

ICPSR 4354

## **Resources for Enhancing Alzheimer's Caregiver Health (REACH II), 2001-2004**

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### **Questionnaire for DC: Discontinued Battery**

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## **CODEBOOK**

**Discontinued Battery**

**(DC)**



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**DISCONTINUED FORM**

***Hello Mr./Mrs./Ms. \_\_\_\_\_. My name is \_\_\_\_\_ and I am calling from the REACH II project. I understand that \_\_\_\_ months ago you discontinued your participation in the REACH II project. I am wondering if you would be willing to complete the 6 month follow-up interview at this time. This interview would help us see how things may have changed since we first interviewed you. This would be done during a home visit and would require about one hour of your time. While we are on the phone, could we go ahead and schedule a time for me to come out? Would that be ok with you?***

1. Caregiver agrees to schedule the 6 month follow-up interview? **FUNOT**

No 0( ) Yes 1( ) (If yes, do not enter this form in PoP)

Record time and date at which the 6 month follow-up is scheduled to take place.

1.1. Time: \_\_\_\_ : \_\_\_\_  
hours minutes

1.2 Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
month day year

***I realize you're very busy, but I wonder if you would be willing to answer a much shorter set of questions over the phone. This set of questions allows us to collect the most critical information from you without requiring you to spend a lot of time answering questions.***

2. Caregiver agrees to answer some questions? **QUNOT**

No 0( ) Yes 1( )

***Thank you very much. We appreciate your participation in the REACH II project. Your participation in completing this short questionnaire will help us to learn more about how to support caregivers. I promise it will only take a few minutes.***

***I will ask you a handful of the same questions you answered at the beginning of this project so we can see how things may have changed since we first interviewed you.***

***Like before, all of the information you give me will be kept confidential, and if you are uncomfortable with a question, you can refuse to answer it. Most of the questions have no right or wrong answers. They are questions about your experience, your feelings, or your opinions. If you don't understand a question, feel free to ask me to repeat it or clarify it. Do you have any questions before we begin?***

***Go to page 3- TRANSITION RMBPC***

2.1 ***I understand, Mr./Mrs./Ms. \_\_\_\_\_. Would you be willing to answer these questions at a more convenient time for you, say, in a couple of weeks? INACT***

No 0 ( ) →

***Thank you for your time. I wish you well.***

Yes 1 ( )



*Record time and date at which the call should take place.*

2.1.2 Time: \_\_\_ : \_\_\_  
          hours minutes

2.1.3 Date: \_\_\_ / \_\_\_ / \_\_\_  
          month day year

TRANSITION RMBPC

Now I'd like to ask you about (CR)'s memory, behavior and mood.

1. **In the past six months, have you seen any cognitive improvement overall? *MBCI***

(RC1)

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



1.1 **Was the improvement minimal or substantial? *MBCIM***  
(RC18)

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

1.2 **Was there no change, minimal decline or substantial decline? *MBCDE***  
(RC19)

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

2. **In the past six months, have you seen any behavioral improvement overall? *MBBI***

(RC1)

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



2.1 **Was the improvement minimal or substantial? *MBBIM***  
(RC18)

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

2.2 **Was there no change, minimal decline or substantial decline? *MBBDE***  
(RC19)

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



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

No 0 ( )	Yes 1 ( )	Unknown -3 ( )	Refused -4 ( )
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3.1 **Was the improvement minimal or substantial?** **MBMIM**  
 (RC18)

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

3.2 **Was there no change, minimal decline or substantial decline?** **MBIDE**  
 (RC19)

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

## TRANSITION BURDEN INVENTORY

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

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

## PREVENTATIVE HEALTH

*I would now like to ask you questions about your health.*

1. **In the past month, have you found that you had the time to see your doctor when you thought you should?** **SEEMD**  
(RC1)
 

No	Yes	Unknown	Refused
0 ( )	1 ( )	-3 ( )	-4 ( )
  
2. **In the past month, have you found that you were able to slow down and get enough rest when you were sick?** **REST**  
(RC1)
 

No	Yes	Unknown	Refused
0 ( )	1 ( )	-3 ( )	-4 ( )
  
3. **In the past month, have you lost or gained weight without meaning to?** **CWEI**  
(RC1)
 

No	Yes	Unknown	Refused
0 ( )	1 ( )	-3 ( )	-4 ( )
  
4. **In the past year, have you seen your primary care physician for a routine check up?** **MCHK**  
(RC1)
 

No	Yes	Unknown	Refused
0 ( )	1 ( )	-3 ( )	-4 ( )
  
5. **In the past 6 months, have you missed any scheduled doctor's appointments?** **MMISS**  
(RC1)
 

No	Yes	Unknown	Refused
0 ( )	1 ( )	-3 ( )	-4 ( )
  
6. **In the past year, have you had your eyesight checked?** **HEYE**  
(RC1)
 

No	Yes	Unknown	Refused
0 ( )	1 ( )	-3 ( )	-4 ( )
  
7. **In the past year, have you had your hearing checked?** **HHEAR**  
(RC1)
 

No	Yes	Unknown	Refused
0 ( )	1 ( )	-3 ( )	-4 ( )
  
8. **In the past year, have you had your teeth/dentures examined by a dentist?** **HTEET**  
(RC1)
 

No	Yes	Unknown	Refused
0 ( )	1 ( )	-3 ( )	-4 ( )
  
9. **In the past year, have you had a flu shot?** **HFLUS**  
(RC1)
 

No	Yes	Unknown	Refused
0 ( )	1 ( )	-3 ( )	-4 ( )
  
10. **In the past year, have you had your blood pressure checked?** **HBP**  
(RC1)
 

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

11. FEMALE ONLY: **In the past two years, have you had a mammogram?** **HMAMM**  
(RC1)
- |       |       |        |         |         |
|-------|-------|--------|---------|---------|
| No    | Yes   | N/A    | Unknown | Refused |
| 0 ( ) | 1 ( ) | -2 ( ) | -3 ( )  | -4 ( )  |
12. FEMALE ONLY: **In the past two years, have you had a pap smear?** **HPAPS**  
(RC1)
- |       |       |        |         |         |
|-------|-------|--------|---------|---------|
| No    | Yes   | N/A    | Unknown | Refused |
| 0 ( ) | 1 ( ) | -2 ( ) | -3 ( )  | -4 ( )  |
13. MALE ONLY: **In the past year, have you had a prostate examination?** **HPROS**  
(RC1)
- |       |       |        |         |         |
|-------|-------|--------|---------|---------|
| No    | Yes   | N/A    | Unknown | Refused |
| 0 ( ) | 1 ( ) | -2 ( ) | -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. <b>BOTHR</b></i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
2. (RC32)	<i>I had trouble keeping my mind on what I was doing. <b>KEEP</b></i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
3. (RC32)	<i>I felt depressed. <b>DEPRS</b></i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
4. (RC32)	<i>I felt that everything I did was an effort <b>EFORT</b></i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
5. (RC32)	<i>I felt hopeful about the future. <b>*FUTUR</b></i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
6. (RC32)	<i>I felt fearful. <b>FEARF</b></i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
7. (RC32)	<i>My sleep was restless. <b>SLEEP</b></i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
8. (RC32)	<i>I was happy. <b>*HAPPY</b></i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
9. (RC32)	<i>I felt lonely. <b>FLONE</b></i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
10. (RC32)	<i>I could not get "going". <b>GOING</b></i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
11. (RC32)	<i>People were unfriendly. <b>UNFRI</b></i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
12. (RC32)	<i>I felt that people disliked me. <b>DISLK</b></i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

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

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



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

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

<b>No change</b> 1 ( )	<b>Minimal decline</b> 2 ( )	<b>Substantial decline</b> 3 ( )	Unknown -3 ( )	Refused -4 ( )
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14. CES-D Score (questions 1 – 10): *CESD* (\* questions are reverse scored)

15. Is the CES-D score greater than or equal to 15? *SDAL1*

No 0 ( )  
 Yes 1 ( )



15.1 **Has the Principal Investigator or appropriate site personnel been notified?** *PIN3*

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

**TRANSITION 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? *FMHLP***

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

2. **How many relatives, friends, neighbors do you see or hear from at least once a month? *SERLT***

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

3. **How many relatives, friends, neighbors, 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? *FLRLT***

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

4. **How many relatives, friends, neighbors, do you feel you can call on for help with chores, transportation etc.? *TRHLP***

<b>None</b>	<b>One</b>	<b>Two</b>	<b>Three or Four</b>	<b>Five to eight</b>	<b>Nine or more</b>	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? *IMPTK***

<b>Never</b>	<b>Seldom</b>	<b>Sometimes</b>	<b>Often</b>	<b>Very Often</b>	<b>Always</b>	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, 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? *PTHLP***

<b>Never</b>	<b>Once in a while</b>	<b>Fairly often</b>	<b>Very often</b>	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? *STHLP***

<b>Not at all</b>	<b>A little</b>	<b>Moderately</b>	<b>Very</b>	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?* **SSHLP**

(RC36)

<b>Never</b>	<b>Once in a while</b>	<b>Fairly often</b>	<b>Very often</b>	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?* **STSUP**

(RC33)

<b>Not at all</b>	<b>A little</b>	<b>Moderately</b>	<b>Very</b>	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?* **HLUND**

(RC36)

<b>Never</b>	<b>Once in a while</b>	<b>Fairly often</b>	<b>Very often</b>	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?* **STSUG**

(RC33)

<b>Not at all</b>	<b>A little</b>	<b>Moderately</b>	<b>Very</b>	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 member.*

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

(RC36)

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

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

(RC36)

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

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

(RC36)

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



15. ***In the past month, how often have others taken advantage of you?*** **TKADV**  
 (RC36)

<b>Never</b>	<b>Once in a while</b>	<b>Fairly often</b>	<b>Very often</b>	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?*** **SSSI** (RC1)

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



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

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