It Takes a Compassionate Community:

Palliative Care

Is Everybody’s Business

British Columbia Hospice Palliative Care Association

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I wished there were a place for gracious dying. A high place with a distant view.

Where we could gather for a celebration of life and death and friendship, old and new.

I’d like a place where there would be good music, Good food and wine – and laughter, games and fun – And quiet talk with friends and good discussion of what will happen when this life is done.

Helen Ansley
It’s What You Learn After You Know it all
That Really Counts!

Later Life Learning Centre

– Mount Royal College 1980’s
“Nothing impacts us and our families more intimately than the death of a loved one”

Re-Shaping End-of-Life Care
The prevalence of human mortality is stable

We know who dies, when and where...
Disruptive Demographics

Percent of the population age 60 and over, 2000-2025

- Latin America & Caribbean: 7.7 in 2000, 14.5 in 2025
- Europe: 19.8 in 2000, 28.8 in 2025
- Former USSR: 16.5 in 2000, 25 in 2025
- Asia: 14.3 in 2000, 25 in 2025
- Africa: 10.6 in 2000, 15 in 2025
- Oceania: 13.5 in 2000, 20.7 in 2025
Canadian Reality

• By 2036, seniors will account for 23-25% of the total population

• 32% of Canadians suffer from a chronic illness

• 74% of seniors have one or more chronic conditions

• 24% of seniors have three or more chronic conditions

• Chronic diseases account for 70% of all deaths
Dying “in the past”

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

*End of life care was everybody’s business*
What Do Canadians Want?

93% believe palliative care services should be available in the \textit{setting of their choice}.

75% indicated a preference to \textit{die in their home}.

52% expect the bulk of their end-of-life care to occur in their home.

Canada is not equipped

- Canada’s Ranking has slipped - 2015 Quality of Death Index Ranking palliative care across the world

- Currently, only 16 to 30% of Canadians have access to or receive good quality hospice palliative and end-of-life services

Canadians need and deserve better access to high quality, integrated, compassionate palliative and end-of-life care
Current Canadian ‘stats’

- 1% of our population is always in the last year of life

- 3 out of 4 visits to the GP/Family doctor in the last two months of life are for social concerns (reassurance, affirmation, accompaniment)

- CIHR grant on end stage heart failure- theme extraction, elderly women and sources of suffering

....not being able to get out and get your hair done
Public Health

Combines the *science, art, and skills* to organize and direct society’s efforts to:

- protect
- maintain, and
- improve the health and wellness of the whole population, and to
- maximize quality of life when health cannot be restored
Ottawa Charter for Public Health - 1986

Health is created and lived by people within the settings of their everyday life; where they learn, work, play and love.

Health is created by caring for oneself and others, having control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members.
Palliative Integrated Care Model

COMMUNITY

HEALTH CARE

SOCIAL CARE
Genesis....

• WHO Ottawa Charter application
• WHO Healthy Cities Movement
• Age Friendly cities domains:
  
  (1) Outdoor spaces and buildings
  (2) Transportation
  (3) Housing
  (4) Social Participation
  (5) Respect and social inclusion
  (6) Civic participation and employment
  (7) Communication and information
  (8) Community support and health services.

• Dr Alan Kellehear
Impact on patient and system outcome:

- Improves the person and provider experience
- Enhances quality of life prior to death
- Makes it possible for more people to die in dignity in home-like settings
- Creates compassionate caring communities
- Results in cost savings

Provides sustainable solutions to problems of access, equity, and quality of palliative care.
NEW INTEGRATED PROCESS APPROACH AND PERSON-CENTERED CARE

Returning to core values…

Attention centred on patients:

Compassionate Communities

• Compassionate communities actively involve citizens in their own end-of-life care

• Build partnerships between services and communities to build on the strengths and skills they possess, rather than replacing them with professional care

Dr. Kellehear
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
Compassionate Communities

Offer access to many social aspects of care not provided by the health care system but central to the well-being of patients’ with advanced illness and their family / friend caregivers. ie

- Respite for caregivers
- Companionship for people with dementia who are often socially isolated
- Bereavement support for caregivers
BIG 7 CHECKLIST

In what way do these Compassionate Community Initiatives:

1. Help **PREVENT** social difficulties around death, dying, loss & care?

2. **HARM–MINIMIZE** difficulties we may not be able to prevent around death, dying, loss or care?

3. Be understood as **EARLY INTERVENTIONS** along the journey of death, dying, loss & care?

4. Alter/change a **SETTING OR ENVIRONMENT** for the better in terms of our present or future responses to death, dying, loss or care?

5. Be **PARTICIPATORY** – borne, partnered & nurtured by *community members*?

6. Be **SUSTAINABLE** without your future input?

7. **EVALUATE** their success or usefulness so that you could justify their presence, their funding & their support?

(From Compassionate Cities, Alan Kellehear, 2005)
Canadian Exemplars

• Kelley Model
• BC Centre for Palliative Care
• Windsor Essex Compassionate Communities initiative (WECC)
• Burlington Ontario- adopting the Compassionate Communities Charter-? First in Canada
• Compassionate Schools promotion-Pallium Canada
• Compassionate Companies- CHPCA
• Bereavement yoga, cooking, McNally Hospice
The Kelley Model of Community Capacity Development

Sequential phases of the capacity development model:

1. Antecedent community conditions
2. Community Catalyst
3. Creating the PC team
4. Growing the PC program

Process of Palliative Care Development

Community empowerment
Sufficient health system infrastructure
Collaborative generalist practice
Vision for change
Building community relationships
Building external linkages
Clinical Care
Education
Advocacy
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
Community development in end-of-life care

• A society wide approach to end-of-life care
• Communities reorient towards death, dying, loss and care and make a commitment to care for relevant experiences within social settings
• Schools, workplaces, church organizations and other social groups create policies and practices that respond to death, dying, loss and care
• People within communities promote activities that strengthen social capital (trust, empathy, cooperation) in relation to end-of-life care
Principles of Capacity Development

• Essentially builds on existing capacities within people, and their relationships

• An embedded process; it cannot be imposed or predicted

• Focus is initially about change, not performance

• 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)
While we cannot add days to your life, we can add life to your days.
Community Hospice Programs

- Day Away Hospice Programs
- In-Home Support
- Transportation
- Caregiver Respite & Support
- Bereavement Support
- Information & Referral
- Client Advocacy
- Volunteer Training and Support
- Community Education & Awareness
- Emerging “Hospice Home”
Service Sectors

Our 2010 Clients

- In-Home Volunteer Support
- Day Hospice
- Phone Support
- Transportation
- Information & Referral
- Bereavement Support

- 245 Clients served in 2010
- 114 clients benefit from two or more programs/services at the same time
- 136 caregiver/bereaved clients served, 25% more than the previous year
Each and every day, something to celebrate
Community of caring and sharing
Care for the Family Caregiver

If you, or someone you know could benefit from a “Caregiver Day Away”

- Where:
- Bus transportation provided, leaving at 8:15am from
- Please call
Caregiver Retreat
May 2011
Bereavement Support

- Care & Share Bereavement Retreat
- Care & Share Grief Walks
- Care & Share Open table lunches
- Telephone Support
- One-on-one Volunteer Support
- Information and Referral
Care & Share Bereavement Retreat
September 2011
United Way Day of Caring - RIM
Sharing community space; church, hospice, and government
Raising funds, engaging church, community, corporation, schools, government & media
Hospice Northwest Presents

Diealogues
Conversations on Life and Death

CONTACT US!
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WWW.HOSPICENORTHWEST.CA
Pallium Canada
“Death neither obeys the school timetable nor appears on it... it enters the classroom without knocking.”
Avoiding Death in Education

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)
What is a Compassionate School?

Our schools will have annually reviewed policies or guidance documents for dying, death, loss and care.

“As educators, we claim to prepare our students for life. We need to prepare them for death as well.”

(Ratner and Song, 2002)
The Compassionate Cities (CC) model

• An end of life care community application of WHO Healthy Cities model

• 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
What is The Compassionate City Charter?

A community that recognizes that all natural cycles of sickness and health, birth and death, and love and loss occur every day within the orbits of its institutions and regular activities is a compassionate city. Its residents recognize that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone’s responsibility.

The Compassionate City Charter is a framework of 12 social changes that lead communities towards being compassionate cities. This is an international initiative that was released May 2015.

1. **Schools** - Will have policies or guidance documents for dying, death, loss and care.
2. **Workplaces** - Will have policies or guidance documents for dying, death, loss and care.
3. **Trade Unions** - Will have policies or guidance documents for dying, death, loss and care.
4. **Churches and Temples** - Will have at least one dedicated group for End Of life (EOL) care.
5. **Hospices and Nursing Homes** - will have community development programs that focus on EOL care and will involve local area citizens.
6. **Museums and Art Galleries** - will hold exhibitions on the experience of ageing, dying, death and loss or care.
7. 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.”
8. 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.
9. 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.
10. All services and policies will demonstrate an understanding of **how diversity shapes** the experience of ageing, dying, death, loss and care.
11. We will encourage and support institutions for the **homeless and the imprisoned** to have support plans in place for EOL care.
12. 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.
Statistics:
Canadian Population (in general):
2013 = 36.2 M
2063 = 51.0 M

Canadian Population 65+:
2013 = 15.3%
2030 = 22.8%

Ontario Population:
Largest growth province.
2013 = 13.5 M
2038 = 14.8 M to 18.3 M

Burlington Population:
Total:
2006 = 165,415
2011 = 175,780
65+:
2006 = 25,355
2011 = 29,720 (↑ 17.2%)

Cost of EOL Care:
Hospital = $1100/day
Long-Term Care = $700/day
Hospice = $460/day
Home = $100/day

How does this tie into current plans and goals?
The Way Forward (TWF) Framework is a national plan for use at all levels of government. There are seven objectives required to achieve a system-wide shift in EOL care. Fifth on the list, creation of a caring community, is the aim of this charter.

How will this change palliative care?
Insert

How does this relate to current agendas?
Insert

How can you help Burlington achieve the Charter?
Insert


Glad to share this tool with others.
Contact Bonnie.

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CCC Update: Aim 2
Compassionate City Charter (CCC)

**Aim #2: Workplace**

- Currently working with the Burlington Chamber of Commerce to roll out a Compassionate workplace initiative.
  - **2 tier:**
    - **Tier 1** = Placing of key resources in staff manual and HR training on resources if needed.
      - Ex. Financial assistance from Service Canada
      - Ex. Employment rights Re. Job security
      - Ex. Key Palliative Care Resource contact numbers.
    - **Tier 2** = Working with CHPCA to Pilot “Canadian Compassionate Companies”
      - Company will receive the above designation upon completion of program requirements.

Bonnie Tompkins: Community Health Coordinator - commhlthcoord@thecarpenterhospice.com
• **Aim #4: Church/Tempses**
  
  o **6 Focus Groups** (1/ward) have been organized for June to start working towards this aim.
    - Working with Knights of Columbus & Catholic Women's League
      » This year’s current focus is “let no one die alone”
      • Helping to train volunteers for this and become a referral system.
  
  o **Education on Charter** and its ability to support better Palliative Care and the impact on Medical Assistance in Dying.

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• **Aim #8: Showcase Gov’t Policies**
  
  - **National** – Working with MP Pam Damoff to highlight CCC and how it will improve palliative care.
    - See [YouTube on May 2nd, 2016](https://www.youtube.com) for MP Pam Damoff to view her discussion.
  
  - **Provincial** – Working with Windsor on collection of common outcome measures.
    - Also recently assisting Grimsby’s McNally house with achieving the charter.
  
  - **Municipal** - Review of recent Strategic Plan update which will guide City of Burlington Until 2040.
    - Working with City to weave in, increased supports for palliative care at policy level.

Bonnie Tompkins: Community Health Coordinator - commhltchord@thecarpenterhospice.com
• **Aim #9: Media to ↑ awareness of Dying Process**
  - **Death Café** – Hoping to run our first one in July, **in a pub.**
  - **Palliative Care Blog**
  - **Weekly** Palliative care piece in the **local paper.**
  - **Launch week:** Oct 3-8, 2016
    - 8th being **World Hospice & Palliative Care Day**
      - tentative activities include:
        » Legacy work
        » Death café
        » Reflection room at the library
        » Movie night
        » Speaker
        » Education seminars
What next for Canada?

1. Legitimize what already exists at grassroots - make our “Compassionate Communities” initiatives explicit

2. Refresh our language; re-embrace social care

1. Engage Public Health in Canada - at all levels

2. Seek third sector partnerships/mobilization

3. Start policy discussions - locally, regionally, provincially

4. Performance and evaluation
What does the literature tell us?

- Difficult to use traditional methods to understand or measure health promotion or community development
- Outcomes and impacts are often hard to determine in advance
- Time frames can be long
- Beneficiaries can be unexpected

(Salnow, 2015)
What, practically, can we do?

1. Gain conceptual clarity
2. Role model, lobbyist, advocate
3. Assess readiness
4. Local-foster third sector mobilization ie service clubs
5. Regional- part of workplans and systems integration; public health colleagues
6. Provincial- a foundational component, public health partnerships
7. National- public health, part of national strategy
Bill's Story
Compassion: “The Heart of Humanity”

Community: “Where We call Home”
What does success look like...?

• A greater sense of ‘normalization’ around Death, dying, loss and bereavement

• Advanced care plans “done” well before they are needed

• Compassionate communities projects everywhere

• Culture shift drives policy change ie funding!

• “A healthcare provider is a poor excuse for a friend”
Dying and grieving are part of life.

Every British Columbian will have a personal advance care plan and access to responsive, quality care when dying or grieving.
Pallium Canada

A community of clinicians, carers, educators, academics, administrators, volunteers and citizen leaders working together throughout Canada to build palliative and end-of-life capacity as an integral part of a sustainable health system and caring communities.

Together we can make a Difference!
Building Communities of Care

Since 2001, Pallium Canada has been the sole national organization supporting continuing interprofessional palliative care education.
Our VISION

‘Every Canadian who requires palliative care will receive it early, effectively and compassionately’
Creating Caring Communities: LEAP as an agent of change
Learning Essential Approaches to Palliative Care

‘LEAP’ Courses for Different Settings

Active

LEAP Core (home/community)
Introduction to LEAP Mini
LEAP Oncology
LEAP Long Term Care
LEAP Paramedics
LEAP Undergraduate

In Development

LEAP Nephro
LEAP Emergency Dept.
LEAP Surgery
LEAP Heart
LEAP Non-Cancer
LEAP for Carers
LEAP Inner City

‘It’s Everybody’s Business’
E-Learning Resources Accessed in 2015

Pallium Canada Portal

Over **7500 Enrolled**

Doodles, Snippets and Communication Videos

Over **157,000** views

3444 Nurses
1257 Physicians
1260 Paramedics
138 Social Workers
53 Pharmacists
641 Others
400+ LEAP Facilitators
No! No!
Don't talk about it
In 2014, the Canadian Medical Association Journal conducted a review of the Pallium Palliative Pocketbook and declared that “there isn’t a clinical question in palliative medicine that this book can’t answer.” (May, 2015)

Over 25,000 sold

Available in Paper, E-book, English & French
Pallium Canada Resource App

Provincial Resources

- Ontario
- Quebec
- British Columbia
- Alberta
- Manitoba
- Saskatchewan
- Nova Scotia
- New Brunswick
- Newfoundland and Labrador
- Prince Edward Island
Our GOAL

Compassionate Communities

Empower Canadian communities to care for persons requiring palliative care and to support their families

- Compassionate Schools Program
- Compassionate Companies Program
- Workshops for carers
Join with Pallium Canada to
Mobilize YOUR Compassionate Community

Palliative Care is Public Health: Principles to Practice

International Public Health and Palliative Care Conference
September 17 - 20th, 2017
Ottawa, Canada

Of special interest to those committed to community engagement, social transformation and a Compassionate Canada
Tenants of Hope During Serious Illness

Found individually, or combined, across the course of all life-threatening or terminal illnesses.

1 Hope that tomorrow I might be better
2 Hope that I might find daily or weekly satisfactions
3 Hope that I might leave something of lasting value to others
4 Hope that I might survive or transcend the present suffering
Dame Cicely Saunders

"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."

Nurse, physician and writer
Founder of the hospice movement (1918 - 2005)
On behalf of Pallium Canada

Thank You

Please visit our website for Compassionate Communities @ pallium.ca