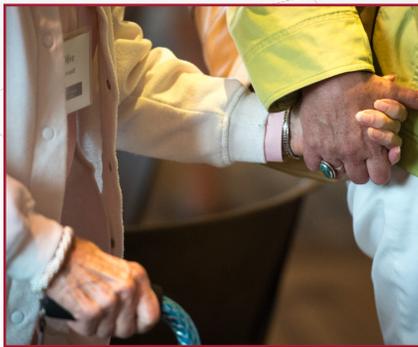




Wisconsin Alzheimer's Institute

UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH



DICE Approach™

A guide on how to train dementia care professionals on the use of the DICE Approach™ with family caregivers and people living with dementia.

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**Training Dementia Care Professionals on the use of the DICE Approach™ with Family
Caregivers and People Living with Dementia**

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Chapter 1

About the DICE Approach™

Approximately 90% of people with dementia will have at least one behavioral and psychological symptom of dementia (BPSD) during the course of their illness (Kales et al., 2014). These symptoms can include wandering, apathy, repetitive questioning, hallucinations, delusions, aggression, and sleep disturbances. As dementia progresses from mild to moderate to severe, these behaviors can become more frequent and severe in nature. Increasing behaviors can be difficult to manage, may require an increase in supervision, and can be very overwhelming for caregivers. Family caregivers often are not equipped to manage BPSD, and the resulting stress can lead to caregiver depression and other health consequences. Additionally lack of a proper response to BPSD can result in the unnecessary use of psychotropic medications, hospitalization, or early nursing home placement. Appropriate management of BPSD is vital for the well-being of the individual with dementia and for caregivers.

Management of BPSD using DICE

BPSD result from environmental or physical factors such as untreated pain, underlying medical issues, an overstimulating environment, or ineffective caregiver interactions. Effectively identifying and managing these factors can be accomplished using the DICE Approach™ (referred to as “DICE” from now on). DICE is a structured and systematic method of assessing and managing BPSD that seeks to minimize the use of psychotropic medications. Effectively using the DICE approach can lessen problematic behaviors, reduce caregiver stress and burden, and prevent poor outcomes for the person with dementia.

Dementia Professional Training

Through the *Dementia Capable Wisconsin* grant from the U.S. Administration for Community Living, the Wisconsin Alzheimer’s Institute (WAI) trained a variety of professionals who

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interface with people with dementia and their caregivers across the State of Wisconsin. We provided four free DICE trainings to dementia care professionals throughout Wisconsin. Participants received the DICE manual, a quick reference guide that covers topics on dementia, medications, how the DICE method is used, and how caregivers can build a support network and learn self-care skills. This manual is now available for purchase on the DICE website (www.diceapproach.com). During the COVID pandemic, we switched to an online format, including a web-based version of DICE.

Complementing the trainings, WAI provided information to participants on how to seek help from their client's primary physician. This involved a letter that the professionals could provide to physicians informing them that their mutual patient is receiving the DICE protocol, and asking their help in evaluating medical concerns that could contribute to challenging behaviors. We also provided information about the locations of WAI's dementia diagnostic clinics, and community resources to refer caregivers to, such as Powerful Tools for Caregivers and other support groups.

By the end of our grant in March 2021, WAI had provided the DICE training to 136 professionals; in turn, 194 family caregivers were educated on the DICE method by our participants. Many participants report that they will continue to use DICE with the caregivers they serve and that their agencies will continue to offer DICE training to new dementia care professionals.

Educating Caregivers on BPSD

The purpose of DICE is to provide solutions to challenging behaviors without resorting to medications as first-line treatment. Trained participants in the DICE project transferred this knowledge to family caregivers by conducting home visits or holding caregiver workshops on DICE, and implementing the approach with caregivers. The goal of educating caregivers on BPSD is to increase their understanding of the triad factors that contribute to behaviors (person with dementia, the environment, and caregiver factors); and to give them the skills to manage BPSD with DICE. The implementation of DICE also involved requesting caregivers to complete

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evaluations to measure their knowledge about dementia, comfort level with caregiving and understanding of how to use DICE. Participants worked collaboratively with caregivers to address a challenging behavior to work on using the DICE steps, identify the potential causes, create a plan to use as an intervention with the behavior, and then evaluate if the plan worked effectively. Participants used a DICE worksheet with the caregivers to take notes through each of the steps, and provided them with copies to use independently with other behaviors that may arise.

For many families dealing with BPSD, they generally face more than one behavioral symptom happening with their loved one. Often, caregivers are dealing with multiple behavioral challenges occurring at one time amongst other complex care needs for their loved one. To help support the DCSs and other professionals working with them, WAI offered DICE consultations as needed for difficult cases. The WAI program manager and geriatric nurse practitioner scheduled phone and email consultations with participants when they wanted to discuss challenging cases with multiple or unique behavioral issues. These consultations also helped them learn more about the medical diagnoses or medications of the person with dementia, brainstorm other factors that could be contributing to the behavior, and discuss ideas on what to create for an intervention plan. Participants consulting with WAI were able to bring back some questions or ideas to the caregivers to help facilitate the use of DICE. Overall, the consultations aided in giving participants additional strategies to consider and allowed WAI to learn more about the implementation process and outcomes achieved.

Chapter 2

DICE Approach™ Implementation at a Glance

Determining Your Organization's Need, Capacity and Readiness

DICE is intended for dementia care professionals and social workers to work with caregivers using the DICE strategies to address behaviors. Trained professionals use DICE with caregivers to develop a better understanding of the causes of BPSD and how to apply simple strategies, such as improving communication or creating a meaningful and safe environment for the person with dementia. Organizations considering purchasing DICE training for their staff should evaluate the following:

Need: Consider staff's current knowledge and level of experience working with people with dementia who have BPSD and their caregivers to determine if DICE training is a good fit for the organization. Professionals that could directly benefit from this training include social workers, case managers, home health nurses, or any social service professional who has direct contact with people with the dementia and their caregivers. Additionally, since DICE involves closely assessing the environment that the person lives in, staff who have access to the persons living environment and conduct psychosocial assessments on the individual would also benefit from this education. Since working through the steps of DICE can take time and various revisions to the intervention plan, organizations should consider training staff who can provide ongoing services and follow-up visits with caregivers.

Capacity: Determine the organization's ability to provide the training including purchase of the training subscription and purchase of the DICE manual. Consider who will be responsible for setting up training accounts for staff, what funding is available for the trainings, how many staff can be trained and how many subscription renewals can be provided. The online training is

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flexible and allows users to watch at their own pace, but organizations should determine if there is a time limit they want staff to complete the training and how their work schedules can be modified to accommodate completing the training. Additionally, organizations are encouraged to identify a staff person who can be a lead person or DICE mentor to help provide support and consult with staff about the use of DICE with their caseload.

Readiness: Determine staff readiness to use DICE with their clients and caregivers. If staff use DICE, develop a plan for when or what circumstances they should use the method, as well as the evaluation plan for their DICE services. Organizations should also consider what resources they would use when implementing DICE, such as the DICE worksheet, letter to primary providers or other tools that may be developed within the organization. Finally, organizations should prepare staff for when situations occur that necessitate a more urgent response. This could be the person with dementia being at risk of causing harm to themselves or others and needing an emergency intervention, or concerns of abuse that may require police or Adult Protective Services involvement.

Benefits to Persons with Dementia

DICE is an evidence-based approach to addressing BPSD and reducing caregiver burden. DICE offers a safer and more sustainable alternative to the prescription of psychoactive medications, which are associated with significant side effects, including increased risk of death. Using DICE can effectively address the potential causes of the behavior, can help create a person-centered plan that takes into account safety risks, health issues and personal preferences, and it can evaluate the outcomes of the plan implemented. In addition, using DICE may reduce the use of unnecessary medications; decrease the use of emergency medical services; allow persons with dementia to live longer in their own homes; and lower the risks associated with BPSD, e.g., accidental injury of self or others.

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Benefits to Caregivers

Caregivers of persons with dementia face unique and ever-changing challenges to caring for someone with dementia, and most caregivers do not receive formal education on how to manage BPSD. This can lead to increased stress, burden, physical illness and mental/emotional burnout for caregivers. Giving caregivers the tools and empowerment to care for their loved one can mitigate these issues, and lead to better outcomes for them. Educating caregivers on DICE can:

- Improve their skills and confidence with caregiving, provide evidence-based techniques to reduce unwanted behaviors
- Support their loved one in keeping them in their own home
- Reduce their stress and burden by helping them feel more in control of challenging situations and building a support network
- Increase their ability to advocate on behalf of their loved one to the primary provider

Benefits to Your Organization

For many social workers and dementia care professionals, calls to their organizations from concerned family members or caregivers comes when the situation has turned into a crisis and may need a more rapid response, such as a hospitalization. This results in increased time, demand and resources for the dementia care staff to respond. Addressing BPSD earlier on before it escalates to an emergent level can reduce the influx of urgent calls that dementia care professionals receive. Organizational benefits of DICE include:

- Increasing the knowledge about BPSD to dementia care staff.
- Improving the self-confidence of staff to educate caregivers on BPSD.
- Staff can educate and empower caregivers to take matters into their own hands and give them the tools to identify and manage BPSD independently in their home before it rises to a crisis response. Caregivers who can address BPSD more proactively can reduce the number of crisis calls to organizations. This will allow staff to allot more time to new cases or assisting families with other resources.

Chapter 3

The DICE Approach™ Online Training

In 2020, the developers of DICE created a web-based training available for purchase that includes a one-year subscription for users to access the training modules. This was an essential training format during the COVID pandemic and it continues to be web-based training product available to professionals and caregivers. The online version is intended to replace in-person trainings, since it includes all the components of the original in-person training including videos on dementia types and symptoms, types of BPSD, the DICE Approach™ method, and case study e-simulation videos.

The online training holds many appealing features for subscribers. These include:

- One-year subscription to the training modules;
- Training videos presented directly by Dr. Helen Kales, the lead developer of DICE;
- Shorter length of time to complete the training (approximately 2.5 to 3 hours);
- Ability for subscribers to stop and start the training at their convenience;
- Subscribers can also skip around to different video modules at their discretion or review the training sections as refreshers when needed.

Chapter 4

Education Resources and Forms

To access these links, we recommend users open this document in Adobe Acrobat. Hard copies of documents are also embedded in the guide in the following pages.

[DICE Training Presentation](#)

[Pre-DICE Training Evaluations for Participants Baseline](#)

[Post-DICE Training Evaluations for Participants](#)

[6-month Evaluations for Participants](#)

[Baseline and 6-month DICE Evaluations for Caregivers](#)

[DICE Flyer for Caregivers](#)

[DICE Letter to Providers](#)

Dissemination of Materials

The DICE Approach training materials, guides and other resource links will be disseminated through the [Wisconsin Alzheimer's Institute website](#). To access and download the guide, users will need to complete a form on the webpage providing their name, organization and email address.

THE DICE APPROACH™

DESCRIBE | INVESTIGATE | CREATE | EVALUATE



“I am so frustrated and I just don’t know what to do.” If you are providing care for a family member with dementia and feel frustrated or overwhelmed, the DICE Approach™ may be able to provide you with useful strategies for managing daily life. The DICE Approach™ is a tool that caregivers can use to understand and respond to the variety of situations that occur when providing daily care to someone with dementia.

PARTICIPATION INCLUDES:

The dementia care professional will meet with you in your home to teach you the steps for using DICE. You will work through the DICE steps together to create a plan that addresses a behavior that is challenging to you. This may take a couple of hours and can be done at one time or over several visits.

The dementia care professional will follow up with you by phone or home visits to see how the plan is working. The dementia care professional will continue to work with you, using the DICE Approach™ until you feel comfortable with the tool. Part of the process may be asking you to work with your loved one’s primary physician, to eliminate other causes of the challenging behavior.

Once the problem is solved, you can use DICE in the future as behavioral challenges arise. Your dementia care professional will be there to help you, but you will have the knowledge to start managing the difficult situation yourself using DICE..

For more information or to participate, please speak with your dementia care professional.



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(Insert Organization Letterhead)

Date:

Physician Name/Address:

City, State, Zip Code:

RE: DICE Approach with Patient Name: DOB:

Dear Dr. _____,

The **DICE (Describe, Investigate, Create, Evaluate) Approach** is a structured algorithmic method developed in collaboration with geriatric experts from Johns Hopkins University and the University of Michigan (pubmed.ncbi.nlm.nih.gov/24635665/), and was designed to address the behavioral and psychological symptoms of dementia. The purpose of utilizing this framework is to provide management and solutions to challenging behaviors by modifying other remediable psychosocial, environmental, and medical factors, without first resorting to the use of medications.

Your patient and their caregiver are receiving assistance from their case worker using the DICE approach. Using DICE, the caregiver can learn to identify and change factors that could be contributing to behavioral symptoms. We are sending you this letter so that you can be involved in the discussion about the patient's behaviors, in particular helping to evaluate and rule out any medical factors that could be contributing to the challenging behaviors (e.g. infections, electrolyte abnormalities, pain, other illnesses, hypoxia, or medication effects). At the same time, the caregiver is learning how to evaluate and modify any environmental factors (caregiver approach, over stimulating environment, other unmet needs) that could be causing the behavior. With your help through use of DICE we hope to bring a positive change to the situation.

We thank you for your time and consideration in assisting us with the implementation of DICE to address challenging behaviors. Your partnership in implementing this approach could help our goals of keeping the patient at home longer and reducing caregiver stress and burden. If you have any questions, please contact _____.

Sincerely,

DICE Reference: Kales, H. C., Gitlin, L. N., & Lyketsos, C. G. (2015). Assessment and management of behavioral and psychological symptoms of dementia. *The BMJ*, 350, h369.

For more information on the DICE Approach and online training, go to: www.diceapproach.com

Dementia Capable WI: Creating New Partnerships in Dementia Care (Pre-Training Evaluation)

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:

Dr. Art Walaszek, Principal Investigator

Wisconsin Alzheimer's Institute

610 Walnut St, Suite 957

Madison, WI 53726

Phone: 608-263-6106

Background Information

1. What is your professional role? _____

2. If you are an employee of a care facility or health care organization, what is your job title?

<input type="checkbox"/> Registered Nurse (RN)	<input type="checkbox"/> Occupational Therapist (OT)
<input type="checkbox"/> Licensed Practical Nurse (LPN)	<input type="checkbox"/> Physical Therapist (PT)
<input type="checkbox"/> Geriatric Nursing Assistant (GNA)	<input type="checkbox"/> Recreational Therapist
<input type="checkbox"/> Certified Nursing Assistant (CAN)	<input type="checkbox"/> Other _____

3. How many years / months have you worked in your role? _____ years _____ months

4. Are you Hispanic, Latino, or Spanish origin?

<input type="checkbox"/> Yes
<input type="checkbox"/> No

5. What is your race? (**Check ✓ all that apply.**)

<input type="checkbox"/> American Indian or Alaska Native	<input type="checkbox"/> Asian or Asian-American
<input type="checkbox"/> Black or African-American	<input type="checkbox"/> Hawaiian Native or Pacific Islander
<input type="checkbox"/> Hispanic	<input type="checkbox"/> White or Caucasian
<input type="checkbox"/> Other: _____	

6. What is your gender? _____

7. 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)

Knowledge of Memory Loss and Care (KAML-C)

We are interested in understanding your knowledge of dementia. Please choose one response per question.

Which of the following is the most common cause of memory loss in persons over age 65?

- 1. Alzheimer's disease
- 2. Senility
- 3. Normal aging
- 4. Hardening of the arteries
- 5. Benign senescent forgetfulness

Which of the following conditions may resemble Alzheimer's disease?

- 1. Major depression
- 2. Pernicious anemia
- 3. Thyroid disorder
- 4. Parkinson's disease
- 5. All of the above

A symptom of Alzheimer's disease usually NOT seen in the early stage is

- 1. Disorientation to time and place
- 2. Word finding difficulty
- 3. Aggressive behavior
- 4. Recent memory loss
- 5. Difficulty with calculations

The BEST way to enable someone with memory loss to understand you is to

- 1. Logically explain your reasoning
- 2. Write out a detailed note
- 3. Repeat yourself until the point is made
- 4. Give brief and simple instructions
- 5. Speak in a quiet tone

Which of the following is NOT likely to be a problem for a person in the early stage of memory loss who is living alone?

- 1. Forgetting to turn off the stove
- 2. Making travel plans
- 3. Managing money
- 4. Remembering to take medications
- 5. Getting dressed in the morning

Which of the following approaches is NOT HELPFUL for persons with memory loss in completing tasks?

- 1. Breaking tasks down into small steps
- 2. Encouragement to try harder
- 3. Repeating old, familiar skills
- 4. Having others assist them as needed
- 5. Companionship

Most persons with Alzheimer's disease live

- _____ 1. In nursing homes
- _____ 2. In retirement communities
- _____ 3. In their own homes
- _____ 4. With their adult children
- _____ 5. In assisted living facilities

Primary caregivers of persons with Alzheimer's disease suffer from major depression

- _____ 1. At about the same rate as the general population
- _____ 2. At a lower rate than the general population
- _____ 3. At a much higher rate than the general population
- _____ 4. At a slightly higher rate than the general population
- _____ 5. At a much lower rate than the general population

Those LEAST likely to be primary caregivers of persons with Alzheimer's disease are

- _____ 1. Their sons
- _____ 2. Their daughters
- _____ 3. Their daughters-in law
- _____ 4. Their husbands
- _____ 5. Their wives

The Dementia Attitudes Scale (Connor & McFadden)

Please rate each statement according to how much you agree or disagree with it. Circle 1, 2, 3, 4, 5, 6, or 7 according to how you feel in each case. Please be honest. There are no right or wrong answers. The acronym "ADRD" in each question stands for "Alzheimer's disease and related dementias."

	Strongly disagree	Disagree	Slightly disagree	Neutral	Slightly agree	Agree	Strongly agree
It is rewarding to work with persons who have ADRD.	1	2	3	4	5	6	7
I am afraid of persons with ADRD.	1	2	3	4	5	6	7
Persons with ADRD can be creative.	1	2	3	4	5	6	7
I feel confident around persons with ADRD.	1	2	3	4	5	6	7
I am comfortable touching persons with ADRD.	1	2	3	4	5	6	7
I feel uncomfortable being around persons with ADRD.	1	2	3	4	5	6	7
Every person with ADRD has different needs.	1	2	3	4	5	6	7

	Strongly disagree	Disagree	Slightly disagree	Neutral	Slightly agree	Agree	Strongly agree
I am not very familiar with ADRD.	1	2	3	4	5	6	7
I would avoid an agitated person with ADRD.	1	2	3	4	5	6	7
Persons with ADRD like having familiar things nearby.	1	2	3	4	5	6	7
It is important to know the past history of persons with ADRD.	1	2	3	4	5	6	7
It is possible to enjoy interacting with persons with ADRD.	1	2	3	4	5	6	7
I feel relaxed around persons with ADRD.	1	2	3	4	5	6	7
Persons with ADRD can enjoy life.	1	2	3	4	5	6	7
Persons with ADRD can feel when others are kind to them.	1	2	3	4	5	6	7
I feel frustrated because I do not know how to help persons with ADRD.	1	2	3	4	5	6	7
I cannot imagine taking care of someone with ADRD.	1	2	3	4	5	6	7
I admire the coping skills of persons with ADRD.	1	2	3	4	5	6	7
We can do a lot now to improve the lives of persons with ADRD.	1	2	3	4	5	6	7
Difficult behaviors may be a form of communication for persons with ADRD.	1	2	3	4	5	6	7

DICE – Pre-Training

Have you previously been trained in dementia care? If so, what did that training consist of?

How well do you feel you can train caregivers to... **Not at all** **A little bit** **Quite a lot** **Very much**

1.)... understand the feelings of a person with dementia?	0	1	2	3
2.)... understand the way a person 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 a person with dementia?	0	1	2	3
4.)... protect the dignity of a person with dementia in your care?	0	1	2	3
5.)... deal with behavior that challenges in a person with dementia?	0	1	2	3
6.)... decide what to do about risk (such as harm to self or others) in a person with dementia?	0	1	2	3
7.)... offer stimulation (for the mind, the senses and the body) to a person with dementia in your daily care?	0	1	2	3
8.)... offer choice to a person with dementia in everyday care (such as what to wear, or what to do)?	0	1	2	3
9.)... engage a person with dementia in creative activities during a normal care day?	0	1	2	3

DICE – Pre-Training

- 1.) Dementia does not change how a person feels pain, but it does change how the person’s ability to express it. Which of the following is NOT a good way to assess for pain:
 - a. Wait for the person with dementia to communicate pain
 - b. look for a behavior change (e.g. restlessness, fidgeting, resistant to care)
 - c. monitor facial expressions (e.g. grimacing, frowning, looking tense)
 - d. notice repeated vocalizations (e.g. shouting, screaming, crying)

- 2.) Which of the following is NOT a good way to care for a person with dementia?
 - a. Pay attention to their nonverbal communication and anticipate their needs.
 - b. Use a gentle, reassuring touch.
 - c. Tell the resident step-by-step what will be happening as care is provided.
 - d. Give the person with dementia several choices while providing care.

- 3.) Mrs. Tenorio taught preschool for 25 years. Which of the following may not be a meaningful activity for this former teacher?
 - a. Looking at picture books together.
 - b. Watching the children play on the playground across the street.
 - c. Looking at a magazine with birds and wildlife.
 - d. Singing the alphabet song with her.

I know and understand...	Not at all	A little bit	Quite a lot	Very much
1.)... the causes of behavioral and psychological symptoms of dementia?	0	1	2	3
2.)... how to assess and manage the behavioral and psychological symptoms of dementia?	0	1	2	3
3.)... that the patient, caregiver, and environmental factors can all contribute to behaviors.	0	1	2	3

Thank you!

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:

Dr. Art Walaszek, Principal Investigator

Wisconsin Alzheimer's Institute

610 Walnut St, Suite 957

Madison, WI 53726

Phone: 608-263-6106

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? _____

Interview Date: _____

DCS CID# _____
(For Office Use Only)

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

Interview Date: _____

DCS CID# _____
(For Office Use Only)

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!

Dementia Capable WI: Creating New Partnerships in Dementia Care (Post-Training Evaluation)

Knowledge of Memory Loss and Care (KAML-C)

Please choose one response per question.

Which of the following is the most common cause of memory loss in persons over age 65?

- 1. Alzheimer's disease
- 2. Senility
- 3. Normal aging
- 4. Hardening of the arteries
- 5. Benign senescent forgetfulness

Which of the following conditions may resemble Alzheimer's disease?

- 1. Major depression
- 2. Pernicious anemia
- 3. Thyroid disorder
- 4. Parkinson's disease
- 5. All of the above

A symptom of Alzheimer's disease usually NOT seen in the early stage is

- 1. Disorientation to time and place
- 2. Word finding difficulty
- 3. Aggressive behavior
- 4. Recent memory loss
- 5. Difficulty with calculations

The BEST way to enable someone with memory loss to understand you is to

- 1. Logically explain your reasoning
- 2. Write out a detailed note
- 3. Repeat yourself until the point is made
- 4. Give brief and simple instructions
- 5. Speak in a quiet tone

Which of the following is NOT likely to be a problem for a person in the early stage of memory loss who is living alone?

- 1. Forgetting to turn off the stove
- 2. Making travel plans
- 3. Managing money
- 4. Remembering to take medications
- 5. Getting dressed in the morning

Which of the following approaches is NOT HELPFUL for persons with memory loss in completing tasks?

- 1. Breaking tasks down into small steps
- 2. Encouragement to try harder
- 3. Repeating old, familiar skills
- 4. Having others assist them as needed
- 5. Companionship

Most persons with Alzheimer's disease live

- _____ 1. In nursing homes
- _____ 2. In retirement communities
- _____ 3. In their own homes
- _____ 4. With their adult children
- _____ 5. In assisted living facilities

Primary caregivers of persons with Alzheimer's disease suffer from major depression

- _____ 1. At about the same rate as the general population
- _____ 2. At a lower rate than the general population
- _____ 3. At a much higher rate than the general population
- _____ 4. At a slightly higher rate than the general population
- _____ 5. At a much lower rate than the general population

Those LEAST likely to be primary caregivers of persons with Alzheimer's disease are

- _____ 1. Their sons
- _____ 2. Their daughters
- _____ 3. Their daughters-in law
- _____ 4. Their husbands
- _____ 5. Their wives

The Dementia Attitudes Scale (Connor & McFadden)

Please rate each statement according to how much you agree or disagree with it. Circle 1, 2, 3, 4, 5, 6, or 7 according to how you feel in each case. Please be honest. There are no right or wrong answers. The acronym “ADRD” in each question stands for “Alzheimer’s disease and related dementias.”

	Strongly disagree	Disagree	Slightly disagree	Neutral	Slightly agree	Agree	Strongly agree
It is rewarding to work with persons who have ADRD.	1	2	3	4	5	6	7
I am afraid of persons with ADRD.	1	2	3	4	5	6	7
Persons with ADRD can be creative.	1	2	3	4	5	6	7
I feel confident around persons with ADRD.	1	2	3	4	5	6	7
I am comfortable touching persons with ADRD.	1	2	3	4	5	6	7
I feel uncomfortable being around persons with ADRD.	1	2	3	4	5	6	7
Every person with ADRD has different needs.	1	2	3	4	5	6	7

	Strongly disagree	Disagree	Slightly disagree	Neutral	Slightly agree	Agree	Strongly agree
I am not very familiar with ADRD.	1	2	3	4	5	6	7
I would avoid an agitated person with ADRD.	1	2	3	4	5	6	7
Persons with ADRD like having familiar things nearby.	1	2	3	4	5	6	7
It is important to know the past history of persons with ADRD.	1	2	3	4	5	6	7
It is possible to enjoy interacting with persons with ADRD.	1	2	3	4	5	6	7
I feel relaxed around persons with ADRD.	1	2	3	4	5	6	7
Persons with ADRD can enjoy life.	1	2	3	4	5	6	7
Persons with ADRD can feel when others are kind to them.	1	2	3	4	5	6	7
I feel frustrated because I do not know how to help persons with ADRD.	1	2	3	4	5	6	7
I cannot imagine taking care of someone with ADRD.	1	2	3	4	5	6	7
I admire the coping skills of persons with ADRD.	1	2	3	4	5	6	7
We can do a lot now to improve the lives of persons with ADRD.	1	2	3	4	5	6	7
Difficult behaviors may be a form of communication for persons with ADRD.	1	2	3	4	5	6	7

DICE – Post-Training

How well do you feel you can train caregivers to... **Not at all** **A little bit** **Quite a lot** **Very much**

1.)... understand the feelings of a person with dementia?	0	1	2	3
2.)... understand the way a person 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 a person with dementia?	0	1	2	3
4.)... protect the dignity of a person with dementia in your care?	0	1	2	3
5.)... deal with behavior that challenges in a person with dementia?	0	1	2	3
6.)... decide what to do about risk (such as harm to self or others) in a person with dementia?	0	1	2	3
7.)... offer stimulation (for the mind, the senses and the body) to a person with dementia in your daily care?	0	1	2	3
8.)... offer choice to a person with dementia in everyday care (such as what to wear, or what to do)?	0	1	2	3
9.)... engage a person with dementia in creative activities during a normal care day?	0	1	2	3

- 1.) Dementia does not change how a person feels pain, but it does change how the person’s ability to express it. Which of the following is NOT a good way to assess for pain:
- a. Wait for the person with dementia to communicate pain
 - b. look for a behavior change (e.g. restlessness, fidgeting, resistant to care)
 - c. monitor facial expressions (e.g. grimacing, frowning, looking tense)
 - d. notice repeated vocalizations (e.g. shouting, screaming, crying)

DICE – Post-Training (continued)

- 2.) Which of the following is NOT a good way to care for a person with dementia?
- a. Pay attention to their nonverbal communication and anticipate their needs.
 - b. Use a gentle, reassuring touch.
 - c. Tell the resident step-by-step what will be happening as care is provided.
 - d. Give the person with dementia several choices while providing care.
- 3.) Mrs. Tenorio taught preschool for 25 years. Which of the following may not be a meaningful activity for this former teacher?
- a. Looking at picture books together.
 - b. Watching the children play on the playground across the street.
 - c. Looking at a magazine with birds and wildlife.
 - d. Singing the alphabet song with her.

I know and understand...	Not at all	A little bit	Quite a lot	Very much
1.)... the causes of behavioral and psychological symptoms of dementia?	0	1	2	3
2.)... how to assess and manage the behavioral and psychological symptoms of dementia?	0	1	2	3
3.)... that the patient, caregiver, and environmental factors can all contribute to behaviors.	0	1	2	3

Any comments about this program that you would like to share with the program team?

Thank you!

Chapter 5

Wisconsin Alzheimer's Institute

The Wisconsin Alzheimer's Institute (WAI), an academic center of the School of Medicine and Public Health at the University of Wisconsin-Madison, was founded in 1998 by a coalition of service providers, community-based organizations, educational institutions, and advocates organized by the Wisconsin Bureau on Aging and Long-Term Care Resources and Bader Philanthropies. The hallmarks of the Public Health Pillar of WAI are community outreach and the development of culturally-tailored, innovative programs to improve the quality of care for people with Alzheimer's disease and other causes of dementias. It is through generous grants from agencies such as the U.S. Administration for Community Living (ACL) that we are able to create and share this guide.

WAI's mission is to promote the health equity and improve the quality of life of people living with Alzheimer's disease and other dementias and their families through research and community engagement. We are committed to helping in improving the lives of people with Alzheimer's disease and dementia, their caregivers, and other professionals who support them. Our purpose is to increase dementia awareness, provide education on Alzheimer's disease and related disorders, identify and disseminate strategies to reduce dementia risk, convene stakeholders across the state, improve access to quality dementia care services, and to develop and support culturally tailored, effective clinical and community-based models of care.

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Training Dementia Care Professionals on the Use of the DICE Approach™ with Family Caregivers of People Living with Dementia

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Wisconsin's Aging and Disability Resource Center and Tribal Dementia Care Specialists
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Chapter 6

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