

Care-Giver Discussion Guide: Assessing Caregiver Ability to Provide Dementia Care

Introduction:

This assessment & discussion guide is provided to assist clinicians to conduct a comprehensive exploration about the care-giver's knowledge, skills, and abilities to provide care. It will assist clinicians to identify the areas where caregivers will need more information, targeted skill-building and assistance in problem-solving everyday care. Self-efficacy, or the belief that one can do something well has been identified in recent research as an important aspect of success in caregiving. Therefore, it is suggested that clinicians ask the caregiver to rate their confidence in providing the care needed, and use their response to provide direction for planning caregiver supports.

The guide is intended to be used selectively, not linearly, as per clinician assessment and judgment of relevant caregiver issues. Each section provides optional sample questions to assist clinicians to focus the inquiry. This guide can be used over time and a number of visits. It is a tool to assist building a trusting relationship with the caregiver over time. The process of engaging with caregivers in these different conversations will assist them to develop insight and perspective into their own abilities, evaluate their confidence in providing care, and identify areas in which additional information; targeted skill-building or added support can thereby be developed into a plan of care.

Instruction:

Selectively choose questions to guide discussion with the care-giver in a private environment.

Exploring and Measuring Caregiver Confidence

Suggested Approach:

- Inquire into the caregiver's knowledge in each of the assessment categories below ("Tell me about...")
- You may need to interpret or explain some of the categories. Sample questions/cues are provided for you. (Note: Use the care recipient's name when you see <CR> in the guide)
- When you have discussed the item, ask the caregiver¹ to rate their level of confidence about the dementia competencies on a scale of 1 to 5 (as illustrated).
- If the caregiver responds that have little confidence, ask for their perception about what might help them to improve their confidence, knowledge, skills, etc.
- Jot any comments or notes that may assist in care-planning (education, skill-building, etc.) for the caregiver.

Caregiver confidence ratings

1 = Very Little
2 = Some
3 = Fair
4 = Good
5 = Very Confident

¹ Example of a suggested introduction of rating scale to caregiver:

"This section is about discussing different aspects of the care you give to <CR>. It lets us talk together about in more detail about your understanding, the skills or special approaches you use while giving care. This section will help us both identify where you may need more help in terms of knowledge or solving problems with caregiving in the home. It asks for you to rate your confidence after each section. This is the scale that will be used from 1 (very little confidence to 5 very good confidence). Do you have any questions?"

Assessment Categories/Areas for Exploration & Discussion:	Rating	Notes/Details for care-planning
<p>General knowledge and understanding about:</p> <ol style="list-style-type: none"> 1. the type of dementia condition 2. recognizing changes over time 3. its progression (what lies ahead) 4. recognizing the effect of the decline on the person 5. recognizing the effect of the decline on themselves 		
<p>Discussion Guide: Sample Questions for Clinicians</p> <ul style="list-style-type: none"> • “Can you tell me about what you understand about <CR>’s type of dementia?” • “What major changes have happened for <CR> since you first started taking care of him/her and how he/she is now?” • “What is your understanding of what lies ahead of <CR> as his/her disease progresses? What do you think that will mean for you in the future as his/her caregiver ?” • “You mentioned several changes that have happened for <CR>. What effect has this decline had on him/her?” • “Can you tell me about what effect all these changes in <CR> have had on yourself?” • “Using this scale from 1-5, can you rate how confident you feel in your knowledge and understanding about <CR>’s dementia?” 		
	Rating	Notes/Details for care-planning
<p>Identifying the skills and ability to meet personal care needs:</p> <ol style="list-style-type: none"> 1. specific ADL or IADL needs of the person with dementia 2. Ability to target, provide and adjust level of assistance variably as needed (none to total as needed); 3. Ability to read emotional and physical cues for basic needs (thirst, hunger, toileting, etc.) 4. Ability to provide meaningful activity or involve the person in some activity of everyday life 		
<p>Discussion Guide: Sample questions for clinicians:</p> <ul style="list-style-type: none"> • “What is your greatest concern about taking care of <CR>? What do you think will help you?” • “I would like to explore a bit more about the daily care that you provide for <CR>. Earlier, you mentioned he/she needs help with (<i>identify from earlier assessment of ADL/IADL</i>). How confident are you in your knowledge of what needs to be done and in your ability to provide that care?” “Do you feel you need any additional information or assistance in giving this care?” (Specify) • “People’s needs for care can vary everyday depending how they are feeling, their energy, the time of day, etc. Sometimes they will need a lot of help, and sometimes just a bit. How confident are you in your ability to adjust the level of care you provide to what <CR> needs at different times of the day?” “Can you give me an example of how you do this?” • “As dementia progresses, the person’s ability to communicate their needs becomes less clear and accurate. Tell me a bit about how <CR> communicates his needs for hunger, thirst, toileting, pain, boredom, etc. How confident are you in your ability to accurately read what he needs if s/he can’t tell you?” • “Everybody has the need to feel needed and to feel they are included and people with dementia still have this need even when they are no longer able to do things independently. Can you tell me if there are ways in which <CR> are or can be involved in everyday living activities with you? For example, can s/he help with something in the kitchen (setting table?), or accompany you grocery shopping by pushing the buggy, etc? How confident are you that you can provide small meaningful activities for <CR> in everyday life?” 		



Interior Health

<ul style="list-style-type: none"> • “In dementia care, roles change and new challenges can crop up, sometimes requiring us to do things we don’t even think about and have never done before. Has that happened to you? Can you tell me about that and how you solved it?” • “If you found yourself in a situation where you didn’t know what to do or how to give the right care to meet <CR>’s needs, what would you do?” • “How confident are you in knowing when to ask for help? Do you know how to ask for help? How comfortable are you in accepting help when it is offered to you?” 		
<p>Skills and Ability to meet medical needs and tasks:</p> <ol style="list-style-type: none"> 1. Appropriate knowledge of medical care tasks (wound care, ability to administer medications correctly, etc.); 2. Appropriate knowledge of direct care tasks (transfer techniques, moving from bed to chair, bathing, etc.) 		
<p>Discussion Guide: Sample questions for clinicians:</p> <ul style="list-style-type: none"> • “You mentioned earlier that <CR> has (<i>specify physical problems from earlier assessment, e.g., diabetes, heart condition</i>) Can you tell me what special medical care s/he needs that you provide for him? How confident are you in doing that for him/her?” • “When <CR> needs help with <specify>, how confident are you in providing that care for him/her?” 		
<p>Skills and Ability to address behavioural and emotional responses of the person with dementia:</p> <ol style="list-style-type: none"> 1. Able to identify behaviours of concern 2. Attributes behaviour to the disease and not feeling the person is doing these things on purpose 3. Able to identify and describe own feelings and emotions associated with the behaviours 4. Understands behavioural sequences: <ol style="list-style-type: none"> a. What triggers behaviours b. Understands behaviours = unmet needs c. How own response to behaviours can change outcomes 5. Able to identify specific care strategies that work when dealing with behavioural and emotional responses 6. Knowledge of shifting different strategies: e.g., when one approach fails, try another. 		
<p>Discussion Guide: Sample questions for clinicians:</p> <ul style="list-style-type: none"> • “Does <CR> behave in any way that concerns you? Can you tell me about that?” • “Do you think these behaviours you mentioned are part of the dementia, or do think <CR> is acting purposefully?” • “How do these behaviours affect you? Can you tell me how you feel when they are happening?” • “Can you explain why you think these behaviours occur or if you notice any patterns? What do you think triggers or sets them off?” 		



Interior Health

- “Behaviours in dementia are often thought to result from unmet needs. When the person with dementia can’t properly express their needs, they act out. Do you think that happens for <CR> ? Can you give me an example?”
- “What happens for you when <CR> behaves (*as described above*) How does that make you feel? Do you think how you respond to the situation can affect what happens?”
- “How often do you feel anxious or angry when you are giving care? Have you ever felt so upset that you have said or done something you regret? Has <CR> ever done these kinds of things to you?”
- “Can you give me examples of things you do, or say or the way you view what is happening, that you think works and is effective in helping <CR> when s/he behaves like that?”
- “Do you sometime try one thing and if it doesn’t work, try a different approach? Can you give me an example?”

	Rating	Notes/Details for care-planning
<p>Skills and Abilities for self care:</p> <ol style="list-style-type: none"> 1) Dealing with change: <ol style="list-style-type: none"> a. Changing life goals, lifestyle and living arrangements b. Changing role(s) 2) Managing competing responsibilities and stressors: <ol style="list-style-type: none"> a. Personal Issues b. Family issues 3) Asking for help when needed 4) Accepting help when offered 5) Finding and using resources to help myself: <ol style="list-style-type: none"> a. Access community resources b. Navigate the health care system c. Contemplate the time for placement 6) Experiencing emotional and physical responses to care: <ol style="list-style-type: none"> a. Facing feelings and emotions b. Engaging in healthy behaviours c. Managing physical symptoms and illness 7) Coping strategies: <ol style="list-style-type: none"> a. How do you think you are currently coping? b. What do you do that helps you to cope on a day-to-day? c. What could assist you to cope better with the demands in your care-giving role? 		

Discussion Guide: Sample questions for clinicians:

- “This section addresses how well you take care of yourself. Dementia care involves a lot of change both for you and for <CR>. Let’s start off talking about how you feel you are dealing with those changes. Can you tell me a bit about how life has changed for you...(etc.)”
- “Can you rate how confident you feel about how you are dealing with all these changes? how about for the future? how confident are you that you can deal with what lies ahead?”
- “Caring for someone with dementia often results in feeling that you are being pushed and pulled in different directions from all the different responsibilities and stressors. Does that happen for you? Can you tell me about it? How confident are you in managing these competing responsibilities?”
- “Through our conversations, I have heard that you (*do/do not*) look for help from different sources. Tell me about your experiences in finding and using different resources. How confident are you in finding the help you need and navigating the health care system?”
- “Have you thought about or discussed with <CR> or anyone else if or when the time might come for placement in a nursing home? Tell me about that”



Interior Health

- “Care giving is very demanding work. Tell me how you take care of yourself physically and emotionally so that you can keep going”
- “What is your greatest concern about taking care of yourself? What would help you? Which supports do you think you need to ensure your well-being?”
- “Think of a recent time in which you were giving care for <CR> and which you found it to be very challenging. Can you tell me how you coped in that situation?”
- “How do you think you are currently coping? What do you do that helps you to cope on a day-to-day? What could assist you to cope better with the demands in your care-giving role?”
- “If you were not able to provide care for <CR>, either short term or long term due to circumstances, what would be needed to ensure his/her well-being?”

Summary Impressions, Notes, Care-planning Directions: