

## **30TH MEETING OF THE INTERNATIONAL WORK GROUP ON DEATH, DYING AND BEREAVEMENT**

June 23–29, 2018 Ivey Spencer Leadership Centre London, Ontario, Canada



# WELCOME FROM THE CHAIR

# The International Work Group on Death, Dying and Bereavement

Dear IWG colleagues and new friends,

Welcome to our 30th Meeting! Time flies. Since our first meeting at Columbia, Maryland in the USA in 1974, we have met nearly every 18 months. This practice has been kept for over four decades!

The topic of death and dying has become more visible in the past few years. The case of Alfie Evans in the UK caught international attention, spurring debate over the medical-ethical topic of death. The legalisation on assisted dying in some places and the promotion of advance care planning around the world, also pushes everyone to think about this taboo topic. Coupled with fatal natural disasters and terror attacks around the world, the topic of death and dying is becoming salient. Death educators, death-related practitioners, and researchers have prominent roles in these recent developments. Members of IWG will face new challenges as well as opportunities in their work. I am expecting the IWG meeting in London, Canada to be an excellent platform for exchanging ideas and sharing practice wisdom as we face the changing horizons of thanatology.

This is the 3rd time we are meeting in London, Ontario. The 9th and 14th meetings, which were held in 1986 and 1993 respectively, were also in this place under the leadership of Dr. John Morgan. Though he will not be with us physically this time, I am sure his spirit will be. Dr. Darcy Harris, a good friend and colleague of John, is the co-chair of the planning committee of this meeting. She infuses the rich history of thanatology at King's into this meeting. I am sure we will be inspired by the exchanges we will share together.

I would like to thank Dr. Darcy Harris, Dr. Phil Carverhill, and Dr. Susan Cadell for making this meeting possible within a tight schedule. Special thanks should also go to King's University College for their enormous support. Last but not least, I would like to express my sincere gratitude to Dr. Gerry Cox, Dr. Penny Tiedt, Dr. Robert Bendiksen, Dr. Rana Limbo, and Dr. Neil Thompson for their earlier work in preparing the proposal for La Crosse meeting.

It is my wish that you will have an inspirational and gratifying time at this meeting, with old and new friends with a shared mission.

Amy Chow, Chair - International Work Group on Death, Dying & Bereavement



## WELCOME FROM MEETING CO-CHAIRS

It is our pleasure to welcome you to London, Canada for the 30th Meeting of the International Work Group on Death, Dying, and Bereavement. Home of Western University and its affiliate, King's University College, London is also a "home" of sorts for IWG, as the 9th and 14th Meetings took place here, organized by Dr. John (Jack) Morgan, who also founded the Thanatology Program at King's.

Our venue, the Ivey Spencer Leadership Centre, is housed in a refurbished Georgian manor that originally belonged to the Spencer family. The centre is located just north of King's College and is situated on 30 beautifully landscaped acres that back onto the Thames River. You'll find walking and bicycle trails along the river that will also lead you to neighbouring sports fields and the "old north" section of the city.

We have put much thought into the speakers and topics that will be part of our Meeting, focusing on contemporary issues in Canada, such as the social determinants of end-of-life care, Medical Assistance in Dying (MAiD) legislation, the recently released report of the Truth and Reconciliation Commission with Indigenous Peoples in Canada, and the loss experiences of refugees from the Global South. We will also honour Jack Morgan's legacy and his appreciation of the work of Ernest Becker and Terror Management Theory, which we believe has particular relevance to our work and the difficult political climate in many places around the world.

London is known as "The Forest City" due to the large number of green spaces and parks that line the length of the Thames River as it passes through the city. In the summer, London is lush and green, and there are opportunities to enjoy many cultural, historical, and scenic offerings.

The land that we refer to as Canada was originally known as part of Turtle Island. We would like to acknowledge that the city of London is situated on the traditional territories of the Anishinaabeg, Haudenosaunee, Lunaapeewak and Attawandaron peoples who have longstanding relationships to the land and region. The local First Nation communities of this area include Chippewas of the Thames First Nation, Oneida Nation of the Thames, and Munsee Delaware Nation.

We also wish to express our deep gratitude to King's University College, for the gift of countless hours of time from staff and administration, and for their unwavering support and assistance with both the Meeting and the Pre-Meeting Conference. We also gratefully acknowledge the Grief & Loss Resource Committee of London and Area for the hours of volunteering to assist with both events. Finally, we want to acknowledge the diligent efforts of the La Crosse, Wisconsin IWG committee. King's and La Crosse share a long history of partnership through the annual International Death, Grief, and Bereavement Conference that was initially held at King's under Dr. Jack Morgan and later moved to the University of Wisconsin at La Crosse under the care of Dr. Gerry Cox.

It is our deepest wish that your time spent in London, Canada will be rich, with many opportunities to learn from each other, share our work, and enjoy our time together in this lovely setting.

Darcy Harris, Phil Carverhill, and Susan Cadell, 30th Meeting co-chairs



## **IWG HISTORY**

### The International Work Group on Death, Dying, and Bereavement: Early History, Recorded by John E. Fryer, M.D.

IWG grew out of an international convocation of workers in this field held at the Urban Life Center at Columbia, Maryland from November 14-19, 1974.

A few of the important events giving rise to the meeting included: Dr. Cicely Saunders's interest in care of the terminally ill starting in the 1940s culminating in the opening of St. Christopher's Hospice in 1967; Dr. Herman Feifel's 1956 symposium on death and dying at the American Psychological Association; Dr. John Hinton's work starting in 1958 that led to his book Dying (1966); Dr. Elisabeth Kubler-Ross's interviews with dying patients reported in On Death and Dying (1969) that resulted in great interest by the lay public; Dr. Colin Murray Parkes's interest in London widows and the publication of Bereavement (1972); a meeting in 1965 among Kubler-Ross, Saunders, and Parkes; conferences organized by Dr.Robert Fulton in Minnesota (1967) and Dr. Robert Kastenbaum in Detroit (1969), and a pivotal meeting in Berkeley, California.

The 1974 International Convocation, bringing together hospice care, research, death education, and concern with death and dying, was organized and funded by Ars Moriendi, a Philadelphia based organization devoted to the study of the professional response to death, dying, and bereavement. Ars Moriendi was a sub-task force of the Health Care and Human Values Task Force founded by Ken Spilman in 1968. Ars Moriendi sponsored several teaching conferences and seminars and was the hub of much activity in the area of death, dying and bereavement in the Philadelphia area between 1972 and 1976, when it died.

Meeting	Date	Location	Organiser(s)
I	Nov 14-19, 1974	Columbia, Maryland, USA	John Fryer
II	Jun 08-12, 1978	New Haven, Connecticut, USA	John Fryer
	Jan 02-06, 1979	Asilomar, Monterey, California, USA	John Fryer
IV	Jun 21-25, 1979	Cantracon, Québec, Canada	Balfour Mount
v	Jan 02-06, 1981	Asilomar, Monterey, California, USA	John Fryer
VI	Jun 20-24, 1982	Rosenon, Dalaro, Sweden	Loma Feigenberg
VII	Feb 24-26, 1984	Banff, Alberta, Canada	William Lamers
VIII	Aug 07-23, 1985	Wuhan, China, and Tokyo, Japan	Paul & Ida Martinson
IX	Jun 15-20, 1986	London, Ontario, Canada	John Morgan
x	Jun 15-18, 1987	London, England	Thelma Bates
XI	Jan 02-07, 1989	Asilomar, Monterey, California, USA	William Lamers
XII	Jun 14-19, 1990	Oslo, Norway	Ulla Qvarnstrom
ХШ	Mar 15-20, 1992	Albufeira/Montechoro, Portugal	John Morgan
XIV	May 11-16, 1993	London, Ontario, Canada	John Morgan
xv	Jun 25-30, 1995	Oxford, England	John Morgan
XVI	Oct 29-Nov 04, 1996	Delphi, Greece	Danai Papadatou
XVII	Jul 19-24, 1998	Sydney, Australia	Michael Stevens
XVIII	Sep 25-30, 1999	Boulder, Colorado, USA	Marcia Latanzi-Licht
XIX	Jun 10-15, 2001	Maastricht, Netherlands	Herman van der Kloot Meijburg

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# **IWG HISTORY**

Meeting	Date	Location	Organiser(s)
xx	Sep 24–30, 2002	Oslo/Bergen, Norway	Britt Hysing-Dahl
XXI	Mar 28—Apr 02, 2004	Tucson, Arizona, USA	Bob & Marcy Wrenn
XXII	Dec 04–09, 2005	Hong Kong, China	Cecilia Chan
XXIII	Jun 17–22, 2007	Sao Paulo, Brazil	Maria-Helena Franco
XXIV	Sep 21–26, 2008	Provincetown, Massachusetts, USA	Carol Wogrin
XXV	May 09—14, 2010	Bergisch Gladbach, Germany	Fritz Roth
XXVI	Oct 23–28, 2011	Melbourne, Australia	Christopher Hall
XXVII	Apr 28—May 03, 2013	Victoria, British Columbia, Canada	Betty Davies & Tom Attig
XXVIII	Feb 1–6, 2015	Taipei, Taiwan	Chun-Kai Fang
XXIX	November 6—11, 2016	Dunblane, Scotland	John Birrell
xxx	June 24—29, 2018	London, Ontario, Canada	Darcy Harris, Phil Carverhill, & Susan Cadell

IWG Board Chairs: 1974–2018 (elected at IWG meetings)	
1974–1979	Dr. John Fryer (Columbia, USA; New Haven, USA; Asilomar, USA)
1979–1980	Dr. Michael A. Simpson (Asilomar, USA)
1980–1981	Mr. Henry Wald (Quebec, Canada; Asilomar, USA)
1981–1984	Dr. William Lamers, Jr. (Asilomar, USA; Rosenon, Sweden; Banff, Canada)
1984–1985	Dr. Jeanne Quint Benoliel (Banff, Canada; Wuhan, China & Tokyo, Japan)
1985–1989	Dr. Thelma Bates (Wuhan, China & Tokyo, Japan; London, Canada; London, UK; Asilomar, USA)
1989–1993	Dr. Charles Corr (Asilomar, USA; Oslo, Norway; Albufeira/Montechoro, Portugal; London, Canada)
1993–1995	Mr. David Adams (London, Canada; Oxford, UK)
1995–1998	Dr. Ken Doka (Oxford, UK; Delphi, Greece; Sydney, Australia)
1998–2002	Dr. Danai Papadatou (Sydney, Australia; Boulder, USA; Oslo/Bergen, Norway)
2002–2005	Dr. Robert Neimeyer (Oslo/Bergen, Norway; Tucson, USA; Hong Kong, China)
2005-2008	Dr. Betty Davies (Hong Kong, China; Sao Paulo, Brazil; Provincetown, USA)
2008–2010	Dr. Stephen Connor (Provincetown, USA; Bergisch Gladbach, Germany)
2010–2013	Mr. Christopher Hall (Bergisch Gladbach, Germany; Melbourne, Australia; Victoria, Canada)
2013–2016	Dr. Philip Carverhill (Victoria, Canada; Taipei, Taiwan; Dunblane, Scotland)
2016	Dr. Amy Chow (Dunblane, Scotland; London, Canada)

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IWG Secreta	iriat: 1987–2018
1986–1997	Dr. John Morgan (Canada)
1997–2005	Dr. Robert Bendiksen (USA)
2005–2006	Dr. Gerry Cox (Interim) (USA)
2006–2013	Dr. Stephen Fleming (Canada)
2013–current	Mr. Christopher Hall (Australia)

IWG Board 2018			
Chair	Dr. Amy Chow	Hong Kong	chowamy@hku.hk
Vice-Chair	Dr. Donna Schuurman	Portland, USA	donna@dougy.org
Secretary/Treasurer	Mr. Christopher Hall	Melbourne, Australia	c.hall@grief.org.au
Membership Chair	Dr. Leslie Balmer	Toronto, Canada	lebalmer@rogers.com
Feifel Award Committee Chair	Dr. Philip Carverhill	Saskatoon, Canada	dr.phil.carverhill@shaw.ca
	Dr. Nancy Hogan	San Diego, USA	nancyhogan1@mac.com
	Ms. Chikako Ishii	Tokyo, Japan	cishii@telljp.com
	Dr. Astrid Ronsen	Fjellhammer, Norway	astrid@communicare.no
	Dr. Jane Skeen	New Zealand	JaneS@adhb.govt.nz
	Dr. Ruthmarijke Smedig	The Netherlands	rmsm1@gmx.net

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Incoming Board Members		
Dr. Amy Chow	Hong Kong, China	chowamy@hku.hk
Dr. Stephen Connor	Fairfax Station, USA	sconnor@thewhpca.org
Dr. Inge Corless	Boston, USA	icorless@mghihp.edu
Dr. Andy Ho	Singapore	andyhyho@ntu.edu.sg
Dr. Regina Szylit Bousso	Sao Paulo, Brazil	szylit@usp.br

Note: Terms ending at the conclusion of the London Meeting for Board Members Carverhill, Hogan, Ishii, and Skeen.

### The Herman Feifel Award for Achievement in Thanatology

#### **Statement of Purpose**

The Feifel Award recognizes exceptional achievement in thanatology on the part of individuals (as opposed to organizations) who have made distinctive contributions to the field, usually of a longstanding nature.

Criteria for such recognition of merit encompass all forms of achievement in the field, whether clinical, organizational or scholarly, in keeping with the spirit of our organization.

Herman Feifel Award Recipients		
2004	IWG Tucson, USA	Jeanne Quint Benoliel
2005	IWG Hong Kong, China	Florence Wald
2007	IWG Sao Paulo, Brazil	Robert Fulton
2008	IWG Provincetown, USA	Balfour Mount
2010	IWG Bergisch Gladbach, Germany	William Worden
2011	IWG Melbourne, Australia	William Lamers
2011	IWG Melbourne, Australia	Colin Murray Parkes
2013	IWG Victoria, Canada	Sandra Bertman
2013	IWG Victoria, Canada	Phyllis Silverman
2015	IWG Taipei, Taiwan	Ida Martinson
2016	IWG Dunblane, Scotland	Charles Corr

## PROGRAM

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Saturday, June 23, 2018	
	Pre- Meeting Conference
08:00 - 16:30	<b>Dying Matters: Current Issues and Approaches in Hospice Palliative Care</b> Labatt Hall, King's University College
	Hotel Shuttle departs from Ivey Spencer Leadership Centre at 7:45 and 8:00 AM and returns back from King's at the end of the day
18:30 - 21:30	IWG Board Meeting, Private Dinner (meet at 18:15 in front of Ivey Spencer)
Sunday, June 24, 2018	3
09:00 - 15:30	IWG Board Meeting Pine Room
14:00 – 17:00	Registration of participants North Atrium Foyer
16:00 – 17:00	Orientation for Member Candidates and Invited Guests Chaired by IWG Board Cherry Room
16:00 – 17:00	Orientation for Accompanying Others Iris Room
17:45	<ul> <li>Opening Ceremony</li> <li>Peter Fragiskatos, MP, London North Centre</li> <li>Dr. Joseph Michalski, Associate Dean, King's University College</li> <li>Bill Hill, Ro'nikonkatste (Standing Strong Spirit) from the Mohawk Nation Asher's Dining Room</li> </ul>
18:00 - 20:00	Dinner
20:00 - 21:30	Workgroup disposition and allocation All IWG Members, Candidates, and Invited Guests to attend Amphitheatre A
21302300	Social time Asher's Lounge

#### Monday, June 25, 2018 Breakfast 06:30 - 08:30 Asher's Dining Room Mindfulness Meditation (Optional) Brad Hunter, King's University College 07:30 - 08:00 Willow Work group session 1 09:00 - 10:30 (All participants attend their chosen group, locations to be assigned) Morning break and refreshments 10:30 - 11:00 Poster Presentation: Memorial Tattoos Dr. Susan Cadell, Renison University College, University of Waterloo, Canada Plenary 1 Reframing the Social Determinants of Health: Towards Palliative Care Equity in our Communities 11:00 - 12:30 Naheed Dosani, M.D. Amphitheatre A Lunch 12:30 - 13:30 Asher's Dining Room Work group session 2 14:00 - 15:30 Afternoon refreshments 15:30 - 16:00 North Atrium Foyer 1600 – 1730 Work group session 3 **Time to Remember** 17:45 - 18:45 **Cherry Room** Dinner 19:00 – 20:30 Asher's Lounge **Special Presentation** Fatal Attraction: The Politics of Mortal Terror 20:15 - 22:00 Sheldon Solomon, Ph.D. Amphitheatre A Social time 22:00 - 23:00 Tuesday, June 26, 2018 Breakfast 06:30 - 08:30 Asher's Dining Room Mindfulness Meditation (Optional) Brad Hunter, King's University College 07:30 - 08:00 Willow Work group session 4 09:00 – 10:30

Morning break and refreshments
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10:30 - 11:00	Poster Presentation - Moments Frozen in Time: Notification from the Point of View of the Notifier. Dr. Ronit Shalev and Dr. Eti Ablin, The Center for Academic Studies, Or Yeuda, Israel North Atrium Foyer
10:30 - 11:00	IWG Membership Candidates Meet with IWG Board Willow
11:00 - 12:30	Plenary 2 Towards Truth and Reconciliation: Feeding the Spirit through Acts of Reclaiming and Acknowledgment Leslee White Eye Amphitheatre A
12:30 - 13:30	Lunch Asher's Dining Room
14:00 - 15:30	Work group session 5
15:30 – 16:00	Afternoon refreshments North Atrium Foyer
16:00 – 17:30	Work group session 6
16:00 – 17:30 18:00 – 19:15	Work group session 6 Dinner Asher's Lounge
	Dinner
18:00 – 19:15	Dinner Asher's Lounge Works in Progress (see pages 21-26 for detailed descriptions) Room 1: Amphitheatre A—Chair: Dr. Leslie Balmer Helping Teens Grieve: The Adolescent Grief Project Speaker: Dr. Chris Davis,
18:00 – 19:15 19:15 – 20:45	Dinner Asher's Lounge Works in Progress (see pages 21-26 for detailed descriptions) Room 1: Amphitheatre A—Chair: Dr. Leslie Balmer Helping Teens Grieve: The Adolescent Grief Project Speaker: Dr. Chris Davis, Carleton University, Ottawa, Canada Development and Testing of the Hogan Inventory of Bereavement (child and
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18:00 – 19:15 19:15 – 20:45 19:15 19:45 20:15	Dinner Asher's Lounge Works in Progress (see pages 21-26 for detailed descriptions) Room 1: Amphitheatre A—Chair: Dr. Leslie Balmer Helping Teens Grieve: The Adolescent Grief Project Speaker: Dr. Chris Davis, Carleton University, Ottawa, Canada Development and Testing of the Hogan Inventory of Bereavement (child and adolescents) Speaker: Dr. Nancy Hogan, Loyola University, Chicago, USA A Phenomenological Inquiry into "Living with Dying" Speaker: Geok Ling Lee, Department of Social Work, National University of Singapore Room 2: Amphitheatre B – Chair: Dr. Philip Carverhill Lived Experience of Parental Bereavement after the Death of a Child: A Qualitative Systemic Review Speaker: Dr. Andy Hau Yan Ho, Nanyang Technological

Tuesday, June 26,	2018
19:15 19:45 20:15	Room 3: Cherry Room– Chair: <b>Mr. Christopher Hall</b> Palliative Care Services and a 'Good Death:' Learning from Family Caregivers Speaker: <b>Dr. Liz Lobb</b> , Calvary Health Care/University of Notre Dame, Australia Life Fulfilled Speaker: <b>Herman Meijberg</b> , Netherlands Pacific Families' Experiences when their Child with Cancer Died - The Tongan Perspective Speaker: <b>Dr. Jane Skeen</b> , Starship Blood and Cancer Centre, Starship Children's Hospital, Auckland, New Zealand
21:30 - 23:00	Social time Asher's Lounge
Wednesday, June	27, 2018

06:30 - 08:30	Breakfast
07:30 - 08:45	IWG Board Meeting Pine
07:30 - 08:00	Mindfulness Meditation (Optional) Brad Hunter, King's University College Willow
09:00 – 10:30	Work group Session 7
10:30 - 11:00	Morning break and refreshments North Atrium Foyer
11:00 - 12:30	Plenary 3 Refuge in a New Land: What has been Lost and Gained? Glen Pearson Amphitheatre A
	<ul> <li>Lunch and afternoon excursions</li> <li>NOTE: Stratford excursion participants will need to take a boxed lunch and meet at the lobby by 12:30 for prompt departure. All others will meet in the lobby at 2:00 for departure.</li> <li>1. St. Joseph's Hospice/Parkwood Institute Palliative Care Unit (walk together to St. Joseph's Hospice and then bus to Parkwood Institute). Local Guide:</li> </ul>
12:30 -	<ul> <li>Darcy Harris</li> <li>2. Ska Nah Dhot Indigenous Village—Local Guide: Carrie Arnold,</li> <li>3. Stratford City and Performance—Local Guide: Daniel Lockwood</li> <li>4. Port Stanley Visit and Shopping—Local Guides: Leslie Misurak and Cathy Walsh</li> <li>5. Downtown London tour—Local Guide: Mary Lee Felder</li> <li>*Dinner on your own; Please see sign up lists for restaurant suggestions.</li> <li>Stratford and Port Stanley tour groups expected to have dinner at the venue.</li> </ul>
20:30 – 22:00	Film Night: "Eve and the Firehorse" Chair: Darcy Harris Eve and her family navigate adjusting to life in Canada as they encounter change, loss, and transition from many sources. Cherry Room

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Thursday, June 28,	2018
o6:30 – 08:30	Breakfast Asher's Dining Room
07:30 – 08:00	Mindfulness Meditation (Optional) Brad Hunter, King's University College Willow
09:00 – 10:30	Work group session 8
10:30 - 11:00	Morning break and refreshments Poster Presentation - Relationships Between Parents and Healthcare Providers in Children's End-of- Life Care in an Oncology Hospital: Encounters that Survive Through Time Dr. Regina Szylit-Bousso, University of Sao Paulo, Brazil
11:00 - 12:30	Work group session 9
12:30 - 13:30	Lunch Asher's Dining Room
13:30 - 14:00	Group photo (outside the registration desk of the Hotel)
14:00 - 15:30	Work group session 10
15:45 – 16:30	IWG Business Meeting Presentation by Organizer(s) of the next IWG Meeting Coffee ice cream (bring back into Amphitheatre to eat) Amphitheatre A
16:45 - 17:45	The Herman Feifel Award for Achievement in Thanatology Amphitheatre A
17:45 – 18:15	Free time
18:30	Transportation to Westhaven Country Club for Gala Dinner Meet outside registration desk
18:45	Welcome Ana Barientos, violinist Indigenous Dance Demonstration Westhaven Country Club
18:45 - 22:30	Farewell Gala Dinner with dancing and cash bar Live Band: 2 Man Advantage Westhaven Country Club
	Two bus departure times from dinner back to Ivey Spencer Leadership Centre: 21:00 and 22:30

Friday, June 29, 2018		
o6:30 — o8:30	Breakfast Asher's Dining Room	
07:30 – 08:00	Mindfulness Meditation (Optional) Brad Hunter, King's University College Willow	
09:00 – 10:30	Work group session 11	
10:30 - 11:00	Morning break and refreshments North Atrium Foyer	
11:00 - 13:00	<ul> <li>Final Plenary:</li> <li>Reports from workgroups</li> <li>Closing ceremony and adjournment of meeting Amphitheatre A</li> </ul>	
13:00 - 14:00	Lunch Asher's Dining Room	
14:30	London 2018 Co-Chairs Meeting Pine	

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# PLENARY PRESENTATIONS

#### Monday, June 25, 11:00 Plenary 1 Reframing the Social Determinants of Health: Towards Palliative Care Equity in Our Communities Speaker: Dr. Naheed Dosani

How do we value dignity at the end-of-life? Is it the same for everyone? There is growing recognition that what makes Canadians sick, is more than just biology or genetics. In fact, it is estimated that up to 60% of what causes us illness, is related to how we live, learn, work and play. These factors, known as the social determinants of health, are often overlooked in our Palliative Care delivery systems. Meanwhile, it is well known that Canada's marginalized populations, including the homeless & vulnerably housed and communities with mental illness & addictions, suffer from higher morbidity and mortality due to illnesses often stemming from social and societal circumstances. All the while, dying in social isolation, falling through the cracks, with few people around them, very few supports and often, with a lack of dignity. Through a



health equity and human rights lens, this plenary address will highlight the unique challenges faced by Canada's most vulnerable communities when dealing with life-limiting illnesses, describe innovative approaches to Palliative Care delivery at the micro, meso and macro levels and challenge our thinking around traditional care models. By dissecting the way poverty, housing insecurity, isolation and other social ailments impact the palliative journey in our communities; we may be able to actualize our full potential, flipping conventional approaches on their head, to provide equity for individuals from all walks of life. In our society, it is clear that we live differently. But, should we really die differently?

Dr. Naheed Dosani is a passionate and respected advocate for marginalized and vulnerable populations with palliative needs. He is a Palliative Care Physician at Inner City Health Associates and the William Osler Health System, where he is also Medical Education Lead. Founder and team leader of Toronto-based Palliative Education and Care for the Homeless (PEACH), he treats an often neglected population with dignity and compassion, whether in a shelter or on the street. A first in Canada, the model of care has inspired similar programs in Edmonton, Calgary, Victoria and Seattle. Dr. Dosani has been recognized by Canada's Governor General, with the Meritorious Service Cross for his work as a trailblazer in palliative care. In 2015 he received the Early Career Development Award from the College of Family Physicians of Canada. Naheed's compelling TEDx talk, 'What's a Life Worth?' has received over 3500 views on YouTube and has become the 'gold standard' tool to educate and highlight the importance of health equity in Hospice Palliative Care. Dr. Dosani is Assistant Clinical Professor in the Division of Palliative Care, Faculty of Health Sciences at McMaster University, Lecturer in the Department of Family & Community Medicine at the University of Toronto, and Medical Director of Palliative Care for the Central West Local Health Integration Network. He was instrumental is founding Journey Home Hospice for the homeless and serves as an advisor to 17 • IWG • June 2018 Students for Medicare.

#### Monday, June 25, 22:15 Special Presentation Fatal Attraction: The Politics of Mortal Terror Speaker: Dr. Sheldon Solomon

"Helpless and fearful people are drawn to magical figures, mythic figures, epic men who intimidate and darkly loom." Don DeLillo, White Noise

Pundits and academics have offered a variety of explanations for Donald Trump's dramatic political ascent. Such explanations are, however, incomplete without considering the role of unconscious death anxiety on human behavior in general and in forging a bond between charismatic leaders and their followers in particular. Sociologist Max Weber and cultural anthropologist Ernest Becker have argued that in times of historical upheaval, people are prone to embrace charismatic politicians to manage existential terror. This presentation will explore an empirically corroborated analysis of how Donald Trump inflamed and exploited existential anxieties to win the 2016 U.S. presidential



election. We will consider the implications of these findings for practitioners in the field of death, dying, and bereavement, and for democratic societies.

**Dr. Sheldon Solomon** is Professor of Psychology at Skidmore College. His studies of the effects of the uniquely human awareness of death on behavior have been supported by the National Science Foundation and Ernest Becker Foundation, and were featured in the award-winning documentary film *Flight from Death: The Quest for Immortality*. In addition to research and numerous published studies related to Terror Management Theory and Mortality Salience, He is co-author of *In the Wake of 9/11: The Psychology of Terror and The Worm at the Core: On the Role of Death in Life*. Dr. Solomon is an American Psychological Society Fellow, and a recipient of an American Psychological Association Presidential Citation (2007), a Lifetime Career Award by the International Society for Self and Identity (2009), and the Association of Graduate Liberal Studies Programs Annual Faculty Award (2011).

#### Tuesday, June 26, 11:00 Plenary 2: Towards Truth and Reconciliation: Feeding the Spirit through Acts of Reclaiming and Acknowledgment Speaker: Leslee White Eye

Without a great deal of confidence, patience, and perseverance, self-identifying as Indigenous could easily take its toll on one's sense of self in Canada. So where does one go to find truth about who you are as an Anishinaabe Kwe in Canada? Leslee will share how learning about her people's ways of knowing, particularly the importance of spirit to heal, led to her own truth and reconciliation. Leslee will draw upon the healing work taking place in First Nation communities to shed light on ways Canadians might find truth and reconciliation with a Canada they thought they knew.

**Leslee White-Eye** is the former Chief of the Chippewas of the Thames First Nation and the nation's 1st elected woman chief. She is Anishinaabe Ojibwe Kwe, mother, wife, and community advocate. Prior to being Chief, Leslee was an Education Officer for the Ontario Ministry of Education writing curriculum, supporting school boards in Indigenous education, and coordinating the development of the



first two Native Studies textbooks to be added to the Trillium List, Ontario's approved textbook list.

Leslee was recently honoured to receive a Honourary Doctorate of Laws from Western University. She earned her Political Science and Master of Education degrees at the University of British Columbia in Vancouver and her teaching degree at Nipissing University in North Bay. She has served as a trustee on Chippewa's Thunderbird Trust for eight years. She sits as a Board member of Kings' University College in London, Ontario and as Chair of the Board of the Wuulaawsuwiikaan Healing Lodge at Munsee-Delaware First Nation education. She currently works in Indigenous education and governance to eight First Nations in Ontario seeking jurisdiction over education.

#### Wednesday, June 27, 11:00 Plenary 3 Refuge in a New Land: What Has Been Lost and Gained? Speaker: Glen Pearson

Grief itself is as portable as the person bearing it, always accompanying the individual across borders, across time, across the spectrum of humanity. If we fail to understand that reality, any attempts to assist can never be complete.

There is no escape from grief; it is the constant companion of the person bearing it, regardless of where they travel or their change in circumstances. They escape from one place to the next, only to discover that it's already there, guised in more affluent garb, or more materialistic plenty. Grief is a human possession, not to be found anywhere but in the human heart - not in possessions or location.



This plenary will explore the losses and gains experienced by many refugees to Canada. The homeland is ultimately the place where the ancestors rest and the natural community where one grieved. Where do we go now to grieve? - the sojourner asks. The new land of Canada represents a bigger, broader world that many were not able to achieve before, but this can also be intimidating. There may paradoxically be fear in living out newfound freedom and respect.

Besides the losses caused by war and conflict, refugees may grieve the loss of ability to live out customs and traditions, while at the same time gaining a sense of peace and hope, including the hope of returning home one day.

**Glen Pearson** has been Executive Director of the London Food Bank for 31 years. He also helped to lead the Ontario Association of Food Banks for three years. Along with his wife, Jane Roy, Glen has directed the non-governmental organization Canadian Aid for Southern Sudan for 18 years. In that time, they have built ten primary schools, one high school, and established a number of women's programs. Glen was a 30-year career firefighter and retired from the force when he became a Member of Parliament for London North Centre from 2006-2011. He was awarded an honourary doctorate from Western University in 2014 and an honourary diploma from Fanshawe College the following year. Glen continues to serve in numerous capacities in the city of London, Ontario and lives happily with his wife and their 3 children they adopted from South Sudan.

# **WORKS IN PROGRESS**

#### Tuesday, June 26, 19:15–20:45

Room 1: Amphitheatre A (Dr. Leslie Balmer, chair)

#### 19:15 - Helping Teens Grieve: The Adolescent Grief Project Speaker: Dr. Chris Davis, Carleton University, Ottawa, Canada

#### Abstract:

Approximately 20-40% of high school students will experience bereavement before they graduate, and for many, this loss is their first grief experience. Several studies suggest that many adolescents have great difficulty with these losses, perhaps in part because they are unprepared and do not know where to turn for help. The purpose of the Adolescent Grief Project was to develop a series of brief, focused, evidence-based videos for adolescent youth, from the perspectives of youth, to access in order to help them navigate their way through the experience of grief following the loss of a parent. We present some of the short videos and offer reflections on the challenges and opportunities in creating this Knowledge Exchange product.

#### Room 2: Amphitheatre B (Dr. Philip Carverhill, chair)

#### 19:15 - The Lived Experience of Parental Bereavement after the Death of a Child: A Qualitative Systemic Review

#### Speaker: Dr. Andy Hau Yan Ho, Nanyang Technological University, Singapore

#### Abstract:

The objective of this qualitative systemic review is to obtain a comprehensive and consolidated understanding of the lived experience of bereaved parents who have suffered and endured the death their child due to a life limiting illness. Findings will be discussed in the light of existing literature with practical recommendations for enhancing parental bereavement support services in contemporary societies. Six hundred and ninety-four articles were identified and screened, and 22 qualitative studies that fit under the sampling frame were selected for full text data analysis using Thematic Synthesis.

Co-authors: Geraldine Tan-Ho, Ping Ying Choo, Oindrila Dutta; Nanyang Technological University, Singapore

#### Room 3: Cherry Room (Mr. Christopher Hall, chair)

#### 19:15 Palliative Care Services and a 'Good Death:' Learning from Family Caregivers Speaker: Dr. Liz Lobb, Calvary Health Care/University of Notre Dame, Australia

#### Abstract:

There is a need for research to identify predictors of poor health outcomes in palliative care family care-givers and to identify those most at risk. This study explored two potentially protective factors, namely 'a good death' and contact with palliative care, and their role in the physical and psychological outcomes of family care-givers of women with ovarian cancer. Key themes related to effective service provision to ensure 'a good death' included; the importance of achieving the preferred place of death; the availability and timing of palliative care delivery for pain and symptom relief and the importance of open, sensitive and timely communication.

Co-author(s): Dr. Jane Mowll, University of New South Wales, Professor Phyllis Butow, University of Sydney; Ms. Naomi McGowan, University of New South Wales, Australia.

#### Room 1: Amphitheatre A (Dr. Leslie Balmer, chair)

#### 19:45 Development and Testing of the Hogan Inventory of Bereavement (child and adolescents) Speaker: Dr. Nancy Hogan, Loyola University, Chicago, USA

#### Abstract:

The purpose of this presentation is to provide data on the development, reliability, and validity testing of a short form of the Hogan Sibling Inventory of Bereavement (HSIB), renamed the Hogan Inventory of Bereavement – Short Form (Child and Adolescent) (HIB-SF-CA). Instrument items were originally derived from children's and adolescent's stories of grieving following the death of their brother or sister. The strong psychometric evidence for the 21 item HIB-SF-CA permits researchers to raise innovative research questions related to grief and personal growth. The reduced number of items lessens response burden for participants and increases the utility of the instrument.

Co-author(s): Lee Schmidt, PhD, Loyola University, Chicago, USA and Katianne Sharp, PhD, Ohio State University, USA.

#### Room 2: Amphitheatre B (Dr. Philip Carverhill, chair)

#### 19:45 A Visit to The Museum of Broken Relationships Speaker: Dr. Phyllis Kosminsky, College of New Rochelle, New York, USA

#### Abstract:

The "Museum of Broken Relationships," housed in Croatia, consists of holdings of donations from people around the world, with descriptions stories of loss, missed opportunities, failures of communication, and regrets shared by contributors. In its purpose and its execution, the Museum embodies many of the principles that underlie or animate our work: There are examples of narrative reconstruction, meaning making, and a recognition that sometimes when a relationship ends we are better off releasing, rather than continuing, the bond. I would like to share the story of the museum, images of the exhibits, and reflections on why this unlikely collection has captured the attention of people around the world.

#### Room 3: Cherry Room (Mr. Christopher Hall, chair)

#### 19:45 Life fulfilled Speaker: Herman Meijberg

#### Abstract:

In the ongoing debate in the Netherlands about decision-making at the end of life, one of the political parties drafted a proposal to include the possibility of legitimizing a request for euthanasia on the basis of the criterion of a "life fulfilled." Under the present criteria, euthanasia can only be considered under the strictest of guidelines and conditions. A request can only be considered if the illness is irreversible, the suffering is unbearable, death imminent and any further treatment futile. But what if someone seeks to die when those criteria do not apply to his/her situation? In the presentation, we will discuss literature/interviews to identify both external and internal factors that lead people to consider this solution.

#### Room 1: Amphitheatre A (Dr. Leslie Balmer, chair)

#### 20:15 - A Phenomenological Inquiry into "Living with Dying" Speaker: Dr. Geok Ling Lee, National University of Singapore

#### Abstract:

Maintaining a good quality of life is highly emphasized in the delivery of palliative care services to patients who are terminally ill. Yet, there remains a need to understand what it takes to help the terminally-ill patients live well while dying. This study aimed to understand the lived experiences of patients receiving palliative care service. Questions asked included, what troubled them? What made life worth living for them? How did they make sense of their life journey over the course of illness? What helped or would have helped them to be congruent with themselves as they faced the impending death? Findings of the study will be presented and discussed.

#### Room 2: Amphitheatre B (Dr. Philip Carverhill, chair)

#### 20:15 Political Grief Speaker: Dr. Darcy Harris, King's University College at Western University, London, Canada

#### Abstract:

Political grief can be defined as a poignant sense of assault to the assumptive world for those who experience struggle with the ideology and practices of their governing bodies and those who hold political power. At the heart of political grief is a sense of despair due to the loss of deeply-held assumptions about what is morally right, the perceived loss of control over external forces that have a personal impact, and the views of self and others as ineffective to bring about change for the better. This presentation will discuss current theories that have been proposed to explain the current political climate and their relationship to loss, grief, and bereavement theory.

#### Room 3: Cherry Room (Mr. Christopher Hall, chair)

20:15 - Pacific Families' Experiences When their Child with Cancer Died the Tongan Perspective Speaker: Dr. Jane Skeen, Starship Blood and Cancer Centre, Starship Children's Hospital, Auckland, New Zealand

#### Abstract:

Tongan resident families were interviewed in Tonga and New Zealand resident families, who identified as Tongan were interviewed in New Zealand. The findings of the two cohorts will be presented. Similar themes emerged in both cohorts, related to knowing that their child would die, the events at the time of the death, funeral preparations, after the funeral, memorialising their child, and making meaning of the life their child lived. This study has gained some insight into the Tongan perspectives of the rituals around death, dying and bereavement when a child dies of cancer.

Co-author(s): Dr. Toakase Fakakovikaetau, Port Vila Central Hospital, Vanuatu, formerly Paediatrician, Vaiola Hospital, Tonga; Jess Jamieson, formerly Palliative Care Social Worker, Starship Children's Hospital, Auckland, New Zealand; and Sitela Payne Vimahi, Fanau Ola Senior Social Worker, Pacific Health Development, Counties Manukau Health, Auckland, New Zealand.

#### Poster Presentations (displayed in the North Atrium Foyer)

#### Monday, June 25, 10:30 Memorial Tattoos Dr. Susan Cadell, Renison University College, University of Waterloo, Canada

#### Abstract:

The overarching objective of this research was to investigate the experience and meaning of memorial tattoos through the photo documentation of such tattoos and the collection and analysis of the narratives that go along with them. The act of choosing and getting a memorial tattoo can be therapeutic in that it is a connection to the person who died. This research deepens our understanding of the social dimensions of meaning making within the grief experience. Memorial tattoos depict the relationship with the deceased on the outside, on the skin: they ink the bond with the person who died.

Co-author(s) and Affiliation(s): Melissa Reid Renison and College Renison University College Lambert, Deborah Davidson, Mary Ellen Macdonald, Marcel O'Gorman, Melanie Baljko

#### Tuesday, June 26, 10:30 Moments Frozen in Time: Notification from the Point of View of the Notifier. Dr. Ronit Shalev and Dr. Eti Ablin, The Center for Academic Studies, Or Yeuda, Israel

#### Abstract:

In our research, we examine the moment of notification from the point of view of the notifier. In preliminary research we conducted, notifiers reported that at the end of each notification delivery, they felt a sense of discomfort, sadness, distress, and relief that the task was over. In earlier research about death notifiers in the Israeli Defence Forces, the notifiers reported only minimal emotional pain. One must take into account that the notifiers may not have expressed their emotional distress due to the appearance of strength they display as part of the task. We will present updated research data which will be obtained after analysis of the results.

#### Thursday, June 28, 10:30 Relationships Between Parents and Healthcare Providers in Child's End-of-Life Care in an Oncology Hospital: Encounters that Survive Through Time Regina Szylit—Bousso, University of Sao Paulo, Brazil

#### Abstract:

There are few evidences which explore how these relationships during the child's last hospitalization influence familial adaptation after loss. This study was undertaken to interpret parents' experience in their relationship with healthcare providers during the child's end-of-life with cancer in the hospital. Looking into the relationship between parents and providers integrating it with caring science provides a basis for non-positivist paradigms which are urgent in end-of-life situations. This study aims to contribute to end-of-life nursing policies in recognizing the components to improve the quality of the relationships as a starting point for care which will allow families to have a safe base while experiencing the child's illness and the bereavement process.

Co-author: Mairara Dos Santos, University of Sao Paulo, Brazil.

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# **GENERAL INFORMATION**

#### **Hotel Information**

The front desk is open 24 hours a day.

The hotel has a fitness center and laundry service. The business center is located on the 3rd floor in the south wing of the building, with three computers and a small printer. Each room has a hair dryer, mini fridge for personal use, and iron/ironing board.

There are nearby hiking/walking trails and bicycles available free of charge to guests. Please inquire at the front desk for maps of the trails and to check out the bicycles.

#### **Registration and Resource Table**

There will be a resource table just outside the main meeting room in the atrium area where we will have our breaks. Information about restaurants, local shopping, maps, and nearby places of interest will be available for attendees. Local volunteers will be available each day to answer questions and to assist you. You can also request more information about your excursions and possible dining options for Wednesday evening in London or in the area where your excursion is planned.

The resource table will also have a clipboard for you write down your question if it is after hours and there is nobody at the table. Your request will be addressed the next morning when people return to the desk.

#### **Internet Access**

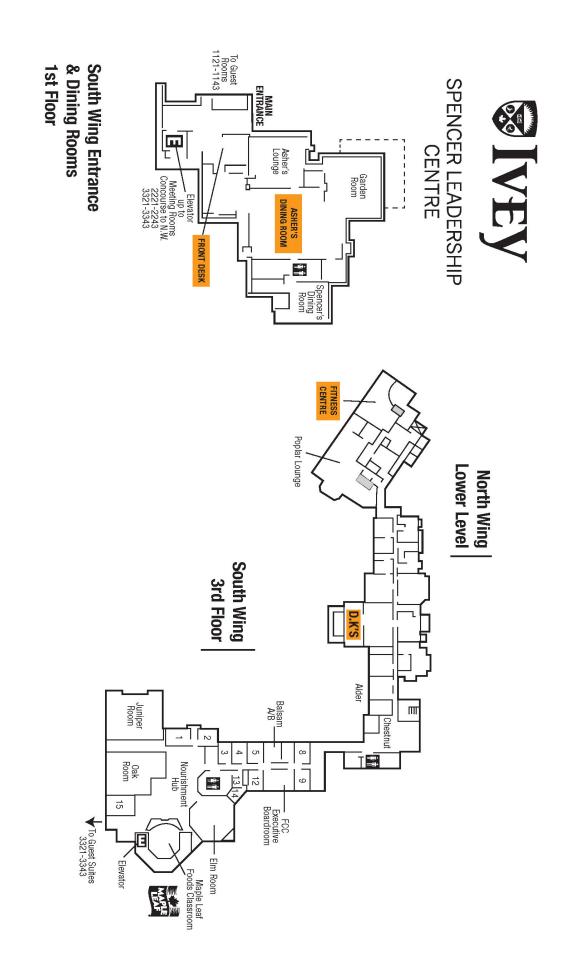
Wifi access is free to all guests. To connect to Wifi:

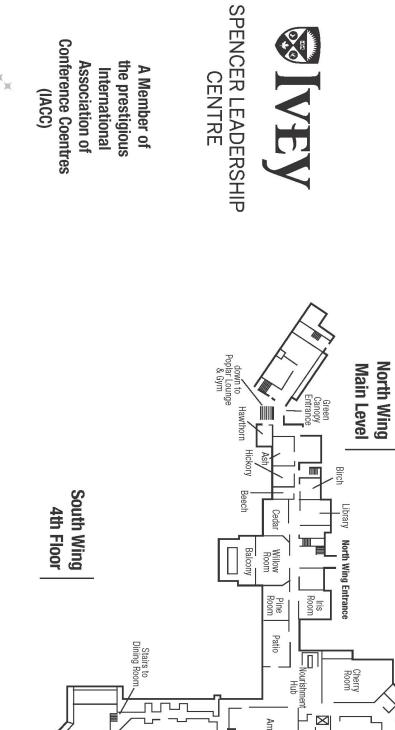
- In your network connection options select SLC Wifi
- Go to your browser and open it (Google, etc...)
- You will be redirected to an Ivey Homepage. Enter your email address.
- You will be automatically redirected and good to go. There is no password.

#### **Public Transit**

Tourism London has graciously donated London Public Transit bus passes for our attendees to use during the meeting as well. If you would like to obtain a pass for the transit system, please inquire at the resource desk.

### MAP OF IVEY SPENCER LEADERSHIP CENTRE







Elevator to Guest Suites 1122-3343 Dining Rooms

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Cherry Room

Amphitheatre B

 $\boxtimes$ 

Amphitheatre A

## ACKNOWLEDGMENTS

The Meeting Co-Chairs wish to extend their sincere thanks to all the speakers and contributors who have helped make this 30th Meeting such a success. In particular we are grateful to Ira Byock, Donna Schuurman, and Andy Ho for generously giving of their time and wisdom in providing the Pre-Meeting Conference day. To all of you who attended this London 2018 IWG Meeting from afar - thank you for making the trip to Canada or across Canada!

It is with enormous gratitude that we acknowledge the diligence and hard work of Daniel Lockwood, who donated incredible time and effort to assist us in planning beforehand and addressing our needs during the week. We also gratefully acknowledge the members of the London and Area Grief, Loss, and Resource Committee for volunteering their time to help in so many ways.

## IN GRATITUDE

The Meeting Co-Chairs and the IWG Board of Directors wish to extend their sincere thanks to King's University College for the incredible amount of time, skill, organization, planning, and use of the facilities as we endeavoured to host the 30th Meeting of the International Work Group on Death, Dying and Bereavement 2018. King's stepped up and willingly donated use of their facilities, staff, and support services to ensure the Meeting's success. We are especially indebted to the following:

Tim Bugler and the ITS staff Tiffany Chisholm, Purchasing Coordinator/Conference Services Phyllis Fidler, Manager of General Accounting Jane Antoniak, Manager, Communications and Media Relations Marilyn Mason, Vice-Principal, Enrolment Services Linda Weber, Manager, King's International Nikki Sasso Mitchell, Communications Assistant, Communications and Media Relations Kim Pega, Coordinator of On-Campus Events, Enrolment Services Wendy O'Toole, Executive Assistant, Vice-Principal, Enrolment Services



# THE INTERNATIONAL WORK GROUP ON DEATH, DYING AND BEREAVEMENT

### **MISSION STATEMENT**

The IWG, a non-profit organization, supports leaders in the field of death, dying and bereavement in their efforts to stimulate and enhance innovative ideas, research, and practice.

### **VISION STATEMENT**

A world where dying, death, and bereavement are an open part of all cultures.

### VALUES

The defining value required to qualify for membership in the IWG is a capacity for leadership in some aspect of the field of Death, Dying & Bereavement. This may reflect leadership in the ideas and theories that guide us, leadership in the research that provides justification for these ideas and the practices that follow, innovation reflecting the application of these ideas, communication of the ideas to others, and/or organisation of services based upon them.





## Thank you for participating in the 30TH MEETING OF THE INTERNATIONAL WORK GROUP ON DEATH, DYING AND BEREAVEMENT

