Palliative Care as Public Health- its "*everybody's business*" !

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Dying “in the past”…now present and future?

- Normal and routine
- Built on community relationships
- Whole person care- ie. whole “citizen “ care, not just service-based
- End of life care is more than medical care
- Death and loss are inevitable and universal

The prevalence of human mortality is stable

We know who dies, when and where…

Currently, in Canada…

- 1% of our community is in their last year of life
- The costs of caregiving are enormous
- ***Still!*** approximately 70% of deaths occur in hospital
- Canada slips to 11th on the international Good Death Index (2015)
- 95% of your last year of life is not spent with healthcare providers
- ¾ visits to your family doctor in the last year of life…
- Newly articulated national and provincial strategies
- CIHR grant and heart failure…sigh

Canadian Secretariat on Palliative and End-of-Life Care

2001

- Creation of the Secretariat

Health Canada / Santé Canada

2002

- Industry Canada announces funding for:
  - Canadian Virtual Hospice
  - First ever research chair in palliative care

2004

- Launch of CVH
- $1.25M in funding for education

CANADIAN Virtual Hospice
Information and support on palliative and end-of-life care, loss and grief.

Educating Future Physicians in Palliative and End-of-Life Care

2007

Auditor General's Report December 2014

Chapter 3
Section
3.08

Ministry of Health and Long-Term Care

Palliative Care

Background

Description of Palliative Care

Palliative care focuses on the relief of pain and other symptoms for patients with advanced illnesses, and on maximizing the quality of their remaining life. It may also involve emotional and spiritual support as well as caregiver and bereavement support, and provides comfort-based care as opposed to curative treatment. Typical illnesses for which palliative care is provided include cancer, heart disease, respiratory disorders, HIV/AIDS, muscular dystrophy, multiple sclerosis, and kidney or liver failure. For patients who are terminally ill and within their last few weeks or months of life, palliative care is often referred to as end-of-life care.

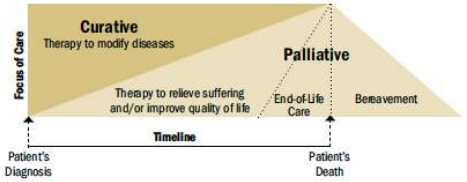
The Palliative-care Continuum

Key stages in palliative care, as shown in **Figure 1**, are as follows:

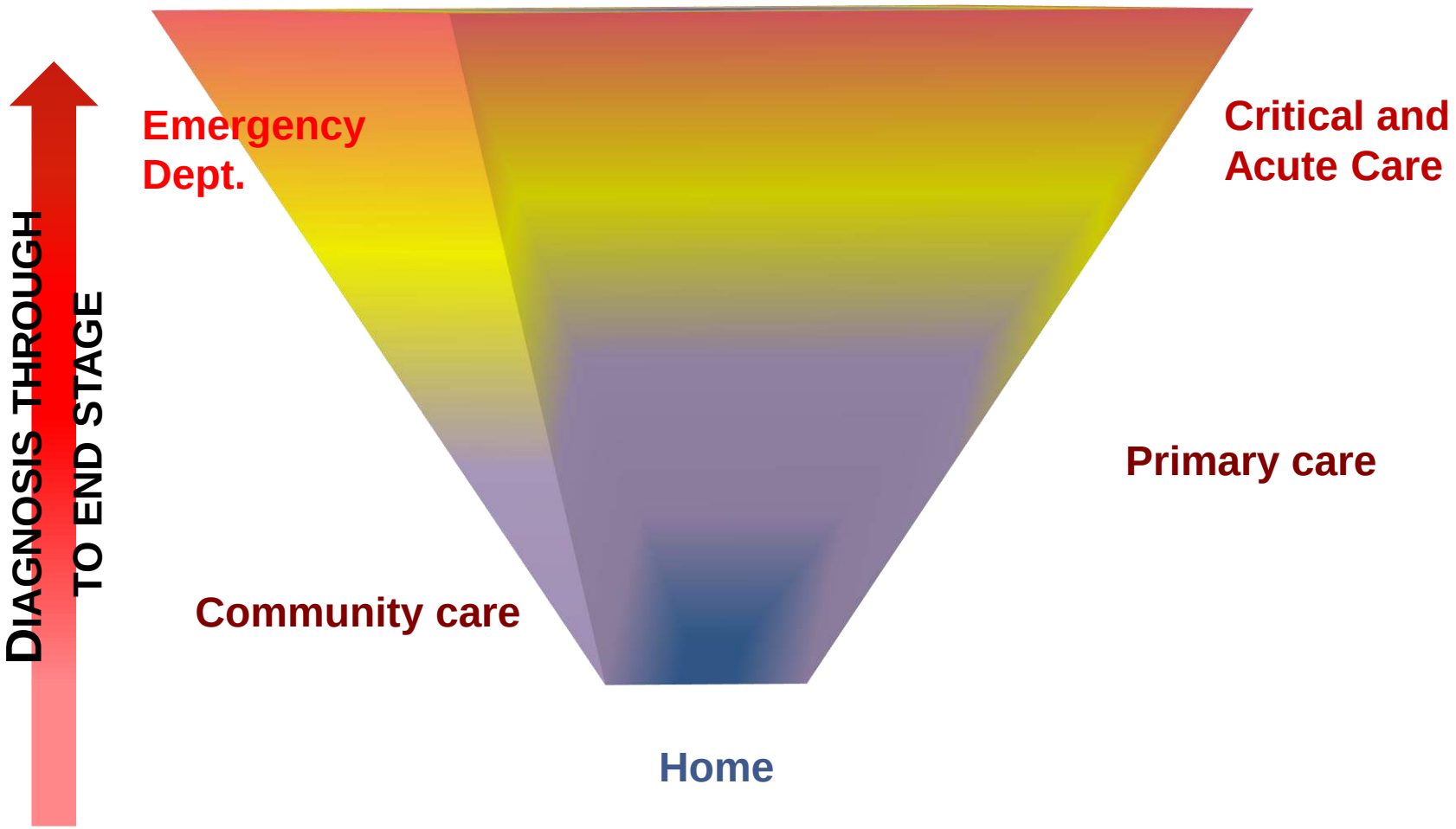
1. ***Patient is diagnosed with a chronic or life-threatening illness.*** The patient might seek measures to fight the disease, such as undergoing curative treatments to stop or alter the disease progression. The patient might also receive some treatment to manage pain and symptoms, but this is not traditionally considered to be palliative care because the main focus of the care is curative.
2. ***Disease progresses.*** If the patient's response to curative treatment is not positive, or the patient and family decide to no longer seek this treatment, the focus of care gradually shifts from curative therapies to palliative care.

Figure 1: Palliative-care Continuum

Adapted by the Office of the Auditor General of Ontario from information from the Canadian Hospice Palliative Care Association



Current care pyramid



Matching complexity of needs with resources

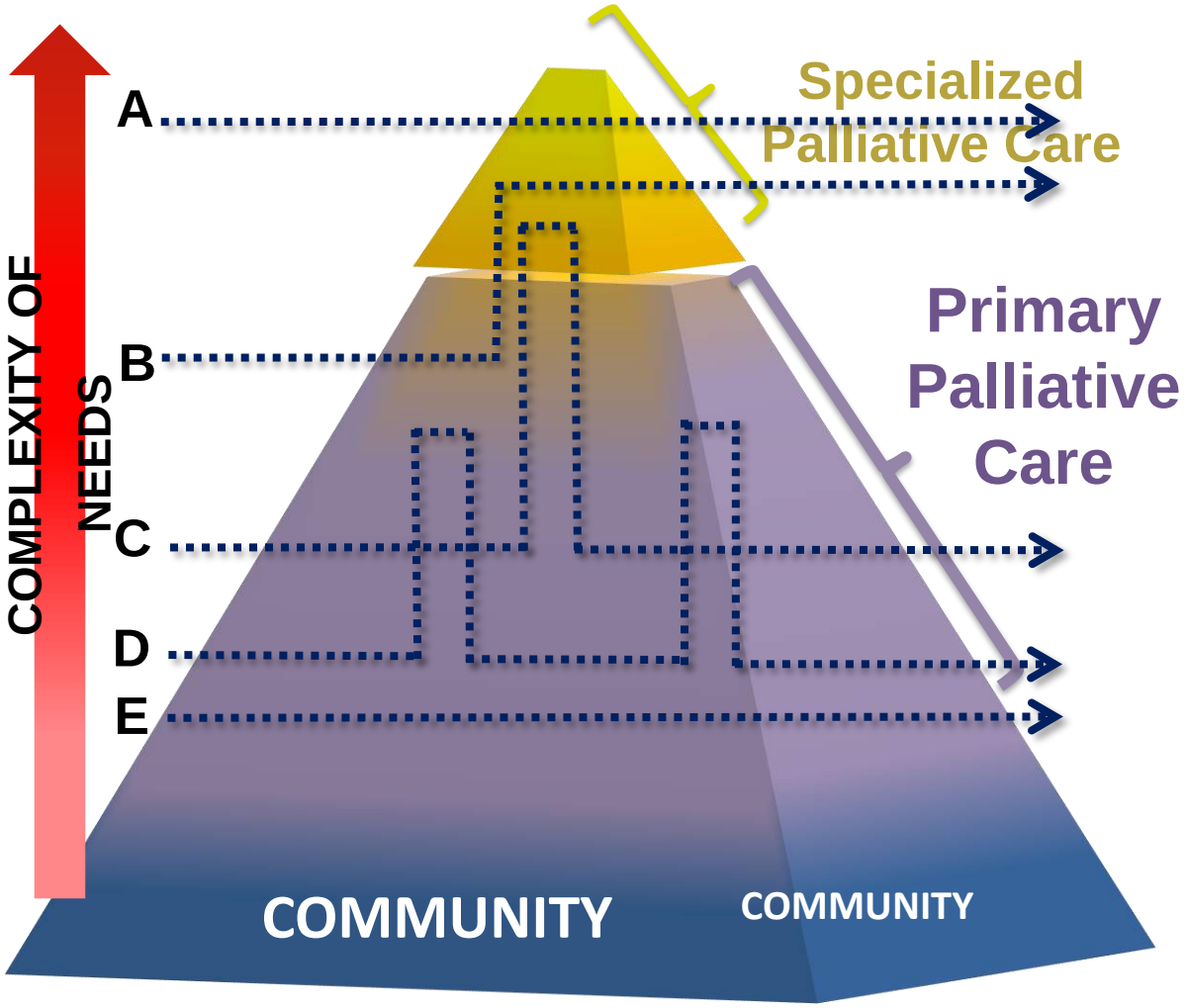
A: Needs are complex such that specialist palliative care is required throughout illness journey

B: At first needs are met by primary clinicians. Specialist palliative care meets needs when they become complex

C: Needs are mostly met by primary clinicians. Specialized palliative care meets the needs for episodes when needs are complex

D: Needs are met by primary clinicians who access mentors (i.e. specialized palliative care) when needs increase in complexity

E: Needs are met by clinicians with primary palliative care competence throughout illness journey



Why does Public Health exist?

- To assemble and analyze community health needs for disease prevention, health promotion and protection
- To develop health policy through scientific knowledge
- To assure the community by providing health protection services

What is a Public Health Problem?

- Prevalence of condition or exposure
- Impact of condition on society
- Condition is preventable
- Effective interventions available
- Equity considerations

Palliative Care as Public Health

- Developing the wider community context within which palliative care services make their contribution
- "Beyond mere services"
- Involves the well, and wellness (beyond illness)
- Palliative care is *"everybody's business"*

Kellehear, A. (1999) Health Promoting Palliative Care, Melbourne, Oxford University Press

….*normalizes* this aspect of living…..

- Every other area of health care has a public health agenda
- Health promotion is part of health- we need the well!
- Synergy with death, dying, loss and bereavement of all kinds, not just those who intersect Palliative Care
- When DDLB is normalized, so too shall ACP
- Engagement of the 95% of the time that people are not with their healthcare provider

....builds social capital

- A community that interacts with itself frequently has a high level of trust, social support and morale
  - is interested in its own health and welfare
  - fostering interest in matters that affect their family, friends, co-workers, neighbours
- Means community capital, not just occupational
- Requires upfront leadership and facilitation
- Transition out from HPC and community continuation

Genesis….

- WHO Ottawa Charter application
- AIDS experience as community developing driving health services and policies
- WHO Healthy Cities Movement
- Age Friendly cities
- Dr Allan Kellehear

The Ottawa Charter (WHO, 1986)

- Build healthy public policy
- Create supportive environments
- Strengthen community action
- Develop personal skills
- Re-orientate health services

World Health Organization

The Compassionate Cities (CC) model

- is an end of life care community application **of WHO Healthy Cities model**
- is ***a theory of practice*** for HPPC
- the principle of healthy communities – health is everyone's responsibility
- the principle of compassionate communities – palliative and end of life care is everyone's responsibility

- IN BOTH – communities and services create partnerships where *both* lead in areas where they have authority and responsibility

CC models have an ecological approach

- Changes the setting and the conditions
- Doesn't add a new setting
- Is not a new building
- Not what we do to others, but with others and is essentially social
- Co–imagining, co-creating and co-accountabilities

Principles of Capacity Development

- Development is essentially about building on existing capacities within people, and their relationships
- Development is an embedded process; it cannot be imposed or predicted
- The focus is initially about change not performance
- Development takes time and has no end
- Development process engages other people & social systems
- Individuals, teams, organizations and communities are interconnected in new ways

(Kaplan 1999; Lavergne & Saxby, 2001)

SEQUENTIAL PHASES OF THE CAPACITY DEVELOPMENT MODEL

5) Embedding Palliative Care in the Community

4) Creating the Palliative Care Program

3) Experiencing a Catalyst

2) Having Community Readiness

1) Grounding the Development in Community Values and Principles

International Examples

- Hospice friendly hospitals (HfH)
- Compassionate Watch ie. neighbourhood Watch
- Death education elementary schools/hospice partnerships- UK Kindergarten curriculum
- Third sector mobilization-Integration of formal and informal care networks
- LTC pubs/beer coasters - Ireland
- Carers' day- Israel
- Australia- PHPC part of system design
- Scotland- primary level palliative care movement and funding contingent on PH Strategies
- Community development strategies – SS Africa

Death literacy

Whether we know it or not, agree or disagree, children are recipients of death education from our actions as well as our inaction. Children grow up in society, learn from it, absorb its wisdom, myths and practices, its ambivalence, and its anxieties

(Wass, 2006,p.27)

“Death neither obeys the school timetable nor appears on it... it enters the classroom without knocking.”

Canadian Examples of Compassionate Communities

- Die-alogues- Hospice Northwest
- BC Centre for Palliative Care- seed grants for community groups
- Windsor Essex Compassionate Communities initiative (WECC) –Windsor Essex Hospice
- Compassionate Schools -Pallium Canada
- Compassionate Schools- McNally Hospice
- Compassionate Companies- Canadian Hospice Palliative Care Association
- Compassionate Cities Charter

Hospice Northwest Presents

Dialogues

Conversations on Life and Death

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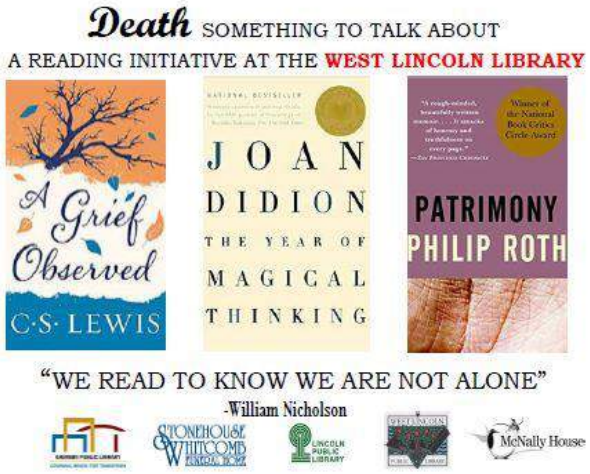
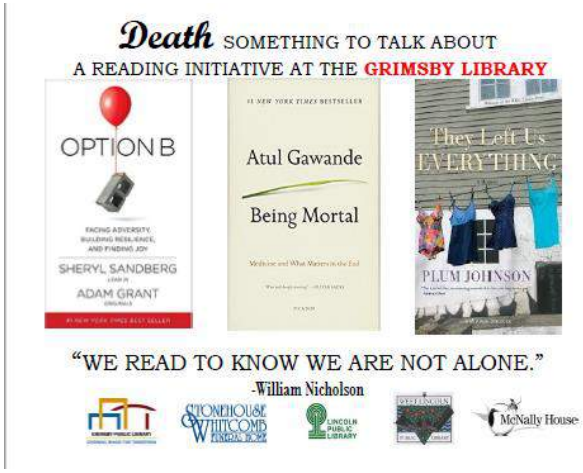
HOSPICE NORTHWEST

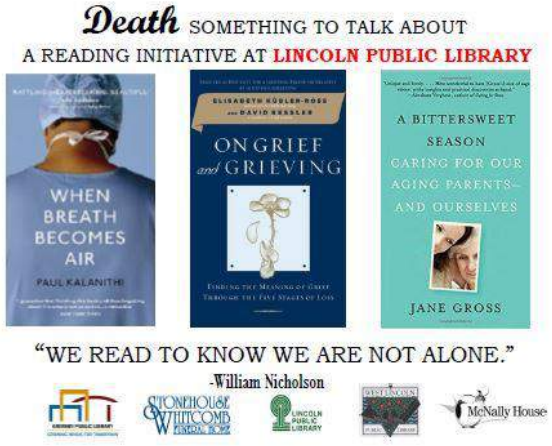
Bereavement in the Workplace Lunch and Learn

- Perspectives: Grief in the Workplace
  - Why is it important to consider grief at the workplace
  - What to know about grief
- Practices: Supporting a Grieving Employee
  - What to do and consider when an employee is grieving
  - Ideas and resources to help improve capacity to support each other
- Policy & Procedure Development
  - Workplace suggestions for employers
  - Policy development

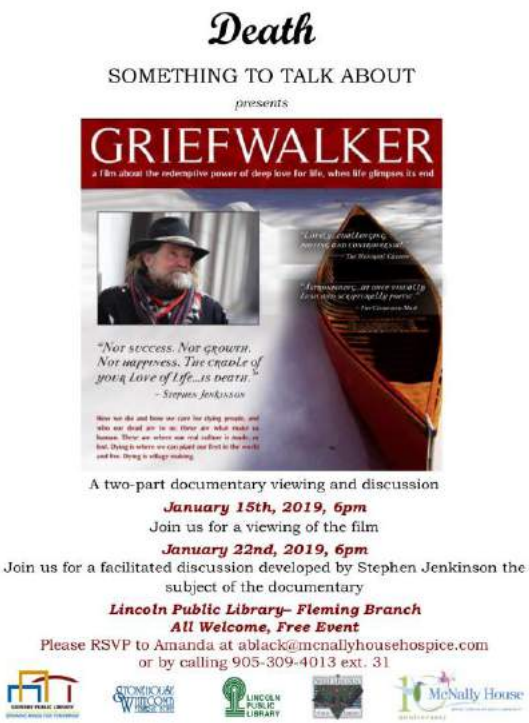
Death: Something to Talk About Reading Initiative

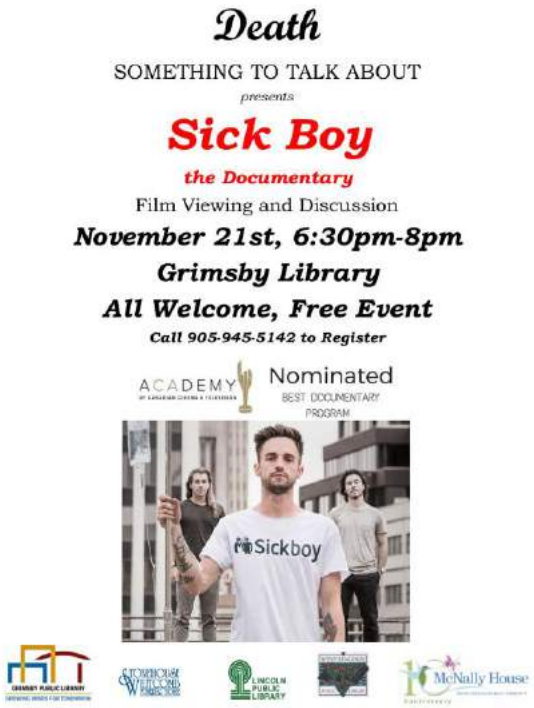






Death: Something to Talk About Film Series





Who bears the responsibility?

- “For public health strategies to be effective, they must be incorporated by governments into all levels of their health care systems and owned by the community .” (WHO PH Strategy)
- Community engagement and education required
- Leadership and facilitation from healthcare providers in relationship with community
- Social responsibility of every palliative care clinician (this requires courage)

Public Health Palliative Care International
www.PHPCI.info

- Global initiative, reach, interactions
- A response to the loss of “social” and “community”
- Fostering Compassionate Communities and the Compassionate Cities Charter
- Emerging evidence and best practice

Compassionate City Charter
Public Health Palliative Care International
www.phpci.info

- Schools – Will have guidance documents for dying, death, loss and care.
- Workplaces – Will have guidance documents for dying, death, loss and care.
- Trade Unions – Will have guidance documents for dying, death, loss and care.
- Churches and Temples – Will have at least one dedicated group for End Of life (EOL) care.
- Hospices and Nursing Homes – will have community development programs that focus on EOL care and will involve local area citizens.
- Museums and Art Galleries – will hold exhibitions on the experience of ageing, dying, death and loss or care.

Compassionate City Charter

- Our city will celebrate and highlight the most creative compassionate organization, event or individual(s) through an incentive scheme, for example a “Mayor’s Award.”
- Through various forms of media, our city will publicly showcase our local government policies, services, funding opportunities, partnerships, and public events that address our compassionate concerns. As well, all EOL services will be encouraged to share this material.
- Our city will work with local social or print media to encourage an annual city-wide short story or art competition to raise awareness of ageing, dying, death, loss or caring.
- All services and policies will demonstrate an understanding of how diversity shapes the experience of ageing, dying, death, loss and care.
- We will encourage and support institutions for the homeless and the imprisoned to have support plans in place for EOL care.
- Our city will establish and review these targets and goals in the first two years. Thereafter will add one new sector annually to our action plan.

What can community partners do?

- Gain conceptual clarity
- Role model, lobby, advocate
- Assess readiness; do surveillance; test ideas
- Foster third sector mobilization ie service clubs
- Make current/successful initiatives explicit
- Regionally-ensure this is part of workplans and system designs
- Hire community developers in our health systems
- Nationally- form public health partnerships and part of national strategy

What does success look like...?

- Participatory partnerships
- ACP done “already” as a normal thing to do
- Compassionate communities projects everywhere
- Health system performance and evaluation based on community development and public health deliverables
- Culture shift drives policy change

"A healthcare provider is a poor excuse for a friend."

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