# The Palliative Approach for Advanced Dementia in Long Term Care



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 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 advancecareplanning.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.



#### **Disease Progression**

## Living with Dementia

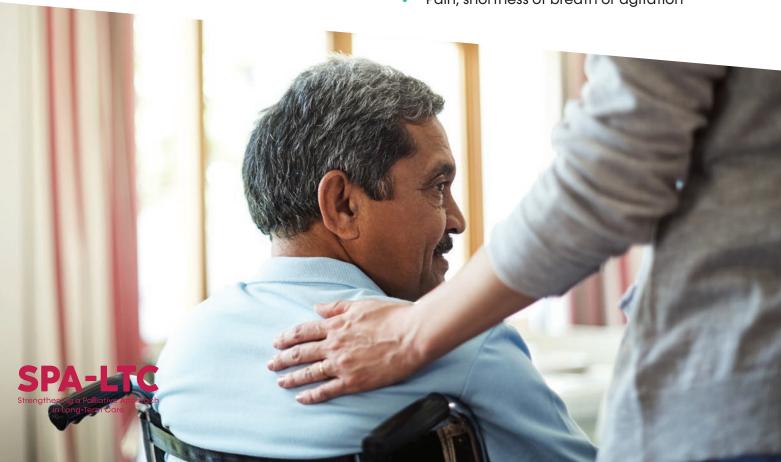
The progression of dementia cannot be reversed and there is no cure. Being well-informed will help you to make care decisions.

# 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



# 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 stores)
- 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 your health care provider and from the Family Councils of Ontario <a href="www.fco.ngo">www.fco.ngo</a> (416) 487-4355 or 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?

ON V4 July 2021

#### Online Resources

- Alzheimer Society of Canada
   <a href="https://alzheimer.ca/en/Home">https://alzheimer.ca/en/Home</a>
- See SPA-LTC website for more resources www.spaltc.ca/resource-library/



## Contact Us

Strengthening Palliative Approach in Long-Term Care (SPA-LTC) McMaster University, School of Nursing

www.spaltc.ca

spaltc@mcmaster.ca

