



# 5<sup>th</sup> International Public Health & Palliative Care Conference

## Palliative Care is Public Health: Principles to Practice

2017 CONFERENCE SYLLABUS



September 17 - 20, 2017

Ottawa Conference and Events Centre • [www.iphpc2017.com](http://www.iphpc2017.com)

**PHPCI**

Public Health and Palliative Care International  
Developing Compassionate Communities



# Welcome!

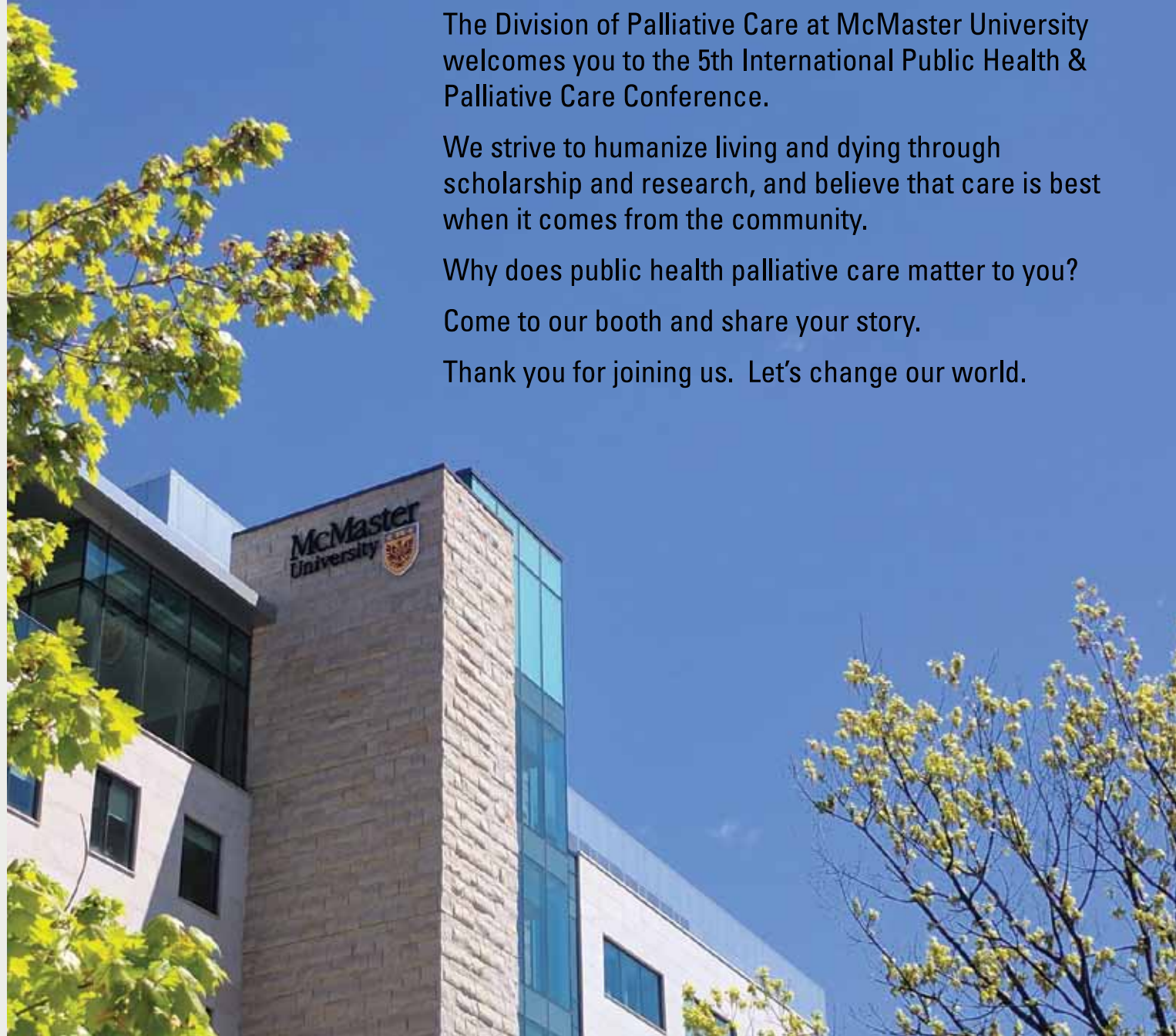
The Division of Palliative Care at McMaster University welcomes you to the 5th International Public Health & Palliative Care Conference.

We strive to humanize living and dying through scholarship and research, and believe that care is best when it comes from the community.

Why does public health palliative care matter to you?

Come to our booth and share your story.

Thank you for joining us. Let's change our world.



Learn more at [www.fhs.mcmaster.ca/palliativecare](http://www.fhs.mcmaster.ca/palliativecare)



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PRIME MINISTER • PREMIER MINISTRE

September 17–20, 2017

Dear Friends:

I am pleased to extend my warmest greetings to everyone attending the 5th International Public Health and Palliative Care Conference.



This event brings together public health and palliative care professionals from across Canada and around the world to share their ideas and experiences. I am certain that everyone in attendance will benefit from the wide variety of speakers, workshops and presentations planned for the conference, and will leave inspired to put what they have learned into practice.

I would like to thank the organizers of this event for putting together a stimulating and informative program, and for providing delegates with a unique learning and networking opportunity.

On behalf of the Government of Canada, please accept my best wishes for an enjoyable and productive conference in Ottawa.

Sincerely,

The Rt. Hon. Justin P. J. Trudeau, P.C., M.P.  
Prime Minister of Canada

September 17, 2017

On behalf of the Program Planning Committee for the 5th International Public Health and Palliative Care Conference 2017, it is our profound pleasure to welcome you to Canada, our wonderful country, and to Ottawa, our beautiful capital city! With deep respect we acknowledge that we are gathering on the unceded territory of the Algonquin people and thank them for welcoming us.

Canada is at its heart, a vast mosaic of communities and peoples. It is here that our beloved Dr. Balfour Mount, Canada's "father of palliative care" initiated the phrase "palliative care" to describe the way a caring society can and should surround its people with care when their health becomes fragile. We have a long history of such care across this land, as our first nations people have demonstrated for countless generations. Now, as we mark the 150<sup>th</sup> anniversary of the confederation of this country we now call Canada, we are mindful of our many strengths as we share our health-promoting palliative care successes with the world. and open ourselves to learn from and with the global community about their accomplishments and successes. It is our hope that a deeper understanding of palliative care as public health and strong connections will develop as a result of this conference. Together, we will continue to advance this movement both nationally and globally.

Our successful bid to bring PHPC17 to Canada and the planning of this conference was a great example of participatory partnerships! We extend our deepest thanks to our Canada-wide planning committee, and to our conference partners Pallium Canada, the International Association of Hospice Palliative Care, our academic partner McMaster University Division of Palliative Care, and to our main conference partner and logistics team, the Canadian Hospice Palliative Care Association.

Thank you for joining us, eh!

**Denise Marshall, MD**  
Program Planning Chair

**Kathy Kortés Miller**  
Program Planning Co- Chair



**Jim Watson**  
Mayor/Maire

**Office of the Mayor**  
City of Ottawa

110 Laurier Avenue West  
Ottawa, Ontario K1P 1J1  
Tel.: 613-580-2496  
Fax: 613-580-2509  
E-mail: Jim.Watson@ottawa.ca

**Bureau du Maire**  
Ville d'Ottawa

110, avenue Laurier Ouest  
Ottawa (Ontario) K1P 1J1  
Tél. : 613-580-2496  
Télééc. : 613-580-2509  
Courriel : Jim.Watson@ottawa.ca

On behalf of Members of Ottawa City Council, it is my distinct pleasure to extend a warm welcome to all those participating in the 5<sup>th</sup> **International Public Health and Palliative Care Conference**, co-hosted by the **Canadian Hospice Palliative Care Association (CHPCA)**, **Public Health and Palliative Care International**, **McMaster University Palliative Care Division**, **Pallium Canada**, and the **International Association for Hospice and Palliative Care (IAHPC)**, and taking place at the Ottawa Conference and Event Centre from September 17<sup>th</sup> to 20<sup>th</sup> 2017.

I am delighted that Ottawa has been selected as the host city for this international gathering providing a valuable forum for public health and palliative care professionals to convene under the theme **Palliative Care IS Public Health: Principles to Practice**. Delegates will benefit from networking opportunities, as well as share knowledge and experiences pertaining to hospice palliative care.

As Head of Council, I want to acknowledge the co-hosts, keynote speakers, sponsors, facilitators and exhibitors for dedicating efforts, expertise and resources to the successful organization of this educational meeting.

As Mayor of the host city, I invite visitors to explore the revitalized Lansdowne park, its restored heritage pavilions, and new TD Place, home of the Ottawa REDBLACKS CFL team, and Ottawa Fury FC United Soccer League team.

Canada celebrates its 150<sup>th</sup> birthday in 2017 and the grandest festivities will be unfolding in Ottawa. I hope you will find time to enjoy our nation's capital for the sesquicentennial anniversary.

Allow me to convey my best wishes to the participants for a very productive conference and to the visitors for a most enjoyable stay in Ottawa.

Sincerely,

J'ai l'immense plaisir de souhaiter, au nom des membres du Conseil municipal d'Ottawa, la plus cordiale bienvenue à toutes les personnes qui participeront au 5<sup>e</sup> **Congrès international sur la santé publique et les soins palliatifs**, organisé conjointement par l'Association canadienne de soins palliatifs (ACSP), le groupe **Public Health and Palliative Care International**, la Division des soins palliatifs de l'Université McMaster, Pallium Canada et l'IAHPC - **International Association for Hospice and Palliative Care**. Ce congrès se déroulera au Centre des conférences et événements d'Ottawa du 17 au 20 septembre 2017.

Je suis ravi que la ville d'Ottawa ait été choisie pour accueillir ce colloque international qui offre aux professionnels de la santé publique et des soins palliatifs un cadre précieux leur permettant de se rassembler sous le thème **Les soins palliatifs SONT la santé publique : des principes à la pratique**. En plus des possibilités de réseautage dont profiteront les délégués, ceux-ci pourront partager leurs connaissances et leurs expériences relatives aux soins palliatifs.

En tant que chef du Conseil, je tiens à remercier les organismes-hôtes, les conférenciers, les commanditaires, les animateurs et les exposants pour les efforts, le savoir-faire et les ressources qu'ils ont consacrés à l'organisation de cette rencontre éducative pour en assurer la réussite.

À titre de maire de la ville hôte, j'invite les visiteurs à explorer le parc Lansdowne, qui a récemment fait peau neuve, ses édifices patrimoniaux restaurés, de même que la nouvelle Place TD, domicile du ROUGE et NOIR d'Ottawa, équipe de la Ligue canadienne de football, et du Fury FC d'Ottawa, équipe de la United Soccer League.

L'année 2017 marque le 150<sup>e</sup> anniversaire du Canada et les festivités les plus grandioses se dérouleront à Ottawa. J'espère que vous trouverez le temps de profiter des attraits de notre capitale nationale à cette occasion.

Permettez-moi de souhaiter aux participants un congrès des plus productifs et aux visiteurs, un séjour des plus agréables à Ottawa.

Meilleures salutations.

  
Jim Watson, Mayor/Maire

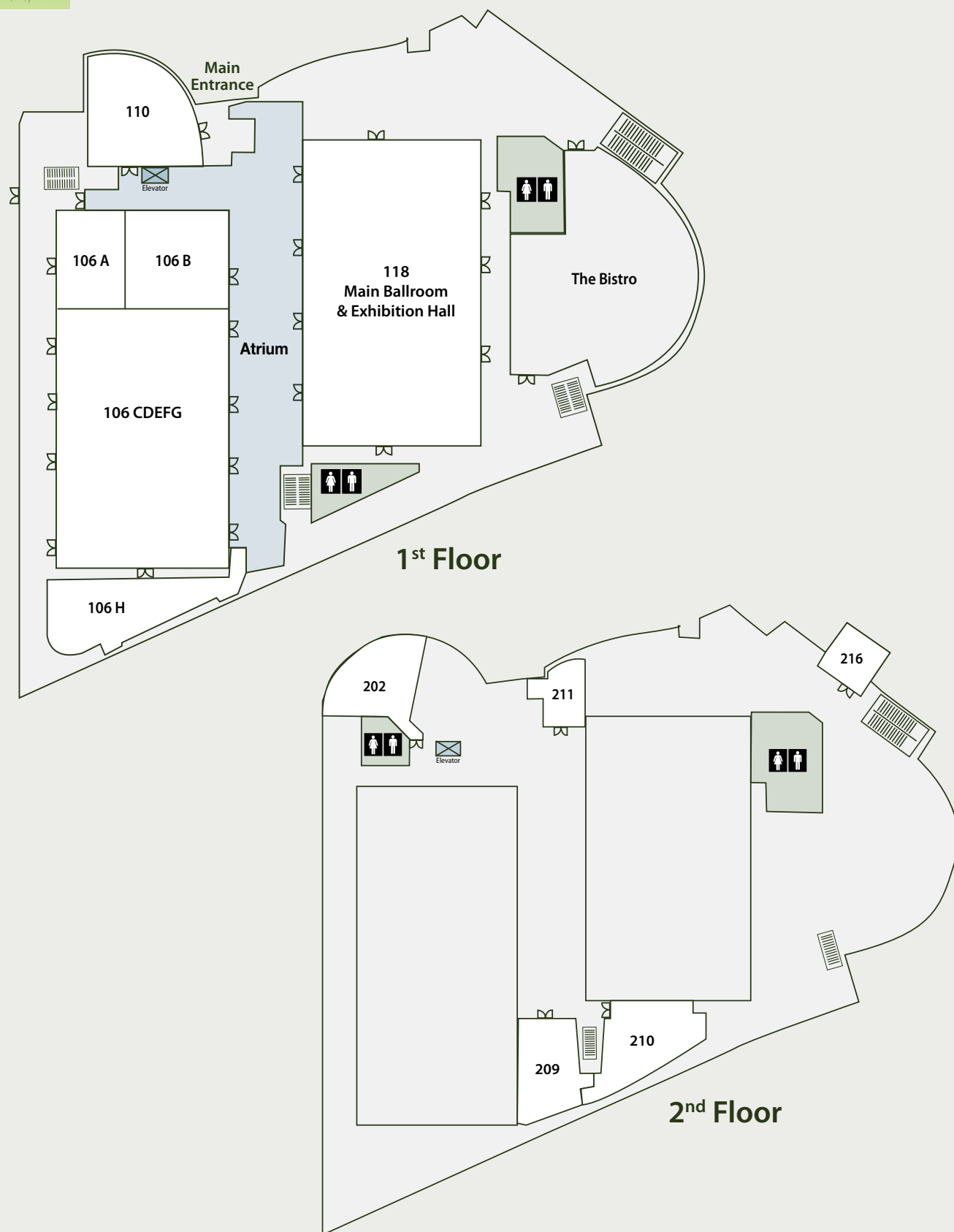


**Schedule-at-a-glance**

TIME	SUNDAY, September 17	MONDAY, September 18	TUESDAY, September 19	WEDNESDAY, September 20
07:30		Refreshment Break	Refreshment Break	
08:00				
08:30				Interactive Workshops
09:00		Welcome & Housekeeping Plenary	Plenary	
09:30				
10:00				Refreshment Break Poster Viewing, Fireside Chats
10:30		Refreshment Break Poster Viewing, Fireside Chats	Refreshment Break Poster Viewing, Fireside Chats	Closing Plenary
11:00		Interactive Workshops	Interactive Workshops	
11:30				Announcements from PHPCI
12:00		Networking Lunch	Networking Lunch	
12:30				
13:00	Registration Open	Oral Presentations	Oral Presentations	
13:30				
14:00				
14:30		Refreshment Break Poster Viewing, Fireside Chats	Refreshment Break Poster Viewing, Fireside Chats	
15:00		Plenary	Plenary	
15:30				
16:00	Welcome & Introductions			
16:30	Opening Panel		Host Country Pitches	
17:00		Community Engagement Evening		
17:30			Reception	
18:00	Reception & Networking Opening of Posters & Exhibits			
18:30			Evening Gala: A Canadian Themed Evening of Entertainment	



## Conference Centre Floorplans



## Thanks & Acknowledgements

The 2017 International Public Health and Palliative Care Conference would like to take a moment to recognize the willing hands, big hearts and minds of the volunteers who continue to generously donate their time to ensure a successful and well-planned Conference. Many of the volunteers who worked to create this event will be present on-site to ensure the smooth running of the Conference. Others have worked behind the scenes for more than a year to provide a top-notch experience for delegates.

*Our thanks goes to them all!*

### Program Committee

Denise Marshall  
 Kathy Kortés-Miller  
 Sharon Baxter  
 Kim Martens  
 Bonnie Tompkins  
 Kathryn Downer  
 Eman Hassan  
 Emilio Herrera  
 Erin Gallagher  
 Ian Culbert  
 Julian Abel  
 Kerrie Noonan  
 Kevin Miller  
 Mary Lou Kelley  
 Odete Carreira  
 Ross Upshur  
 Doris Barwich

### Abstract Review Committee

Alan Taniguchi  
 Anne Boyle  
 Bonnie Tompkins  
 Dan Malleck  
 Denise Marshall  
 Eman Hassan  
 Emilio Herrera  
 Erin Gallagher  
 Hilary Mettam  
 Jenna Garlick  
 Joshua Shadd  
 Kathryn Pfaff  
 Kathy Kortés Miller  
 Kevin Bezannson  
 Kevin Miller  
 Kimberly Ramsbottom  
 Kirsten Wentlandt  
 Mary Lou Kelley  
 Maryse Bouvette  
 Michelle Howard  
 Rosemary Leonard  
 Ross Upshur  
 Srin Chary

### Planning Committee

Denise Marshall  
 Kathy Kortés-Miller  
 Sharon Baxter  
 Kim Martens  
 Bonnie Tompkins  
 Kathryn Downer  
 Cheryl Spencer



# General Information for Participants

PLEASE SEE FLOORPLAN ON PAGE 6 FOR ROOM LOCATIONS

### Scent-Free Event

Out of consideration for fellow attendees who may have allergies, please refrain from using / wearing aerosol products, perfumes, cologne or other strong fragrant products.

### Refreshment Breaks

All Refreshment Breaks will take place in the Main Ballroom 118 of the Conference Centre. Please refer to the 'Schedule at a Glance' on page 4 for specific times.

**Breakfast:** A light Continental Breakfast will be served on Monday and Tuesday morning at 07:30 in the Main Ballroom 118.

**Lunch:** Lunch will be served on Monday and Tuesday at 12:15 in the main Ballroom 118, then eaten in room 106 CDEFG.

### Information Desk

The information desk, located near the registration area, in the Atrium of the Conference Centre, is

available for general inquiries, lost and found, and restaurant and tourist information.

### Admission to Events

Your name badge is required for admission to all sessions and events. Your ticket is required for admission to the Gala.

### Speaker Ready Room

Presenters should report to the speaker ready room no less than two hours before their scheduled presentation time to upload a copy of their PowerPoint presentation. The speaker ready room is located in Room 216 of the Conference Centre.

### Welcome Reception

The opening of exhibits and posters is being held on Sunday from 18:00 to 20:00. This event will take place in the Main Ballroom of the Conference Centre. Please take this opportunity to visit the many conference exhibitors and view the conference poster presentations. Limited light snacks will be provided.

### Community Engagement Evening

Monday from 17:30 to 20:00: An evening open to the public as well as conference registrants covering community engagement topics. Location: Room 106 CDEFG.

### Gala – A Canadian Themed Evening of Fun

Come together on Tuesday, September 19<sup>th</sup> from 17:00 to 22:00 for a Canadian themed evening of fun! While enjoying a sit-down dinner, network with other compassionate community leaders to celebrate the exceptional individuals who dedicate their lives to providing extraordinary humanitarian help, care and service to those in the field of public health and palliative care. Location: Room 106.

### Exhibit Hall

Please take time over the next few days to visit the Exhibit Hall in the Main Ballroom of the Conference Centre, to meet with our many conference exhibitors and sponsors. Also visit the poster exhibits located throughout the Main Ballroom.

### Posters

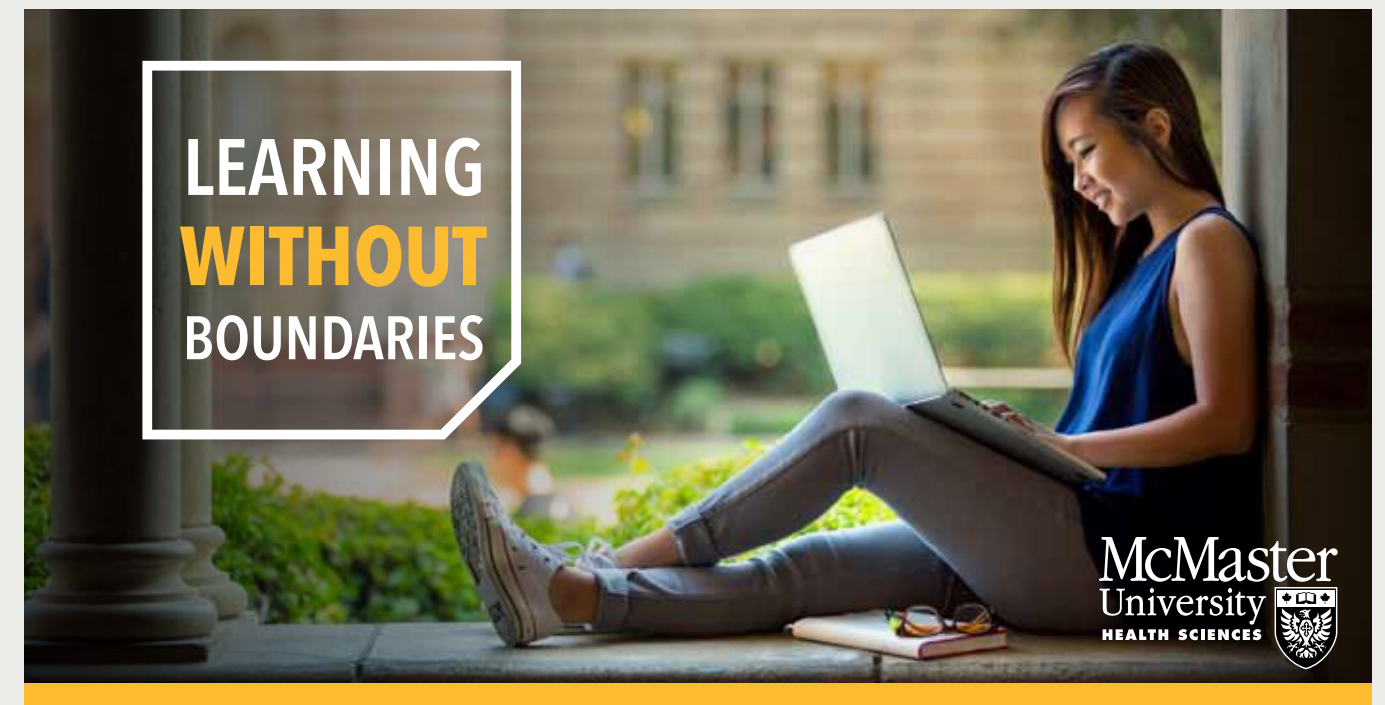
Posters representative of the conference streams will be on display in the Main Ballroom 118 of the Conference Centre, starting Sunday at 18:00. Authors of posters will be available during the opening reception from 18:00 on Sunday. Please refer to page 36 of this syllabus for a listing of the poster presenters.



# Exhibitors

Please visit the conference exhibitors located in the Main Ballroom 118. The exhibition opens at 18:00 on Sunday, September 17 and runs throughout the conference.

Name	Booth Number
Pallium Canada .....	203, 205
CARF .....	207
Life and Death Matters .....	209
Canadian Virtual Hospice .....	211
McMaster University .....	302 & 304
Canadian Hospice Palliative Care Association .....	303 & 305
Department of Health Research Methods, Evidence and Impact .....	306
African Contingency .....	307
Room 217– Care Through Music .....	308
BC Centre for Palliative Care .....	309
National Initiative for the Care of the Elderly (NICE) .....	310
Saint Elizabeth Reflection Room – Room 211 (2 <sup>nd</sup> floor, see floorplan on page 6)	



[Mc]Master of Public Health  
fhs.mcmaster.ca/ceb/mph/

PhD in Health Policy  
fhs.mcmaster.ca/hpphd/



## Our Supporters

### Partner Level



#### International Association for Hospice and Palliative Care

IAHPC is a global non-profit, membership organization dedicated to the development and advancement of palliative care to assure that any patient's and family caregiver's suffering is relieved to the greatest extent possible.

IAHPC works with UN agencies, governments, associations and individuals, to develop and implement appropriate policies for the inclusion of palliative care as a component of Universal Health Coverage; increase access to essential medicines for palliative care; foster opportunities in palliative care education, research and training; and increase service provision around the globe.



#### McMaster University

The Division of Palliative Care in the Department of Family Medicine at McMaster University is an interprofessional academic body dedicated to the vision of humanizing living and dying in our community. We are a team of academic clinicians, researchers, and administrators who are

leading the development of palliative care at the primary, secondary and tertiary levels in our region and beyond. We are committed to our communities, and believe that interprofessional collaboration is fundamental to the care of individuals, the education of our learners and the design of our health care systems.



#### Pallium Canada

Pallium Canada is a not-for-profit, internationally recognized, pan-Canadian organization that has been at the forefront of developing, testing and implementing strategies to increase primary-

level palliative care. It takes the approach that palliative care is everyone's business, not just the responsibility of a small number of palliative care specialist physicians and nurses. It has, for example, developed workshops and tools for doctors, nurses, pharmacists, emergency first-responders and other health care professionals that work across different settings - from home and community to long term care and hospitals. Pallium's work with mobilizing Compassionate Communities builds upon Pallium's model of the Continuum of Compassionate Care.



#### Canadian Hospice and Palliative Care Association

The CHPCA is the national voice for Hospice Palliative Care in Canada. Advancing and advocating for quality end-of-life/hospice palliative care in Canada, its work includes public policy, public education and awareness. Established in 1991, its volunteer Board of Directors

is composed of hospice palliative care workers and volunteers from Canadian provinces and territories as well as members-at-large.

### Dignity Level

#### Department of Health Research Methods, Evidence, and Impact

The Department of Health Research Methods, Evidence, and Impact (HEI) conducts world-leading research into the nature, prevention and management of health care problems. HEI is where evidence-based medicine got its start, and where modern-day clinical epidemiology came into its own.



#### About Saint Elizabeth - The Reflection Room

We invite you to visit The Reflection Room to pause, reflect and share your experiences with dying and death.

Does an experience stand out in your memory? Have you been inspired by others? Have you had experiences with family members or friends? Add your reflection to the Reflection Wall and see the collective story that we all are building.

The Reflection Room is a project led by the research team at Saint Elizabeth, a national health care provider supporting residential hospice, education and research. The Reflection Room leverages the power of shared storytelling and experiential design to engage people in thinking and talking about end of life. We are studying whether reflection and storytelling are positive for people who have experienced a death and whether reading the stories of others helps in thinking about dying and death.

Come visit the Reflection Room in **room 211**, opening Sunday, September 17 at 13:00 and closing Friday, September 22, at 19:00.

Visit us online at [thereflectionroom.ca](http://thereflectionroom.ca); [saintelizabeth.com/research](http://saintelizabeth.com/research)



## Program Guide

### Sunday, September 17, 2017 *See floorplan on page 6 for locations*

#### 13:00 REGISTRATION OPENS

Location: Atrium

#### 16:00 - 16:30

#### Welcome and Introductions

Greetings from Public Health Palliative Care International presenter, Dr. Allan Kellehear

Location: Room 106 CDEFG

#### 16:30 - 18:00 – OPENING PANEL

#### Public Care as Public Health?? Really??

Panelists: Dr. Alex Jadad, Canada; Dr. John Rosenburg, Australia; Dr. Allan Kellehear, United Kingdom;

Dr. Denise Marshall, Canada; Dr. Shadaduz Zaman, United Kingdom

Location: Room 106 CDEFG

#### 18:00 - 20:00

#### Reception and Networking

Location: Main Ballroom 118

#### Opening of Posters and Exhibits

Location: Main Ballroom 118

### Monday, September 18, 2017 *See floorplan on page 6 for locations*

#### 07:30 – 09:00 REFRESHMENT BREAK

Location: Main Ballroom 118

#### 09:00 - 09:15

#### WELCOME AND HOUSEKEEPING

Location: Room 106 CDEFG

#### 09:15 - 10:30 – PLENARY

#### Theme 1: Building Public Policies that Support Health (Public Policy) – “What Makes a Problem a Public Health Issue? The Case for Palliative Care”

Presenter: Ross Upshur

Location: Room 106 CDEFG

In this presentation, presenter, Ross Upshur will argue that ethical and evidential considerations lead to the inescapable conclusion that the mission of public health necessarily entails a deep commitment to palliative care. He will demonstrate this by linking the core mission of public health to the core mission of palliative care. Ross will draw on recent thinking in health systems thinking, particularly the integration of population health with health systems and the overarching concern with health equity to show that the future of both palliative care and public health are closely aligned.

#### 10:30 - 11:00 REFRESHMENT BREAK

Location: Main Ballroom 118

#### POSTER VIEWING *(please see page 36 for a complete list of Poster Presentations)*

Location: Main Ballroom 118

#### FIRESIDE CHATS *(location to be announced)*

#### Dying Homeless in Canada – the Vision of PEACH

Presented by: Dr. Naheed Dosani

#### Mobilizing at a Provincial Level in Canada

Presented by: Dr. Eman Hassan and Dr. Doris Barwich

#### 11:00 - 12:15 – INTERACTIVE WORKSHOPS

*NOTE: This time slot contains 1 x 60 minute workshop*

#### Lessons We are Learning: Using Participatory Action Research to Integrate Palliative Care, Health Promotion and Public Health through the Döbra

Presented by: Carol Tishelman, Olav Lindqvist, Ida Goliath

Location: Hampton Room 1

Public health and health promotion approaches to end-of-life (EoL) research and care are still rare in Sweden. People remain generally ill-prepared for encounters with death and unable to advocate for quality EoL care; this may be reflected in Sweden's low scores for community engagement in the 2015 Quality of Death index. We have consolidated our endeavors into a cohesive national transdisciplinary research program, DöBra (a pun meaning both 'dying well' and 'awesome' in Swedish). In DöBra, we investigate how culture, the environment and conversation can promote constructive change and support better quality of life and death among the general population, in specific subgroups and in interventions directed to staff caring for dying individuals, their friends and families. DöBra uses ideas from new public health and the Ottawa Charter as umbrella theoretical frameworks and participatory action research as an overarching methodological approach. *(continues on next page)*

WKSP

In DöBra we aim to achieve change in communities in a broad sense. In this interactive workshop, we therefore focus on the particular challenges we encounter in conducting stringent research when trying to catalyze, rather than control, change processes. We will share our ideas, experiences, reflections, tools and approaches as well as results, related to using a variety of strategies to bring together a broad range of stakeholders to co-create experience-based evidence through innovative approaches. We begin by linking theory, research and practice through discussion of the overarching ideas and individual projects, with the second part of the session based on audience engagement with various tools used in DöBra.

**NOTE: This time slot contains 1 x 60 minute workshop**

WKSP

### Embracing Life – The Bethlehem Schools’ Project, an “Icebreaker” and “A Foot in the Door”

**Presented by:** Mary Hocking, Andrea Grindrod

**Location:** Hampton Room 2

This workshop details a Partnership involving a High school, a Hospital (Calvary Health Care Bethlehem), La Trobe University and Palliative Care Victoria which seeks to support Community Capacity and resilience in dealing with Life-Limiting illness, death, dying and Loss.

This alliance has produced an educational resource which may be used, not only as a tool to normalize death, but also as a means of exploring ‘keys to well-being’ at any stage of life, through any loss or challenge.

This workshop features a template which has been trialed, adapted and evaluated in High School, workshop and Hospital induction settings within Australia.

Responses thus far have been “overwhelmingly positive”.

Translating evidence of positive outcomes into Education & Health Care Systems, is a challenge – This workshop offers a means of approaching both.

The conclusion of the workshop provides a number of insights:

- Engaging communities in discussions about well-being and harnessing the insights of youth is a palatable means of discussing well-being at end-of-life.
- What we know, as a community about supporting people with life-limiting illness is applicable across the span of life – not just at the end.
- Just as it takes a village to raise a child – it takes a village to ensure a quality end-of life experience.

What began as a one-off hospital immersion for Secondary School students, has grown to become a sustainable educational resource, applicable across a number of domains – with the capacity to become an evidence-based means of increasing community EOL capacity.

**NOTE: This time slot contains 1 x 60 minute workshop**

### Linkage Strategies for Successful and Sustainable Partnerships: A Practical Framework for Community Engagement by Palliative Care Services

WKSP

**Presented by:** John Rosenberg, Wendy Gain

**Location:** Room 106 A

Partnerships are central to the success of linkages between palliative care services and the communities they support. The goal of partnership is to achieve more than individuals and groups can achieve on their own, yet the concept is often poorly understood. A clearly articulated understanding of partnership is a powerful step in transforming an organization's engagement with the community.

The aim of this workshop is to enable participants to gain a clear understanding of partnership, understand the recognized evidence-based principles of establishing and maintaining partnerships, and identify practical approaches to partnering to take back to their organizations and communities.

**NOTE: This time slot contains 1 x 60 minute workshop**

### A New Method for Developing Compassionate Communities and Cities Movement: “Todos Contigo” Programme (We are All With You): Experiences in Spain and Latin America Countries

WKSP

**Presented by:** Dr. Emilio Herrera Molina, Tamen Jadad García

**Location:** Room 106 B

Todos Contigo (We are All With You) is a social awareness, training, and implementation network of care programme for citizens to support, accompany and care for those who face advanced chronic disease and end of life situations. From New Health Foundation this programme collaborates with the Public Health and Palliative Care International Charter of Compassionate Communities. It seeks to promote a new integrated palliative care model in the daily lives of individuals, to make families and health/social professionals the main promoters of compassionate communities and cities movement.

New Health Foundation has developed a new methodology for the development of Compassionate Cities.

The method has defined resources, tools and steps for developing compassionate communities that will increase public health and palliative care knowledge and a series of indicators for structure, processes and results that allow us to measure the impact of the implementation in compassionate cities.

This poster will give an overview of the map of Spanish and Latin American cities that have joined the movement. At the moment (January 2017) the following cities are involved: Seville and Badajoz in Spain; Cali, Medellín, Fasagasugá, Bogotá and Buenos Aires in Latin America.

**NOTE: This time slot contains 1 x 60 minute workshop**

WKSP

### The Social Determinants of Health in Life and Death: Research and Promising Practices in Three Canadian Cities to Improve Access to Palliative Care for Structurally Vulnerable People

**Presented by:** Ashley Mollison, Naheed Dosani, Simon Colgan, Sonya Jakubec

**Location:** Room 106 H

People who experience a deficit in the social determinants of health (SDOH) including inadequate housing, poverty, and racialization, as well as high rates of mental health and substance use, and stigmatization of diseases such as HIV/AIDS, are often underserved by current palliative care services. “Structurally vulnerable” people have fewer social supports, lack financial resources, adequate and ‘safe’ housing for formal care provision, and often die in places that do not meet their unique needs, alone, or in the care of workers who have limited training and support to provide quality palliative care. In this workshop we will draw on our experiences of working with structurally vulnerable people through the Palliative Education And Care for the Homeless (PEACH) program in Toronto and the newly developed, Calgary’s Allied Mobile Palliative Response Program (CAMPP), and findings from a three-year ethnographic study in Victoria examining access to palliative care for structurally vulnerable people.

Responses to this public health issue require community-led, participatory partnerships. In this interactive workshop, we will engage participants in conversations related to promising practices to improve access to high quality palliative care for individuals experiencing structural vulnerabilities, and encourage (re)conceptualizations and (re)orientation of home, family, and caregiving. We will: (1) synthesize research regarding care for structurally vulnerable populations in need of palliative care; (2) discuss promising practices for improving access to care for these populations; and (3) work with participants to apply these promising practices in diverse case examples.

**NOTE: This time slot contains 1 x 60 minute workshop**

WKSP

### Kids Grieve2: A Free Monthly On-Line Q&A to Bridge the Knowledge Gap

**Presented by:** Andrea Warnick

**Location:** Room 209

Kids Grieve2 Q&A is a free monthly on-line question and answer session aimed at bridging the knowledge gap that exists between the current literature and the adults who are supporting grieving children and youth. This initiative, which is open to anyone who has access to a computer and the internet, was launched in 2016 by Canadian Virtual Hospice and is utilized by parents and other caregivers, as well as professionals and volunteers from across Canada and beyond. It directly engages individuals and organizations to meet the needs of children who are experiencing dying, death or bereavement in their lives.

Community partnerships play an important role in this resource as different children's grief organizations are invited to co-host the Q&A so participants have access to not only the expertise of Virtual Hospice, but from other organizations as well.

This workshop will provide an overview of the literature on supporting grieving children and youth, and will identify the disconnect that often exists between the literature findings and current practice. The workshop will describe the creation and evolution of the Kids Grieve2 Q&A, including a description of the toll-free children's grief helplines available throughout Great Britain which served as the inspiration for the initiative. A segment of one of the recorded Q&A sessions will be played to allow participants to experience the platform. An in-person Q&A session will be included in the workshop, to give participants the opportunity to have their own questions answered and to learn from the questions of others.

**NOTE: This time slot contains 1 x 60 minute workshop**

WKSP

### Developing a Bereavement Care Service in Pediatric Palliative Care: Lessons from the Trenches

**Presented by:** Leigh Donovan, Karen Joy

**Location:** Theatre Hall 110

The inaugural Bereavement Support Program based in the Paediatric Palliative Care Service, Lady Cilento Children's Hospital was established in 2010. This was the first service of its kind to be established in Australia. Over the course of the past six years the service has grown and responded to the needs of families whose child has been diagnosed with and died from a life limiting condition. Drawing on practice wisdom; contemporary theoretical approaches informing loss, grief and bereavement; public health models of palliative care; and research findings from doctoral studies, Leigh and Karen will guide workshop participants through the critical steps in establishing a sustainable and holistic paediatric bereavement care service which straddles the acute hospital setting, palliative care service and community setting. Core service components discussed will include anticipatory grief support for family members; education as a tool for building self-efficacy within the family system and their community of supporters in the context of paediatric palliative care; advocacy in the hospital and community health setting around the needs of families following the death of a child; adopting public health approaches to bereavement care. Workshop participants will be encouraged to translate this new knowledge into their own professional context taking into consideration geographical, cultural and spiritual features of the families they care for. Participants will leave this workshop with a framework for establishing a bereavement care program based in a paediatric palliative care service.

**12:15 - 13:00  
NETWORKING LUNCH**

**Location:** Served in Main Ballroom 118 and eaten in Room 106 CDEFG.



13:00 - 14:30

**ORAL PRESENTATIONS**

**Location:** Hampton Room 1

**NOTE:** This time-slot contains 4 x 20 minute oral presentations

ORAL

**Understand the Socio-Cultural Context in Low and Middle Income Countries in a Global Health Perspective of Death, Loss and Bereavement for Rethinking a New of Care: Case Study from Rwanda Post-Genocide Society**

**Presented by:** Christian Ntuzimira

The aim of this workshop is to identify and understand the socio-cultural context between low and middle income countries and high income countries regard dying which will help to rethink a new concept of care in palliative care and bring a comprehensive platform of exchange experiences. One of the most challenging encounters in medicine for clinicians and families are the ones between healthcare providers whose reality is rooted in science and medical data and patients and family members whose primary reality is rooted in culture. In LMICs, where the socio-cultural context has ruled the environment of the patient and avoid the complexity of goals of care which is sometimes considered as a non-scientific methodology in HICs, could generate a source of conflict and lack of trust in the future development of partnership.

In most of African reality, conversations about death can become adversarial and cause stress to the healthcare team and perhaps undue suffering for the patient. There are different methodologies from African culture perspectives which involves the community to talk about death and support families during the loss and bereavement.

By engaging the community to be responsive to death of the patient and loss & bereavement from the families in a post-genocide society where 1 million people died in 100 days there is a tremendous contribution to bring back the part of humanity lost during the tragedy

ORAL

**A Public Health Perspective on Bereavement Care**

**Presented by:** Bruce Rumbold, Samar Aoun

In recent decades most attention devoted to bereavement has focused on providing counselling for bereaved individuals. Only recently have there been attempts to consider bereavement experiences in general society.

Our survey of nearly seven hundred bereaved clients of four funeral providers in two Australian states confirms a public health model predicting that over half the group would demonstrate low risk of complicated grief, another third moderate risk, while a small minority would meet the criteria for prolonged grief disorder. The survey also shows differing patterns of need and sources of support for each of the groups. Our findings suggest not only that the bereavement care provided by health services should be carefully targeted, but that a primary public health interest should be in the care that supports the majority of bereaved people. This care is provided in community settings by a range of people. Some are

healthcare practitioners contributing through their everyday activities, not bereavement programs per se. Most care comes from people already involved in the everyday lives of those recently bereaved. These people are assets already in place, contributing to each other's resilience. The most effective way to provide bereavement care is to support these 'everyday assets', ensuring that their care is recognized, appreciated, and not disrupted by over-reach from professional services.

In this presentation we will outline the findings of surveys and interviews undertaken with recently-bereaved people, and focus upon the types of partnerships needed for sustainable bereavement care by local communities.

**Raising Bereavement Awareness in Communities Using the 9 Cell Tool**

**Presented by:** Jennifer Hunt

A growing body of literature supports tapping into the wisdom that is inherent in societies to support individuals and families in crisis. People often seek bereavement counselling because their families and communities seem uncomfortable with the extreme emotions that grief brings and are unwilling to allow the natural course of grief to unfold over what appears to be too lengthy a time. The bereaved are often 'prevented' from grieving normally and complications can set in. Grief is a highly personal experience yet played out within one's culture with all the accompanying rules. The 9 cell tool is a simple yet effective group-work technique designed in Zimbabwe to draw upon the knowledge of a community in order to normalise and support the bereaved within that community. The presentation will describe the tool that draws upon experiences of the participants and combines these with a didactic process to raise awareness of what grief feels like over time, how people express their grief depending on gender, context and culture and how one's environment expects or accepts manifestation of grief over time. Anecdotal evidence suggests this is an effective approach in normalising bereavement, resulting in appropriate grief support within families and communities. Plans to formally evaluate the tool are currently in process.

ORAL

**Grief Matters**

**Presented by:** Rachelle Mcguire

In our current culture grief continues to be treated as pathology both by our larger social contexts and by health care professionals. This inhibits us from the ability to metabolize that which is a deeply normal, frequently occurring human experience. This workshop will address the ways in which we pathologize grief and explore some ideas as to how we might choose to do this differently in the future. The workshop will identify four things that are required to metabolize grief well as well as ideas for how we may engage our communities to assist in this very metabolization.

ORAL

**ORAL PRESENTATIONS**

**Location:** Hampton Room 2

**NOTE:** This time-slot contains 3 x 20 minute oral presentations

ORAL

**Using Photovoice to Capture the Impact of Creating Caring Communities in St. James Town**

**Presented by:** Krystyna Kongats

Background: Despite growing interest worldwide in health promoting approaches to palliative care, little has been written in the context of ethnically diverse urban settings. This is problematic as current evidence on health promoting approaches to palliative care may not adequately reflect the experiences of those living in such diverse urban communities.

Aim: In collaboration with Hospice Toronto, we seek to understand how community members living in an ethnically diverse, high density urban neighbourhood support each other through chronic life-limiting illness and palliative care. Second, we will map out the perceived impacts of such an approach on those involved and the wider community.

Methods: To achieve our aims, we used Hospice Toronto's Creating Caring Communities model as a participatory case study in St. James Town, one of Canada's most densely populated and ethnically diverse neighbourhoods. In total, 19 community helpers, clients, carers, and staff joined the project and participated in a 7-month photovoice project.

Results: Project members developed strong relationships with their neighbours and identified different ways they provided support to those who are isolated with a serious illness (e.g., interpretation, help at home, connecting with local social agencies). Participants emphasized that care was 'organic' and 'reciprocal'. Different impacts were also identified including reduced isolation and an opportunity to gain 'Canadian experience'. Facilitators (e.g., speaking the same language) and challenges (e.g., balancing volunteer protocols with 'just being a neighbour') were also noted.

Conclusion: This study contributes to the evidence base on health promoting approaches to palliative care in diverse urban communities.

ORAL

**Building Compassionate Communities Through School, Workplace and Faith Community Initiatives**

**Presented by:** Bonnie Tompkins, Pam Blackwood

Death, dying, loss, and bereavement are often taboo topics. Discussing them in schools and workplaces can thus present very hard nuts to crack.

In this presentation, participants will learn about successful initiatives to engage schools, workplaces, and faith communities in discussions about the sensitive topics of death, dying, loss, and bereavement. The presentation will highlight why the initiatives were created, the pros and cons of the strategies adopted, and final outcomes. Participants will be able to use the experiences from these compassionate community projects to help build their own initiatives within their community.

**Compassionate Ottawa: A Case Study**

**Presented by:** James Nininger, Jacquelin Holzman

The compassionate community palliative care movement is a recent development in Canada. A group of Ottawa leaders held a community meeting in November 2016 to determine interest in Ottawa becoming a compassionate city. The interest was strong and since then the leadership group has accomplished a great in the first phase of the initiative. The purpose of the presentation is to share the Ottawa experiences.

ORAL

**ORAL PRESENTATIONS**

**Location:** Room 106 A

**NOTE:** This time-slot contains 4 x 20 minute oral presentations

ORAL

**Compassionate Community Networks from Within a GP Practice – Reducing Hospital Emergency Admissions By 30%**

**Presented by:** Helen Kingston, Jenny Hartnoll

Frome Medical Practice provides care for the 29,000 residents of Frome and the surrounding area. Since 2014, the practice has combined a community development service with an internal hub in the GP practice which identifies those in need of support. The community development service fulfills 2 functions; enhancing the naturally occurring supportive networks that surround people and connecting people into community resource. If the resource needed creating, the community development service helped this process, creating new groups according to community requests.

The outcomes have had a significant impact in a wide variety of areas. Whereas Somerset county has seen a rise of 32% in emergency hospital admissions in the last 3 years, this remained stable in Frome. For those with 3 or more long term conditions, there has been a 30% drop in admissions. A compassionate communities programme focused on people at end of life is showing a marked increase in home death rates. Patient qualitative outcomes show improved quality of life in a number of areas. Working lives of the health professionals involved in the project also improved. The presentation will describe the model and give details of the outcomes, which are continuing to improve. We will also describe how components of the model can be adapted to local circumstances, with the use of Institute of Healthcare Improvement quality improvement methodology as the main tool of change management.

ORAL

**Community Responses to Home-Based End-of-Life Care for Chronically-Ill Cancer Patients in Lagos, Nigeria**

**Presented by:** Olanrewaju Onigbogi

**Background:** Current global trends seem to encourage the gradual shift of end-of-life care for cancer patients from the hospital settings to homes. This has created increased complexity in resource-limited settings with many at risk of low quality or inadequate end-of-life care. This study was conducted to determine the perception of relatives of cancer patients in Lagos about home-based end-of-life care.

**Methods:** We conducted key informant interviews for relatives of cancer patients who were recruited from the a cancer clinic. Each interview was recorded and transcribed with the data analyzed using NVivo 8.0. Emerging concepts from the data were labeled, categorized and coded as appropriate.

**Results:** We interviewed a total of twenty eight persons (eighteen females and ten males) who had accompanied cancer patients to the clinic. We excluded those who did not currently reside in the same location with the patients. By the 24<sup>th</sup> interview, we had no new ideas or themes emerging

through the later interviews. A key concept is that of the expenses involved in creating supportive environments for these patients. Another important concept was the perceived inability to manage pain appropriately at home.

**Conclusion:** There is a need to encourage the development of personal skills or care givers and strengthen community action as it relates to end-of-life care for cancer patients in resource-limited settings.

**Caring Through Uncertainty: Sharing a Practical Guide by Palliative Carers at Home**

ORAL

**Presented by:** Merryn Gott

This presentation showcases a new book written by Ros Capper, who cared at home for her husband, Mike, while working part time prior to his death from cancer. Ros identified a significant gap in the current available support for palliative home carers. She decided to address this gap by writing a book drawing on her own experience and inviting four other families who had also provided palliative home care to contribute. The book addresses many issues which have been overlooked by the 'professional' palliative care literature. These include tips for how to build a 'home care team' and when to have honest conversations about care choices; Ros, for example, identifies periods of temporary respite from symptoms following palliative treatments such as chemotherapy as a good time to embark on these.

The need to share knowledge amongst palliative home carers was identified in a participatory project led by Lisa Williams. The Te Arai Palliative Care and End of Life Research Group provided support for the project, including some of the production costs of the book. As such, this project also provides an example of how researchers can work collaboratively with the people who hold the real knowledge and expertise regarding palliative home caring to create practical resources to support their vital work.

Ros is not able to attend the conference in person, but will appear via video to describe the project and her plans to use the book as a foundation for a larger community initiative.

**Developing an Intervention for Optimizing End of Life Care in any Setting**

ORAL

**Presented by:** Emily Dobson

**Background:** It is a 'wicked problem' (1) that the gold standards of care created within the hospice setting are not always effectively influencing national, regional or local policy. This struggle is something which the public health sector has successfully contended with. In particular an approach known as Health in All Policies(1) (HiAP) has been developed to lay down the rules of engagement and guide the exchange between organisations from all sectors. This synergy allows for an exploration of the possibilities of utilising HiAP within end of life care. In particular this study will look at how the HiAP can be adapted to better integrate end of life care throughout the population.

**Objectives:** To investigate HiAP as an intervention; To develop a framework for implementing a HiAP approach to end of life care; To evaluate the possible impacts of changing the manner in which end of life care integrates within England

**ORAL PRESENTATIONS**

**Location:** Room 106 B

**NOTE:** This time-slot contains 4 x 20 minute oral presentations

ORAL

**'Let's Do This!': 'Releasing' Community Capacity**

**Presented by:** Rachel Zammit

An oral presentation detailing our experiences of developing and strengthening sustainable community partnerships in Cheshire, UK. Challenges, successes and key lessons learnt.

ORAL

**Collaborative and Participatory Approaches to Building Community Capacity for Palliative and End of Life Care**

**Presented by:** Martin Labrie, Harold Pliszka, Emma Buzath

People living in rural and smaller urban areas near Calgary experience difficulty accessing palliative care services which are concentrated in metropolitan areas. The Cumming School of Medicine, Alberta Health Services and community hospice palliative care societies in two rural communities have been working to develop a partnership that incorporates local health system resources and community initiatives in supporting individuals and families living with progressive, life – limiting illnesses. This presentation will provide an understanding of how academic institutions and health services can collaborate with community members to enhance capacity for end of life care, and enrich communities in the process.

ORAL

**Community Capacity Development to Enhance Hospice Palliative Care in Alberta, Canada Communities: Evidence Demonstrating the Value of a Community Engaged Model**

**Presented by:** Kyle Whitfield, Martin Labrie

Our study explored the value of a community engaged model for good hospice care in three rural communities in Alberta, Canada. When communities are highly engaged in planning and implementing hospice care in their communities, our study discovered that they have key characteristics: that volunteerism needs to be balanced to prevent burnout; that the local knowledge of community members is used in a number of ways to plan and provide good hospice care; that a variety of resources, infrastructure, policies and expertise are used by the community to nurture community-focused palliative care initiatives. The value to the community or social capital, that accrues from these initiatives is not easily appreciated by the community members, and community-based initiatives benefit when this value is identified for them. In all three communities a focus group was conducted separately with the Hospice Society board and with family members and volunteers connected with the Hospice Society. Participants attending this oral presentation will learn how community palliative care is perceived by non-professional community leaders, as well as strategies that may help address barriers that are encountered when communities become engaged in addressing their own hospice and end of life care needs.

**Collaborative Model Used to Develop a Resource Guide for Communities to Enhance Their Palliative and End of Life Care: The Case of Alberta, Canada**

ORAL

**Presented by:** Kyle Whitfield, Eleanor Foster

Collaborative model used to develop a resource guide for communities to enhance their palliative and end of life care: The case of Alberta, Canada

In response to the desire of community organizations in Alberta for information and guidance as they seek to improve palliative and end of life care in their communities, a large number of organizations collaborated to develop a resource guide. In order to achieve this goal, it was first necessary to identify the common information needs of Alberta communities as they pursue their vision for improving local Palliative and End-of-Life Care. A committee comprised of representatives from Alberta Health Services, Alberta Health, Alberta Hospice Palliative Care Association, Hospice Societies, University researchers, Indigenous Health and Palliative Care physicians surveyed numerous community groups and stakeholders about their information needs, and as a result of their feedback several themes were identified which formed the basis of the Resource Guide for Community-based Palliative and End-of-Life Care. This oral presentation will leave participants with a good understanding of how multiple stakeholders can work together to strengthen community-led palliative and end-of-life care, at a provincial level, when there is a common goal.

**ORAL PRESENTATIONS**

**Location:** Room 106 H

**NOTE:** This time-slot contains 4 x 20 minute oral presentations

ORAL

**Lights, Camera, Action: The Creative Dissemination of Palliative Care Research Findings**

**Presented by:** Lisa Williams

Digital media, including the Internet and social media, is a popular conduit for public health information, promotion and education. Statistics from the United States indicate adults regularly search online and use social media to access health information. In addition, social media can reach audiences, such as ethnic minorities and lower socio-economic groups that tend not to access health information by more traditional means. Given digital media's facility for conveying health information, creating digital content in the form of films could be an effective way to distribute evidence-based palliative care research findings to audiences beyond those typically accessed through journal articles and academic conferences. However, little research exists to support the use of films in such a manner.

The purpose of this presentation is to help address this gap by exploring the opinions of health care professionals' who evaluated our 28-minute film Farewell, Haere Atu Ra. Farewell dramatises selected research findings from Te Pākeketanga: Living and Dying in Advanced Age. Te Pākeketanga examined the end of life circumstances of Māori and non-Māori people aged 80+ and the experiences of their family caregivers. Amongst the findings we will report on are healthcare

professionals' views about its usefulness for promoting reflection on practice, presenting research findings in a non-traditional manner, prompting discussion about death and dying and implications for Māori. Clips from the film, which uses actors to present the actual, mostly word-for-word accounts of the family caregivers will be shown

ORAL

### Getting to the Grappa, Using Films as Icebreakers in Community Engagement, Learn How to Make Simple Films for Use in Your Communities

**Presented by:** Rebecca Lloyd

When we communicate with our communities we have an opportunity to invoke and create empathy, passion, aid learning and help them help each other. Communicating effectively through the medium of a short films provides;

An effective exchange of information:

- Forces the presenter to think of the easy explanation to sometimes complex problems
- Saves time – a few minutes a film if done well can replace a long explanation
- Is Popular: Short Films are increasingly being used as an aid to communicate avoiding 'death by powerpoint' long speeches and long explanations. Short films provide a simple clear message
- Presenting something visually engaging and artful adds impact to the information, and aids for quicker understanding.

ORAL

### Healing Through Storytelling

**Presented by:** Vanessa Eldridge

Mythology, mysteries and spirituality lay deep within the Maori culture. Oration, singing and storytelling remain a source of both of delight and solace. 'Healing Through Storytelling' is a grief support programme created with Maori and delivered alongside Maori authors. The programme has been running for four years and reminds us that 'good grieving' is within cultural practices for Maori, indeed enhancing cultural norms, and valuing our cultures can be good for everyone.

Vanessa Eldridge, Maori Liaison at Mary Potter Hospice in Wellington, Aotearoa New Zealand will share learning gained as the programme evolved. Important to Maori is the concept of 'nga taonga tuku iho' (treasures handed down, or, intergenerational knowledge transfer). Cultural knowledge is important for all of us, and this is especially so for colonized indigenous peoples.

Recent years has seen research emerging regarding Māori people's experience of palliative care – from both Maori and Western lenses. Preserving the concept of 'mana', retaining purpose, and promotion of identity is highlighted in the work of Professor Sir Mason Durie and Dr. Simon Bennett of Massey University. Cultural support of the older person helps the whole family with bereavement according to Professor Merryn Gott and the Te Arai Team at Auckland University. Death projections to 2068 shows Māori are living longer. Data shared by Professor Heather McLeod reveals that elders will experience rates of frailty and dementia never seen before within this indigenous group.

Mary Potter Hospice is committed to our cultural relevance, and development of best practice for those we serve.

### Public Health by Stealth

**Presented by:** Jessie Williams

What does it take to light a fire to create cultural change about the way we do death, dying and bereavement in Australia? The GroundSwell Project set out to embark on a bold journey to create cultural change in the death and dying space in Australia. For 7 years we have delivered over 55 arts/health projects and have punched well above our weight. What have we learned about change and innovation?

We've learned that we had to set up a fiercely independent organisation, drawing on short term funding so that we were never locked into delivering results that perpetuated 'systemic malaise'. We grew a network of activators across Health and Palliative care, community as well as other non-health related workplaces. We sought to find the right people, likening them to 'positive outliers' and engaged their head, heart and hands so they may influence others for a ripple effect. We work well with power or rank, a critical skill when leaning into complex social change. We've learned that we must engage leaders not just in health but ALL sectors, institutions, all walks of life... Why not make it possible for any change to be truly 'social'?

In this presentation, you will glean highlights from a range of our innovations and our approach to leadership, social research and collaboration. You'll have pause to reflect on how in your current role in the health system, you too can create change, by drawing on non-health specific discourse, using a stronger social lens.

ORAL

### ORAL PRESENTATIONS

**Location:** Room 209

**NOTE:** This time-slot contains 2 x 20 minute oral presentations

ORAL

### Beyond the Spotlight: Developing a Public Health Framework for Palliative Care Volunteers

**Presented by:** Alex Huntir, Linda Hansen

An oral presentation about the research and development behind a statewide framework for palliative care volunteers in NSW that takes a population health approach to proposing public policy for improving the support of people and carers at or near end of life.

ORAL

### Involvement of Formal, Direct Patient Care Volunteers in Organisations Providing Palliative Care: Results from a Nation-Wide Survey

**Presented by:** Steven Vanderstichelen

Background: Governments expect communities to take up increasing shares of palliative care provision, e.g. through volunteerism. An overview of current volunteer involvement and how organisations view volunteer contributions is therefore crucial to prepare and optimise volunteer integration.

Aim: Describe how involved in the organisation of care formal, direct patient care volunteers are in organisations providing palliative care in Flanders (Belgium) and how these organisations evaluate this involvement.

Method: A postal survey was conducted among organisations providing care for patients with chronic, life-threatening conditions at the end of life in Flanders, Belgium. The sample included every palliative care unit, palliative day care center, multidisciplinary home care support team, medical oncology department, sitting service, volunteer community home care organisation, and a random sample of nursing homes.

Results: Response rate was 79% (N=258). 75% of organisations inform their volunteers about the organisation of care, 35% consult them, 47% take their opinion into account, 15% give them decision rights and 7.5% allow them to make autonomous decisions. Most organisations (74%) rate their volunteers' involvement as sufficient. 17% indicate their volunteers should be more informed, 18% feel volunteers should be consulted more, however there was low support for more decision rights (6.7%) or autonomous decision making (2.6%).

Conclusion: Care organisations seem generally content with the overall low degree of involvement by direct patient care volunteers. Results suggest potential for more volunteer responsibilities in care organisations, but most organisations are reluctant. Increasing the volunteer contingent, however, might increase their demand for involvement in care organisation

### ORAL PRESENTATIONS

**Location:** Theatre Hall 110

**NOTE:** This time-slot contains 4 x 20 minute oral presentations

ORAL

### "Ingredients" of a Caring Community. Findings from a Participatory Research Project in Austria

**Presented by:** Patrick Schuchter, Klaus Wegleitner

Background & interest: The project 'Caring community in living and dying' in the Tyrolean community Landeck aimed to strengthen networks and solidarity in the community in order to support family caregivers. The whole project lasted three years (2012-2015). In our presentation we focus on findings from the first period ('survey') the objective of which was to understand the local care culture with its resources, deficits, and peculiarities. The research questions of the survey were:

- What are important characteristics of the local care culture in its strengths and weaknesses as perceived by our interview partners?
- Which general conclusions can be drawn from our research to understand the elements that build resilient communities and networks in end-of-life care?

Method: Focus groups and individual interviews were carried out with: family carers, hospice volunteers in the region, coordination persons of self-help groups, the local undertaker, the local catholic pastor, the general practitioners of the community, and the ambulatory nursing care team.

Results: Our data analysis and interpretation revealed general categories (dimensions or 'ingredients') of a web of care relationships. We interpret these elements as 'ingredients' because a) it cannot be determined from the outset who contributes a certain 'ingredient' to the care-web, and b) the required 'dosage' may differ from case to case. For this reason the 'ingredients' are described as abstract entities which come to life through persons (and organisations) in their different roles. These ingredients are: competency, wisdom, keeping each other in mind, access to house and soul, coordination, moderation, freedom from care.

Discussion: In our contribution we will present findings, discuss the practical relevance and consequences for community development and reorientation of health care services and will briefly point at some conceptual implications for public health approaches in end-of-life care and for care ethics.

ORAL

### Measuring Appropriateness and Inappropriateness of End of Life Care in Cancer Patients on a Population Level Using Routinely Collected Databases

**Presented by:** Robrecht De Schreye

Proportions of patients will receive aggressive curative treatment close to the end of life. To evaluate to what extent end-of-life cancer care is appropriate or inappropriate within a health care system, population-level quality indicators can be used. We previously validated a set of indicators to measure appropriateness of end-of-life care for people with cancer using routinely collected population-level administrative data. The

results can be used to support public health policy.

**Aim:** To measure appropriateness and inappropriateness of end-of-life care in people dying from cancer on a population level.

We link together 7 major Belgian routinely collected administrative databases with full-population information on health care use, cancer diagnostics and social, demographic and socio-economic variables. Indicators of appropriate and inappropriate end-of-life cancer care are calculated for the full population of persons dying of cancer based on an indicator set that has previously been validated using a RAND/UCLA appropriateness method.

Multivariable linear regression analysis is used to examine how the different dimensions of inappropriate or appropriate end-of-life cancer care are associated with diagnostic, social, demographic and socio-economic characteristics of the patient.

**Results:** In 2012 in Belgium, 26,464 (24.54% of all deaths) people died of cancer.

The extent of inappropriate end-of-life care within the Belgian health care system is measured by 14 indicators.

Appropriateness of end-of-life cancer care is measured by 10 indicators.

ORAL

### Evaluation of a Palliative Care Capacity Building Project for Rural Mauritania in West Africa

**Presented by:** Alhousseynou Sall

Palliative care capacity in rural communities across Mauritania was reinforced in 2016 and 2017, through the training of community health workers and visits to several of these communities. Over 70 community health workers, selected from across Mauritania were trained in the foundations of palliative care. The three 5-day trainings were interactive, employing a variety of teaching approaches, these included lectures, small group learning and role play. Eight communities were visited, incorporating mentoring of participants, jointly visiting palliative patients, and running community conversation workshops, during which the principles of PC were discussed.

The project was evaluated through the use of participant evaluations, confidence rating scales, pre- and post-training knowledge tests, semi-structured interviews, and focus groups. Over 20 semi-structured interviews were carried out with participants, and nine focus groups with either participants, bereaved relatives or local community leaders. These were audio-recorded and transcribed into French. Thematic analysis was carried out on these transcripts by an international team experienced in social science and anthropology research.

The training was well received by participants, with many hearing about palliative care and holistic care for the first time. It is vital to involve the local community in the implementation of palliative care in the community. A Mauritanian interpretation of palliative care should be established for further incorporation into the health care system.

### Death Literacy – Developing a Tool to Measure The Social Impact of Public Health Initiatives

**Presented by:** Kerrie Noonan

This presentation provides an overview of the development of the death literacy concept and of our recent research work to develop a death literacy benchmarking tool. This tool will provide a national benchmark of death literacy in the general population, providing a way to measure the social impact of existing and new public health initiatives.

**14:30 – 15:00**  
**REFRESHMENT BREAK**

**Location:** Room 106

**POSTER VIEWING** (please see page 36 for a complete list of Poster Presentations)

**Location:** Main Ballroom 118

**FIRESIDE CHATS** (location to be announced)

**Todos Contigo “All With You”**

**Presented by:** Dr. Emilio Herrera Molina

### In the Beginning...the Genesis of Public Health Palliative Care

**Presented by:** Bruce Rumbold

**15:00 – 16:30**  
**PLENARY**

### Theme 2: Creating Participatory Community Partnerships – “Creating Participatory Community Partnerships-Experiences from a Low Middle Income Country”

**Presenter:** Zipporah Ali

**Location:** Room 106 CDEFG

Dr. Ali will share her experiences with work going on in Kenya and other African Countries to increase access to palliative care right to the community level.

**Biography:** Dr. Zipporah Ali is the Executive Director or of Kenya Hospices and Palliative Care Association (KEHPCA). She serves on the board of several organizations including; Hope for Cancer Kids; International Children's Palliative Care Network, Worldwide Palliative Care Alliance and ehospice and Youth Against Cancer in Kenya. She was among several others who received the African Palliative Care Association (APCA) award for her contribution to palliative care in Africa and her work on the inaugural board of APCA. She has previously served on the International Hospice and Palliative Care Association (IAHPC) board, African Palliative Care Association (APCA) board, St. George's Secondary School board and Kenya Cancer Association Board. She was also on the steering committee of Kenya Network of Cancer Organizations. Dr. Ali is involved in advocacy and creating awareness on pain relief and palliative care in Kenya for children and adults. In her leadership role as the Executive Director for KEHPCA, she has been instrumental in fostering strong relationships with the Ministry of Health to integrate palliative care into government hospitals. She has

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also been instrumental in advocating for palliative care to be integrated in undergraduate medical and nursing schools in Kenya. She is a strong advocate for cancer prevention, control and treatment and was instrumental in developing the first National Cancer Control Strategy and the National Guidelines for Cancer Management-Kenya Dr. Ali holds an MD from Ege University, Izmir, Turkey, a Master's Degree in Public Health from the University of Nairobi, a Higher Diploma in Palliative Care from Oxford Brookes University and a Masters in Palliative Care from the University of Dundee. She has completed the International Pain Policy Fellow program with the International Pain Policy Studies Group (WHO Collaborating Centre for Policy and Communication in Cancer Care, University of Wisconsin) as well as the International Palliative Care Leadership Development Initiative at The Institute of Palliative Medicine at the San Diego Hospice. In 2012, Zipporah was awarded an Honorary Doctor of the University by Oxford Brookes University in recognition of her outstanding contribution in palliative care both internationally and locally. She was also awarded the Individual Advocacy Award by the African Palliative Care Association and Open Society Foundations.

**17:30 – 20:00**  
**COMMUNITY ENGAGEMENT EVENING**

**Location:** Room 106 CDEFG

An evening open to the public as well as conference registrants covering community engagement topics.

**07:30 – 09:00**  
**REFRESHMENT BREAK**

**Location:** Main Ballroom 118

**09:00 – 09:15**  
**WELCOME & HOUSEKEEPING**

**Location:** Room 106 CDEFG

**09:15 – 10:30**  
**PLENARY**

### Theme 3: Strengthening Sustainable Community Partnerships – “Strengthening Sustainable Community Action in the UK; Compassionate Communities go ‘Mainstream’”

**Presenter:** Julien Abel

**Location:** Room 106 CDEFG

As Bruce Rumbold says, paying attention to all 5 components of the Ottawa Charter is necessary for effective health promotion. In the UK, 'communities are prepared to help' has become one of the six ambitions for end of life care 2015 - 2020. Embedding community development into health policy gives incentives to health and social care organizations to participate in building community resource, allowing this to grow lasts for generations..

**Biography:** Dr. Julian Abel was appointed as a consultant in palliative care in Weston Super Mare, southwest England in 2001. Dr. Abel worked in both a district general hospital and a hospice. He has been involved in with strategic developments in End of Life Care in England since 2008. This has included development of the first electronic palliative care coordinating system, advance care planning and end of life care in acute hospitals. Inspired by Professor Allan Kellehear's vision of a

compassionate society, Dr. Abel has dedicated the last 5 years to embedding a public health approach to end of life care in the UK, running programs locally, regionally and nationally. They have seen community development being included as one of six ambitions for end of life care in the Ambitions Framework for End of Life Care 2015 - 2020 published by NHS England. Dr. Abel co-authored the National Guidance to Ambition 6, Communities are Prepared to Help, published in July 2016. He was chair of the organizing committee for the 4th International Conference Public Health Palliative Care: Community Resilience In Practice held in Bristol, England in 2105. Dr. Abel is the Vice President of Public Health Palliative Care International and Chair of Public Health Palliative Care UK.

**10:30 – 11:00**  
**REFRESHMENT BREAK**

**Location:** Main Ballroom 118

**POSTER VIEWING** (please see page36 for a complete list of Poster Presentations)

**Location:** Main Ballroom 118

**FIRESIDE CHATS** (location to be announced)

**Meet the Author!**

**Presented by:** Dr. Allan Kellehear

### Palliative Care in Low Middle Income Country

**Presented by:** Dr. Zipporah Ali and Dr. Christian Nzitimara

(continues on next page)

11:00 - 12:15 – INTERACTIVE WORKSHOPS

*NOTE: This time slot contains 1 x 60 minute workshop*

WKSP

**Celebrating Indigenous Communities  
Compassionate Traditions**

**Presented by:** Holly Prince, Maxine Crow, Lori Monture

**Location:** Hampton Room 1

Living in a compassionate community is not a new practice in First Nations communities; they have always recognized dying as a social experience. First Nations hold extensive traditional knowledge and have community-based practices to support the personal, familial, and community experiences surrounding end-of-life. However, western health systems were imposed and typically did not support these social and cultural practices at end of life. In fact, the different expectations of western medicine and the community related to end of life care has created stress and misunderstanding for both. One solution is for First Nations communities to develop palliative care programs so that people can receive care at home amongst their family, community and culture.

Our research project "Improving End-of-Life Care in First Nations Communities" (EOLFN) was funded by the Canadian Institutes of Health Research (2010-2015) and was conducted in partnership with four First Nations communities in Canada (see [www.eolfn.lakeheadu.ca](http://www.eolfn.lakeheadu.ca)). Results included a community capacity development approach to support Indigenous models of care at end-of-life.

The workshop will describe the community capacity development process used to develop palliative care programs in First Nations communities. It will highlight the foundation to this approach, namely, grounding the program in community values and principles, rooted in individual, family, community and culture. Two First Nations communities will share stories about their experiences developing their own palliative care programs, which celebrated cultural capacity in their communities while enhancing medical palliative care services in a way that respected and integrated with their community cultural practices.

*NOTE: This time-slot contains 1 x 60 minute workshop*

WKSP

**Rural Communities Have a Big Heart for Hospice  
Palliative Care**

**Presented by:** Karen Wagner, Lisa Hubers

**Location:** Hampton Room 2

Small rural communities have a big heart for hospice palliative care and if given the opportunity and a financially stable option, will support it with dollars and volunteer hours. We wish to present our unique and successful model that relies on over 85 trained volunteers that are the heart of our robust program, working together with and leveraging existing community partners.

*NOTE: This time slot contains 1 x 60 minute workshop*

**Starting From Scratch: Engaging Communities Using  
an Asset-Based Approach**

WKSP

**Presented by:** Mary Matthiesen, Lisa Deal

**Location:** Room 106 A

Hospices have significant experience around end of life issues, yet can find themselves isolated as solely 'end of life' providers in a community. Communities have the capacity to engage and reach the healthy, aging, advocates to become informed, start conversations, inform needs and support community-based care for our last days of living. Yet how can we begin to engage with the wider, healthy community to aid efforts to raise awareness and become engaged when most still aren't holding conversations, have myths about hospice and palliative care and fear opening this wider conversation? What is our role?

Using an asset-based approach to community engagement around end of life issues delivered first in the UK and published in the BMJ Supportive and Palliative Care Journal, our hospice launched a pilot in two communities to learn how and if we could help to begin a partnership, participatory approach to wider awareness/education and compassionate community initiatives in our region.

Starting from Scratch workshop/presentation will engage participants in the background, process and steps we used to engage 30 community agencies, share the key themes identified by each as essential to reach a wider community, first steps taken as a result, and lessons we are learning as we continue this journey with our community partners.

*NOTE: This time slot contains 1 x 60 minute workshop*

**Addressing the Cultural, Spiritual and Religious  
Perspectives of Palliative Care**

WKSP

**Presented by:** Hodan Nalayeh, Shelly Cory, Kali Leary

**Location:** 106 B

Healthcare services are often out of sync with cultural, spiritual and religious perspectives on health, death, and grieving. This dissonance affects attitudes and behaviours in seeking and utilizing end-of-life health services and can lead to poor clinical communication, misunderstanding, and anxiety as patients, families and health providers interact during a serious illness.

To address a gap in cultural-specific information Canadian Virtual Hospice launched LivingMyCulture.ca – an evidence-informed collection of videos of immigrants, refugees, and Indigenous people sharing their stories about the intersection of culture, spirituality, and religion with their experiences of advanced illness, palliative care, and grief. The video repository includes over 650 video clips, available in 11 different languages. These narratives empower and educate patients and their families by raising their awareness about accessing, advocating, and receiving culturally safe and inclusive care as they navigate the Canadian healthcare system. LivingMyCulture.ca also promotes culturally sensitive care among health providers to enhance their knowledge and skills in providing culturally safe and inclusive care in order to improve care outcomes.

This presentation will introduce LivingMyCulture.ca, provide strategies for incorporating the tool into practice to support patient and family care and share summative evaluation results. A Somali-Canadian journalist and community leader will share her unique Muslim and Somali perspective about the way illness, dying and grief is approached and the impact of LivingMyCulture.ca in the community. Overviews of other culture groups' video resources will also be shared, reflecting Canada's rich cultural tapestry.

*NOTE: This time slot contains 1 x 60 minute workshop*

WKSP

**Organizing Existential Conversations and Enhancing  
Worldly Wisdom of Care in the Community**

**Presented by:** Klaus Wegleitner, Patrick Schuchter, Kathleen Mcloughlin

**Location:** Room 106 H

Background: The political philosopher and care ethicist Joan Tronto suggests that a caring society and a caring democracy require settings where people can learn from and about the lives of others. In this sense, compassionate communities enable people to exchange their existential experiences, to generate common knowledge of local care cultures and resources in end-of-life care and to engage in care. In some way, to share existential experiences and "wisdom of care" could help to ensure the strengthening of social resources and social cohesion, and the promotion of supportive environments. Within the scope of compassionate community initiatives and participatory research projects in Austria, Germany and Ireland, we have created and tested various settings and methods of organizing existential conversation.

Aim & Approach: On the basis of our insights at both a practical and conceptual level from three European settings we will: a) dialogue with the participants about their personal experiences and points of reference; b) reflect and analyse underlying contradictions and challenges; and c) discuss overall conclusions with regard to potential implications and conditions required to strengthen compassion in our communities. A number of different methods to enable ethical dialogue and generate wisdom of care will be presented and one method will be tested jointly as a basis for reflection and discussion.

Conclusions: Our approaches to organizing existential conversations and enabling ethical dialogue in the community incorporate community development, in the frame of health promotion, and practical, communal ethics. Telling and sharing stories of care and ethical reflection creates connectedness, brings relief, and offers new perspectives; worldly wisdom of care becomes shared knowledge in the community.

*NOTE: This time slot contains 1 x 60 minute workshop*

WKSP

**The Role of Hospices in Participatory Community  
Partnerships**

**Presented by:** Heather Richardson, Libby Sallnow, Shaun O'Leary

**Location:** Room 209

Community participation in end of life care is an area of development that is of interest to many hospices in the UK

as well as palliative care services in other parts of the world. For some hospices it is viewed as a natural extension to their work using volunteers; for others it represents a new approach that could improve the quality of their care – enabling them to reach more people, reduce inequities in provision and increase the scope of support and help available. There is some evidence of improved services and outcomes as a result. Even so the number of hospices in the UK that are actively engaged in participatory community partnerships is relatively low.

In the course of the workshop we are interested to explore why this is the case, whether the interest and concerns of UK hospices are shared by palliative care providers in other countries and what we can learn from each other to support and enhance community participatory partnerships in the future. New research undertaken by one of the authors confirms that hospices can play an important role in facilitating community involvement in end of life care – a premise that we will consider in the course of the workshop with due attention to other opportunities and challenges proffered by their involvement and the related tensions arising for the different stakeholders. Towards its end we will seek views about the relative value of hospices in participatory community partnerships and whether this role should be transitory or more permanent in nature.

*NOTE: This time slot contains 1 x 60 minute workshop*

WKSP

**The 'Healthy End of Life Program' (HELP): Offering,  
Asking for and Accepting Help**

**Presented by:** Andrea Grindrod

**Location:** Theatre Hall 110

The 'Healthy End of Life Program (HELP): offering, asking for and accepting help' is a research-informed initiative aimed at creating a collaborative community culture for end of life care. Based on recent community-based research conducted by La Trobe University Palliative Care Unit in Melbourne Australia, the HELP program is designed to shift the dominant culture of a local community from one where members instinctively decline help from personal and community networks to one that 'asks for and accepts help', thus creating and reinforcing a community culture that is confident of their capacity in 'offering and providing help'. The program provides both a public health framework and resources to guide a local community, or those supporting a local community, in developing a collaborative culture for end-of-life care.

In this workshop, participants will be guided through the three-step community planning guide to support a community member to remain at home, and how to implement community development initiatives in the context of end-of-life through the HELP framework. At each step they will be invited to participate in an exercise that applies that step to the real-life scenario. Seven strategies have been developed to guide and focus community driven action using the HELP program, including Healthy End of Life Projects, Planning, Policy, People, Partnerships, Place and Practice.

**12:15 - 13:00**

**NETWORKING LUNCH**

**Location:** Served in Main Ballroom 118 and eaten in Room 106 CDEFG.

13:00 - 14:30  
ORAL PRESENTATIONS

Location: Hampton Room 1

NOTE: This time-slot contains 4 x 20 minute oral presentations

ORAL

### Building Community End of Life Capacity Beyond the Health System: The Victorian Local Government End-of-Life Project

Presented by: Andrea Grindrod, Bruce Rumbold

A fundamental issue in forming compassionate communities is to develop capacity for end of life care in agencies, organisations and informal networks that are not involved explicitly in healthcare. This has also been identified as a priority by the Victorian State Government in Victoria's end of life and palliative care framework, adopted late in 2016. As part of the implementation of this framework, the La Trobe University Palliative Care Unit has been funded by the state government to incorporate end of life care into local government policy, planning and practice. Based on a Compassionate Communities approach, this three-year project (2017 – 2020) will provide resources and build organisational capability in local councils throughout Victoria to facilitate their development of community capacity in end of life care. The project has been designed, and will be carried out, in partnership with the state's local government peak body, the Municipal Association of Victoria.

This presentation will share the project rationale, design, strategies for sustainable implementation that are currently emerging, the evaluation strategies being put in place, and the evidence we hope to produce. Successful implementation will see end of life care embedded in the next iteration of the Municipal Public Health Plans mandated for each local government authority. The project has the potential to be rolled out through all other states in Australia, and should also offer possibilities for collaboration with international projects aimed at developing community-based end of life care initiatives.

### Citizen End-of-Life Care: Innovation Action Designs in Europe

Presented by: Aliko Karapliagkou

This oral presentation will address the challenges involved in the process of moving beyond the Compassionate Communities model and into a civic model of end-of-life care that utilises the organisational principles of the Compassionate Cities Charter and the methodologies of the public health approach to palliative care, including participatory community partnerships, sustainable frameworks of care and environmental reorientation towards death, dying, loss and bereavement. The formulation of proposals for change towards a citizen-led model to end-of-life care will be contextualised. Emphasis will be placed upon identifying ways in which we can engage local governments and incorporate community or neighbourhood initiatives in wider policy-

led interventions led by social institutions and other public sectors in Europe. Within the framework of the European Union administration supported by scientific innovations, the paper will examine possible action designs and their implications for the Compassionate Cities model, its theoretical principles, including required adjustments and revisions of the basic conceptual model.

### Using Appreciative Inquiry as a Tool to Build Sustainable Community Partnerships

Presented by: Wendy Gain

Appreciative Inquiry is a strengths-based approach to change management. In an Australian project called Decision Assist – Palliative Care Linkages, 20 collaborative partnerships were formed to support dying elders through implementing one or more evidence-based linkage strategies. One of these partnerships was located in an aged care facility for Aboriginal elders, however the collaborating partners had a long and fractious history. Members of the local indigenous community were approached to contribute to identifying solutions to this discord. The unique concept of 'community' for Aboriginal Australians was a major consideration in the strengths-based approach to change for this partnership.

An Appreciative Inquiry Facilitator utilized this strengths-based approach to develop a shared vision for the community and service providers. Utilizing the five partnership principles of mutual benefit, equity, diversity, courage and openness, an agreed activity plan was developed for the partners to develop and deliver their shared vision. In doing so, the partners embedded the key principles into the partnership and resolved past discord in order to work more positively together. Appreciative Inquiry is a tool to move forward from a difficult past to a collaborative future.

### The Evolution of the Kelley Community Capacity Development Model for Palliative Care

Presented by: Dr. Mary Lou Kelley

This oral presentation will describe and discuss the evolution of the Kelley model for community capacity development. It will illustrate how and why the model changed to become a powerful Canadian example of a public health approach to developing community based palliative care programs. Based on conducting participatory action research in rural, First Nations communities and long term care homes, the perspective of "community" gradually expanded beyond health care professionals to include natural helpers, front line care providers, formal and informal community leaders, and social services. The Kelley model has potential to be applied internationally since it builds a context specific palliative care program that is grounded in the local community and uses existing informal and formal resources.

ORAL

ORAL

NOTE: This time-slot contains 1 x 60 minute workshop

Location: Hampton Room 2

WKSP

### A community health systems strengthening approach to integrating palliative care within a resource constraining environment; lessons from the Collaborate Project in Zimbabwe

Presented by: Franciscah Tsikai

Integrating palliative care into the HIV programs in communities is necessary to achieve access to palliative care for all. Experience has proved that working with the community leaders made it possible for the community members to buy into the project and own the project. This presentation is about experiences, lessons learned and challenges experienced

ORAL PRESENTATIONS

Location: Room 106 A

NOTE: This time-slot contains 3 x 20 minute oral presentations

ORAL

### Seville is With You, Compassionate City

Presented by: Dr. Emilio Herrera Molina

The oral presentation details the development of community networks related with the end of life through "We are all with you" methodology of New Health Foundation for the development of compassionate communities and cities movement, implementing a public health and integrated care approach. We explain how the City Council, Social and Health Services can collaborate with the community to accompany and care for those who face advanced chronic disease and at the end of life.

To achieve this, we begin by creating networks of citizens and stakeholders that are interested in developing the project. Each individual or group of people who is willing to participate is given a role to promote end of life care in their environment. Simultaneously, we carry out awareness campaigns in the city (schools, universities, nursing homes, companies, public spaces of the neighbourhood, etc), and training programmes for social and health professionals and citizens.

Since beginning this project a year ago, we now have more than 30 organizations that collaborate and participate in the development of Seville as a compassionate city. We even have the participation from the City Council, which has signed a MOU to make public its contribution to the project. In January 2017, we have started a pilot project in the San Pablo district with 60,000 citizens. We have now introduced the role of a Community Promoter who works with a GP, Social Workers and Nurses that act as Case Managers, and stimulate the creation of a Compassionate Community and manage networks of care for people with advanced chronic conditions and at the end of life.

ORAL

### Becoming a Compassionate Organisation – Somerset Clinical Commissioning Group

Presented by: Julian Abel

Somerset Clinical Commissioning Group (CCG) commissions healthcare for the 500,000 people who live in Somerset.

The end of life strategy, which aims to achieve a 50% home death rate by creating compassionate communities, includes developing compassionate organisations. The end of life lead for the CCG undertook an initiative to turn Somerset CCG into a compassionate organisation. This served the dual purpose of providing an example for other organisations as well as making the theory and practice of compassionate communities familiar to the commissioners.

Becoming a compassionate organisation has 3 steps, which do not have a particular order. These are developing a compassionate workplace policy, training compassionate champions within the workplace and setting up a bank of volunteer support for people undergoing hardship surrounding the experiences of death, dying and loss. The CCG started with supporting a small group within 1 area of the CCG to become compassionate champions and friends. The group met on a regular basis and put posters up to let workplace colleagues know if they wanted informal support during times of stress and loss. They kept count of the number of contacts and the subject matter. Use of informal support quickly broadened into areas other than death, dying and loss. Once the group had gained experience they opened the training up to other areas of the CCG and to other organisations who worked in the same building. The CCG is now going through the process of developing a compassionate workplace policy

### BC Compassionate Communities Movement - Where We Are Now

ORAL

Presented by: Eman Hassan

Like elsewhere in Canada, the British Columbia population is ageing and the number of people with serious conditions continues to rise. Although medicalized dying in hospital continue to be the norm, the health system lacks the capacity and resources required to address the social and emotional dimensions associated with serious illness, dying and loss. These dimensions are central to the well-being of patients and families. Research indicates that communities have the resources that can help patients and families feel supported and cared for close to home.

Based on international best practices, the BC Centre for Palliative Care has launched a provincial grassroots movement to foster the spread of Compassionate Communities across BC by engaging citizens and community groups to be part of a network of compassionate champions and ambassadors.

In Spring of 2016, the movement was sparked by a Seed Grant Program to mobilize proactive community support networks, under the leadership of local hospice societies, whose mission is to promote awareness around end of life issues and leverage opportunities to support seriously ill patients and their families. In the Fall of 2016, the BC CPC has widened its circle of focus to involve population health and community organizations and groups from all sectors and at all levels.

As a social change organization, we will share our experience with the BC Compassionate Communities movement and the progress of the Compassionate Cities initiatives that are underway in BC and the Centre is supporting.

**ORAL PRESENTATIONS**

**Location:** Room 106 B

**NOTE: This time-slot contains 4 x 20 minute oral presentations**

**ORAL**

**Building Partnerships Between Hospital and Home: A Contemporary Model of Transitional Bereavement Care**

**Presented by:** Leigh Donovan

Following the diagnosis of childhood cancer, parents often come to think of their child's hospital as a 'second home' over weeks, months and sometimes years of treatment. Throughout this time, parents describe a growing disconnect with their existing support networks, including friends in their local community, schools and colleagues. Distance between the treatment centre and home, the impact of a new life experience and associated personal adjustment, and the reality of those in the local community 'getting on with life' are all factors which contribute to this growing divide. An innovative model of transitional bereavement care will be presented which complements existing models of integrative palliative care honouring the symbiotic transition between curative and palliative care, acknowledging the continual cycle of bereavement experienced by parents following the diagnosis of childhood cancer. The gradual oscillation between formal hospital bereavement care and community support is further supported by the Dual Process Model of Grief. Through gradual re-integration into their community family members oscillate between hospital-based care (loss oriented coping) and their community (restoration oriented coping). This model recommends bereavement care take a community capacity building approach with health care professionals taking an educative role commencing with anticipatory guidance and support for families and their community of supporters prior to the death of a child and facilitating ongoing connections with formal and informal support providers in bereavement.

**ORAL**

**'My Normal Thing Ended': The Place of Social Support in the Lives of Bereaved Parents**

**Presented by:** Leigh Donovan

**Background:** Enabling strong and active social support networks for parents throughout their child's cancer trajectory and end of life may facilitate ongoing connections with a family's social network into their bereavement, reducing the sense of isolation parents so frequently describe following the death of their child.

**Aims:** This multi-site study assessed 1) the professional and social support utilized by parents throughout their child's palliative and end of life care and their bereavement, and 2) barriers and gaps to accessing support at each of these time points.

**Method:** Parents whose child had died from cancer (>6 months; < 10 years bereaved) were invited to complete a questionnaire and participate in a semi-structured telephone interview through four paediatric oncology facilities in Australia. One hundred and nineteen parents participated (34% interview opt in; 23% male, mean age 48 years, mean bereavement 5.6 yrs, SD

3.0). Data were analyzed using SPSS22 and NVivo10.

**Results:** Before their child's death, 51% of parents indicated they would have liked more help than they received. Bereaved parents reported that their most helpful supports included: their partner/spouse (89%), friends/neighbors (92%), and other oncology and/or bereaved parents (57%). Empathic gestures (e.g. sympathy cards) were highly regarded ('somewhat'/'very helpful': 86%). 'Needing to be strong for others' was parents' greatest barrier to accessing support before ('often'/'always': 80%), and following, the child's death ('often'/'always': 78%).

**Wired for Living: Developing A Palliative Approach to Care for Young Adults**

**Presented by:** Karen Cook, Kim Bergeron

A growing population of young adults (YAs) with life-limiting conditions require a developmentally appropriate approach to care. Like all YAs, they are wired for living and aspire to attend post-secondary education, have meaningful vocation or work, and live independently. However, their developmental goals may collide with changing symptoms or end of life. Further, adult services are not designed to address their developmental, social, education and financial needs.

YAs with life-limiting conditions will benefit from a public health palliative approach to care, that matches their chronic disease trajectories of a series of declining plateaus over a period of months to years, punctuated by unpredictable periodic crises. A palliative approach to care for YAs facilitates collaborative partnerships across community and health agencies to ensure timely and seamless resources to meet their needs. These resources will support their quest to maximize their quality of life and opportunities in an abbreviated time frame. Currently, there are few programs that recognize the unique palliative needs of YAs.

Successes, challenges and results of our research, Bridging the Gap: Developing a Palliative Approach to Care for Young Adults will be described. We used a three-phase online patient engagement strategy to hear the voice of YAs with life limiting conditions, their families, and health and community professionals. This research culminated in a prioritized plan to enhance well-being, improve access to services and funding, build relationships, and develop a supportive community. Opportunities and barriers for research engagement with the YAs, their parents, and community and health providers will also be presented.

**Religious Leaders Are Reliable Community Owned Resources to Scale Up Public Health and Palliative Care Health Initiatives**

**Presented by:** Dr. Frank Manase

Religious leaders acknowledged the need for health knowledge on prevention and provision of primary health care for their followers. Active bilateral referrals between health providers and religious leaders were appreciated and the two professions perceived a beneficial partnership. Religious congregations enhanced the community's access to preventive health services. Also the congregations have unexplored resources if well mobilized can optimize scale up of public and palliative health scale up initiatives.

**ORAL**

**ORAL**

**Conclusion:** Religious congregations are essential vehicles to expedite the public health and palliative care practices and it is possible to engage them.

**ORAL PRESENTATIONS**

**Location:** Room 106 H

**NOTE: This time-slot contains 3 x 20 minute oral presentations**

**ORAL**

**Responding to a "Deprivation Of Access" Epidemic: Rwanda's Success in Developing its Local, Sustainable Morphine Production Program**

**Presented by:** Tayari K. Jean Claude, Marie Aimee Muhimpundu

Globally, the recent growing opioid epidemic has torn the world's eye away from a silenced, very different reality: severe shortages and, in some areas, a complete lack of access to pain medications has left millions dying in pain. To simultaneously answer this critical human rights concern and also create a crucial, accompanying protective layer to opioid production, prescription and use, developing countries must now, perhaps more than ever before, be strategic and responsible in their development of local production chains. Rwanda serves as an example of this attentive, strategic design and implementation. Prior to the 2014 development of its local morphine production program, the country's dependence on imported morphine from foreign production and procurement chains created an extreme barrier: less than 0.1 mg of morphine was given per capita and an estimated 98% of end of life pain was left untreated. Today, by locally manufacturing oral morphine and adapting procurement chains, Rwanda is challenging this barrier and reorienting its environment to equip providers to alleviate patients' physical pain. Within the contexts of both the local, historic extreme lack of access and the current global abuse epidemic, this presentation will examine the steps Rwanda has taken and its continuous demand for equity, sustainability, and safety as it has created its high-quality, local production since 2014. A detailed picture of the stakeholders and sectors Rwanda included in its initiative will also be reviewed and discussed, including national policy, procurement, labor, law, training and clinical care, interdisciplinary disciplines, and community sensitization and partnerships.

**ORAL**

**The Availability of Opioid Analgesics for Pain Management in Your Setting: Strategies to Empower Pharmacists to Create, Rather Than Disrupt, an Equitable Supply Chain**

**Presented by:** Diane Mukasahaha, Arielle Eagan

Focused on a patient as a person in an environment, public health and palliative care call for a holistic, interdisciplinary view of care delivery, both clinically and through the health care system's design as whole. If engaged in palliative care training, treatment decisions with the clinical team, and advocacy around the procurement of pain medications, pharmacists stand as key stakeholders in ensuring, in particular,

that pain management medicines flow through procurement chains properly and reach the hands of physicians, and thus patients in need. But if left out of trainings, not informed of care decisions, and not empowered to understand and advocate for pain medicines in supply chains, pharmacists risk creating a cascading barrier for palliative care at the clinical level. As Rwanda experienced, pharmacists ordering less pain medications can unintentionally create stock outs and, ultimately, disrupting the supply chain flow of the medicine to the patient in need. Rwanda's Medical Procurement and Production Division recognized this growing systemic barrier and created trainings to dispel morphine myths and educate pharmacists on palliative care. Beginning with an interactive quiz based on the Morphine and Pain Management Skills Initial Assessment that Rwanda created and now uses, the audience will assess their own skills and envision how this tool, training, and concept of the cross-sector inclusion of pharmacy can apply in their own settings. Coming from all disciplines and backgrounds, attendees will be encouraged to develop action steps for how to reorient pharmacists to become advocates in their local palliative care systems.

**Opioids in the Community: Chronic Pain, Palliative Care and Addiction**

**Presented by:** Ahmed Jakda, Tara Gomes, Tara Walton, Darren Cargill

The appropriate use of opioids has become a national health issue in Canada. To address growing concerns around inappropriate prescribing and public misuse of opioids, in the summer of 2016 policy makers in Ontario announced the delisting of high strength opioids from public funding through the Ontario Drug Benefit Formulary. This provided an opportunity for a unique collaboration of palliative care experts from the Ontario Palliative Care Network, the Section of Palliative Medicine at the Ontario Medical Association to work closely with the Ministry of Health and Long-Term Care to ensure that the needs of patients requiring high strength opioids for pain and symptom management in the palliative care setting would be maintained. Furthermore, researchers have been engaged to provide evidence to inform the potential impact of the proposed policy changes. This oral presentation will provide recent statistics in Ontario around opioid prescribing in palliative care, review chronic pain guidelines, as well as instances of overdose. We will also discuss solutions that have been developed to maintain access of opioids for those requiring them for legitimate uses, by way of redeveloping the prescriber-based Palliative Care Facilitated Access designation. Results of the solutions will also be shared. This work accomplished demonstrates a strong partnership between relevant stakeholders, and proves the value of working together to address a major health concern.

**ORAL**

## ORAL PRESENTATIONS

Location: Room 209

**NOTE: This time-slot contains 2 x 20 minute oral presentations**

ORAL

### Building Research Evidence Alongside Community Initiatives for Palliative Care

**Presented by:** Michelle Howard, Kathy Pfaff

One in five Canadians are elderly or live with disabilities and many of these same citizens are also in their last year of life. They often experience systematic and invisible disparities in access to care and exposure to risks and are more likely than other citizens to 'fall through the cracks' of care systems, have poorer quality of life, experience social isolation, and depression. Many lack a voice in seeking help and the autonomy with which to direct and achieve what is most important to them. These issues are predictable and preventable.

The 'Compassionate Communities' model is a population-based theory of practice for palliative care that mobilizes citizens to address these concerns as universal public health issues.

Health TAPESTRY is a program that leverages personal technology and community volunteers to help people illuminate their functional and quality of life issues, identify goals, and create plans that are shared through primary health care services. Originally developed in Hamilton, Ontario, the model is now being employed as a template to expand the Compassionate Communities model in Ontario, and has thus been coined 'Community TAPESTRY'.

Integrating various research paradigms and methodologies, in tandem with program development can promote the scalability and sustainability of new and existing Community TAPESTRY initiatives. In this presentation, we will describe our emerging research community of practice, and highlight the conceptualization, research and evaluation approaches that are unfolding and being integrated into the Hamilton-Niagara and Windsor-Essex Compassionate Community initiatives.

ORAL

### The Limits of Community for People Dying in Advanced Age

**Presented by:** Merryn Gott

In many resource rich countries, death now most commonly occurs in advanced age. However, limited consideration has been given to how the unique palliative care needs of this age group could be better addressed by adopting a public health approach. In this presentation we report on a study conducted with the family and whānau (extended family) carers of participants in the LiLACS NZ longitudinal study of ageing dying aged >80 years in Aotearoa/New Zealand. Interviews were conducted with 58 people (19 Māori and 39 non-Māori) who had cared for 52 family/whānau members at end of life. Kaupapa Māori and social constructionist frameworks informed the research design and analysis. Recognised analytic techniques were adopted to promote data rigour. Overall, we found that family and whānau noted a reduction in the older person's social networks prior to death due to the death/ill health of peers and moving, for example into

an aged care facility. Barriers to community engagement were reported including access, poor health (notably dementia) and the reported preference of the older person to receive care primarily from family/whānau. Whilst there was some limited evidence that the older person could draw on existing social networks where these were already strong, there was very little evidence of new networks being established. Family and whānau had low expectations of what communities could provide at end of life to support people dying in advanced age, but did identify a potential role for community members in terms of reducing social isolation and loneliness.

## ORAL PRESENTATIONS

Location: Theatre Hall 110

**NOTE: This time-slot contains 3 x 20 minute oral presentations**

### Creating a Sustainable, Participatory Palliative Care Programme in an Urban Slum in Dhaka, Bangladesh

**Presented by:** Dr. Nezamuddin Ahmad

The Centre for Palliative Care, based at the only medical university (BSMMU) in Dhaka, Bangladesh, in collaboration with Worldwide Hospice Palliative Care Alliance, piloted a one year project focussed on improving the quality of life of 100 older people and their families in two slum settings in Dhaka. This project was developed following the identification of significant palliative care needs of older people in the slum settings. In addition, the project was formed in response to the absence of programmes delivering palliative care to the poorest and most marginalised in poor urban settings in a sustainable manner within the context of the low development of palliative care and the human and financial resource limitations in Bangladesh. The programme was developed using a participatory approach which focussed on engaging members of the community in the delivery of the project through the identification and training of 8 palliative care assistants from the slum setting itself, who delivered basic care supported by health professionals, the development of palliative care activists within the community and the engagement of the slum community leadership. The impact of the project showed improved quality of life for the target population and the potential for further development as a sustainable, community owned model over a further 2 years, which could be translated into other urban settings. This presentation will highlight lessons learned from the development and implementation of the project and findings from the independent evaluation that was completed in December 2016, overseen by Glasgow University.

### Using Creativity to Design a Public Health Approach to Palliative Care Education in Aotearoa, New Zealand

**Presented by:** Teresa Read

Health, according to WHO, is 'everyone's responsibility' so too is death, dying, loss and bereavement care. Mary Potter Hospice has evolved its model of Education in palliative care to promote a public health approach.

This presentation outlines the creative initiatives tested through enhanced collaboration and participation with the Wellington community. We have increased engagement with Maori and

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Pasifika communities, Arts and Creative practitioners, Schools and Community Development agencies.

These include:

- Strategically engaging at governance level to integrate a public health approach to strategic planning and restructuring education services with dedicated hours to promote a public health approach to education
- Compassionate Communities programme developed: masterclass, public talks, participation in community events and increased media and social media presence in community.
- Medical Students using a creative reflection to explore their responses to visiting the dying
- Building Resilience in Midwifery with creative reflection: an interactive workshop on grief, loss and unexpected outcomes of birth
- Creative workshops exploring memory making and grief with patients, family/whānau and staff with the Voice Arts Trust
- Developing resources and using creative methods (puppet and kite-making) for working with school children to unlock their feelings and experiences of loss and grief.
- Healing through Storytelling with Maori and development of a Pasifika liaison role
- Engaging Wellington Artist Sheyne Tuffery in design of a Hospice street mural

ORAL

### Filling Gaps in End of Life Education: The Patient's Point of View

**Presented by:** Kathy Kastner

Presenting results of collaboration between patients of Family Doctors at Women's College Hospital and BestEndings.com: Evaluating the only patient-developed website on end of life education.

**14:30 – 15:00**  
**REFRESHMENT BREAK**

Location: Main Ballroom 118

**POSTER VIEWING** (please see page 36 for a complete list of Poster Presentations)

Location: Main Ballroom 118

**FIRESIDE CHATS** (location to be announced)  
**Meet the PHPCI Board and Discuss the Charter**  
**Presented by:** PHPCI Board Members

**Empowering Leadership, and Vision: Developing Palliative Care in First Nations Communities**  
**Presented by:** Lori Monture, Maxine Crow, Holly Prince

**15:00 – 16:30**  
**PLENARY**  
**Theme 4: Evaluation and Performance – "Out with the Old, In with the New?": How the Research Methods of Classic and New Public Health Each**

### Contribute to Studying a Public Health Approach to End-of-Life Care."

**Presenter:** Joachim Cohen and Libby Sallnow

**Location:** Room 106 CDEFG

As the recognition and adoption of public health approaches to end of life care builds around the world, so do questions about what is needed for whom and when, and how to properly evaluate what actually works and what does not. The answers to these questions require a concerted research approach, drawing on a range of methods such as participatory research and qualitative methodologies and more traditional epidemiological techniques. We should see such approaches as complementary rather than contradictory and this talk will explore this relationship and potential.

**Biography:** Prof. Joachim Cohen is a medical sociologist and a professor of the End-of-Life Care Research Group of the Vrije Universiteit Brussel and Ghent University. In the research group he is chairing a research program public health and palliative care. He graduated in 2001 as a Master in Sociology and in 2007 as a PhD in Social Health Sciences. His research has been awarded with the Kubler Ross Award for Young Researchers and the Young Investigator Award from the European Association of Palliative Care 2010. Both prizes were awarded to him, mainly because of his large-scale population-based and population-level cross-national research on end-of-life care. Prof. Cohen has published over 110 articles in international peer reviewed journals and co-edited the Oxford University Press book: "A public health perspective on end of life care".

**Biography:** Dr. Libby Sallnow is a palliative medicine doctor working in London and a doctoral student at the University of Edinburgh. She has a longstanding interest in new public health approaches to end of life care, with a detailed working knowledge of such projects in London and Kerala. She has published articles and book chapters in this field and co-edited the book "International perspectives on public health and palliative care" in 2011. She graduated in 2004, obtained a Masters in Palliative Care and Policy in 2011 and is finishing her PhD which examines the impact of a new compassionate communities initiative in East London. She has supported the development of the international movement in new public health approaches, is research lead for PHPCI and vice chair of PHPCI UK.

**14:30**  
**2019 HOST COUNTRY PITCHES**  
**Location:** Room 106 CDEFG

**17:00 – 18:00**  
**RECEPTION**  
**Location:** Main Ballroom 118

**18:30 – 22:00**  
**GALA – A CANADIAN THEMED EVENING OF ENTERTAINMENT**  
**Location:** Room 106



08:30 - 10:00

**ORAL PRESENTATIONS**

**Location:** Hampton Room 1

**NOTE:** This time-slot contains 2 x 20 minute oral presentations

ORAL

**Proposal of a New Public Health End of Life Approach for Brazil: How the Project Estaraoseulado- Primary Palliative Care is Working and How it Can Help**

**Presented by:** Julian Abel

Brazil has 206 million people, and 1.2 million deaths and 600,000 new cases of cancer per year. Palliative Care services are patchily distributed.

The Family Health Strategy, made up from 50,000 primary care teams across Brazil, forms a comprehensive primary care network.

The Project EstaraoSeuLado- Primary Palliative Care developed working from Community Centers. We created a model based on compassionate communities, with community carers working alongside primary care teams. We identified people who need palliative care, gave them specific care and enrolled their carers into a program of monthly meetings called "Comunidade Cuidadora". We discussed caring at end of life and provided skills training. During 2015 we ran 8 training programmes with an average of 10 carers. The major themes of discussion were carer burnout, dealing with denial and skills needed daily. The effect of these meetings were better relations between carers and professionals with expansion of the naturally occurring supportive network. The results of this project have been remarkable. The joint working of professionals and supportive networks together is recognized as being transformational. Carers themselves spread this approach by recommending it to others they know with life limiting illness.

We will discuss the model and how it can be replicated more broadly across Brazil. Family Health teams can use tools of identification, evaluation and assessment working with networks including the community as an important part. We will propose anew model of End-of-Life Care to be adopted as national policy.

ORAL

**Example of Public-Partnership in Low and Middle Incomes Countries to Strengthen the Integration of Palliative Care in Public Health System: Case Study of Rwanda Public Health**

**Presented by:** Blaise Uhagaze, Christian Ntizimira, Theodosie Mugwaneza

22 years after the genocide against Tutsi, Rwanda has made remarkable steps towards recovery by rebuilding health sector. Despite the tremendous improvements in vertical and horizontal approach, there is a need of palliative care approach for patients with life-limiting illness. This work focused to demonstrate the good experience Rwanda has made to integrate the concept of palliative care after the genocide and different methodologies to support patients with life-limiting

illness and affected by the Genocide.

Rwanda palliative care and hospice organization is the first local non-profit organization located in Kigali which signed a memorandum of understanding with the Ministry of Health and work closely with the Rwanda Biomedical Center to implement the home based care services at the community level for patients with life-limiting illness and their families. The private-public partnership between the 2 institutions created a strong synergy for the implementation of the concept of palliative care at home. The triage program for the patients with life-limiting illness from public hospitals selected patients to refer to the private organization for continuum care and the quarterly report of patients managed at the community level from the organization has also sent to the Ministry of health.

Anecdotal data indicates a high level of satisfaction by patients and family members with palliative care assisted at community level and a reduced stress of continuum care.

08:30 - 10:00

**INTERACTIVE WORKSHOPS**

**Location:** Hampton Room 2

**NOTE:** This time-slot contains 1 x 60 minute workshop

**Being Compassionate**

**Presented by:** Bruce Rumbold

This workshop will provide a setting in which participants can explore how they experience and understand compassion through an arts-based collaborative enquiry. The aim is to find both convergence and diversity in the way we conceptualise compassion in order to consider how this might affect communication about and implementation of a 'compassionate communities' approach.

The idea that communities should be compassionate elicits a (mostly) favourable response from a wide range of people. What being compassionate actually means in practice, and how this might shape professional collaborations and local communities, is less often explored. We're already seeing, for example, that recent healthcare interest in compassionate care often considers compassion to be a desired (or required) attribute of individual practitioners: exploring the structural expression of compassion is avoided or ignored.

The fundamental assumption of this workshop is that an adequate understanding of compassion has profound implications not only for the everyday behavior of health practitioners but also for reforming health systems and for transforming the societies they serve. It also assumes that palliative care offers experience and insights that are important to the undertaking, and that renewed attention to compassion throughout the health system will also support palliative care in regaining aspects of its original mission.

Ideally the session will be conducted as a participatory arts-based enquiry, with participants invited to provide consent for their responses to be used in a subsequent publication. Conduct of the workshop does not depend upon this but, if the proposal is accepted, I would like to explore strategies for obtaining ethics approval for gathering evidence through the workshop process.

**Location:** Room 106 H

**NOTE:** This time-slot contains 2 x 20 minute workshops

WKSP

**Building of Compassionate Communities Across Canada**

**Presented by:** Bonnie Tompkins, Kathryn Downer, Deborah Sattler, Dr. Eman Hassan

Compassionate Communities are communities that support their residents during death, dying, loss and bereavement. Canada has embraced the need for a community approach to palliative/end of life care in conjunction with the medical stream. This presentation will inform the participants of several approaches to building a compassionate community which are uniquely different but have commonalities that allow for collaboration. They will also highlight how a national palliative care organization can take a lead role to support compassionate communities across Canada. Three approaches covered include: initiatives in Burlington and Niagara West using a public health approach known as the Compassionate city charter, the Windsor-Essex Compassion Care Community, and Compassionate Communities initiative through the BC Centre of Palliative Care.

Due to a variety of approaches, participants will be able to walk away with an idea of the approach that suits their community best. The more compassionate communities we develop worldwide, the more we make social change where people are more comfortable talking about, planning for, and supporting their fellow citizen when on a journey through death, dying, loss and bereavement.

**How Burlington Ontario is Using the Compassionate City Charter to Build Compassion**

**Presented by:** Bonnie Tompkins, Karen Candy

As you may be aware, there is great discussion around the need for a public health approach to palliative care/end of life. With that, in 2015 the Compassionate City Charter was released at the 4th International Public Health Palliative Care conference. This charter is public health driven as it is set in the idea of community engagement and community driven. Carpenter Hospice in Burlington Ontario was present for the launch of this charter and felt this was the perfect initiative to meet what the hospice board had been looking for. The board had much discussion on how to help the community more and those who did not make it through their doors. They are known for doing a great job within their 4 walls, but how to take that out into the community? The compassionate City Charter was the fitting answer.

At the presentation participants will have a play by play description of how the Carpenter Hospice used the framework laid out by the charter. The presenters will cover the initial steps they took, what connections were made and how, how they got their foot in the door with sectors that were not as receptive to the idea of talking about death and all related topics, launch of the charter in Burlington and the evaluation plan they are using throughout this initiative.

**Location:** Room 209

**NOTE:** This time-slot contains 1 x 60 minute workshop

WKSP

**MyGrief.ca**

**Presented by:** Shelly Cory, Sylvie Lalande, Susan Cadell

Research confirms that a significant number of family members suffer not only in anticipation of a death but also into bereavement. The accompanying physical, social, and emotional distress is often referred to as grief. Bereavement represents a significant public health concern as grievers often suffer from co-morbid health problems, increased use of health care resources, periodic hospitalizations, and even mortality in the first two years after the death. Furthermore, grievers frequently encounter major obstacles when seeking formal support, including lack of access to specialized grief support due to temporal, financial or geographic constraints.

To address these gaps in service, the Canadian Virtual Hospice, in collaboration with pan-Canadian partners developed MyGrief.ca, the world's first evidence-based, online psycho-educational tool to support those who do not or cannot access existing in-person loss and grief supports and as a supplementary resource for those who do. The tool also serves as a rich educative tool for health providers. The content was developed with families and international leaders in the field of bereavement, with attentiveness to issues of cultural diversity. Funding was provided by the Canadian Partnership Against Cancer.

MyGrief.ca includes nine self-directed modules that cover a diversity of topics across the bereavement trajectory. Embedded within each module is a great variety of video testimonials detailing grief narratives that represent diverse age, cultural, gender, and sexual orientation groups.

Attendees will be given an in-depth tour of MyGrief.ca, followed by an interactive conversation on the tool with a bereft family member, health provider and educator on their unique perspectives and the overall impact of using MyGrief.ca.

**Location:** Theatre Hall 110

**NOTE:** This time-slot contains 1 x 60 minute workshop

WKSP

**Developing Community Palliative Care Programs Using a Capacity Building Approach: The Northwestern Ontario Experience**

**Presented by:** Hilary Mettam, Jill Marcella

Northwestern Ontario, Canada, is a large, sparsely populated geographic area with many small rural and remote communities. Most health services are delivered by primary care generalists. The goal of the North West LHIN Regional Palliative Care Program (RPCP) with St. Joseph's Care Group is to create an integrated system of palliative care accessible to all individuals in Northwestern Ontario who would benefit from a palliative approach, regardless of location, prognosis, or diagnosis. To achieve this goal and increase access to palliative care at the primary care level, the RPCP has used the Kelley Community Capacity Development Model to guide their process of developing palliative care programs in 8 different

rural communities. In each community, a local community facilitator is identified and a palliative care committee is established. Subsequently, other community members and health care providers with an interest in death, dying, loss, and bereavement are engaged in a local workshop to discuss their community's strengths, identify areas of improvement, and develop a plan to implement their local palliative care program. Throughout, the RPCP team acts as a resource for the Kelley capacity development process, introduces tools and resources that have been created to support this work, and shares lessons learned from other communities. At the conference, rural community facilitators will share their experiences engaging their communities and highlight accomplishments in developing palliative care. Participants will discover how the Kelley community capacity building approach can mobilize rural, remote, and northern communities and improve access to a palliative approach to care

**Location:** Room 106 CDEFG

**NOTE:** This time-slot contains 1 x 60 minute workshop

WKSP

### Understanding How Belief Systems May Hinder Us in Developing Compassionate Communities

**Presented by:** Barbara Gale

This interactive workshop draws on findings from a qualitative narrative research study to help participants explore how belief systems influence how they work with volunteers and people in the community. The research with community hospice volunteers in the UK, heard their stories about their experiences and their attitudes to death and dying was important because:

Recommendations that increasing use of volunteers could widen the reach of hospices in the community

The impact of increasing regulation on volunteer roles and relationships between professional staff and volunteers, and volunteers and patients.

Concepts from systems theory were used to underpin this study and understand the stories heard about the rules and belief systems that influenced how the volunteers managed their relationships with dying people and the hospice. The findings show the importance of the social nature of the volunteer role and the value of friendships, but highlight the dilemmas that volunteers face when working with systems that are heavily regulated. The volunteers' beliefs about relationships and rules did not just come from hospices, but from their own belief systems.

This workshop will encourage participants to consider the systems they work in and explore beliefs (personal and institutional) held about rules and relationships when working with volunteers and dying people.

Participants will then explore how those different belief systems might influence how they work with volunteers and people in the community.

**08:30 - 10:00**

### ORAL PRESENTATIONS

**Location:** Theatre Hall 201 - 202

**NOTE:** This time-slot contains 2 x 30 minute oral presentations

### End-of-Life Care in Disability Residential Services: Building Organisational Capacity

**Presented by:** Andrea Grindrod

This presentation reports on a three year study that used a public health approach (health promoting palliative care) to embed end-of-life care into the core practice of government-managed residential services for people with intellectual disabilities in Victoria, Australia. Our research began in response to the finding that this group has poorer end-of-life outcomes compared to other citizens, and proceeded by surveying the resources available for end-of-life care in residential services in one Victorian health region that included both metropolitan and rural settings. Staff attitudes to providing end-of-life care to residents were explored through a survey (n=174) while focus groups (n=26) and research interviews (n=6) elicited staff members' experiences. Findings from analysing the structural, cultural and practical factors that influence end of life outcomes will be shared, with a focus upon how these factors inform a model for sustainable organisational change. In particular, we developed organisational strategies that encourage residential care workers to see themselves as central to end-of-life care, rather than existing on the fringes of, or being secondary to, palliative care expertise. Making the model sustainable has also meant revisions to some health and welfare policy.

We will share with participants our experiences of developing and implementing this model both at the study site and more broadly in other related Australian disability systems. Although our findings are drawn from the disability sector, the approach potentially applies to other settings where citizens are dependent upon the welfare sector.

### Reducing the Gaps in Care: A Systems Approach for the Provision of End of Life Care Between Sectors

**Presented by:** Andrea Grindrod

Disadvantaged citizens who are dependent upon social welfare systems for their well-being become even more vulnerable when an unfamiliar system is introduced, such as health. In our study with one of the most disadvantaged populations in society, those with intellectual disability, we found the interface of collaboration between systems in providing care at end of life further increased the gaps. Unhelpful assumptions, such as most disability support staff viewing dying as a medical event, resulted in transfer to hospital for what was deemed better care. When community-based collaboration was attempted in a disability setting, each through the other was co-ordinating care resulting in no-one overseeing service provision. Palliative care and disability policies were often dissonant and further inhibited collaboration between services.

ORAL

ORAL



The International Association for Hospice & Palliative Care (IAHPC) is a global non-profit, membership organization dedicated to the development and advancement of hospice and palliative care to assure that any patient's and family caregiver's suffering is relieved to the greatest extent possible.

IAHPC works with UN agencies, governments, associations and individuals, to develop and implement appropriate policies for the provision of palliative care as a component of Universal Health Coverage; increase access to essential medicines for palliative care; foster opportunities in palliative care education, research and training; and increase service provision around the globe.

Visit the IAHPC Exhibit Booth to learn more and see how you can become involved!

WWW: HOSPICECARE.COM

The recent White Paper produced by the European Association for Palliative Care provided 13 Consensus Norms on what is good end of life care for this population, but the question of how these standards of care might be systematically implemented remains. Cases of excellent care are apparent, but evidence suggests this occurs despite systems and structures, not because of them.

We have designed a systems-based implementation strategy by assigning the Consensus Norms to sectors, thereby increasing accountability and leadership, and reducing gaps in service provision. Submitted to the Victorian Government, work has commenced in Australia and findings will be shared in this presentation. The strategy offers a workable solution to improving end-of-life outcomes for people with intellectual disability. This systems-model might suggest strategies to be considered in other jurisdictions.

**10:00 - 10:30  
REFRESHMENT BREAK**

Location: Main Ballroom 118

**POSTER VIEWING** (please see page 36 for a complete list of Poster Presentations)

Location: Main Ballroom 118

**10:30 - 11:15  
CLOSING PLENARY**

**Theme 5: Reorientating/Engaging Environments to be Responsive to Death, Dying, Loss and Bereavement – “New Connections and Community Practices: What’s Next for Public Health Palliative Care?”**

Presenter: Kerrie Noonan and Kathy Kortés-Miller

Location: Room 106 CDEFG

Marking the end of the 5<sup>th</sup> International Public Health Palliative Care Conference, Kathy and Kerrie have the unenviable task of examining the highlights of PHPC17 through the lens of conference theme: ‘Reorienting and engaging environments to be responsive to death, dying loss and bereavement’. We invite you to deeply consider your personal learning and the role that you have in leading compassionate communities work in your family, local community and workplace. Further, how can the PHPC community continue to work together and collaborate across the globe? What are our key challenges as researchers and practitioners as we move toward the next international conference? We will conclude with a call to action challenging all of us to return to our home communities fully aware that palliative care IS everyone’s business.

**Biography:** Kerrie Noonan is a social researcher at the school of social sciences and psychology, Western Sydney university and a clinical psychologist within the palliative care service at Liverpool Hospital, Sydney Australia. Kerrie has a long-standing interest in capacity building approaches to death, dying and bereavement and how people and communities can build their death literacy. Over the past 20 years, Kerrie has led the delivery of multiple community capacity projects, and she cofounded The GroundSwell Project and organizations

transforming end of life conversations into deep community engagement and social action. Kerrie is a member of the ‘caring at end of life research team’ and is an inaugural council member of Public Health Palliative Care International. She has a Masters degree in Clinical Psychology, a BA (Psychology), and a Grad. Dip. in Systemic Therapy (Family Therapy).

**Biography:** Dr. Kathy Kortés-Miller is an assistant professor at the School of Social Work and the Palliative Care Division Lead at the Centre for Education and Research On Aging and Health (CERAH) at Lakehead University, Thunder Bay, ON, Canada. Her research experience has been interdisciplinary and collaborative contributing to a broad range of fields of study including: social work, palliative care, interprofessional education, gerontology and LGBTQ. Kathy completed a two year research fellowship with the Canadian Frailty Network (CFN) and worked with Pallium Canada co-leading their Compassionate Communities initiative before becoming faculty at LU. She is also the past chair of the board of directors for Hospice Northwest.

**11:15 - 12:00  
ANNOUNCEMENTS**

**Breaking News from Public Health Palliative Care International**

You won’t want to miss hearing our colleagues from PHPCI announce the next host country for PHPC2019, nor their hot-off-the-press announcement on cities around the world who are achieving Compassionate City Charter status. Who will it be????!!

As a part of  Pallium Canada’s efforts to mobilize **COMPASSIONATE COMMUNITIES** across Canada

**PLEASE JOIN US AS A COMPASSIONATE COMMUNITIES COLLABORATOR, WE BELIEVE SUPPORTING ONE ANOTHER DURING CRISIS AND LOSS IS “EVERYONE’S BUSINESS”.**

**WE’RE LOOKING FOR:**

- **Pilot sites:** we’ll need locations to pilot our Compassionate Communities support kits.
- **Peer Reviewers:** content experts to review resources and tools within support kits.

**COMPASSIONATE COMMUNITIES SUPPORT KITS**

**START-UP**

Support those with a desire to start a **Compassionate Community** initiative. The kit will include tools to build community engagement and initial steps.

**WORKPLACE**

Designed for any size **workplace** with **supportive tools** for employers and employees including topics such as a summary of local policies and employment insurance, supporting employees during grief, how to find local supports and more.

**NEIGHBOURHOODS**

Provide **supports for neighbourhoods** which will encourage conversations around the journey with death, supporting neighbours and more.

For more information contact Pallium’s **Compassionate Communities National Lead Bonnie Tompkins: btompkins@pallium.ca or (613)-562-6262 ext. 1733 visit: pallium.ca/cc/**

For more on palliative care, check out Pallium’s resources and LEAP courses at [pallium.ca](http://pallium.ca)

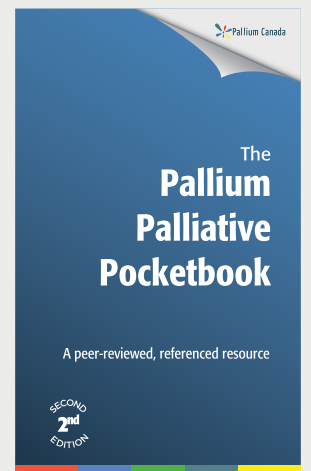
Pallium App



Pallium Palliative eBook 2nd Edition



Pallium Palliative Pocketbook 2nd Edition





## Poster Presentations Located in Main Ballroom 118

**Assessment of knowledge, attitude and practice towards palliative care among nurses working in governmental health institution, Mekelle, North Ethiopia 2015**

Presented by: Gebre Abyu

**It's Now or Never: Meaningful Conversations at End of Life**

Presented by: Kate Munro

**Impact of Cancer on Patients and Families**

Presented by: Habiba Omary Mahuna

**Understanding 'crises' in primary palliative care using the concept of total pain and the analysis of six cases in the community**

Presented by: Santiago Corrêa

**When Grieving is regarded as a luxury**

Presented by: Valerie Maasdorp

**Evaluation of palliative care awareness for oncology residents in 2016 at Joliot Curie Institute, Senegal**

Presented by: Coumba Gueye

**Compassionate Communities Multi-Sited Case Study – Contrasting Patients' experience and Providers' understanding of Compassionate Communities**

Presented by: Manjula Patel

**The Maple Key to Well-being Project**

Presented by: Mary Hocking

**Reducing financial and manpower problems to provide palliative care: Experience of an Indian NGO**

Presented by: Aditya Manna

**Wide gap of trained manpower in the field of palliative care in rural areas of West Bengal, India**

Presented by: Aditya Manna

**Structural barriers to Compassionate Communities**

Presented by: Shahaduz Zaman

**Closing the mental health treatment gap in palliative care: an education and research project**

Presented by: Janelle Wheat

**The use of health behavior theories in end-of-life care research**

Presented by: Anne-Lore Scherrens

**Uptake of policy measures to support palliative home care: a population-level study using linked administrative databases**

Presented by: Arno Maetens

**The place of palliative care (PC) in jurisdictions permitting assisted dying**

Presented by: Jan L Bernheim

**Managing the care and the death in the rural palliative care home setting –how do carers feel?**

Presented by: Caroline Short

**Caring to the beat: Expressing messages of support for kaiga (family) caregivers through the use of a music video**

Presented by: Ofa Dewes, Lisa Williams

**Policy measures to support palliative care in the home setting: a cross-country case comparison in Belgium, France and Germany**

Presented by: Arno Maetens

**Main Themes, Barriers and Solutions to Palliative and End-Of-Life Care in the English-speaking Caribbean. A Scoping Review**

Presented by: Nicholas Jennings

**What Does Hope Mean? Exploring Dr. Larry Librach's Legacy**

Presented by: Keri-Lyn Durant

**Developing local champions for palliative care**

Presented by: Zipporah Ali

**Palliative care and services in Bangladesh: elderly population in fringe**

Presented by: Sanchoy Kumar Chanda

**Public Health is Palliative Care: a solution to address the burden of non-communicable diseases in low resource settings**

Presented by: Victorina Ludovicky, Frank Manase, Dorris Frank

**The role of social work in public health approaches to palliative care: a case for wider involvement**

Presented by: Sally Paul, Rebecca Chaddock

**Lived experiences of healthcare workers with palliative care provision in humanitarian crisis**

Presented by: Kevin Bezanson

**Enhancing Care of the Frail Elderly: Roles for Public Health in Canada**

Presented by: Kevin Willison

**Exploring sexuality issues in women with cancer of the cervix at Tiyanjane Palliative Care Unit: Queen Elizabeth Central Hospital – Blantyre: Malawi**

Presented by: Mwandida Nkhoma

**The Good Wishes Project: An end-of-life intervention for individuals living in homelessness**

Presented by: Alissa Tedesco, Naheed Dosani

**What can learn from professional death industry, and how can they play their part in building a compassionate community?**

Presented by: Rebecca Lloyd

**Encouraging Community Participation In Setting Up Palliative care Clubs for Cancer patients in Lagos, Nigeria**

Presented by: Olanrewaju Onigbogi, Omobola Ojo

**A new method for developing Compassionate Communities and cities movement: "Todos Contigo" Programme (We are All With You): Experiences in Spain and Latin America countries.**

Presented by: Silvia Librada Flores, Emilio Herrera Molina, Cristina Castillo Rodriguez, Tamen Jadad García

**Ten Commandments in Palliative Care**

Presented by: Santiago Corrêa

**Seville is with you, Compassionate City: Preliminary Results**

Presented by: Cristina Castillo Rodriguez, Silvia Librada Flores, Emilio Herrera Molina, Tamen Jadad García

**Using Death Certificate Data to study Place Of Death in Trinidad & Tobago**

Presented by: Nicholas Jennings

**Community Engagement In Setting Bereavement Support Groups among residents of poor neighborhoods in Lagos, Nigeria**

Presented by: Modupe Onigbogi

**The effectiveness of private-public partnership in palliative care case of RD Congo"**

Presented by: Mukaya Kananga Simplicie, Kabamba Kananga Herve, Mubeneshayi Kananga Anselme

**What does the general public associate palliative care with and how does it help us to form partnerships with the community?**

Presented by: Monica Fliedner

**Integration of social care for palliative patients: a public health problem Case of RD Congo.**

Presented by: Kabamba Kananga Herve, Mukaya Kananga Simplicie, Mubeneshayi Kananga Anselme

**The community at the heart of the development of palliative care in R D Congo**

Presented by: Mubeneshayi Kananga Anselme, Kabamba Kananga Herve, Mukaya Kananga Simplicie

**Public Last Aid Course – Sharing knowledge and experiences about end-of-life care and strengthening local care networks**

Presented by: Klaus Wegleitner, Patrick Schuchter

**School Children and Their Understanding of "Major Change or Losses in Life" and How They Communicate With Their Parents and Teachers to Improve Coping and Life Skills.**

Presented by: Srini Chary

**Proving that Health Promoting Palliative Care at the End-of-Life is Possible: Creating a 'living while dying' guideline to respond to someone living with, caring for, or touched by delirium.**

Presented by: Shirley H. Bush, Pamela A. Grassau, Elise Skinner

**Strengthening palliative care support to rural communities**

Presented by: Michelle Rodda, Katie Durbin

**Determinants of Regret in Elderly Dialysis Patients in Singapore**

Presented by: Edlyn Gui Fang Tan

**Carpenter Hospice's Compassionate Community Volunteer Initiatives**

Presented by: Jennifer Sharman, Bonnie Tompkins

**Implementing Compassionate Communities in Canada: Emerging Approaches**

Presented by: Bonnie Tompkins

**Fostering Compassionate Education Across Canada**

Presented by: Bonnie Tompkins

**Pallium's Compassionate Schools Initiative**

Presented by: Bonnie Tompkins

**Pallium's Compassionate Communities Start-up Kit**

Presented by: Bonnie Tompkins

**Implantation of Palliative Care Facilities in Iran; New Experiences, Challenges, and success**

Presented by: Hamed Sattari-Bahabadi, Abdolrahim Hazini, Hosein Shirazi

**The Psychosocial and Economic Effects of Caring for Terminally Ill Patients: The Case of Hospice Africa Uganda**

Presented by: Nasur Buyinza

**Current Standards for Sidewalks in Canadian Urban Areas, Supportiveness to Healthy Aging and Recommendations**

Presented by: Haopu Ren



## Poster Presentations (cont'd) Located in Main Ballroom 118

### **Integration of Palliative Care in Public Health in Guanajuato Mexico**

Presented by: Gabriela Toledo

### **Increasing Early Support for Palliative Clients and Caregivers in our Community**

Presented by: Susan Cathro

### **Ensuring access to advance care plans across settings and providers**

Presented by: Brian Cassel

### **Colombia is With You, Compassionate Cities**

Presented by: Camila Ronderos

### **The Place of Parks and Nature in Palliative Care**

Presented by: Sonya Jakubec

### **Development and Evaluation of a Training Curriculum for Peer-Facilitated Advance Care Planning Workshops**

Presented by: Rachel Carter

### **Experiences of volunteer peer-facilitators of public Advance Care Planning workshops**

Presented by: Rachel Carter

### **The Efficacy of Peer-Facilitated Advance Care Planning Workshops for the Public**

Presented by: Rachel Carter

### **Advance Care Planning in British Columbia: A Population-based Study**

Presented by: Eman Hassan

### **Witness to Medically-Assisted Dying in Canada**

Presented by: Charles Walsh

### **The Challenges & Facilitators of Dying at Home with Dementia: A Systematic Review**

Presented by: Caroline Mogan

### **Family caregiver palliative care education in cancer patients**

Presented by: Shaimaa Ali

### **Achieving Sustainable Change - Using a population health approach to engage the general public, community professionals and the health care sector in Advance Care Planning**

Presented by: Sheli O'Connor, Ashley Tyrrell, Chris Bigelow

### **Ocular Status, Health seeking behaviors and Barriers to Uptake Eye Care Services among children of slum community in Chittagong, Bangladesh**

Presented by: Syed Mohammad Didarul Alam

### **Compassionate communities to care for the terminally ill in Medellín, Colombia**

Presented by: Camila Ronderos

### **Community inter-professional end-of-life care for persons with dementia and frailty: A scoping review**

Presented by: Madeline Press

### **Conversations that count: Harnessing the community to promote Advance Care Planning**

Presented by: Kate Grundy

### **Understanding existing interventions to address MDR TB symptom burden for palliative care patients in resource limited settings**

Presented by: Nasur Buyinza

### **Palliative approach in MS care trajectory: Views from home-based professionals**

Presented by: Jérôme Leclerc-Loiselle

### **Benefits of palliative care in Iran: A framework analysis**

Presented by: Abdolrahim Hazini, Sara Aghababa

### **Tuberculosis in Choke Chai hospital Nakhon Ratchasima province**

Presented by: Phiman Thirarattanasunthon, Niratchanu Thirarattanasunthon, Kamin Thirarattanasunthon

### **Spirituality: what public health can learn from New Zealand hospice and palliative care?**

Presented by: Richard Egan

### **Environmental Impact of Coal Clay Brick Kiln Exposure on the Reproductive Health of Adult Male Workers**

Presented by: Saadia Shahid

### **Paeditric palliative care out patient department for cancer patients**

Presented by: Abhishek Kumar

### **From the Inside Out – Building Compassionate Companies**

Presented by: Camila Ronderos, María Lucia Samudio



## Evaluation Form (Please note this will also be available on line in a survey format)

Please take a moment to complete this evaluation form and leave it in the designated boxes located at the registration or information booths. Your feedback assists us in planning future conference programs.

*Please circle your choice:*

Overall Conference Rating	Excellent	Good	Average	Fair	Poor
Conference Program Content	Excellent	Good	Average	Fair	Poor
Registration Process – on-line	Excellent	Good	Average	Fair	Poor
Registration Process – on-site	Excellent	Good	Average	Fair	Poor
Conference Website	Excellent	Good	Average	Fair	Poor
Exhibit Hall	Excellent	Good	Average	Fair	Poor
Poster Hall	Excellent	Good	Average	Fair	Poor
Audio/Visual	Excellent	Good	Average	Fair	Poor
Volunteers	Excellent	Good	Average	Fair	Poor
Social Activities/Entertainment	Excellent	Good	Average	Fair	Poor
Length of Conference	Excellent	Good	Average	Fair	Poor
Poster Hall	Excellent	Good	Average	Fair	Poor
Opportunity to Collaborate and share with colleagues	Excellent	Good	Average	Fair	Poor

What did you find **most** valuable about the conference?

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What did you find **least** valuable about the conference?

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Are there any issues, topics, or suggested speakers you would like to see highlighted at future conferences?

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Is location a factor in your decision to attend a CHPCA conference? If yes, please explain why.

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If the International Public Health and Palliative Care Conference was to return to Ottawa in 2019, would you attend?

Additional Comments:

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# 5<sup>th</sup> International Public Health & Palliative Care Conference

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