

“What’s Diagnosis Got to do with it?”: Providing Palliative Care in Long Term Care Homes

Presented by Dr. Mary Lou Kelley
Quality Palliative Care in Long Term Care
Alliance (QPC-LTC)

palliativealliance.ca

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Presentation Objectives

- To compare resident-centred care, palliative care and dementia care
- To describe the work of the Quality Palliative Care in Long Term Care Alliance
- To illustrate the benefits of palliative care for LTC residents with dementia
- To advocate for common action to promote excellent palliative and dementia care in LTC homes

Project Background

- Funded by Social Sciences and Humanities Research Council (SSHRC) for a five year Community-University Research Alliance called: *Quality Palliative Care in Long Term Care Alliance (QPC-LTC)*.
- Knowledge Translation for this project funded by Canadian Institute for Health Research (CIHR)
- Includes 30 organizational partners and more than 20 researchers nationally and internationally.
- Involves 4 LTC homes in Ontario

Setting the Context

- It is common for 40% to 50% of residents to die each year in LTC homes (CIHI)
- Currently, 65% + residents in Ontario's LTC homes have dementia (Alzheimer Society Ontario, 2010)
- Caring for older people with chronic conditions with a long trajectory to death, the most common being dementia, is a core function of LTCH. (Abbey et al., 2006)

- 67% of dementia-related deaths occur in nursing homes (Mitchell, et al., 2005)
- Alzheimer's is a terminal disease (Gordon, 2011) and people can benefit by palliative care.
- Family members and clinicians need to recognize that when dementia is clearly in its terminal phase, the focus should be on symptom relief rather than acute medical interventions that rarely provide benefit and often result in prolonging suffering. (Gordon, 2011)

Resident-centered Care

- Empowers residents to be decision makers in their own care
- Respects residents choice, wishes, values, goals
- Treats residents as unique, whole persons
- Provides residents tools to care for themselves
- Advocates for residents; acts on their concerns

What is Palliative Care?

- A philosophy of care and a unique set of interventions that aim to enhance quality of life for all residents with life limiting illness regardless of diagnosis
- Interprofessional in approach
- *Identifier: “We would not be surprised if the resident died within the next year”*
- Focus is on advance care planning
- Plan of care is resident-centred and multi-dimensional, focusing on quality of life, symptom control, physical, emotional, spiritual and financial domains
- Family education and support important to avoid unnecessary family stress or hospitalization of resident

What is End-of-Life Care?

- Last phase of palliative care
- Last days or weeks of life
- Restorative care is no longer the focus as death is imminent
- Trajectory is short (1- 6 months)
- Focus is on supporting resident and family choices
- Addresses anticipatory grief

Dementia Care

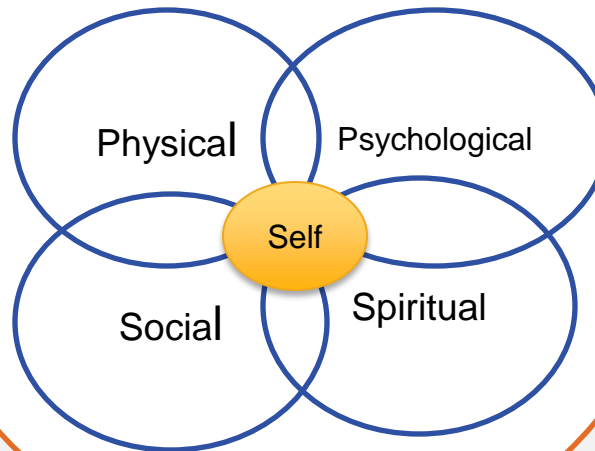
- Dementia Care (Personhood): respects the essence of person's humanity, encompassing the domains of physical, psychological, spiritual, and social aspects of self.

Personhood at the End of Life

Care that Supports Personhood = A Good Death

- Treating the older adult with dignity and respect
- Having pain control
- Being touched
- Having choices
- Autonomy is respected
- Being resilient
- Having an awareness of not being alone
- Having a sense of peace
- Maintaining social interactions (with family, staff, and other older adults)

A personhood model integrating palliative and dementia care



Care that does not Support Personhood = A Bad Death

- Unmanaged pain
- Experiencing specific problems (hearing, vision)
- Being agitated/frustrated
- Experiencing deaths of family and friends and having little bereavement support
- Experiencing boredom
- Having few opportunities for spiritual fulfillment
- Being distressed
- Staff/volunteers being unfamiliar with the older adult's history

Goals of the QPC-LTC Alliance

- Improve the quality of life for residents in LTC
- Develop interprofessional palliative care programs
- Create partnerships between LTC homes, community organizations and researchers
- Create a toolkit for developing palliative care in LTC Homes
- Promote the role of the Personal Support Worker



PALLIATIVE CARE WEEK

May 6th – 12th, 2012



Palliative Care...

- **is resident-centered**
- **supports family members**
- **benefits residents living with and dying from progressive, chronic and life-limiting conditions**
- **is available at Bethammi Nursing Home and Hogarth Riverview Manor**







Psychological and Social Care



Spiritual Care



Grief and Bereavement Support

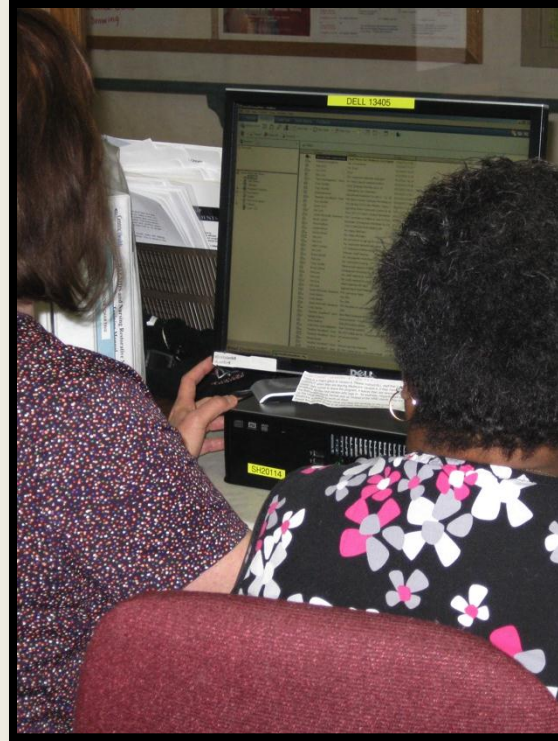


End-of-Life Care



Practical Care

Palliative Care includes....



Doing Assessments

Information-sharing

Decision-making

Care Delivery

Care Planning

Confirmation



Bethammi Nursing Home and Hogarth Riverview Manor have Palliative Care Resource Teams to support residents, families, volunteers and other staff with information and guidance



We are creating a palliative care program model and many resources to share with other long term care homes



Some things that we are doing to support our residents, families, volunteers and staff include...



Palliative care education using simulation labs which allows staff to practice their skills outside the home

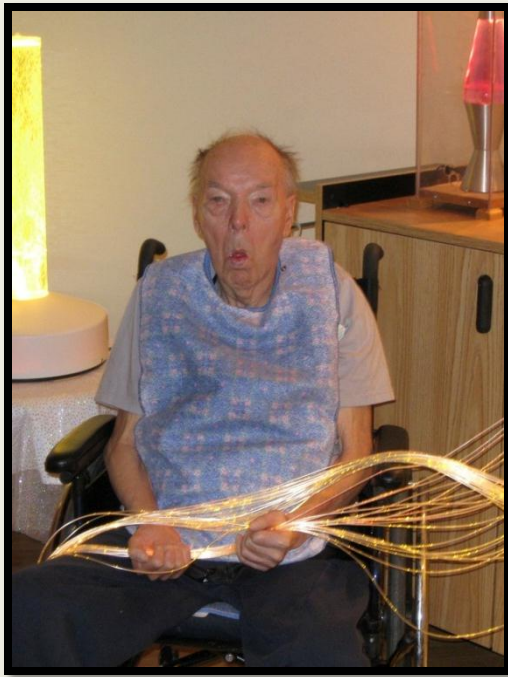
Updating our policies and procedures ...



- To reflect that we offer palliative care
- To help guide our teams in the end-of-life care process



We offer social and therapeutic activities that benefit all of our residents, including those receiving palliative care, such as...



The Snoezelen Room



Music Programming



For more information about our palliative care programs



talk to the Palliative Care Resource
Team



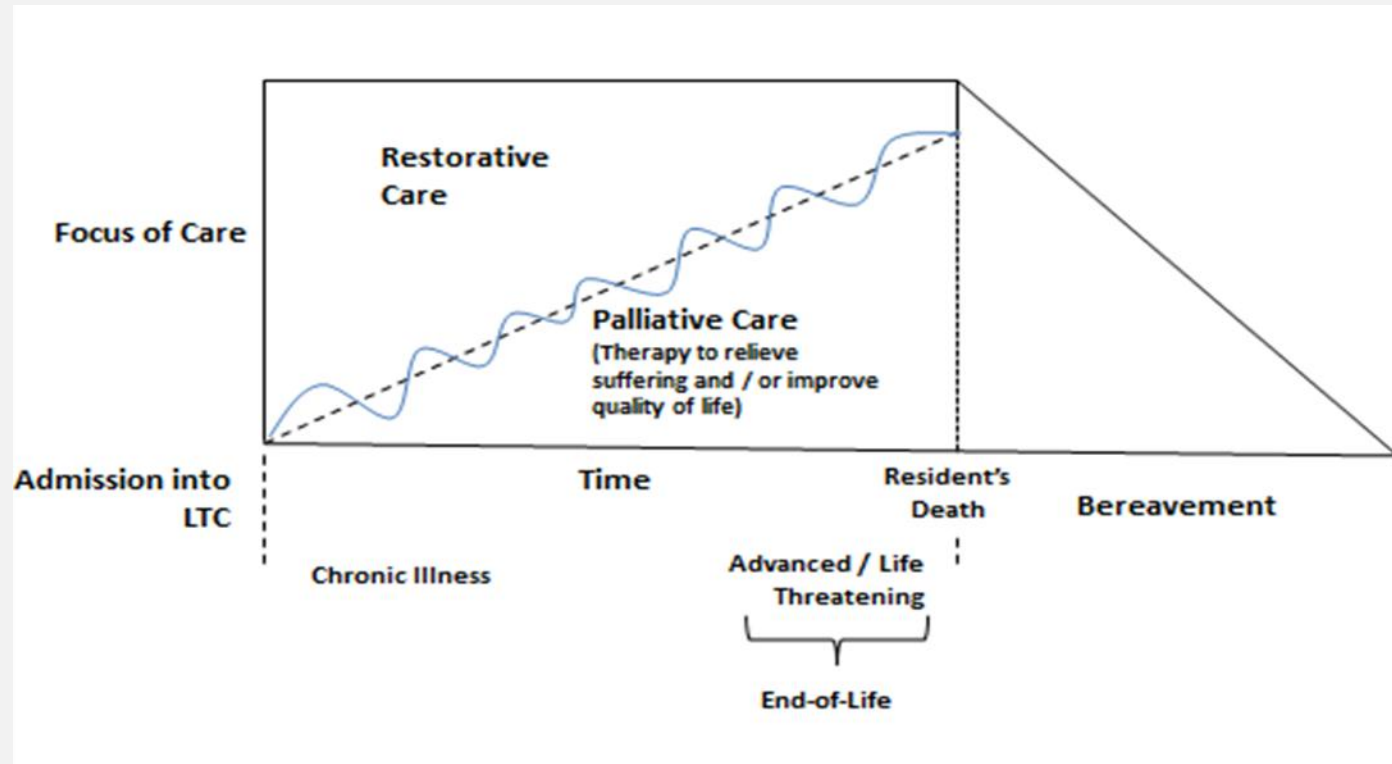
Centre for Education
& Research on
Aging and Health

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Conspiracy of Silence

- The medicalization of death has created a conspiracy of silence surrounding the process of death and dying
- Early in the disease trajectory is the appropriate time to dialogue with residents and families (SDM) about wishes (ACP)
- Lack of dialogue often leads to aggressive interventions, hospitalization, shock and denial at end of life. (Gordon, 2011)

Transitions from admission to death



Palliative Approach for those with Chronic Illness

- applies the principles of palliative *care* to the care of any sick person regardless of their illness
- focuses on conversations with patients/families about their goals of care, comfort measures, support for psychosocial, spiritual and cultural issues; information requirements; and provisions for death and care after death

A Palliative Approach Assessment

Includes:

- a pain/symptom assessment
- a social/spiritual assessment
- an assessment of the individual/family's understanding of the illness, prognosis, and treatment options
- an identification of resident-centered goals of care.

Shared Features of Dementia and Palliative Care

- Require education, resources and protocols to support excellent care
- A multi-disciplinary team (which includes resident and family) participates in the care
- Includes social, spiritual, physical, disease management, grief and bereavement
- Advance care planning is important
- Holistic in nature
- **RESIDENT -CENTRED**

Shared Challenges and Issues

- Lack of policy and resources dedicated to palliative care and dementia in LTC
- Programs in LTC are Silos
- Division of limited resources in meeting changing priorities

Shared Challenges and Issues

- Insufficient training for staff in LTC about PC and dementia.
- Communication barriers at all levels
- Families and LTC residents need opportunities to discuss and learn about the disease process and end-of-life options.
- Advance Care Planning only medical (not holistic).
- Utilization of RAI indicators (responsive behaviours and PC indicator)

Facilitators

- Resident is the focus of care
- Synergies between initiatives
- Goal is to support and care for the resident in LTC and avoid hospitalization
- Common goal of living in the moment
- Family participation in care delivery and planning
- Use of Inter-professional teams

Interventions

- **Direct Care**
 - Sensory Stimulation (Snoezelen, Music)
 - Standardized assessment tools
 - Pain and Symptom management
- **Community**
 - Collaboration with community resources
 - Hospice Volunteers
 - Alzheimer's Society Education Seminars

Interventions

- **Education**
 - Resources and Information for families (advanced care planning, signs of end-of-life, the dying process, and palliative care)
 - Education for staff
 - Experiential learning opportunities
- **Policy and Procedure**
 - Program Policy
 - RAI for Palliative Care Identifier including responsive behaviours
 - Advance Care Planning Protocol

LTC Home & Alzheimer's Society

- **Objective:** To develop recommendations about how the Alzheimer Society can further support families with relatives who have dementia and are at the end of life in LTC
- **Methods:** 11 family members at one LTC home and 3 Alzheimer Society staff participated in focus group discussions and individual interviews.

Family Information Needs:

COMMUNICATION	CARE FOR THE CAREGIVER	WHAT TO EXPECT
Successful Visiting How to Comfort Stimulating Activities	Support Guilt The Grieving Process	Advanced Planning Signs of End-of-Life The Dying Process Palliative Care

Authors: Ginette Moores, Dr. Carrie McAiney, Dr. Sharon Kaasalainen, Diane Crawshaw, McMaster University

Recommendations:

- Resources Within LTC Homes
 - A one-stop source for information within LTC homes that families could use as needed
 - Contain pamphlets, books, handouts, etc. on a variety of topics and stages of care
- Alzheimer Society to Further Support Activities Within LTC Homes
 - Facilitate successful visiting sessions for residents with dementia within the LTC home setting 2-3 times per year
 - Provide stimulating activities within LTC homes that families and LTC staff could also do

Recommendations cont'd

Increase Communication Within LTC Homes

- To better inform families of what is going on within the LTC home (i.e. education sessions, activities)
- Through a variety of mediums: mail, email, flyers, and posters in resident's rooms

Support Groups for Family Members in LTC

- Promotion of ongoing support groups offered by the Alzheimer Society for family members of residents in LTC homes
- Opportunity for caregivers to share stories and offer support

Shared Vision for Residents

- Long term care will provide a home-like environment where people can come to live well until the end of their lives
- Care will support autonomy, comfort, dignity and quality of life.
- People living in LTC will have their decisions and wishes respected by their care givers.

Conclusion

- Palliative Care benefits people with dementia and their families
- Long-Term Care homes have an important role with residents who have dementia and will require end-of-life care
- Both dementia care and palliative care have common goals and require specialized skills
- LTC homes and staff need support through education and advocacy to provide quality palliative care and dementia care
- Families and Residents need every opportunity to talk about their end of life care and wishes

Questions to consider

- Can you think of examples from your own practice when you have provided palliative care for someone with dementia?
- How is end-of-life care different with a resident who has dementia and one that does not?
- How well is end of life care provided in the LTC setting for people with dementia?

Resources for EOL & Dementia

World Health Organization and Alzheimer's Disease International. *Dementia: A Public Health Priority* (2012)

University Institute of Geriatrics of Sherbrooke *Comfort Care at the end of life for Persons with Alzheimer's Disease or other Degenerative Diseases of the Brain* (2005)

Michael Gordon with Natalie Baker

*Late Stage Dementia: Promoting Comfort
Compassion and Care (2011)*

Neil Small, Katherine Froggatt, Murna
*Downs Living and Dying with Dementia:
Dialogues about Palliative Care (2007)*

Quality Palliative Care in Long-Term Care; Tools for Change

- Date: Wednesday October 17th, 2012
- Location: 89 Chestnut St. Toronto
- Objectives:
 1. A forum to promote palliative care innovations for long term care homes
 2. Showcase effective practices developed through the QPC-LTC Alliance
 3. Share ideas to address gaps and barriers for developing PC programs in long term care homes
 4. Identify effective ways for decision makers to be catalysts for organizational change

Further Information

Visit our website

www.palliativealliance.ca

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Special Thanks to...



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