

Looking Again at the End of Life

by Jane Slemon, Aug 14, 2016, UCV

“In the loss or in the growing, of the things we can’t untie, presently progressive knowing, is the tuning of the why”—These words from Bernard’s song, *For The Time Being* offer the context of today’s heady topic—entering the present moment tuned with a ready question and being open to whatever answers might unfold.

Each year, on my birthday, I give myself a gift that takes all year to unwrap. It’s a single word to accompany me throughout the year, to toy with, write about, and live by. I’ve done this for about a dozen years, and I notice I steer clear of imperative verbs that might feel like a command. Since I’m an August baby, my birthday word arrives while I’m swimming in the bay by my Mom’s cottage. Last August my word arrived reluctantly. By mid-afternoon I was in despair of finding one I could live with for a whole year and said out loud to the cabin walls, “I want it to feel like a present!” And there it was. My word, *present*: at once verb and noun, I thought it intriguing enough to live with. And this year, perhaps especially since I’m director of a 10-bed hospice, watching the *present* situation in Canada unfold—this shift toward accepting Medical Aid in Dying—made me keenly aware this is no small event in our history. In the early 80s, when I was a nurse in an Intensive Care Unit, families and medical teams would often come together to discuss whether, given all their efforts and evidence, we should be continuing to work toward a patient’s survival or whether we should be letting go of treatments that might be *causing* discomfort or that might be standing in the way of a palliative and comfort-based approach. For most families, there was clarity—we could see what we should do and we were comforted that we were supporting the person in the bed in the direction nature was taking them. But not everyone has nature on their side, it seems; sometimes a relatively stable and difficult existence is the problem not easily solved.

Let’s look at what gave rise to this present moment: I began to hear the name Sue Rodriguez in the early 90s; Sue had ALS (or Lou Gehrig’s Disease) and wanted assistance to end her life at some future point when she could no longer move her limbs, or when the

quality of her life would be diminished. While the law had changed in 1972 to state it was no longer illegal to take one's own life, she challenged the Criminal Code, which held that assisting someone else to die was not legal. She famously said, if I don't have the right to decide when I die, then, "Whose body is this?" Sue Rodriguez represented those whose lives posed a conundrum to the medical community. Legally, the country said to Sue, we cannot help you; humanly, they said, we see you are suffering.

I became aware that the BC Civil Liberties Association was challenging the Canadian government with its Death with Dignity lawsuit in 2011, but the story didn't really come alive to me until the group was joined by Gloria Taylor (who also had ALS). They argued that the Criminal Code denied individuals their right to have control over choices that were fundamental to their physical, emotional and psychological dignity. Not having the right to medical aid in dying contravened the Charter of Rights and Freedoms: the Criminal Code, they said, discriminated against those whose physical limitations meant they could not commit suicide. Gloria Taylor was being denied a right to part of her life in that she would be forced to commit suicide while still able-bodied enough to do so. Gloria died of natural causes in 2012 but her life and her question to us made its mark on the present moment too.

Kay Carter suffered from spinal stenosis and went to Switzerland to end her life in 2010. After her death, Kay's family challenged the government—this became the Carter vs Canada case—and the Supreme Court ruled in February of 2015 that Canadians who suffered "grievous and irremediable" illness could appeal to have the right to medical aid in dying. The Court gave the provinces one year to work out how exactly to support this new right, a deadline that was extended to June 6th. Last January, I was impressed by Dr. Doug Cochran, the head of the Advisory Group on medical aid in dying. His group diligently surveyed people from all over Canada, including me as a palliative care nurse and including faith-based groups who made recommendations such as these from the Salvation Army which hoped the government would: "respect the sanctity of human life and protect marginalized and vulnerable people"; "protect the conscience of individuals as well as facilities and the organizations that operate them"; and "embrace this opportunity to

ensure all Canadians have access to palliative care” (*Submission*). The survey presented complex scenarios, asking our opinion as to whether aid in dying should be available to someone, with, say, a painfully debilitating, physically limiting and even disfiguring condition, and then, once our responses were submitted, the question would add to the scenario that the person was 17 and hadn’t yet had conversations with a counselor to discuss ways to cope. That survey took me days to complete. The final wording of the government’s Bill C14 recognizes the “autonomy of persons who have a grievous and irremediable condition that causes them enduring and intolerable suffering.” The bill is careful to state we need “robust safeguards” against error. *And* we need to be offering a full range of options for end of life care. So part of the response to any request for medical aid in dying is to examine what palliative approaches can offer. Some say the bill doesn’t go far enough, but it *is* a step in a changing legal process; it reminds Canadians to advocate for our right not just to more hospice beds and palliative care wards but to palliative approaches within the care Canadians already receive.

Now let’s look at what made the present so hard to unwrap this year, what a complicated the conversation within the medical community: When Canadian provinces were asked how they would implement and organize medical aid in dying, policy makers looked to palliative care doctors: since they were the ones already dealing with the dying, wouldn’t it be easiest to send those requesting it to palliative physicians and hospices? Well, it wasn’t as simple as that. Many palliative care doctors spoke up, saying it’s not the right fit. They would support the individual in talking about their options and referring them to someone who could help. They wouldn’t abandon the patient or even shut down the question. They just didn’t want hospice or palliative care units to be the go-to place for medical aid in dying. Supporting someone through their final months and days, some said, was as different from medical aid in dying as was knee surgery—it’s not what they do, and it may not be what they will do well. On CBC radio, I heard one palliative physician put it this way: “If I am at a resident at hospice and I know it’s a place that offers medical aid in dying, I’ll worry that in a confused moment, I might ask for it. If I associate a certain place with medical aid in dying, I’ll worry about going there.” Palliative care offers people options

toward comfort in our final days, specializing in nursing practices that support not just physical comforts but also emotional accompaniment and spiritual development and openness.

One of the best things a nurse can do is to accompany someone, to be present with them. I suspect every nurse has heard real and heartfelt questions, like *“Can you help me shorten my life? Or, Why do we go on beyond our best-before date?”* In the hospice, we would say something like, *we can’t shorten your life, but we can consider what we might be doing that is lengthening it. Now tell me more about what you are feeling?* We may begin to explore what the question might mean. Is the person suffering pain or discomfort? Are they afraid that pain will come? Or are they worried about being a burden to others? Seeing the question as a window into that hidden place in someone’s heart is an opportunity for communication that might not yet have been available.

This past spring, I heard about Linda from a home care nurse; Linda had been at home and waiting for June 6th and wanted medical assistance in dying. She had thought about suicide too but worried it would bring her more suffering if she didn’t get it right. She was without close family and was worried about the physical pain of dying. Because she’d mentioned suicide, a psychiatrist was consulted and came to see her. But the psychiatrist found Linda perfectly reasonable in her fears and her weighing of the options. When the Home Care Nurse called, I said our hospice would be happy to welcome Linda, if she could accept palliative care, our care of the physical body, of the emotional self and of the spirit. While we could not offer her medical aid in dying, we could accompany her as she approached death, attend to her pain and discomfort, help her to connect to distant family, and work on whatever goals she might think up during her time with us. Linda arrived in an unusual manner—not on a stretcher, accompanied by family and attendants, but alone; she’d turned the key in her apartment for the last time and taken Handi-Dart. She walked to the nursing station and introduced herself, her belongings perched on her walker. Later, she remarked in her London accent on how lovely the garden looked, how the cook had visited to ask what she liked to eat, how welcome she felt. Everything we did made her feel special, not the least the shower and spa treatment. I wasn’t too surprised, as we managed

her pain, that she never spoke of medical aid in dying again. Linda died on June 6th of natural causes.

Early this spring, Kevin asked about receiving medical aid in dying. Kevin was a resident at the hospice but instead of asking his palliative physician, he asked his own family doctor. The family doctor referred the question to the palliative physician, so together we discussed what to do. Why had he not said anything to the physician who saw him every day? Perhaps he worried he'd be jeopardizing doctor-patient trust, as if complaining about his care? Did we have a right to approach him about it? Just the day before, Kevin had sung beautifully at the piano beside the music therapist, his wife and children streaming tears and recording every minute. It was hard to believe he wished to end his life when surrounded by such love, when he had so much joy to give his family. Kevin died naturally but in the days that followed, we learned that as patriarch, he saw himself as no longer helpful to his family, a burden to them. We cannot place a measure on how much emotional pain he was in based on his shifting role in the family, from protector and guide to the one needing their care. Kevin—carpenter, singer, and owner of the biggest smile that ever was bestowed upon our staff members whom he continually commanded to sing and dance for his delight—died naturally and surrounded by family.

In 2015, while considering what rights people should have in deciding when to die, The Supreme Court looked at the so-called the Quebec Model (physicians administering an injection) and the Oregon Model (physicians offering a prescription the individual could fill). With the Oregon model, 60% of people do not fill their prescriptions, perhaps because they are already helped by asking for one and receiving it; along with the prescription maybe they gained from a conversation; maybe someone listened long enough to figure out what was behind the question. Our present model is more like Quebec's and insists on two doctors separately assessing the individual's needs and wishes, assuring that decisions are made carefully and on the basis of sensitive conversations.

At a panel discussion I was moderating in April (2016) on what medical aid in dying means to faith based institutions, retired oncology physician Cicely Bryce was asked how the new law affected her relationship to the Hippocratic oath. The question was this: if doctors vow

to heal and do no harm, then how can aiding someone to die *not* be thought of as harm? Dr. Bryce responded by saying that the doctor is committed to *alleviating suffering* and must find out from the individual the qualities and sources of that suffering; continuing to live might be a source of suffering. She was also asked about society's need to protect the vulnerable. Her response was to consider the complexities of who we consider *vulnerable*. Whole groups of people might be deemed large "V" vulnerable—the marginalized, the isolated, and those with chronic and incurable illnesses—yet many people within these categories may not themselves be truly (or what she called small "v") vulnerable—that is, without the power to speak for themselves and assert their beliefs and wishes. The doctor doing the interviewing must assess the unique complexities of the situation and then, together with the individual, figure out the right course from all the possible choices.

My dear friend Elizabeth uses a ceiling lift to take her from bed to wheelchair; she cannot turn the pages of her book yet still loves to sail in the Disabled Sailing Association's specialized boats, their Martin 16s; Elizabeth is the life of any party, and, at a dinner for 10, our host (a friend who has been hemiplegic since he suffered a major stroke 16 years ago) offered her the use of a cup with a straw so she could enjoy her wine without assistance. But Elizabeth opted for a regular glass and said, "I'd much rather let someone raise it to my lips, thanks." Our host said that maintaining as much independence as possible was important. She said, "Oh but, dependence is an art form. It's going to challenge all of us." Then with a laugh, "So far, I'm *way ahead of all of you* in understanding that." Elizabeth and I have just completed a book—she the brains and I the hands. Elizabeth may be extraordinary in her enjoyment of life. These are her words: "With each step further in the process of degeneration, I am more fully alive. I remember, reflect, regret, reinvent, dream, think, observe, listen. Sing. Hum. All of these and imagination too, are neurological acts". Extraordinary? Certainly. For every person I've heard say, *when I reach this or that inability, I'll be done with life; let me go*, I have also met individuals *with every limitation and* who are still enjoying each day.

do not imagine that the exploration
ends, that she has yielded all her mystery
or that the map you hold

cancels further discovery

Gwendolyn McEwan's poem is dear to me in its imperative that there should be no imperative, no certainty. When we think we hold the map, she tells us, we should keep looking to see what else the landscape yields and be open to it, or to *she* who is teaching us something new. Her poem is a sonnet—the form that asserts a terrific orderliness by its line length and rhyme scheme. But “The Discovery” both calls up and bends those rules.

I tell you her uncovering takes years,
 takes centuries, and when you find her naked
look again,
 admit there is something else you cannot name,
 a veil, a coating just above the flesh
 which you cannot remove by your mere wish

The line, “look again,” three syllables and not the required ten, forces us to notice the terra incognita, the great empty space beside the words, “look again.” Do we know how it will be for us? Look again. In saying, “(burn your maps, that’s not what I mean), the speaker at once takes away and gives us back the image we hold: the imperfect map. She opens our minds to our visions and revisions in the ways we look at our world. If we are a little more aware of the maps we hold, we can begin to question the assumptions they carry. Does the name of a specific diagnosis or condition bring to mind a map of how things will go such that we are frightened even before we have discussed treatment and palliative options?

The form of the sonnet, meaning sound, *sciono* or little song, was created by **Giacomo da Lentino, il Notaro**, or lawyer of the time, around the year 1200, in the service of Italy's Frederick II; he took the familiar 8 line *strambotto* and added 6 lines, but added too the notion that, when the heart is challenged by a complex problem, pressing it into a strict form of meter and sound might just trick the mind into spying a solution. In a Shakespearean sonnet, the speaker bemoans his “disgrace with fortune and men's eyes” wanting to “trouble deaf heaven with [his] bootless cries”; the exercise of the sonnet allows him to work out his envy and finally assert that “For thy sweet love remembered such wealth brings/ That I would scorn to change my state with kings” (Sonnet 29). The rich

rhyme clicks the sonnet closed, solution found. It is the lawyer's conceit: that for every problem there is a solution. But McEwan's poem ends with slant rhyme: "the moment when it seems most plain/is the moment when you must begin again." Plain/again: the slant rhyme bends us toward something more, something less sure, some other beginning. We may think we have the map in our hands--the map of a human life perhaps, or a relationship, or a philosophy—but we may be on the verge of finding some new curiosity that peeks around a corner, that opens another window. If/when we arrive at some life limiting illness, a conundrum of *not dying perhaps, or not dying* as quickly, as peacefully, as simply as we hoped, perhaps then our own imaginations will allow us to live more fully than we can presently, today, conceive of.

Cicely Saunders began the hospice movement in 1967, believing that in caring for the dying, in bringing comfort, we needed also to understand that suffering isn't just physical, but also emotional and spiritual. Suffering can result from bureaucratic woes, from a frustrating navigation of the health care system, or from financial constraints, loss, complex relationships, guilt, two religions competing within one family—pain comes from so many sources. Cicely Saunders knew that families help caregivers to more fully understand the values and beliefs an individual lives by. At the hospice, Ting's husband, who is a chemist, valued evidence-based medicine; he was trying to convince Ting to try chemo once more, at least radiation, and was encouraging her to keep taking the chemo drugs. Ting couldn't speak but she wrote long letters on her lap, expressing her feelings in Cantonese; even so, it took her several days to drum up the courage to say what really mattered: She didn't want treatment; she wanted her husband's intimacy. Simple touch was what her spirit most needed. As she explained this to her doctor through a translator, her husband sat across the room and argued cancer couldn't possibly be caused from lack of touch; his wife was talking nonsense. The doctor listened, assured them that yes a lack of touch wouldn't have caused cancer but that the body's natural chemicals in response to touch, the neurotransmitters dopamine and norepinephrine as well as the hormone oxytocin could indeed effect a decrease in pain and an elevation of mood. The next days were among Ting's happiest at hospice. If we honour and are open to someone's unique values or their philosophy built on a life of experiences—whatever these may be—we can leave plenty of

room for a search for meaning to continue even to someone's last breaths. One fellow, in his last few days was reviewing parts of his life that weighed heavily on his heart. He said suddenly to his daughter, "Oh I get it, God is *love*. You let *love* into your heart!"

Kelli Stadjuhar, *nursing professor and researcher at the University of Victoria's Institute on Aging and Lifelong Health*, is a mentor to many in the world of palliative care. While the headlines spoke of who would be able to avail themselves of medical aid in dying, Stadjuhar's *Vancouver Sun* articles and SFU public lectures reminded us that most won't choose medical aid in dying and that palliative care is what we should be striving for, not just for those at the end of life but for anyone with a life limiting condition, even while they are engaged in curative treatments. Such an approach means we add a focus on palliative comforts alongside curative treatments—not just for those in hospices or palliative care wards, but everywhere people are cared for; it means we discuss palliative approaches earlier in our discussions with medical people and with one another. My husband remarks, "I'm already doing palliative yoga."

A woman at hospice told me what her oncologist had said to her when she declined further chemo treatments—they made her terribly sick and weren't necessarily helping. He said to her, "If you want to end chemotherapy, I'll send you to the palliative care physician next. You won't be alive in 6 months." Hopefully, he was unusual. I know another oncologist who would have spent the next 45 minutes discussing what the patient might most want to do with whatever time she had. Someone who is open to a palliative approach would not have made her feel dropped, let go, or made to feel guilty, as if *she'd failed* curative measures. Stadjuhar says, "People receiving palliative care live longer than those who only get treatments for their diseases. It reduces hospital and emergency room visits, allows people to die where they choose, and improves family satisfaction with end-of-life care." As well, she states, "people receiving palliative care are more likely to find life worth living than patients who are not. Because they are spared severe pain, depression and family exhaustion, they spend a lot less time in hospitals, which is the most dangerous setting for frail older and seriously ill people." So if Canadians can make palliative care the norm, not the exception, if palliative care could be given even the same focus even as, say, pre-natal care, then this legal shift to include medical aid in dying could also become a much more

significant shift in many more lives toward a better quality of life. That would truly feel like a present, a gift to unwrap.

When people create works of to honour the memory of someone's passing, the person remembered *is present* in the work of art. Hearing the light step of Cameron's memorial tune, "Bernie Mathieu," I get an image of Bernie and Linda in their happiest moments at the Vancouver country-dances. At the hospice, Connie was dying of cancer. She and Alan had travelled the world and loved meeting new people; every night Alan brought in one of their albums and they laughed and talked as he recalled their stories. Connie's mother had said to her when she was close to the end, "I'll be dropping pennies from heaven." So Connie told Alan, "All things considered, I'll be dropping dimes for *you*, dear." A week after she passed, Alan said he felt he was living inside a poem, finding meaning everywhere; he was still discovering things about Connie; he had found no less than three dimes in a week; she was present for him. Anywhere a palliative approach is taken, we work to protect our memories of the person by making the very best of the present moment, and truly accompany the individual along a path they have never been down before. We make the most of joyful moments, keep open to discovery, and remind people they've done the very best they can do.

Last April, Sandra Martin published her book, *A Good Death*, and revealed the secret that Al Purdy took his own life 20 years ago. Purdy's wife had been by his side; John Hofsess, founder of the Right to Die Society, supported him in figuring out how to go about it. When BC poet Susan Musgrave found out, said she felt betrayed; the manner of Purdy's death changed the story for her. Hearing that made me realize how important legalizing medical aid in dying is to preserving the story and the memory. The illegal and covert measures Hofsess and others kept secret made the story of Purdy's passing so much darker than it needs to be; we can't know the nature of Al Purdy's suffering. We can't know what his request for legal medical aid would have resulted in. I would rather a system that helps us protect our memory of him and his work. "Whether we are feather or we're stone," choosing *one path* of setting ourselves free *or another*, whether we have the luck of a peaceful passing and a hospice setting, or we find ourselves suffering an unlivable life and in need of another's help, "still our final moments are our own" (Slemon).

“Amos was old and Amos was cold” and Amos wasn’t happy about giving up wool he needed to stay warm. And Amos didn’t sit quietly in his vulnerable state, but took measures to insist on what he needed. Those around him had to learn how to listen to him, read the signs, figure out what the mess he was making all meant before they arrived at their elegant solution. I don’t know what’ll happen for me, but I am deeply comforted to believe people will care for me one day, will listen as I explain what I’m feeling and help me in the best ways possible.

Next week, on my birthday, I’ll be choosing a new word to take me through the year. It should be a word that relieves the last, that I can unwrap throughout the year and invite into my days, thoughts, and relationships, a word to open my mind to discovery. Birthdays remind us of time marching on, and Bernard’s song, *For the Time Being*, reminds us we are all *time* beings, existing in the present. His phrases carry my sentiments for the days I’m alive: “Sing me songs of affirmation, love and life and poetry, ordinary perfect magic, copied to eternity.”

We all know people who face great difficulties in life and in navigating their medical worlds; their stories shape in us strong opinions about this deeply sensitive topic. So, as we hear medical aid in dying spoken of, I hope we don’t shy away from the conversation, from telling others what it’s like to live our lives. And I hope we don’t simply wait until curative treatments fail before we find out about palliative approaches to compliment other treatments. Whatever our dear ones choose for the end of their life, I want us to remember them with a healthy respect for the whole life they have lived. Gwendolyn McEwan teaches me to “look again” at the “map [I] hold” about what end of life means to Canadians. In this new legal context, may we rediscover what caring for one another means, what listening entails; may the present moment expand, not just go by, so we can compassionately accompany one another in that most human journey, the end of life.

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Readings/ songs:

The Discovery

by Gwendolyn McEwan

1969

do not imagine that the exploration
ends, that she has yielded all her mystery
or that the map you hold
cancels further discovery

I tell you her uncovering takes years,
takes centuries, and when you find her naked
look again,
admit there is something else you cannot name,
a veil, a coating just above the flesh
which you cannot remove by your mere wish

when you see the land naked, look again
(burn your maps, that is not what I mean)
I mean the moment when it seems most plain
is the moment when you must begin again

Feather and Stone

by Jane Slemon 2016

A feather we saw floating over land
A stone you found for me upon the strand
Things come free, they are like grains of sand
Falling from the fingers of my hand

If you stay or if you don't
If you wait or if you won't
I am standing right here by your side
With all I know about you safe inside

You say to me that you are nearly done
You have completed all your tasks but one
You'd like your soul to be the skipping stone
And disappear into the setting sun.

If you stay or if you don't
If you wait or if you won't
Either way, my heart will be the same
I'll speak of love when I speak your name

You said goodbye and now you'd like to go
You're not afraid; sweet eyes tell me so
Whether we are feather or we're stone
Still our final moments are our own.

If you stay or if you don't
If you wait or if you won't
Love is still that feather floating free
Your story's still a stone found by the sea.

