

McGill Council on Palliative Care

National Hospice Palliative Care Week
May 7-13, 2017

20th Annual Sandra Goldberg Lecture
Wednesday, May 17, 2017

www.mcgill.ca/council-on-palliative-care

"Inevitably, each human life reaches its end. Ensuring that it does so in the most dignified, caring and least painful way that can be achieved deserves as much priority as any other. This is a priority not merely for the medical profession, the health sector or the social services. It is a priority for each society, community, family and individual."

World Health Organization

"Once it was difficult to see end of life care beyond conventional medical intervention, but hospice and palliative care introduced a more holistic approach, providing quality of life for the dying and their families. This groundbreaking work takes end-of-life care beyond these palliative boundaries, describing a public health vision that involves whole communities adopting a compassionate approach to dying, death and loss. Written by a leading academic in the field of death and bereavement, this text outlines the historical, political and conceptual basis of compassionate cities, providing a community development model for end-of-life care."

Moving away from infection control and health promotion Allan Kellehear invites us to think of a third wave movement of public health, joining empathy, equality and action together as practical policies. Presenting a radical new perspective to death, ageing and public health, Compassionate Cities is essential reading for academics and professionals alike."

THE COMPASSIONATE CITY CHARTER

Allan Kellehear

People who live with life-threatening or life limiting illness, their caregivers, and the bereaved are segmented social groups, forced to experience lifestyles that are commonly socially hidden and disenfranchised from the wider society. Outside of the health services that deal specifically with their immediate problems, these populations suffer from a range of other troubles that are separate but linked to their health conditions or social circumstances – loneliness, isolation, job loss, stigma, depression, anxiety and fear, or even suicide. These populations also suffer from a range of other debilitating health problems often caused by their social and psychological troubles - insomnia, cardiac arrhythmias, chronic fatigue and headaches, hypertension, and gastric-intestinal disorders.

Compassionate Cities are communities that publicly recognize these populations, and these needs and troubles, and seek to enlist all the major sectors of a community to help support them and reduce the negative social, psychological and medical impact of serious illness, caregiving, and bereavement. A compassionate city is a community that recognizes that care for one another at times of health crisis and personal loss is not simply a task solely for health and social services but is everyone's responsibility.

Compassionate Cities are communities that publicly encourages, facilitates, supports and celebrates care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and

burdens of long term care. Though local government strives to maintain and strengthen quality services for the most fragile and vulnerable in our midst, those persons are not the limits of our experience of fragility and vulnerability. Serious personal crises of illness, dying, death and loss may visit any us, at any time during the normal course our lives. A compassionate city is a community that squarely recognizes and addresses this social fact.

Through auspices of the Mayor's office a compassionate city will - by public marketing and advertising, by use of the cities network and influences, by dint of collaboration and co-operation, in partnership with social media and its own offices – develop and support the following 13 social changes to the cities key institutions and activities.

- Our schools will have annually reviewed policies or guidance documents for dying, death, loss and care
- Our workplaces will have annually reviewed policies or guidance documents for dying, death, loss and care
- Our trade unions will have annually reviewed policies or guidance documents for dying, death, loss and care
- Our churches and temples will have at least one dedicated group for end of life care support
- Our city's hospices and nursing homes will have a community development program involving local area citizens in end of life care activities and programs
- Our city's major museums and art galleries will hold annual exhibitions on the experiences of ageing, dying, death, loss or care
- Our city will host an annual peacetime memorial parade representing the major sectors of human loss outside military campaigns – cancer, motor neuron disease, AIDS, child loss, suicide survivors, animal companion loss, widowhood, industrial and vehicle accidents, the loss of emergency workers and all end of life care personnel, etc.
- Our city will create an incentives scheme to celebrate and highlight the most creative compassionate organization, event, and individual/s. The scheme will take the form of an annual award administered by a committee drawn from the end of life care sector. A 'Mayors Prize' will recognize individual/s for that year those who most exemplify the city's values of compassionate care.
- Our city will publicly showcase, in print and in social media, our local government policies, services, funding opportunities, partnerships, and public events that address 'our compassionate concerns' with living with ageing, life-threatening and life-limiting illness, loss and bereavement, and long term caring. All end of life care-related services within the city limits will be encouraged to distribute this material or these web links including veterinarians and funeral organizations
- Our city will work with local social or print media to encourage an annual city-wide short story or art competition that helps raise awareness of ageing, dying, death, loss, or caring.
- All our compassionate policies and services, and in the policies and practices of our official compassionate partners and alliances, will demonstrate an understanding of how diversity shapes the experience of

ageing, dying, death, loss and care – through ethnic, religious, gendered, and sexual identity and through the social experiences of poverty, inequality, and disenfranchisement.

- We will seek to encourage and to invite evidence that institutions for the homeless and the imprisoned have support plans in place for end of life care and loss and bereavement.
- Our city will establish and review these targets and goals in the first two years and thereafter will add one more sector annually to our action plans for a compassionate city – e.g. hospitals, further & higher education, charities, community & voluntary organizations, police & emergency services, and so on.

This charter represents a commitment by the city to embrace a view of health and wellbeing that embraces community empathy, directly supporting its inhabitants to address the negative health impacts of social inequality and marginalization attributable to dying, death and loss.

A city is not merely a place to work and access services but equally a place to enjoy support in the safety and protection of each other's company, in schools, workplaces, places of worship and recreation, in cultural forums and social networks anywhere within the city's influence, even to the end of our days.

Compassionate Cities, Allan Kellehear

YouTube link – Allan Kellehear

https://www.youtube.com/watch?v=AhiNY5_ub7E

Palliative care reimagined: A needed shift. Julian Abel & Allan Kellehear

<https://www.mcgill.ca/council-on-palliative-care/events-resources>

Public Health Palliative Care International. *Creating Compassionate Communities*

<http://www.phpci.info>

Palliative Care as Public Health. Bringing the International Compassionate Communities Model to Canada

Denise Marshall, Pallium Canada

<http://pallium.ca/wp-content/uploads/2015/11/Palliative-Care-as-Public-Health-Bringing-the-International-Compassionate-Communities-Model-to-Canada-Dr.-Denise-Marshall.pdf>

<http://pallium.ca/compassionate-communities-2>

Our Activities...

Annual Sandra Goldberg Lecture

2016 Sandra Goldberg Lecture

Attendees, at the May 2016 Sandra Goldberg Lecture, were in for a treat from the moment Dr. BJ Miller took to the stage to deliver his address. Entitled *The Civics of Dying Well*, Miller juxtaposed a harrowing description of his personal journey with an enlightened perspective on death and dying.

‘Less horrible – more wonderful’ is central to Miller’s message. That’s the perspective he wants to bring to dying. He speaks about how the system needs a redesign to be more people centered. How death needs to shift to a civic issue. It affects 100% of us so the need is great to not only dialogue about it but to design for it

as well. More specifically, he challenges the audience to make Montreal a ‘good place to die’ – a Compassionate City.

Listening to Miller speak reminds me of the question *‘Do you have the courage to live the dream that picked you?’* A hospice and palliative care specialist, Miller has dedicated his life to helping others with life threatening illness. His approach to medicine is to *‘act from compassion and awareness’*. He suggests that the most potent medicine is *‘to come from a place of love and kindness’*.

While in college, Miller suffered a triple amputation after being electrocuted atop a parked train car. He lost two legs and half an arm. He shares a painfully beautiful story about the joy of holding a snowball, of having that precious, fleeting contact with the outside world as he lay recovering for months in hospital. After a long, agonizing convalescence, he eventually returned to school, changing his major from art history to medicine, becoming a doctor.

Living near death for so long attracted him to palliative care and he has become a very vocal advocate for bringing good end of life care to the forefront. His speech on TED in 2015 garnered over 5,000,000 views, helping to establish him as a worldwide speaker on the subject.

Miller describes his journey with unflinching, inspiring frankness. He elaborates how he became BJ after the accident as opposed to BJ before the accident. Two different people. He was always comparing himself to the old BJ, seeing himself as less than his previous self. Until one day, the comparing stopped and he accepted himself as he was, limbless, different. Then he began to see himself as whole.

Coinciding with this personal process is the advocacy work he’s doing within the medical system to help galvanize a shift toward whole patient care. Patient centered care. Whole person care. There are several terms all describing the same thing. I’m struck by how his personal journey toward wholeness is mirrored by the push he’s giving the medical community toward whole person care of the dying.

The palliative experience is so many different things. Joanne B. had barely eight hours with her father in palliative care. She remembers it fondly.

Irene P. had four months in palliative accompanying her husband. She would be there every day without fail. She too recognizes the value of accompanying her life partner, bringing dignity and love to his last days as his body broke down.

Each experience is unique in its makeup but universal in its inevitability.

‘Why aren’t we addressing this issue front and centre?’ Miller challenges. *‘Because the medical profession is set up to cure, to fix, to treat. Not to accompany and offer quality of life and the relief of suffering’*, he answers.

Miller wants to see all that change. He advocates for people to have more affinity and less aversion for the process. He explains that we need to talk about end of life care, to express our wishes, to converse while we’re healthy and well and can choose for ourselves. And we also need to let go of the concept of burdenhood.

Conversations with his college friends, who remained close throughout his ordeal, confirmed to him that every act of giving is also one of receiving. The giver and the receiver both benefitting so that, in fact, there are

only receivers who give to each other. We do not become a burden when we get sick. We become an opportunity for those who love us to step up.

Thank you to the McGill Council on Palliative Care for bringing us this unique, powerful speaker. Thank you Dr. Miller for having the courage to follow the dream that picked you. Despite all the odds, you stepped up and you inspire us to do the same.

Dr. Miller's complete Goldberg Lecture can be seen on the Council's web site:

https://www.youtube.com/watch?v=MizA7_YPzqM&feature=youtu.be

His TED Talk can be seen at the following link:

https://www.ted.com/talks/bj_miller_what_really_matters_at_the_end_of_life?language=en

2017 Sandra Goldberg Lecture

This year marks the 20th Sandra Goldberg Lecture. The speaker, David Prail, has worked in hospice and palliative care internationally for over 25 years.

A graduate of the Universities of York and Durham in the UK, David moved from mathematics student to Episcopal Parish Priest to Course Director of St George's College, Jerusalem. He joined St. Luke's Hospice in 1991 and became the chief executive of Help the Hospices (now hospiceUK) in 1996.

David led the development of the Worldwide Hospice Palliative Care Alliance and has held various international roles including international board member of both the National Hospice and Palliative Care Organization in the USA and the Indian Association of Palliative Care. He is on the advisory panel of the Hospice Palliative Care Association of South Africa and is the founder and chairman of *ehospice*.

The title of his lecture will be *Celebrating Innovation in Palliative Care – Where Next?* It will take place on the main campus at McGill University on Wednesday May 17th at 6:00 PM in Moyses Hall.

Workshops

2016 Workshops

Every year, in the spring and fall, the Council on Palliative Care holds a series of free public workshops focusing on different themes that explore and discuss the barriers and strategies for achieving quality palliative care after a diagnosis of a life threatening illness. It is hoped that participants leave with a better understanding of how to access care and what care to ask for, for either a member of their family, a friend or for themselves. These workshops are of interest to the general public as well as all members of the health care team wanting to expand their knowledge.

The workshops are always open to the public and always free of charge.

Our spring workshops presented a diversified group of presenters and topics that reinforced our collective understanding of compassionate palliative care. There were three workshops in this series.

April 4, 2016

The film *Little Stars - Accomplishing the extraordinary in the face of serious illness*, was shown. "*Little Stars* is tells the surprisingly life-affirming stories of young people around the world living with life-limiting

illnesses. Against the odds, these children and young adults are making the most of every moment thanks to the support of their loved ones, working in harmony with passionate 'pain and palliative care' teams.”

The film was followed by a discussion led by Dr. Stephen Liben, Director of Pediatric Palliative Care at the Montreal Children’s Hospital. Julie Brouillard, a clinical nurse specialist with neuro-oncology, as well as Palliative Care expertise, also contributed to the discussion. Personal stories were shared by the audience and were very moving.

This was our first attempt at presenting a Palliative approach to children and dying. The workshop was well received and reinforced our commitment to remain diversified in our workshop topics.

Little Stars – trailer - YouTube

<https://www.youtube.com/watch?v=uXczFTnglSk>

April 11, 2016

A presentation about Grief in two parts:

Part 1 “What Matters Most” - Finding what to say at the end of life.

Part 2 “Lessons of Loss” - Inspirational video vignettes of stories in bereavement.

The presenter was Christopher McKinnon, Senior Psychologist at The Balfour Mount Palliative Care Unit at the McGill University Health Centre (MUHC) and member of the development team of mygrief.ca, a Canadian web-based bereavement support resource. Also present was Bonnie, one of the participants in the video vignettes, whose husband, Ray, was diagnosed with pancreatic cancer in 2011 and who died two years later. They had been married for 41 years and had three children. Bonnie’s journey is one of the many stories featured on mygrief.ca. Her lived experience from Ray’s diagnosis, through his illness and death and her ability to articulate her grief journey was a gift, which created a dialogue for new insights and growth.

Monday April 18th 2016

The third and final workshop in the series examined the healing power of music and art. Entitled, “**Music and Art: Alive in the Home**”, it was presented by Samantha Borgal, Music Therapist at the Jewish General Hospital and Sarah Tevyaw, Art Therapist at the West Island Palliative Care Residence.

They each shared their insights on how the arts can be an additional form of support and creative expression for those supporting someone, or living with, a life threatening illness. Using experiential learning activities in music and art expression, the attendees experienced hands on the power of the arts. Many of whom thought that that this type of expression was beyond their skill-set.

For people who may be agitated or who are restless and need to relax, I may bring in art materials to help them refocus their attention on something other than their pain. Other times art is used as a way to leave a trace, a legacy, so I have made memory boxes with patients, helped people write letters, record sounds, voices or images to leave for someone close to them. A big part of what I do is work with patients and their families to create hand sculptures as a form of a legacy in a very physical and visual form.

Art therapy deals with the visual arts- it could be anything from painting, drawing, or fabric and textiles. I think what’s different about art therapy from art education or art as recreation is that it’s really about the relationship and creating a safe holding space for people to explore something they have never tried before.

Sarah Tevyaw

Fall Workshops

In our Fall workshop series the theme was **Navigating and Negotiating the Health and Social Services System**. This theme was inspired by Gord Downie of the Tragically Hip who, when asked about how he was coping with his diagnosis of terminal cancer, stated–“I am learning how to do it, because I've never done it before.” There were two workshops in this series.

November 14, 2016

The first workshop, “**Starting the Journey**”, was given by Joan Foster, a registered nurse and Zelda Freitas, a social worker, who both work in Home Care. They presented and discussed how to access help for those with a life threatening illness and reflected on how families and friends can be supportive.

Topics discussed were;

- setting individual goals of care;
- accessing palliative care across the continuum of care (acute care, home care or long term care);
- identifying key members of your care team;
- exploring services and advocating for resources;
- communicating effectively with the Health Care Team
- defining and developing a supportive care network.

Each of these topics is important in the often-steep learning curve of fighting a life threatening illness. Presentations were followed by a question and answer period.

November 21st, 2016

The second workshop, “**Empowering your Choices**” was led by Franco Carnevale a nurse, psychologist and clinical ethicist at McGill University and Sue Britton, a registered nurse and yoga instructor.

Dr. Carnevale presented an interesting array of issues related to ethical decision making. He described the concept of autonomy as the pillar of ethical practice and the need for respect as being at its foundation.

One of many noteworthy comments was the reminder that families are not visitors and that relationships need to be respected. He reminded us that palliative care is much more than end-of-life care and should be introduced at time of diagnosis and he emphasized the importance of balancing the benefits and burdens when communicating information for difficult decisions.

Dr. Carnevale and Sue Britton presented several case scenarios that illustrated the complex issues and principles related to ethical issues. The presentation also included some reflection on Bill 52 in Québec (*An Act Respecting End-of-Life Care*) in relation to the ethics of several complex practices.

More information can be found on his PowerPoint presentation:

<https://www.mcgill.ca/council-on-palliative-care/events-resources/video-archived-events>

2017 Workshops

Please check our web site for information about upcoming workshops.

Palliative Care Volunteer Training – McGill Affiliated Centres

The McGill Palliative Care Volunteer Training is based on, and conforms to, the standards of the Canadian Hospice Palliative Care Association (CHPCA) and the Plan directeur de développement des compétences des intervenants en soins palliatifs de la direction de la lutte contre le cancer du Québec.

This rich and exciting series of lectures and workshops has outstanding faculty and staff as presenters. The 24-hour training is designed to enhance one's understanding of end of life issues and covers a broad number of topics: history and philosophy of palliative care, the role of the volunteer and coordinator; the dying process; communication skills, boundary issues, self-care, confidentiality, ethics, bereavement, as well as, spiritual and cultural diversity. The Volunteer Coordinators from each of the McGill affiliated sites organize group discussions and experiential work to cover the topics. Upon completion, volunteers will be able to offer basic supportive listening, compassionate presence, empathy and active listening to palliative patients and their family members at any of the McGill affiliated hospitals and hospice palliative care sites. Volunteers will receive a certificate upon full attendance and completion of the training.

The Palliative Care Volunteer Training is given once or twice a year, either Spring and/or Fall. The format is decided prior to the training and is usually two to three full day workshops and one to two evening sessions. The training is mandatory for all new volunteers in Palliative Care at McGill affiliated adult centres: Hope and Cope at Jewish General Hospital, Mount Sinai Hospital, Cedars Can Support at McGill University Health Centre at The Glen, St. Mary's Hospital Centre and West Island Palliative Care Residence. There is a small fee to cover the cost of photocopies, lunch, coffee and refreshments.

For more information: fmpa202@gmail.com.

Article(s) of Interest...

Canada's health-care system favours the cradle and ignores the grave

By David Henderson and Susan MacDonald

Globe and Mail. May 26, 2016

David Henderson is the president of the Canadian Society of Palliative Care Physicians. Susan MacDonald is the organization's past president.

While our parliamentarians and media pundits focus on the narrow machinations of Bill C-14 that deal with medical assistance in dying, we palliative-care physicians continue to try to give birth to a long-overdue national discussion on holistic and compassionate end-of-life care for all Canadians.

Each day we face desperately ill patients and their anguished families, who literally beg us for help – with their pain, their nausea, their mental torment and the financial burden of their illness. The agony of suffering ravages their bodies and often saddles their families with immense guilt born of helplessness and a sense of isolation.

This is a national failure to address dying with dignity from an ethical, funding and continuum-of-care perspective. This failure must be acknowledged and corrected in the current discussions around a new health accord between Ottawa, the provinces and territories and our indigenous peoples.

As a country, our public policy and health system choices have favoured our collective cradle but eschewed our inevitable grave. Pre-birth programs, newborn immunizations and early childhood interventions across our health-care, social-welfare and education systems are laudable and should be expanded. This same dedication of resources must also underpin our approaches to better pain and symptom management and a range of palliative-care options for us, our loved ones and friends as we bravely face our own mortality.

But this is not the case in Canada today – and it is the pinnacle of injustice. While Bill C-14 is in the process of becoming law, palliative-care units in Ontario are closing due to funding cuts, and there is no law on the table about the right to palliative care. Tragically, many people die at home, with no access to palliative-care supports such as home-care nursing or visits from a family doctor or, when needed, a palliative-care team.

In this context, how is opting for medical assistance in dying voluntary when your only other choice is suffering?

Palliative care must be embedded in the next health accord in a substantial manner. While medical science in pharmacology, genetics, nanotechnology and a host of other fields strives to extend life, we cannot escape the certainty that death awaits us all. Wellness and health include dying and death.

Canada needs national leadership on this issue – ideally a federal, provincial and territorial palliative-care secretariat. This secretariat would work to address gaps in education for undergraduate and postgraduate health-care professionals (doctors, nurses, pharmacists and allied health and social-welfare professions); highlight best practices in palliative care; drive the establishment of specialty teams for complex care patients; collect relevant data; and work with public and private employers, insurers and civil society organizations to strengthen palliative-care policy understanding, supports and resources in our workplaces and communities.

Dying is a part of living, and everyone who reads this will die at some point. We should not let our incomes, our postal codes or family support networks determine how well or poorly we die. We need to think about this, discuss it and fix it. The time is right to insist that our health ministers address this issue in Canada's new health accord.

“There are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.”

Rosalynn Carter

Thanks to our sponsors in 2016

Marlene Bourke
Equinoxe
The Goldberg Family
The Hay Foundation
RBC Capital Markets
West Island Palliative Care Residence
Zeller Family Foundation

Thanks to those who contributed to this newsletter:

Sue Britton
Andrea Courey
Anna Feindel
Joan Foster
Zelda Freitas
Devon Phillips

Archived events and other resource material

can be found on our web site.

www.mcgill.ca/council-on-palliative-care