Spring 2016

Council on Palliative Care

National Hospice Palliative Care Week
May 1-7, 2016

19th Annual Sandra Goldberg Lecture
Tuesday May 3, 2016

21st International Congress on Palliative Care
October 18-21, 2016

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

> How far you go in life depends on your being tender with the young, compassionate with the aged, sympathetic with the striving and tolerant of the weak and strong. Because someday in your life you will have been all of these.
>
> George Washington Carver

Defining Palliative Care

Government of Canada, Department of Justice
Consultations on Physician-Assisted Dying (Chapter 13A.)

People living with, or dying from, advanced life-limiting illnesses have unique health care needs. Palliative care services are designed to help them live the remainder of their lives in comfort and dignity. The key components of palliative care are pain relief and symptom management, along with social, psychological, emotional and spiritual supports for patients, families, friends and other caregivers.

The World Health Organization (WHO) defines palliative care as follows:
Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The WHO definition makes it clear that the objective of palliative care is to achieve the best possible quality of life for patients. The definition also sheds light on some misconceptions related to palliative care. For one, the definition specifies that the aim of palliative care is neither to accelerate nor to delay

death. Also, even though palliative care is more commonly associated with incurable illnesses in near-death situations, it should be mentioned that persons in the earlier stages of illness may also benefit from a palliative approach to improve their quality of life in combination with treatments aimed at curing or resolving aspects of their illness.
Palliative care can be provided not only in hospital, but also in the community, such as at a hospice, long-term care facility, or in the home. Empirical research has found that palliative care is associated with better outcomes for patients (symptom management, quality of life, overall satisfaction), family caregivers (reduced burden) and the healthcare system (reduced hospital admissions).

Most people approaching the end of their lives are primarily cared for by family members, friends and their family physicians.

People with greater personal wealth and resources are often more able to access private services and supports. Where palliative care teams are available, there are specially trained doctors, nurses and other health care providers to provide assistance. Depending on the person's needs, the palliative care team may include nurses with specialized training, a physician who specializes in palliative medicine, a pharmacist, a social worker, a spiritual counsellor, a bereavement support worker, a home care worker, a nutritionist, a physiotherapist and an occupational therapist.

Trained volunteers and informal caregivers may also be considered part of the team.

http://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/toc-tdm.html

Our Activities…

Workshops in 2015

Bridging the Gap of End-of-Life Care

Continuing the discussion from the Sandra Goldberg Lecture on physician-assisted death, on Tuesday, October 27, 2015 Sue Britton, RN interviewed Dr. Manny Borod, Director of Palliative Care at the McGill University Health Centre (MUHC).

Question: With the budget cuts in the healthcare system, how can access to palliative care be increased from the current 30% availability?

Answer: It's up to the public to make demands on the government. We, the professionals, have stated our needs.

Question: Many doctors will not be willing to euthanize patients. How do you see the situation being resolved?

Answer: The MUHC has agreed to have these wishes honoured but the palliative care physicians will not participate. The team at the Glen is in the process of discussing how this will be managed.

Question: Morphine has been considered a form of euthanasia as it hastens death.

Answer: There are many myths around morphine and a lot of fear about it just like the fear about the words Palliative Care. Morphine is widely used and it has been successful in treating chronic pain.

These questions stimulated a lively discussion from the audience of approximately 50.

The Last Chapter in the Book of Life

On Tuesday November 3rd, the second workshop entitled, The Last Chapter in the Book of Life was presented by Joan Foster BN and Zelda Freitas SW to an audience of about 40 Participants.

Most families enter the transition into the last chapter of their loved one's life (transition is defined by the Merriam-Webster dictionary as a change or passage from one state or stage to another) without a road map and consequently, many are unaware of the challenges that lie ahead. Many enter with great hesitation, a range of emotions and differing strengths and vulnerabilities. The journey is unique to each individual, their family and friends.

The workshop gave an overview of some of the challenges faced by a person with a life threatening illness, their caregivers and families. The participants left with some thoughts and tools that could help their transition or that of someone they are supporting. Accessing resources, both personal and professional was a major theme throughout the evening's presentation.

The Film: "Death Makes Life Possible"

On Tuesday, November 10, 2015 the film, "Death Makes Life Possible" was shown and was followed by a discussion led by Sue Britton. Through interviews with mental health experts, cultural leaders and scientists, the film looks at how popular culture deals with the ever-present fear many have about their mortality. It explores the meaning of death and how we can learn to live without fear. The interviews and evidence presented are interwoven with personal stories of people facing their own death as well as those who report encounters beyond death. One of the experts was Dr. Peter Fenwick, who presented the David Bourke Memorial Lecture at the 20th International Congress on Palliative Care in 2014.

Annual Sandra Goldberg Lectures

2015 Sandra Goldberg Lecture

The 18th Annual Sandra Goldberg Lecture was held on Tuesday, May 5, 2015 at McGill University. The title of the lecture was *Public Choices, Private Lives: An End-of-Life Conversation*. The format was a 'facilitated conversation' between Dr. Harvey Schipper, an Oncologist and Professor of Medicine at the University of Toronto and Véronique Hivon, the MNA for Joliette (Québec) and former Minister for Social Services, who drafted Bill 52, An Act Respecting End-of-Life-Care – the Bill that legalizes physician-assisted death. The moderator was Daniel Jutras, Dean of the Faculty of Law at McGill University.

Given the topic, the lecture was quite controversial. However the intention of the lecture, in keeping with the Council's mandate, was to educate the public and the objective was to stimulate dialogue on the subject of physician-assisted death. The palliative care community is divided on the issue, as is the rest of society and it is unlikely that any outcome would have satisfied everyone. However, working within a university environment freedom of speech and thought are paramount.

The "facilitated conversation" did not unfold exactly as envisioned -- some areas of relevance were not discussed due to time constraints. Dr. Schipper approached the evening from a philosophical rather than a medical point of view and some in the audience thought the palliative care perspective was not in evidence.

2016 Sandra Goldberg Lecture

The Council on Palliative Care, in its series *Lessons in Living from the Dying*, presents Dr. B. J. Miller who will speak on "The Civics of Dying Well". The lecture will be held on **Tuesday, May 3, 2016 at 6:00 P.M.** at the Charles Martin Amphitheatre, in the McIntyre Medical Sciences Building at McGill University.

Dr. Miller is a hospice and palliative care specialist. He is the Senior Director of the Zen Hospice Project (ZHP) in San Francisco, a non-profit organization. After an accident nearly killed him 23 years ago and left him a triple amputee, he has built a life helping others who are nearing death.

"Working from the vantage point of death as an essential part of life, Dr. Miller is actively engaged in cultivating a larger dialogue about this universal experience, as much through ZHP's own human-centered model of care, as through exploratory work with the international design firm IDEO, participation in various healthcare policy initiatives, including San Francisco's Palliative Care Task Force, and through public speaking, including the closing talk at TED2015, all helping to make empathy-driven end-of-life care available to all."

Dr. Miller is a dynamic speaker and his Ted Talk can be seen at the following link:
https://www.ted.com/talks/bj_miller_what_really_matters_at_the_end_of_life?language=en

21st International Congress on Palliative Care

The **21st International Congress on Palliative Care** will take place from **October 18 to 21, 2016**, at the Palais des Congrès in Montréal, Canada. Organized under the auspices of **Palliative Care McGill, McGill University**, the Congress will once again welcome the worldwide palliative care community, as multidisciplinary colleagues from 60 countries gather to share experiences, exchange ideas, learn from world renowned experts, and refresh their skills, all while renewing their commitment to providing the highest standard of care.

21st International Congress on Palliative Care

October 18-21 2016

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Supportive and Palliative Care Services at the McGill University Health Centre

By Rosemary O'Grady

The origins of Palliative Care in Montreal, under the inspirational leadership of Dr. Balfour Mount, has grown and developed into our current day Supportive and Palliative Care Service. Dr. Manny Borod and I co-lead the interdisciplinary programs, which currently fall under this umbrella.

The heart of the service can be found on D9 North at the RVH of the Glen site, where the Balfour Mount Palliative Care Unit currently resides. This department provides Whole Person Care to patients with complex symptoms and psychosocial needs. We have an interdisciplinary team that is comprised of volunteers, nurses, doctors, psychologists, spiritual care, a social worker, music therapist, physiotherapist, occupational therapist, volunteer and bereavement coordinator and many complimentary therapists provided through Cedars CanSupport. Patients benefit from this expert, interdisciplinary team, as well as from the beautiful private space offered by the newly built Glen site.

Our outpatient Supportive Care Program is comprised of five interdisciplinary clinics: Palliative Care, Cancer Pain, Cancer Rehabilitation/Cachexia, Lymphedema, and Survivorship as well as a Supportive and Palliative Care Consult Service, Psychosocial Oncology Program, and CanSupport services.

The Palliative Care Day Hospital began in 1998 with excellent nursing support provided by Clemence Rheaume who continues 18 years later. The day hospital team is comprised of palliative care physicians and nurse clinicians. Patients have access to a social worker, psychologist, occupational therapist, physiotherapist, nutritionist, and CanSupport services on a referral basis. Patients are most often referred for complex symptom management and end of life planning. The Palliative Care Day Hospital is located on the 2nd floor of the Cedars Cancer Centre and is open 5 days per week.

The Cancer Pain Program was launched in 2011 and is now under the dynamic leadership of Dr. Jordi Perez. This program serves patients with complex pain problems which are managed by an interdisciplinary team comprised of a nurse clinician, palliative care physicians, an anaesthesiologist, and a radiation oncologist. Psychosocial and allied health support is available upon request. This clinic operates three and a half days per week and shares space with the Palliative Care Day Hospital on D2 of the Cedars Cancer Centre. The program has been shown to significantly reduce patients' pain scores and was awarded "le prix Quebecoise de cancerologie" for exemplary practice in 2015.

The Cancer Rehabilitation/Cachexia program moved to 5252 De Maisonneuve in June of 2015 under the leadership of Dr. Antonio Vigano and Mary Lou Kelly and operates two days per week. The goal of this program is to help patients optimize their functional status and reduce morbidity associated with the disease and its treatment. This team is comprised of palliative care physicians, a nurse clinician, physiotherapist, occupational therapist, and nutritionist. Patients are often referred with a combination of severe fatigue, deconditioning, nutritional problems, peripheral polyneuropathy, and cognitive problems. The approach of the team includes an in-depth assessment and evaluation of the patient's rehabilitation needs. Interventions are then provided with the aim to improve the patient's quality of life.

The Lymphedema program also operates at 5252 De Maisonneuve under the leadership of Dr. Anna Towers and is open three days per week. The mandate of the program is to provide expert clinical care for complex lymphedema problems. The clinic team is comprised of a palliative care physician, physiotherapists, a fitness instructor, as well as volunteers. The MUHC Lymphedema Program is internationally recognized for its clinical, educational and research leadership. It is the only Quebec supraregional referral centre for lymphedema following cancer treatment. In addition, the team creates standards of care for lymphedema in Canada and internationally in collaboration with the Canadian and International Lymphedema Frameworks. The team takes a leadership role as national and international educators and advocates for resources to develop lymphedema prevention and rehabilitation for those suffering from chronic cancer-related disability.

The newly created Survivorship Program under the direction of Dr. Geneviève Chaput and Nathalie Aubin, Clinical Nurse Specialist, is set to launch in May 2016. The program will begin with a pilot project for Breast Cancer patients who have recently completed treatment. These patients will receive an educational session, treatment summary, and surveillance care plan. Much work has gone into the preparation for this pilot, including both building links with, and educating family doctors in the community.

In 2015 the Psychosocial Oncology Program under the co-directorship of Dr. Marc Hamel and Dr. Anita Mehta, joined the Supportive and Palliative team. Psychosocial Oncology is comprised of psychologists, a social worker, nurse, and psychiatrist. The mandate of the program is to offer professional psychosocial services to ambulatory oncology patients and family members who are identified by their cancer teams as needing support. It provides education to professionals via in-services or conferences on topics related to psychosocial oncology. The team also conducts psychosocial research as well as clinical training in psychosocial oncology to PhD students.

Under the direction of Andreanne Robitaille, Cedars CanSupport joined our team in June 2015. This organization provides invaluable support to cancer patients and their families. CanSupport offers not only practical support and humanitarian assistance, but also provides education, support groups, and the services of many complimentary therapists (music, massage, Reiki, relaxation, art). The jewel within CanSupport is the over 200 dedicated volunteers who come to the hospital to visit cancer patients, provide help with 'way-finding' (help patients find their way to their appointments), organize pet therapy visits, listen and provide friendly support and a caring presence. We are most grateful for their contribution.

We are very proud of the services offered within Supportive and Palliative Care and of the interdisciplinary model that is so much a part of the palliative care culture. We are also aware that there will be some changes coming to our Division in the coming weeks and months. We count on the commitment and resilience within our teams to skillfully and mindfully maneuver through these changes together. It's been a privilege to be a part of it all.

Rosemary O'Grady is Nurse Manager
MUHC Supportive and Palliative Care Services

Articles of Interest…

We need a Role Reversal in the Conversation on Dying

By VJ Periyakoil
The New York Times, April 22, 2015

In most doctor-patient conversations, the doctor leads the way.

But when it comes to planning for the end of life, we need a role reversal. The patient — you — may have to take the lead in conducting end-of-life conversations. While this may seem surprising, remember that dying is essentially a social and intimate family event that has become overly medicalized in the past century.

Patients and families need to reclaim dying from the hospitals and return to what we used to do before the 20th century: Prepare for the end of life as a family and care for our seriously ill and dying in a homelike environment.

You, as the patient, know when you are ready to discuss this sensitive issue with your family and your doctor. You also have a deep understanding of how your culture, beliefs and values shape what matters most to you in the last chapter of your life. You need to help us — doctors — overcome our innate reticence so that we can discuss the sensitive topic of death. You need to know that our ability to predict your life span may be an educated guess, as death prediction is a complex art determined by numerous and ever-changing variables.

We know that many of the 2.6 million Americans who die every year never get to shape how and where they die – or even talk to their doctors about it. Without these conversations, doctors don't know what the patients' goals are for living their last days. What are their hopes, wants, needs and fears? Do they want to die at the hospital connected to a machine? Do they want to die at home? The current default is for doctors to give patients every possible treatment for their condition, regardless of its impact on the patient's quality of life, the cost or the patient's goals.

To find out why most doctors don't talk about this with their patients, our research team started investigating at my home institution, Stanford University. The results, published Wednesday in PLOS One, were telling.

Of 1,040 multispecialty doctors working in the two large hospitals affiliated with Stanford, 99.99 percent reported that they faced barriers to conducting end-of-life conversations with patients. Doctors felt stressed about discussing end-of-life issues with patients who belonged to an ethnicity other than their own. They were reluctant to talk to patients who were not fluent in English or did not understand medical terminology. They also felt frustrated when the family would not allow the doctor to talk to the patient about the diagnosis.

As one doctor said, "certain groups feel that honesty and frankness is not good for the emotional outlook on life for the patient and they do not want the physician to be frank with the patient in discussing end-of-life issues at all." Finally, when patients talked about their faith and beliefs about God, death and the afterlife, the doctors did not know how to respond.

We can continue to do what we are doing right now, which is to work hard to maintain our collective culture of silence. Or we can take a big step toward one another and begin to talk about a topic that scares many of us: the end of our own lives.

With guidance from patients and families from various racial and ethnic groups, my team has developed a format for a letter that can help in this conversation. Unlike legal documents, which can be intimidating and expensive, a letter is a familiar format, so the entry bar is low. The letter can empower the patient and the family to take the first step and engage the doctor in a conversation on what the patient wants. The letter can also guide the path for official documents such as advance directives and Physician Orders for Life-Sustaining Treatment, known as Polst forms.

The letter offers certain advantages over those forms, however. They do not give clues about how a patient prefers to handle bad news, or how to handle a situation where the family does not want the doctor to disclose the diagnosis to the patient. This is especially challenging when the patient and the doctor do not speak the same language. The letter could also offer guidance when the family wants something different from what the patient wants — as sometimes happens when the patient is too sick and vulnerable to have a voice.

We invite you to write your letter now. And, the next time you see your doctor, start the conversation by saying “Doctor, let me help you talk about some things that matter most to me at the end of my life.”

VJ Periyakoil is a physician and director of palliative care education and training at Stanford University School of Medicine.

Living Will – Jewish General Hospital: http://jgh.ca/en/LivingWill

We are camouflaging morbidity in clichés: It’s time to talk about death.

By Sandra Martin
The Globe & Mail, January 1, 2015

Have you noticed how few people seem to die these days?

Despite an aging demographic, calls from the medical profession for political parties to enunciate their seniors strategies, an anticipated ruling from the Supreme Court of Canada on the constitutionality of the Criminal Code prohibition against assisted suicide and the implementation of Quebec’s medical aid in dying legislation, Canadians have become increasingly prudish about the language of mortality.

Instead of dying, people “breathe their last” or “pass away” – most of them peacefully, often after a heroic struggle. Some of them just pass and they do it unexpectedly, which always reminds me of flatulence.

At a time when the inevitability of death – our parents, ourselves – confronts us as never before, we are camouflaging morbidity in clichés. We rarely speak directly to mourners of the death of a loved one, especially by name or relationship. Rather, we mumble the generic (and anonymous) chestnut: “I’m sorry for your loss," as though a car has been stolen. The deceased is no longer "survived by" next of kin; instead he or she "leaves" spouses, siblings and offspring behind like objects forgotten in a storage locker at a bus station.

Death today is like sex was for the Victorians. We know it occurs, we may even feel a prurient pleasure in hearing gruesome details, but most of us don't want to talk about the prospect of our own deaths or of those ahead of us in the trenches – and certainly not in public. In the last few days I have read about an octogenarian "who slipped away with the light in the late afternoon," a nonagenarian whose "peaceful passing into the spirit of the universe" was marked by "a glorious golden Southern California sunrise," and the disappearance of "the best and brightest star in the sky" with the death in a car accident of a high-tech entrepreneur.

The death notices are one thing – after all, family and friends are mourners, not writers, and they are paying good coin to announce the deaths of loved ones. But I can't help suspecting that far too often they allow their own words and judgments to be overridden by the smarmy templates of funeral directors. What bothers me more are the banalities creeping into news reports in print and broadcast media. The extensive coverage of the unexpected death of Canadian criminal lawyer Edward Greenspan is a recent example. He died in his sleep on Dec. 24, the last night of Hanukkah, on a family holiday in Arizona, after watching his grandchildren light the final candle of the menorah – a good, if untimely, demise, by my standards. I am sad for his family, his colleagues and all of us who respected his principled campaigns against the death penalty and on behalf of defendants who deserved a day in court no matter how heinous their alleged crimes. But what I also remember is Greenspan's precise and eloquent use of the language and so I cringed every time I heard or read that he had been "laid to rest" rather than buried.

Instead of bromides, we need to talk frankly about our universal and ultimate experience: Death. Will you join me in a collective resolution to rip the shroud off death imagery? When I wrote obituaries, I often found that the elderly and the infirm were eager to talk about their lives and their impending deaths. It was the people around them who were squeamish. Do your parents and grandparents a favour – ask them about their hopes and fears about dying, how they want their lives commemorated, discuss their wishes with doctors, lawyers and next of kin and put it down clearly and succinctly on a readily accessible document. And while you are at it, please give a thought to replacing language that is confusing or complicated, such as Do Not Resuscitate, with clear directions, such as Allow Natural Death. It is time to take death out of the closet and lay the platitudes to rest.

WORDS TO LIVE BY

When helping a patient prepare for death, talk about life instead.

By David Cameron
Harvard Medicine (2015)

Joanne Wolfe is no stranger to situations charged with the sort of emotional intensity that would shake most of us to the core. Take, for example, the time a group of clinicians under her supervision was caring for a teenage girl who was going to die from a metastatic brain tumor. The team was desperate to discuss with the girl and her mother a potential nonresuscitation order. Without such an order, resuscitation is the default treatment, and the doctors worried that the girl could end up on a ventilator, with her mother forced to decide whether such life support should continue. So, at different times the doctors had presented the girl and her mother with the various options and had asked, "What do you want us to do?" Each time they brought the issue up, however, the girl and her mother evaded the conversation. The doctors came to Wolfe for advice.

"That's often the way it's done," says Wolfe '89, an HMS associate professor of pediatrics and director of pediatric palliative care at Boston Children's Hospital and Dana-Farber Cancer Institute. "Doctors spell out a menu of options without any real context, and the patients are expected to simply choose what they want."

Wolfe recommended a more oblique approach. Rather than asking the patient to make a choice, they asked her to make a list. The girl was encouraged to write down all the things that she wanted, in no particular order, from the sublime to the silly. Nothing was out of bounds.

She put together a document that Wolfe still uses to mentor physicians.

I want a hot tub, the girl wrote. I don't want to be intubated. I want to believe in God. I don't want chest compressions. I want to be able to walk again.

Wolfe continues to be struck by the blended goals the patient put on paper once she was given the opportunity to express herself without conditions. This allowed the girl to find her voice, and from there the decisions flowed naturally.

Eventually she died comfortably, without resuscitation, intubation, or chest compressions.

"The point," says Wolfe, "is to allow the patient's desires to establish a framework, and then you, as a physician, can own the responsibility for making a recommendation."

Doctors are trained to save lives, not to inform patients that they are at the end of theirs. There is, however, a growing consensus in the medical profession that for too long end-of-life conversations have been marginalized to a few brief options that a doctor presents to a patient only after all other interventions have been exhausted. And even then, it occurs rarely. This approach is both a tragedy and source of crisis.

Physicians need to know that there are ways to have these conversations, ways that can produce effective and profound outcomes. Just as doctors are trained in the latest interventions, they need to learn how to compassionately, effectively, and honestly guide patients through their final days.

Deafening Silence

In the world of medical specialties, palliative care is a newbie. Only in 2006 was it recognized by the American Board of Medical Specialties as an official subspecialty. Although this may seem inexplicably tardy, consider that as recently as 50 years ago, doctors often withheld a terminal diagnosis from a patient. Susan Block, an HMS professor of psychiatry and medicine and co-director of the HMS Center for Palliative Care, recalls the early days of her own residency, roughly four decades ago, when physicians routinely excluded patients from end-of-life decisions. The doctor called the shots, and there was little transparency.

“This was very typical of the field,” she says. “And I was morally troubled by that.”

While this sort of paternalism is increasingly the exception, there is still no standardized approach to addressing end-of-life issues. As a result, these conversations happen too infrequently.

“Patients, of course, are ambivalent,” says Block, “and doctors are often too attached to the patients or too insecure about their own competencies. It becomes a collusion of silence.”

Even when the subject is broached, the conversations tend to happen late. In one study involving patients with metastatic cancer, the first conversation about end-of-life care occurred, on average, 33 days before the patient died, and three-quarters of the conversations were initiated by someone the patient had never before met.

The content of these talks tends to take the form of a data presentation: Here is the reality of your condition. Here are the options. Here are all the pros and cons of each option. Choose.

“As a palliative physician once said about me, the problem is that we’re explain-aholics,” says Atul Gawande ’94, Samuel O. Thier Professor of Surgery at Brigham and Women’s Hospital and author of the 2014 book *Being Mortal*. “We think that what people lack is information. But what they lack is more complicated. People have goals and priorities in their lives besides just living longer—and they want doctors who can understand that and help tune their care to those priorities.”

In other words, for physicians to effectively engage patients in end-of-life discussions, they need to fight their tendency to focus on data and instead engage patients on a fundamentally human level.

“This requires transitioning from sounding like medical retailers to being like counselors,” adds Gawande, “ones whose approach is, ‘Tell me what matters to you, and I’ll tell you which options seem best based on that.’ ”

Voice Activation

There’s an irony about end-of-life conversations. When done correctly, they’re really not about the end at all. In fact, they are probably more about life than any other conversation you’ll ever have. The incongruity is not lost on many palliative-care experts.

"I don't find that phrase helpful with most patients," says Lachlan Forrow '83, an HMS associate professor of medicine and director of palliative-care programs at Beth Israel Deaconess Medical Center. "Kierkegaard said, 'Life can only be understood backwards; but it must be lived forwards.' We don't actually know when it is truly the end of life until someone's died. It's the living that's the most important thing."

Wolfe dispenses with "end-of-life" altogether and instead uses "goals of care."

And according to Block, the conversations aren't about dying at all. "These conversations are about goals and quality of life—issues that are meaningful to patients."

The approach taken by Wolfe and her colleagues when talking with a child's family illustrates Block's point:
Tell us about your child as a person. What is she like, and how has that changed since she's become ill?
Tell us your understanding of your child's illness.
What is most important to you and your child?
What are your hopes?
What are your worries?
During difficult times, what gives you strength?

"These kinds of questions help you adapt your approach to the language and values of the family," says Wolfe.

Angelo Volandes, an HMS assistant professor of medicine at Massachusetts General Hospital and author of the 2015 book *The Conversation*, begins these conversations gently.

"I ask, 'What's a good day in your life like? Tell me about a happy day.' I get rid of all the medical language. I get rid of any disease language or prognosis. I try to get rid of any framework of Western medical technology and simply have them tell me what a good day looks like to them."

Speak for Yourself

If the medical field has suffered from a lack of training, incentives, and guidelines concerning such conversations, Block and Gawande are working to change that. For five years they have been working with others to develop and test what Block calls a "serious-illness care program." It is both a program for improving physicians' skills in communicating and planning with patients who have serious illnesses and a support system to ensure that patients who would benefit from these conversations have them.

The program begins with a simple step. A doctor looks over her patient list and for each individual asks herself one question: If this person were to die within a year, would I be surprised? If the answer is no, then it's time to have a conversation.

The physician, together with others in the program, then receives a two-and-a-half hour training program based on a seven-question guide to what Block calls "patient-centered conversations about serious-illness care goals." Patients are also told in advance that the physician caring for them is going to initiate this conversation and are instructed in how to prepare for it.

Once the conversation is complete, the doctor documents it in the patient's electronic medical record, so that any physician in the patient's care continuum can access it.

A clinical trial evaluating the program's effectiveness is ongoing, and preliminary analysis is encouraging, says Block, suggesting that doctors involved in this program have these conversations earlier and more often than other doctors, and that patients are indeed experiencing better quality of life.

Training Tapes

Volandes is also developing an educational curriculum, but he is tackling the problem from a different angle. Rather than training doctors, he's training patients.

Volandes and his colleagues have created nearly 100 videos in ten languages that offer patients advice on how to "explore goals of care" with their physicians. Other videos describe many of the aggressive medical interventions about which patients with life-threatening diseases are often asked to make decisions. The videos provide concrete demonstrations of how these interventions might affect the patients' daily lives.
"This is really a re-envisioning of the patient-doctor relationship," says Volandes.

So far, more than 200 health care systems, hospitals, hospices, and clinics have made these videos available, including Mass General. A study at the hospital, authored by Volandes and colleagues and published this year in the *Journal of General Internal Medicine*, showed that only 43 percent of seriously ill patients have a goals-of-care conversation with their physicians. When patients viewed the videos that number rose to 81 percent.

The study also found that, in general, about 22 percent of seriously ill patients receive some sort of unwanted intervention. But for patients who have been given access to the videos, that percentage was four.
"If we give patients more knowledge," Volandes says, "we can radically change what happens in health care. Now we have data to show that you can actually budge the needle if you empower patients."

The Human Condition

If, ultimately, end-of-life conversations are less about death and more a focus on life itself, then working in this field is not so much about perfecting medical interventions as it is about perfecting being human—an insight so simple it's radical.

This awareness was driven home to Block a few years back when she went to a parent-teacher night at her son's high school. That day had been particularly brutal for her, heartbreaking and poignant, and she was barely keeping it together. At some point, a father of another student approached her and asked, "How was your day?" She burst into tears. The man, no doubt, was a bit shocked, but Block didn't hold back and told him everything that had happened. When she finished, the man, who worked in finance, looked at her and said, "I would give anything to have a day as close to what it means to be a human being as you've just had."

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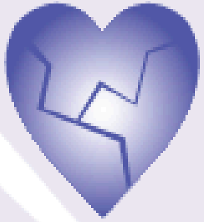
Dealing with Grief



When a relationship
is severed, a reaction,
psychological,
physical or social,
is set in motion,
which we call grief.

The loss can be the result of a lengthy illness, a short illness, a sudden death or suicide.

Grieving is a natural, healthy and necessary process. It involves feelings, thoughts and behaviours.

There are no ready made solutions for dealing with grief. Each person is different and responses to the death of a loved one vary tremendously.

Nevertheless, it is possible to learn from the experience of others. The following is a list of suggestions to consider during bereavement. Some will be helpful; others will not.

They have been divided into five areas: psychological, physical, social, economic and spiritual.

Psychological

Everyone can benefit from support; do not be afraid to accept it.

While you may feel pressured to put on a brave front, it is important to make your needs known by expressing your feelings to those you trust.

Often numbness will see you through the first days or weeks. Do not be too surprised if a letdown comes later.

Many people are more emotionally upset during bereavement than at any other time in their lives and are frightened by this. Be aware that severe upset is not unusual and if you are alarmed, seek a professional opinion.

Whether you feel you need to be alone or to be with people, make it known. Needing company is common and does not mean you will always be dependent upon it.

There is no set time limit for grieving. It varies from person to person, depending upon individual circumstances. Grieving often takes a lot longer than anticipated.

Physical

It is easy to neglect yourself because you may well feel you do not care about anything.

You are under great stress and may be more susceptible to disease. It is especially important to take good care of your health.

Try to eat reasonably even if you derive no enjoyment from it.

Although sleep may be disturbed, try to get adequate rest.

If you have symptoms or if people urge you to see your doctor, do so even if it does not seem important to you at the time.

Grieving takes a lot of energy and it is important not to overextend yourself.

Social

Friends and family are often most available early in bereavement and less so later. It is important to be able to reach out to them when you need them. Do not wait for them to guess your needs. They will often guess incorrectly and too late.

Someone who is not too close to you but who is willing to listen may be particularly helpful.

During a period of grief it can be difficult to judge new relationships. Do not be afraid of them, but be aware that it is usually unwise to rush into them.

No one can substitute for the person you have lost. Try to enjoy people as they are. Do not avoid social contacts because of the imperfections of those you meet.

Sometimes, in an effort to stop the pain of grief, people act to replace the lost person (e.g. by adopting a child or remarrying) too soon. This kind of solution may only lead to other problems.

Try to make clear to children that sadness is perfectly normal and that neither theirs nor yours needs to be hidden. It is important that periods of happiness are enjoyed and do not become a cause of guilty feelings.

Economic

Avoid hasty decisions. Try not to make major life changes within the first year unless absolutely necessary.

In general, most people find it best to remain settled in familiar surroundings until they can consider their future calmly.

Do not be afraid to seek advice.

Consult experts before making any major financial decisions.

A job will not fulfil all your needs. It is better not to turn to excessive involvement in work, or sacrifice relationships with family and friends in an effort to keep busy.

Spiritual

Many people find that personal faith is a major source of comfort during bereavement.

For some, however, maintaining faith may be difficult during this period of loss.

Either or both may occur, and both are consistent with later spiritual growth. It may be helpful to discuss these matters with a spiritual counsellor or a trusted friend.

Dealing with grief in children

Children often act as if they have not been affected by the loss of a loved one.

Symptoms such as lack of appetite, sleep disturbance or a return to the type of behaviour which characterizes a younger age group are signs that a child has been affected by the loss.

It is important to talk about the death □ with the child.

A visit to the cemetery may help.

If possible, it is better to avoid any abrupt change of routine since this can foster another sense of loss for the child.

If problems persist, seek professional help.

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