A Palliative Approach to Care for Persons with Dementia

Dr Stephanie Connidis
Oct 2018 Championing Change in Dementia Care
Disclosures

- No financial disclosures
- Volunteer Executive Board (Secretary) Canadian Society of Palliative Care Physicians
- Medical Director of Hospice Halifax
- Medical Director (Central Zone) INSPIRED COPD Outreach program
- National Task Force member – Advance Care Planning
What is a Palliative Approach to Care?

What is Palliative Care? Hospice Care? Hospice Palliative Care? End of Life Care?
WHO definition of Palliative Care:

- Palliative care is an *approach* that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

- Intends neither to hasten or postpone death
Canadian Virtual Hospice: defines palliative care as “an approach to care that focuses on comfort and quality of life for those affected by progressive, life-threatening illness. The goal of palliative care is to control pain and other symptoms, support emotional, spiritual and cultural needs and maximize functioning.”
What IS Palliative vs Hospice Care?

- **“Hospice Palliative Care”**: Term adopted by the CHPCA. Indicates the integration of care throughout a variety of settings.
  
  Refers to a philosophy of care for incurable illness that occurs along a continuum.

- **Palliative Care**: can begin any time after a non-curable illness is identified. It is NOT synonymous with withdrawing of treatment.

- **Hospice Care**: refers to palliative care in the terminal phase of illness.

- **‘Hospice’ Residence**: refers to a place of care where patients receive palliative care in the terminal phase of illness.
Who receives a Palliative Approach to Care?

... And who does not?
Integrated Palliative Care

Primary Palliative Approach to Care

Community Supports

Care Delivery

PC Consultant

PC SubSpecialist

Persons Needs

Complex and persistent

Intermediate and Fluctuating

Straightforward and predictable

Supportive Care and Bereavement
## Table 1. Access and utilization rates by country.

<table>
<thead>
<tr>
<th>Category</th>
<th>Canada</th>
<th>England</th>
<th>Germany</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of inhabitants and percentage of</td>
<td>~34 million, 17%</td>
<td>~63 million, 17%</td>
<td>~81 million, 21%</td>
<td>~317 million, 14%</td>
</tr>
<tr>
<td>population over 65 years of age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of hospice and palliative care</td>
<td>&gt;600 (including</td>
<td>&gt;975 (including</td>
<td>&gt;1150 (including</td>
<td>&gt;5000 (with</td>
</tr>
<tr>
<td>programs</td>
<td>six children's</td>
<td>36 children's</td>
<td>86 children's</td>
<td>many willing to</td>
</tr>
<tr>
<td></td>
<td>ones)</td>
<td>ones)</td>
<td>ones)</td>
<td>accept children)</td>
</tr>
<tr>
<td>Number of hospice and palliative care</td>
<td>&gt;200</td>
<td>&gt;500</td>
<td>5417</td>
<td>&gt;4300</td>
</tr>
<tr>
<td>physicians(^a)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of hospice and palliative care</td>
<td>unknown number</td>
<td>&gt;100,000</td>
<td>~80,000</td>
<td>~460,000</td>
</tr>
<tr>
<td>volunteers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death under hospice and palliative care (</td>
<td>~4000 (16% to</td>
<td>~15,000 (23%</td>
<td>~110,000 (12%</td>
<td>&gt;1,029,000 (41%</td>
</tr>
<tr>
<td>utilization rate)</td>
<td>30%</td>
<td>(33(^b))</td>
<td>(24(^b))</td>
<td>(34(^b))</td>
</tr>
<tr>
<td>Hospice and palliative care patients with a</td>
<td>&gt;90(^c)</td>
<td>~90(^d)</td>
<td>~90%(^e)</td>
<td>~41%(^f)</td>
</tr>
<tr>
<td>cancer diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home deaths (place of residence)(^g)</td>
<td>~30%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^a\) Estimate likely to be too low because of the lack of information.

\(^b\) National Cancer Registration (2008).

\(^c\) National Health Interview Survey (2007).

\(^d\) National Health Interview Survey (2007).

\(^e\) Statistics Canada. 2006 Census.

\(^f\) National Health Interview Survey (2007).

\(^g\) Based on nursing homes and hospitals.

Source: Bekelman et al, JAMA 2016
Prognostication

It is hard. We get it wrong more than we get it right!

<table>
<thead>
<tr>
<th>Dementia Type</th>
<th>Life Expectancy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Disease</td>
<td>10 years following diagnosis</td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td>5 years following diagnosis</td>
</tr>
<tr>
<td>Lewy Bodies</td>
<td>2 to 8 years following pronounced symptoms</td>
</tr>
</tbody>
</table>
Frailty / Dementia Trajectory

Onset could be deficits in ADL, speech, ambulation

Time - quite variable - up to 6-8 years

Death
How far have I progressed?

Scales used to measure progression:

- **Global Deterioration Scale (GDS)** – 7 stages of cognitive decline. Stage 4 is ‘early’ (Alzheimer type) – Stage 7 is ‘late’
- **Functional Assessment Staging Test (FAST)** – 7 point scale focusing on individual’s level of functioning and activities of daily living. Stage 1 (normal adult) to Stage 7 (bed bound). Helpful to determine care needs
- **Clinical Dementia Rating (CDR) Scale** - five-point system based on cognitive (thinking) abilities and the individual’s ability to function. Used mostly in research
- **Palliative Performance Scale (PPS)** – scores in 10% increments (0 death – 100% normal adult) using 5 domains (both functional and level of consciousness) Communication tool, prognostic value

Adapted from www.dementiacarecentral.com/aboutdementia/facts/stages/#scales
<table>
<thead>
<tr>
<th></th>
<th>ECOG 0</th>
<th>ECOG 1</th>
<th>ECOG 2</th>
<th>ECOG 3</th>
<th>ECOG 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambulation</td>
<td>Full</td>
<td>Full</td>
<td>Reduced</td>
<td>Mainly sit/lie</td>
<td>Totally Bed Bound</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mainly in Bed</td>
<td>Bound</td>
</tr>
<tr>
<td>Activity and Evidence of Disease</td>
<td>N activity &amp; work</td>
<td>N / with effort</td>
<td>Unable N Job work/hobby work</td>
<td>Unable to do work/most activity</td>
<td>Unable any activity</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Extensive Disease</td>
<td>Extensive Disease</td>
</tr>
<tr>
<td>Self Care</td>
<td>Full</td>
<td>Full</td>
<td>Full/Occasional assistance needed</td>
<td>Considerable / Mainly assistance</td>
<td>Total Care</td>
</tr>
<tr>
<td>Intake</td>
<td>N</td>
<td>N or reduced</td>
<td>N or reduced</td>
<td>N or reduced</td>
<td>N or reduced / Mouth care only</td>
</tr>
<tr>
<td>Conscious Level</td>
<td>Full</td>
<td>Full</td>
<td>Full or Full or confusion</td>
<td>Full or Drowsy +/- confusion</td>
<td>Full or Drowsy / Coma +/- confusion</td>
</tr>
</tbody>
</table>

Adapted from: Interconversion of three measures of performance status: An empirical analysis
Clement Ma, Shezvin Bandukwala, Dhivya Burman, John Bryson, Dori Seccarmane, Subrina Banerjee, Jeff Myers, Gary Redin, Deborah Dudgeon, Camilla Zimmermann
Dementia stages

- **MILD**
  - Memory

- **MODERATE**
  - Behavior

- **SEVERE (ADVANCED)**
  - Physical
Symptoms of advanced dementia

Interplay of underlying illnesses
Many are similar to other end stage diseases and can include:

*fatigue/weakness (unable to do ADL), drowsiness, discomfort, dyspnea, pruritus, agitation, decreased oral intake*

In addition:

*No consistently meaningful conversation*

*urinary and fecal incontinence*

*Recurrent pneumonia, UTI*

*Recurrent fever, pressure sores*
Artificial Hydration and Nutrition

- Limited studies - most studies suggest risk outweighs any potential benefit in terms of quality or length of life in end stage disease

Most studies in people with terminal cancer
Some studies in advanced dementia
Some studies in ALS
Anorexia - Cachexia and weight loss

Causes of weight loss are multi-factorial and not always reversible!

- Malnourished – insufficient energy intake
- Sarcopenia – disuse or muscle atrophy
- Anorexia – appetite loss
- Cachexia – inflammatory effects of disease
Life-Sustaining Treatment: Terminology

Withholding
not starting treatment that has the potential to sustain the life of a patient
e.g. CPR

Withdrawing
stopping treatment that has the potential to sustain the life of a patient
e.g. artificial nutrition

http://eol.law.dal.ca/ End of Life Law and Policy in Canada- Health Law Institute, Dalhousie University
3 Triggers that suggest patient is nearing the end of life

- The Surprise Question: ‘Would you be surprised if this patient were to die in the next few months, weeks, days’?

- General indicators of decline - deterioration, increasing need or choice for no further active care.

- Specific clinical indicators related to certain conditions.
True or False?

Initiating Palliative Care earlier in the illness:

- Reduces emergency department visits?
- Shortens life expectancy?
- Decreases hope?
- Increases anxiety/depression?
Does our current end-of-life care reflect patient’s and family wishes?

Yes?
No?
Care people want at the end of life

**Last orders**

Thinking about your own death, how important is:

2016, % replying extremely or very important

- Living as long as possible
- Having your wishes for care followed
- Having loved ones around you
- Family not burdened by decisions
- Family not burdened financially
- Being at peace spiritually
- Being comfortable/without pain

Source: Kaiser Family Foundation/The Economist
Two Canadian studies using ADBFMI* illustrate unmet needs of family members:

- Communication  
- Emotional Support  
- Bereavement

1) Family members’ perceptions of end-of-life care across diverse locations of care. Romayne Gallagher, Marian Krawczyk, BMC Palliative Care 2013 July 20, 12 (1): 25. HOSPICE best at meeting needs

2) Bereaved family member perceptions of patient-focused family-centred care during the last 30 days of life using a mortality follow-back survey: does location matter? Fred Burge, Beverley Lawson, Grace Johnston, Yukiko Asada, Paul F McIntyre, Eva Grunfeld and Gordon Flowerdew BMC Palliat Care. 2014; 13: 25. HOME (we had no hospice!) more satisfied with overall care and communication
Quality of Life

What does it mean... to you?
How to Talk End-of-Life Care with a Dying Patient - Atul Gawande
Conversations about what you want as time runs short (Atul Gawande)

- Do you **KNOW** your prognosis?
- What are your **FEARS** about what is to come?
- What are your **GOALS** – what would you like to do as time runs short?
- What are the **TRADE OFFS** you are willing to make for the sake of the **POSSIBILITY** of added time?
SpeakUp!

"I might have been given a bad break, but I've got an awful lot to live for."

Lou Gehrig
July 4, 1939

http://www.myspeakupplan.ca/
Supporting decisions

Managing Symptoms – physical, emotional, spiritual
Benefit vs Risk (Morbidity) vs Mortality
Autonomy – voluntary refusal, withholding and withdrawing
Supporting families and caregivers
Accessing Resources
Planning Ahead and Speaking Up
Why is a Palliative Approach to Care relevant to Dementia-related illness?

Do we have a cure yet?

Do we hope to receive good care throughout our illness?
What exists now to help us care for each other?
EHS - Special Patient Program

Paramedics provide care consistent with patients wishes

Enrollment Form completed by health care providers in d/w patient etc

Legally valid physician order (Prov Med Director) but does not replace Advance Directive
Resources?

- **Continuing Care Nova Scotia (CCNS)** - Continuing Care Services, Palliative Home Care.
  https://novascotia.ca/dhw/ccs/
- **EHS -Special Patient Program (SPP)**
  https://novascotia.ca/dhw/ehs/palliative-care.asp
- **Palliative Care Drug Program (PCDP)**
  http://novascotia.ca/dhw/pharmacare/palliative-drug-program.asp
- **Federal Compassionate Care Benefit**
- **Alzheimer Society of Nova Scotia (ASNS)**
  Http://asns.ca
- **Canadian Hospice Palliative Care Association**: Compassionate Communities and Companies.
  www.CHPCA.ca

The Canadian Virtual Hospice
www.virtualhospice.ca
Doctors Nova Scotia: Position Paper 2018

SUPPORTING THE PALLIATIVE CARE APPROACH:
RECOMMENDATIONS FOR NOVA SCOTIANS

10 Recommendations:

► DNS RECOMMENDATION #3

Develop guidelines to help identify patients who would benefit from a palliative care approach earlier. These guidelines will assist physicians in determining when and how to transition from chronic care management to a coordinated approach with palliative care.

► DNS RECOMMENDATION #4

Provide ongoing support to providers providing care to people with life-limiting illnesses, including most of the chronic diseases, helping them to recognize and transition to a palliative care approach when appropriate.
Doctors Nova Scotia: Position Paper 2018

- DNS RECOMMENDATION #5
  Ensure that palliative care services are distributed equitably and can adjust to meet the changing needs of the population.

- DNS RECOMMENDATION #6
  Expand access to residential hospice facilities in areas large enough to support them, and to palliative care or hospice beds to provide an alternative to hospitalization for people whose end-of-life care needs cannot be met at home.
Hospice Halifax provides Nova Scotians and their families affected by life-limiting illness with compassionate support and comfort. Our goal is to create a respectful, meaningful environment for patients and their families as patients approach their death. We believe everyone should have access to quality care at end of their life.

Today, thanks to volunteers’ ongoing hard work and generous donor support, our area’s first hospice residence, now under construction at 618 Francklyn Street in Halifax, Nova Scotia, is closer to becoming a reality.
618 Franklyn St, Halifax Nova Scotia
“Hospice is a place of meeting. Physical and spiritual, doing and accepting, giving and receiving, all have to be brought together... the dying need the community, its help and fellowship... the community needs the dying to make it think of eternal issues and to make it listen... we are debtors to those who can make us learn such things as to be gentle and to approach others with true attention and respecting and accepting, giving and receiving, all have to be.”

– Dame Cicely Saunders MD
Championing Change for a Palliative Approach to Care

“You matter because you are you and you matter until the end of your life.”

Dame Cicely Saunders
Thank You

s.connidis@hospicehalifax.ca
Place of Care

1. **Home/Care Facility** - able to be safely and comfortably supported at home or in a care facility (such as LTC, Group Home or Retirement Residence) with family and professional caregivers and additional resources.

2. **Hospice Residences** - if unable to remain at home due to care needs, challenging symptom management, lack of caregiver support, or other reasons and will require a skilled palliative approach to care for the last days and weeks of life.

3. **Hospital Tertiary Palliative Care Unit** - have complex and unstable pain management and symptom control issues requiring specialized assessments and interventions over a short period of time and/or require diagnostic tests, complex treatments or invasive procedures.
“Hospice is a place of meeting. Physical and spiritual, doing and accepting, giving and receiving, all have to be brought together... the dying need the community, its help and fellowship... the community needs the dying to make it think of eternal issues and to make it listen... we are debtors to those who can make us learn such things as to be gentle and to approach others with true attention and respect.”

– Dame Cicely Saunders MD

CMA Seniors Strategy: 

DEMAND A PLAN

Promising Practices

- **Integrated Palliative Care Strategy from Nova Scotia** includes the use of advance care paramedics to support patients at home. EHS - Special Patient Program

- The **PATH program**, offered through the Palliative and Therapeutic Harmonization (PATH) Clinic in Nova Scotia, assesses older adults and consults with them and their families so they understand the true state of their health and the outlook for the future. It creates time and space for frail, older people to make complex health care decisions.

- **Home First Program** provincial governments in Nova Scotia, Ontario and New Brunswick provide support for both caregivers and patients so they can return home after a hospitalization, rather than moving to an institution.

- **Care by Design** is improving care for nursing home residents in Nova Scotia’s Capital Health Region. Residents are the centre of a collaborative, on-site health care team that includes physicians, facility medical directors, nurses and paramedics. This allows them to be cared for in the comfort of the place they call home, instead of being transferred to a hospital.

- The **Canadian Virtual Hospice** provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators.

www.demandaplan.ca
A national seniors strategy - Targeted funding for a national seniors strategy

Caregiver tax credit - Amend and improve awareness of the Canada Caregiver Credit

Investing in residential care facilities - More investment in residential care facilities for our seniors

Home care funding - Develop explicit operating principles for home care funding

Acute care study - Convene a study on appropriate use of acute care for elderly people
ESAS-r
Edmonton Symptom Assessment System

- To assist in the assessment of 9 symptoms: pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety and wellbeing.

- One blank scale is available for patients to assess an “other problem” as needed.

- The severity of each symptom is rated from 0 to 10 by the patient on a numerical scale; with 0 meaning that the symptom is absent and 10 that it is the worst possible severity.

https://www.cancercare.on.ca/toolbox/symptools/
Legislation

- There is a common law right to refuse even potentially life-sustaining treatment

- Health Care providers must follow principles of informed consent

- Advance Directives and SDM acting on expressed wishes of the person/in their best interests
Adapted from the Center to Advance Palliative Care (CAPC) definition:

- **Palliative care is** medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

- **Palliative care is provided by** doctors, nurses, and other care specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.
Patient and Public Involvement in Identifying Dementia Research Priorities
Jennifer Bethell, PhD,* Dorothy Pringle, PhD,† Larry W. Chambers, PhD,‡§¶k** Carole Cohen, MD,††‖ Elana Commissio, MA,* Katherine Cowan, MA,§§ Phyllis Fehr, RN,¶¶kk Andreas Laupacis, MD,***††‖‡‡ Paula Szeto, OT Reg (Ont),* and Katherine S. McGilton, PhD*

The Canadian Dementia Priority Setting Partnership (PSP) was established to engage individuals with personal or professional experience of, or interest in, dementia—including persons with dementia, friends, family, caregivers and health and social care providers—and to use the James Lind Alliance (JLA) methods to identify and prioritize questions for research on dementia that are important to these individuals and informed by their experiences.