



Central West Palliative Care Network

The Blending of Two Lens: Residential Hospice and Long Term Care

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Faculty/Presenter Disclosure

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Relationships with commercial interests:

“NOT APPLICABLE”

Welcome to Kensington Hospice

- The Kensington Hospice is a not-for-profit residential hospice in Toronto providing 24-hour care, comfort and relief to people with life-limiting illnesses. We focus on improving quality of life and getting the most out of each day in a warm, home-like setting.



Welcome to Kensington Gardens

We provide palliative and end-of-life care warm, holistic approach.

Palliative care includes

- Pain Management
- Symptom Control
- Anticipatory Grief Support for Family Members
- Spiritual Care

We work closely with you to ensure your wishes are a central element of the care you receive and that this end-of-life journey is one of dignity, peace and autonomy.



What is 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.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;

- World Health Organization, 2012

Types of Palliative Care

- A trajectory with a steady progression and usually a clear terminal phase (cancer).
- A trajectory with a gradual decline, followed by episodes of acute deterioration and some recovery, with a more sudden and unexpected death (respiratory and heart failure)
- A trajectory with prolonged gradual decline (frail elderly people, dementia)

Walshe, C. 2001. What Do We Mean by Palliative Care. In: Preddy, V.2001. *Diet and Nutrition in Palliative Care*. [online]. CRC Press. Available from <http://www.mylibrary.com.ezproxy.lancs.ac.uk?ID=32793619> March 2016, pp 17-28.

EOL Professionals present

PALLIATIVE CARE

"pal-lee-uh-tiv"



WHY HAVE I
BEEN
OFFERED
THIS?

Palliative Care is a gentle and distinct approach to caring for people with illnesses that can't be cured (like advanced heart, lung, kidney and neurological diseases and advanced cancers.)

Palliative Care doesn't necessarily mean you only have 'days' to live! In fact, the earlier you have contact with palliative care services, the easier it is for you to get access to a whole range of services, equipment and expertise designed to make your life more COMFORTABLE regardless of the stage of your illness.



BUT I'M NOT
READY TO DIE
JUST YET!



WILL I HAVE TO GIVE UP SEEING MY
SPECIALIST DOCTORS?

No. Palliative Care teams are keen to work with you, and alongside your specialist doctors and services, to make sure all aspects of your illness are managed in the best, most appropriate manner that suits you.

IF YOU HAVE ANY CONCERNs , PLEASE TALK WITH
YOUR GP AND/OR YOUR PALLIATIVE CARE TEAM.

You Are a Bridge...



<https://youtu.be/lDHhg76tMHC>

What is End-of-life Care?

- “End-of-life” care is the term that is often used to define the point in time during palliation where the end of one’s life becomes more imminent (Reith & Payne, 2009).



Challenges with the delivery of Palliative Care in Long-Term Care

- Perception of "Long-Term Care"
- Death denying environment
- Lack of training and expertise
- Funding for specialized care
- Regulations

The Uniqueness of our Model of Care

- Shared resources and expertise
- Palliative Care Committee
- Palliative Care Week
- Cross Training
- Fundraising
- Hospice is a component of the orientation for all new staff working at the Gardens.
- Quality Improvement (Balance scorecard)
- Accreditation

Accountability Framework



Accountability Framework®



Philosophy of Care

- Person-centered care
- Family as unit of care
- Domains for Care
- Interdisciplinary Team approach to addressing “Total Pain” – taking into account not only physical but also an individual’s emotional, spiritual pain



Barriers to Care

- Misunderstanding of the word ‘palliative’
 - Fear of dying
 - Fear of the unknown
 - When do you define ‘end-of-life’?
 - Systemic barriers of hospice and LTC



'Relief of Suffering'



Instead of asking ourselves, “How can I find security and happiness?” we could ask ourselves:

- Can I touch the center of my pain?
- Can I sit with suffering, both yours and mine, without trying to make it go away?
- Can I stay present to the ache of loss or disgrace—disappointment in all its many forms—and let it open me?” This is the trick.

~ Pema Chodron

Read more:

<http://www.beliefnet.com/columnists/beginnersheart/2014/10/sitting-with-suffering.html#ixzz44ylwtLl9>

Supportive care...

- “In-house supports” (Emotional and practical support for residents and families)
- Practical Supports: financial, documentation, funeral planning, etc. etc....
- Emotional Support:
 - Anticipatory Grief
 - What’s left undone? Unsaid?
 - Facilitating meaningful communication
 - Legacy work

Final Hours

4 dimensions of care important to a family member's assessment of care during the last 24 hours:

- Accessibility of staff
- Continuity of personnel
- Anticipatory guidance
- Symptom management

(Cassarett et al., 2003)

Supporting Families

- In last hours...
 - Reassurance about what to expect
 - Honoring pre-established rituals
 - To be defined by the individual/family member...
- At the time of death...
 - Family may want to stay with loved one after death for a period of time
 - Important to respect family's needs/preferences

Supporting Families

When leaving ...

- Family may or may not want to stay for procession ritual
 - Personalized words about the resident
 - Candle lighting
 - Moment of silence
 - Procession proceeds to curbside...
- Memorial book
- Another key time of transition for the family

How LTC support the Hospice ...meet Alfonso



- Admitted to the hospice for end of life care
- Slow improvement
- Stabilized and medical needs reduces
- Improved relationship with sons
- Application to LTC
- Transferred to Kensington Gardens
- Quality of Life moments

How the Hospice supports LTC ...meet Susan ??



- 61 years old, admitted in 2014 with a degenerative neuro muscular disease
- Physically compromised
- Issues with pain management and deterioration
- Referral to hospice
- Holistic Care Assessment

Take Home Messages

- Teamwork
- Communication
- Thinking outside of the box
- Focus on goals of care
- Individuality of Palliative Care
- Be creative (working with legislation)
- Ongoing education
- Start the conversation early



“You matter because you are you,
and you matter to the end of your life.
We will do all we can not only to help you die
peacefully,
but also to live until you die.”

Dame Cicely Saunders

Founder of the Modern Hospice Movement.
St Christopher's Hospice