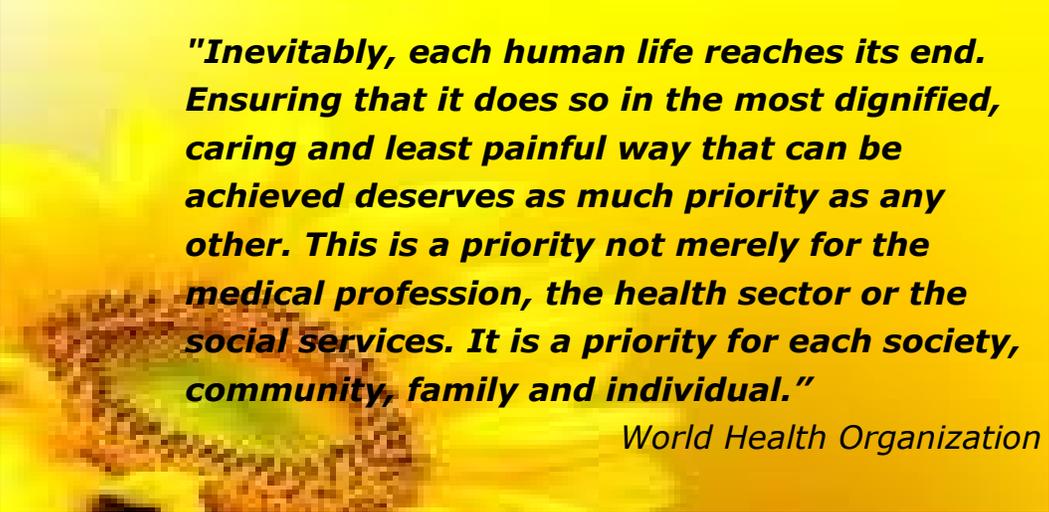


The Council on Palliative Care

National Hospice
Palliative Care Week
May 3-9, 2015

Sandra Goldberg Lecture
May 5, 2015

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



"Inevitably, each human life reaches its end. Ensuring that it does so in the most dignified, caring and least painful way that can be achieved deserves as much priority as any other. This is a priority not merely for the medical profession, the health sector or the social services. It is a priority for each society, community, family and individual."

World Health Organization

The Contribution of the Near Death Experience (NDE) and End-of-Life Experiences to Palliative Care

By Dr. Peter Fenwick

In virtually every culture throughout recorded history there have been myths surrounding the process of dying and of death itself. Most of these stories focus on the journey that the dead must make to reach the next stage of their existence. In some cultures, the apparitions seen by the dying on their deathbed – the so-called deathbed visions – seem to have a dual role, as both the harbingers of death, and the guarantors of a safe passage to the afterlife.

More recent anecdotal accounts suggest that these end-of-life experiences (ELEs) consist of a much wider range of phenomena than only deathbed-visions. These phenomena include the ability to transit to and from other realities – usually involving love and light, very similar to that reported by people who have a near death experience, coincidences around the time of death involving the dying person appearing to a relative or close friend who is not present at the time of death, and a need to settle unfinished business such as reconciling with estranged family members, or putting affairs in order before death.

And yet when, in about 2002, I first became interested in

the whole process of death and dying and searched the scientific literature I found that only one or two publications in this area ever mentioned these phenomena. You could become a world expert in the area with only ten minutes reading. Moreover, most people in the medical profession who I questioned said they never happened.

However, our first pilot study, with a palliative care team, suggested things were not quite like that. People who worked closely with the dying were certainly aware that these things happened. They just didn't talk about them. Two further studies, a five year retrospective and a one year prospective, with nurses, doctors, chaplains and end-of-life carers from two hospices and a nursing home, confirmed what we had already suspected – that staff were split in their attitudes towards these experiences. The medical staff knew that they very rarely happened. The nursing staff were well aware that they did. The only nurses who did not know about end-of-life experiences were the ones who never actually sat with the dying. It seemed to us that the medical attitude which had filtered down to the carers in their earlier general palliative care

Continued on page 2

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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The Contribution of the NDE and End-of-Life Experiences to Palliative Care. (cont...)

training, was that death was simply a turning off and that the experiences of the dying were likely to be due to organic causes or 'dreams', and as such were unimportant. Although this view was not so strongly held by the medical staff in the hospices, it was still adhered to, to some extent by the carers, and was often repeated to us in the one-to-one retrospective interviews.

What we found was that end-of-life experiences were certainly not uncommon and we divided them into two main categories. The first were what we termed transpersonal ELEs – those which had 'other-worldly' or transcendent qualities and could not easily be explained by the pathological process of dying- the deathbed visions, usually of deceased family members, who came to help the dying person and be with them through the death process; the transiting to new realities very similar to those seen in the Western near-death experiences, often involving love and light, and 'coincidences' at or around the time of death, when someone emotionally close to the dying person is made aware of their death. Our interviewees also described other ELE phenomena which they had noticed around the time of death, such as clocks stopping or lights and equipment turning on and off, shapes leaving the body, light surrounding the body and often in the room, and strange animal behaviour.

One thing all these end-of-life experiences (ELEs) had in common was that they were enormously comforting to both the dying and the bereaved. Even though many of the experiences we were told about by carers had happened several years previously, they were vividly remembered because of their comforting nature and because in many cases they helped to abolish a fear of death. Our interviewees also confirmed that these

ELEs were very different in character from drug -induced hallucinations and that they occurred in clear consciousness. Since our initial studies a number of other studies have been published which show that 60% -70% of the dying will have at least one of these deathbed phenomena in the days before they die. But much more important, a recent research paper showed that 80% of those patients who have them die tranquilly, whereas only 25% do so if they do not have them.

The second category of experiences we noticed we called 'Final Meaning ELEs.' These were firmly based in the here and now, and were often prompted by profound waking dreams, or dreams which help the person to process unresolved business so they can let go and die peacefully. These include a desire to put their affairs in order and to become reconciled with estranged family members. Sometimes a patient seems able to hang onto life if they know that someone they particularly want say goodbye is on their way to see them. Also often reported was what the Victorians called 'lightening before death' but is now called terminal lucidity, a short period of clear consciousness that a previously confused or semi-conscious patient may have, enabling them to say their farewells.

General practitioners, geriatricians and palliative care workers, are those most often involved in the care of the dying and the bereaved, and yet spiritual care of the dying and a knowledge of end-of-life experiences is not yet a standard part of the medical or palliative care curriculum. Many people now die in hospital but unfortunately nurses have neither the time nor the training to deal adequately with this very important aspect of the dying and grieving process. In the UK, 50% of complaints about hospital care relate to care of the dying. We are very

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Mandates: making the best of a sad situation

By John Archer

Special to the Montreal Gazette. October 20, 2014

In Quebec, if an individual is incapacitated due to sickness or illness, she or he needs a legally recognized mandate to allow others to officially act on their behalf in matters regarding their personal health care and/or finances. If a mandate is not in place, they are exposed to having the public curator act on their behalf and this is something to be avoided, if at all possible.

First of all, what is this mandate? A mandate in the event of incapacity is a legal document drafted by a healthy individual that specifies whom they wish to do what in the event the individual is unable to represent himself if he should become incapacitated due to illness or accident. It is a document that is preferably notarized to ensure it is properly drafted, and then registered, to represent the individual's wishes. A mandate drafted before a notary or lawyer is also proof that the capacity of the individual was verified. There are do-it-yourself versions that may be accepted by the courts (or refused) but those are often poorly constructed and incomplete.

An individual can appoint one mandatory to act on his behalf for all personal care decisions and a different person, or a trust company, to act for all of his financial affairs. Often the same person does both but not always. For example, a relative or friend might be capable of making decisions over the incapacitated person's personal health care but may not be experienced in handling finances. A trust company can act only in regards to a person's financial affairs.

Having a mandate in place is merely the first step and may never be needed at all. However, when a person begins to show advanced signs of dementia or is severely injured or disabled due to a sudden ailment or accident, it is time to initiate the homologation process.

'Homologating' a mandate may sound like something a cat might do after a big meal but, in fact, it represents a process that must be followed in order for a mandate to be verified by the courts and put into force.

This is designed to protect both the incapacitated person and the person appointed to represent them when executing both financial and personal care decisions. Unfortunately, it is a process that is ill-understood and sometimes swept under the carpet, often at the peril of the parties involved. Understanding the process of homologation can save caring individuals from potential years of legal tur-

moil after their services have been rendered and can make their work easier while providing such care.

To homologate a mandate, one must have medical and psychosocial assessments completed in order to establish the mandator's incapacity. The medical assessment is usually done by the individual's personal physician while the psychosocial assessment can be done by a social worker found either in the private sector or through the CLSC in the area where the incapacitated persons resides. These documents, along with the mandate itself, must be submitted along with an application for homologation to a clerk or judge of the Superior Court of the judicial district where the mandator resides. A payment of \$118 is also required for an application for homologation.

Due to the complexity of the homologation procedure, it is often recommended a notary or lawyer be engaged to steward the process through the courts. This, of course, adds to the expense, but can be worth it to ensure its prompt execution. In fact, before one applies for homologation one must make sure the mandate being submitted is the most recent mandate entered in the Registres des dispositions testamentaires et des mandats of the Chambre des notaires or at the Barreau du Québec. A legal professional can assist with these mandate searches.

Having a homologated mandate in hand will then allow the mandatory to transact important transactions such as the sale of real estate, automobiles, the paying of bills and the management of investments. It also facilitates the placement of the mandatory into a senior's residence or other long-term care facility. Without a homologated mandate, one's friends or family may find themselves handcuffed in acting on the incapacitated person's behalf and usually at exactly the worse time possible.

John Archer is Wealth Advisor with RBC Dominion Securities in Montreal and can be reached at 514-878-5040 or at john.archer@rbc.com.



The Contribution of the NDE and End-of-Life Experiences to Palliative Care. (cont...)

good at providing practical end-of-life care but research into the dying process and the mental states of the dying is often overlooked. In our survey we found that many people who had witnessed or experienced these end-of-life phenomena felt uncomfortable about discussing them with their doctor and that something which was intensely meaningful to them was often dismissed as insignificant. The lack of research into the dying process may be influenced by the continuing social taboos which surround death, and the tendency of doctors to concentrate on the survival of patients, rather than help them achieve a good death. Consequently, the prevailing scientific view is that ELEs, particularly deathbed visions, have no intrinsic value, and are either confusional or drug induced. Even amongst palliative care professionals, ELE training is lacking and many palliative care nurses feel inadequate when dealing with spiritual issues.

But the good news is that the whole process of death and dying is now regarded much more widely as a very important area which must never be neglected again. Training in this area should be part of standard palliative care training. ELEs are profoundly subjective and meaningful events which usually occur in clear consciousness and often help the individual to let go of life and lessen the fear of dying. They are spiritual events with a meaning for the patient which takes them beyond the distress of dying.

Imhof (1996, 2008) points out that since death is not taught as a medical subject, and 'dying right' is not part of medical studies, this special awareness of the dying process is often ignored by those who care for the dying. He considers that "*Although all of us will die, hardly anyone is prepared, or is preparing to die right*". Sherwin Nuland (1994) comments, '*Death is not usually a time of wonderful experience. But is frequently a time for healing experiences.*' Our research confirms that ELEs are such healing experiences, are commonly part of the dying process, and the understanding of them must contribute to best practice in spiritual end-of-life care. Finally, we have to consider the very positive comments that some of the dying make just before they die. I had a letter from someone who told me that her mother, a life-long materialist who believed that death was just switching off, said just before she died, "*Come on, come on, I am ready to go.*" The great inventor Thomas Edison said, just before he took his last breath, "*It is very beautiful over there.*" And Steve Jobs' sister reported that just before he died he simply said, in wonder, "Oh wow! Oh wow! Oh WOW!"

Dr. Peter Fenwick is Honorary Senior Lecturer at the Institute of Psychiatry King's College, London, UK. One of Dr. Fenwick's main interests for some years has been near death experiences and the dying process.



"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

Wild Messengers

By Jennifer S. Holland

New York Times, November 1, 2014

About a decade ago, a brain tumor came to steal my mother away. It was diagnosed after she'd exhibited a series of strange behaviors (stranger than usual, I should say, as she was a quirky lady to begin with), and she very quickly went to a dark, quiet place that none of us could reach. Still, for a number of weeks, as she curled into an ever tightening ball under a growing mound of blankets, she continued caressing her three cats as they snuggled against her. When her hands finally went still, a week or so before her death, I knew we were nearing the end.

Escorting a loved one through her last days wrings your heart dry. You keep smiling, helping and hugging, knowing that soon enough you'll be able to collapse and grieve. But until then, you stay strong.

One cold, gray day in February, in search of that one last bit of strength, I took a break. Family friends agreed to sit with my mom as she slept the day away, so I set aside guilt and got in the car and drove. Minnesota that winter morning was all steel sky. The pan-flat landscape slid by, farm after farm, an austere poetry in the scenery that seemed about right.

Anger was driving, its foot heavy on the gas, and my thoughts were boxed in tight and spinning. It took a while to banish my circular thinking with deep breaths, and feel unbound. And then, along one curving road lined with a particularly tall row of trees, something pulled at my gaze. Way up, against the somber sky, a bald eagle perched on a branch. It was a splendid creature, and not an animal I was privy to seeing often in my usual suburban world. It alone would have lifted my spirits.

But then, I saw a second one. And a third. It seemed for a little while that every time I looked up from the road (I'd slowed to a near crawl by then), a bald eagle appeared. One flapped its huge wings, circled around and landed in the next tree. Another preened, its head twisted impossibly far to get at feathers around its back. Still another fell from above like Tennyson's famed thunderbolt. Two others perched like statues, doing nothing in particular but looking spectacular.

There were, in total, nine bald eagles along that stretch of road. It was the ninth of February. And later, after I'd returned home and settled back on the couch next to the baby monitor broadcasting from her room, my mother took her last jagged breath. The quiet that followed knifed through me, but then came a sense of ease, of calm. The suffering was over.

I'm not a religious person, not even a particularly spiritual one, though I often turn to the natural world to ease stress and quiet the mind. That night, though, I couldn't help but think that those birds were nature's messenger, sharing what was coming. Perhaps even telling me that final exhale was a good thing, powerful and beautiful in its lasting quiet. Given a list of possible messengers, I can certainly imagine my mom, a true animal lover, choosing majestic birds, their number matching the date (a little nudge to see if I was paying attention), to prepare me and say her goodbye. When I suspended my disbelief, it made perfect sense.

Many describe the experience of being "visited" by a wild animal soon after a loved one's death or on an important anniversary of that death. For example, the author Cheryl Strayed, after losing *her* mother, wrote about an odd, yet comforting encounter with a fox in her book "Wild."

When we mourn, isn't it not just for our relationship with a person, but also for the physical presence of her, her aliveness? The voice, smell, textures and warmth, the gestures we know intimately, all of these are replaced with their opposites in death. We are left with a hole that the energy that powered the person through life once filled. And so I think many of us seek signs of that energy at work somewhere else. A butterfly keeps circling you and perching on your arm. A deer raises its head from grazing, landing its gaze on you. A dog you've never seen before makes a beeline to you from nowhere, demands a little love, then moves on. I admit to taking an extra look at a particularly tame squirrel or a bird chirping right outside my back door, thinking, Mom, is that you? I feel a little silly, yes, but even a quick connection with that warm, energetic thing soothes me in that moment.

So many traditions look for the ethereal in animals. The Hindus, among others, believe we are reincarnated over and over, taking on animal and human forms as we move toward the divine. Cats were deified in ancient Egypt, and in the Catholic tradition, St. Francis of Assisi communicated with and preached to animals. Many Native American cultures have totems — wolves, hawks and others — to guide, protect and test individuals throughout life. Human beings may look to animals to embody what we can't see but want to believe is there.

And so it is with a loved one's energy. People slip away, but then maybe, just maybe, some part of them is conserved and finds a way into something living around us. Could there then be a personal message that's playing

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Events & Happenings!..

Sandra Goldberg Memorial Lecture—May 5, 2015

This year's Sandra Goldberg Lecture will take place on May 5th from 6:00-7:30 PM in the Leacock Building, room 132, on the main campus of McGill University. The format of the lecture will be a 'facilitated conversation' between Dr. Harvey Schipper, an Oncologist and Professor of Medicine at the University of Toronto and Véronique Hivon, MNA and former Minister of Social Services, who introduced Bill 52 -- An Act Respecting End-of-Life Care.

Bill 52, which advocates for physician assisted suicide, has been very controversial, but has proven to have greatly stimulated the conversation about the need for increased palliative care as an alternative and preferred option.

The talk entitled, *Public Choices, Private Lives: An End-of-Life Conversation*, will be moderated by Daniel Jutras, Dean of the Faculty of Law at McGill and we hope the talk will shed light on some of the nuances in the bill.

This lecture and previous ones can be found on the Council's web site.

Free Public Workshops

The Council in Palliative Care offers several series of workshops each year covering a spectrum of topics of interest to those involved in caring for people with a life-threatening illness. The workshops occur once a week over a 2-3 week period and usually follow a theme. However, participants can attend all, or only those that interest them. They are open to everyone and there is usually a mixed audience of health care professionals, students, family members and caregivers. The workshops are always very well received.

The Council will offer three free workshops, open to the public, on Tuesdays, April 13, 20 and 27th from 6:00-8:00 PM at Temple Emanu-El-Beth Sholom in Westmount.

The first, *What you wanted to know about hospitals and were too afraid to ask*, will be given by Dr. Eugene Bereza, a family physician and medical ethicist. The second will show the film, *"Being Mortal: Medicine and What Matters in the End"*, a Frontline documentary with author Atul Gawande. A discussion will follow with Sue Britton, RN and Zelda Freitas, SW. The third, *Advocating for Excellent Care*, will be given by Joan Foster, BN.

In November 2014 three workshops took place at The Temple Emanuel-Beth Sholom, a very inviting environment, both because of the hospitality and the easy access.

The topics covered were:

Navigating The System

This is a popular workshop and is offered frequently. Joan Foster, BN and Zelda Freitas, SW were the presenters. Both work at the CSSS Cavendish which covers NDG and Montreal West regions.

An End Of Life Choice

The presenter was Sue Britton RN, a pioneer Palliative Care Nurse, Psychotherapist and Yoga teacher.

The film, "Dying Wish" was shown. It is about a doctor's decision to stop eating and drinking and die with dignity. It is an extraordinary and beautifully made film of a courageous physician facing his final days with the help of a loving family and supportive hospice team. It is thought provoking and reassuring.

A set of questions were presented for table discussions.

Death Café

The presenter was Kit Racette BSC, a certified Grief Educator and Alexander Technique teacher. She gave a brief history of Café Mortel/Death Café which was started by Bernard Crettaz who hosted 40 Café Mortel events in Switzerland before he wrote his book of the same name. Since 2011, Jon Underwood has expanded the movement internationally and there have now been over 1000 Death Café events in 22 countries.

More information is available at <http://Kitracette.com/deathcafé/>.

Everyone received a booklet, *Elizabeth Where Are You? A Journey Through Grief* that Kit had written following the death of her 40-year old daughter. Participants then played a card game, My Gift of Grace. It is a game used to stimulate conversation around 'living and dying well.' Each card had a question such as, "If only one story is told at your memorial service, who should tell it?"

More helpful information can be found on two very recognized websites:

www.virtualhospice.ca

www.advancecareplanning.ca

Add your name to the Council's mailing list (email address is preferred) so you can always be aware of upcoming workshops. Share your info with others.

Palliative Care Volunteer Training

Volunteers are crucial to our health care system. With this in mind the Council on Palliative Care has agreed to organize the volunteer training for the McGill University Health Centre (MUHC) in order to standardize the train-

Events & Happenings!..(cont.)

ing. The participating organizations are the Montreal General, the Jewish General, St. Mary's, Mount Sinai and the West Island Palliative Care Residence.

35 registrants will be accepted and they will have to go through a pre-screening process.

The course will consist of three full days and one evening - Sundays, April 12, 19 and 26 (full days) and Wednesday, April 29th.

The cost for the course is \$75 and covers all materials, refreshments and lunch.

A celebration of 40 years of palliative care at McGill: the 20th International Congress on Palliative Care

The International Congress on Palliative Care, which takes place in Montreal, is the longest-running, and has been a leading event in the field, since 1976. The 20th International Congress took place at the Palais des Congrès in September 2014, welcoming close to 1500 health care providers and volunteers, from 49 countries. Circuses, games and fun were featured in the spirit of celebration.

Continuing the tradition established over the previous 19 editions, the 2014 Congress featured:

- ◆ A strong and diverse scientific programme, with 604 abstracts presented in addition to the invited speakers.
- ◆ The Opening Plenary by Stephen Lewis inspired participants to draft "The Montreal Declaration", an online petition calling for the inclusion of Hospice and Palliative Care as part of the United Nations Sustainable Development Goals.
- ◆ A highly successful David Bourke Memorial lecture (with overflow audience!) featuring Dr Peter Fenwick on "The Art of Dying" was well received.
- ◆ Special day-long seminars featured Whole Person Care for persons with cognitive impairment, nursing issues, care for those with non-malignant disease and pediatric palliative care.
- ◆ In-depth workshops and seminars in 14 break-out rooms covered all aspects of end-of-life care, from the most current scientific developments in pain and symptom control; to the large existential questions; to hands-on experiential sessions addressing practical issues faced every day.
- ◆ Live music before the plenaries set the stage for learning that bridged science and humanism. Reflections – images and music at the start of each Plenary, once more provided a unique and moving experience.
- ◆ A Retrospective Display about the development of palliative care at McGill and around the world drew

many of the registrants, who were also able to contribute to a "wish list" for the future of palliative care.

- ◆ An evening performance at the Metropolis was a memorable "At the Circus" performance by "Les 7 Doigts de la Main" who thrilled attendees with a spectacular display of acrobatic artistry.

Mark your calendars!!! The 21st International Congress on Palliative Care will be held October 17 - 21, 2016.

R. David Bourke Memorial Lecture

The R. David Bourke Memorial Lecture took place in September of last year during the 20th International Congress on Palliative Care. The speaker was Dr. Peter Fenwick, a Neuropsychologist and one of the world's leading researchers in end-of-life phenomena. Dr. Peter Fenwick is Honorary Senior Lecturer at the Institute of Psychiatry King's College, London, UK. Dr. Fenwick's main interest for some years has been near death experiences (NDEs) and the dying process.

Dr. Fenwick's lecture entitled, "The Art of Dying," captivated the standing room only audience of more than 350 at the Palais des Congrès. His presentation outlined current research and first-hand narratives on NDEs.

His booklet, "Nearing the End of Life. A Guide for Relatives and Friends of the Dying," can be found in English and French on our website, www.mcgill.ca/council-on-palliative-care.

Retrospective

The RETROSPECTIVE, a significant project celebrating 40 years of Palliative Care at McGill was displayed at the Congress as a series of eight panels highlighting milestones of the development of Palliative care since 1973.

A blank panel was available for delegates to submit answers to "my hope for the future of Palliative Care is ..." to which there were 63 responses.

Additionally a large kiosk at the centre of the room showed the current state of Palliative Care globally, pointing out how far we have come but how much further we have still to go.

To DOWNLOAD the PowerPoint version of the timeline, the responses and the global kiosk, please visit the Council's web site.



Wild Messengers (cont...)

through the eyes and gestures of that animal? What other explanation is there for suddenly seeing bluebirds, a favorite of the deceased, over and over again?

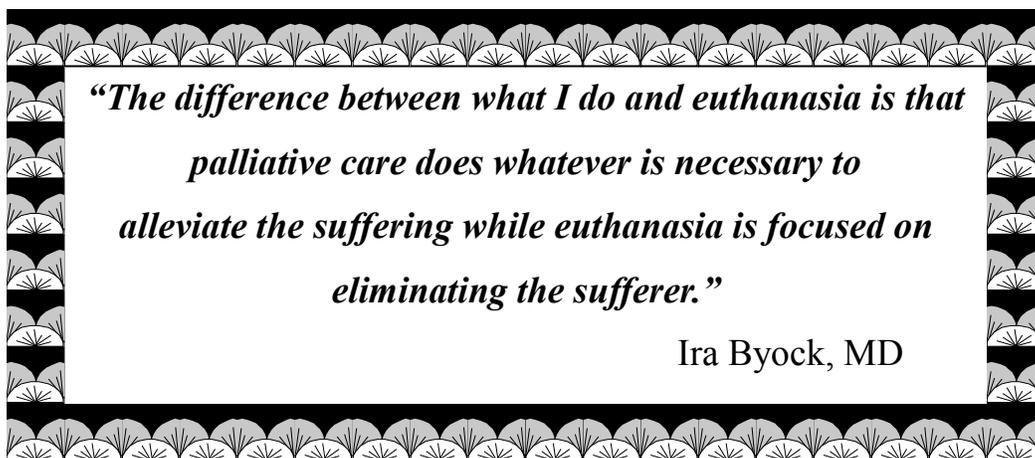
While steeped in grief, our defenses down, it seems we are more open to that kind of thinking. The Buddhist teacher and author Tara Brach says that in some religious traditions, one who is mourning “is considered most holy, is open to that which is beyond this world.”

We also may be subconsciously looking for something we wouldn't normally notice or think important, something that might even have been there all along. And then, there it is, maybe more than once. How strange, how meaningful it seems, that it keeps showing up, that it showed up at all.

One doesn't have to be religious to look beyond oneself for meaning. It is universal to want answers and to crave comfort in times of stress, to want to know that your loved one is O.K. and that you're O.K. without her. If that comfort comes in the shape of a fellow creature, I see that as a wonderful gift. If I were trying to communicate with those I love, I'd certainly do it through something that's beautiful and that breathes, there for a moment, then gone.

My mother may have sent those nine eagles; what a lovely thought. But if she didn't, I'm still grateful for the moment of elation and strength those birds brought me at a time when I felt I had nothing left to give.

Jennifer S. Holland, a National Geographic contributor, is the author, most recently, of “Unlikely Heroes: 37 Inspiring Stories of Courage and Heart.”



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