

The Council on Palliative Care

National Hospice
Palliative Care Week
May 4-10, 2014

Sandra Goldberg Lecture
May 6, 2014

20th International Congress on
Palliative Care
September 8-12, 2014

R. David Bourke
Memorial Lecture
September 9, 2014

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

"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

Palliative Care in Montreal Celebrates 40 Years!

By Dawn Allen, Ph.D.

Whether you are a regular, occasional, or new attendee at the McGill International Congress on Palliative Care, this year's 20th Congress will bowl you over! We have a lot to celebrate, so we're pulling out all the stops.

Our 2014 Congress, marks not only the 20th anniversary of this biennial congress, but 40 years of Palliative Care at McGill, 20 years since the establishment of the Eric M. Flanders Chair in Palliative Medicine, and 20 years since the founding of the Council on Palliative Care!

In the fall of 1974, inspired by the work of Dame Cicely Saunders and others, Dr. Balfour Mount and his colleagues initiated a uniquely comprehensive palliative care service in Montreal's Royal Victoria Hospital (RVH), a service that has since served as the model for many palliative care services around the world. The RVH model was unusual not only because it integrated palliative care into the hospital

context (as opposed to a separate, free-standing hospice), but also because it provided a broad range of services for dying patients and their families: an inpatient unit, an in-hospital consult service, a homecare service, a bereavement follow-up program, and a volunteer service that included trained volunteers in the care team.

Almost simultaneous with the establishment of the RVH palliative care service, Dr. Mount began to develop an academic program of palliative care at McGill. The RVH service soon welcomed residents, and research initiated in the pilot study phase of the new service began to grow. In 1990, Palliative Care became one of the McGill Faculty of Medicine's academic programs, and palliative care services in seven different sites (the Chest Hospital, the Montreal Neurological Institute and Hospital, the Children's, St. Mary's, Mount Sinai, Queen Elizabeth Hospital, and Hôpital Notre Dame de la Merci) united

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The Council on Palliative Care is a non-profit organization that was established in 1994. The objectives of the Council are to increase public awareness, public support and availability of palliative care within and beyond the McGill University Health Centre (MUHC) network. It pursues these objectives by working with healthcare planners, educators, practitioners and the community at large.

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Kappy Flanders

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Celebrating 40 years of palliative care in Montreal (cont.)

with the RVH to strengthen the palliative care research program.

In 1994, Kappy Flanders took two important steps to strengthen awareness of and respect for palliative care in Montreal broadly and at McGill specifically. In that year, Ms. Flanders founded the Council on Palliative Care and established the McGill University Eric M. Flanders Chair in Palliative Medicine. Both grew out of Ms. Flanders' personal experience with the needs of the dying and the powerful role of palliative care in addressing those needs.

The Council was founded as a not-for-profit organization dedicated to raising public awareness of palliative care and to advocating for better access to such care for all those who need it. The establishment of the Flanders Chair (the first of whom was Dr. Mount) strengthened and protected the academic program of palliative care at McGill. In 1992, Dr. Robin Cohen joined the team as a postdoctoral fellow and became the program's Director of Research in 1996.

By 1999, palliative care physicians across Canada had not only established national competencies for the practice of palliative care, but secured a residency program – recognized and certified by both the Royal College of Physicians and Surgeons and the College of Family Physicians – that offered a full year of palliative care residency. Palliative Care McGill welcomed its first such resident that year.

Under the leadership of Dr. Mount, then Dr. Anna Towers, and most recently, Dr. Bernard Lapointe (the second Eric M. Flanders Chair) Palliative Care McGill has developed not only its residency program, but also a rich undergraduate

medical education curriculum. That curriculum is integrated into all four years of medical school and covers a broad range of palliative care topics: communication at the end-of-life; pain assessment and management; palliative care as a global health issue; bereavement; end-of-life care for patients with heart disease, lung disease, cancer and many others. Its program of research, under the directorship of Dr. Robin Cohen for almost 20 years, is rich and varied. Areas of research expertise include pain management in children and adults, bereavement, family caregivers, ethics in end-of-life care, psychosocial care of cancer patients, lymphodema, anorexia-cachexia, and the list goes on. This broad body of palliative care research is representative of the relatively rapid changes in palliative care (clinically and academically) over the 40 years since the establishment of the RVH service in the mid 1970s.

In 1976, shortly after the doors opened for the RVH Palliative Care Service, Dr Mount and his colleagues hosted the first McGill Congress on Palliative Care, then known as “the International Seminar on Terminal Care.” In attendance with the 317 delegates at that Congress were Dame Cicely Saunders, who gave a talk on “the philosophy of total care of the terminally ill” and Elizabeth Kübler-Ross whose two presentations focused on “the psychological needs of the patient and family” and on “grief work.” Other speakers included many of the pioneering members of the RVH palliative care team: Sue Britton, Ron Melzack, Ina Ajemian and Balfour Mount, of course.

The second Congress, held in 1978, almost tripled in size. With an unexpected 828 delegates, the organizers had to arrange for an overflow room with closed circuit TV. In addition to presentations

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Pioneering in Palliative Care

By Sue Britton, Pioneer Nurse

It was Tuesday, January 21, 1975 when the doors of the Palliative Care Unit at the Royal Victoria Hospital in Montreal opened. I was on duty for the evening shift, along with a nursing assistant. We had had a three-day training with two nurses from St. Christopher's Hospice in South West London, England and had read Dr. Elizabeth Kubler-Ross', *On Death and Dying*. We were keen to give good nursing care, proper symptomatic care, support to the families and have intimate conversations with our first two patients. Both were very sick men and those intimate conversations were with their wives. To prevent pain we used "The Brompton Cocktail", a liquid analgesic, administered by mouth every four hours.

Flash back to the late 50's, early 60's, same hospital, I was a nurse in training and was disturbed by the attitude and practice of staff working with patients who had life threatening illnesses. Visiting hours were curtailed and families were not kept informed. Patients suffered isolation often in single rooms. Regardless of gender, culture, or tolerance to pain, patients were given a standard dose of injectable morphine because no professional seemed to understand either drug tolerance or everyone's fear of addiction.

By the 70's, when as a graduate nurse, I was working on a 32 bed surgical unit with sometimes 20% of the patients in a terminal phase of their illness, things were changing. Pre-op and post-op patients were the priority. But Dr. Balfour Mount, after spending time at St. Christopher's Hospice, wanted to sensitize the medical community to the needs of the 20% of patients who were dying. Two medical students were hired to interview and record the experiences of the terminally ill patients and their families. The findings were documented and presented to all the administrators of the hospital. They were shocked into agreeing to

support the two year pilot-project of which I became a part on that Tuesday at the beginning of 1975.

This practice of palliative care was delivered by a multi-disciplinary staff addressing the physical, psychological, spiritual, social and financial needs of the patients and their families. It began with simple things, at each bedside there was a welcome card with the patient's name and a fresh flower in a vase. The bed had an air mattress filled with warm water to prevent bedsores. The results were immediate. I remember Bill, a 59-year old with carcinoma of the esophagus who was admitted in a fetal position, riddled with pain. After receiving a small, regularly administered Brompton Cocktail, he was up shaving at the sink the next morning.

The family of a woman newly diagnosed with advanced breast cancer requested to be her primary caregivers. Their wish was granted. They were most appreciative of the opportunity to be able to give back to her all the love she had given them.

The initial philosophy of practising palliative care has not changed, although the drug combinations are more sophisticated. Bringing comfort and support to patients and their caregivers remains true in 2014. Palliative Care is given in general hospitals, units, hospices, community based services from public to private agencies. My hope is that these services will continue to grow to accommodate the needs of our population.

Sue Britton has been a practising Palliative Care Nurse since 1975 and is a psychotherapist and certified 500hr Kripalu yoga teacher working at the Griffith Edward's Addiction Unit at The Montreal General Hospital.



“The difference between what I do and euthanasia is that palliative care does whatever is necessary to alleviate the suffering while euthanasia is focused on eliminating the sufferer.”

Ira Byock, MD
Palliative Care Physician

Celebrating 40 years of palliative care in Montreal (cont.)

by Dame Cicely and by Eric Cassel, John Scott spoke on the relevance of spiritual concerns; Robert Fulton spoke of cross-cultural considerations; Kitty Markey – the first volunteer coordinator and educator for the RVH service – spoke on “volunteers as part of the care team;” and Susan Munro gave a special presentation on “music therapy for the terminally ill.”

Over the years, the Congress has, of course, grown and changed. Today’s delegates can exceed 1,600 people coming from over 65 countries around the globe. To capture and celebrate the distance that palliative care has travelled since its early days in the mid 70s, a timeline of palliative care at McGill and internationally will be on display at the Congress, near the booths and posters. The first section of this three-part display will focus on the development of palliative care at McGill. The second and largest section will provide a geographically-organized overview of the development of palliative care world wide. The third and final section will offer the beginnings of a wish-list for the future of palliative care, a list that delegates will be encouraged to expand.

In addition to the Tuesday seminars on Palliative Care Nursing, Palliative Medicine Master Class, Pediatric Palliative Care, and Whole Person care, this year’s Congress offers a rich lineup of speakers including the esteemed Stephen Lewis, Sheldon Solomon, Carlo Leget, Irene Higginson, Tanguy Châtel, and our very own Dean David Eidelman and Flanders Chair Bernard Lapointe. A special opening reception will launch the celebrations, and an extra-special social event plus many self-care activities are sure to lift your spirits.

As is the tradition during the International Congress, the Council on Palliative Care will host the David Bourke Memorial Lecture, a biennial lecture that honors the memory of one of the founding members of the Council. This year, the David Bourke Memorial lecture will be given by sociologist Lawrence Samuel, author of *Death American Style: A cultural history of dying in America*. To be held at the *Palais des Congrès* on the evening of September 9, the lecture will be open to the public. Don’t miss this great opportunity to think a little differently about death and dying.

Dawn Allen is the Associate Director of the Palliative Care program at McGill University

An end-of-life glossary

Palliative Care: Care for people living with a life-limiting illness that is usually at an advanced stage. Care is aimed at improving the quality of living and dying. It includes pain and symptom control, as well as psychological, emotional, social and spiritual support for both the patient and his/her family.

Comfort measures: Treatments to keep patients comfortable (such as pain control) but not to keep people alive artificially or cure any illness.

Palliative sedation therapy: The use of pharmacological agents to reduce consciousness. Reserved for the treatment of "intolerable" or uncontrollable symptoms in patients with an advanced, progressive illness. Continuous palliative sedation therapy is the use of ongoing sedation continued until the patient's death.

Advance directives: Verbal or written instructions that the patient has provided about the type of care they want or, do not want, in the event they cannot speak for themselves.

The right to refuse medical treatment: The right of a competent adult to refuse unwanted medical treatment or to demand that treatment, once begun, be stopped.

Life support: Medical or surgical procedures such as tube feeding, mechanical ventilation, kidney dialysis and CPR. All use artificial means to restore or prolong life. Without them, the person would die.

Medical aid in dying: A generic term encompassing both euthanasia and physician-assisted suicide.

Physician-assisted suicide: Knowingly and intentionally providing a person with the knowledge or means, or both, required to commit suicide, including counselling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs.

Euthanasia: Knowingly and intentionally performing an act that is explicitly intended to end the life of a person with an incurable illness.

When the Doctor Disappears

By Judith Graham, *The New York Times*, November 14, 2013

Dr. Daniel Geynisman felt as if he had abandoned his patient, a sickening sensation.

A 65-year-old man with metastasized gall bladder cancer had developed intractable pain before the doctor went away on vacation. By the time Dr. Geynisman returned, the patient was enrolled in hospice; he died soon thereafter. The oncologist never saw him again.

The sudden termination of a close doctor-patient relationship is a common, wrenching scenario. “I can tell you, it happens all the time and it breaks the heart of patients and families and oncologists,” said Dr. Diane Meier, director of the Center to Advance Palliative Care at Mount Sinai’s Icahn School of Medicine in New York City.

In an article published recently in the *Journal of Clinical Oncology*, Dr. Geynisman described his own experience with this sort of estrangement. He referred to his patient as “MM,” but the man’s actual name was Paul Rieger. He was a math teacher in the Chicago Public Schools who loved to golf and fish and who was married to his college sweetheart. Dr. Geynisman saw the couple every two or three weeks — and sometimes more often — during the last year of Mr. Rieger’s illness.

In a phone interview, the doctor described his patient as “very accepting, very calm, very kind, a gentle soul.”

From the beginning, the Riegers made clear what they wanted from their physician. “I distinctly remember during our first meeting they said they were looking for someone who would be with them through the end, throughout the whole journey,” Dr. Geynisman said.

Yet it was routine for oncologists at University of Chicago Medicine, where the doctor was then working, to stop seeing patients when treatment ended. “The model was, you get to know the patient and their family, you treat them aggressively, but when the time comes that you don’t have any more therapy to offer, you make a referral to palliative care or hospice and the patient goes under their auspices,” Dr. Geynisman said.

Dr. Otis Brawley, chief medical officer of the American Cancer Society and professor of oncology at Emory University, offered another reason oncologists sometimes disappear from their patients’ lives in these circumstances. “It’s a way of protecting yourself from the devastating feeling that you’re letting this person down and your inability to keep them alive is a professional failing,” he said.

That isn’t to say it’s justified. “No physician should ever say there’s nothing more I can do,” said Dr. Timothy Moynihan, medical director of the Mayo Clinic hospice, who wrote a response to Dr. Geynisman’s article noting that oncologists can remain involved with patients in hospice as the physician of record. “There’s always something more we can do for the patient — if only to be there and listen to their stories and deal with their pain and suffering.”

Dr. Geynisman said he had never received training about how to interact with a patient whom he could no longer help. But he felt terrible about not calling Mr. Rieger before his death and vowed this would never happen again.

“Do patients and their families want me, the primary oncology physician, to be around for the last phase of their lives?” he wrote in his article, which inspired dozens of emails from fellow oncologists across the country. “Do I ultimately break my pledge to patients as I prematurely end my journey with them when there is no longer ‘active therapy’ to offer them?”

The answer is yes, suggested Dr. Meier of Mount Sinai.

“Very often, one of the major sources of emotional and spiritual suffering among patients who are nearing the end of life or a prolonged illness is the abandonment they feel when they stop being cared for by a physician to whom they have become attached,” she said.

Dr. Meier told the story of a New York City oncologist who gave “impeccable” care to a woman with lung cancer, keeping her alive for almost seven years. Dr. Meier began caring for the patient as well when the oncologist turned away from addressing her questions about death. (“What exactly is likely to happen? Will I be in pain?”)

During a home visit three weeks before this woman passed away, Dr. Meier asked her what was on her mind. “She said, ‘I am really upset this doctor has not called me or come to see me.’ It was taking up most of her emotional energy.”

With the patient’s permission, Dr. Meier called the physician, whose response was, “There’s nothing I can do for her.” Dr. Meier had to explain: “She loves you. She wants to thank you.” That got through: the oncologist made a visit, and the patient died a few days later.

Mrs. Rieger has stayed in touch with Dr. Geynisman during the year since her husband’s death; she doesn’t blame the physician in any way. “He was our guiding light and he never disappointed us,” she told me. “Dan made the whole year so bearable, because I knew there was someone there for us.” The doctor, she noted, never let more than 10 minutes lapse before answering an email.

“He was the one person who knew our cancer journey better than anyone else,” Mrs. Rieger said. “He became so important to us. He touched our souls.”

Currently, Dr. Geynisman is an assistant professor of medical oncology at Fox Chase Cancer Center in Philadelphia. “I’m committed to being there through the end with all my patients, though I still haven’t figured out the best way to do that,” he said.

To his patients, he puts it something like this: “I’m still your physician and no matter what happens, I’m still here for you.”

Events & Happenings!..

17th Annual Sandra Goldberg Lecture

The 17th Annual Sandra Goldberg Lecture will be held on Tuesday, May 6, 2014 at McGill University. It will feature Robin Marantz Henig, journalist, author, science writer and contributing writer for the New York Times, in conversation with Sue Smith, host of CBC Radio One's *Homerun*.

Ms. Marantz Henig wrote an article for the New York Times Magazine on July 17, 2013, entitled *A Life or Death Situation*. It is the story of Margaret Pabst Battin (Peggy) an international leader in bioethics who had long championed peoples' "right to die" and who is forced to examine the complexities of end-of-life decision making after her husband, Brooke Hopkins suffers a debilitating accident.

"Suffering, suicide, euthanasia, a dignified death — these were subjects she had thought and written about for years, and now, suddenly, they turned unbearably personal. Alongside her physically ravaged husband, she would watch lofty ideas be trumped by reality — and would discover just how messy, raw and muddled the end of life can be."

The Sandra Goldberg Lecture, *A Life And Death Situation* will look more closely at some of these issues.

David Bourke Memorial Lecture

This year's David Bourke Memorial Lecture will be held on Tuesday, September 9th, at the Palais des Congrès during the 20th International Congress on Palliative Care, which runs from September 8-12 in Montreal.

The speaker will be Lawrence Samuel, Ph.D. Dr. Samuel will speak on *Death American Style: A Cultural History of Dying in America*.

Council Workshops

The Council on Palliative Care offers free workshops covering a spectrum of topics which are of interest to those involved in caring for someone with a life threatening illness. Most workshops occur over a 2-3 week period but each one stands alone – allowing people to attend only one and still feel that their evening is complete. The workshops are open to anyone who wishes to attend and often there are both health care personnel and family caregivers present.

In April 2013, three workshops were held at the Temple Emanu-El -Beth Sholom – a wonderful venue, both for its hospitality and ease of access for those travelling on public transport.

Topics covered at these three workshops were:

- Transitions in Care -- when an illness cannot be cured;
- Grief and Loss - for both the patient and the family;
- Advance Care Planning -- starting conversations on how we care for each other and the choices that have to be made.

Christopher MacKinnon from the McGill University Health Centre (MUHC) Palliative Care Unit was the guest speaker on grief and the expertise of Zelda Freitas SW, Sue Britton RN and Joan Foster BN was shared with all. Zelda, Sue and Joan are members of the Council and practicing professionals. Among them they have over 100 years of experience caring for patients and families in the Montreal community.

If you were unable to attend these workshops you will find very helpful information on two very recognized web sites: www.virtualhospice.ca and www.advancedcareplanning.ca.

Death and dying are NEVER the plans we have for life and yet all of us must die one day. The Council's workshops help anyone, either to start to think about this eventuality or, to learn how to navigate through it if it is here and now.

Make sure your name is on the Council's mailing list (email addresses preferable) so you can always be aware of upcoming workshops. Be sure to share this information with family and friends.

Men and Grief: Workshop with Dr. David Kuhl

What is grief? How can we gauge its intensity? How does it affect our relationships? What role does gender play? These were some of the interesting questions that Dr. David Kuhl explored during a Council workshop on October 7, 2013 at Temple Emanu-El-Beth Sholom. The Founder and Director of the Centre for Practitioner Renewal and an Associate Professor of Family Medicine at UBC, Dr. Kuhl is a grief expert whose most recent research focuses on the experience of grief amongst men in the military.

Eighty attendees (including 29 men) gathered around tables to discuss experiences of loss and grief, and to explore the potential role of gender. One of Dr. Kuhl's first messages was that one should be wary of overly simplistic or rigidly categorical interpretations of grief along gender lines. He emphasized grief as highly individualized with each of us choosing unique paths to healing from loss. That said, though, Dr. Kuhl's research shows some interesting gender-based patterns in how men and women grieve. For example, women tend to verbalize and share their grief, while men are more inclined to collude in a conspiracy of silence in order to control or suppress emotion. Women also generally focus on bringing closure to the past, whereas men are prone to action and prefer to focus on the future. Dr. Kuhl's research findings suggest that for some men, finding a healing path through their grief requires working through "unfinished" and accumulated business. For more information about Dr. Kuhl's research, please refer to a selected bibliography at the end of this article.

Having raised the participants' awareness of possible gender-based patterns in grief, Dr. Kuhl then discussed the general predictors and qualities of grief. Some of these predictors include: the degree of one's attachment to, and dependency on, the person who has died; how expected and natural the death is; and whether grief is suppressed and accumulated, or experienced and released. A more thorough discussion of the intensity and duration of grief can be found in Dr. Kuhl's book. (see references below)

The workshop finished with an activity in which participants were invited to contemplate their life's priorities in the context of its impermanence. The activity was a powerful way to look at the full trajectory of one's life from birth to death, and to consider the ways that death and grief can shape our priorities and give our life new meaning.

Bibliography:

- Swallowed by a snake: The gift of the masculine side of healing* by Thomas R. Golden
Being with dying: Cultivating compassion and fearlessness in the presence of death by Joan Halifax
What dying people want: Practical wisdom for the end of life by David Kuhl.



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**A unique opportunity to
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exchange ideas with
colleagues from 60
countries, representing
all disciplines involved
in palliative care**



20th International Congress on Palliative Care

■ *Inspiring speakers such as:*

- Stephen Lewis, Canada
- David Eidelman, Canada
- Irene Higginson, United Kingdom
- Sheldon Solomon, United States
- Tanguy Châtel, France
- Nicole Poirier, Canada
- Carlo Leget, The Netherlands
- Bernard Lapointe, Canada

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- **Whole Person Care for Persons with Cognitive Impairment**
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■ *New for **Palliative Care Volunteers:***

- Special registration fee (\$80 per day) offered to palliative care volunteers (can be applied to any day or combination of days)
- Over 250 workshops, proffered papers, research forums, and special seminars, and 300 posters

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Palliative Care

Care that aims to relieve suffering and improve the quality of living and dying.

What is Palliative Care?

Palliative Care is both a philosophy of care and a combination of therapies intended to enhance quality of life of persons living with a life-threatening illness. Palliative Care provides whole person care by striving to meet the physical, psychological, social and spiritual needs.

The goal is to help people live comfortably and to provide the best possible quality of life for patients* and their families.

Care is delivered through the collaborative efforts of an interdisciplinary team including the individual, the family and others involved in the provision of care. Where possible, palliative care should be available in the setting of personal choice.

When is the right time for palliative care?

Palliative Care helps through all stages of illness. It is best introduced early in the disease trajectory, and is provided at the same time as curative treatments.

What can we expect from palliative care?

- Relief from distressing symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping.
- Improved ability to tolerate medical treatments.
- Better understanding of your condition and your choices for medical care.

* The term patient, as opposed to client, is used in recognition of the individual's potential vulnerability at any time during the disease trajectory.

The word 'patient' derives from the Latin *patiens*: to suffer, to undergo, to bear.

The patient is a contributing member of the care team.

(Source: Palliative Care McGill Standards)



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