Spring 2011

Newsletter

The Council on Palliative Care

Inside this issue:

Sandra Goldberg Lecture
Wednesday, May 4, 2011

Palliative Care Week
May 1—7

With Poem, Broaching the Topic of Death

By Ben Biatz, M.D.

Mitzie Begay, an elegant 76-year-old Navajo, can interpret the nuances of her language and traditions with contemporary verve and understated wit — qualities that make her a good fit for a job that could hardly have been imagined in the Navajo Nation a generation ago.

Ms. Begay, whose title is cross-cultural coordinator for the home-based care program at the Fort Defiance Indian Hospital here in northeastern Arizona, helps Navajos deal with the complex and confusing process of decision-making at the end of life.

In Navajo culture, talking about death is thought to bring it about, so it is not discussed. A dead person's name is never spoken. Only designated tribal members are permitted to touch and bury the dead.

So it is up to Ms. Begay and her colleagues to find ways to teach people (many with little or no English) about things like living wills, durable powers of attorney, do-not-resuscitate orders, electroencephalograms, feeding tubes and ventilators. In spite of the taboos, they are trying to find a comfortable way to begin a conversation with patients and their families about death and dying.

Until last month, the program's director was Dr. Timothy Domer, a geriatrician who practiced medicine for more than 20 years in this remote, high-desert, red-rock landscape on the eastern fringe of the vast Navajo reservation. Its goal, he said, is to keep elderly patients healthy, starting with a thorough physical exam and a comprehensive, interdisciplinary assessment, followed by home visits.

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

Dr. Domer, who is moving to New York State to practice geriatrics and palliative care, said it soon became clear that when it came to end-of-life matters, his patients had a different perspective from many other Americans.

"When I explained to an old Navajo patient of mine that we sometimes have to shock the heart to get it started, he said, 'Why would anybody do a crazy thing like that?' " he said. "That made me think there were people who didn't necessarily want the standard resuscitative efforts that we routinely practice at the end of life."

When Dr. Domer started the home-based care program five years ago, he reviewed hospital records to see how many charts contained advance directives. "There were none — zero," he said.

For patients who had terminal illnesses, Dr. Domer wanted to be able to provide hospice and palliative care.

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.

With Poem, Broaching the Topic of Death (cont...)

"Our goal is not just to change the way people die," he said, "but to change the way dying people live, and how their families experience and will remember the death."

On this day Ms. Begay and Gina Nez, the program's director of nursing, are bumping along in a four-wheel-drive S.U.V. to visit elderly patients in isolated communities. They drive past hogans, the six-sided traditional Navajo dwellings, past herds of cattle and sheep that dot the grass meadows.

"At first I was uncomfortable," Ms. Begay said about her introduction to end-of-life discussions. "But the staff got together and we talked about it, and we agreed on a way to approach it."

The vehicle was a poem: "When that time comes, when my last breath leaves me, I choose to die in peace to meet Shi' dy' in" — the creator. Written in both Navajo and English, it serves to open a discussion about living wills and advance directives.

Fewer than 30 percent of Americans have signed advance directives for health care. But Dr. Domer says almost 90 percent of patients in the program have signed the poem and other standard directives.

"Our elders tell us they want to die with dignity — the way they lived," he said. "We've changed how patients live their final days by opening the discussion on death and dying, and giving patients and families the opportunity to tell us what is important to them.

"Before we started this program, the subject was generally avoided out of 'cultural sensitivity,' depriving patients and families of preparing for death spiritually, emotionally and practically."

When someone dies in the family hogan, for example, a hole is made in the north wall to let the good spirit out, and then the hogan is abandoned.

"I've seen my share of dying patients, particularly elderly patients who spoke only Navajo, whose families brought them to the hospital to die," Dr. Domer said. "One of the reasons they came to the hospital was that if they died in the hogan, the rest of the family would have to leave, and for poor people that's a real hardship."

James S. Taylor, a bioethicist who teaches philosophy at the College of New Jersey, has written about Navajo views of end-of-life care.

"Navajos value the principle of autonomy or self-determination," he said in a telephone interview. "But their cultural taboos — you can't think negatively, or it will happen — restrict their ability to autonomously plan for their end-of-life care, since the planning itself requires such negative thinking.

"Using the poem and open-ended questions allows nuanced and respectful solutions to this problem because it gives people the opportunity to discuss end-of-life planning impersonally. It's a compassionate approach, and it's in accord with the twin values that Navajos share with mainstream American culture — individual autonomy and personal dignity."

Ms. Begay and Ms. Nez visit Jimmy Begay (no relation), a bright-eyed man of 87 who lives with his wife in the little community of Sawmill. In World War II, Mr. Begay was one of the Navajo "code talkers" whose radio transmissions were never deciphered by the Japanese; the walls of his modest home are covered with photos, a squadron's worth of family members who have served in the military.

Mr. Begay has signed the poem and the advance directives, and so has Mitzie Begay.

"Traditionally, it's our belief to always have a positive attitude," even when someone is dying, she said. "The family has a five-day sing" — a Navajo ceremony — "drink herbs and paint their bodies. All these things are done for the patient, and then we know we did all we could.

"After a patient dies, you don't hang on, because the deceased is no longer on Mother Earth. You wash up, take your corn pollen and go on with life."

Features of the 18th International Congress on Palliative Care: once again, a successful and stimulating conference!

By Anna Towers, M.D.

Palliative care has grown into a strong interdisciplinary discipline. This was evident from the palliative care congress that took place in Montreal October 4-8, 2010, which set an attendance record with almost 1600 participants. They came from 64 countries, compared to 40 countries in 2008. This congress has a well-deserved reputation as one of the world's preeminent gatherings of palliative care professionals and others who are interested in the field. True to tradition, the conference featured a blend of plenaries and break-out sessions ranging from spirituality and whole person care to current issues in pain management. Participants tell us that they appreciate the interdisciplinary, humanistic and holistic nature of this Congress. This trilingual Congress (English, French, Spanish) allowed for links between Spanish and Latin-American participants. There is a new Hispanic palliative care collaboration that has emerged as a result of this.

The four-day Congress began with five all-day Concurrent seminars, one of which (paediatrics) continued for a second day. There was much exchange noted between adult and pediatric palliative care providers at these sessions.

The plenaries included one on volunteerism as a core value in palliative care, and another on a vision of the future with new internet technologies becoming integrated into care.

The Congress featured an enhanced program for nurses, with a concurrent seminar in French and a series of three 90-minute seminars covering the basics of palliative care nursing. The sessions on volunteerism were also well received.

Special efforts were made for the first time at this Congress to involve students in the organization of the Congress. There was a new student section that was very successful in providing students with opportunities for networking.

Poster prizes were awarded for the best scientific, innovative program, pediatric and trainee posters, chosen from amongst the 272 posters on display.

The Reflections, photographic and music meditations prior to each plenary, continued as a feature of the Congress. The programme also included lunch time film screenings and a poignant play entitled "Ed's Story- the Dragon Chronicles", about a teenage boy facing terminal illness. New this year was the Art Display, featuring a range of works in a variety of media, all by the congress participants. There is much hidden talent amongst palliative care providers!

A performance by the Montreal Jubilation Gospel Choir at St James United Church attracted 800 attendees who joined in with great enthusiasm.

Mrs. Kappy Flanders again generously hosted a Faculty Dinner at the University Club that featured excellent food, dynamic discussion and a moving performance from a group of singers from McGill University -- *Effusion A Cappella*.

Planning has begun for the next Congress that will take place October 8-12, 2012, again in Montreal. This will be the 19th edition of the biennial Congress that began under Dr. Balfour Mount's direction in 1976. We will be exploring new frontiers, so mark your calendars!

Dr. Anna Towers is Chair of the International Congress on Palliative Care and a palliative care physician at the McGill University Health Centre.

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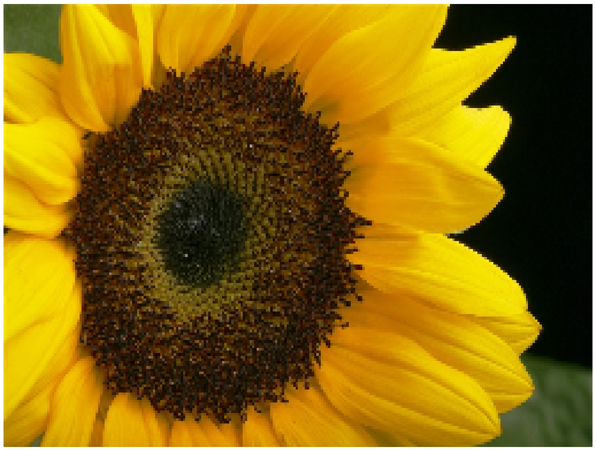


"The difference between what I do and euthanasia is that palliative care does whatever is necessary to alleviate the suffering while euthanasia is focused on eliminating the sufferer."

Ira Byock, MD
Palliative Care Physician

Events & Happenings!..

14th Annual Sandra Goldberg Lecture—May 4, 2011

This year's Annual Sandra Goldberg Lecture will be held on **Wednesday, May 4th,** in Moyse Hall at McGill University.

The speaker will be Dr. Ira Byock ho will speak on "The Ethics and Practice of Loving Care."

Dr. Byock is Director of the Palliative Care Service at Dartmouth-Hitchcock Medical Center. Professor Byock holds the Dorothy & John J. Byrne, Jr. Distinguished Chair of Palliative Medicine at Dartmouth Medical School. He was President (1997) of the American Academy of Hospice and Palliative Medicine. From 1996-2006, he directed 'Promoting Excellence in End-of-Life Care', a national program of The Robert Wood Johnson Foundation. Dr. Byock has been a consistent advocate for the voice and rights of incurably ill patients and their families. His books include *Dying Well* (1997) and *The Four Things That Matter Most* (2004).

Workshop—The ABC's of Palliative Care

By Joan Foster

You could have heard a pin drop at the Jewish General Hospital (JGH) Hope & Cope Wellness Center on Tuesday April 20, 2010 when 75 people attended one of the free workshops given by the Council to inform the public about accessing Palliative Care in the Montreal area. Those present were enriched by the wisdom and experience of **Dr Balfour Mount**, a pioneer in developing Palliative Care in Montreal and Canada, **Rose De Angelis**, the Nursing Director of the West Island Palliative Care Residence and **Laura Boroditsky**, talking personally about the caregiver's journey in Palliative Care.

The warm welcome of Suzanne O'Brien, Executive Director and Marcelle Kecman, Co-coordinator of the Jewish General Hospital Hope and Cope Wellness Center set the stage for two hours of incredible information sharing, covering the principles, goals, interdisciplinary partners, settings, challenges in accessing services, hurdles in care giving and timing of good palliative care. The workshop was informative both for those new to the topic and those working many years in the field of palliative care.

The '***A***' of the ABC's was addressed by Rose De Angelis, Nursing Director of the West Island Palliative Care Residence – ***Accessing*** Palliative Care. Rose talked about receiving palliative care in acute care hospitals as an inpatient or a clinic outpatient; at home with the help of the CSSS home care program, using philanthropic organizations like NOVA or Entraide Ville-Marie, or with private resources; and through Hospice/Palliative Care Residences. Rose described the importance of collecting a whole team of health care providers around you to help you and support you. She ended by asking those present to take the time now to think of what questions they would ask their doctor if he/she said they were palliative and to think about what is important in their lives now.

Dr. Balfour Mount shared his knowledge of years of caring for families and patients who are fighting a life threatening illness. He addressed the '***B***' of the ABCs - ***Being present*** to help patients have the best quality of life that is possible each and every day. When the goals of care are no longer cure or prolongation of life then quality of life is the main goal for all who care for another. Dr. Mount explored what determines good quality of life and one's experience of being healthy and whole in the face of illness. His sharing of lessons learned from his patients, their families and other colleagues gave us all great insight into the quest for healing in our lives and those we care for.

Closing the evening was Laura Boroditsky talking about the '***C***' of the ABC's of Palliative Care – ***Care-giving***. Laura shared with those present how she saw her role as primary caregiver – the everyday advocate and the person responsible for creating the partnerships needed for the best end of life care for all in her family. Laura navigated the audience through all the changes that her family experienced and how decisions were made in the changing family structure. She stressed the importance of a partnership with the health care team and with others who help to plan the care of patients, in understanding the unique situation of each person and their community. Laura addressed the scarcity of resources and how to access them in a timely fashion. Her clear directives for meeting each challenge gave all present much insight into the journey that one travels.

Thank you to the three presenters and to the JGH Hope & Cope Wellness Center for a great evening.

This and other workshops and lectures are available for viewing on the Council's website at: www.council-on-palliative-care.org.

If you have suggestions for future workshop topics or themes do not hesitate to contact us with your suggestions. Please forward them to: Fmpa202@aol.com

Joan Foster is a community nurse.

N.B.: If requested, the money from the sale of clothes given to the store ***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

Volunteers highlighted at the 18th International Congress on palliative Care in Montreal.

By Pedro Mejia

The 18th International Congress on Palliative Care, held in Montréal from October 5 to 8, 2010, was the venue of an unprecedented event on the broad circuit of worldwide conventions. For the first time, the work of volunteers in palliative care was highlighted for an entire day, even during one of the plenary sessions.

This event of international scope dedicated October 8th to volunteering and volunteers. Numerous speakers examined the key role played by volunteers in palliative and end-of-life caregiving and stressed the core value of their contribution.

The day began with a presentation by Dr. Bernard Lapointe, Director of the Palliative Care Division of McGill University's Department of Oncology and Eric M. Flanders Chair in Palliative Care at the Jewish General Hospital (Montréal, QC). He first reminded us of a very important, though frequently forgotten, fact: Volunteers are not a new resource in palliative care. They have been a part of it from the very beginning.

Dr. Lapointe recalled the pioneering role played by Cicely Saunders during the post-World War II changes that revolutionized care given to terminally ill patients. He gave a moving tribute to this British nurse, who subsequently became a qualified doctor. She had been the first to acknowledge how difficult it was for doctors and health care providers to cope with the feeling of failure they experienced when providing care for patients who medicine could no longer cure. The movement launched by Dr. Saunders was eventually to give birth to the concept of "palliative/ hospice care". Dr. Balfour Mount brought the concept to North America and opened the first palliative care unit at the Royal Victoria Hospital. From the moment Saunders started to think about palliative care and its applications, she gave considerable importance to the volunteer caregivers who, embedded within health care units, took care of patients.

Next, Mrs. Kappy Flanders, Co-Chair of the Council on Palliative Care, provided an overview of the educational and lobbying roles of this organization. The Council aims to educate both the volunteers who work in the palliative care units of the hospitals affiliated with McGill University and the general public. With this goal in mind, Mrs. Flanders underscored the importance of tightening up relations with the volunteers and reminded us that the Council also provides extensive information to patients and to their families through various sources.

The plenary was brought to a close by Suzanne O'Brien, the Executive Director of "Hope and Cope", an organization that coordinates large bodies of volunteers providing support to patients who are dealing with a diagnosis of cancer as well as to individuals nearing death.

Mrs. O'Brien first highlighted the manner in which volunteers bring palliative care closer to the community. She then talked about volunteer training. To fulfill their role, volunteers who have chosen to give their time to accompany people nearing death, not only need to demonstrate kindness but must also receive appropriate training. She suggested that volunteers are an integral component of a health care team. She stressed the fact that they must share the same values as the health care team with regards to commitment, interdependence, quality of intervention and accountability. In common with health care providers, volunteers must also regularly update their skills and be able to react appropriately to various situations. Mrs. O'Brien also underlined the unique character of palliative care volunteering, an activity that requires volunteers to accept the fact that death is the only possible outcome to the relationship they have established with the person to whom they are providing support. And it is an activity that is also predicated on a form of respect that is devoid of any cultural bias. To be a volunteer in a palliative care setting requires a high level of flexibility and adaptability in interpersonal relations. And as she concluded, a well-trained volunteer is a priceless treasure for a palliative care unit.

On this special day, the volunteers who work in the palliative care units of the McGill affiliated hospitals were invited to the Congress, free of charge, by the Congress organizers and The Council on Palliative Care. Many of them were thus able to benefit from in-depth seminars and workshops on topics such as the conceptual model of "styles or patterns of grieving" presented by Dr. Ken Doka. Dr. Doka said that gender is the only factor that affects an individual's style or pattern of grief. He differentiated between "intuitive grievers", where the pattern is more affective, and "instrumental grievers", who grieve in a more cognitive and behavioural way. In another workshop, Senator Sharon Carstairs, Yude Henteleff a Canadian lawyer and Kiera Hepford from the Open Society Institute in New York, demonstrated why and how access to palliative care should be a human right recognized by law, how this right is entrenched in the Constitution, and how it can be promoted elsewhere in the world.

Highly positive feedback was also provided by the volunteers who attended a workshop entitled "The power of mindfulness and compassion in the healing encounter", conducted by Ms. Judy Leif of Vermont, as well as another presentation on "Complementary Therapies".

From my own perspective as Palliative Care and Bereavement Coordinator at the Jewish General Hospital, the 18th International Congress on Palliative Care in Montréal provided a unique opportunity to meet and converse with colleagues from as far away as Spain, Brazil, Singapore, Mexico, Australia and France. It was an ideal venue to discuss my views and methods. And the meetings allowed me to delve more deeply into the mechanisms of anger, anxiety and stress management

Volunteers Highlighted at the International Congress (cont...)

within families where a loved one nears the end of life.

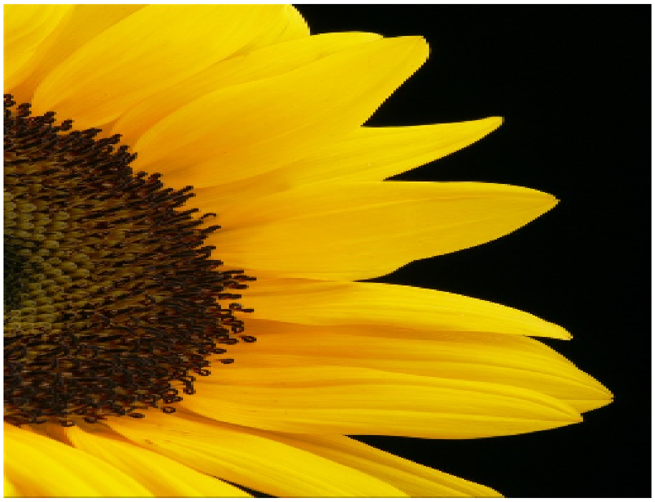
The workshop on pain (in all its expressions) and on its ethical dimension – a topic at the core of palliative care – gave me particular food for thought. Ms. Marie de Hennezel's workshop on death and on all the manifestations of existential anguish it brings to the surface also touched me deeply, as witnessing the death of a human being never leaves one indifferent.

But the greatest satisfaction I derived from that day was to see the recognition given to the contribution of volunteers in palliative care units. As Mrs. O'Brien had indicated, volunteers are a treasure for health care teams as well as for patients and their loved ones; a treasure for patients and teams whom they enable to occasionally question themselves. Volunteers simply listen, without talking, without imposing their presence. This is a difficult and sometimes frustrating task as listening skills presuppose remarkable self-discipline and strength of character.

At the bedside of patients whose life is ending, volunteers represent our society. They provide practical and spiritual support. They embody the fact that palliative care also aims to restore the social link between end of life and dying. Death is a normal phenomenon that is a part of life.

Pedro Mejia is the Palliative Care and Bereavement Coordinator at the Jewish General Hospital.

> *"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)*



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