

Interview Date: _____

DCS CID# _____
(For Office Use Only)

Dementia Capable WI: Creating New Partnerships in Dementia Care

We are asking you to provide this information to help us comply with federal reporting requirements. Completing this form is voluntary, but we hope that you will choose to fill it out. We also need it to help us analyze and evaluate programs that facilitate care and support for people with dementia. This information will be stored in a secure electronic database. We will not share your information with another agency without your permission. We will not sell this information to anyone.

If you have questions regarding this questionnaire, please contact:

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Feelings about Caregiving

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, circle one option of how often over the past month you have each of these feelings. There are no right or wrong answers; we just want to know how you feel based on your interpretation on the questions.

	Never	Rarely	Sometimes	Frequently	Nearly Always
1. Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?	0	1	2	3	4
2. Do you feel stressed due to caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
3. Do you feel angry when you are with your relative?	0	1	2	3	4
4. Do you feel that your relative currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
5. Do you feel strained when you are around your relative?	0	1	2	3	4
6. Do you feel that your health has suffered because of your involvement with your relative?	0	1	2	3	4
7. Do you feel that you do not have much privacy as you would like because of your relative?	0	1	2	3	4
8. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4

	Never	Rarely	Sometimes	Frequently	Nearly Always
9. Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
10. Are you not sure of what to do about your relative?	0	1	2	3	4
11. Do you feel that you should be doing more for your relative?	0	1	2	3	4
12. Do you feel that you could do a better job in caring for your relative?	0	1	2	3	4

We are also interested in how confident you are that you can keep up your own activities and also respond to caregiving situations. Please think about the questions carefully, and be as frank and honest as you can about what you really think you can do. I will read items which cover activities and thoughts that could come up for you as a caregiver. Please think about each one and tell me how confident you are that you could do each item. Rate your degree of confidence from 0 to 100 using the scale given below:

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

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

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

Questions:

How confident are you that you can do the following activities? The _____ stands for the name of your family member with dementia. (If a question is not applicable to your situation, put N/A.)

- _____ 1. When _____ forgets your daily routine and asks when lunch is right after you've eaten, how confident are you that you can answer him/her without raising your voice? (For interviewer: clarify that "answer" can be direct or a distraction.)
- _____ 2. When you get angry because _____ repeats the same question over and over, how confident are you that you can say things to yourself that calm you down?
- _____ 3. When _____ complains to you about how you're treating him/her, how confident are you that you can respond without arguing back?
- _____ 4. When _____ asks you 4 times in the first one hour after lunch when lunch is, how confident are you that you can answer him/her without raising your voice?
- _____ 5. When _____ interrupts you for the fourth time while you're making dinner, how confident are you that you can respond without raising your voice?

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

The _____ stands for the name of your family member with dementia. (If a question is not applicable to your situation, put N/A.)

- _____ 6. How confident are you that you can control thinking about unpleasant aspects of taking care of _____?
- _____ 7. How confident are you that you can control thinking how unfair it is that you have to put up with this situation (taking care of _____)?
- _____ 8. How confident are you that you can control thinking about what a good life you had before _____'s illness and how much you've lost?
- _____ 9. How confident are you that you can control thinking about what you are missing or giving up because of _____?

_____ 10. How confident are you that you can control worrying about future problems that might come up with _____?

Additional Caregiver Characteristics

In this section, please circle one option of how often you have been feeling each of the things listed in the last 6 months. The _____ stands for the name of your family member with dementia.

	Never	Rarely	Sometimes	Frequently	Nearly Always
11. How often do you wish you had more help from community services in caring for _____?	0	1	2	3	4
12. How often have you felt that _____ might be better off in a nursing home or assisted living facility?	0	1	2	3	4
13. In the last 6 months, how often have you and other family members discussed moving _____ to a nursing home or assisted living facility?	0	1	2	3	4

Medical services

Please provide the following information about your family member with dementia.

1. Did your family member go to the emergency room within the past 6 months?	NO / YES	If Yes, # of times? _____
2. Was your family member hospitalized within the past 6 months?	NO / YES	If Yes, # of times? _____
3. Did your family member go to urgent care within the past 6 months?	NO / YES	If Yes, # of times? _____

Community services

Did you and/or your family member with dementia use the following caregiver services within the past 6 months?

1. Memory Care Connections (MCC)?	NO / YES	
2. Services from the Alzheimer’s Association?	NO / YES	
3. Services from the Alzheimer’s and Dementia Alliance of Wisconsin?	NO / YES	
4. Adult Day Center services?	NO / YES	
5. Respite?	NO / YES	If Yes, # of times? _____
6. Powerful Tools for Caregivers (PTC)?	NO / YES	If Yes, when did you begin? Give approximate date: _____

DICE

How well do you feel you can...

Not at all A little bit Quite a lot Very much

	0	1	2	3
1. Understand the feelings of your family member with dementia?	0	1	2	3
2. Understand the way your family member with dementia interacts with people and things around them?	0	1	2	3
3. Use information about their past (such as what they used to do and their interests), when talking to your family member with dementia?	0	1	2	3

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How well do you feel you can...	Not at all	A little bit	Quite a lot	Very much
4. Protect the dignity of your family member with dementia in your care?	0	1	2	3
5. Deal with behavior that challenges in your family member with dementia?	0	1	2	3
6. Decide what to do about risk (such as harm to self or others) in your family member with dementia?	0	1	2	3
7. Offer stimulation (for the mind, the senses and the body) to your family member with dementia in your daily care?	0	1	2	3
8. Offer choice to your family member with dementia in everyday care (such as what to wear, or what to do)?	0	1	2	3
9. Engage your family member with dementia in creative activities during a normal care day?	0	1	2	3

I know and understand...	Not at all	A little bit	Quite a lot	Very much
10. The causes of behavioral and psychological symptoms of dementia.	0	1	2	3
11. How to assess and manage the behavioral and psychological symptoms of dementia.	0	1	2	3
12. That the patient, caregiver, and environmental factors can all contribute to behaviors.	0	1	2	3

Caregiver Demographic Information

- 1. What is your age?
 - Under 60 years old
 - 60 years old or over

- 2. What is your gender? _____

- 3. Are you of Hispanic, Latino, or Spanish origin?
 - Yes
 - No

- 4. What is your race? **(Check ✓ all that apply.)**
 - American Indian or Alaska Native
 - Asian or Asian-American
 - Black or African-American
 - Hawaiian Native or Pacific Islander
 - White or Caucasian
 - Other: _____

- 5. What type of geographic area do you live in?
 - Urban (place with a minimum population of 50,000 residents or more)
 - Rural

- 6. Have you ever served in the military?
 - Yes
 - No

- 7. What is the relationship with the person with dementia that you are caring for?
 - Spouse / Partner
 - Parent
 - Other: _____

- 8. Please circle the highest year of school you have completed:
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23+
(primary) (middle/high school) (tech/college) (graduate school)

Family Member Demographic Information

- 1. What is the age of the family member with dementia?
 - Under 60 years old
 - 60 years old or over

- 2. What is the gender of your family member with dementia? _____

- 3. Is the family member with dementia of Hispanic, Latino, or Spanish origin?
 - Yes
 - No

- 4. What is the race of your family member with dementia? (Check all that apply.)
 - American Indian or Alaska Native
 - Asian or Asian-American
 - Black or African-American
 - Hawaiian Native or Pacific Islander
 - White or Caucasian
 - Other: _____

- 5. What type of geographic area does the family member with dementia live in?
 - Urban (place with a minimum population of 50,000 residents or more)
 - Rural

- 6. What is the living arrangement for the family member with dementia?
 - Lives alone, has an identified caregiver
 - Does not live alone, has an identified caregiver

- 7. Has the family member with dementia ever served in the military?
 - Yes
 - No

- 8. Please circle the highest year of school that your family member with dementia completed:
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23+
(primary) (middle/high school) (tech/college) (graduate school)

Survey is complete. Thank you!