

Council on Palliative Care

**Palliative Care Week
May 7 to 13, 2007**

**Hike for Hospice
May 6, 2007
(see page 6 for details)**

*“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)*

10th Annual Sandra Goldberg Memorial Lecture

This year marks the tenth anniversary of the Sandra Goldberg Memorial Lectures. Sandra Goldberg was a psychologist and marriage counselor who died, in 1997, of colon cancer. She was active in the Montreal community and beloved by many. In her memory, her family – her husband Gerry and her three children, Lynne, Adam and Peter – established this lectureship.

The lectures are intended to inform the community about the current status of palliative care; highlight ethical and psychosocial issues related to end-of-life care; and further encourage public initiatives to address the needs of dying patients.

We have had nine very distinguished lecturers:

- 1998 Dr. Balfour Mount, Palliative Medicine, McGill University, Montreal
“Whole Persons in a New Age: A Concept Revisited”
- 1999 Dr. Kathy Foley, Pain and Palliative Care Service, Department of Neurology, Memorial Sloan-Kettering Cancer Centre, New York
“Transforming the Culture of Death”
- 2000 Dr. Nuala Kenny, Bioethics Education and Research, Dalhousie University, Nova Scotia
“Rethinking the Goals of Medicine”
- 2001 Dr. David Roy, Centre for Bioethics, Clinical Research Institute of Montreal
“Suffering is Where Meaning Crosses Paths with Biology”
- 2002 Dr. Ned Cassem, Department of Psychiatry, Harvard Medical School, Massachusetts
“Celebrating Life Together”
- 2003 Dr. Eric Cassell, Department of Public Health, Weill Medical College, Cornell University, New York
“Suffering and Healing”
- 2004 Dr. David Kissane, Department of Psychiatry, Memorial Sloan-Kettering Cancer Centre, New York
“Discovering Meaning in Illness and Suffering”
- 2005 Dr. Diane E. Meier, Centre to Advance Palliative Care, Departments of Geriatrics and Medicine, Mount Sinai School of Medicine, New York
“Palliative Care in Hospitals”
- 2006 Dr. Gerri Frager, Department of Pediatrics, Dalhousie University, Nova Scotia
“Critical Communication in the Care of Children”

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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 health care 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
Ann Hébert
Lois Hollingsworth
Linda Kenemy
Cicely Lawson-Smith
Margrit Meyer
Suzanne O'Brien
Dany Pollack
Andrée Prendergast
John Sanford
Ibby Shuster
Carol Steadman
Joe Stratford
Daniel Sup
Anna Towers
Michèle Viau-Chagnon
Ellen Wallace
Sharon Wexler

Secretary:
Frances Morris

David Bourke Memorial Lecture — Life in the Balance with Dr. Marla Shapiro

By Dr. Richard L. Cruess

The Third Annual David Bourke Memorial Lecture was given on November 26, 2006 at the Temple Emanu-El-Beth Sholom. David Bourke was a much loved and respected member of his community who made many contributions to a wide variety of important activities. One of his major interests was end-of-life care and he served as Co-Chair of the Council on Palliative Care. With the support of his family, the Council established an annual lecture in order to honor his memory. The 2006 lecture was given by Dr. Marla Shapiro, a 1979 medical graduate of McGill University who is one of the most trusted and recognized health professionals in Canada. She is Associate Professor of Family Medicine at the University of Toronto, in addition she has both a private practice and raises a family. She is the medical consultant for CTV National News and Canada AM. She also hosts the show "Balance: Television for Living Well" and writes on health issues for the Globe and Mail. She has been honoured by medical societies for her role in communicating medical issues to the general public in an extraordinarily responsible way.

In 2004 she was diagnosed with breast cancer at a relatively young age, an event which she states changed her life. In her talk, which was to a very large (approximately 500) and very attentive audience, she recounted her early life in Montreal and expressed her lasting debt to Gwen Vineberg who began their relationship as her sixth grade teacher and became a lifelong mentor and

friend. Gwen introduced her and their great regard for each other was evident to all.

Dr. Shapiro talked in very personal and moving terms of her response to her diagnosis, her family's reactions, the support she received from her friends and professional colleagues, and how these events coloured her outlook on the world. The talk was rich in personal anecdotes. As an example, she described both her own and her son's response to her loss of hair. Her use of humour enhanced rather than diminished the emotional impact of her story. The auditorium was absolutely silent, undoubtedly because everyone realized that they were hearing a remarkable tale recounted by one of the premier medical communicators in Canada.

Following the formal talks, Dr. Shapiro answered questions from the audience. As she did during the presentation, she was in constant motion, moving to wherever she could communicate best with the individual posing the question. Most of the questions related to medical matters and her answers were very firm in endorsing science-based medicine and discouraging the use of approaches for treatments which lacked a foundation in modern medical science.

The audience was clearly appreciative and those who knew David Bourke, who was himself an outstanding communicator, felt that he would have been pleased.

We would like to thank Barbara Bishop and Gwen Vineberg for organizing the lecture and the Temple-Emanu-El-Beth Sholom for hosting it.

Living Wills/Advanced Directives

By Jane Chambers-Evans

What is a Living Will?

Living Wills, or Advanced Directives as they are sometimes called, came into existence in the late 60's. They are used as a tool to communicate end-of-life decisions. As opposed to a 'last will and testament', the directives, or the wishes stated within the Living Will, are carried out prior to death. A Living Will then, is a document that you complete, or that you write yourself, and it is meant to speak for you when you cannot speak for yourself.

In Quebec, Living Wills are officially known as mandates (Mandat en cas d'inaptitude). The Civil Code in Quebec is crafted to protect our individual rights and a Living Will extends our rights by allowing us to name someone (a spokesperson, advocate, mandatory) to speak for us.

Why do I need one?

To be able to make our own decisions and to have those decisions respected is important to us all. Many worry that if they become ill or incapacitated that they will lose control over decisions about their care. Living Wills are a way of taking control. Before attempting to prepare a Living Will it is important to understand what they can and cannot do, and how to maximize their usefulness.

Why would you take the time to prepare a Living Will?

Life can be unpredictable. Despite the fact that most of us work hard to keep control of our lives and our world, sometimes events such as illnesses or injuries, turn our life in an unexpected direction. Knowing that we have both the right and the responsibility to make our own

decisions and taking the proactive choice to prepare in advance for any eventuality makes good sense.

The process of preparing a Living Will is an opportunity to think about your health, your values and, if you have an illness, to explore the options that are available to you and decide which of these seem reasonable and sensible.

During a crisis, or an illness, the situation is often chaotic, exhausting and filled with emotion. The better prepared and aware of your wishes that your spokesperson is, the better he or she will be able to represent you wisely - even in a stressful situation.

How do you begin to prepare a Living Will?

There are three important components to be considered:

- ◆ the type of Living Will that you want to make
- ◆ deciding who will be your spokesperson/advocate/mandatory
- ◆ thinking about and giving directives to your caregivers.

Types of Living Wills

As Living Wills become more widespread, there are several forms that have been created. Many hospitals have designed forms that will help you to prepare a Living Will. Some are simple checklists; some are disease specific and some give checklists of treatment options. The McGill University Health Centre (MUHC) has published a handbook that gives detailed information on how to write a Living Will. It provides examples for those who wish to write their own and a check-

list for those who prefer to be guided in their choices. The booklets can be picked up in the Patient Ombudsman offices of the MUHC. For an electronic version contact the Council at fmpa202@aol.com. The Jewish General Hospital, and the University of Toronto Joint Centre of Bioethics have also created Living Wills that can be downloaded and completed. (www.jgh.ca, go to Departments & Programs, then to Clinical Ethics Committee) (www.utoronto.ca/jcb/outreach/living_wills.htm)

Some people prefer to have a notary prepare their Living Will. There is a cost to this and the notary is not able to advise about medical choices. But for those who wish to nominate someone to attend to their business or household affairs as well, or for other legal reasons, a notary is a good option.

Choice of a spokesperson/advocate/mandatory

On the surface this may seem like the easiest part, and in fact for many the natural choice will be obvious, their spouse, a close relative, or even a special friend. However, it is imperative that you understand the role that your spokesperson will be asked to play once you are unable to speak for yourself. By understanding this, you will have a better idea of who, in your family or circle of friends, will be able to fulfill the role, will be comfortable in the role, and will be able to communicate your wishes.

A spokesperson will be asked to discuss your care and treatment options with the health care team.

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Happenings!..

WORKSHOPS

By Barbara Bishop and Gwen Connors

The Council on Palliative Care presented two series of workshops in 2006. Each series consisted of three workshops. The first series was held in March at Temple Emanu-El-Beth Sholom in Westmount and the second, at the Ste-Geneviève United Church in Dollard-des-Ormeaux, in November. The participants included health professionals, caregivers, family members, students and volunteers.

Each workshop started with a film and was followed by small-group discussions, each with a facilitator. The evening ended with everyone sharing their thoughts and asking questions. The discussions were all led by members of the Council.

The films:

“Mr. Mergler’s Gift” tells the story of a piano teacher, dying of cancer, who finds meaning in his final days by teaching a gifted student. The evening was noteworthy because, not only was a former student of Mr. Mergler’s in the audience, but Mr. Brahms Silver, one of the film’s producers was present. Mr. Silver mentioned that although he had seen the film many times, it still touched him and he saw something new each time.

Dawn Cruchet, a grief educator, led a very stimulating and informative discussion afterwards.

“The First Snowfall - Saying Goodbye”, a docudrama, depicted the family dynamics and multiple communication challenges in a family where the mother was terminally ill. Scenes captured the tensions of siblings – the hometown child always present, versus the revered out-of-towner whose infrequent visits were paired with strong opinions; the coping skills of different family members; changing the focus to the patient – her needs and desires as a wife, a mother, a person.

Sue Britton, a nurse, psychotherapist and yoga teacher, encouraged participants to look at the situations presented from different viewpoints and to respect the fact that people respond to situations in their own way.

“Laugh Your Way to Health” is a film by Annette Goodhart, which shows how important laughter is in our lives and how it can be used to help in the healing process. Learning to laugh at situations in our lives that are usually taken very seriously can be therapeutic.

Illness, depression, crisis, grief - all can be dealt with using laughter. Sue Britton led the discussion that followed.

“Give Me Your Hands” showed the experiences of several Irish families caring for terminally-ill loved ones. While the accents and use of Gaelic were a challenge to the audience at times, a profound response was elicited during the discussion through the use of still photos that pinpointed moments in the film. Wisdom, emotion and warm personal experiences were shared as participants chose a photo and reflected on the thought or memory it evoked.

Joan Foster’s depth of experience as a homecare nurse and love of her work was evident in her presentation.

“Kids Care” was introduced by Dawn Cruchet. A remarkable group then presented the film addressing the issues and needs of young people who have lost a loved one to cancer. The raw emotion, the tender memories, the anger, the hopes and the honest, frank discussion of children, from 8-year olds to teens, evolved on the backdrop of a camp retreat in the tranquil beauty of Ontario’s Muskoka Lakes region. A young man, who was in the film, was present to share his experience and confirmed the obvious bond that developed among the kids, regardless of age, culture or background. Participants left enriched by the transparency of these extraordinary young people.

A comment that was made at one of the workshops was very meaningful to those of us involved in their organization – “When we come together and share together, we become more well-rounded in the care we provide.”

Our workshops are free and open to everyone. The participants are always very diverse and this leads to stimulating interactions and discussions.

We thank Temple Emanu-El-Beth Sholom and Ste-Geneviève United Church for hosting the evenings.

16TH INTERNATIONAL CONGRESS ON CARE OF THE TERMINALLY ILL

By Dr. Anna Towers

The International Congress on Care of the Terminally Ill has been held in Montreal every two years since 1976. The 16th edition of the Congress, which was held at the Palais des Congrès from September 26-29, 2006, succeeded beyond all expectations and set a new standard in terms of attendance, sponsorship and depth

Happenings!..(cont.)

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and breadth of the programme. 1500 participants attended, with 28 countries and 6 continents represented. There were 62 invited speakers and 241 presenters of proffered workshops, research papers and posters over the four days. There were full-day concurrent seminars on Non-cancer End-of-Life Care, Whole Person Care and Pediatrics and special seminars on volunteer issues, self-esteem, international development and respiratory issues. The Council on Palliative Care was involved in organizing the volunteer day that attracted outstanding participation. The Congress Executive Committee put together Reflections for each of the plenaries, continuing a much appreciated Congress tradition. There was a special presentation to Dr. Balfour Mount at the closing plenary.

The next International Congress will take place at the same location from September 23-26, 2008. That version will feature simultaneous Spanish translation as well as French and English, increased involvement by international partners and a strong clinical and interdisciplinary programme. Note the dates now and see you there!

Volunteer Seminar – Strengthening the Team

By Joan Foster

During the 16th International Congress on the Care of the Terminally Ill in September 2006, a ‘Special Seminar’ was held, sponsored by the Council on Palliative Care – *Volunteers: Amateur Professionals or Professional Amateurs?* The three-hour seminar guided volunteers and health care professionals through the process of strengthening the team to better care for the patient.

To ignite the flame under those present, we first heard from Kappy Flanders, Founder and Co-Chair of the Council on Palliative Care; Gwen Nacos, Founder and Director of Cedars CanSupport; and Suzanne O’Brien, Executive Director of Hope and Cope who spoke on behalf of Sheila Kussner, Founder and Chairman of Hope and Cope. Their words clearly demonstrated the importance of the volunteer in the interdisciplinary team – supporting the patient and their family.

The greatest strength of a team is its people – committed, talented and resourceful. Volunteers especially are recognized as dedicated and devoted – often the organi-

zation’s greatest resource. In our Global world families are not concentrated together in the same area making daily care-giving very difficult, if not impossible. Even if families are present, career and family pressures conflict with the need to be at the bedside of someone who is very ill. Volunteers on the Palliative Care Team are more important than ever and the families are so appreciative of the time and caring that a volunteer can offer their loved one. Professionals and staff are also trying to cope with fewer resources in today’s health care reality and a well-trained volunteer adds so much to patient satisfaction and family comfort levels.

After the three keynote speakers, the participants broke up into groups under one of the following headings:

- ◆ Advocacy and Community
- ◆ Families
- ◆ Expectations: Staff of volunteers; Volunteers of staff
- ◆ Training: Recruitment, Retention, Curriculum
- ◆ Self Care: Coping with Attachment and Loss

As it was an international congress, the exchange of how teams function in different countries was both stimulating and educational. It was very difficult for the fantastic facilitators to bring the tables back to the larger group for feedback.

The 3 hours flew by and all present wished that there could have been another 3!

The uniqueness of this event was the graphic recording of Sara Heppner – an amazing artist who was able to put into a visual presentation all the issues raised – the challenges that are faced and lessons learned:-

Communication, continuity, confidentiality, mentoring, respite and life balance, defined roles, access to best practice guidelines, training, standards, recognition and expectations...and the importance of training more volunteers at a higher level.

Each topic was a full day seminar unto itself, yet all 200 present stated that they had walked away with a new skill and a new pathway defined to reach ideal care for those we care for at the end of life.

There was a strong commitment from all to the missions of their organizations and a pride in their abilities to operate within, what is perceived to be, an increasingly constraining environment. This seminar explored new ways of drawing on the talent, energy and commitment of volunteers in the Palliative Care Team.

Happenings!..(cont.)

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VOLUNTEER TRAINING

By Dany Pollack

The use of volunteers in the hospital system has become more and more important in providing supportive care for inpatients. As a result, the Council on Palliative Care has undertaken to support an initiative involving the training of volunteers for the McGill University Teaching Hospital network. Using modules from the Canadian Hospice Palliative Care Association (CHPCA) Support Workers training manual, the Council will offer a level 2 training course to those volunteers working in the system who have already received a general overview of Palliative Care from the McGill University Institutions.

Using the Simulation Centre at McGill University, the first of its kind in North America, the Council will explore the benefits of using new technologies to enhance the level of volunteer education. Small groups will have the opportunity to study specific cases, practice through role-playing and the use of standardized patients (actors) to provide simulated scenarios.

The hypothesis is that volunteers can be trained more effectively, at the level required for the hospital setting, with a higher level of comprehension than previously achieved through traditional courses. This will improve both their effectiveness and confidence in their work with the terminally ill and bereaved.

KID'S CORNER

During the past few years, we have seen an increase in the number of children coming to visit relatives on the palliative care units in our McGill affiliated institutions. There is a need to have 'kid's corners' in the Family Rooms, if possible, on each of the Units — a place where they can sit and read, draw, do a puzzle or play a game.

Responding to this need the Council has provided activities and 'distraction bags' — bags with a stuffed toy and a travel size game — to various hospitals as well as the West Island Palliative Care Residence.

HIKE FOR HOSPICE PALLIATIVE CARE 2007

The Hike for Hospice Palliative Care 2007 will be held on Sunday, May 6th at Parc Jean-Drapeau—L'Aire de pique-nique de la navette fluvial, Île Sainte-Hélène beginning at 9:00 A.M.

The Hike is held in many cities across Canada annually to raise awareness of palliative care.

Proceeds from the hike will be divided among, The Council on Palliative Care, The Lighthouse, Children and Families and the McGill University Health Centre (MUHC) palliative care units.

Come and join us for a day of fun — bring the whole family — pets are welcome!

Living Wills (cont...)

They will be asked to speak as if they were 'inside your head', to think as you think — so they need to know you well and most importantly, they must know what you want them to say and do on your behalf. Although in most cases the health care team will work very hard to help them to understand the medical information, there may be times when the spokesperson will need to be pro-active, even assertive, in speaking on your behalf. Because of this, you need to choose carefully who will speak on your behalf, considering those who are not afraid to speak up, those who know you well, and who are able to reflect your ideas and can cope in stressful situations. Remember, the situation may be very emotional. Your spokesperson must agree to be willing to speak for you. You must discuss your Living Will and why you have made the decisions you have with them, so that they are prepared to work in partnership with the medical team.

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Living Wills (cont...)

Preparing your Living Will

First and foremost, a Living Will must be a reflection of you and your wishes. There are usually two reasons for writing such a document:

- ◆ because you know you have a certain illness and want to ensure that your end-of-life wishes are clearly documented for your spokesperson and your doctor.
- ◆ because you feel strongly about your wishes and want them documented for use in the event that your circumstances change.

Once you have decided to proceed, it is a good idea to discuss your situation with your physician. What are the options that would be available? How would you make those decisions? If you have a specific disease, what would be considered reasonable and effective in your case and what would be considered not effective.

Most important is to take the time to think about what makes life meaningful to you. For example, some might consider permanent disability or infirmity unacceptable. Some feel that physical disability is less of an issue than not being cognitively intact, with no way to interact with family or friends. Others would like to continue receiving all treatments that will keep them alive.

It is imperative that each of us remembers that life is finite and not all options or consequences can be predicted. Doctors cannot be obliged to provide treatments that will not be beneficial to the patient. It is essential that patients and their spokespersons are in partnership with the physician, in order to ensure that the best decisions can be made.

What do I do with my Living Will once it is written?

The most essential action is to communicate your wishes to others. First and foremost, you must speak to your spokesperson and, if you have not already spoken to your doctor take him/her a copy of your Living Will, discuss it and have it officially placed on your chart. If you are followed by the CLSC, they too should have a copy. Once written, you should carry a card in your wallet that states that you have a Living Will and gives the contact details of your spokesperson (the MUHC version has an example of a wallet card). You should also bring your Living Will with you to the hospital if you are to be admitted, giving the medical team a copy to be put on your chart.

How and when will the Living Will be put into effect?

A Living Will only comes into effect when you are not able to speak for yourself – until that time you are expected to make your own decisions. This does not mean that you must make your decisions alone, in fact, research shows that we make our best decisions when supported by those we trust and who care for us. In most clinical situations, the medical team will work with the spokesperson you have chosen to ensure that your decisions reflect your wishes. However, if you become permanently unable to speak for yourself, your spokesperson, your family and your notary (or lawyer) will work together to protect your interests.

Living Wills are not a panacea to solve all the problems of decision-making. In fact, those that are poorly crafted, or which have not been discussed with family members, may be more of a nuisance than a support. But when taken seriously, and prepared with care, they can be an excellent tool to support the decisions that family members and physicians must make on our behalf.

Jane Chambers – Evans, N, MSc.A, MSc. (Bioethics)
Nursing Practice Consultant and Clinical Ethicist
McGill University Health Centre

Goldberg Lectures (cont...)

This year's speaker will be Dr. Gian Domenico Borasio. Dr. Borasio is a neurologist and palliative care physician. He is Professor and Chair of the Interdisciplinary Centre for Palliative Medicine and the Department of Neurology at the University of Munich in Germany; and Head of the Motor Neuron Disease Research Group and Outpatient Clinic in the Department of Neurology at the University of Munich. Dr. Borasio was instrumental in creating a dedicated palliative care unit at the Munich University Hospital.

The Tenth Annual Sandra Goldberg Lecture will be held on Tuesday, May 8th at 5:30 p.m. at McGill University in the Charles Martin Amphitheatre. The title of Dr. Borasio's lecture will be "*Palliative Care Isn't Just About Cancer.*"

In addition to the Goldberg family, these lectures are sponsored by The Council on Palliative Care and many have been co-sponsored by The Beatty Memorial Lectures Committee of McGill University. This year's lecture is co-sponsored by the Montreal Neurological Institute and Hospital.

We would like to take this opportunity to thank the Goldberg family, the distinguished lecturers, our sponsors, the members of the Council and all who participate in making these lectures a success.

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 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, 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 on 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)