The Palliative Approach for Advanced Dementia in Long Term Care

A Resource for Residents, Family and Friends

Version 4

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, please seek support from your health care provider.

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

Online Resources

1) Alzheimer Society of Canada:

2) All About Me Booklet:
   http://www.alzheimer.ca/~media/Files/national/Core-lit-brochures/all_about_me_booklet_e.pdf

3) Alzheimer Association (US): interactive brain tour, common myths
   http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp

4) Comfort Care at the End of Life: how to support residents in LTC
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.

<table>
<thead>
<tr>
<th>What is a Palliative Approach?</th>
<th>What is Dementia?</th>
<th>Living with Dementia</th>
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</thead>
<tbody>
<tr>
<td><strong>A Palliative Approach:</strong></td>
<td>Dementia is a <strong>chronic progressive life-limiting illness</strong>. This means that symptoms worsen over time and may affect how long one lives. Dementia:</td>
<td>The progression of dementia cannot be reversed and there is no cure. Being well-informed will help you to make care decisions.</td>
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<tr>
<td>• Is for residents in long term care (LTC) with conditions that have no cure</td>
<td>• Affects a person’s thinking, mood, language, and behaviour</td>
<td><strong>Late or Advanced Stage Signs:</strong></td>
</tr>
<tr>
<td>• Shifts focus from prolonging life to maintaining quality of life</td>
<td>• Is a group of illnesses (e.g. Alzheimer’s, Vascular, Frontotemporal, Lewy Bodies, and Parkinson’s dementias)</td>
<td>• Severe memory loss (e.g. names, events)</td>
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<tr>
<td>• Is an active approach that can start at <strong>any stage chronic illness</strong></td>
<td>Residents with dementia:</td>
<td>• Loss of concept of time and space</td>
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<tr>
<td>• Is part of usual care</td>
<td>• Will have bad days (more confusion) and good days (less confusion)</td>
<td>• Difficulty with speech/language (aphasia)</td>
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<td>• Does not require a referral</td>
<td>• Can live for years</td>
<td>• Loss of ability to use toilet, bathe and walk without help</td>
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</table>

**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

**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.

![Brain Function vs. Disease Progression graph](image)

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 and skin breakdown)