



TIPS FOR FAMILY & FRIENDS

Before a care decision is made:

- Consider your relative or friend's end of life values and preferences
- Stay informed and ask questions
- Encourage your relative or friend to be as independent and participate in as many decisions as he or she is able

With a health care provider, explore and discuss options:

- To learn about how your relative or friend expresses feelings through his or her behaviour
- For communication (e.g. play music, show pictures, aromas, and tell comforting stories)
- For eating, if your relative or friend can no longer swallow food
- To maintain physical or social activities

Your health is important too. If you are feeling overwhelmed, seek support from the Family Councils of Ontario.

www.fco.ngo

(416) 487-4355
1-888-283-8806

What should I ask about?

- What are my or my relative or friend's biggest fears about my/his/her health?
- How can I help maintain my or my relative or friend's quality of life?
- How long can someone be in the late stages of dementia?
- What should I expect when I am or my relative or friend is dying?

Online Resources

1. Alzheimer Society of Canada
<https://alzheimer.ca/en/Home>
2. See SPA-LTC website for more resources
<https://spaltc.ca/resource-library/>

The Palliative Approach for Advanced Dementia in Long Term Care

Version 4

A RESOURCE FOR RESIDENTS, FAMILY AND FRIENDS

Contact Us

Emily Di Sante
McMaster University
disante@mcmaster.ca
www.spaltc.ca





WHAT IS A PALLIATIVE APPROACH?

This pamphlet was made to help persons with **Dementia** and their families know what to expect at the end of life so they can plan ahead. Talking about preferences early on is an important first step to a **Palliative Approach to Care**.

A Palliative Approach:

- Is for residents in long term care (LTC) with conditions that have no cure
- Shifts focus from prolonging life to maintaining quality of life
- Is an active approach that can start at any stage of chronic illness
- Is part of usual care
- Does not require a referral

A **Palliative Approach** includes:

- Treatment of curable conditions
- Pain and symptom management
- Social and spiritual support

For more information, please visit:

www.virtualhospice.ca

www.speakupontario.ca

What is Dementia?

Dementia is a chronic **progressive life-limiting illness**. This means that symptoms worsen over time and may affect how long one lives. Dementia:

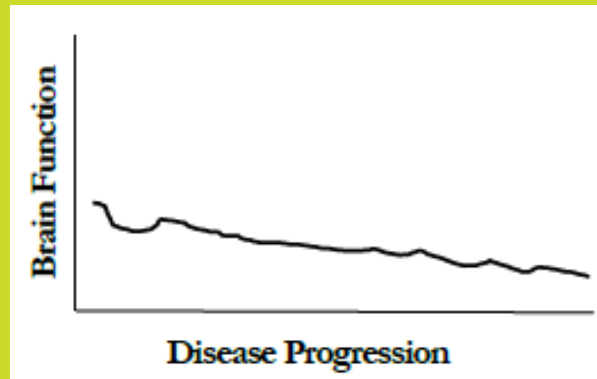
- Affects a person's thinking, mood, language, and behaviour
- Is a group of illnesses (e.g. Alzheimer's, Vascular, Frontotemporal, Lewy Bodies, Parkinson's dementias)

Residents with dementia:

- Will have bad days (more confusion) and good days (less confusion)
- Can live for years

HOW DOES DEMENTIA PROGRESS?

It is difficult to predict how long someone with dementia will live, so it is good to hope for the best and plan for the worst.



Living with Dementia

The progression of dementia cannot be reversed and there is no cure. Being well-informed will help you to make care decisions.



LATE OR ADVANCED STAGE SIGNS

- Severe memory loss (e.g. names, events)
- Loss of concept of time and space
- Difficulty with speech or language (aphasia)
- Loss of ability to use toilet, bathe, and walk without help
- Difficulty swallowing (pneumonia risk)
- Reduced interest in activities

END OF LIFE STAGE SIGNS

- Change in circulation (e.g. cold hands or feet, skin breakdown)
- Gradual organ failure
- Pain, shortness of breath or agitation