

Dementia-Caregiving PREP (PRactical Evaluation of Preparedness)

A. Background Information about this Measurement Tool

Dementia is an umbrella term that describes progressive illnesses, including Alzheimer's disease, that affect thinking, functioning, and memory. As the number of people living with dementia grows worldwide, the number of people caring for someone living with dementia is growing, too. Although many people *anticipate* becoming caregivers during their adulthood, most caregivers describe being *underprepared* for dementia caregiving roles.

This measurement tool was developed to help **researchers** learn about preparedness for dementia caregiving, to help **care specialists** assess caregivers' preparedness for dementia caregiving, and to help **care organizations** identify ways to support caregivers to feel more prepared for their care roles.

How this Tool was Developed: Researchers from Emory School of Nursing and Yale School of Public Health partnered with community dementia care specialists to complete a multi-phase process to develop this measure. This process revealed three domains that all contribute to preparedness:

- Caregivers' confidence and psychological readiness (C – 8 items)
- Caregivers' care skills and insights (S – 11 items)
- Caregivers' personal circumstances and related capacity (P – 11 items)

We found that sometimes caregivers feel better prepared in some domains, and less prepared in others. As such, this measure assesses all three domains to provide a comprehensive assessment of preparedness.

Target Population for this Tool: This tool was developed to be used in the early stages of caregiving for someone living with dementia, as the caregiver looks ahead and considers the entire caregiving journey with a specific person they are, or are anticipating, caregiving for. When administering the tool, feel free to change the term 'caregiver' to fit better with the population you are working with (e.g., care partner). Within each item, you can also change the term 'someone' to be specific to a care recipient population (e.g., parents, spouses).

How to Administer the Tool and Score Responses: Users can complete the items in this self-report tool independently. They should be encouraged to choose a response to each item that fits best with how they feel in the present. Items can be scored within each domain, or as one composite score of preparedness for dementia-caregiving.

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B. Instructions for Users

Many people take care of someone who is living with Alzheimer's disease, memory loss, or dementia. You might be caring for someone like this right now, or you may care for someone like this in the near future.

We are interested in learning more about the ways adults feel *prepared* to take care of someone living with dementia. People can be 'caregivers' in lots of different ways. Caregiving means supporting the health, wellbeing, or decision-making of someone living with dementia. First, please choose the option below that best represents you:

- ☐ As I complete this survey, I AM currently a caregiver for someone living with dementia. This person is (please describe them in terms of their relation to you, such as 'my mother' or 'my good friend'): _____
- ☐ As I complete this survey, I have someone in mind who I expect to be a caregiver for in the future, but I AM NOT currently a caregiver for this person. This person is (please describe them in terms of their relation to you, such as 'my mother' or 'my good friend'): _____
- ☐ As I complete this survey, I am thinking of MORE THAN ONE person who I am currently, and/or expect to be, a caregiver for. These people are (please describe each in terms of their relation to you, such as 'my mother' or 'my good friend,' separated by commas): _____
- ☐ None of the above options are true for me (pause your responses and discuss with the person who administered this survey to you).

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Next, please respond to the statements that follow by thinking about the current or future caregiving experience that you noted above. For each statement, please try to choose one answer that best represents how you feel right now.

		Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
C	1. I am the right type of person to take care of someone living with dementia.	1	2	3	4	5	6
S	2. I understand how to manage the medications that someone living with dementia might need.	1	2	3	4	5	6
P	3. I am in a good stage in my life to dedicate time and effort to care for someone living with dementia.	1	2	3	4	5	6
C	4. I will be able to adapt when challenges occur while caring for someone living with dementia.	1	2	3	4	5	6
S	5. I know how to collaborate with someone living with dementia to make decisions together.	1	2	3	4	5	6
P	6. If I needed to make decisions on behalf of someone living with dementia, my family and friends would be ready to support my decisions.	1	2	3	4	5	6
C	7. I can be a patient person when caring for someone living with dementia.	1	2	3	4	5	6
S	8. I would know how to advocate for the medical care that someone living with dementia would prefer.	1	2	3	4	5	6
P	9. The community where I live provides enough resources and supportive services for me to care for someone living with dementia.	1	2	3	4	5	6
C	10. When I think about the ways someone living with dementia may change over time, I feel like I can accept those changes.	1	2	3	4	5	6
S	11. I have a good understanding of the journey of dementia, what someone living with dementia might be going through.	1	2	3	4	5	6
P	12. At this time, I feel physically able to care for someone living with dementia.	1	2	3	4	5	6

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		Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
C	13. I can handle frustrations that will come when caring for someone living with dementia.	1	2	3	4	5	6
S	14. I understand what symptoms to expect with dementia.	1	2	3	4	5	6
P	15. At this time, I feel mentally able to cope with the challenges that come with caring for someone living with dementia.	1	2	3	4	5	6
C	16. I would be good at being respectful towards someone I'm caring for who is living with dementia.	1	2	3	4	5	6
S	17. I know how to help someone living with dementia avoid potential hazards and dangers.	1	2	3	4	5	6
P	18. I have enough room in my schedule to give good quality time to someone living with dementia.	1	2	3	4	5	6
C	19. I would be capable of making big decisions that sometimes need to be made when caring for someone living with dementia.	1	2	3	4	5	6
S	20. I know how to enlist the help I'd need to take care of someone living with dementia.	1	2	3	4	5	6
P	21. My current living situation makes good sense for taking care of someone living with dementia.	1	2	3	4	5	6
C	22. I am the type of person that can handle the difficult emotions that may come when caring for someone living with dementia.	1	2	3	4	5	6
S	23. I have strategies for responding when someone living with dementia is confused, misremembering, or repeating behaviors.	1	2	3	4	5	6
P	24. In my community, I am aware of healthcare teams and centers that can help me take care of someone living with dementia.	1	2	3	4	5	6
S	25. When new problems came up while caring for someone living with dementia, I would know how to look for solutions.	1	2	3	4	5	6

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		Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
P	26. In my life right now, I have enough emotional support to help me care for someone living with dementia.	1	2	3	4	5	6
S	27. I understand how to navigate financial and legal issues that may come up when caring for someone living with dementia.	1	2	3	4	5	6
P	28. I think my job responsibilities are flexible enough to allow me to give someone living with dementia the time and energy they need.	1	2	3	4	5	6
S	29. I have strategies to help me take care of myself while caregiving.	1	2	3	4	5	6
P	30. I know how to use available technology to help me take good care of someone living with dementia.	1	2	3	4	5	6

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