 - \$99,999**
- 10 () **\$100,000 or more**
- 3 () *Unknown*
- 4 () *Refused*

13. **How hard is it for you to pay for the very basics like food, housing, medical care, and heating? Would you say it is:**
(RC14)

- 0 () **Not difficult at all**
- 1 () **Not very difficult**
- 2 () **Somewhat difficult**
- 3 () **Very difficult**
- 3 () *Unknown*
- 4 () *Refused*

14. **What best describes the type of dwelling that you live in?**

(RC15)

- 1 () **Single-story single family home**
- 2 () **Multiple-story single family home**
- 3 () **Condominium**
- 4 () **Apartment**
- 5 () **Assisted living facility**
- 6 () **Other** _____ ▼

14.1 **If other, specify** _____

- 3 () *Unknown*
- 4 () *Refused*

15. **How many people are living with you in your home excluding yourself?** ___ ___ *persons*

16. **How long have you and (CR) lived together?** ___ ___ *years*

17. **Did you and (CR) start living together so that you could take care of him/her?**

(RC1)

- | | | | |
|-------|-------|---------|---------|
| No | Yes | Unknown | Refused |
| 0 () | 1 () | -3 () | -4 () |

Now, I would like to ask you for some information that may be viewed as sensitive by some people. However, one of the things that we are trying to learn more about is the use of healthcare services by caregivers. The best place to get this information without taking up a lot of your time is the Medicare files. I would like to record your Medicare and social security numbers for this purpose. Let me remind you that if you prefer not to answer, it will not affect your eligibility or continued participation in the REACH II Project. While some people may not be comfortable giving this information, I want to assure you that your responses will be kept strictly confidential and will be used for research purposes only.

18. **May I please have your Medicare number?**

— — — -- — — -- — — — — -- — —

19. **May I please have your social security number?**

— — — -- — — -- — — — —

20. **May I please have (CR)'s Medicare number?**

— — — -- — — -- — — — — -- — —

21. **May I please have (CR)'s social security number?**

— — — -- — — -- — — — —

ADL/IADL

(Read aloud:) **Now I am going to ask you some questions about the specific kinds of problems (CR) might have been having this past week. For each area, I will ask you whether he/she has needed any kind of help. "Help" means supervision, direction, or personal assistance.**

1. **During the past week, has (CR) needed any kind of help using the telephone?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

1.1. **Did you help with this?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

1.1.1 **How much does helping with this bother or upset you?**
(RC16)

0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

2. **During the past week, has (CR) needed any kind of help with shopping (going to a store for light groceries)?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

2.1. **Did you help with this?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

2.1.1 **How much does helping with this bother or upset you?**
(RC16)

0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

3. **During the past week, has (CR) needed any kind of help with food preparation (making lunch or light meals)?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

3.1.1 Did you help with this?
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

3.1.1 How much does helping with this bother or upset you?
(RC16)

0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

4. **During the past week, has (CR) needed any kind of help with housekeeping (making bed, vacuuming, dusting)?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

4.1 Did you help with this?
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

4.1.1 How much does helping with this bother or upset you?
(RC16)

0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

5. **During the past week, has (CR) needed any kind of help with doing laundry?**
(RC1)

No 0 () Yes 1 () Unknown -3 () Refused -4 ()

<p>5.1 Did you help with this? (RC1)</p> <p>No 0 () Yes 1 () Unknown -3 () Refused -4 ()</p>	
<p>5.1.1 How much does helping with this bother or upset you? (RC16)</p> <p>0 () Not at all 1 () A little 2 () Moderately 3 () Very Much 4 () Extremely -3 () Unknown -4 () Refused</p>	

6. **During the past week, has (CR) needed any kind of help traveling by car, bus, etc.?**
(RC1)

No 0 () Yes 1 () Unknown -3 () Refused -4 ()

<p>6.1 Did you help with this? (RC1)</p> <p>No 0 () Yes 1 () Unknown -3 () Refused -4 ()</p>	
<p>6.1.1 How much does helping with this bother or upset you? (RC16)</p> <p>0 () Not at all 1 () A little 2 () Moderately 3 () Very Much 4 () Extremely -3 () Unknown -4 () Refused</p>	

7. **During the past week, has (CR) needed any kind of help taking his/her medications in the correct dosages or at the correct time?**
(RC1)

No 0 () Yes 1 () Unknown -3 () Refused -4 ()

7.1 Did you help with this? (RC1)	
No 0 ()	Yes 1 ()
Unknown -3 () Refused -4 ()	
7.1.1 How much does helping with this bother or upset you? (RC16)	
0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

8. **During the past week, has (CR) needed any kind of help handling his/her finances?**
(RC1)

No 0 () Yes 1 () Unknown -3 () Refused -4 ()

8.1 Did you help with this? (RC1)	
No 0 ()	Yes 1 ()
Unknown -3 () Refused -4 ()	
8.1.1 How much does helping with this bother or upset you? (RC16)	
0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

9. **In the past six months, have you seen any improvement overall, in the areas we just discussed?**
 (RC1) (e.g. using the telephone, shopping, handling finances, taking medications, traveling).

No 0 () Yes 1 () Unknown -3 () Refused -4 ()

9.1 Was the improvement minimal or substantial?
 (RC18)

Minimal improvement 1 ()	Substantial improvement 2 ()	Unknown -3 ()	Refused -4 ()
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9.2 What were the areas of improvements? (check all that apply)
 (RC17)

<input type="checkbox"/> Using the phone	<input type="checkbox"/> Laundry
<input type="checkbox"/> Shopping	<input type="checkbox"/> Traveling by car, bus, etc.
<input type="checkbox"/> Food preparation	<input type="checkbox"/> Taking medication
<input type="checkbox"/> Housekeeping	<input type="checkbox"/> Finances

9.3 Was there no change, minimal decline or substantial decline in these areas?
 (RC19)

No change 1 ()	Minimal decline 2 ()	Substantial decline 3 ()	Unknown -3 ()	Refused -4 ()
---------------------------	---------------------------------	-------------------------------------	-------------------	-------------------

10. **During the past week, has (CR) needed any kind of help getting into or out of a bed, chair or wheelchair?**
 (RC1)

No 0 () Yes 1 () Unknown -3 () Refused -4 ()

10.1 Did you help with this?
 (RC1)

No 0 ()	Yes 1 ()	Unknown -3 ()	Refused -4 ()
-------------	--------------	-------------------	-------------------

10.1.1 How much does helping with this bother or upset you?
 (RC16)

0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

11. **During the past week, has (CR) needed any kind of help eating meals?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

11.1 **Did you help with this?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

11.1.1 **How much does helping with this bother or upset you?**
(RC16)

0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

12. **During the past week, has (CR) needed any kind of help bathing, either in the tub, shower, or a sponge bath, such as rinsing or drying the body, excluding the back?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

12.1 **Did you help with this?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

12.1.1 **How much does helping with this bother or upset you?**
(RC16)

0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

13. **During the past week, has (CR) needed any kind of help dressing from the waist up?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

13.1 **Did you help with this?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

13.1.1 **How much does helping with this bother or upset you?**
(RC16)

0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

14. **During the past week, has (CR) needed any kind of help dressing from the waist down?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

14.1 **Did you help with this?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

14.1.1 **How much does helping with this bother or upset you?**
(RC16)

0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

15. **During the past week, has (CR) needed any kind of help toileting, such as adjusting clothing before and after toilet use or cleansing?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

15.1 Did you help with this?
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

15.1.1 How much does helping with this bother or upset you?
(RC16)

0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

16. **During the past week, has (CR) needed any kind of help grooming, such as brushing teeth, combing or brushing hair, washing hands, washing face, and either shaving or applying makeup?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

16.1 Did you help with this?
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

↓

16.1.1 How much does helping with this bother or upset you?
(RC16)

0 ()	Not at all
1 ()	A little
2 ()	Moderately
3 ()	Very Much
4 ()	Extremely
-3 ()	Unknown
-4 ()	Refused

17. **In the past six months, have you seen any improvement overall, in the areas we just discussed**
 (RC1) (e.g. bathing, grooming, dressing, eating, toileting).

No 0 () Yes 1 () Unknown -3 () Refused -4 ()

17.1 **Was the improvement minimal or substantial?**
 (RC18)

<i>Minimal improvement</i>	<i>Substantial improvement</i>	Unknown	Refused
1 ()	2 ()	-3 ()	-4 ()

17.2 **What were the areas of improvements?** (check all that apply)
 (RC20)

<input type="checkbox"/> Getting into/out of bed, chair etc.	<input type="checkbox"/> Dressing from the waist down
<input type="checkbox"/> Eating meals	<input type="checkbox"/> Toileting
<input type="checkbox"/> Bathing	<input type="checkbox"/> Grooming
<input type="checkbox"/> Dressing from the waist up	

17.3 **Was there no change, minimal decline or substantial decline in these areas?**
 (RC19)

<i>No change</i>	<i>Minimal decline</i>	<i>Substantial decline</i>	Unknown	Refused
1 ()	2 ()	3 ()	-3 ()	-4 ()

18. **How many days in the past week have other family members or friends (who are not being paid) provided help?** ("Help" means supervision, direction or personal assistance).
 (RC21)

- 0 () **No others have provided help**
- 1 () **One day in the past week** _____
- 2 () **Two days in the past week** _____
- 3 () **Three days in the past week** _____
- 4 () **Four days in the past week** _____
- 5 () **Five days in the past week** _____
- 6 () **Six days in the past week** _____
- 7 () **Seven days in the past week** _____
- 3 () Unknown
- 4 () Refused

18.1 **How useful is this help to you?**
 (RC22)

1 ()	Not at all useful
2 ()	Somewhat useful
3 ()	Moderately useful
4 ()	Very useful
-3 ()	Unknown
-4 ()	Refused

VIGILANCE

The last set of questions were about the kinds of assistance (CR) requires with daily activities. What I want to ask you now concerns the time you spend supervising, or just "being around" for (CR).

1. (RC1) **In the case of a family emergency, are you able to leave (CR) home alone, that is with no one else there?**

No Yes Unknown Refused
 0 () 1 () -3 () -4 ()



1.1 **How long can you leave (CR) home alone?** ___ : ___
hours : minutes

2. (RC1) **Can (CR) be left alone in a room as long as someone is in the house?**

No Yes Unknown Refused
 0 () 1 () -3 () -4 ()



2.1 **How long can you leave (CR) alone in a room?** ___ : ___
hours : minutes

3. **Some people have told us that they feel their caregiving is a time-consuming job. They say that even when they aren't actually doing something special for or with their relative, they feel "on duty" or the need to "be there" for him/her. About how many hours a day do you feel the need to "be there" or "on duty" to care for (CR)?**

___ hours

4. **About how many hours a day do you estimate that you are actually doing things for (CR)?**

___ hours

REVISED MEMORY AND BEHAVIOR PROBLEMS CHECKLIST

Now I'd like to ask you about some of the problems you may have encountered while caring for (CR). I will read a list of specific problems (CR) may 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.

1. **Within the past week, has (CR) experienced any memory or behavior problems?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

1.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
1.2 (RC16)	How confident do you feel about handling these problems?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

2. **Within the past week, has (CR) been asking the same question over and over?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

2.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
2.2 (RC16)	How confident do you feel about handling this behavior?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

3. **Within the past week, has (CR) had trouble remembering recent events** (e.g., items in the newspaper or on TV)?
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

3.1 **How bothered or upset were you by this?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

3.2 **How confident do you feel about handling this behavior?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

4. **Within the past week, has (CR) had trouble remembering significant past events?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

4.1 **How bothered or upset were you by this?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

4.2 **How confident do you feel about handling this behavior?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

5. **Within the past week, has (CR) been losing or misplacing things?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

5.1 **How bothered or upset were you by this?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

5.2 **How confident do you feel about handling this behavior?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

6. **Within the past week, has (CR) been forgetting what day it is?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

6.1 **How bothered or upset were you by this?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

6.2 **How confident do you feel about handling this behavior?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

7. **Within the past week, has (CR) been starting but not finishing things?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

7.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
7.2 (RC16)	How confident do you feel about handling this behavior?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

8. **Within the past week, has (CR) had difficulty concentrating on a task?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

8.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
8.2 (RC16)	How confident do you feel about handling this behavior?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

9. **In the past six months, have you seen any cognitive improvement overall?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()



9.1 Was the improvement minimal or substantial? (RC18)				
<i>Minimal improvement</i>	<i>Substantial improvement</i>	Unknown	Refused	
1 ()	2 ()	-3 ()	-4 ()	

9.2 Was there no change, minimal decline or substantial decline? (RC19)				
<i>No change</i>	<i>Minimal decline</i>	<i>Substantial decline</i>	Unknown	Refused
1 ()	2 ()	3 ()	-3 ()	-4 ()

10. **Within the past week, has (CR) been destroying property?**
(RC23)

<i>Not in the past week</i>	<i>1 to 2 times in the past week</i>	<i>3 to 6 times in the past week</i>	<i>Daily or more often</i>	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()



10.1 (RC16)	How bothered or upset were you by this?						
	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>Very Much</i>	<i>Extremely</i>	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
10.2 (RC16)	How confident do you feel about handling this behavior?						
	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>Very Much</i>	<i>Extremely</i>	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

11. **Within the past week, has (CR) been doing things that embarrass you?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

11.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
11.2 (RC16)	How confident do you feel about handling this behavior?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

12. **Within the past week, has (CR) been waking you or other family members up at night?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

12.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
12.2 (RC16)	How confident do you feel about handling this behavior?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

13. **Within the past week, has (CR) been talking loudly and rapidly?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

13.1 **How bothered or upset were you by this?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

13.2 **How confident do you feel about handling this behavior?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

14. **Within the past week, has (CR) appeared anxious or worried?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

14.1 **How bothered or upset were you by this?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

14.2 **How confident do you feel about handling this behavior?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

15. **Within the past week, has (CR) been engaging in behavior that is potentially dangerous to him/herself or others?**
(RC23)


Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

15.1 **How bothered or upset were you by this?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

15.2 **How confident do you feel about handling this behavior?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

 16. **Within the past week, has (CR) threatened to hurt him/herself?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

16.1 **How bothered or upset were you by this?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

16.2 **How confident do you feel about handling this behavior?**
(RC16)

Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

17. **Within the past week, has (CR) threatened to hurt others?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

17.1 (RC16)	How bothered or upset were you by this?					
Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
17.2 (RC16)	How confident do you feel about handling this behavior?					
Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

18. **Within the past week, has (CR) been aggressive to others verbally?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

18.1 (RC16)	How bothered or upset were you by this?					
Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
18.2 (RC16)	How confident do you feel about handling this behavior?					
Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

19. ***In the past six months, have you seen any behavioral improvement overall?***
(RC1)

No 0 ()	Yes 1 ()	Unknown -3 ()	Refused -4 ()
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19.1 <i>Was the improvement minimal or substantial?</i> (RC18)				
<i>Minimal improvement</i>	<i>Substantial improvement</i>	Unknown	Refused	
1 ()	2 ()	-3 ()	-4 ()	

19.2 <i>Was there no change, minimal decline or substantial decline?</i> (RC19)				
<i>No change</i>	<i>Minimal decline</i>	<i>Substantial decline</i>	Unknown	Refused
1 ()	2 ()	3 ()	-3 ()	-4 ()

20. ***Within the past week, has (CR) appeared sad or depressed?***
(RC23)

<i>Not in the past week</i>	<i>1 to 2 times in the past week</i>	<i>3 to 6 times in the past week</i>	<i>Daily or more often</i>	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()



20.1 <i>How bothered or upset were you by this?</i> (RC16)						
<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>Very Much</i>	<i>Extremely</i>	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
20.2 <i>How confident do you feel about handling this behavior?</i> (RC16)						
<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>Very Much</i>	<i>Extremely</i>	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

21. **Within the past week, has (CR) been expressing feelings of hopelessness or sadness about the future?**
 (RC23) (Such as, "Nothing worthwhile ever happens", or "I never do anything right")

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

21.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
21.2 (RC16)	How confident do you feel about handling this behavior?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

22. **Within the past week, has (CR) been crying and tearful?**
 (RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

22.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
22.2 (RC16)	How confident do you feel about handling this behavior?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

23. **Within the past week, has (CR) been commenting about the death of him/herself or others?** (such as, "Life isn't worth living", or "I'd be better off dead")

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

23.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
23.2 (RC16)	How confident do you feel about handling this behavior?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

24. **Within the past week, has (CR) been talking about feeling lonely?**

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

24.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
24.2 (RC16)	How confident do you feel about handling this behavior?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

25. **Within the past week, has (CR) made comments about feeling worthless or being a burden to others?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

25.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
25.2 (RC16)	How confident do you feel about handling this behavior?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

26. **Within the past week, has (CR) made comments about feeling like a failure or about not having any worthwhile accomplishments in life?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

26.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
26.2 (RC16)	How confident do you feel about handling this behavior?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

27. **Within the past week, has (CR) been arguing, irritable, and/or complaining?**
(RC23)

Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
	↓	↓	↓		

27.1 (RC16)	How bothered or upset were you by this?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
27.2 (RC16)	How confident do you feel about handling this behavior?						
	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

28. **In the past six months, have you seen any improvement in (CR)'s mood overall?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()
↓	↓		

28.1 (RC18)	Was the improvement minimal or substantial?		
	Minimal improvement	Substantial improvement	Unknown
	1 ()	2 ()	-3 ()
			Refused
			-4 ()

28.2 (RC19)	Was there no change, minimal decline or substantial decline?			
	No change	Minimal decline	Substantial decline	Unknown
	1 ()	2 ()	3 ()	-3 ()
				Refused
				-4 ()

29. **Within the past week, has (CR) had any other memory or behavior problems that I haven't already mentioned?**
(RC1)

No 0 () Yes 1 () Unknown -3 () Refused -4 ()

↓

29.1 Specify: _____

29.2 **How often has this problem occurred in the past week?**
(RC23)

	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
	1 ()	2 ()	3 ()	-3 ()	-4 ()

29.3 **How bothered or upset were you by this?**
(RC16)

	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

29.4 **How confident do you feel about handling this behavior?**
(RC16)

	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

30. **Any other memory or behavior problems within the past week? (Ask question only if a "Yes" response to question #29 was made)**
(RC1)

No 0 () Yes 1 () Unknown -3 () Refused -4 ()

↓

30.1 Specify: _____

30.2 **How often has this problem occurred in the past week?**
(RC23)

	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused
	1 ()	2 ()	3 ()	-3 ()	-4 ()

30.3 **How bothered or upset were you by this?**
(RC16)

	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

30.4 **How confident do you feel about handling this behavior?**
(RC16)

	Not at all	A little	Moderately	Very Much	Extremely	Unknown	Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

31. **Any other memory or behavior problems within the past week?** (Ask question only if a “Yes” response to (RC1) question #30 was made)

No 0 () Yes 1 () Unknown -3 () Refused -4 ()



31.1	Specify: _____					
31.2 (RC23)	How often has this problem occurred in the <u>past week</u>?					
	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Unknown	Refused	
	1 ()	2 ()	3 ()	-3 ()	-4 ()	
31.3 (RC16)	How bothered or upset were you by this?					
	Not at all	A little	Moderately	Very Much	Extremely	Unknown Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 () -4 ()
31.4 (RC16)	How confident do you feel about handling this behavior?					
	Not at all	A little	Moderately	Very Much	Extremely	Unknown Refused
	0 ()	1 ()	2 ()	3 ()	4 ()	-3 () -4 ()

INTERVIEWER ANSWERS FOLLOWING QUESTIONS:

32. Is the answer to **question 16** “Within the past week, has (CR) threatened to hurt him/herself?” either 2 () “3 to 6 times in the past week” or 3 () “Daily or more often”?

No 0 ()

Yes 1 () →

32.1 Has the Principal Investigator or appropriate site personnel been notified?
No 0 () →
Yes 1 ()
Please notify the Principal Investigator or appropriate site personnel.

33. Is the answer to **question 23** “Within the past week, has (CR) been commenting about the death of him/herself or others ”either 2 () “3 to 6 times in the past week” or 3 () “Daily or more often”?

No 0 ()

Yes 1 () →

33.1 Has the Principal Investigator or appropriate site personnel been notified?
No 0 () →
Yes 1 ()
Please notify the Principal Investigator or appropriate site personnel.

BURDEN INTERVIEW

Now I am going to ask you some questions regarding your feelings about caring for (CR).

Do you feel:	Never	Rarely	Sometimes	Quite frequently	Nearly always	Unknown	Refused
1. (RC24) that because of the time you spend with (CR) that you don't have enough time for yourself?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
2. (RC24) stressed between caring for (CR) and trying to meet other responsibilities (work/family)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
3. (RC24) angry when you are around (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
4. (RC24) that (CR) currently affects your relationship with family members or friends in a negative way?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
5. (RC24) strained when you are around (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
6. (RC24) that your health has suffered because of your involvement with (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
7. (RC24) that you don't have as much privacy as you would like because of (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
8. (RC24) that your social life has suffered because you are caring for (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
9. (RC24) that you have lost control of your life since (CR)'s illness?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
10. (RC24) uncertain about what to do about (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
11. (RC24) you should be doing more for (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
12. (RC24) you could do a better job in caring for (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

FORMAL CARE AND SERVICES

Now I have some questions about services that you or (CR) may have received in the past month from an agency or from someone paid privately to provide this help.

1. **In the past month, did you or (CR) have a homemaker who helped with shopping, cleaning, laundry, preparing meals, etc?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()



1.1 **Which one of you received this service?**

Caregiver	Care Recipient	Both
0 ()	1 ()	2 ()

1.2 **In the past month how often did you/CR make use of/receive this service?** _____
times/month

2. **In the past month, did you or (CR) have a home health aide come to the home to help with personal care (i.e. bathing, feeding, and health care tasks)?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()



2.1 **Which one of you received this service?**

Caregiver	Care Recipient	Both
0 ()	1 ()	2 ()

2.2 **In the past month how often did you/CR make use of/receive this service?** _____
times/month

3. (If applicable), **Is your homemaker and home health aide the same person?**
(RC1)

No	Yes	Not Applicable	Unknown	Refused
0 ()	1 ()	-2 ()	-3 ()	-4 ()

4. (If applicable), **Is (CR)'s homemaker and home health aide the same person?**
(RC1)

No	Yes	Not Applicable	Unknown	Refused
0 ()	1 ()	-2 ()	-3 ()	-4 ()

5. **In the past month, did you or (CR) go to a center for low cost meals or have cooked meals delivered to you at home?**

(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()



5.1	Which one of you received this service?
	Caregiver Care Recipient Both
	0 () 1 () 2 ()
5.2	In the past month how often did you/CR make use of/receive this service? _____
	times/month

6. **In the past month, did you or (CR) use a formal service that provided transportation to places outside the home (i.e doctors, clinics, shopping)?**

(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()



6.1	Which one of you received this service?
	Caregiver Care Recipient Both
	0 () 1 () 2 ()
6.2	In the past month how often did you/CR make use of/receive this service? _____
	times/month

7. **In the past month, did you or (CR) have a visiting nurse come to check medications, blood pressure or other medical needs?**

(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()



7.1	Which one of you received this service?
	Caregiver Care Recipient Both
	0 () 1 () 2 ()
7.2	In the past month how often did you/CR make use of/receive this service? _____
	times/month

8. **In the past month, did you or (CR) attend a senior day care or senior day health program?**
(RC1)

No Yes Unknown Refused
0 () 1 () -3 () -4 ()

8.1	Which one of you received this service?			
	<table style="width: 100%; border: none;"> <tr> <td style="text-align: center; width: 33%;">Caregiver 0 ()</td> <td style="text-align: center; width: 33%;">Care Recipient 1 ()</td> <td style="text-align: center; width: 33%;">Both 2 ()</td> </tr> </table>	Caregiver 0 ()	Care Recipient 1 ()	Both 2 ()
Caregiver 0 ()	Care Recipient 1 ()	Both 2 ()		
8.2	In the past month how often did you/CR make use of/receive this service? _____ times/month			

9. **Are you (CG only) participating in any support groups on a regular basis?**
(RC1)

No Yes Unknown Refused
0 () 1 () -3 () -4 ()

9.1	In the past month how often did you make use of/receive this service? _____ times/month
-----	---

10. **In the past month, did you or (CR) have any visits to a physician and/or psychiatrist?**
(RC1)

No Yes Unknown Refused
0 () 1 () -3 () -4 ()

10.1	Which one of you received this service?			
	<table style="width: 100%; border: none;"> <tr> <td style="text-align: center; width: 33%;">Caregiver 0 ()</td> <td style="text-align: center; width: 33%;">Care Recipient 1 ()</td> <td style="text-align: center; width: 33%;">Both 2 ()</td> </tr> </table>	Caregiver 0 ()	Care Recipient 1 ()	Both 2 ()
Caregiver 0 ()	Care Recipient 1 ()	Both 2 ()		
10.2	In the past month how often did you/CR make use of/receive this service? _____ times/month			

11. **In the past month, have you or (CR) seen a counselor, psychologist, or clergy for help with personal or family problems?**
(RC1)

No Yes Unknown Refused
0 () 1 () -3 () -4 ()

11.1	Which one of you received this service?			
	<table style="width: 100%; border: none;"> <tr> <td style="text-align: center; width: 33%;">Caregiver 0 ()</td> <td style="text-align: center; width: 33%;">Care Recipient 1 ()</td> <td style="text-align: center; width: 33%;">Both 2 ()</td> </tr> </table>	Caregiver 0 ()	Care Recipient 1 ()	Both 2 ()
Caregiver 0 ()	Care Recipient 1 ()	Both 2 ()		
11.2	In the past month how often did you/CR make use of/receive this service? _____ times/month			

12. **In the past month, did you or (CR) have any visits to an emergency room?**
(RC1)

No Yes Unknown Refused
0 () 1 () -3 () -4 ()

↓

12.1	Which one of you received this service?			
	<table style="width: 100%; border: none;"> <tr> <td style="width: 33%; text-align: center;">Caregiver 0 ()</td> <td style="width: 33%; text-align: center;">Care Recipient 1 ()</td> <td style="width: 33%; text-align: center;">Both 2 ()</td> </tr> </table>	Caregiver 0 ()	Care Recipient 1 ()	Both 2 ()
Caregiver 0 ()	Care Recipient 1 ()	Both 2 ()		
12.2	In the past month how often did you/CR make use of/receive this service? _____ times/month			

13. **In the past month, have you or (CR) been a patient in a hospital overnight or admitted as a patient to a hospital and discharged on the same day?**
(RC1)

No Yes Unknown Refused
0 () 1 () -3 () -4 ()

↓

13.1	Which one of you received this service?			
	<table style="width: 100%; border: none;"> <tr> <td style="width: 33%; text-align: center;">Caregiver 0 ()</td> <td style="width: 33%; text-align: center;">Care Recipient 1 ()</td> <td style="width: 33%; text-align: center;">Both 2 ()</td> </tr> </table>	Caregiver 0 ()	Care Recipient 1 ()	Both 2 ()
Caregiver 0 ()	Care Recipient 1 ()	Both 2 ()		
13.2	In the past month how often did you/CR make use of/receive this service? _____ times/month			

14. **In the past month, has (CR) been a resident in a nursing home?**
(RC1)

No Yes Unknown Refused
0 () 1 () -3 () -4 ()

↓

14.1	How often? _____ times/month
14.2	How long? _____ total days

15. **Do you receive any other service from an agency or organization** (such as overnight respite; professional (RC1) service that calls regularly such as Telephone Reassurance Service or Friendly Visitor; help from a social worker (RC25) or case manager in getting social or health services; see a physical/occupational therapist; receive help with home repairs or maintenance from an agency; receive recreational services such as trips arranged by a senior center), **and if so how often, per month, do you receive the service?**

No 0 () Yes 1 () Unknown -3 () Refused -4 ()



15.1 **Specify:** _____ **How often?** 15.2 _____
times/month

16. **Any other service?**

(RC1) No 0 () Yes 1 () Unknown -3 () Refused -4 ()



16.1 **Specify:** _____ **How often?** 16.2 _____
times/month

17. **Any other service?**

(RC1) No 0 () Yes 1 () Unknown -3 () Refused -4 ()



17.1 **Specify:** _____ **How often?** 17.2 _____
times/month

18. **Does CR receive any other service from an agency or organization** (such as overnight respite; professional (RC1) service which calls regularly such as Telephone Reassurance Service or Friendly Visitor; help from a social worker (RC25) or case manager in getting social or health services; see a physical/occupational therapist; receive help with home repairs or maintenance from an agency; receive recreational services such as trips arranged by a senior center), **and if so how often, per month, does he/she receive the service?**

No 0 () Yes 1 () Unknown -3 () Refused -4 ()



18.1 **Specify:** _____ **How often?** 18.2 _____
times/month

19. **Any other service?**

(RC1) No 0 () Yes 1 () Unknown -3 () Refused -4 ()



19.1 **Specify:** _____ **How often?** 19.2 _____
times/month

20. **Any other service?**

(RC1) No 0 () Yes 1 () Unknown -3 () Refused -4 ()



20.1 **Specify:** _____ **How often?** 20.2 _____
times/month

21. **How difficult is it for you to pay for the services you and (CR) are getting?**
(RC26)

Very Difficult	Somewhat Difficult	Not At All Difficult	Unknown	Refused
0 ()	1 ()	2 ()	-3 ()	-4 ()

22. **Are there other services you would like that you can not afford?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()



Specify (up to 3):

22.1 _____

22.2 _____

22.3 _____

23. **Is (CR) in any other study for Alzheimer's Disease or dementia?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()



23.1 Specify study name: _____

POSITIVE ASPECTS OF CAREGIVING

Some caregivers say that, in spite of all the difficulties involved in giving care to a family member with memory or health problems, good things have come out of their caregiving experience too. I'm going to go over a few of the good things reported by some caregivers. I would like you to tell me how much you agree or disagree with these statements. Please refer to the responses listed on this card. [Give card to respondent.]

Providing help to (CR) has.....	Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot	Unknown	Refused
1. made me feel more (RC27) useful.	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
2. made me feel good (RC27) about myself.	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
3. made me feel needed. (RC27)	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
4. made me feel (RC27) appreciated.	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
5. made me feel (RC27) important.	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
6. made me feel strong (RC27) and confident.	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
7. given more meaning (RC27) to my life.	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
8. enabled me to learn (RC27) new skills.	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
9. enabled me to (RC27) appreciate life more.	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
10. enabled me to (RC27) develop a more positive attitude toward life.	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
11. strengthened my (RC27) relationships with others.	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

DESIRE TO INSTITUTIONALIZE

Now I want to ask you several questions about your plans regarding (CR). Please answer no or yes to these questions.

1. ***In the past six months, have you considered a nursing home, boarding home or assisted living for (CR)?***
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

2. ***In the past six months, have you felt that (CR) would be better off in a nursing home, boarding home or assisted living?***
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

3. ***In the past six months, have you discussed the possibility of a nursing, boarding home or assisted living with family members or others?***
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

4. ***In the past six months, have you discussed that possibility with (CR)?***
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

5. ***In the past six months, have you taken any steps towards placement?***
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

6. ***In the next six months, are you likely to move (CR) to another living arrangement?***
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

CAREGIVER HEALTH AND HEALTH BEHAVIORS

Now I would like to ask you some questions about your health.

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

(RC28)

Excellent	Very Good	Good	Fair	Poor	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

2. **Compared to 6 months ago, how would you rate your health in general now?**

(RC29)

Much better now	Somewhat better now	About the same	Somewhat worse now	Much worse now	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()

3. **During the past month, how would you rate your sleeping quality overall?**

(RC30)

Very Bad	Fairly Bad	Fairly Good	Very Good	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

4. **During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?**

(RC31)

Never	Less than once a week	Once or twice a week	Three or more times a week	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

5. **Have you been smoking more than usual in the past month?**

(RC1)

No	Yes	N / A	Unknown	Refused
0 ()	1 ()	-2 ()	-3 ()	-4 ()

6. **Have you been drinking (alcohol) more than usual in the past month?**

(RC1)

No	Yes	N / A	Unknown	Refused
0 ()	1 ()	-2 ()	-3 ()	-4 ()

7. **In the past 6 months, have you found that you had the time to see your doctor when you thought you should?**

(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

8. **In the past 6 months, have you found that you were able to slow down and get enough rest when you were sick?**

(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

Do you currently have, or has a doctor told you that you currently have, any of the following health problems?

	No	Yes	Unknown	Refused
9. Arthritis (RC1)	0 ()	1 ()	-3 ()	-4 ()
10. High Blood Pressure (RC1)	0 ()	1 ()	-3 ()	-4 ()
11. Heart Condition (RC1) <i>(Specifically heart disease, heart attack, chest pain due to your heart, congestive heart failure, angina, MI)</i>	0 ()	1 ()	-3 ()	-4 ()
12. Chronic Lung Disease such as chronic bronchitis or emphysema <i>(not asthma)</i> (RC1)	0 ()	1 ()	-3 ()	-4 ()
13. Diabetes (RC1)	0 ()	1 ()	-3 ()	-4 ()
14. Stroke (RC1)	0 ()	1 ()	-3 ()	-4 ()
15. Stomach ulcers, irritable bowel syndrome, or any other serious problems with your stomach or bowels (RC1)	0 ()	1 ()	-3 ()	-4 ()
16. Problems with your kidneys (RC1)	0 ()	1 ()	-3 ()	-4 ()
17. Cirrhosis or any other serious liver problem (RC1)	0 ()	1 ()	-3 ()	-4 ()
18. Do you currently have cancer? (RC1) <i>If yes: What type? _____</i>	0 ()	1 ()	-3 ()	-4 ()
19. Problems with your vision or hearing (RC1)	0 ()	1 ()	-3 ()	-4 ()
20. Do you currently have any other health problems that I have not asked about? (RC1) <i>If yes: What _____</i>	0 ()	1 ()	-3 ()	-4 ()
21. In the past, have you ever been diagnosed with, or received treatment for, emotional or psychiatric problems? (RC1) <i>If yes: Please describe the nature of the problem(s) and time frame: _____</i>	0 ()	1 ()	-3 ()	-4 ()
22. Because of any physical or health problem, do you need the help of other persons for your personal care needs, such as eating, bathing, dressing, or getting around the home? (RC1)	0 ()	1 ()	-3 ()	-4 ()
23. Because of any physical or health problem, do you need the help of other persons in handling your routine needs, such as everyday household chores, doing necessary business, shopping or getting around for other purposes? (RC1)	0 ()	1 ()	-3 ()	-4 ()

In the past month, have you experienced any of the following symptoms?

	No	Yes	Unknown	Refused
24. Temperature of 100 degrees F (37.7C) or more (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
25. Headache lasting more than 1 hour (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
26. Skin rash or hives (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
27. Painful, irritated, or burning eyes (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
28. Ear ache or ear infection (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
29. Toothache (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
30. Sore throat (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
31. Sneezing, stuffy, or runny nose (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
32. Dry cough (more than occasional) (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
33. Coughing up substances other than saliva, or thin phlegm (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
34. Wheezing (from chest) (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
35. Unusual shortness of breath (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
36. Unplanned weight loss (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
37. Nausea and/or vomiting (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
38. Stomach pain or abdominal cramps (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
39. Heartburn (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()
40. Chest pain other than heartburn (RC1) <i>If yes: total days with symptoms</i> _____	0 ()	1 ()	-3 ()	-4 ()

	No	Yes	Unknown	Refused
41. Rapid or pounding heart (RC1) If yes: total days with symptoms _____	0 ()	1 ()	-3 ()	-4 ()
42. Diarrhea (RC1) If yes: total days with symptoms _____	0 ()	1 ()	-3 ()	-4 ()
43. Bloody or black stools (RC1) If yes: total days with symptoms _____	0 ()	1 ()	-3 ()	-4 ()
44. Discomfort from hemorrhoids (RC1) If yes: total days with symptoms _____	0 ()	1 ()	-3 ()	-4 ()

45. (Enter N/A if CG does not work) **In the past month, how many work days have you lost due to illness?** _____
46. **In the past month, how many days did you need to cut down on activities due to illness?** _____
47. **In the past month, how many days did you spend most of the day in bed due to illness?** _____
48. **In the past six months, do you feel your physical health has improved?**
(RC1)

No 0 ()	Yes 1 ()	Unknown -3 ()	Refused -4 ()
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48.1 Was the improvement minimal or substantial? (RC18)				
Minimal improvement	Substantial improvement	Unknown	Refused	
1 ()	2 ()	-3 ()	-4 ()	

48.2 Was there no change, minimal decline or substantial decline? (RC19)				
No change	Minimal decline	Substantial decline	Unknown	Refused
1 ()	2 ()	3 ()	-3 ()	-4 ()

CES-D

This section deals with statements people might make about how they feel. For each of the statements, please indicate how often you felt that way during the past week.

		<i>Rarely or none of the time</i>	<i>Some or a little of the time</i>	<i>Occasionally or a moderate amount of time</i>	<i>Most or almost all of the time</i>	Unknown	Refused
		(< 1 day)	(1-2 days)	(3-4 days)	(5-7 days)		
1. (RC32)	<i>I was bothered by things that don't usually bother me.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
2. (RC32)	<i>I had trouble keeping my mind on what I was doing.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
3. (RC32)	<i>I felt depressed.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
4. (RC32)	<i>I felt that everything I did was an effort</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
5. (RC32)	<i>I felt hopeful about the future. *</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
6. (RC32)	<i>I felt fearful.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
7. (RC32)	<i>My sleep was restless.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
8. (RC32)	<i>I was happy. *</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
9. (RC32)	<i>I felt lonely.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
10. (RC32)	<i>I could not get "going".</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
11. (RC32)	<i>People were unfriendly.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
12. (RC32)	<i>I felt that people disliked me.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

13. **In the past six months, do you feel your mood or emotional well-being has improved?**
(RC1)

No 0 () Yes 1 () Unknown -3 () Refused -4 ()

13.1 **Was the improvement minimal or substantial?**
(RC18)

Minimal Improvement 1 ()	Substantial Improvement 2 ()	Unknown -3 ()	Refused -4 ()
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13.2 **Was there no change, minimal decline or substantial decline in these areas?**
(RC19)

No change 1 ()	Minimal decline 2 ()	Substantial decline 3 ()	Unknown -3 ()	Refused -4 ()
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14. CES-D Score (questions 1 – 10): ____ (* questions are reverse scored)

15. Is the CES-D score greater than or equal to 15?

No 0 ()
Yes 1 ()

15.1 Has the Principal Investigator or appropriate site personnel been notified?

No 0 ()	Yes 1 ()	Please notify the Principal Investigator or appropriate site personnel.
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SOCIAL SUPPORT

Now I would like to ask you some questions about your friends and family.

1. **Overall, how satisfied have you been in the past month with the help you have received from family members, friends, or neighbors?**
(RC33)

Not at all	A little	Moderately	Very	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

2. **How many relatives, friends, neighbors, other than (CR) do you see or hear from at least once a month?**
(RC34)

None	One	Two	Three or Four	Five to eight	Nine or more	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	5 ()	-3 ()	-4 ()

3. **How many relatives, friends, neighbors, other than (CR) do you feel close to? That is, how many do you feel at ease with, can talk to about private matters, or can call on for help?**
(RC34)

None	One	Two	Three or Four	Five to eight	Nine or more	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	5 ()	-3 ()	-4 ()

4. **How many relatives, friends, neighbors, other than (CR) do you feel you can call on for help with chores, transportation, etc.?**
(RC34)

None	One	Two	Three or Four	Five to eight	Nine or more	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	5 ()	-3 ()	-4 ()

5. **When other people you know have an important decision to make, do they talk to you about it?**
(RC35)

Never	Seldom	Sometimes	Often	Very Often	Always	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	5 ()	-3 ()	-4 ()

6. **In the past month, how often has someone, such as a family member, friend or neighbor, other than (CR), provided transportation, pitched in to help you do something that needed to get done, like household chores or yardwork, and/or helped you with shopping?**
(RC36)

Never	Once in a while	Fairly often	Very often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

7. **Overall, how satisfied have you been in the past month with the help you have received with transportation, housework and yardwork, and shopping?**
(RC33)

Not at all	A little	Moderately	Very	N/A	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-2 ()	-3 ()	-4 ()

8. ***In the past month, how often has someone been there with you (physically) in a stressful situation, provided comfort to you, or expressed concern about your well-being?***
(RC36)

Never	Once in a while	Fairly often	Very often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

9. ***In the past month, how satisfied have you been with the support, comfort, interest and concern you have received from others?***
(RC33)

Not at all	A little	Moderately	Very	N/A	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-2 ()	-3 ()	-4 ()

10. ***In the past month, how often has someone given you information and guidance on some action? For example, they made a difficult situation clearer and easier to understand or told you what they did in a similar situation?***
(RC36)

Never	Once in a while	Fairly often	Very often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

11. ***Overall, how satisfied in the past month have you been with the suggestions, clarifications, and sharing of similar experiences you have received from others?***
(RC33)

Not at all	A little	Moderately	Very	N/A	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-2 ()	-3 ()	-4 ()

I'd like to ask you a few more questions about your relationship with others. Remember, when the term "others" is used, it includes friends, neighbors, or family members other than (CR).

12. ***In the past month, how often have others made too many demands on you?***
(RC36)

Never	Once in a while	Fairly often	Very often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

13. ***In the past month, how often have others been critical of you?***
(RC36)

Never	Once in a while	Fairly often	Very often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

14. ***In the past month, how often have others pried into your affairs?***
(RC36)

Never	Once in a while	Fairly often	Very often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

15. ***In the past month, how often have others taken advantage of you?***

(RC36)

Never	Once in a while	Fairly often	Very often	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

16. ***In the past six months, do you feel the amount of help and support that you receive from others has improved?*** (RC1)

No
0 ()

Yes
1 ()

Unknown
-3 ()

Refused
-4 ()



16.1 Was the improvement minimal or substantial?				
(RC18)				
Minimal improvement	Substantial improvement	Unknown	Refused	
1 ()	2 ()	-3 ()	-4 ()	

16.2 Was there no change, minimal decline or substantial decline?				
(RC19)				
No change	Minimal decline	Substantial decline	Unknown	Refused
1 ()	2 ()	3 ()	-3 ()	-4 ()

RELIGIOUS/SPIRITUAL COPING

The next set of questions is about your religious or spiritual beliefs. We would like to know if religion or spirituality affects caregiving. Please respond to the following statements.

1. ***I think about how my life is part of a larger spiritual force.***
 (RC37)

A great deal	Quite a bit	Somewhat	Not at all	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

2. ***I work together with God as partners to get through hard times.***
 (RC37)

A great deal	Quite a bit	Somewhat	Not at all	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

3. ***I look to God (or a higher force) for strength, support, and guidance in times of trouble.***
 (RC37)

A great deal	Quite a bit	Somewhat	Not at all	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

4. ***I feel that stressful situations are God’s way of punishing me for my sins or lack of spirituality.***
 (RC37)

A great deal	Quite a bit	Somewhat	Not at all	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

5. ***I wonder whether God has abandoned me.***
 (RC37)

A great deal	Quite a bit	Somewhat	Not at all	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

6. ***I try to make sense of the situation and decide what to do without relying on God.***
 (RC37)

A great deal	Quite a bit	Somewhat	Not at all	Unknown	Refused
0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

Now I am going to ask you about your religious preferences and practices.

7. **What is your current religious preference?**

- 0 () None
- 1 () Lutheran
- 2 () Methodist
- 3 () Baptist
- 4 () Episcopal
- 5 () Presbyterian
- 6 () Roman Catholic
- 7 () Orthodox Christian
(e.g. Greek, Russian, Eastern)
- 8 () Jewish
- 9 () Islamic
- 10 () Buddhist
- 11 () Confucian
- 12 () Shintoist
- 13 () Hindu
- 14 () Jehovah's Witness
- 15 () Other
15.1 Specify: _____
- 3 () Unknown
- 4 () Refused

8. **How often do you usually attend religious services, meetings and/or activities?**

(RC38)

- 0 () **Never**
- 1 () **Once a year**
- 2 () **A few times a year**
- 3 () **At least once a month**
- 4 () **At least once a week**
- 5 () **Nearly every day**
- 3 () Unknown
- 4 () Refused

9. **How often do you pray or meditate?**

(RC38)

- 0 () **Never**
- 1 () **Once a year**
- 2 () **A few times a year**
- 3 () **At least once a month**
- 4 () **At least once a week**
- 5 () **Nearly every day**
- 3 () Unknown
- 4 () Refused

SOCIAL ACTIVITIES

We are interested in how satisfied you are with the amount of time you have been able to spend in various activities that you might enjoy.

		<i>Not at all</i>	<i>A little</i>	<i>A lot</i>	<i>Unknown</i>	<i>Refused</i>
1. (RC39)	Over the past month, how often have you been able to engage in activities that you enjoy?	0 ()	1 ()	2 ()	-3 ()	-4 ()
1.1 (RC39)	How satisfied are you with this amount of time?	0 ()	1 ()	2 ()	-3 ()	-4 ()
2. (RC39)	Over the past month, how often have you been able to spend quiet time by yourself?	0 ()	1 ()	2 ()	-3 ()	-4 ()
2.1 (RC39)	How satisfied are you with this amount of time?	0 ()	1 ()	2 ()	-3 ()	-4 ()
3. (RC39)	Over the past month, how often have you been able to attend church or go to other meetings of groups or organizations?	0 ()	1 ()	2 ()	-3 ()	-4 ()
3.1 (RC39)	How satisfied are you with this amount of time?	0 ()	1 ()	2 ()	-3 ()	-4 ()
4. (RC39)	Over the past month, how often have you been able to take part in hobbies or other interests?	0 ()	1 ()	2 ()	-3 ()	-4 ()
4.1 (RC39)	How satisfied are you with this amount of time?	0 ()	1 ()	2 ()	-3 ()	-4 ()
5. (RC39)	Over the past month, how often have you been able to go out for meals or other social activities?	0 ()	1 ()	2 ()	-3 ()	-4 ()
5.1 (RC39)	How satisfied are you with this amount of time?	0 ()	1 ()	2 ()	-3 ()	-4 ()

Not at all A little A lot Unknown Refused

6. (RC39) **Over the past month, how often have you been able to do fun things with other people?** 0 () 1 () 2 () -3 () -4 ()

6.1 (RC39) **How satisfied are you with this amount of time?** 0 () 1 () 2 () -3 () -4 ()

7. (RC39) **Over the past month, how often have you been able to visit with family and friends?** 0 () 1 () 2 () -3 () -4 ()

7.1 (RC39) **How satisfied are you with this amount of time?** 0 () 1 () 2 () -3 () -4 ()

QUALITY OF CARE

I. Living Environment – RA Observation and CG Report

This next section is about the ways that you use your home to care for (CR). First I will ask you some general questions and then I will ask you to show me the rooms that (CR) uses so that you can show me any changes you have made in your home to help you provide care.

A. Positive Aspects of Environment	No	Yes	N/A	Unknown	Refused
1. (RC1) Do you keep materials present to occupy CR or that provide comfort or meaning (e.g., games, sorting tasks, magazines, photos, stuffed animals)?	0 ()	1 ()	-2 ()	-3 ()	-4 ()
2. (RC1) Have you <u>removed</u> any objects or furniture in your home in response to (CR's) memory problems (i.e. wastebaskets, throw rugs, any sharp or dangerous objects)?	0 ()	1 ()	-2 ()	-3 ()	-4 ()
3. (RC1) Have you <u>added, modified or rearranged</u> any furniture or objects in response to (CR)'s problems or to make caregiving easier?	0 ()	1 ()	-2 ()	-3 ()	-4 ()
4. (RC1) Do you use signs or label objects to offer cues to your (CR)? OBSERVE: if cues to CR are present to enhance orientation and way finding (e.g., signs, objects labeled)	0 ()	1 ()	-2 ()	-3 ()	-4 ()
5. (RC1) Are there assistive devices or special equipment that (CR) uses or you use to help (CR) in daily care (e.g., bathing, dressing, monitoring, communicating).	0 ()	1 ()	-2 ()	-3 ()	-4 ()
B. Hazards in Environment	No	Yes	N/A	Unknown	Refused
<i>BEGIN WALK-THRU OF HOME</i>					
6. Let's start in the room that your (CR) uses the most during the day. OBSERVE if clutter present in room of greatest daily use by CR (clutter is the presence of an excessive number of objects or visual and auditory stimulation in a living space that increase its complexity)	0 ()	1 ()	-2 ()	-3 ()	-4 ()
7. OBSERVE: Objects on floor or pathways in main areas used by CR	0 ()	1 ()	-2 ()	-3 ()	-4 ()

	No	Yes	N/A	Unknown	Refused
8. STAIRS: (RC1) a. Do you have a handrail/banister on the stairs that either you or your CR use?	0 ()	1 ()	-2 ()	-3 ()	-4 ()
b. OBSERVE if all interior stairs used by CG and CR have handrails/banisters that are securely attached.	0 ()	1 ()	-2 ()	-3 ()	-4 ()
c. OBSERVE if Stairs need repair (steps too steep, handrail broken or unstable)	0 ()	1 ()	-2 ()	-3 ()	-4 ()
9. BATHROOM: (RC1) Do you have a grab bar in the bathroom primarily used by (CR)? Observe if Grab bars installed in bathroom	0 ()	1 ()	-2 ()	-3 ()	-4 ()
10. EXIT DOORS (RC1) Do you have locks on exit doors of your home? (Verify presence of locks)	0 ()	1 ()	-2 ()	-3 ()	-4 ()
11. OBSERVE: Are windows broken or in need of repair?	0 ()	1 ()	-2 ()	-3 ()	-4 ()
12. OBSERVE: Inadequate lighting (e.g., glare, dim light, no lampshade)	0 ()	1 ()	-2 ()	-3 ()	-4 ()
13. OBSERVE: Presence of vermin (roaches, rats, etc.)	0 ()	1 ()	-2 ()	-3 ()	-4 ()
14.. OBSERVE: Garbage or offensive smells	0 ()	1 ()	-2 ()	-3 ()	-4 ()

II. Frustrations of Caregiving

Next, I'm going to read a list of items that describe methods that caregivers often use when people with memory problems won't follow the doctor's orders or do what caregivers feel they should do. When you have these kinds of problems with (CR), which of these methods have you either felt like using or have used? Please tell me the word that best describes how often in the past six months, you have felt like using or have used this method.

	Never	Sometimes	Often	Always	Unknown	Refused
15. How often in the past six months, have you felt like screaming or yelling at (CR) because of the way he/she behaved? (RC40)	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
16. How often in the past six months, have you considered using physical restraint (such as tying in a chair)? (RC40)	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
17. How often in the past six months, have you considered confining (CR) (e.g., to a room)? (RC40)	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

		Never	Sometimes	Often	Always	Unknown	Refused
18. (RC40)	How often in the past six months, have you had to keep yourself from hitting or slapping (CR) because of the way he/she behaved?	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
19. (RC40)	How often in the past six months, have you felt like shaking (CR) because of the way he/she behaved?	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
20. (RC40)	How often in the past six months, have you used a harsh tone of voice with (CR)?	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
21. (RC40)	How often in the past six months, have you blamed (CR) for having created difficulties?	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
22. (RC40)	How often in the past six months, have you told (CR) to stop doing things that caused worry because of what it did to you (or to other family members)?	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

III. Exemplary Caregiving

The following statements have to do with the interactions you have with (CR). For each statement, please tell me which one of these answers you feel is most accurate.

		Never	Sometimes	Often	Always	Unknown	Refused
23. (RC40)	I make sure (CR) is included in special gatherings such as family and friends getting together for religious or national holidays (such as Thanksgiving) when at all possible.	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
24. (RC40)	I show special amounts of physical affection to (CR).	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
25. (RC40)	Before making a big decision about something that will affect (CR), I talk it over with him/her first if at all possible.	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
26. (RC40)	I go out of my way to make sure (CR's) birthday is a special one.	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
27. (RC40)	I actively avoid treating (CR) like a child.	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

		Never	Sometimes	Often	Always	Unknown	Refused
28. (RC40)	<i>To make (CR) feel refreshed and good about him/herself, I do things like being sure that he/she is dressed nicely or that his/her hair is clean and styled.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
29. (RC40)	<i>I make sure that where (CR) lives is bright and cheery.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
30. (RC40)	<i>I try to arrange (CR)'s environment to safeguard him/her against causing problems, getting into trouble, or endangering him/herself.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
31. (RC40)	<i>I take the time to sit and talk with (CR).</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
32. (RC40)	<i>I do everything I can to avoid making (CR) feel that he/she is a burden to me.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
33. (RC40)	<i>I really try to avoid interrupting (CR) when he/she is talking.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
34. (RC40)	<i>When at all possible, I make sure that (CR) gets to do some of the things he/she enjoys (e.g., playing cards, visiting friends, going for a walk, listening to music).</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
35. (RC40)	<i>I try to maintain a relaxed, unhurried atmosphere for (CR).</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
36. (RC40)	<i>I make sure the food (CR) likes is available for meals and snacks.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
37. (RC40)	<i>I avoid being overcritical of (CR).</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
38. (RC40)	<i>I make a point of praising (CR) when he/she does what I consider appropriate.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
39. (RC40)	<i>I try to soothe (CR)'s emotions when he/she gets upset.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()
40. (RC40)	<i>I try to hold my anger and frustration in, to protect (CR) from these feelings.</i>	0 ()	1 ()	2 ()	3 ()	-3 ()	-4 ()

RISK APPRAISAL

We are nearing the end the interview. I would now like to ask you questions that will cover all the areas we've discussed today as a general overview. We realize that many of these questions may seem repetitive, and we appreciate your patience and participation.

Education

1. **Do you have written information about memory loss, Alzheimer's Disease, or dementia?**

(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

2. **Do you have written information about different treatments available for memory loss, Alzheimer's Disease, or dementia?**

(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

3. **Do you have a living will for (CR)?**

(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

4. **Do you or a family member have durable power of attorney or guardianship for (CR)?**

(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

Safety

5. **Is there a working smoke detector and fire extinguisher in your house?**

(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

6. **Can (CR) get to dangerous substances (e.g., medicines, cleaning supplies)?**

(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

 7. **Can (CR) get to dangerous objects (e.g., gun, knife or other sharp objects)?**

(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

8. **Does (CR) wear a safety ID bracelet or other form of identification that would alert police and fire officials of his/her memory problem and home address?**


(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

9. **Does (CR) smoke when alone in the house?**

(RC41)

Never	Sometimes	Often	Unknown	Refused
0 ()	1 ()	2 ()	-3 ()	-4 ()

10. **Does (CR) leave things on the stove or store objects in the oven?**
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
11. **Do you ever leave (CR) alone or unsupervised in the home?**
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
12. **Does (CR) get lost in familiar surroundings (e.g., home, church, or neighborhood)?**
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
13. **Does (CR) try to leave the home and wander outside?**
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
-  14. **Does (CR) drive?**
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |

Caregiving Skills

15. **Is it hard or stressful for you to take care of basic household chores, like cleaning, yard work, or home repairs?**
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
16. **Is it hard or stressful for you to help (CR) with toileting, including cleaning up after accidents?**
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
17. **Is it hard or stressful for you to prepare (CR) meals or help (CR) eat?**
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
18. **Is it hard or stressful for you to help (CR) in basic daily activities, like bathing, changing clothes, brushing teeth, or shaving?**
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
19. **Is it hard for you to get helpful information from (CR' s) doctor or nurse?**
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |

20. **Is it hard for (CR) to understand what you are saying or want him/her to do?**
(RC41)

Never	Sometimes	Often	Unknown	Refused
0 ()	1 ()	2 ()	-3 ()	-4 ()

21. **Is it hard for you to understand what (CR) needs or wants?**
(RC41)

Never	Sometimes	Often	Unknown	Refused
0 ()	1 ()	2 ()	-3 ()	-4 ()

22. **Do you face problem behaviors when caring for (CR) such as (CR) asks the same question over and over, becomes irritable, argumentative or aggressive?**
(RC41)

Never	Sometimes	Often	Unknown	Refused
0 ()	1 ()	2 ()	-3 ()	-4 ()

Social Support

23. **If you were unable to care for (CR) or yourself, do you have someone who would take over?**
(RC1)

No	Yes	Unknown	Refused
0 ()	1 ()	-3 ()	-4 ()

24. **Do you have someone (other than CR) you can talk to about important decisions or difficult caregiving situations?**
(RC41)

Never	Sometimes	Often	Unknown	Refused
0 ()	1 ()	2 ()	-3 ()	-4 ()

25. **Do you have someone, like a family member, friend, or neighbor (other than CR) who can take you places if you needed help?**
(RC41)

Never	Sometimes	Often	Unknown	Refused
0 ()	1 ()	2 ()	-3 ()	-4 ()

26. **Is it hard for you to find services like adult day care, sitters, or respite care?**
(RC41)

Never	Sometimes	Often	Unknown	Refused
0 ()	1 ()	2 ()	-3 ()	-4 ()

27. **Is it hard for you to find a friend or family member who can stay with (CR) to give you a break from caregiving?**
(RC41)

Never	Sometimes	Often	Unknown	Refused
0 ()	1 ()	2 ()	-3 ()	-4 ()

28. **Do you have someone to comfort you, listen to your feelings, or express concern for you?**
(RC41)

Never	Sometimes	Often	Unknown	Refused
0 ()	1 ()	2 ()	-3 ()	-4 ()

29. **Do you feel isolated from your family/friends?**
(RC41)

Never	Sometimes	Often	Unknown	Refused
0 ()	1 ()	2 ()	-3 ()	-4 ()

Caregiver Emotional and Physical Well-being

30. **In the past month, have you lost or gained weight without meaning to?**
(RC1)
- | | | | |
|-------|-------|---------|---------|
| No | Yes | Unknown | Refused |
| 0 () | 1 () | -3 () | -4 () |
31. **In the past year, have you seen your primary care physician for a routine check up?**
(RC1)
- | | | | |
|-------|-------|---------|---------|
| No | Yes | Unknown | Refused |
| 0 () | 1 () | -3 () | -4 () |
32. **In the past 6 months, have you missed any scheduled doctor's appointments?**
(RC1)
- | | | | |
|-------|-------|---------|---------|
| No | Yes | Unknown | Refused |
| 0 () | 1 () | -3 () | -4 () |
33. **In the past year, have you had your eyesight checked?**
(RC1)
- | | | | |
|-------|-------|---------|---------|
| No | Yes | Unknown | Refused |
| 0 () | 1 () | -3 () | -4 () |
34. **In the past year, have you had your hearing checked?**
(RC1)
- | | | | |
|-------|-------|---------|---------|
| No | Yes | Unknown | Refused |
| 0 () | 1 () | -3 () | -4 () |
35. **In the past year, have you had your teeth/dentures examined by a dentist?**
(RC1)
- | | | | |
|-------|-------|---------|---------|
| No | Yes | Unknown | Refused |
| 0 () | 1 () | -3 () | -4 () |
36. **In the past year, have you had a flu shot?**
(RC1)
- | | | | |
|-------|-------|---------|---------|
| No | Yes | Unknown | Refused |
| 0 () | 1 () | -3 () | -4 () |
37. **In the past year, have you had your blood pressure checked?**
(RC1)
- | | | | |
|-------|-------|---------|---------|
| No | Yes | Unknown | Refused |
| 0 () | 1 () | -3 () | -4 () |
38. FEMALE ONLY: **In the past two years, have you had a mammogram?**
(RC1)
- | | | | | |
|-------|-------|--------|---------|---------|
| No | Yes | N/A | Unknown | Refused |
| 0 () | 1 () | -2 () | -3 () | -4 () |
39. FEMALE ONLY: **In the past two years, have you had a pap smear?**
(RC1)
- | | | | | |
|-------|-------|--------|---------|---------|
| No | Yes | N/A | Unknown | Refused |
| 0 () | 1 () | -2 () | -3 () | -4 () |
40. MALE ONLY: **In the past year, have you had a prostate examination?**
(RC1)
- | | | | | |
|-------|-------|--------|---------|---------|
| No | Yes | N/A | Unknown | Refused |
| 0 () | 1 () | -2 () | -3 () | -4 () |

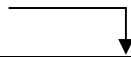
41. ***Have you cut back on your physical activities, like exercise and walking because of caregiving?***
(RC1)
- | | | | |
|-------|-------|---------|---------|
| No | Yes | Unknown | Refused |
| 0 () | 1 () | -3 () | -4 () |
42. ***In the past month or so, has caregiving made you feel overwhelmed or extremely tired?***
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
43. ***In the past month, have you felt depressed, sad, had crying spells or felt like you often needed to cry?***
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
44. ***Is it hard for you to have quiet time for yourself or time to do the things you enjoy?***
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
45. ***In the past month, have you been angry or frustrated as a result of your caregiving?***
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
46. ***In the past month or so, have you had headaches, a sore throat, the flu, or a cold?***
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
47. ***In the past month, have you had stomach or intestinal problems, like cramps, heartburn, or diarrhea?***
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
48. ***In the past month, have you had trouble falling asleep, staying asleep, or waking up too early in the morning?***
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
49. ***In the past month, has your back hurt, or have you had pains in other muscles or joints?***
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
50. ***In the past month, has it been hard to eat healthy or well-balanced meals on a regular basis?***
(RC41)
- | | | | | |
|--------------|------------------|--------------|---------|---------|
| Never | Sometimes | Often | Unknown | Refused |
| 0 () | 1 () | 2 () | -3 () | -4 () |
51. ***Do you miss taking your prescription medication on a regular basis?***
(RC41)
- | | | | | | |
|--------------|------------------|--------------|--------|---------|---------|
| Never | Sometimes | Often | N/A | Unknown | Refused |
| 0 () | 1 () | 2 () | -2 () | -3 () | -4 () |

INTERVIEWER ANSWERS FOLLOWING QUESTIONS:

52. Did the respondent answer “yes” to **question 7** “Can (CR) get to dangerous objects (e.g., gun, knife or other sharp objects)?”

No 0 ()

Yes 1 ()



52.1 Was the dangerous object identified as a gun

No 0 ()

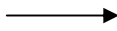
Yes 1 ()



52.2 Has the Principal Investigator or appropriate site personnel been notified?

No 0 ()

Yes 1 ()



Please notify the Principal Investigator or appropriate site personnel.

53. Did the respondent answer “(1) Sometimes or (2) Often” to **question 14** “Does (CR) drive?”

No 0 ()

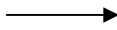
Yes 1 ()



53.1 Has the Principal Investigator or appropriate site personnel been notified?

No 0 ()

Yes 1 ()



Please notify the Principal Investigator or appropriate site personnel.

CAREGIVER MEDICATIONS

Copy the name of the medications that (CG) takes onto each blank line below. Include both prescription and non-prescription medications in pill and liquid form. Include medications obtained outside the U.S. Include all medications that (CG) has taken within the past month even if they were prescribed for someone else.

1. Are you currently taking any medication?

(RC1)

No 0 () Yes 1 () Unknown -3 () Refused -4 ()

Table with columns: Medication Code, Medication Name, Is the medication being taken for... (Anxiety, Depression, Stress). Rows 1.1 to 1.30.

2. Are you (CG) currently taking any of these medications for anxiety, depression or stress?

(RC1)

No 0 () Yes 1 () Unknown -3 () Refused -4 ()

(if YES, check the appropriate column on the immediate right of the medication name to identify that it is being taken for anxiety, depression or stress).

CARE RECIPIENT MEDICATIONS

Copy the name of the medications that (CR) takes onto each blank line below. Include both prescription and non-prescription medications in pill and liquid form. Include medications obtained outside the U.S. Include all medications that (CR) has taken within the past month even if they were prescribed for someone else.

1. **Is (CR) currently taking any medication?**

(RC1)

- No 0 ()
- Yes 1 ()
- Unknown -3 ()
- Refused -4 ()

Medication Code	Medication Name	Is the medication being taken for...		
		Anxiety	Depression	Stress
1.1	1.1.1	()	()	()
1.2	1.2.1	()	()	()
1.3	1.3.1	()	()	()
1.4	1.4.1	()	()	()
1.5	1.5.1	()	()	()
1.6	1.6.1	()	()	()
1.7	1.7.1	()	()	()
1.8	1.8.1	()	()	()
1.9	1.9.1	()	()	()
1.10	1.10.1	()	()	()
1.11	1.11.1	()	()	()
1.12	1.12.1	()	()	()
1.13	1.13.1	()	()	()
1.14	1.14.1	()	()	()
1.15	1.15.1	()	()	()
1.16	1.16.1	()	()	()
1.17	1.17.1	()	()	()
1.18	1.18.1	()	()	()
1.19	1.19.1	()	()	()
1.20	1.20.1	()	()	()
1.21	1.21.1	()	()	()
1.22	1.22.1	()	()	()
1.23	1.23.1	()	()	()
1.24	1.24.1	()	()	()
1.25	1.25.1	()	()	()
1.26	1.26.1	()	()	()
1.27	1.27.1	()	()	()
1.28	1.28.1	()	()	()
1.29	1.29.1	()	()	()
1.30	1.30.1	()	()	()

2. **Is (CR) currently taking any of these medications for anxiety, depression or stress?**

(RC1)

- No 0 ()
- Yes 1 ()
- Unknown -3 ()
- Refused -4 ()

(if YES, check the appropriate column on the immediate right of the medication name to identify that it is being taken for anxiety, depression or stress).