Quality Palliative Care in Long Term Care: Tools for Change

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Lakehead University | McMaster University | Halton Region | St. Joseph's Care Group | Social Sciences and Humanities Research Council of Canada / Conseil de recherches en sciences humaines du Canada

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The Context of LTC

- It is common for 40% to 50% of residents to die each year in LTC homes. (CIHI)
- LTC is a unique palliative care context.
  - frail older people living with progressive life limiting disease
  - A home where residents will both live and die
  - Heavily regulated and inspected (external standards)
- The majority of LTC homes in Canada lack formalized palliative care programs.

Quality Palliative Care –Long Term Care 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 four LTC homes in Ontario as study sites

Goals of the Project

- Improve the quality of life for residents dying 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 that can be shared nationally
- Promote the role of the Personal Support Worker (PSW) in palliative care

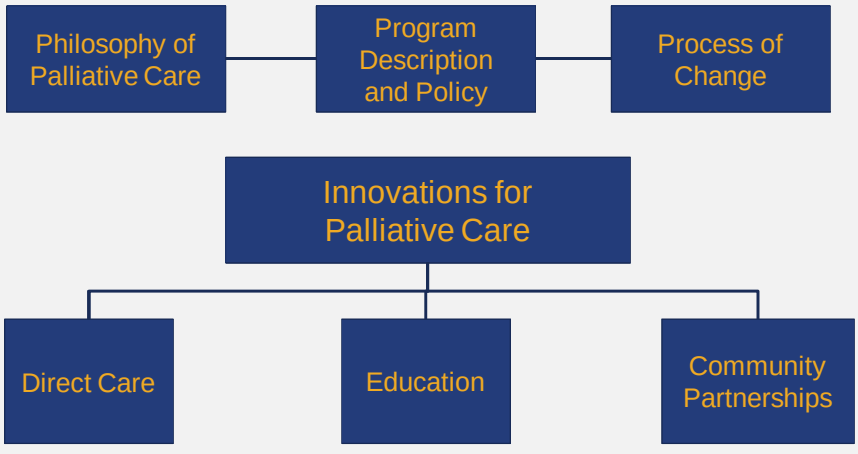
4 Key Messages

"We will care for you for the rest of your life"
"It's hard to watch people die for a living"
"Resident's are not like paperwork"
"You can't regulate humanistic care"

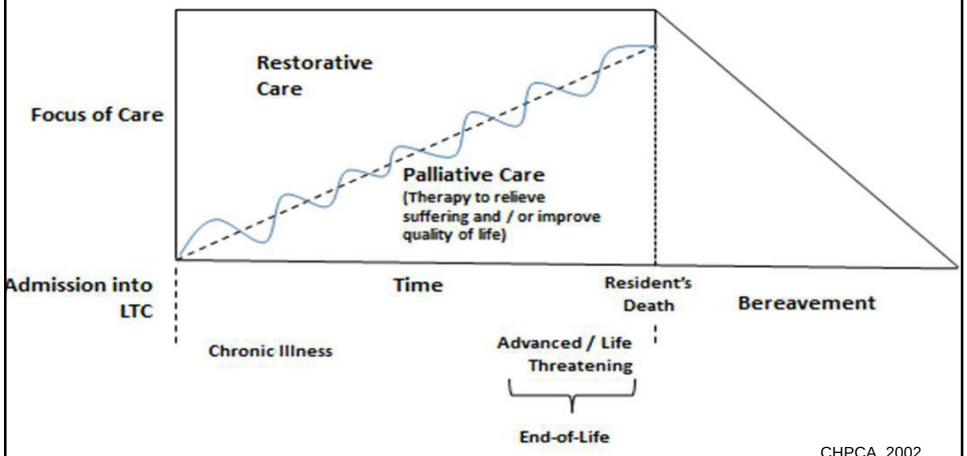
Family Perspective

- Families want residents to die in long term care IF resources and education are available to staff
- There needs to be open communication between families and staff
- Families need to feel part of “the team”
- Families see that there is a shortage of staff
- They recognize the contribution that community partners can play in delivering palliative care

Framework of Palliative Care in Long Term Care



Transition from Admission to Death



CHPCA, 2002

What is Palliative Care and End-of-Life Care?

Palliative Approach to Care

- Focus is on quality of life, symptom control
- Interdisciplinary in approach
- Client centered and holistic
- Begins when death would not be "unexpected" in the next year

EOL Care

- Death is inevitable
- Trajectory is short (6 months or less)
- Focus is on supporting patient and family choices
- Addresses anticipatory grief
- Supports resident with a "good death"

When does EOL Care begin?

Palliative Performance Scale (PPSv2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasion assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death				

Stages: Stable, Transitional, End of Life

Reproduced with permission from Victoria Hospice Society, 2003.

Philosophy of Care

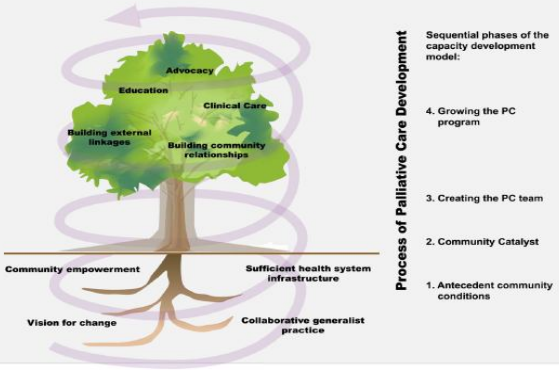
- Resident-Centred Care/Relationship-Centred Care
  - Empowers residents to be decision-makers in their own care
  - Respects residents choice, wishes, values, goals
  - Treats residents as unique, whole persons
  - Provides residents tools to care for themselves
  - Advocates for residents; acts on their concerns
  - Focuses on relationships as the core process in quality care
  - Values interdependence

Program Description and Policy

- Goals of the program
- Program objectives
- Relevant Definitions
  - Palliative Approach
  - End-of- Life Care
  - Advance Care Planning
  - Interdisciplinary Palliative Care Resource Team
- Relevant Programs Policies and Procedures related to PC delivery

Processes of Change

- Capacity development model for developing palliative care



Getting Started…

- Self Assessment Audit

Description	Progress	Document or Evidence to Support
Organization Context **Formalized palliative care program Description that includes:**		
• Goals and objectives of the program	☐Yes ☐No ☐In Development	
• Definition of palliative care, end-of-life care, and care planning	☐Yes ☐No ☐In Development	
• List of services that are available within the palliative care program	☐Yes ☐No ☐In Development	
• There is a process in place to identify residents who would benefit from a palliative care approach.	☐Yes ☐No ☐In Development	
• Assessments specific to palliative care and end-of-life are listed (ie. Palliative Performance Scale)	☐Yes ☐No ☐In Development	
• Staff have a formal process of communicating the palliative care needs of a resident (shift to shift report, reporting on electronic charts)	☐Yes ☐No ☐In Development	
• There is pain and symptom management built within the program	☐Yes ☐No ☐In Development	
• Residents and Families are actively contributing and participating in the palliative care program development	☐Yes ☐No ☐In Development	
• Residents and families have access to palliative care education	☐Yes ☐No ☐In Development	
• Protocols are in place to support staff around grief and loss	☐Yes ☐No ☐In Development	
• There is a quality improvement strategy in place for palliative and end-of-life care initiatives (e.g. process mapping)	☐Yes ☐No ☐In Development	
• Evaluation of resident, family and staff satisfaction	☐Yes ☐No ☐In Development	

Benefits of using Self Assessment

- Self-assessment provides an opportunity to identify gaps in your palliative care program and areas of strength/capacity
- Can guide the development of your program and policies
- When used regularly it can be an ongoing evaluation of your program
- Can help to determine organizational palliative care priorities

Key Goals for change

- Expand Advance Care Planning
- Promote Formalized Palliative Care Programs
- Enhance human resources to provide holistic palliative care
- Support creation of palliative care teams
- Strengthen interprofessional collaboration within LTC homes and with community, and
- Integrate PC Philosophy into Resident-Centred Care

*** Supported by Family Councils of Ontario and Concerned Friends of Ontario**

Palliative Care Resource Team

- Interprofessional including PSWs
- Engages community partners (eg. Alzheimers Society)
- Not a clinical team
- Meets monthly
- Chaired by a staff member
- Provides leadership and mentorship within the home
- Provides a formal structure to organize education, identify needs, create strategies & support staff

Resources for families

- Information in resident handbook
- Promote discussion of advance care planning more broadly than medical directives
- Discuss palliative care and EOL care in annual care conference
- Promote dedicated palliative care conference when appropriate
- Promote referral to hospice volunteers and grief support group when appropriate
- Promote referral to Alzheimer's Society for end of life issues workshop

Resources for Staff

- Post death debriefing sessions
- Education about palliative and end of life care
- Pain screening and communication tools
- Palliative performance scale
- Promote use of Pain and Symptom consultants and teams for management of pain, feeding/hydration issues and delirium

Getting Started with our toolkit

http://www.palliativealliance.ca/news

- Organizational Self Assessment tool of structures, process and outcomes
- Education: Palliative Care for Front Line Workers course and LEAP for Long Term Care
- Brochure on the progression of palliative care and end-of -life care to help discussions with families
- Toolkit on implementing the PPS (coming soon)
- Brochure on the role and structure of the palliative care program and team

Innovations of Palliative Care in Long Term Care:

Direct Care Processes

- Comfort Care Rounds
- Snoezelen
- Comfort Care Bags
- Pain Screening, Assessment and Follow-up Protocol
- PPS and Palliative Care Conferences

Education for Staff and Volunteers

- Simulation Lab Experience for PSWs
- Palliative care for LTC workers – 10 module course
- Hospice Visits
- Spiritual Care in-services

Innovations of Palliative Care in Long Term Care:

- Community Partnerships
  - Collaboration with community resources
  - Hospice Volunteers
  - Alzheimer's Society Education Seminars
  - Palliative Pain and Symptom Management Consultants
  - Nurse led outreach teams (nurse practitioners)

Implementation Barriers – Require Advocacy!

- Human resources needs to be supplemented at all levels for palliative and end-of-life care
- Homes now choose between a spiritual care advisor or a social worker
- Time lacking for interprofessional teamwork
- J5 on RAI is not linked to CMI and funding
- No dedicated training dollars (to access training / backfill)

Further Information

Visit our website:
www.palliativealliance.ca

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Special thanks to:

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