



## 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 Alberta Health Services Counselling Services.

<https://www.albertahealthservices.ca/amh/page16759.aspx>

## 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 1

**A RESOURCE FOR RESIDENTS, FAMILY AND FRIENDS**

## Contact Us

Emily Di Sante  
McMaster University  
[disante@mcmaster.ca](mailto:disante@mcmaster.ca)  
[www.spaltc.ca](http://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](http://www.virtualhospice.ca)

[www.advancecareplanning.ca](http://www.advancecareplanning.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:

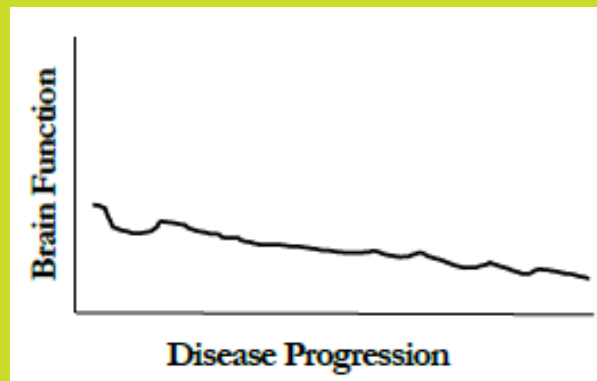
- Affects a person's thinking, mood, language, and behaviour
- Is a group of illnesses (e.g. Alzheimer's, Vascular, Frontotemporal, Lewy Bodies, Parkinson's dementias)

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