

The Council on Palliative Care



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

Home Care: How to Access Palliative Care at Home

By Sue Britton, Pioneer Nurse of Palliative Care, Royal Victoria Hospital, Psychotherapist and Yoga Teacher

Most people say they would prefer to die at home. But how does one access palliative care at home?

Each hospital is responsible for sending a referral to the CLSC closest to the patient's home, before they are discharged. The accompanying family member/friend must be assertive and ask if this has been done. Otherwise an important part of care is missed. Equipment such as hospital beds, wheelchairs, commodes, etc. can be borrowed from the CLSC. The equipment ideally should be in place

at the home before discharge. The referral should include the patient's nursing needs along with a list of current medications so that there is continuity of care. If the patient has private insurance, the equipment can be obtained through a private medical supply company as long as it has been prescribed by a doctor.

Home care provided by CLSCs is a free service for everyone. The family should have the telephone number of the patient's CLSC so they can follow-up in case there is a delay. An assessment will

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**David Bourke
Memorial Lecture**

Tuesday, October 9th

**“Dying at Home: A
Choice”**

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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Home Care (cont...)

be made once the patient is at home and a team member is assigned to each case. It is important for the primary caregiver to be informed of when the medications are to be administered and why. A list of telephone numbers for the CLSC will be provided so that the caregiver can reach a professional for advice and emergencies.

When care at home becomes more demanding and symptoms are more challenging, there is a service to which the CLSC can refer. It is a 'priority line' with a doctor and a nurse on call who can make emergency visits to the home. They have access to narcotics and end-of-life medications when pharmacies are closed. This service has to be activated by the CLSC with the patient's information. This makes for continuity.

Often what is needed is a partnership between services such as the CLSCs, which are free, and non profit organizations such as Nova or Entraide Ville Marie. People can access Nova or Entraide Ville Marie services by themselves. If 24 hour care is needed to compliment the family/friend caregiver, there are private nursing agencies that employ a full range of caregivers. This is paid for by private insurance or personal financial resources.

The success of a home death depends on both patient and family dealing with crises that may arise. There must be adequate professional help available 24 hours of the day. A contingency plan should also be in place in case the death cannot take place at home. I.E. Being on a waiting list for a Palliative Care bed in hospital, a hospice or a nursing home. The Priority Line Service helps to keep patients out of the emergency rooms.

The Heart Beat of Death

From The Tibetan Book of Living and Dying by Sogyal Rinpoche.

There would be no chance at all of getting to know death if it happened only once. But fortunately, life is nothing but a continuing dance of birth and death, a dance of change. Every time I hear the rush of a mountain stream, or the waves crashing on the shore or my own heartbeat, I hear the sound of impermanence. These changes, these small deaths, are our living links with death. They are death's pulse, death's heart beat, prompting us to let go of all the things we cling to. So let us then work with these changes now, in life, that is the real way to prepare for death. Life may be full of pain, suffering, and difficulty, but all of these are opportunities handed to us to help us move toward an emotional acceptance of death. It is only when we believe things to be permanent that we shut off the possibility of learning from change.

If we shut off this possibility, we become closed, and we become grasping. Grasping is the source of all our problems. Since impermanence to us spells anguish, we grasp on to these things desperately, even though all things change. We are terrified of letting go, terrified, in fact, of living at all, since learning to live is learning to let go. And this is the tragedy and the irony of our struggle to hold on: not only is it impossible, but it brings us the very pain we are seeking to void.

My Faith: What People Talk About Before They Die

By Kerry Egan, hospice chaplain in Massachusetts and the author of *Fumbling: A Pilgrimage Tale of Love, Grief, and Spiritual Renewal on the Camino de Santiago.*

As a divinity school student, I had just started working as a student chaplain at a cancer hospital when my professor asked me about my work. I was 26 years old and still learning what a chaplain did.

"I talk to the patients," I told him.

"You talk to patients? And tell me, what do people who are sick and dying talk to the student chaplain about?" he asked.

I had never considered the question before. "Well," I responded slowly, "Mostly we talk about their families."

"Do you talk about God?"

"Umm, not usually."

"Or their religion?"

"Not so much."

"The meaning of their lives?"

"Sometimes."

"And prayer? Do you lead them in prayer? Or ritual?"

"Well," I hesitated. "Sometimes. But not usually, not really."

I felt derision creeping into the professor's voice. "So you just visit people and talk about their families?"

"Well, they talk. I mostly listen."

"Huh." He leaned back in his chair.

A week later, in the middle of a lecture in this professor's packed class, he started to tell a story about a student he once met who was a chaplain intern at a hospital. "And I asked her, 'What exactly do you *do* as a chaplain?' And she replied, 'Well, I talk to people about their families.'" He paused for effect. "And *that* was this student's understanding of faith! *That* was as deep as this person's

spiritual life went! Talking about other people's families!" The students laughed at the shallowness of the silly student. The professor was on a roll.

"And I thought to myself," he continued, "that if I was ever sick in the hospital, if I was ever dying, that the last person I would ever want to see is some Harvard Divinity School student chaplain wanting to talk to me about my family."

My body went numb with shame. At the time I thought that maybe, if I was a better chaplain, I would know how to talk to people about big spiritual questions. Maybe if dying people met with a good, experienced chaplain they would talk about God, I thought.

Today, 13 years later, I am a hospice chaplain. I visit people who are dying – in their homes, in hospitals, in nursing homes. And if you were to ask me the same question – What do people who are sick and dying talk about with the chaplain? – I, without hesitation or uncertainty, would give you the same answer. Mostly, they talk about their families: about their mothers and fathers, their sons and daughters.

They talk about the love they felt, and the love they gave. Often they talk about love they did not receive, or the love they did not know how to offer, the love they withheld, or maybe never felt for the ones they should have loved unconditionally.

They talk about how they learned what love is, and what it is not. And sometimes, when they are actively dying, fluid gurgling in their throats, they reach their hands out to things I cannot see and they call out to their parents: Mama, Daddy, Mother.

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"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

Events & Happenings!..

David Bourke Memorial Lecture

This year's David Bourke Memorial Lecture will be a staged reading of a play originally on the stage in London, England — *Home Death* by playwright Nell Dunn.

The lecture entitled, "**Dying at Home: A Choice**", will be presented during the 19th International Congress on Palliative Care at the Palais des Congr s on Tuesday, October 9, 2012 from 7:00-9:00 PM. It will be open to the public, free of charge.

Palliative Care Week 2012 and The 15th Annual Sandra Goldberg Lecture

For this year's Palliative Care Week and Sandra Goldberg Lecture, the Council and Palliative Care McGill co-hosted a series of lectures by Dr. Michael Kearney, recent recipient of the Royal College of Physician and Surgeons Balfour Mount Visiting Professor Scholarship. A palliative care physician for over 30 years, Dr. Kearney is an internationally known teacher and author in the area of the psycho-spiritual aspects of end-of-life care and has published two books on the topic: *Mortally Wounded: Stories of Soul Pain, Death and Healing* and *A Place of Healing: Working with Nature and Soul at the End of Life*. Currently based in Santa Barbara, California, Dr. Kearney is the Medical Director of the Palliative Care Service at Santa Barbara Cottage Hospital and the Associate Medical Director at Visiting Nurse and Hospice Care.

On Tuesday May 8, 2012 Dr. Kearney was the speaker for the 15th Annual Sandra Goldberg lecture, a public lecture held every year during Canada's National Palliative Care Week, and organized by the McGill Council on Palliative Care. Dr. Kearney's talk on "Caring for Self while caring for others at the end of life" wove together examples from the research literature and his own professional experiences to emphasize care of self as essential to effective care of another.

From the painful moments he has both witnessed and felt in his many years as a palliative care physician, Dr. Kearney related experiences of compassion fatigue, a phenomenon well known to professional and family caregivers alike. To illustrate ways of thinking about, responding to, and perhaps pre-empting compassion fatigue, Dr. Kearney drew on the ancient Greek story of Chiron as well as an old Chinese tale of the Rainmaker. Through these stories, he elucidated the significance of the Wounded Healer and the

importance of coming into Tao (balance, order) for achieving the self-awareness and self-empathy essential for caregivers who are caring for others at the end of life.

The lecture attracted an audience of over 200 professional and family caregivers and thereby enriched both the medical community and the broader society.

Following the lecture, Dr. Kearney joined approximately 100 members of the McGill Community in the annual Sandra Goldberg dinner, an event hosted by the Council to thank and celebrate all those who contribute so much to this important field.

Palliative Care McGill and the Council were honoured to have Dr. Kearney as our guest this year. His thoughtful lectures and general presence enriched health professionals and volunteers within and beyond palliative care. If you were unable to attend this year's Sandra Goldberg lecture, or if you would like to hear it again, please visit the Council website to watch the video.

Workshops

The Challenges of Caregiving

Caring for the Whole Person – Mind Body and Spirit

This well attended and practical two-part workshop held on two consecutive Wednesdays, April 18 and 25 was designed to provide information and support to the caregiver whether, professional, volunteer or family member. Participants were encouraged to engage in the discussions and in the yogic relaxation and stress relieving exercises, which began and ended each session. The focus of the workshops was on the needs of the caregiver and the importance of living in the moment and caring for oneself while caring for another.

The three animators: Joan Foster BN, Sue Britton BN and Zeldia Freitas MSW suggested many tools caregivers need to provide care for their patient, family member or friend without losing themselves in the process. Each of the facilitators, a seasoned professional, with years of experience in palliative care working with patients, families and a range of professionals, shared their personal experience of helpful tools and concrete information: how the health care system works, who does what, how to recognize when to ask for help and the language which gets the help required.

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Volunteering in Palliative Care

By Sandra Watson, Bereavement Program and Volunteer Coordinator, McGill University Health Centre (MUHC), Palliative Care Division

Why become a Palliative Care volunteer? The question should be why not? Volunteers are the cornerstone of Palliative Care. In 1973, the Royal Victoria Hospital Palliative Care Unit was opened, the first in Canada. Dr Balfour Mount, the founding Director of the unit, made sure from the very beginning that volunteers were a part of the team.

People volunteer for many different reasons. Many have had a loved one die and would like to 'give back' because of the care their loved one received. Or, perhaps they have had an experience or life changing event that led to a need to be involved with more meaningful issues. And some just want to be involved in their community -- to give something back to society and sharing with others allows them to do this.

Volunteers are seen as an important and valued part of the palliative care multidisciplinary team. Their primary role is to assist and hopefully, to improve the quality of life for both the patient and the family. Volunteers provide companionship, social and emotional support and help to facilitate services to the patients. They are a comforting presence. They listen and accept the patient and family fully and without judgement. Ultimately, volunteering in palliative care allows one the privilege of accompanying a person who is at the end of their life's journey.

Each volunteer offers something unique and I am always deeply moved, impressed and inspired by the volunteers I meet.

The smallest gesture can make a difference -- bringing a cup of tea to a patient or a family member; helping a patient make a phone call or simply lending a listening ear. Volunteers are not the primary medical or psychological caregivers; rather, they complement the other team members. This allows them time to spend with the patients and families. For example, at the Montreal General Hospital volunteers organize tea time and happy hour in the solarium. Patients and family members come to the solarium, listen to a volunteer play the piano while others serve refreshments. For those who are unable to come to the solarium, the volunteers go room to room and take the refreshments to them. This allows the patients and families to feel connected to others and to have a sense of normalcy.

Training is mandatory for Palliative Care volunteers. The McGill Palliative Training is based on and, conforms to, the standards of the Canadian Hospice Palliative Care Association (CHPCA). It is a seven-week training course,

given twice a year in collaboration with the McGill affiliated hospitals; MUHC (Royal Victoria and Montreal General Hospitals and the Montreal Neurological Institute and Hospital) and the Jewish General, St-Mary's and Mount Sinai Hospitals. The training program is designed to enhance the volunteer's understanding of end-of-life issues and to offer basic psychosocial education so that they can support patients and families during a very difficult time. This rich and stimulating series of lectures and workshops is given by our outstanding faculty and staff. Ongoing training is also given to volunteers throughout their volunteer experience.

If you would like to donate your time and volunteer, or if you simply would like more information please contact me at 514-934-1934 Ext. 43810 or Email: Sandra.watson@muhc.mcgill.ca.

Volunteer Quotes

"...even bringing a simple cup of tea to a patient or family member can make a difference. It is the little things that matter."

Martine R.

"...it is a privilege to be welcomed into a patient's space."

Nancy J.

"...our patients are still living. Giving them the best quality of life at this very moment is so important."

Helene P.

"...volunteering in Palliative Care makes me realize how lucky I am to have a family. When I see a patient who doesn't have any visitors, I am especially drawn to them. Everyone deserves to have someone."

Ray C.

"...we are a family of volunteers. Being part of the Palliative Care team brings me great joy. I feel so privileged."

Diana K.

When Doctors Grieve

By Dr. Leeat Granek, Health Psychologist and Postdoctoral Fellow at the Hospital for Sick Children, Toronto, Canada.

MY mother died of breast cancer in 2005 after living with the disease for nearly 20 years. Her oncologist, whom I had known from the time I was 9 years old, was her doctor for most of that time. I practically grew up in the hospital, and my family felt quite close to the health care providers, especially the oncologist. After my mother died I wondered if the feeling was mutual.

Do doctors grieve when their patients die? In the medical profession, such grief is seldom discussed — except, perhaps, as an example of the sort of emotion that a skilled doctor avoids feeling. But in a paper in *Archives of Internal Medicine* (and in a forthcoming paper in the journal *Death Studies*), my colleagues and I report what we found in our research about oncologists and patient loss: Not only do doctors experience grief, but the professional taboo on the emotion also has negative consequences for the doctors themselves, as well as for the quality of care they provide.

Our study took place from 2010 to 2011 in three Canadian hospitals. We recruited and interviewed 20 oncologists who varied in age, sex and ethnicity and had a wide range of experience in the field — from a year and a half in practice in the case of oncology fellows to more than 30 years in the case of senior oncologists. Using a qualitative empirical method known as grounded theory, we analyzed the data by systematically coding each interview transcript line by line for themes and then comparing the findings from each interview across all interviews to see which themes stood out most robustly.

We found that oncologists struggled to manage their feelings of grief with the detachment they felt was necessary to do their job. More than half of our participants reported feelings of failure, self-doubt, sadness and powerlessness as part of their grief experience, and a third talked about feelings of guilt, loss of sleep and crying.

Our study indicated that grief in the medical context is considered shameful and unprofessional. Even though participants wrestled with feelings of grief, they hid them from others because showing emotion was considered a sign of weakness. In fact, many remarked that our interview was the first time they had been asked these questions or spoken about these emotions at all.

The impact of all this unacknowledged grief was exactly

what we don't want our doctors to experience: inattentiveness, impatience, irritability, emotional exhaustion and burnout.

Even more distressing, half our participants reported that their discomfort with their grief over patient loss could affect their treatment decisions with subsequent patients — leading them, for instance, to provide more aggressive chemotherapy, to put a patient in a clinical trial, or to recommend further surgery when palliative care might be a better option. One oncologist in our study remarked: "I see an inability sometimes to stop treatment when treatment should be stopped. When treatment's futile, when it's clearly futile." From a policy standpoint, this is an especially worrisome finding, given the disproportionately high percentage of health care budgets spent on end-of-life care.

Unease with losing patients also affected the doctors' ability to communicate about end-of-life issues with patients and their families. Half of our participants said they distanced themselves and withdrew from patients as the patients got closer to dying. This meant fewer visits in the hospital, fewer bedside visits and less overall effort directed toward the dying patient.

It's worth stressing that most physicians want what is best for their patients and that the outcome of any medical intervention is often unknown. It's also worth noting that oncologists and other physicians who are dealing with end-of-life issues are right to put up some emotional boundaries: no one wants their doctor to be walking around openly grief-stricken.

But our research indicates that grief is having a negative impact on oncologists' personal lives and that there is a troubling relationship between doctors' discomfort with death and grief and how patients and their families are treated. Oncologists are not trained to deal with their own grief, and they need to be. In addition to providing such training, we need to normalize death and grief as a natural part of life, especially in medical settings.

To improve the quality of end-of-life care for patients and their families, we also need to improve the quality of life of their physicians, by making space for them to grieve like everyone else.

My Faith: What People Talk About Before They Die (cont...)

(from page 3)

What I did not understand when I was a student then, and what I would explain to that professor now, is that people talk to the chaplain about their families because that is *how* we talk about God. That is *how* we talk about the meaning of our lives. That is *how* we talk about the big spiritual questions of human existence. We don't live our lives in our heads, in theology and theories. We live our lives in our families: the families we are born into, the families we create, the families we make through the people we choose as friends. This is where we create our lives, this is where we find meaning, this is where our purpose becomes clear.

Family is where we first experience love and where we first give it. It's probably the first place we've been hurt by someone we love, and hopefully the place we learn that love can overcome even the most painful rejection. This crucible of love is where we start to ask those big spiritual questions, and ultimately where they end. I have seen such expressions of love: A husband gently washing his wife's face with a cool washcloth, cupping the back of her bald head in his hand to get to the nape of her neck, because she is too weak to lift it from the pillow. A daughter spooning pudding into the mouth of her mother, a woman who has not recognized her for years. A wife arranging the pillow under the head of her husband's no-longer-breathing body as she helps the undertaker lift him onto the waiting stretcher. We don't learn the meaning of our lives by discussing it. It's not to be found in books or lecture halls or even churches or synagogues or mosques. It's discovered through these actions of love.

If God is love, and we believe that to be true, then we learn about God when we learn about love. The first, and usually the last, classroom of love is the family. Sometimes that love is not only imperfect, it seems to be missing entirely. Monstrous things can happen in families. Too often, more often than I want to believe possible, patients tell me what it feels like when the person you love beats you or rapes you. They tell me what it feels like to know that you are utterly unwanted by your parents. They tell me what it feels like to be the target of someone's rage. They tell me what it feels like to know that you abandoned your children, or that your drinking destroyed your family, or that you failed to care for those who needed you. Even in these cases, I am amazed at the strength of the human soul. People who did not know love in their families know that they *should* have been loved. They somehow know what was missing, and what they deserved as children and adults.

When the love is imperfect, or a family is destructive, something else can be learned: forgiveness. The spiritual work of being human is learning how to love and how to forgive.

We don't have to use words of theology to talk about God; people who are close to death almost never do. We should learn from those who are dying that the best way to teach our children about God is by loving each other wholly and forgiving each other fully - just as each of us longs to be loved and forgiven by our mothers and fathers, sons and daughters.

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, A Montreal vintage shopping destination.

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Events & Happenings!..(cont...)

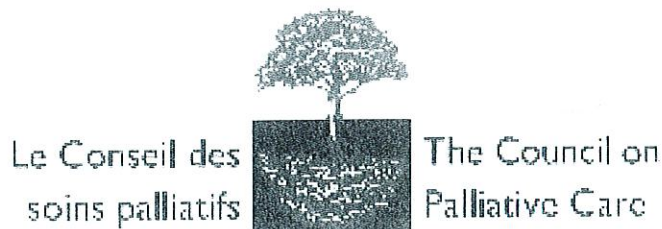
Psychological, emotional, spiritual and social needs of caregivers were explored with the participants engaged in the discussion.

Note:

Between 75 and 80 people participated in the first workshop, 60 in the second of which 50% were repeats. At least two-thirds of the participants were health care workers; the others had personal or family caregiving experience. The venue was accessible, comfortable but a

bit too small for the larger than anticipated attendance. The 6 – 8pm time slot and the fact that there was, as usual, no fee or advanced registration may have contributed to the high rate of participation but the topic and the expertise of the workshop leaders were probably the primary factors in the resounding success.

The Council wishes to thank Temple Emanu-El-Beth Sholom for hosting these workshops.



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