



**BC Centre for Palliative Care**  
The First 5 Years 2013 - 2018



“

Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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.

WORLD HEALTH ORGANIZATION DEFINITION

”



**Palliative Care focuses on the person and family affected by serious illness, not just the illness itself.**

**A palliative approach to care offers real opportunities to:**













- Enhance quality of life,
- Improve quality of care,
- Align care with the person's goals and wishes, and
- Improve the experience of patients and families.

#### **Provincial Action Plan to Improve Palliative and End of Life Care**

**Improving quality of life and outcomes for individuals living with serious illness and life-limiting conditions and their families has been a priority for the BC Ministry of Health** since the Provincial Framework for End of Life Care was announced in 2006. Several Ministry documents identify “increasing the capacity of individuals, community and health care services to cope with end of life challenges” as a key provincial priority to enhance care for our growing population of seniors and people living with complex medical conditions and frailty. Although only 2% of the population is coping with end of life issues this population accounts for over 35% of health services expenditures.<sup>1</sup>

<sup>1</sup> <http://www.health.gov.bc.ca/library/publications/year/2015/primary-and-community-care-policy-paper.pdf>

# Provincial End of Life Care Action Plan 2013

Priorities	Actions supported by BC Centre for Palliative Care	
A Redesign health services to deliver timely, coordinated End of Life (EOL) care	 01	Implement a population needs-based approach to planning EOL care services including early identification and quality care in the most appropriate setting
	 02	Integrate quality EOL care into service planning for all life limiting chronic diseases
	 03	Leverage opportunities to expand telehealth and telemonitoring
B Provide individuals, caregivers and health care providers with palliative care information, education, tools and resources	 04	Improve capacity to provide quality EOL care in residential care facilities & other housing/care settings
	 05	Increase public knowledge and awareness of palliative care as an approach to care at any stage in a serious illness
	 06	Provide information & resources to support advance care planning, including available options to ensure choices for EOL care are respected by health care providers
	 07	Provide awareness & education on the unique EOL needs of specialized populations
	 08	Promote excellence in EOL care including innovation and best practices and support for education
C Strengthen health system accountability & efficiency	 09	Develop and report on provincial EOL care service information and performance measures
	 10	Implement provincial EOL care clinical guidelines, protocols, and standards
	 11	Provide equitable access to BC Palliative Care Benefits Program (including in residential care)
	 12	Streamline policies & administrative processes used to improve access to services and supplies in a timely manner

**In March 2013 the Ministry of Health released the Provincial End of Life Care Action Plan with three key priorities:**

- Health system redesign to deliver timely, coordinated care at end of life;
- A focus on education and awareness of palliative care options and advance care planning, and
- Increased health system accountability for quality and efficiency of care at end of life.

Ministry priorities around improvements in end of life and palliative care in April 2013 also included a commitment to double hospice spaces throughout the province by 2020.

## Establishing the BC Centre for Palliative Care

To support implementation of the Provincial Plan, the Ministry provided two million dollars to the Institute for Health System Transformation & Sustainability (IHSTS) to establish a Centre of Excellence for end of life care. Based on input from key palliative care stakeholders in **June 2013, the BC Centre for Palliative Care was formed.**

## Stakeholder Consultation

**The inaugural Executive Director (Dr. Doris Barwich) initiated further consultation with stakeholders in 2014. The stakeholders recommended:**

- Integration of a palliative approach to care within the continuum of care
- Enhancing education for health care professionals
- Including patients, families and informal caregivers in the change process
- Measuring and evaluating care processes and outcomes, and
- Changing societal perceptions of palliative care

**Recommendations were consistent with global best practices** which had shown that, as well as building capacity with the health system, a larger public health focus was needed to ensure public education and mobilization of community-based support for people with serious illness and their caregivers. This required deep community engagement and support for partnerships with community-based organizations as well as public awareness and education.

**The recommended approach-integrating system level improvements with public health strategies-**would enable people living with serious illness to receive better care within the system and help them and their family caregivers feel more supported at home by their community.

**The Centre's role in this approach was to work collaboratively with community and health system partners to influence uptake of best practices in palliative care and enable transformation change to the way we live in and die in BC.**

**A strategic plan was developed and approved** by the Institute for Health System Transformation & Sustainability Board in September 2014.



# Strategic Plan 2015 - 2018



## WHO WE ARE

The BC Centre for Palliative Care (BCCPC) is a provincial, non-profit organization established in 2013 with funding from the Ministry of Health to support the implementation of the 2013 Provincial End of Life Care Action Plan and the commitment by the government to double hospice spaces.

BCCPC is located within the governance structure of the Institute for Health System Transformation & Sustainability (IHSTS) and supported by its Board of Directors.

**Our mandate** is to promote awareness and accelerate uptake of best practices in person-centred care for all British Columbians living with serious illness.

**Our team** are experts and leaders in palliative care and in broad system and social change as well as program implementation and evaluation. We engage, consult and collaborate with patient and family groups, health care providers and educators, local and provincial community-based organizations, health authorities, policy makers, researchers and others.

**We work with networks of partners** to enable system transformation through a collaborative, evidence-based approach.

## How do we make a difference?

We engage with our partners in four ways:



### Catalyzing:

identifying best practices and engaging in transformative conversations to implement, evaluate and spread evidence-based, innovative solutions with partners



### Convening:

bringing together system and community partners to identify and advance priorities



### Collaborating:

coordinating efforts and work in partnership with system and community partners across the province towards a collective impact



### Creating Capacity:

supporting partners with education, tools, resources, and coaching

## How was our funding invested?

In 2013, the BC Centre for Palliative Care was established through a **\$2 million** grant from the BC Ministry of Health.

- The grant was used to identify the Centre's strategic directions and priorities through stakeholder consultations, establish the Centre's infrastructure and support its ongoing operations and organizational development between 2013-2018.

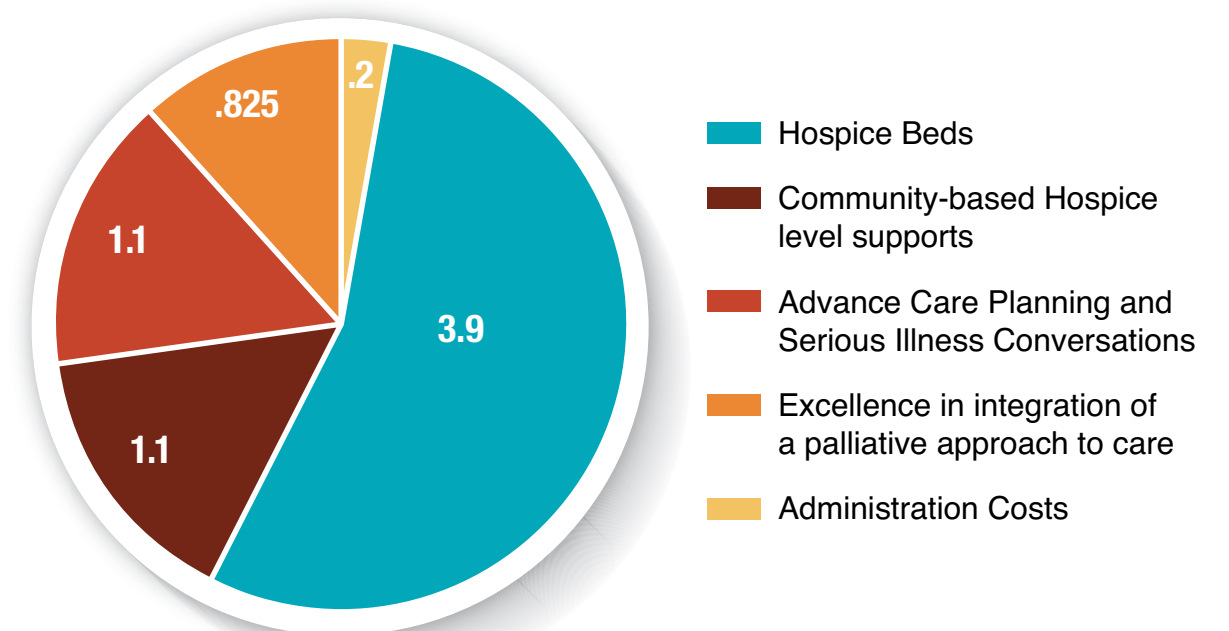
In 2015, the Centre received two additional grants from the BC Ministry of Health:

**\$ 5 million** to enhance access to hospice spaces and community-based care across BC in partnership with community-based organizations.

- \$ 3.9 million** awarded to hospice societies to support the development of **51 new hospice beds in partnership with Health Authorities,**
- \$ 1.1 million** used to enhance ***hospice level care and community-based supports*** through Seed Grants and mobilizing Compassionate Communities.

**\$ 2,125 million** to support best practices-based initiatives.

- \$ 1.1 M** used to support research, promote public awareness and engagement in **Advance Care Planning (ACP)** and enhance health care provider capacity for **Serious Illness Conversations,**
- \$ 825,000 for Education** of health care providers and development of tools and resources to promote excellence in palliative care and integration of a palliative approach to care,
- \$ 200,000 for project management and administrative supports.**





# Strategic Priority #1

Promote person-centred care for patients and families affected by serious illness



## We facilitate More, Better, Earlier Conversations that matter.

Most Canadians want a voice in decisions about their health and personal care, but often **Advance Care Planning** and **Serious Illness Conversations** that can inform these decisions are not happening.

### Advance Care Planning and Serious Illness Conversations help

- people get the care that is aligned with their wishes
- people avoid receiving non-beneficial or unwanted treatments
- reduce stress on families

### Our public poll in 2016 of 500 British Columbians told us that:

- **Only 28%** had heard about Advance Care Planning
- **49%** had talked with family about their health care wishes
- **27%** had documented their health care wishes
- **10%** had talked with their doctor about their health care wishes.

### We help British Columbians with serious illness to get the care that is right for them by:

1. **Enhancing public awareness and engagement** in Advance Care Planning,
2. **Training of health care providers** to initiate Serious Illness Conversations, and
3. **Working with various healthcare partners to inform policies and develop infrastructure** to facilitate consistent documentation of the person's goals and wishes.

## Advance Care Planning Initiative

*Our Goal is to enhance public awareness and engagement in Advance Care Planning.*

### What have we done?

- **Conducted 2 provincial surveys** to understand the level of awareness, knowledge and engagement in Advance Care Planning amongst British Columbians
- **Conducted current state analysis** including a review of Advance Care Planning policies and programs
- **Launched 3 Provincial Advance Care Planning Day campaigns**
- **Developed user-friendly public resources** about Advance Care Planning for the public
- **Developed toolkits for communities** to promote Advance Care Planning
- **Trained and supported community organizations** to deliver awareness activities
- **Conducted research and evaluation** to generate evidence of impact.

### Accomplishments in Numbers

- **Over 100 community volunteers** trained to facilitate Advance Care Planning sessions;
- **Over 4,000 public resources are being used across BC;**
- **Over 2500 British Columbians attended** Advance Care Planning sessions hosted by local community organizations;
- **Over 1400 Hello Game booklets** are being used by local communities across BC to stimulate Advance Care Planning conversations.

## What is it?

A process where you:

think about and share your values, beliefs and wishes, to

support informed health-care decisions making that

can help you get care that's right for you



### After attending Advance Care Planning sessions, British Columbians reported:

↑ **69%**

in knowledge of ACP concepts

↑ **76%**

in ACP conversations with those close to them

↑ **75%**

in ACP conversations with health care providers

↑ **46%**

in ACP conversations with substitute decision maker

### After playing the Hello game, British Columbians said:

**83%**

The game made the conversation more meaningful

**86%**

They intend to think more about their future healthcare wishes

**85%**

They intend to have more conversation with people close to them

## Serious Illness Conversation Training Program

*Our Goal is to help health care providers to initiate quality conversations with seriously ill patients and their families about their fears, wishes, goals and priorities for care.*

Through this Program, we train health care providers to use a structured guide to initiate conversations with seriously ill patients and families about their wishes, goals and priorities for care. Our evidence-based Program has been adapted from the Serious Illness Care Program of Ariadne Labs in Harvard Medical School.

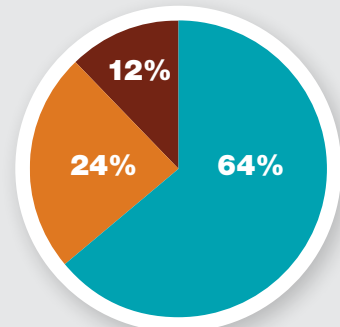


### What have we done?

- **Sponsored the training of 8 healthcare providers from BC at Ariadne Labs** to become Master Trainers so they can train other clinicians.
- **Hosted a roundtable consultation with over 60 decision makers and clinicians from across BC** which led to endorsement and support for a Provincial Serious Illness Conversation Training Program under the leadership of BC Centre for Palliative Care.
- **The Program offers:**
  - One-day Train-the-Trainer Workshops and
  - 2.5-hour Clinician Training Workshops.
- **Supported the integration of the Serious Illness Conversation Guide** into care provided to seriously ill patients in various care settings.
- **Developed an online module** of the workshop to support the training of clinicians based in rural and remote communities.
- **Facilitated training of undergraduate and postgraduate clinicians.**



### 1,300+ clinicians trained



■ Allied Health Professionals  
■ Physicians ■ Nurses



110

Facilitators  
trained



97%

of workshop attendees  
increased their knowledge of  
serious illness conversations



23

Master  
facilitators  
trained

## What they're saying



What British Columbians say  
about Advance Care Planning sessions.

I needed this [Advance Care Planning] session to motivate me to finally complete my advance care plan... my family and friends are grateful I've been to the session.

What British Columbians say about the Hello Game.

The questions [in the Hello Conversation game] get to the heart of being alive and finite. They are the questions everyone has before them and yet we never ask. I would highly recommend this game!



What trained clinicians say:

The Serious Illness Conversation Guide helped my patients think through what is important to them and feel less anxious and more in control.






*We provide provincial coordination for palliative care education, training, guidelines and resources.*

**We work closely with Pall Ed BC -** a network of palliative care educators, clinicians, researchers and operational leaders - **to educate and support health care providers to use the palliative approach to care** with patients who could benefit from it.


**What have we done?**

• **Developed Palliative Symptom Management Guidelines.** More than 100 clinicians, educators and policy makers from all health authorities, including the First Nations Health Authority, were involved in developing guidelines to support primary care providers with evidence-based best practices for common symptoms at end of life. The guidelines went through a rigorous literature search and review process and include Indigenous perspectives and adaptations for rural and remote settings. We launched this online resource in November 2017, with 15 evidence-based guidelines. **To date over 6,000 health care providers have accessed the guidelines on our and partners' websites.**


• **Coordinated LEAP Training for Health Care Professionals in BC** (Learning Essential Approaches to Palliative Care Training). In partnership with Pallium Canada and the regional health authorities in BC, we have trained 94 Facilitators to educate more than 1,800 health care professionals - nurses, physicians, pharmacists, social workers, paramedics, health care assistants, spiritual care practitioners in 44 BC communities, sharing practical knowledge on providing quality palliative care.



**94 FACILITATORS**



**44 BC COMMUNITIES**




**1,850 CLINICIANS TRAINED**


• **Developed Palliative Care Competency Framework.** We developed this framework to support widespread uptake of quality palliative care in all settings along the continuum of care, by defining the competencies health care providers need to deliver a consistent standard of excellence, with targets for education and training. We also reviewed available education and developed a resource guide for health authorities to use in choosing training materials.

• **Created a Community of Practice to Enable Uptake of Palliative Care in Long Term Care.** A group of 85 leaders come together to develop and share strategies, standards of practice and educational programs related to the integration of palliative approaches in long term care homes. The group was formed in support of the recommendations of a provincial scan which identified a need or coordination and support in this sector.


### Provincial Partners and Examples of Joint Activities




First Nations Health Authority  
Health through wellness



fraserhealth




Interior Health




island health




Provincial Health Services Authority  
Province-wide solutions. Better health.




Providence HEALTH CARE  
How you want to be treated.




northern health  
the northern way of caring




Vancouver Coastal Health  
Promoting wellness. Ensuring care.




- Early Palliative Integration into Cancer Care Project
- Palliative Care Committee (Member)
- Advance Care Planning Committee (Member)




- Paramedics providing palliative care at home



Provincial Health Services Authority  
Province-wide solutions. Better health.




Vancouver Coastal Health  
Promoting wellness. Ensuring care.




Providence HEALTH CARE  
How you want to be treated.

- Advance Care Planning documentation in electronic health records (Cerner Initiative)




BCRenal  
Provincial Health Services Authority

- Integrated Palliative Nephrology Working Group (Member)




BC PATIENT SAFETY & QUALITY COUNCIL  
Working Together. Accelerating Improvement.

- What Matters to You Day Program



British Columbia HOSPICE PALLIATIVE CARE Association

- BCCPC Seed Grants Program Planning Committee for BCHPCA annual conference (Member)



First Nations Health Authority  
Health through wellness

- Adaptation of Serious Illness Conversation Guide for First Nations

**National Partners and Examples of Joint Activities**



CANADIAN PARTNERSHIP AGAINST CANCER

- Palliative & End of Life Care Network (Member)
- Quality Committee Person-Centred Care (Member)
- ACP Working Group (Co-chair)



Canadian Hospice Palliative Care Association  
Association canadienne de soins palliatifs

- Advance Care Planning legal resources for Canadians
- National Advance Care Planning Framework
- Nurses Palliative Care Interest Group (Member)



Pallium Canada

- LEAP for BC Compassionate Communities Evaluation



Canadian Frailty Network

- Knowledge Translation Committee (Member)



CSPCP SCMSP  
Canadian Society of Palliative Care Physicians / Société canadienne des médecins de soins palliatifs

- Working Group on Models of Care (Member)



CARENET  
Canadian Researchers at the End of Life Network

- CARENET (Member)



## Research and Knowledge Exchange

We have led various provincial and national research and evaluation projects in partnership with academic researchers across Canada. The goal is to pilot innovative solutions and identify effective practices in advance care planning and access to quality palliative care.

We have shared our experience, learnings and knowledge gained from research and evaluation in over 20 provincial, national and international conferences.

### Examples of our research activities:

- **The iGAP research project** aimed to improve the quantity and quality of Advance Care Planning in primary care practices. The research project was funded by a Catalyst Grant from Canadian Frailty Network (2014 - 2016, Co-PI) to assess barriers and facilitators to Advance Care Planning, as well as developing and testing tools. The project was conducted in partnership with academic researchers and primary care providers in Ontario, Alberta and BC.
- **Research to assess the feasibility and efficacy of a community-delivered intervention** to educate and engage the public in Advance Care Planning. The research project was funded by a Catalyst Grant from Canadian Frailty Network (2016 - 2017, PI). We led this innovative approach, which has attracted national attention at the Canadian Foundation for Healthcare Improvement's (CFHI) CEO Forum Innovation Challenge (2017) and Canadian Frailty Network Innovation Showcase (2018). Our intervention trained community volunteers to facilitate public ACP workshops and was found to be:
  - **Effective:** Attendees had increased knowledge, skills and engagement in ACP activities
  - **Feasible:** Facilitators felt confident, energized and excited about their role
  - **Sustainable:** Community-based organizations benefited with increased profile and scope
- **A study that aims to improve the uptake of Advance Care Planning in primary care** settings using the Serious Illness Conversation Guide. The study is funded by a Transformation Grant from Canadian Frailty Network (2015-2020, Co-PI) and is conducted in partnership with academic researchers and primary care providers in Ontario and BC.

### Our research partners include faculty from:

- McMaster University
- McGill University
- University of British Columbia
- Simon Fraser University
- University of Victoria
- Trinity Western University
- University of Calgary
- Athabasca University



## We build **Compassionate Communities** where people

Have conversations  
about “How to  
live well to the  
end of life”



Support each  
other during  
illness, dying  
and loss



**Strategic  
Priority #3**  
Mobilize Citizen  
Engagement and  
promote  
Compassionate  
Communities

*We build supportive  
community networks for  
patients and families*



**The problem.** Stress, feelings of loneliness, and isolation are common parts of living with a serious illness for both the person and families. These experiences will continue to be more visible around as the number of seniors with chronic conditions is steadily increasing in BC



**A promising international solution.** A global **Compassionate Communities'** movement started in 2012 to inspire people to create supportive networks for individuals experiencing a health crisis, dying, or death. **Compassionate Communities in the United Kingdom and Australia have been successful** in building social connection and improving quality of life for people going through these experiences as well as reducing unnecessary visits to hospital.



**Mobilizing a Compassionate Communities movement in BC.** The **Compassionate Communities'** movement in BC was ignited in May 2015 with a visit from Dr. Allen Kellehear, the international leader of the movement. **Over 40 BC-based community organizations supported the idea** of mobilizing compassionate communities across the province.



**The Advisory Committee for the BC Compassionate Communities' Movement supported the Centre's plan** to mobilize the movement by raising up community champions who can play a leading role in enhancing public awareness and creating supportive networks.

**The Advisory Committee includes** BC Hospice Palliative Care Association, Family Caregiver of BC, BC Healthy Communities, BC Patient Safety and Quality Council and patient and caregiver representatives.

## Our role in the Compassionate Communities movement in BC

- We **educate, inspire and empower** community-based organizations to become Compassionate Community Champions.
- We **facilitate networking** of Compassionate Community Champions to spread successful ideas.
- **Through our Seed Grant Program**, we provide funding, training, toolkits and coaching for interested community organizations and groups.

### What have we done?

We funded and supported the implementation of:



**68 Compassionate communities' projects by  
48 Community-based organizations across BC.**

These organizations included hospice societies, disease support organizations, Neighbourhood Houses and faith-based organizations

### Examples of Compassionate Communities' projects in BC

**Compassionate Companions:** Training high school students in eight remote and First Nation communities to become compassionate companions for hospitalized patients awaiting placement in long term care.

**Compassionate City Crew:** Training volunteers to help people affected by serious illness who need support to stay at home. The role of the trained compassionate crew includes assessing the practical and psychosocial needs of the person, mapping of person's social circle, assigning tasks to individuals from the social circle, follow up home visits to ensure the person's needs are addressed.

**Grief Support:** Some community organizations used group dialogues and arts-based healing practices such as signing, arts and crafts to enable individuals to process intense grief and experience a sense of belonging and connectedness. Others trained volunteers to provide one-on-one support for individuals experiencing grief.

**Public Education and Training:** to engage and enhance the knowledge and skills of community members to help them support seriously ill people in their social circle.

**Compassionate City:** Community-wide efforts, led by the local Hospice Society, to effect 13 social changes listed in an international charter to enable recognition of New Westminster as a Compassionate City. The initiative has the support of city council, local MPs and MLAs, and is connecting with local businesses and community groups to make this a reality.



## BC COMPASSIONATE COMMUNITIES IN NUMBERS

- **68 projects** implemented by 48 organizations across BC:

**32 PROJECTS**

on Advance  
Care Planning

**25 PROJECTS**

on Compassionate  
Care & Support

**11 PROJECTS**

on Palliative Care  
Awareness



**50%** in rural  
communities



**221** tools developed  
by communities

- **Over 6,300** British Columbians reached:



ADVANCE CARE  
PLANNING



COMPASSIONATE  
CARE



PALLIATIVE  
CARE EDUCATION

over **3,030**

over **1,850**

over **1,420**

### Compassionate Communities Champions Say:

**“ We are appreciating the partnership – to be connected to the larger picture. To be part of a solution helps us to realize we are not alone and that together we are making a difference at the provincial level.”**

— North Okanagan Hospice Society

**“ This grant in a box, with its tools, training, coaching and resources, made it easy. This program is our biggest asset. We host sessions at the local library every month as well as sessions for First Nation's communities, nursing and social work students.”**

— Terrace Hospice Association



## FIVE YEARS AT A GLANCE

Over the past five years, the BC Centre for Palliative Care has worked hard to help British Columbians living with serious illness achieve the best quality of life possible.

**We have been successful in establishing collaborative working relationships with a large network of partners within the health system and in the community, across the province and beyond.** Through this network we helped improve access to palliative services and mobilized citizens and communities to become more resilient and supportive for patients and families.

**We helped create 51 new hospice beds in communities around BC and supported improvements to expand access to hospice spaces.**

**We enabled thousands of healthcare professionals to integrate the palliative approach and serious illness conversations into their routine care.**

**We are accelerating the uptake of best practices in the Palliative approach to care and Advance Care Planning in different care settings through partnership projects with BC Cancer, BC Renal Agency, BC Emergency Health Services and regional health authorities.**

**We have succeeded in developing and spreading innovative ideas and user-friendly resources to increase public awareness and uptake of Advance Care Planning including:**

- **Our Hello Game and ACP Day Campaigns reduced stigma and stimulated conversations in communities throughout BC**
- **We trained hundreds of community volunteers and organizations and provided toolkits and coaching to organizations to enable communities to host Advance Care Planning sessions and empower people to advocate for care aligned with their wishes.**

**We inspired and supported 68 Compassionate Communities' projects in urban, rural and remote regions.** We made more British Columbians aware of the psychosocial issues and non-medical needs associated with aging and serious illness and helped communities to be well prepared to address these issues and support patients and families to live well at home.

**Our partnership with academic researchers and institutions across Canada have enabled us to identify best practices, pilot promising innovations and rigorously evaluate our work.**

**The significant reach and remarkable impact of the Centre's efforts led to national recognition of our initiatives as innovative interventions that should be spread nationally.**

**The BC Centre for Palliative Care would like to offer special words of thanks to our healthcare and community partners, the IHSTS Board of Directors, the BC Ministry of Health and the patients and family members who participated in our advisory and working groups.**

**All have contributed to our success** by enriching the BC Centre for Palliative Care with their valuable expertise, informative perspectives, and lived experience.

**In the coming years, we will continue to build on this momentum of collaborative work and success. Our plan is to expand our research and practice networks and our reach to underserved populations such as First Nations and culturally diverse communities.**





## BC Centre for Palliative Care Team



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Director
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Ministry of Health Liaison







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*All British Columbians affected  
by serious illness will have equitable  
access to compassionate,  
person-centred care and resources.*

