

CONTEMPLATING THE END OF MY LIFE – REFLECTIONS ON LIVING AND DYING AS PARLIAMENT DEBATES MEDICALLY ASSISTED DYING

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John Buttars (bjbuttars@sympatico.ca)

Welcome...and a profound thanks for coming this evening and entering into this conversation. This will be an exercise for the heart (because it is a very challenging topic, a tear jerker sometimes) and an exercise for the mind (because we are going to look at it from various angles).

Format for the evening...hand out sheet...two times to talk with each other and if time I will respond to questions.

A little over two years ago I was asked to make a presentation to Guelph's Third Age Learning on the right to die, a euphemism at the time for physician assisted dying. We were waiting at the time for the Supreme Court to rule on the issue but once it did a clock started to tick. The Harper government dragged its feet but established a commission to investigate. There was a federal election with a Liberal majority which established a Parliamentary committee co-chaired by Rob Oliphant, a United Church minister incidentally. Their report entitled "Medical Assistance in Dying: A Patient-Centred Approach"ⁱ called for a broad law but the Liberal government actually presented to Parliament was considerably narrower in scope. Within 10 days of the bill passing into law it was challenged by Julia Lamb of Chilliwack, B.C. who is arguing that Bill C-14 "has robbed her of her right to a timely assisted death by restricting that right to those whose 'natural death has become reasonably foreseeable'."ⁱⁱ In addition, you may have noticed that obituaries are starting to include wording that the deceased was aided in their dying. In a news story of early October, it was reported that at least 374 people have received assisted death in Canada.ⁱⁱⁱ So, here we are. Where do you find yourself on the subject?

As I explored this topic I began to believe that what might be most helpful is not a talk arguing the pros and cons but a talk encouraging conversation. What prompted this was medical writer Andre Picard arguing that "In Canada, the...debate is long overdue. It's a discussion that needs to happen in the courts, in Parliament and, above all, around all our kitchen tables."^{iv} And in the quite marvelous book, *Being Mortal* the American surgeon Atul Gawande notes that in La Crosse, Wisconsin, all entering the local hospital are required to complete a form asking the following questions (Resource Sheet, 1st page, #3 towards bottom of the page):^v "Do you want to be resuscitated if your heart stops? Do you want aggressive treatments such as intubation and mechanical ventilation? Do you want antibiotics? Do you want tube or intravenous feeding if you can't eat on your own?" Significantly, it is not the written answers that have been crucial but the conversations that have been generated, such that their end-of-life costs have been lowered to half the American national average. Here in Canada, the Senate

Subcommittee report of June 2000, "Quality End-Of-Life Care: The Right of Every Canadian," notes that Advance Care Directives are most useful, not as legal documents, but "...as part of a planning and communication process that helps people prepare for death in the context of their loved ones."^{vi} Sandra Martin in her recently published book on the topic has stated, "If we want choices, we need to think about what matters to us and discuss our wishes and our fears with family, loved ones and the doctors and lawyers who are entrusted with our lives and our affairs."^{vii}

Sandra Martin is the author of countless obituaries and in a *Globe and Mail* article wrote, "Have you noticed how few people seem to die these days."^{viii} Some months ago I was looking at the obituaries in *The Globe and Mail*. Not one of them used the word "died." Most "passed away peacefully" but some didn't even say that, not even "predeceased by." It reminded me of being called to the cardiology unit at the Toronto General Hospital during my chaplaincy residency. A man had collapsed on the street and as the on-call chaplain I had to go through his belongings and track down his family. Later with three doctors, his wife and daughter crowded in a circle, it was left to me to deal with all of them. The doctors had lost the battle and were silent. The daughter said over and over, "He's asleep, he's asleep, Mom." "No," me, the chaplain said in response, "I'm sorry, he has died."

We are surrounded by dying and death. Just look at the trees and gardens at this time of year. That I am going to die is a fact. The same for you. We live in a world saturated with human deaths--suicide bombings, car crashes, planes dropping out of the air, cancer, old age. The 20th century was the bloodiest century in human history, filled with industrial war. The beginning years of the 21st century have been increasingly scary. An unknown Japanese author wrote: "I have always known that at last I would take this road, but yesterday I did not know it would be today."^{ix} How many of us have been with a person in the last hours or minutes of their life? I don't know about you but I have been riveted to their breathing, one agonizing breath at a time. When that last breath comes it feels as if their very spirit has left, a husk remaining. Indeed, if I am correct, the Hebrew word for breath is the same word for spirit. So in beginning tonight I invite you to take a moment just to breathe consciously, to be grateful for our breath and our ability to breathe, to be grateful for here and now. For this one moment just breathe and unite ourselves to each other in this venture that we are undertaking tonight to contemplate the end of our life.

Here's the challenge. We don't like talking about death. We live in a death-denying, death defying society. On the day I gave the talk in February 2015 for Guelph's Third Age Learning an article in the paper began, "Doctors say that when patients are seriously ill, the main obstacles to discussing what the goals of care should be are family disagreement and patient denial."^x And Dr. Brian Goldman on CBC Radio 1 reported on a very careful study where terminally ill patients were shown two videos, one of a doctor hedging the truth to make it more palatable and a second doctor being more clear and forthright. The terminally ill patients trusted, trusted the doctor fudging the truth over the more honest and straight-forward outline of the truth.^{xi}

In a talk at War Memorial Hall (30 October 2014), the Irish philosopher and theologian Peter Rollins picked up on the phrase, “The truth will set you free” (John 8:32). He substituted the word “truth” with “ghosts,” “the ghosts will set you free.” What you don’t or won’t talk about, if you can raise them up to the surface will bring freedom. So what are the ghosts needing liberation in your life, in your family, whether having to do with illness, death and dying, or any number of other issues? All the Twelve Step programs, from Alcoholic Anonymous to Emotions Anonymous, are based on naming the ghosts. “Because of alcohol, my life is unmanageable.”

To talk about something makes it more real. One of my mentors, the Rev. Bob McLean, shared with me a life truth that I have found profoundly helpful: “I know what I know only when I say it.” One of my grandchildren did something they shouldn’t have done. They were asked, “Did you do that?” Of course they did because we saw them do it but for them to admit it would make it not just real but really real. How many of us have exclaimed in emotionally charged circumstances, “I don’t want to talk about it” when we fear we might ‘flood’ because the saying it in words makes it “realer.” The emotions flood up and we cannot get a word out; men more than women are prone to flooding.

In addition, there is a whole school of thought that has developed a theory of terror management, managing our visceral terror of dying.^{xii} We humans are unique in that we know about death in a way that maybe our pet dog or parakeet doesn’t. If to talk about something makes it really real and we are terrorized by the thought of dying, why not just talk about...anything else. Moreover, there are two other aspects. First, although we humans love change we absolutely hate loss and to die is to lose big time. Second, assisting someone to die crosses a line in the sand for humans: We are not to take another life.

With that long introduction, let’s start with “right to die” and “dying with dignity.” They are euphemisms for a reality, a quality which I, for one, want to support, but they don’t describe what is actually being promoted in terms of process. As I researched and thought about this topic I finally decided I needed to be upfront about two words, suicide and euthanasia. I dislike euphemisms because I fear people might be trying to hide something. Euphemisms camouflage truth, like supporters in Quebec arguing that “medical aid in dying” is really part of health care.^{xiii} That’s not how it felt when we put our dog down; health care was going to the vet and bringing him home alive. I think we could take a leaf from educators in the field of sexuality who use anatomically correct language. If it is a penis or a vagina, call it that. Barbara Coombs Lee,^{xiv} a proponent of assisted dying convinced me that being accurate in description was being responsible and that it was important to take responsibility for our actions, our personal actions and our corporate actions as a society. This really spoke to me because of the death of my sister. I used to say that she died in a car accident. Gradually I changed my language to, “She was killed in a car crash.” I understand accidents as unavoidable. But the truth is, as long as we call them car accidents, accidents just being chance events, unavoidable, we never face the public health issue that we have had for 100 years, people getting maimed and killed because

of engineering design, distracted drivers, alcohol and drugs, speeding, because of a whole host of actual preventable causes. Clarity in description paints truer pictures.

Suicide is “the intentional killing of oneself.” Suicide is not euthanasia. The difference has to do with who does the very last act. Suicide is not a description of the state of mind and heart of a person. Literally, it describes an action. Is the person picking up and swallowing the pills or pushing the button on the mechanized injection? Then it is suicide. Is it a third party who does the last act? Then it is euthanasia.^{xv} It is assisted because, first, society has decided through Parliament and the courts that there will be a system by which individuals can exercise their autonomy and choice to end their lives under certain specified circumstances and second there is a person or persons who prescribe and deliver a drug that will cause the death.

I acknowledge using the word “suicide” is very tough because in society there is shame attached to suicide. For all of you who have had a suicide in your family or with friends, you will know it is a death like no other. I know that personally because of the death by suicide of one of my partner’s uncles when he was in his 80’s. Family and friends sometimes feel guilt, as if they have failed. In every instance where I have been involved with a suicidal person my instinctive reaction has been to prevent the suicide and get medical help. In the Bible, King Saul is not condemned for dying by suicide (I Samuel 31: 4) after his armour bearer refused to kill him. St. Augustine argued that the commandment, “Thou shall not kill” applied to any act that hastened death and St. Thomas Aquinas reinforced that by extending it to one’s own death. The Catholic Church allowed exceptions to this absolute prohibition by making intention supreme and developing the idea of “double effect.” “Double effect” absolves a person from responsibility for a death if the primary intent is an acceptable outcome. Thus, if the accepted outcome is relief from pain and suffering then the act is accepted, like giving medication that puts a person into a coma that results in suppressed breathing and no more eating or drinking. In addition, it has been argued that the commandment “not to kill” is really a commandment “not to murder,” that is not to kill another human being illegally, wickedly or inhumanly.^{xvi}

As tough as it is, let’s stick to suicide and euthanasia for a moment in the context of Bill C-14. By using the more politically correct language of medical assistance in dying (MAID for short), we may avoid the public health issue of suicide in our country. Bill C-14 declares that “vulnerable persons must be protected from being induced, in moments of weakness, to end their lives” and that “suicide is a significant public health issue that can have lasting and harmful effects on individuals, families and communities.”^{xvii} On the day before Bill C-14 passed in the House of Commons Justice Minister Jody Wilson-Raybould said, “The bill achieves the most appropriate balance between individuals’ autonomy in deciding how their death will occur and protection of vulnerable individuals, as well as broader societal interests. These interests include suicide prevention, equal valuation of every person’s life and preventing the normalization of death in response to suffering.”^{xviii} One of the things we know about suicide is that one suicide can produce social contagion. In 2009, a 32-year old German soccer player, Robert Enke, jumped in front of a train. A study published two years later noted that railway

suicides in Germany spiked by 117% in the following 28 days. The same happened in 1998 when a Hong Kong woman died by suicide by burning barbecue charcoal in an enclosed space.^{xix}

Here in Canada, consider this news item of a few weeks ago: *“A new survey of Canadian university and college students finds many have struggled with mental health issues, while a disturbing number have also faced unwanted sexual advances and assaults. In the area of mental health, 46.9 per cent of students considered themselves to be “flourishing,” meaning they were experiencing positive mental health.*

But others were struggling with mental health:

- *18.4 per cent of respondents reported having been diagnosed or treated for anxiety in the last year*
- *14.7 per cent had been diagnosed or treated for depression*
- *13.0 per cent of students reported seriously considering suicide within the last 12 months.*

The results were released on the same day that a new [survey from Kids Help Phone](#) suggests that one in five Canadian teens has seriously considered attempting suicide in the previous year.

The survey found that 22 per cent of more than 1,300 respondents thought about taking their own life, and almost half had also formulated a plan.”^{xx}

About 3600 people die by suicide each year in Canada.^{xxi} In addition with the report of The Truth and Reconciliation Commission, we have an opportunity to truly begin a different journey with indigenous peoples. To do so requires our facing suicide openly. “Among young Indigenous peoples age fifteen to twenty-four, the suicide rate is five hundred per one hundred thousand people, almost fifty times the rate for this age group nationally.”^{xxii} On what basis do you say that a person at age 67 with ALS or brain cancer is eligible for assisted dying but not a person who is 18 and living on an Indian reserve, consumed by loss of hope plus violence and abuse, a tragedy maybe generated by the decades of residential schools that have gutted both individuals and the community?

Let’s also be clear about palliative care which is “aimed at alleviating suffering – physical, emotional, psychosocial, or spiritual – rather than curing.”^{xxiii} The goal of palliative, whether at home or in a hospice, an institution dedicated to palliative care, is to improve the quality of a patient’s last weeks, days, hours by offering comfort and dignity while addressing all symptoms of the illness. Palliative care neither hastens nor postpones death.^{xxiv} In the book *Physician-Assisted Dying*, the editors, writing in favour of assisted dying, state that their position “...is...not...an alternative to excellent palliative care but as a last resort for those relatively infrequent cases in which palliative care becomes ineffective or unacceptable to dying patients

whose conception of dying well includes some measure of control over the circumstances of death.”^{xxv}

The ultimate reason we are having this conversation in Canada is because of the recognition of a conflict. On one side is scientific-technological medicine which is geared to fight the enemies of illness and death with no built in limits. This is absolutely key: There are no built in limits to modern medicine; one more thing can be tried. We now know that many patients at the end of their lives receive treatments they don't want and which unfortunately make their lives more miserable.^{xxvi} This even has huge financial consequences. An American Pew study discovered that “In 2010 Medicare paid \$55 billion—more than the budgets for the Department of Homeland Security or the Department of Education—for doctors and hospital bills during the last two months of patients' lives, and about a third of the treatment they paid for had no meaningful effect.”^{xxvii} On the other side of technological medicine with no built-in limits is death that always, without fail, wins. We are caught, as Atul Gawande notes, between two polarities neither of which we want to cause or experience – prolonging suffering or shortening valued life.^{xxviii} How to drive between those two goalposts?

One way to start driving between those goalposts is to talk. Significant conversations matter. To facilitate such conversations I have been finding questions bubbling up within me that are found on the sheet you have received along with a short list of resources. I begin with broad general questions because my mind always wants to put an issue within a panoramic perspective.

First, what specific memories, fears, opinions, stories do you already have stored within you? My mom with Alzheimer's disease, my sister-in-law with aggressive breast cancer, both deaths shape my response to this topic. I also have thoughts about dying alone because of my mother-in-law. She lived the last three years of her life in Guelph and one day Stone Lodge called wanting family to come. As I sat with her she opened her eyes and said, “Go home John.” She died a few hours later on her own as she wanted and counter to the accepted wisdom I was taught in chaplaincy that no one should die alone. Past experiences and memories shape your responses to any health crisis and to all questions surrounding death and dying, even if those past memories are not similar to the situation being faced in the present.

A second global area is to think of the story out of which you live your life. I easily panic when unable to get my breath. As an asthmatic child I learned to catastrophize when illness strikes. I jump to, “This isn't going to get any better.” But is that inner self-talk true? Actually, the truer story out of which I live my life is contained in the image of gift. Life is unbelievable gift with amazing abundance. In contrast, our culture actually has a story of scarcity and almost every advertisement we see or hear emphasizes that scarcity. If we would just buy this car, put on that makeup, eat this food, or drink that product, then there would be abundance, happiness, joy, beauty, or fulfilling relationships. So what is the self-talk, the internal story you tell yourself either consciously or unconsciously out of which you live your life because that inner story will influence your dying?

Here's the weird thing: Being forthright about my dying has a positive side. As Steve Jobs says: "Remembering that I'll be dead soon is the most important tool I've ever encountered to help me make the big choices in life. Almost everything—all external expectations, all pride, all fear of embarrassment or failure—these things just fall away in the face of death, leaving only what is truly important. (Dying) is life's change agent. It clears out the old to make way for the new."^{xxix} After my father died, I overheard a member of Harcourt Church say that she had noticed my taking on aspects of ministry with a zest and energy that she had not detected before and she could only put it down to the impact on me of my father's death. That chance overheard comment got me thinking about not just grieving my dad's death but also about the legacy that he had given me in his living and in his dying. A 50 year old man said, after losing a very significant job, "It was the best bad thing in my life. I feel like a new person." In the *Guelph Tribune* there was the story of 30 year old Meghan Andrews who has published a photo book *Huntington's Disease: Trials and Triumphs*. After her father's death by Huntington's, Meghan decided to get genetic testing and was shocked that she has it. "Once the news had settled in, Meghan started to live her life in the here and now. She traveled...began a successful photography business...and volunteered at the Huntington Society of Canada."^{xxx} These stories are counter-intuitive but they come out of the realization that every end has a beginning. If one's life can be given away, can one's death be given away? Printed on the wall towards the end of the Alex Colville retrospective at the Ontario Art Gallery were the words, "I think of things as beginning rather than ending."

Don't get me wrong. I don't want to die and am intent on avoiding it for a long time. However we actually live our lives within a cascading round of beginnings and endings. Our bodies are amazingly complex with our taking our first breath but it takes more than twenty years before our brains mature and then by age thirty the peak output of our hearts starts to decline. Sexual functioning declines gradually over a very long time. So does bone loss and acuity of our senses. Our bodies fail, randomly, gradually. It is wear and tear and as Felix Silverstone says, "We just fall apart."^{xxxi}

It is not 'we are born, live and die.' Millions of cells in our bodies emerge, live, die and are replaced by other cells. And every day is filled with countless beginnings and endings and at least in some spiritual traditions it is argued that how we navigate the multiple daily beginnings and endings informs how we will navigate our final ending in death. Think about all the meals we eat. They all begin and end but every morsel that enters our mouths ends something, like the carrot that crunches between our teeth. Can you imagine this prayer before a meal: "From the death of these plants and creatures of the earth and sea comes the new life of this food on our plates. So we give thanks for life and death." So are you able to treat all the daily endings and beginnings of your life as countless rehearsals of your final ending when your heart finally stops beating? And in that regard, Ronald Rolheiser argues that we are all given a palliative sentence and how we respond to it matters,^{xxxii} the palliative sentence given right from birth, and the one moral imperative, he argues, is not to die angry or bitter^{xxxiii} and you sure don't

work that one out in the last weeks of life. The paradoxical truth is that the more we are able to face our dying the greater capacity we have for joyful vibrant living.

(At some point, we have to get to the specific ghost of our own dying and death. But we are about half way through my talk and a little ways down on the handout and I am wondering if we might take a few minutes and have a conversation with those around us, just little groups of 2 or 3, no more than 4 because it is going to be noisy unless nobody says anything. I suspect you are going to have to get close to each other to hear. If you are in a family unit, you decide how many can be in the group. And if you don't want to talk, you want to just be, just say that to your neighbor. So a few minutes talking break and if the handout helps in the conversation, by all means use it. And feel free to stand up and get off those hard pews, even have your conversation standing.)

Some days after my sister was killed in that car crash when I was in my last year of theological studies I was sitting in our apartment in Kingston and this blackness swept over me, a cold chill rising up my spine, a black void, a pure terrifying atheism. It is an experience that every once and a while still visits me and it chills my soul as nothing else. I know viscerally I don't want to die. I know how I don't want to die. It is a terror to contemplate my dying. Please God, not drowning whether in a lake or by pneumonia, not in a fire, not in a car crash like my sister. Yet we all get clues of how we might succumb. One person approaching 100 said to me, "I always knew my adrenal gland would get me in the end." I know because of family history my respiratory and circulatory systems are vulnerable and with my mom there is always Alzheimer's out there beckoning.

We need to plan for the inevitable. We all know of our need for wills and powers of attorney for property and personal care but if I were to name a few resources that I would encourage all of you to consider looking at it would be the website, "Advance Care Planning" (the first website listed) and three books by Shirley Roberts, Atul Gawande and Paul Kalanithi. At a minimum, they would help prepare us for the role of being an advocate either for ourselves or for another. The medical system is a system, a complex bewildering system, and once you have a diagnosis you get fed into unfamiliar territory. Do you have a sense of a patient's rights and how you might function as an advocate who can play that role without falling into, on the one hand, passivity and defeat or at the opposite extreme, anger, cynicism or bitterness? In preparation, I talked to a number of people including Lynda and Keith Marsland and Rosalind and Keith Slater, both men when I talked to them on what the system calls "life support," both living at home and finding meaning, purpose, even joy in their limiting circumstances. Both families talked of the significance of being an advocate or having an advocate. For Lynda it was easier being a nurse but Ros has learned the role too. It is no easy task to stand up to doctors, nurses and anonymous administrators and demand attention, demand that they relook at tests already done, demand that no more tests be done until this question or that issue be resolved. Modern medicine has a built-in momentum with busy people caring for a multitude of patients. It is not geared necessarily for taking the time to just be with people and provide the time for

the issues to surface and be worked through. And medicine is actually an art based on probabilities and statistical averages. I have seen that strange art/science dance as I go to my endocrinologist who discusses my bone health based on statistics of post-menopausal women, a category I don't quite fit.

But at some point we have to listen to those who support assisted dying and they do so for three principal reasons: Mercy, non-abandonment, and autonomy and choice. I want to talk about all three.

Mercy for those in pain and suffering: First, there are some in the palliative care community who argue that all pain and suffering can be mitigated. The assisted community argues some pain and suffering is simply pointless. If you have watched Dr. Donald Low's video recorded just before his death there is a poignant moment where he asks us to imagine ourselves in his ravaged body. One article that I read suggests that 95 to 98% of pain among those terminally ill can be adequately relieved. That is amazing unless you are one of the 2 to 5%.^{xxxiv}

I think there is something to be learned from some of the spiritual traditions where pain and suffering are distinguished, pain being what we experience in our bodies and suffering what our minds do with pain. You hear of athletes competing with torn muscles, illness and broken bones. We call it mind over matter but there you have it, the distinction between pain in our bodies, suffering what our mind does with the pain. On a June day my 43 year old sister-in-law finally had in her hospital room her birth mother who had given her up at age 13, her adoptive mother and her mother-in-law as well as her children and some other family members. After everyone had gone she said to her husband that the pain was too much, more morphine was given to her and she died the next day. By having all those strands of her life tied together she had completed her life. I wonder whether her mental/emotional suffering overwhelmed her, not necessarily her bodily pain. I have had the same sense with people who, in their depression, die by suicide. The pain of depression has been dealt with for years and for those who have experienced mental illness you know it is felt not just in the mind but also in the body but sometimes the mental and spiritual energy to battle against the suffering is overwhelmed. I have no need to think badly of the person who dies by suicide but only grieve the loss. I think it must be said, if it is true that suffering is what the mind does with the bodily pain then there is no drug that can deal with that. I for one am not going to fault anyone who finds that they have run out of resources to battle their suffering. I mean, the end of our mortal life is always death and mercy, compassion and deep caring can be our only response.

In using those words, however ("mercy, compassion and deep caring"), I am raising up the significance of life-giving relationships. Years ago, I was called in the evening to a home where a person, in their 50's, was dying of cancer. The caller told me that their spouse was in unbearable pain and that the nurse said she could do nothing more. Could I come over? Ministers, priests, elders, chaplains, padres, rabbis, imams all have experiences of being called in when no one else can think of what to do. So I went and not able to think of anything else I read from parts of John's Gospel, slowly, quietly, meditatively and after 20 or 30 minutes the

patient was no longer agitated. I recognize that was in the days when pain medications were measured out fearing a person would become addicted, a concern that is no longer felt in the same way. But I went to that home not as a stranger. I had a deep relationship with every member of the family, including the dying person. That is so different from so many relationships in our present medical system which are often with strangers, fragmentary and short. This is not to fault those who work within the health care system for my experience is they provide excellent, even superlative care, but it is humanly impossible to have deep sustaining relationships with a host of people. Being with someone, just sitting in silence with a person with whom you have a deep relationship can speak to the mind and heart and change the course of physical pain.

But, if mercy is paramount, when does the merciful act of ending a life happen? Bill C-14 says when “natural death has become reasonably foreseeable.” It’s tricky. For instance, how do you define terminal, unbearable suffering whether physical or mental, incurable debilitating, severe and enduring distress, hopelessly ill, poor quality of life, end of life, all terms that have been used in this debate? The spouse of Dr. Donald Low, in an interview on the CBC, said that she believed her husband would have taken a lethal drug 8 days before he actually died. The Royal Society Expert Report on *End of Life Decision Making*^{xxxv} defined end of life beginning with any serious diagnosis or injury. How many of you have today a serious diagnosis or have experienced an injury? Do you consider yourself in the “end of life” stage? Some people live meaningfully for years after terrible injuries or with a life-threatening disease. Just think of HIV/AIDS or cancer. In my own family experience my mother would fit into all of those categories with her Alzheimer’s disease and yet when she had the disease but still had intellectual competence I question whether she would have chosen assisted dying. What I don’t know is whether my mother would have signed in the early stages of her Alzheimer’s an Advance Care Directive that would have allowed euthanasia nor, at the moment, can I get my head around how I would deal with such a Directive. The Right Rev. Gary Paterson, former Moderator of the United Church, has written in favour of assistance, although never as a first choice but he recognizes there is great moral ambiguity with situations like dementia.^{xxxvi} The medical writer Andre Picard has written about the extreme ambiguity around assisted dying with mental illness and dementia. He would not support an Advance Care Directive be turned into a legal document that results in an assisted death after the person is deep in dementia.^{xxxvii}

The criteria of mercy is not straight forward. Non-abandonment, the second defense for assisted death, is. It refers to medical personnel staying with a patient to the end. The argument is that if a patient is overwhelmed by their pain and suffering they should not be left to endure it without help. Jill Kannegiesser of Toronto wrote in *The Globe and Mail*, in response to a letter from Dr. I. M. Wilm of Guelph, “...the elderly don’t necessarily want unnecessary medical intervention when the quality of life is gone. I just watched for 11 days as my aged mother starved herself so she could die. It was undignified and cruel. How archaic that she couldn’t be offered the compassionate option of medical intervention for assisted passing. It is time for change...(for) moral courage.”^{xxxviii} This could be understood as an

example of abandonment, a woman determined to die. We can well ask, “What was gained or learned by this 90 year old woman living 11 more days?”

Which brings us to autonomy and choice: Autonomy refers to personal freedom and freedom of the will and choice refers to being able to do what we select and live with the consequences. For the last 30 years or so, I have been one of the people who cooks in our family. When I am in the kitchen Barbara has given me autonomy by generally staying out of the kitchen. Sure, I make a bigger mess, use more utensils but I am in charge and being autonomous I get to live with the consequences of my choices. Keith Slater (one of the people I interviewed and who died February 2016), has written a book called *The Joys of ALS: finding happiness in a dark place*. He writes, “...about seven years after the symptoms first began to be evident, I have reached the stage where I can’t breathe, speak, eat, or move any part of my body without considerable help from machines and other people. I have chosen, in a phrase coined by Rosalind, to **embrace** the illness. That is, I accept it as a normal part of life, to be tolerated and dealt with in the same way as any other inconvenience.”^{xxxix} I cannot think of a more striking example of the significance of autonomy and choice. Keith chose to embrace his illness. Interestingly, my own doctor reported to me “that when people are given the choice and the means to end their lives...they often do not choose to do so which says that autonomy to choose is very important and that pain is complex and often complicated and exacerbated by fear and loss of control.”^{xl}

Atul Gawande argues in *Being Mortal* that everyone needs to be “the author of their own lives.”^{xli} In particular he provides five questions that he learned from Susan Block, a palliative care specialist, questions that so struck Barbara and me when we read the book that we recorded them separately for future reference because we know we will need them and probably need them more than once.^{xlii} (You will find the questions on the back page, number 5, of the resource sheet.)

- What do you understand the prognosis to be? Or what is your understanding of your situation and potential outcomes?
- What are the concerns you have about what lies ahead? Or what are your fears and hopes?
- What kinds of trade-offs are you willing to make and not make?
- How do you want to spend your time if your health worsens? Or what is the course of action that best serves your present understanding?
- Who do you want to make decisions if you can’t?

To deal with these questions is to exercise autonomy and to make wiser choices, be the author of your own life. Those questions become essential when we need oxygen at home, when the chemo fails, when we face high-risk surgery, when liver failure keeps progressing, when we cannot dress ourselves, when there are falls, when...? When would you have conversations using these questions? For instance, I wished my doctor had asked me, when discussing a

change in medication, “What is your understanding of your situation.” I could have answered that question. Instead, he asked, “What do you think about going on this new drug?” Yikes, I’m a medical layperson. How do I answer that.

The tricky thing is how to balance autonomy and choice with society’s obligation to protect the vulnerable. We have a long tradition in our society of empowering physicians, for instance, to intervene with a person with mental health issues and obtain a time-limited hospitalization. Humans have an almost unlimited ability to dehumanize each other and to prey upon the weak and vulnerable. Think Nazis in Germany, fundamentalists in Syria or Nigeria or France. The McGill ethicist, Margaret Somerville, is reported to have said at the Centre for Clinical Ethics meeting in Toronto that an Australian politician declared to her that when you are past your “best before” date you should be disposed quickly and cheaply.^{xliii} I, for one, quite reject such a utilitarian view of life. It assumes that being no longer productive means that we are no longer of service. Although I never got used to feeding my mother the last year of her life, at the very same time, it was an opportunity to meet her needs and to thank her for the price she paid in bringing me into the world and helping to raise me. Who among us has not felt blessed by simply helping another person? Being non-productive gives other people the opportunity to exercise their humanity. We must maintain the sanctity of human life or if you don’t like the word “sanctity” because of its religious connotations then profound respect for human life. For me, it is not either personal autonomy with the individual being supreme with choices or the need for society to respect human life. It is both/and, both we honour individual autonomy and personal choice, even the autonomy of the helpless and vulnerable, and society’s need for respect of all humans but those two can potentially be in deep conflict.

If you become a patient in a hospice or are at home receiving palliative care this to help you not die but to live your life as fully as possible and thus to have a good death. Life is difficult and death can be distressing and ugly. And we live in a society that is youth-focused and wants to make things pretty. Consider the day you were born. It was not a peaceful affair. There was blood, sweat and tears that brought you into this world. Since our births, we have all struggled. Our bodies are wired for survival and will not give up easily. The goal of autonomy is to live a life as meaningful as possible as close to the end as possible. From Atal Gawande: “...as our time winds down, we all seek comfort in simple pleasures—companionship, everyday routines, the taste of good food, the warmth of sunlight on our faces. We become less interested in the rewards of achieving and accumulating, and more interested in the rewards of simply being. Yet while we may feel less ambitious, we also become concerned for our legacy. And we have a deep need to identify purposes outside ourselves that make living feel meaningful and worthwhile.”^{xliv}

Our legacy depends on the choices we make including the choices we make in the living of our dying. I find myself, on the one hand, leaning towards accepting assisted dying but I know I agonized over putting our dog Fraggie down. To go through the same process for myself or for my loved ones, wow, this takes guts to talk about. But that’s what we have to do. The choice

of assisted dying cannot be a response to fear. Nor can it be a response to a utilitarian view of human life nor an attempt to avoid the unpleasant and ugly. Nor, strangely, can it be simply a way to avoid pain and suffering. Paul Kalanithi, author of *When Breath Becomes Air* (a book that I would encourage you to consider reading), died at age 37. He was a neurosurgeon and his oncologist was adamant that he had to figure out what was most important to him.^{xlv} As Kalanithi says, "...the easiest death is not necessarily the best."^{xlvi} I suspect he would support the Rev. William Huntington who spoke to the people of Grace Church in New York City in 1901, declaring, "the Stoics betrayed themselves when they sanctioned suicide as the brave man's last resort. For what kind of courage is that...which can be brave enough to die, but confesses itself, under some circumstances, not brave enough to live? As old age draws on, with its prospect of isolation by bereavement, its prospect of increasingly bodily infirmity, its prospect of waning mental powers, its prospects of declining influence, the man is brave indeed who puts on a bold front. This is more than physical courage, because it includes physical courage. It is physical courage plus."^{xlvii} I would personally want to add that whether I die with assistance or without, it takes "physical courage plus."

We can make choices now while robust and healthy in the living of our dying. Those choices we make today will be part of the legacy we leave our loved ones and the larger community. If we don't talk about it with our family we are choosing a particular path and I would suggest it is a foolish path. For Christmas 2014, I gave my daughters each a copy of the book *doris, inc.* I wished I had had such a book 25 years ago when my parents were starting to deal with serious health crises. Just in that act, hopefully years before I die, I am facing reality and asking them to face reality, a small example of living my dying today.

As we come to the end I have some final comments. First, researching this project has caused me to think about our Canadian health care system. Just what kind of system do we want? Besides having the best hospital and physician care as possible what about education and prevention, pharmaceuticals, end-of-life, palliative and hospice care, dental care? We are proud of it but read Jeffrey Simpson's *Critical Condition*^{xlviii} and you realize that we do not have the best medical system in the world, just better than the American one. We need a healthy debate, adult discussions about our health care system, not just turning money over to the provinces for them to sort it out.

Second, I want to acknowledge that the faith traditions find themselves all over the map on this debate. I have numbered the resources and two websites, 8 and 11, provide, as two examples, different responses to the issue. What I have not talked about is how one's faith can inform one's view on dying. It can help and it can make it worse. Christianity that emphasizes a judgmental God makes it worse, for instance.

Third, when you read the obituary page in the papers you notice here and there, "no funeral at the request of the deceased." I actually take strong exception to that and not because I am a minister or support traditional funerals. I am glad we rarely have funerals like I used to conduct when I became a minister 46 years ago. I was delighted when other people began to share

their memories in services or families got creative in honouring their loved ones. I am responsible for deciding how I wish my body to be disposed – cremation, burial, donation. It is my body. I have no right to inflict my choices on those who will be left behind regarding how they grieve and honour my life. I have no prior knowledge of the impact my death will have on anyone and it is they who need the freedom to decide how to both honour me and grieve me. They need the freedom to make choices that make sense to them. I may have some ideas to offer but I am hoping my family and friends will treat them lightly and not as obligations.

Fourth, I support the narrow definition in Bill C-14. First, we need to improve palliative care in this country. Second, I am an evolutionist. I believe it is important to learn from experience. Start small is my general rule of thumb, learn as you go, expand if it seems appropriate. I would be very reluctant to see mental illness included as well as dementia as these raise far more troubling issues than the more straight-forward with a person close to death and having “a grievous and irremediable medical condition that causes them enduring and intolerable suffering.”^{xlix} But again, it all comes down to talking, having significant conversations. In this country, we are not to the end of the debate.

But we need to come to an end of my talking and continue the conversations....

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ⁱ <http://www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&DocId=8120006&File=57#13>.

ⁱⁱ “Bill C-14: The right challenge,” *The Globe and Mail*, editorial, 29 June 2016.

ⁱⁱⁱ Grant, Kelly, “At least 374 people have received assisted death, survey shows,” *The Globe and Mail*, 7 October 2016, A1.

^{iv} Picard, Andre, “Our laws, and our lawmakers, have not kept pace,” *The Globe and Mail*, 9 October 2014, pg. A9.

^v Gawande, pp 178-180.

^{vi} “Quality End-of-Life Care: The Right of Every Canadian,” pg. 12.

^{vii} Sandra Martin, “Glove Books,” *The Globe and Mail*, 16 January 2016, pg. R13.

^{viii} Martin, Sandra, “Let’s talk about death,” *The Globe and Mail, Globe Life & Arts*, January 2, 2015, pg. L7.

^{ix} Quoted in Klug, Lyn, ed., *All Will Be Well: A Gathering of Healing Prayers*, Augsburg, 1998, pg. 142.

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- ^x Doyle, Kathryn, "Patients' families a hurdle in care planning, doctors say," *The Globe and Mail*, February 4, 2015, L5.
- ^{xi} CBC Radio, Ontario noon show, Monday, 23 March 2015.
- ^{xii} Solomon, Sheldon; Greenberg, Jeff; Pyszezynski, Tom, *The Worm at the Core: On the Role of Death in Life*, Random House, 2015.
- ^{xiii} Lysiane Gagnon, "Time for a clear debate," *The Globe and Mail*, 9 December 2015, pg. A17.
- ^{xiv} Lee, Barbara Cooms, "A Progressive View of Decision-Making at Life's End," *Tikkun*, undated article.
- ^{xv} Marker, Rita L., Hamlon, K., "Euthanasia and Assisted Suicide, Frequently Asked Questions," *Patients Rights Council*, www.patientsrightscouncil.org/site/frequently-asked-questions/, pg. 1. Lee, Barbara Cooms, *Tikkun*, undated article.
- ^{xvi} Lee, Barbara Cooms, undated article.
- ^{xvii} <http://www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&DocId=8183660>.
- ^{xviii} Quoted in *Maclean's Magazine*, 4 July 2016, pg. 41.
- ^{xix} *Maclean's Magazine*, 4 July 2016, pg. 41.
- ^{xx} <http://www.ctvnews.ca/health/one-in-10-post-secondary-students-face-unwanted-advances-assaults-survey-1.3063548>.
- ^{xxi} Goldbloom, David, Bryden, Pier, *How Can I Help? A Week in My Life as a Psychiatrist*, Simon and Schuster, 2016, pg. 322.
- ^{xxii} Goldbloom, Bryden, pg. 139.
- ^{xxiii} "Quality End-of-Life Care: The Right of Every Canadian," Final Report of the Senate Subcommittee to update "Of Life and Death," June 2000, pg. 7.
- ^{xxiv} With thanks to Erin McInnis in a phone conversation November 2014.
- ^{xxv} Quill, Timothy E., Battin, Margaret P., ed., *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice*, The John Hopkins University Press, 2004, pg. 8.
- ^{xxvi} Leung, Wendy, "End-of-life patients aren't being heard," *The Globe and Mail*, 7 November 2014, pg. L7.
- ^{xxvii} Halpern, Sue, *A Dog Walks into a Nursing Home: Lessons in the Good Life from an Unlikely Teacher*, Riverhead Books, 2013, pg. 43.
- ^{xxviii} Gawande, Atul, *Being Mortal: Medicine and What Matters in the End*, Metropolitan Books, 2014, pg. 244.
- ^{xxix} Source unknown; received in an email.
- ^{xxx} Beattie, Samantha, "Book helps battle with Huntington's," *Guelph Tribune*, Vol. 29, No. 1, January 1, 2015, pg. 11.
- ^{xxxi} Gawande, pg. 33 with quote on pg. 35.
- ^{xxxii} Rolheiser, Ronald, *Sacred Fire: A Vision for a Deeper Human and Christian Maturity*, Image, 2014, pg. 305.
- ^{xxxiii} Rolheiser, pg. 259.
- ^{xxxiv} Quill, Timothy E., Battin, Margaret P., "Excellent palliative Care as the Standard Physician-Assisted Dying as a Last Resort," *Physician-Assisted Dying*, pg. 323.
- ^{xxxv} Royal Society Expert Report, *End of Life Decision-Making*,
- ^{xxxvi} Paterson, Gary, "Going into that Good Night," www.garypaterson.ca/2014/10/13going-into-that-good-night/.
- ^{xxxvii} Andre Picard, "A dignified end for dementia patients: Who makes the Call?" *The Globe and Mail*, 16 February 2016, pg. A11.
- ^{xxxviii} "On Reflection Letters to the Editor," *The Globe and Mail*, January 3, 2015, pg. F8.
- ^{xxxix} Slater, Keith, *The Joys of ALS: finding happiness in a dark place*, pg. 78 and 79.
- ^{xl} Dr. Carl Mackie, email, January 2014.
- ^{xli} Gawande, pg. 140.
- ^{xlii} Gawande, pp 182-183, 259.
- ^{xliii} Speaking at the Centre for Clinical Ethics Annual Conference, Toronto, 12 October 2012.
- ^{xliv} Gawande, pg. 127.
- ^{xlv} Paul Kalanithi, *When Breath Becomes Air*, 2015, pg. 165.
- ^{xlvi} Kalanithi, pg. 144.
- ^{xlvii} Quoted in Halpern, pp 172-173.

^{xlviii} Simpson, Jeffrey, *Critical Condition: why Canada's health-care system needs to be dragged into the 21st century*, Allen Lane, 2012. Also see, "Canada's crisis-in waiting," *The Globe and Mail*, January 17, 2015, F9.

^{xlix} <http://www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&DocId=8183660>.