

Preparing for the future

PREPARING FOR THE FUTURE: Learning about Dementia and Care near the End of Life

Asking questions of health care providers can sometimes be hard. Many of us simply do not know the questions we could be asking to help us better understand and plan for the future.

This question prompt sheet has been designed to open up conversations between you, your family and members of the health care staff in this facility. The answers to these questions may not be simple or straightforward; dementia affects each person in different ways.

By asking these important questions, we hope you are able to get the information you need regarding how things might progress towards the final stages of life and help prepare you for the future.

Let's Talk About...

Check the topics you'd like to discuss with your health care provider.

1. DEMENTIA IN GENERAL

- Can you explain to me the type of dementia my family member has?
- Can you explain the key changes, especially changes in behaviour that I might see in my family member as their dementia progresses?

2. DEMENTIA TOWARDS THE END OF LIFE

- What are some of the signs and symptoms most frequently associated with the last few months of life for someone with dementia?
- What might the final days and hours of my family member's life look like?
- Do people die from dementia?
- My loved one has dementia but also other medical conditions. How might this affect their care at the end of life?

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3. CARE OF PERSON WITH DEMENTIA

a) Care and Comfort

- How might your care of my family member change in his/her final days?
- Can you tell me what “comfort care” means?
- How can we provide the important cultural, spiritual, and/or religious rites and rituals that are important to us or our family member during their last days?

b) Pain and Symptoms

- How might you assess and manage my family member’s pain?
- My family member is restless. What could that mean and how might it be managed?
- My family member looks and sounds uncomfortable when they are breathing. What can be done to help them?
- My family member can no longer swallow. How might they still get their medications?
- Are pneumonia and urinary infections common in people with dementia and how might those be managed?

c) Food and Fluid

- My family member is not eating or drinking much. What might this mean and is this normal?

4. MY ROLE AS A DECISION-MAKER

- What do I need to know about the following documents and how often do they get reviewed?
 - Health care directives
 - Advance directives
 - Living wills
 - Advance care plans
 - Power of attorney
 - Substitute decision-maker
 - Health care proxies
 - Levels of care
 - Committeeship
- Under what circumstances might my family member be transferred to the hospital?
- What role might I or other family members be expected to play in the decision to transfer to hospital?
- Members of my family and I are having a disagreement or can’t reach a decision related to our family member with dementia. What assistance is available to help us work things out?

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5. MY ROLE AS A CAREGIVER

- What is the best way for me to respond to and interact with my family member as their health declines?
- How do I best respond to my family member when they don't know who I am?
- How can we provide interesting experiences each day for my family member?
- What can I do to help in caring for my family member who is dying?

6. HOW I AM MANAGING

- What are the most common emotions I may go through as a caregiver?
- Dementia can be frustrating and unpredictable. What are the emotional supports and informational resources available to help me cope?
- When my family member dies, what happens next and what should I do?

7. RELATIONSHIPS WITH STAFF

a) Communication

- What is the best way for me and my family to communicate our needs, concerns, and questions to the staff?
- What is the best way for staff to communicate with our family?
- How can I make arrangements to meet with the doctor?
- How confidential is information about my family member?

b) Supporting Us

- What would you like to know about my family member or us as a family to provide the best care possible?
- I would like to talk about how my family member would want to be cared for.
- I would like to talk about how my hopes and wishes for the care of my family Member at the end of their life.

c) Staff Roles and Responsibilities

- Tell me about the roles of different people who work in this facility?
- What is the role of the doctor in this facility and how often might I see them?

8. GENERAL QUESTIONS ABOUT LIFE IN A LONG-TERM CARE FACILITY

- Am I allowed to bring in treats and the family pet to visit?
- What steps are in place to keep my family member safe?
- What meaningful activities are being offered which are suitable for people with dementia, in particular when my family member is in the advanced stages?

For more information on these topics or if you have any questions, talk to your health care provider or visit virtualhospice.ca