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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(FOR WAI OFFICE USE ONLY)
Interview Date: _____

HH CID#_____
(For Office Use Only)

HH Main Interventionist ID _____
HH 2nd Interventionist ID _____
HH 3rd Interventionist ID _____

Information about Medical Conditions and Treatment

We are also interested in your confidence level to identify and carry out prevention and management strategies for types of medical conditions that your family member may develop because of dementia. In this section, please circle one option for each item. There are no right or wrong answers; we just want to know how you feel based on your interpretation on the questions.

Carrying out prevention strategies	Confidence Level			
How confident are you that you can prevent the following in your family member with dementia:	**Not at all**	**Low**	**Moderate**	**High**
1. Pressure injury (also known as pressure ulcers or bed sores)?	0	1	2	3
2. Falls?	0	1	2	3
3. Swallowing problems?	0	1	2	3
4. Weight loss and related complications?	0	1	2	3
5. Pneumonia and related symptoms?	0	1	2	3
6. Incontinence (including leakage or "accidents") & risk-factors?	0	1	2	3
7. Dehydration?	0	1	2	3
8. Behavior changes?	0	1	2	3
9. Infections?	0	1	2	3
10. Constipation?	0	1	2	3
11. Pain?	0	1	2	3
12. Communication changes?	0	1	2	3

Identification of complications — Confidence Level

How confident are you that you can identify the following in your family member with dementia:	**Not at all**	**Low**	**Moderate**	**High**
1. Pressure injury (also known as pressure ulcers or bed sores)?	0	1	2	3
2. Swallowing problems?	0	1	2	3
3. Weight loss?	0	1	2	3
4. Pneumonia?	0	1	2	3
5. Bladder infection?	0	1	2	3
6. Dehydration?	0	1	2	3
7. Condition changes related to medication?	0	1	2	3
8. Other Infections?	0	1	2	3
9. Constipation?	0	1	2	3
10. Cognitive or thinking changes?	0	1	2	3
11. Pain?	0	1	2	3
12. Stages of dementia and related complications?	0	1	2	3
13. End-of-life stages?	0	1	2	3
14. Communication changes?	0	1	2	3

Management strategies — Confidence Level

How confident are you that you can manage the following in your family member with dementia:	**Not at all**	**Low**	**Moderate**	**High**
1. Pressure injury (also known as pressure ulcers or bed sores)?	0	1	2	3
2. Swallowing problems?	0	1	2	3
3. Weight loss?	0	1	2	3
4. Pneumonia?	0	1	2	3
5. Incontinence of bladder?	0	1	2	3
6. Incontinence of bowels?	0	1	2	3

How confident are you that you can manage the following in your family member with dementia:	**Not at all**	**Low**	**Moderate**	**High**
7. Dehydration?	0	1	2	3
8. Condition changes related to medication?	0	1	2	3
9. Other Infections?	0	1	2	3
10. Constipation?	0	1	2	3
11. Cognitive or thinking changes?	0	1	2	3
12. Pain?	0	1	2	3
13. End-of-life stages?	0	1	2	3
14. Communication changes?	0	1	2	3

Other management strategies	Likelihood Level			
	Not at all	**Low**	**Moderate**	**High**
1. How likely are you to call the clinic if the person that you are caring for is more confused?	0	1	2	3
2. How likely are you to call the clinic if the person who you are caring for is much more tired?	0	1	2	3
3. How likely are you to call the clinic if the person who you are caring for is suddenly having trouble getting out of the chair or getting out of bed?	0	1	2	3
4. If you think the person you are caring for is sick, how likely are you to ask to speak to a nurse when you call the clinic?	0	1	2	3
5. How confident are you in identifying resources to help you to take care of your loved one?	0	1	2	3

6. What would you would do if there was a change in condition for the person you are caring for? Please give an example of the change in condition and what you would do.

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 toward the person you are caring for. 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

	Never	Rarely	Sometimes	Frequently	Nearly Always
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
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

13. Please share other thoughts or feelings that you have about caregiving for your person with dementia:

Revised Scale for Caregiving Self-Efficacy (Steffen et al, 2002)

Instructions: We are 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. 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

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 ____?

In this section, please circle one option of how often you felt or thought about each item in the last 6 months. The ____ stands for the name of your family member with dementia.

	Never	Rarely	Sometimes	Frequently	Nearly Always
1. How often do you wish you had more help from community services in caring for _____?	0	1	2	3	4
2. How often have you felt that _____ might be better off in a nursing home or assisted living facility?	0	1	2	3	4
3. 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 and Community Service Use

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: _____ How many sessions did you complete? _____

7. Please share thoughts or feelings that you have about your needs for additional support in caring for your family member:

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 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)

Demographic Information of Family Member with Dementia

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 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. Have 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!