

Tips for Family and 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/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/social activities

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

www.fco.ngo

Phone: (416) 487-4355

Toll-Free: 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:**

<http://www.alzheimer.ca/en/We-can-help/Resources/Alzheimer-Society-brochures-and-publications>

1) **All About Me Booklet:**

http://www.alzheimer.ca/~media/Files/national/Core-lit-brochures/all_about_me_booklet_e.pdf

2) **Alzheimer Association (US):**

interactive brain tour, common myths

http://www.alz.org/alzheimers_disease_publications.asp

3) **Comfort Care at the End of Life:**

how to support residents in LTC

http://www.expertise-sante.com/modules/AxialRealisation/img_repository/files/documents/guide_eng.pdf

The Palliative Approach for Advanced Dementia in Long Term Care

Version 4

A Resource for Residents, Family
and Friends



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 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.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:

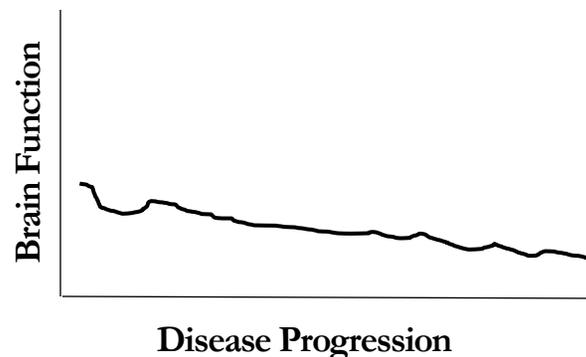
- Affects a person's thinking, mood, language, and behaviour
- Is a group of illnesses (e.g. Alzheimer's, Vascular, Frontotemporal, Lewy Bodies, and Parkinson's dementias)

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 may 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/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/feet, skin breakdown)
- Gradual organ failure
- Pain, shortness of breath or agitation