

Council on Palliative Care

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Sandra Goldberg
Lecture

Tuesday, April 28th

Hike for Hospice
Sunday, May 3

(see page 4 for
details)

Palliative Care Week
May 3 to 9

Highlights of the 17th International Congress on Palliative Care, 23-26 September 2008

Gayle A. Shinder and Dr. Anna Towers

The International Congress on Palliative Care, organized by the Palliative Care Division of McGill University and held in Montreal, aims to promote the exchange of leading edge ideas in our rapidly growing discipline of palliative care. Since its beginnings over 30 years ago this biennial Congress has seen increasing agreement that palliative care should be provided from diagnosis, hence the shift to “Palliative Care” from “Care of the Terminally Ill” in its title.

The first Congress was held in 1976 under the direction of Dr. Balfour Mount, and has taken place every other year since then. His inspired leadership over the years ensured the Congress a pre-eminent place, internationally, among such events in the field of palliative care, and provided a foundation upon which we are continuing to build.

The recent International Congress was a very successful event, attracting close to 1500 participants from 48 countries. Delegates represented many disciplines—physicians, administrators and policymakers, nurses, social workers, physical and occupational therapists, music therapists, pharmacists, pastoral care persons, volunteers, psychologists, etc.

For the first time the Congress was a trilingual one, with French and Spanish simultaneous interpretation. The four day programme included five Plenaries, with the opening plenary by Charles Taylor, four concurrent Day Seminars, three Re-



*Palliative Care, improving quality
of life for patients and families.*

search Fora and two special seminars—one on volunteer issues and another on caregivers. There were 65 invited speakers from ten countries and 413 submitted abstracts from 31 countries. Some of the psychosocial highlights of the Congress are presented here.

As palliative care organizations are now mobilizing to encourage international human rights organizations to promote access to palliative care as a human rights issue, it seemed an opportune time to put this topic on the agenda at the 2008 International Congress on Palliative Care. Organized and chaired by Dr. Martin Chasen, the day-long seminar on international issues entitled **Palliative Care is a Basic Human Right – How Can We Right the Wrong?** focused on palliative care delivery around the world and featured presenters from Africa,

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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.

Co-Chairpersons:
Richard L. Cruess
Kappy Flanders

Advisor:
Balfour M. Mount

Members:
Barbara Bishop
Sue Britton
Gretta Chambers
Gwen Connors
Linda Crelinsten
Dawn Cruchet
Teresa Dellar
Armand Des Rosiers
Joan Foster
Zelda Freitas
Lois Hollingsworth
Cecily Lawson-Smith
Suzanne O'Brien
Dany Pollack
Andrée Prendergast
John Sanford
Ibby Shuster
Carol Steadman
Marla Stovin
Daniel Sup
Anna Towers
Michèle Viau-Chagnon
Ellen Wallace
Sharon Wexler

Secretary:
Frances Morris

Highlights of the

Continued from page 1

Europe, the Middle East, the United States and Canada. Many issues and points were highlighted including the lack of hospice and palliative care services in many parts of the world and the barriers that need to be overcome; the importance of collaboration between palliative care organizations and human rights groups to bring the message to governments around the world that palliative care needs to be a priority; international efforts currently being done to drive home that message; the challenges of providing palliative care in a medical centre which has patients and healthcare providers from both sides of the Palestinian-Israeli conflict, and how bridges have been built as a result of the universality of the illness experience; the mandate of the European Society for Medical Oncology (ESMO) in encouraging medical oncologists to play a central role in coordinating the care of cancer patients; great strides in palliative care in Canada; and the universal issues facing people with a terminal illness.

The pediatric palliative care day-long seminar entitled: **From the Intensive Care Unit to the Home: An Examination of Hope and Meaning in Palliative Care for Children** was organized and chaired by Dr. Stephen Liben and focused on communication between palliative care physicians and the families of children in intensive care. Topics included the need for the integration of the palliative care team within the intensive care unit to help support patients and families and guide them through the difficult process as end-of-life care becomes a reality; and the importance of clear communication between the healthcare

team and the family which encompasses talking, listening and ensuring that the issues are well understood by the family so that they can make informed decisions.

Continuing a past tradition, there was a day-long seminar on holistic care entitled **Healing and Whole Person Care: Palliative Care – Just Another Specialty?** This seminar, organized and chaired by Dr. Tom Hutchinson, brought to the forefront the notion that palliative care becomes more than just another specialty when the physician or other healthcare worker puts him or herself, at least partly, in the shoes of the person who is ill and possibly dying. This changes the relationship of patient and caregiver in a profound way and fosters healing.

There was a talk focusing on how people manage their fears and cope with the notion of death. Studies were presented which illustrate that one's own sense of mortality can have dramatic effects on how a person reacts in particular situations.

Another talk dealt with the notion of separation anxiety when coming to terms with illness and impending death and how palliative care patients search for ways to cope with this by forming connections which have meaning to them, such as with their inner selves, with others, with childhood memories, with deceased loved ones, etc.

Organized and chaired by Dr. S. Robin Cohen, each of the three **Research Fora** featured three speakers and a discussant, followed by a question and answer period. Research studies included looking at the impact of caregiving on parents of children with life-limiting illness; the care-



17th International Congress, cont...

giver's perspective on the quality of dying and death of the patient with metastatic cancer; the experience of healthcare aides who are caring for dying seniors in a personal care home; issues facing adults with advanced heart failure, their family caregivers and formal healthcare providers; patient learning in patients with GI cancer; the Meaning Making Intervention (MMi) in people newly diagnosed with advanced ovarian cancer; and a group education program which helps family caregivers prepare themselves for the role of supporting a dying relative at home.

The **Family Caregivers special seminar** was organized and co-chaired by Drs. S. Robin Cohen, Serge Dumont and Johanne de Montigny. The first part of the session focused on the needs of caregivers from the standpoint of whether they view themselves as partners with the healthcare professionals or as clients of the healthcare system. In the former case these people saw themselves as taking a lead role in the primary care of the patient with the clinicians taking a secondary role, while in the latter case the caregivers are viewed as potential clients because of their need for support as they deal with the issues involved in caring for a dying patient. The second part of the session highlighted the importance of taking into consideration the concerns and needs of family caregivers, and key issues and challenges that need to be considered during a routine family meeting.

The Congress also featured a brief presentation on the **Canadian Virtual Hospice (CVH)** (www.virtualhospice.ca/), an internet-based network created by Dr. Harvey Chochinov and colleagues which provides support for people dealing with life threatening illness. Launched in February 2004, this website features pages specifically geared towards the patient, family/friends, healthcare professionals or volunteers. Questions frequently asked deal with a range of issues such as physical symptoms, psychosocial and spiritual matters, resources and administration information.

Seminar on Volunteer Training

This special seminar at the International Congress was organized by The Council on Palliative Care together with the McGill Medical Simulation Centre. Following a brief introduction by Kappy Flanders, co-chair of The Council on Palliative Care, Linda Crelinsten, Assistant Director of the Simulation Centre, gave an overview of teaching and training methods and described the objectives of the session.

Participants viewed four videos during the course of the three hours, with time allotted between each video for small group discussions. The videos were dramatizations of actual situations volunteers had experienced when working with palliative care patients, and depicted both the emotional and ethical issues encountered. These videos served as a springboard for discussions on training, challenges and opportunities. The objectives were to identify the role of the volunteer in the different settings, describe the common challenges related to family dynamics, identify the communication issues between patients and families and between the team members and finally, to recognize ongoing opportunities for training. The final part of the session moderated by Suzanne O'Brien, Executive Director of Hope & Cope, was devoted to presentations by each group of the key conclusions and points they discussed regarding a particular video.

The first video illustrated a situation where the patient requested a favour from the volunteer which went above and beyond reasonable expectation and which had ethical and legal implications. The second video depicted a situation highlighting the issue of how much information a volunteer should impart to a family member regarding the patient's condition. The third video focused on the issue of complicated family dynamics and how a volunteer deals with this kind of situation. The fourth video focused on the cultural sensitivity issues when dealing with patients and families.

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"You matter because you are you. You matter up to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die."

*Dr. Cicely Saunders
(pioneer of the modern Hospice movement)*

Upcoming Events & Happenings!..

Take A Hike!...Hike for Hospice Palliative Care May 3, 2009

Hike for Hospice Palliative Care 2009 will be held on **Sunday, May 3rd** along the Lachine Canal—starting at 1800 Saint-Joseph Boulevard, corner 18th Avenue. Registration will begin at 9:00, warm-up at 9:30 and the 5K walk at 10:00 AM.

The Hike is held in cities across Canada annually to raise awareness of hospice-palliative care. Last year the Council participated in the 6th annual Hike for Hospice Palliative Care and along with 90 other sites across Canada, helped to collect over \$950,000 for palliative care. What is exceptional about this Hike is that 100% of the funds raised remain in the local community.

Last year the Hike was a great experience. We had our largest crowd to date — over 100 people and everyone was in great spirits!

Come and join us for a day of fun — walk, run, bike, rollerblade — bring the whole family.

Annual Sandra Goldberg Lecture— April 28, 2009

This year's Annual Sandra Goldberg Lecture will be held on **Tuesday, April 28th at 5:30 p.m.** at McGill University in the Charles Martin Amphitheatre.

The speaker will be Dr. Nathan Cherny. Dr. Cherny is a Australian born oncologist working with Israeli and Palestinian patients in Jerusalem. He is the Co-founder and Director of the Cancer Pain and Palliative Medicine Service at Sha'are Zedek Medical Centre in Jerusalem, Israel.

The title of Dr. Cherny's lecture will be ***“Caring for the Dying in Situations of War and Conflict: Finding Hope and Building Bridges.”***

Last year's lecture was a great success. There were approximately 200 in attendance to hear Dr. Linda Emanuel whose topic was, *Understanding and Implementing Preferences for Care*. She gave an excellent lecture on medical directives.

Workshops

The Council continues its public outreach with its popular workshops. In 2008, we offered two series of workshops at Mount Sinai Hospital -- a wonderful venue in Cote St. Luc that has a 15-bed palliative care unit on site.

The first series was offered in April and covered ***Ethical Dilemmas in Palliative Care***, which was presented by Dr. Manny Borod, the Medical Director of Palliative Care Services at the McGill University Health Centre (MUHC) and ***Palliative Care and Advanced Directives—Controlling Your Life in Difficult Times***, presented by Jane Chambers Evans who chairs the McGill University Health Centre's Clinical Ethics Committee and has interests in end-of-life care, surrogate decision-making and the role of family in care decisions.

The second series of workshops was held in November and used the Volunteer Training videos which had been so successful at the International Congress on Palliative Care. Two members of the Council, who work at CSSS Cavendish in palliative care – Zelda Freitas a social worker, and Joan Foster a nurse, gave the presentations and facilitated the discussion. Judith Marchessault, a homecare palliative care nurse at Mount Sinai also brought wisdom and insight into caring for someone with a life threatening illness.

The second series of workshops covered ***Palliative Care 101*** which addressed the why, who, what and where of excellence in palliative care in Montreal. ***Palliative Care Isn't Less Care*** looked more into total symptom management during a life threatening illness for which there is no cure and ***Palliative Care Never Ends*** addressed the needs of the entire family during the illness and bereavement.

For information on future workshops visit our website at www.council-on-palliative-care.org.

We would like to thank the doctors, nurses and other health professionals who donate their time and allow us to offer these workshops free of charge.

N.B.: If requested, the money from the sale of clothes given to ***Sharyn Scott*** will be donated to the Council on Palliative Care

Sharyn Scott (consignment by appointment)

4925 Sherbooke Street W., Westmount. Tel.: 514-484-6507

Highlights of the 17th International Congress, cont...

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Some of the key points regarding the role of the volunteer that were highlighted during the group presentations include: the importance of validating the needs of the patient even if they are unable to comply with the request; volunteers need to ensure they are giving enough space to the family members; the role of the volunteer is not always clear and can change from situation to situation; and cultural sensitivity is important in the home setting and can be a challenge.

In summary, the videos are an excellent training tool for volunteers as they provide an opportunity for learning and reflection about key issues and challenges in providing support to palliative care patients and their families.

The making of the videos

A few years ago, following numerous workshops and discussions with volunteers, volunteer coordinators and healthcare professionals, the need to provide advanced training for volunteers became apparent.

The Council, in collaboration with the McGill Medical Simulation Centre and with financial support from the Goodman Family Foundation and the Zeller Family Foundation, decided to make four videos that could be used in the training process.

The McGill Medical Simulation Centre is an interprofessional centre of excellence that uses medical simulation to enhance the skills of healthcare professionals through education, research, evaluation and innovation, thereby improving patient safety and the quality of care. The Centre opened in September 2006. It offers all the modalities of simulation including working with standardized patients (actors), mannequins and task trainers to teach healthcare students and professionals, both individual and team skills. As volunteers in palliative care are members of the multidisciplinary team, the Simulation Centre welcomed the opportunity to be involved with the Volunteer Seminar at the International Congress on Palliative Care in Montreal. Providing training for palliative care volunteers improves the care of patients and their families.

It was felt that the use of standardized patients (actors), who are trained to help to teach medical students, nursing students and residents, would be a valuable educational resource that could best realize the goals of the seminar. Scenarios were developed with the help of volunteer coordinators, healthcare professionals working in palliative care and members of The Council on Palliative Care. The scenarios depicted difficulties in communication, ethical

dilemmas, complex family dynamics and a culturally charged home visit. In the videos, the standardized patients played the roles of the volunteers, patients, family members and staff. The videos would be the educational resource but were only a part of the teaching package that was to be offered to the volunteers who would register for the Seminar.

Members of the Council, palliative care team members from many hospitals and the homecare community came to the Medical Simulation Centre to learn how to be facilitators for the Seminar. This group made a strong contribution to the final teaching package that was offered to the registrants of the Seminar. They worked together to develop the questions on which the discussion would be focused, and offered suggestions on how to refine the objectives. The success of the Volunteer Seminar was realized through the efforts of teamwork and expertise of many who work and volunteer in palliative care.

Volunteers in palliative care face many challenges while helping staff to care for patients and families. The videos and the subsequent teaching package will provide an educational resource for ongoing use.

Using the videos

Based on the incredible success of the videos shown at the Congress and the numerous requests from participants who would like to have access to them, the Council on Palliative Care has assembled a training package to accompany the videos and will send this package to all interested parties, free of charge. The package consists of the four videos plus guidelines for facilitators and suggested uses for the training of volunteers and healthcare professionals in palliative care. It is hoped that this project will continue and that further scenarios can be developed and will be available for the next Congress in 2010. For further information and ordering, please email the Council at fmpa202@aol.com.

The next Montreal International Palliative Care Congress will take place October 5-8, 2010. Hope to see you there!



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 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)

THANK YOU TO OUR SPONSORS IN 2008

The Goodman Family Foundation
The Zeller Family Foundation

Special mention: to *Bayshore Home Health* for sponsoring volunteers from The Lighthouse to attend the Volunteer Seminar hosted by the Council at the International Congress on Palliative Care.