

7th Annual Advance in Palliative Care Conference
“Marking Mortality Moments”
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This talk has three parts. First I will identify three (3) key concepts that frame care at life's end. Our assumptions about finitude, mortality, and death will enhance or may unwittingly limit our effectiveness in caring for people near death. In the second part we will explore the importance of marking ordinary mortality moments that occur in daily living. In the third part, I will talk about the decision Karen Speerstra made to take the turn toward death as the final marking of mortality. All of that in 50 minutes or less. This talk will be available online. At the end of the conference, you will all receive a copy of the book *The Divine Art of Dying: How to Live Well While Dying* that I wrote with Karen when she was dying.

Part One

Finitude or being finite, as I am using the term, is the condition of being limited that is an essential part of our humanness. It is something we share with all creatures. There is a beginning and an end to life, and in life there are beginnings and endings. Finitude is not mysterious. Clocks and calendars are reminders that life is limited. So are creaky knees or a faulty memory. If we resist the claim of clocks or avoid boundaries or physical signs of finitude that accompany aging like walking with a cane, admitting that we are mortal will be more difficult. If, however, we could acknowledge human limits and accept the fact that not everything is possible, we might reduce the excessive amount of money that is spent in the last 6 months of life and along the way avoid bankrupting our health care system. The acceptance of human finitude is the prelude to both responsible decision-making and faithful care at life's end.

Malcolm was taking a walk when he saw a frog on the sidewalk. He was startled to hear the frog speak. “Hey, old man, if you kiss me I will turn into a beautiful princess. I will be yours forever and we could make mad passionate love every day.” Malcolm put the frog in his jacket pocket and kept walking. “Hey, Old man, I don't think you heard me. If you kiss me, I will turn into a beautiful princess and we can make passionate love everyday.” “I heard you,” Malcolm said, “but at my age I'd rather have a talking frog.” Life would be a lot simpler, aging a lot easier, and dying less complex, if we were all a little more accepting of finitude like Malcolm. But learning to live as finite creatures is never simple: it requires courage because with finitude comes contingency and the suddenness with which things happen.

There are three reasons why the acceptance of finitude is critical for the dying and for caregivers at life's end. First, the unwillingness to acknowledge finitude may prompt people to spend down their emotional or financial capital to extend life a little longer. A wise friend has often reminded me that not everything is possible. And even if possible, not necessarily desirable. What you know better than me is how often people overlook the gifts of palliative

care and have nothing left for living by the time they sign up for hospice. Second, caring for those who are dying is a constant reminder to caregivers that we are also finite and mortal. We need to face our own limits and practice powerlessness in order to care effectively with those who are dying.

The third reason why facing finitude is necessary applies to family and friends as well as professional caregivers. In order to live fully until one dies, human agency and patient autonomy need to be supported as cherished values. Making it possible for someone dying to have limited but significant acts of freedom is or least should be a priority for caregivers. However, honoring agency and helping people live as fully as possible until they die depends on the willingness of caregivers to make sacrifices, relinquish their own freedom or at least set aside their own agendas in order to be attentive to a patient's wishes at the end. Finite choices matter! And honoring even finite choices may limit caregivers. Family and friends might regard it as too risky to take one more trip to the cabin in the woods or attend one more Giants game at ATT Park or make one more trip abroad. And it may require considerable accommodating to make it happen. Even though options narrow as we come closer to death, deciding and deciding again and again is the work dying people can do. It is our work as caregivers to support deciding as long as it possible. Respecting their agency and empowering people who are dying to make these simple choices keeps them in the game. Here is what Karen Speerstra wrote in her Hospice Journal:

I daily decide what to eat and how much. I listen to my body for clues. What am I thirsty for that won't be too acidic? So far, I can decide what to wear. How much to sleep. When to nap. What to read. Which Netflix to watch. And how to spend my time with my friends.... I choose active dying just as I've chosen active living. I want to die as I have lived – a full participant in all life has to offer.

Mortality is the second image that frames care at life's end. At the conclusion of his remarkable book *Being Mortal: Medicine and What Matters in the End*, Atul Gawande writes this: "Being mortal is about the struggle to cope with the constraints of our biology, with the limits set by genes and cells and flesh and bone." In one way, mortality is another way of talking about finitude. But it is more specifically about the body. Even if we are not clear that death is final, we may be willing to admit that the body is mortal. My three hip surgeries in the last four years have been a reminder to me that body parts wear out. They have a limited shelf life, so to speak. I also know that my body is aging when I look in my shopping cart and realize that half the stuff says "for instant relief." A friend of mine said he knew he was getting older when he started making the same noises as the coffee maker. These are mortality moments to be sure.

Mortality becomes personal when I can admit I will die. But arriving at that realization takes time – even for those who spend their working days with people near death. Here is what Atul Gawande says: "Arriving at an acceptance of one's mortality and a clear understanding of the limits and the possibilities of medicine is a process, not an epiphany." One of the ways to enhance that process, I propose, is to mark mortality moments when they occur and pay attention to the times or situations or moments in our lives when we are more keenly aware

that we are mortal – that we will die. A mortality moment may be prompted by an experience of loss or by retirement or by purchasing a cane or it may simply happen in conversation as we reflect on life. A friend of mine in her late 60's was telling her husband and daughter about she wanted "if I die." After listening to all her requests prefaced by "if", her husband asked quietly "if"? Not "when"? This "if-when" moment makes death personal rather than abstract. It was for my friend a Mortality Moment. One of my mortality moments came 19 years ago when I was diagnosed with prostate cancer. **Stand where you are – as you are able – and describe very briefly a mortality moment in your life to someone nearby. You will have only 3 minutes for this exercise.**

In his forward to the book *The Divine Art of Dying*, Ira Byock writes this: "Mortality is a harsh teacher. The first lesson it delivers is that death is inevitable. It will happen to you. The final exam it gives entails just one question: **How then shall we live?**" This is, of course, a life question for every one of us whatever our age and at every point in life. If we allow ourselves to be aware of our mortality as part of living – we will ask questions about the meaning and purpose and how we shall live day by day even when we are not sick or dying.

Gawande is very clear about the implications of mortality for caregivers. "If to be human is to be limited, then the role of caring professions and institutions – from surgeons to nursing homes – ought to be aiding people in their struggle with those limits." Attending to the mysteries of mortality in the patient's situation is as essential to effective end-of-life care as accurate assessment and charting for the medical process. Facing mortality daily in your work is a challenge, but it is also a gift. We have a deeper awareness of what matters, however small or seemingly insignificant. At the end of each chapter in *The Divine Art of Dying*, there is a page called "From the Caregiver's Guidebook." Here are a couple entries that address the mortality of caregiver's as well as the one dying.

1)When we accept that cure is no longer possible and only care is called for, we need an extra measure of commitment to stay present with someone whose life circumstances cannot be altered. Resist the impulse and often unspoken desire to flee from helplessness and futility.

2)Volunteers, friends, and family members provide a safety net for catching each other. Be as compassionate to yourself as you are to others.

The image of mortality is important because it makes it possible for us to see death not just as the enemy of life, but as an inevitable and necessary part of life. Death is the third image that frames end of life care. Paul Tillich, a widely respected theologian of the 20th century, is reported to have offered this prayer in the Harvard University chapel. **Lord, help me to bring my death into my life, lest death take my life from me.** If death is part of my life, then it – death – cannot 'take' my life – my living – from me. For that reason, we can say the dying are still living and death is part my life. When we say that "death took" Sam Jones or "cancer took" Jessica Riley much too young, we suggest the opposite: that death or cancer has agency outside us and can take life from us. Many religious people believe that God decides when people die. They will say "God took Bernie" and maybe they will say that "God took Bernie" because God needed a carpenter in heaven more than Bernie's children needed a father.

Although we may have outgrown the boogiemer or the grim reaper as the agent of death, we think of death as a force or agent that acts on us – from outside. That makes it difficult to understand death as a part of life – my life. Other times, when it seems like death happens from within, like an act of self-completion or self-fulfillment, it is easier to think of death as part of my life. I die.

Each death, like each life, is personal and paradoxical. It is personal because no one can die for me. Whether by accident or cancer or a stroke or heart failure or old age or choice or hidden determination, it is personal. It is my death. Death does not come to us. I die. Death and life, dying and living are bound together. In order to avoid glamorizing the good death or demonizing a brutal death, it is necessary to keep insisting that death is a contradiction, a paradox: a friend and an enemy, a moment and a process, a fate and an act, a disruptive end and the gracious fulfillment of a life. We say death is both friend when we are frail or weary from the pain or simply worn out from living **and** an enemy when it disrupts life suddenly and prematurely. Death is both moment **and** process. It is a definable instant when breath ceases and the bodily systems shut down **and** it is also a process of dying while living during which our genetically programmed resources are diminishing. Death is also both a problem to be solved **and** a mystery to be experienced. Because death is a problem, we keep asking what must be done about this medical situation or that. Because death is also a mystery to be experienced, we ask a different question: How shall I behave toward this situation? This is the question that shapes *The Divine Art of Dying: How to Live Well While Dying* – the book you will receive at the end of the Conference.

Arriving at an acceptance of our mortality and a clear understanding of the limits and possibilities of medical care, according to Gawande, is a process, not an epiphany. That process is the title of this talk: **marking mortality moments**. The initial awareness that we are mortal is usually internal and could happen at any time in the life journey. It might occur simultaneously with bifocals or begin with an ‘ahah’ after reading a book about loss or realizing that all our living college classmates are over 60 or learning about the death of a same-age friend or going through a battery of medical tests even though nothing was wrong. It is always an interpretation and therefore these events may not necessarily become occasions for increased awareness of our mortality. **Marking Mortality Moments** improves with practice.

In a recent interview, Paul Simon said this about beginning his final tour: “What do I have to do in the time I have left to do it?” That line from Paul Simon reminded me of the end of a poem by Mary Oliver entitled “The Summer Day” and addressed ironically to high school students who were probably not thinking about their mortality.

I do know how to pay attention, how to fall down
 Into the grass, how to kneel down in the grass,
 How to be idle and blessed, how to stroll through the fields,
 Which I have been doing all day.
 Tell me what else should I have done?
 Doesn't everything die at last, and too soon?
 Tell me what is it you plan to do with your one wild and precious life?

The most important internally prompted mortality moment occurs when we make decisions about the end of a life. I suspect many people avoid making these decisions about the end of a life precisely because they do not want to face the reality of mortality. We may, however, be motivated to make a will, revise our trust in light of new circumstances, and make advance healthcare decisions **because** we have come to terms with our mortality **or** making these decisions may become a mortality moment in the doing. It is interesting to me that people who have established a trust and determine the advance directives may still be reluctant to share that information with adult children. The decisions we make in preparation for the end of a life are usually initiated from within and not in response to a medical diagnosis. They are the result of a being aware of our mortality because we are human, not because we are seriously sick or terminally ill. Marking mortality moments is a choice from within.

Other mortality moments are not by choice. The moment may occur after a physical exam when the physician simply says she would like to order some tests to check the spot on the lung. You may have been experiencing fatigue for no apparent reason and the tests showed pancreatic cancer. This mortality moment could also be the result of a stroke or an accident that permanently limits physical movement or sets in motion physical deterioration but not dying. I was in the kitchen with a paintbrush in hand on my birthday when the urologist called 19 years ago yesterday to tell me I had prostate cancer. That news set in motion medical procedures that were successful. I was fortunate. I remember getting a haircut shortly after the phone call and telling the barber that I had prostate cancer. I was marking a mortality moment by making it public.

There is a third moment that may be the result of both an external change and an internal choice. This brings us to the third and final focus for this talk on **marking mortality moments**. It occurs when a person with a life-limiting illness whose treatment may even have been successful for a time decides to discontinue further treatment in order to live more fully while dying. This is a difficult choice – especially when there may still be medical options to pursue. The book *The Divine Art of Dying* is about this moment and the difficult decision Karen Speerstra made to discontinue chemotherapy after living with ovarian cancer for 10 years. It was for Karen a “moment of blessed recognition.” In the book we wrote together, we call this moment “**taking the turn toward death.**” The prayer we have already noted by theologian Paul Tillich says very well what happens in this act of taking the turn toward death. “Lord, help me bring my death into my life lest death take my life from me.” Karen Speerstra and I wrote the book to encourage people facing a life-threatening or life-limiting illness to consider foregoing further curative treatment **sooner rather than later** and take the turn toward death **so that** they will have the time and capacity and emotional resources to live as fully as possible until they die.

Karen Speerstra and I had been friends since 1977 when we lived together in Dubuque, Iowa. Karen had a remarkable career as an editor for a publishing company in Boston. When she retired, Karen and her husband John moved to very rural Vermont. Shortly after retiring,

she was diagnosed with ovarian cancer. Karen lived for 10 years with ovarian cancer during which time she wrote three other books, maintained a blog called *Sophiaserv*, and traveled extensively. The treatment had been successful and she had tolerated chemotherapy well but by Christmas 2012 when we saw her and her husband John in Connecticut, she had lost her appetite and her nails were turning black. If her nails were falling out, Karen wondered, what was happening to her stomach.

Our aim in writing the book was twofold. The first was to encourage people facing a life-limiting illness to consider foregoing curative treatment and take the turn toward death sooner rather than later **so that** they will have the time and resources to live as fully as possible until they die. The second is this: to explore how to live fully while dying once the decision has been made to suspend further treatment and take turn toward death. It was an effort to answer the question asked by Ira Byock in the Preface: how then shall we live? Our intent was to step back from the **moment of death** or even the time of **actively dying and end of life issues** in order to explore how and when we might responsibly decide to forego further medical treatment when we are irreversibly dying. The risk in deciding to ‘take the turn toward death’ by suspending any further potentially life-prolonging treatment is that you could die sooner than you might have with more treatment. However, by deciding to suspend further treatment sooner rather than later – the possibility of living fully while dying is increased. Whenever someone takes the turn toward death, we believe it is in the interest of living more fully in the time is left.

The decision to suspend treatment or discontinue medical procedures designed to prolong life is never made easily. People who have avoided hard choices throughout their lives will put off taking the turn. People who are angry at the diagnosis or disappointed about an incomplete life or anxious about an uncertain future may postpone taking the turn toward death until the decision is made for them. It takes personal courage and gracious understanding from family and friends to take the turn toward death. It is particularly difficult for others to understand taking the turn toward death when people don’t look sick. Karen reported on one son’s reaction in the first journal entry. “You made the decision,” he said, “to stop chemotherapy just because you couldn’t walk through some snow up to the house?” His question sums up the common response from family and friends when it seems as though someone is making a decision to die ‘on purpose’ rather than ‘with purpose’.

The decision to take the turn toward death is not the last decision a dying person will make and may not even be the most difficult. Even before the Hospice “Do not Resuscitate” sign is on the refrigerator door, a decision about transparency needs to be made. Here is what Karen Speerstra wrote: “It takes a lot of energy to figure out whom you can safely talk to, so I’ve decided on full disclosure even though it’s hard for some of my friends to accept my candor about death.” The consequences of Karen’s transparency were astounding. Old friends reconnected, local newspapers interviewed her, unknown people wrote to her about what she said on the radio. Something she had painted for the wedding of old friends 40+ years before was returned. You know all too well the consequences of secret-keeping. Withholding the truth about a diagnosis or a treatment plan isolates. I had a college roommate who wrote one letter a day to his friends telling them he was died pancreatic cancer. He created an incredible

network of care. Transparency makes it easier for communities of compassionate care to evolve. Of course, truth-telling is not an absolute and not everyone was glad for Karen's openness, but deciding to be transparent made it possible for Karen to harness her energies for quality living to the end. And she did.

There are many more moments big and small, simple and complex in living while dying when the dying person needs to decide what to do or how to live while dying. They will include relinquishing or handing over what we value, waiting, tolerating ambiguity, waiting some more, trusting the kindness of strangers, telling stories, sharing memories, giving gifts, waiting some more, grieving all our losses and then grieving some more for the new friends we have made or new experiences we have enjoyed. One more word from Atul Gawande in support of careful listening at these moments in dying: "Medicine has forgotten that people want to share memories, pass on wisdom and keepsakes, connect with loved ones and to make some last contributions to the world. These moments are among life's most important, for both the dying and those left behind." These mortality moments need to be listened to attentively.

For Karen, activity and passivity were not mutually exclusive. The other side of agency or activity is passivity, of waiting and not having or possessing because we wait. The human creature is both subject and object, both actor and acted upon. Activity and passivity are both essential qualities of being human. We are thus fully human when we are actively creating, producing, initiating, and making things happen, but we are also fully human when we are passively incapacitated, ill, waiting, needing, dependent, suffering, receiving, and submitting. In a culture that prizes autonomy, promotes agency, and idolizes independence and self-sufficiency, we may need to remind ourselves and the dying and their family and friends that living and dying are always a contradiction of acting and waiting, activity and passivity. And both sides of the contradiction or paradox are true. We are always acting and waiting, strong and needy, subject and object. We are simultaneously choosing and deciding about living **and** waiting for a mystery. A poem Karen wrote shortly before her death entitled "We Wait: Notaries of Time" includes these lines:

*So, we wait. Watch. Touch
memories and share stories.
We watch planets and stars
dance to velvet rhyme.
For we are notaries of time.*

If death is a mystery to be experienced as well as a problem to be solved, then we need to ask how shall I live towards that moment. And living fully and actively toward that moment includes waiting. We are, after all, *notaries of time*.

Our task as caregivers is a sacred one: helping the dying walk with lighter foot prints lest they fall. We will do that many ways as professional caregivers and family and friends. We will stay present. Honor agency when we can. Eliminate secrets when possible. Bear witness to their story. Eradicate isolation and eliminate loneliness. Translate mute pain into suffering that can be shared. Practice powerlessness and embody hopefulness. And most of all, live in their

mystery. They know what we do not know. For that, I leave you with one more entry from Karen's Hospice Journal:

As I view my planet now from my upstairs hospice room, sharper colors outline the mountains in the distance. Two words come to mind: intensity and perfection. I look up and notice more magnificently tinged clouds. Stars pepper the night sky, and the labyrinthine Milky Way that will undergird my passage becomes a scarf of light. This same sky has been hanging over my head for seventy-three year but now I can finally see it. Everything is mystery! It's all so much more than I thought. All this is not easy, but it is, at some mysterious level, perfect.

We can all tell stories of individuals who waited until the last child arrived from New Jersey or the last child be married before they died. My mother had been too long in coronary care and so the space utilization review committee had determined that she would leave the hospital on a Friday morning and go to a nursing facility in the complex where she and my father lived. Her heart was not so good but her hearing was just fine. She was very upset when she overheard this decision and terrified about leaving the safety of coronary care. And so she died at 4 a.m. on Friday before they could take her away. My mother died. She was determined not to be taken from coronary care. It was a human act.