Hope and Good Dying
What do Chaplains have to offer when cure is “off the table”?

Remaining hopeful in a global community marred by war, increasing attacks of violence, and profound inequities that leave millions dying of hunger, thirst and treatable diseases is at best a challenge. When age, infirmity, and serious illness complicate our lives by threatening our very sense of self and continued existence, despair is a real option. With assisted suicide now an option in a growing number of states more are likely to choose this option. If it’s true that each and every human being lives by hope, each and every human being expects hope, is hoping for hope--then we as spiritual caregivers need to be skilled in cultivating hope. This session will explore why hope matters and explore strategies for enabling hope in the seriously ill and dying.

Objectives:
Upon completion of this session participants will be able to:
1. Define hope and its role in helping individuals meet developmental needs
2. Describe strategies to nurture (enable) hope in the seriously ill and dying
3. Newly value the ability to be a hope-filled healing presence for those struggling with hopelessness and despair

Introduction: Mark’s Story
1. The Theory Practice Gap and limits of the bio-psycho-social-spiritual model of health

2. Components of a good death
Participants in a recent study identified six major components of a good death: pain and symptom management, clear decision-making, preparation for death, completion, contributing to others, and affirmation of the whole person. The six themes are process-oriented attributes of good death, and each has biomedical, psychological, social and spiritual components. Physicians’ discussion of a good death differed greatly from those of other groups. Physicians offered the most biomedical perspective, and patients, families, and other health care professionals defined a broad range of attributes integral to the quality of dying (Steinhauser, et. al, 2000).

Quality Indicators for End-of-Life Care (EOLC) within the Seven EOLC Domains
1. Patient and family centered decision-making
2. Communication within the team and with patients and families
3. Continuity of care
4. Emotional and practical support for patients and families
5. Symptom management and comfort care
6. Spiritual support for patients and families
7. Emotional and organizational support for ICU clinicians (Crit Care Med 2003, 31(9), 2258)
3. **U.S. Death-denying culture**

These days, swift catastrophic illness is the exception; for most people, death comes only after long medical struggle with an incurable condition--advanced cancer, progressive organ failure, or the multiple debilities of very old age. In all such cases, death is certain, but the timing isn’t. So everyone struggles with this uncertainty--with how, and when, to accept that the battle is lost. ...Besides, how do you attend to the thoughts and concerns of the dying when medicine has made it almost impossible to be sure who the dying even are? Is someone with terminal cancer, dementia, incurable congestive heart failure dying, exactly? [Gawande A. Letting go. The New Yorker, August 2, 2010, pp. 36-49.]

4. **My agenda**

I want to address the increasing tendency of health care professionals to obfuscate knowing and accepting that the battle to overcome death is lost by restricting attention to discrete pathologies, infection, renal failure, decreasing cardiac ejection fractions, with discrete interventions, antibiotics, dialysis, ionotrophic drugs, and ventricular assist devices--often at the expense of the person, his/her dignity, and quality of life. By promoting false hopes of cure, health care professionals rob the seriously ill and dying of the timely opportunity to prepare for death, and this paradoxically often results in end states of despair and hopeless-ness for both patients and their loved ones. I believe that we can do better as professional caregivers but it will take a radical rethinking of the ends of medicine. Should good dying as an end of medicine be restricted to hospice professionals or rather be a legitimate goal of all who care for the seriously ill and dying? Similarly, if good dying is an outcome that obligates all who care for the seriously ill and dying, we need to question how skilled professional caregivers are when identifying and meeting noncurative goals. I begin with a narrative that issued a personal challenge to my clinical competence, and will focus specifically on hopelessness and spiritual care interventions to address such hopelessness.

5. **The difference between “healing” and “curing”**

- **Curing**: the alleviation of symptoms or the termination or suppression of a disease process through surgical, chemical or mechanical intervention
- **Healing**: may be spontaneous but more often it’s a gradual awakening to a deeper sense of self (and of the self in relation to others) in a way that effects profound change. Healing comes from within and is consistent with a person’s own readiness to grow and to change. A healing attitude is “a belief system that recognizes that all of life’s experiences, including injury, illness, and other setbacks, provides us with opportunities to learn and to grow toward that we are meant to be. Seen in this light, disease is not an enemy but a teacher and motivation. Disease is manifesting, in a physical way, the desire or need of the psyche to reestablish balance and integration through a change of direction in one’s lifestyle, behavior, or attitudes.” [McGlone, M.E. (1990). Healing the spirit. Holis Nurs Pract, 4(4), 77-84.]
- **Healing is the integration of self. People move from a sense of brokenness to a sense of wholeness. C. Puchalski**
Spirituality

1. Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred. [Puchalski, C. Ferrell, B., et. al. (2009). Improving the quality of spiritual care as a dimension of palliative care: The report of the consensus conference. *Journal of Palliative Medicine, 12*(10), 885-904.]

2. In the words of theologian Karl Rahner, spirituality is . . . simply the ultimate depth of everything spiritual creatures do when they realize themselves—when they laugh or cry, accept responsibility, love, live and die, stand up for truth, break out of preoccupation with themselves to help the neighbor, hope against hope, cheerfully refuse to be embittered by the stupidity of daily life, keep silent, not so that evil festers in their hearts, but so that it dies there—when, in a word, they live as they would like to live in opposition to selfishness and to the despair that always assails us (1971, p. 229).

Universal Spiritual Needs

According to Fish and Shelly (1978) there are three spiritual needs underlying all religious traditions and common to all people: (1) need for meaning and purpose, (2) need for love and relatedness, and (3) need for forgiveness.

Why hope matters to the *individual with a serious and life threatening illness*

Erikson’s last developmental stage: *ego integrity vs despair*

Patient-Centered Spiritual Care

Spiritual care models offer a framework for health care professionals to connect with their patients; listen to their fears, dreams and pain; collaborate with their patients as partners in their care; and provide, through the therapeutic relationship, an opportunity for healing. Healing is distinguished from cure in this context. It refers to the ability of a person to find solace, comfort, connection, meaning, and purpose in the midst of suffering, disarray, and pain. The care is rooted in spirituality using compassion, hopefulness, and the recognition that, although a person’s life may be limited or no longer socially productive, it remains full of possibility. [Puchalski, C., Ferrell, B., et. al. (2009). Improving the quality of spiritual care as a dimension of palliative care: The report of the consensus conference. *Journal of Palliative Medicine, 12*(10), 890.]

...Suffering is the exhibition of the presence in our existence of that which is not under our control,...of an activity operating under another law than ours, it cannot be brought adequately within the spheres of teleological and deontological ethics, the ethics of man-the-maker, or man-the-citizen. Yet it is in response to suffering that many and perhaps all men, individually and in their groups, define themselves, take on character, develop their
Although psychological distress is well documented in dying patients, it tends to be under recognized and underrated. Psychological distress impairs the patient’s capacity for pleasure, meaning and connection; erodes quality of life; amplifies pain and other symptoms; reduces the patient’s ability to do the emotional work or separating and saying good-bye; and causes anguish and worry in family members and friends. Finally, psychological distress, particularly depression, is a major risk factor for suicide and for requests to hasten death (Block, 2000).

Responding to Human Suffering and Engendering Hope

Aquinas writes that hope is a desire characterized by a special type of object. The object of hope must be 1) clearly good, 2) apparent in the future, 3) difficult or arduous to attain, and yet 4) possible to attain.

Quick Exercise: If you discovered a lump this morning...

Hope develops from the basic human need to achieve, to create. At its root, it embodies the question of the essence of ourselves that will live on after we die, our contribution. The power of this need fuels our will to live: the loss of such a drive leads to feelings of helplessness and despair. ... Hope is the ingredient in life that enables an individual both to consider a future and to actively bring that future into being. Hope originates in imagination, but must become a valued and realistic possibility for an individual in order to energize action. Hope has the capacity to embrace the reality of the individual’s suffering without escaping from it (false hope) or being suffocated by it (despair, helplessness, hopelessness). Hope is unique to each person. During terminal illness, the future being considered will become more focused, yet hope is essential for an individual to transcend despair and complete crucial life tasks. [Ted Creen. Enabling Hope.]

J. Donald Schumacher, president and chief executive officer of the National Hospice and Palliative Care Organization, identifies six circles of hope for the terminally ill that have an ever-narrowing focus of identification:

1. Hope for a cure;
2. Hope for a sudden and long remission of disease;
3. Hope for a pain-free existence;
4. Hope for the resolution of interpersonal relationships;
5. Hope for self-forgiveness; and
6. Hope to be remembered well.
Ultimate hope is not about cure. The source of ultimate hope must be located beyond the limits of our finite, corporal, individual existence. **The object of ultimate hope must then be a source of meaning, however this might be construed.** For Christians, Muslims, and Jews, this transcendent object of desire is the one, holy, all-loving and almighty God. To reject, or to discover, or to re-cover, or to hold onto an ongoing source of transcendental meaning is one of the major spiritual tasks of the dying. The object of hope is called despair, but despair is really just another name for meaninglessness. To suffer without any sense of meaning abject hopelessness (Sulmasy 2002)

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<th>ENABLING HOPE IN THE TERMINALLY ILL</th>
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<td>These guidelines are the product of an interdisciplinary team of those providing care for the terminally ill. They are presented to encourage anyone providing care for the terminally ill to consider the crucial place of hope in their caring and also their own potential to enable such hope.</td>
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**Hope**  
Hope is the ingredient in life that enables an individual both to consider a future and to actively bring that future into being. Hope originates in imagination but must become a valued and realistic possibility for that individual in order to energize action. Hope has the capacity to embrace the reality of an individual’s suffering without escaping from it (false hope) or being suffocated by it (despair, helplessness, hopelessness).

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**Enabling Hope**  
**Acknowledging Individual Uniqueness**  
To enable such hope, the care provider must acknowledge the uniqueness of the individual and take seriously the dreams of the terminally ill person within the changing nature of the illness. Steps that can be taken to translate hope into accomplishment must be considered. For this to happen, care providers need to do the following:

- Consider all language used, and appreciate how easily hopes can be disabled by such terms as “hopeless situation” or “nothing more can be done.”
- Encounter the individual’s feelings at his or her own level; be willing to stay at that individual’s level and allow him or her to lead.
- Be willing to take the necessary time to establish rapport with the individual in order that his or her hopes can be shared in a supportive atmosphere. Where appropriate, use physical contact to build trust.
- Realize the changing nature both of the disease and the accompanying hopes. At one point, a hope for a cure may be the necessary activating force for an individual to undergo treatment; at another, a hope to consider one’s dying may give the energy to complete crucial life tasks or endure the many losses of terminal illness.

**Granting Control**  
A factor crucial to the nourishing of hope within an individual is that of control. An individual must be willing to take the necessary action to achieve what is hoped for. Terminal illness places
many restrictions upon an individual and often robs that person of a feeling of being able to control the situation, thus leading to increasing helplessness and hopelessness. To counter this, efforts must be made not only to support an individual in hoping, but also to grant the person control in bringing realistic hopes into being.

To help support an individual’s sense of control in order to enable active hoping, care providers need to do the following:

- Provide honest and accessible information regarding the progress of the illness.
- Allow an individual to express and work through many hopes in order to develop those hopes appropriate to him or her in the present context.
- Allow for freedom of choice regarding treatment options to the degree possible within the setting.
- Maximize the present possibilities for achieving hopes while allowing for the changing realities of terminal illness.

**Being Aware of One’s Own Feelings**

Hope is strengthened by those who care for and support a terminally ill individual. Within the context of illness and suffering, hope may be fragile and must be nurtured in relationships with professional caregivers, family, and friends. To enable hope, care providers must be aware of their own hope for that individual.

Care providers need to do the following:

- Recognize their own assumptions regarding that particular individual and how those assumptions may inhibit the enabling of hope for that person.
- Be aware of how their own hope for that individual may differ from the hope being expressed by that person.
- Resist judging expressed hope and be willing to explore such hope further.
- Accept the individual’s present suffering. Avoid giving “false hope” that minimizes the reality of the situation (“It can’t be that bad,” or “Don’t worry, everything will be fine”) or encouraging despair by focusing only upon the illness (“God can’t possibly heal you now. That cancer’s all through you!”).

**Supporting Spirituality**

A component of hope is spirituality. Supported by faith in God, hope is the capacity to transcend present suffering, to lift one’s perspective to future possibilities, and so to enable that individual to accomplish important life tasks. This capacity to transcend is facilitated by one’s belief in the presence of God within the changing context of terminal illness.

To enable this spiritual aspect of hope, care providers need to do the following:

- Accept the individual’s own spiritual journey and present level of faith (or lack of).
- Be open to expressed hopes that link with religious belief (e.g., “God will cure me” or “I pray that God will take me home soon”).
- Allow for spiritual struggle and its resultant emotions (e.g., anger when “the cancer is back and God has failed to cure me!”). Recognize that the level of spiritual struggle during terminal illness may increase to enable the accomplishment of crucial hope for life tasks such as reconciliation and forgiveness.
- Be prepared to accept the reality of death as an aspect of hope. Accept an individual who has shifted hope to how he or she wishes to die, to life after death, to a meeting with deceased loved ones, and so on.
Questions of value and meaning:
In the final analysis, every dying person who retains the capacity to hear and to understand the call of death faces two important sets of questions: questions of value and questions of meaning. ...The first set of questions relates to value. At some level, the dying person must ask questions such as the following: Do I, as an embodied person, now dying, have any value here and now as me dying? Has my life, as I have lived it until now, had any value? Will there be anything of value about me that persists after I have died? The second set of questions related to meaning. At some level, the dying person must ask such questions as the following: Does my dying now, as an embodied person, have any meaning here and now? Has my life, as I have lived it until now, had any meaning? Has there been any meaning in what I have suffered? Will there be any meaning in my living and dying that perdures beyond the moment of my death. Questions of value have been subsumed under the word dignity; questions of meaning have been subsumed under the word hope. (Sulmasy, The Health Professional as Friend and Healer, 2000).

Responses to Suffering
Finding Meaning in Life Experiences
The concept of suffering in life experience is not new. Nietzsche was one of the first modern philosophers to call attention to this phenomenon: “He who has a ‘why’ to live for can bear almost any ‘how.’” Jaspers confirmed this need of the person to experience meaning: “As soon as an individual wakes he does not merely want to live out the day, but wants to live for something in his life.” Frankl, addressing himself to what he termed today’s “existential vacuum,” developed the conviction that “life holds a meaning for each and every individual, and even more, it retains this meaning literally to his last breath.” “Whenever one is confronted with an inescapable, unavoidable situation...e.g., an incurable disease... just then is one given a last chance to actualize the highest value, to fulfill the deepest meaning... the meaning of suffering.”

Travelbee, one of the first nurse conceptualists to advocate humanistic nursing, explored the nurse’s responsibilities and opportunities to help individuals and their families to meet their need for meaning in the experience of suffering and illness.

The human being is motivated by a search for meaning in life experiences, and that meaning can be found in the experience of illness, suffering and pain. When such meaning is found and the individual is able to use the experience of illness as an enabling life experience, i.e., enabling in the sense that it is possible for the individual to achieve self-actualization and that which lies beyond—self-transcendence.

Intimacy [M. Fowler]
That which heals suffering is one thing only: INTIMACY
Yea, though I walk in the valley of darkness I fear no evil for You are with me...

Lamentation: lances the boil of suffering; when spent, it forces you to climb back up the pit!

**Becoming a Hope-filled Healing Presence**

**Healing Testimonies:**
Seven years ago I was faced with three life-threatening events in a period of three years. Those life-threatening experiences taught me that it is possible to “heal” and to live fully even when we are in the abyss of suffering. I believe everyone would benefit if we redefined “healing.” Here are elements I now include in my definition.

HEALING IS:

♦ Becoming whole, a life-long journey of becoming fully human, involving the totality of our being: body, mind, emotion, spirit, social and political context, as well as our relationships with others and with the Divine. Healing does not necessarily mean being happy or getting what we think we want out of life; it means growth, often with pain.

♦ Becoming our authentic self, releasing old unreal self-images, discovering who we really are, not what we think we should be, knowing why we are here and what we really value, restoring our ability to heed our aspirations.

♦ Reconnecting lost aspects of ourselves, paying attention to buried feelings and places inside us that are distressed or sick, enabling us to express our self in fullness, both the light and shadow sides.

♦ Being open to change and new possibilities; responding to problems by changing the picture; being willing to let in more life, to open up to what may have been previously closed or destroyed for us and that which holds promise of giving us new life and fulfillment.

♦ Facing our fears and refusing to be injured or wounded; changing our belief systems; breaking unnecessary taboos; letting go of what is familiar, and stepping into the unknown.

♦ Accepting that problems, pain, and suffering are part of life and inseparable from us – not a peripheral relationship, not something isolated and avoidable – enabling us to enter into problems and use suffering, pain, and life-threatening events to enrich our lives.

♦ Being empowered by the Divine; discovering meaning in our defects, disorders, problems, and disease; experiencing new degrees of creativity and life forces that we might never have imagined before our difficulty; finding that our pains and fears are transformed into relief and confidence.

♦ Recognizing the value and preciousness of life, knowing that every moment is unique and significant, which usually leads to greater appreciation of the wonder of our minds, bodies, and spirits and of the Divine.

♦ Having faith and hope – important preconditions for mental and physical health; having a belief in the Divine, the meaning of human life, and the universe; helping us to claim our capacity to create and make something new.

♦ Finding inner peace, contentment, and tranquility amid the realities of daily life, including its problems, changes, and chaos; experiencing a sense of fullness that makes the burdens of pain or illness lighter.

♦ Being forgiving of ourselves and others and being forgiven; giving ourselves and others the
freedom to let go of rivalry, strife, anger, hatred, fear and limitations.

♦ Feeling connected to one another, a sense of interdependence; knowing we are not isolated or autonomous, giving up the illusions of boundaries in life; taking responsibility, acting justly, and accepting that we share our humanity.

♦ Being loving and loved; loving one’s self and wanting to love and serve others, as well as being capable of receiving love; having an ability to trust, a feeling of aliveness, and a sense of greater participation in life.


Becoming a Healing Presence


_Healing presence is the condition of being consciously and compassionately in the present moment with another or with others, believing in and affirming their potential for wholeness, wherever they are in life._

Your healing presence can take many forms. You cannot _do_ healing presence—you _become_ healing presence, expressing it gently yet firmly in various ways: Listening, holding, talking, being silent, being still, being in your body, coming home to yourself, being receptive. ...You can deepen your healing presence by slowing down, by doing only one thing at a time, by reminding yourself regularly to come back to the present moment. You can encourage healing presence by being appreciative, forgiving, humble kind.

Steps for Being a Healing Presence

_Inasmuch as it’s more art than science, you’ll have your own ways of bringing healing presence into your life and the lives of others. Following is a rough order for how you might proceed._

1. **Open Yourself**

   Begin not with the other person but with you. Become present to yourself in a way that is honest, insightful, and accepting. Open to your uniqueness, humanness, prejudices, brokenness, and wholeness. Do this by owning your life story, continually fathoming who you are in a holistic manner, and developing or utilizing a support system to which you hold yourself accountable.

2. **Intend to Be a Healing Presence**

   Aware that healing presence doesn’t just occur out of the blue, you intentionally decide to be such a presence with another. Intend to promote healing in its many forms, while being understanding of yourself as you emerge in the day-to-day intricacies of this practice.

3. **Prepare a Space for Healing Presence to Take Place**

   Clear a space to interact with the other or others, assuring as much privacy as possible and
creating an atmosphere of calm. Prepare a space also within by placing yourself out of the way and clearing away your personal expectations for what the other should be or do.

4. **Honor the One in Your Care.**

   Approach those you accompany as people with dignity and worth. Show your regard for them by honoring their individuality, equality humanness, separateness, and sacredness. Respect their natural and unique healing capacity.

5. **Offer What You Have to Give**

   Freely and simply make available what you have to offer realizing it’s up to the other or others to accept or not. Offer presence, loving acceptance, empathy, dependability, an unselfish focus on them, your firm belief in them, your willingness to follow their lead, and, as much as anything, hope.

6. **Receive the Gifts that Come**

   Accept with a grateful heart what is yours to receive. This may include living you life more fully as a result of this practice. Other gifts may include uncovering your genuine self, enjoying wonderful relationships, finding personal satisfaction, realizing you have made a difference, receiving your own healing, and exploring some of life’s most valuable lessons.

7. **Live a Life of Wholeness and Balance**

   There is more to life than being a healing presence. So live your days fully, caring for your own needs, setting appropriate boundaries, encouraging your own growth, and nurturing a loving attitude toward life, including the sacred dimension. Affirm and live out the truth of the transforming potential of healing presence. Be grateful for the possibilities.

This requires Intentionality...

**A personal narrative from a physician chaplain: Preparing One’s Attention and Intention**


I now appreciate that the most important thing I bring to each bedside encounter is myself, and how my presence comforts and heals. Before visiting a patient, I stop to prepare two things, my attention and intention. This is something I teach to all my students. This allows for greater connection and meaning. It also can open us to the sacred. It applies whether one is providing routine medical treatment or spiritual care.

There are many ways different people prepare their attention and intention. I have developed a simple ritual for myself. Before I enter my patient’s room, I stop. While washing (or gelling) my hands, I prepare my attention. I bring my awareness to my
feet on the ground, then to my breath, and to the flow of water (or gel) over my hands, as if they are washing aside (evaporating away) my preoccupations, leaving only my best intentions. I make a blessing before I dry my hands (or as my hands are drying): I lift up my hands. May I be of service. Then I take a full breath and remind myself: What matters for you, my patient, is what matters for me. May I meet you in your world as it is for you and accompany you from there. Whatever time I have with you, may I be fully present. May I serve you with all of my life experience as well as my expertise? May I listen fully with a generous heart, without judgment, and without having to fix what cannot be fixed. May my presence allow you to connect with your source of comfort, strength, and guidance as it is for you. May I be well used. Before entering the room, I stop again, take another full breath to keep my focus, and then I knock. When I enter, I scan the room, “touch” the patient with my eyes, then with my voice, and then, as appropriate, with my hand. I cannot know who and what I will encounter when I enter the room. What stories, what emotions, will I even be welcome? I do know that my preparation can facilitate meaningful connection. It also can open the way to what may normally be unseen, which can announce itself to any of us at unexpected times, in unexpected ways, with unexplainable, sometimes extraordinary, moments of awe. Such moments can help sustain one through challenging times.
Critiquing Our Ability to Respond to Human Suffering: Jean’s Narrative

When my doctor first told me that I was going to die from my disease, the image that came floating to my mind was this: I would just be going along living as usual, and living a little more, then I would just fall into a big hole in life (opened up just for me) and be dead. It was a shocking thing—thinking of being dead. Thinking about it now, that first image—fall in, be dead, sounds pretty dang naïve and optimistic.

My real life dying is turning out to be a whole lot harder than that. Lots slower and lots more demanding. I’m going in bits. I mourn each individual piece as I lose it.

The first thing to go was my equilibrium. I lost it the moment my prognosis seeped through the haze and into my head. I lost that sense I had when I woke up in the morning that the world was in balance and that my spot in it was solid and secure. Then I lost that feeling of being all in one piece. Body, mind, spirit. Be. Body had created such a breach. Breach of trust. Breach of faith. Breach of peace. My peace. It was hard to know what to trust if I couldn’t trust my own body.

After that, my mind demonstrated to me its limitations. I had always believed that I could rely on my mind to overpower any frailty of body or spirit. Then one day, it couldn’t. I walked myself into the bathroom at work and when I was finished in there, I simply could not get my legs to stand back up. I tried for hours. I sat there, deep toilet grooves around my bottom in disbelief. I had walked to the absolute end of my strength.

Then my bones started breaking. I stood up using my crutches and my arm broke. When that healed, I stood again and my leg broke. Five times my arm or leg broke within a few seconds of my standing. Hello wheelchair. The worse consequence of being in a wheelchair is that I can’t go visit friends at their homes. Almost none of them have accessible housing. They come to visit me, and I’m very glad that they do, but I really miss getting to see them in their own places. Back to bones. Breaking. Now a cough or a sneeze can break a rib. Roll over wrong while I’m asleep and I can wake up with a broken foot. Or arm. Or....

Now my body is getting too spent for chemo. Chemo used to lay me low for four days. Then it stretched to five and now it is usually six. Then comes my nadir. How low can you go? Pretty dang low. Nurses come twice a day to give me lasix transfusions to keep some blood in me. It’s not enough. Blood leaks out of me everywhere. I try to ignore it, but it’s bright and scary.

The tumors in my head have grown. They say they’re benign. Let’s see...what does benign mean? “Gentle or kindly, tender, compassionate.” Well, these kindly tumors grew enough so that they created pressure in my head. Then, when my platelets bottomed out, I had a head bleed. Now my left side works only when I think hard about it. Concentrate. Don’t neglect that left arm. Leg.

That happened two months ago. Last nadir. Now it’s this nadir. I’ve been home for five days. Waiting to see how low I can go. To see if I bleed, if I break. Waiting.

I have learned so many forms that mourning can take. The form seems to be connected more to what shape I’m in than to the severity of the loss. I have wailed over very small losses and have furrowed my brow and move on over some pretty significant ones.

If, when my doctor told me I was going to die, she had told me it would be bit by bit, I would have thought, “Thank God! What a mercy. Not all at once. Bit by bit.” Now I sometimes find myself wondering what will be next. How many more losses can I stand? How much less


can I be and still be alive and counted?
If I saw that hole in life that I first imagined, I don’t know if I’d fall through it on purpose or not. I’m not looking for it, but if it just appeared in front of me...I don’t know. Tonight I’m tired and sick and glad I don’t see the hole so I don’t have to decide.

1. Am I the type of person who would elicit this story? What kind of persons do we need to be to elicit the telling of stories?

2. If this woman was entrusted to my care, what would my clinical priorities be? Do I possess the broad-based clinical competencies, which would allow me to be responsive to the human needs of this woman?
   Is it reasonable to expect health care professionals to pay attention to human suffering?

3. How does the system need to change in order for us to be more responsive to individuals like this woman?

   "If one seeks to influence, shape, direct, heal, elevate, and enrich a complex industrial democracy, it cannot be done simply by integrity of individual witness. It is done by institutions that lay hands on life at the critical points where life can be injured or fostered, where people are born and die, where they learn and teach, where they are cured and healed, and where they are assisted when in trouble." [Rev. J. Bryan Hehir]

Changing individual behavior is difficult, but changing an organization or culture is potentially a greater challenge--and often is a precondition for individual change. Deficiencies in care often reflect flaws in how the health care system functions, which means that correcting problems will require change at the system level. [AMA]

4. If I want to be a person of integrity, how should my religious beliefs and faith commitments influence my care of the dying?
5. What are the societal forces which are impeding and facilitating quality end-of-life care?
Reflective Practice

And now, weak, short of breath, my once-firm muscles melted away by cancer, I find my thoughts, increasingly, not on the supernatural or spiritual, but on what is meant by living a good and worthwhile life — achieving a sense of peace within oneself. I find my thoughts drifting to the Sabbath, the day of rest, the seventh day of the week, and perhaps the seventh day of one’s life as well, when one can feel that one’s work is done, and one may, in good conscience, rest. [Sacks, O. (August 14, 2015). Oliver Sacks: Sabbath. Sunday Review, New York Times.]

What Four Icons, Emmanuel, Maynard, Sacks and Kalanithi Have to Contribute to Our Creative Conversations about Good Dying

The 1983 President’s Commission Report on Health Care Decision Making recommended the model of shared decision making over the Hippocratic/paternalistic model and the patient sovereignty model. In recent years major forces in the U.S., including the current HCAHPS patient satisfaction scores, have resulted in many clinicians abdicating their role in treatment decisions and capitulating to patient preferences/demands. Too often these choices result from deficient knowledge, unrealistic expectations, fears, etc.

In the last two years several very public figures have engaged media attention by sharing their preferences about how to confront aging, serious illness, and anticipated death. Given the moral heterogeneity in the U.S. and the lack of consensus about the role aging, suffering, illness, dying and death play for humans: evils to be avoided at all costs, necessary evils to be suffered stoically, or paths to our transformation and flourishing, what guidance can any clinician, ethicist or sage offer?

I share the following questions for your reflection and discourse.

1. In his new book, The Road to Character (2015), David Brooks focuses on the deeper values that should inform our lives. Responding to what he calls the culture of the Big Me, which emphasized external success, Brooks challenges us, and himself, to rebalance the scales between our “resume virtues”—achieving wealth, fame, and status—and our “eulogy virtues,” those that exist at the core of our being: kindness, bravery, honesty, or faithfulness, focusing on what kind of relationships we have formed.
   a. What role can the challenges of aging, suffering, illness, dying and death play in our lives? Are they necessarily evils to be avoided at all costs?
   b. Might they be invitations/opportunities to focus on what really matters and to cultivate the virtues that give meaning and purpose to our lives?
   c. We often hear that suffering can “make” or “break” us. How can professional healers help those who are suffering use their experiences to become more integrated and whole?

2. Do health care professionals working with individuals experiencing aging, suffering, illness, dying and death have an obligation to “journey” with them as experienced and wise guides? Is it ever appropriate to make a recommendation or to challenge
an expressed preference? Is it obligatory to do so? Do any of us believe we are qualified to be “wise guides?” Should we be?

3. The last of Erik Erikson’s psychosocial stages is ego integrity versus despair. Universal spiritual needs are meaning and purpose, love and relatedness, and forgiveness. What role should clinicians play as individuals struggle with questions about their lives’ meaning and worth?

4. What role do/should clinical ethicists play in informing conversations and decisions about treatment and care for those experiencing aging, illness, suffering, dying and death?

5. Given the coming silver tsunami (mass geriatric society) these questions assume a special urgency. Is there a better way to think about aging and death than enemies to be conquered? [Think war on aging and death...] When we think about human flourishing... what do we do with the assaults related to aging, illness and death? We live in a society that hardly reveres its elders. Should we be part of challenging what we message to older and seriously ill brothers and sisters?

Ezekiel Emanuel
That’s how long I want to live: 75 years. I am sure of my position. Doubtless, death is a loss. It deprives us of experiences and milestones, of time spent with our spouse and children. In short, it deprives us of all the things we value. But here is a simple truth that many of us seem to resist: living too long is also a loss. It renders many of us, if not disabled, then faltering and declining, a state that may not be worse than death but is nonetheless deprived. It robs us of our creativity and ability to contribute to work, society, the world. It transforms how people experience us, relate to us, and, most important, remember us. We are no longer remembered as vibrant and engaged but as feeble, ineffectual, even pathetic. [Emanuel, E.J. October 2014. The Atlantic Monthly. Why I hope to die at 75].

Brittany Maynard
In April, I learned that not only had my tumor come back, but it was more aggressive. Doctors gave me a prognosis of six months to live. After months of research, my family and I reached a heartbreaking conclusion: There is no treatment that would save my life, and the recommended treatments would have destroyed the time I had left. I considered passing away in hospice care at my San Francisco Bay-area home. But even with palliative medication, I could develop potentially morphine-resistant pain and suffer personality changes and verbal, cognitive and motor loss of virtually any kind. Because the rest of my body is young and healthy, I am likely to physically hang on for a long time even though cancer is eating my mind. I probably would have suffered in hospice care for weeks or even months. And my family would have had to watch that. I did not want this nightmare scenario for my family, so I started researching death with dignity. It is an end-of-life option for mentally competent, terminally ill patients with a prognosis of six months or less to live. It would enable me to use the medical practice of aid in dying: I could request and receive a prescription from a physician for medication that I could self-ingest to end my dying process if it becomes unbearable. I quickly decided that death with dignity was the best option for me and my family. [Maynard, B. November 2, 2014. My right to death with dignity. http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/index.html]
Oliver Sacks
It is up to me now to choose how to live out the months that remain to me. I have to live in the richest, deepest, most productive way I can. I feel intensely alive, and I want and hope in the time that remains to deepen my friendships, to say farewell to those I love, to write more, to travel if I have the strength, to achieve new levels of understanding and insight. I cannot pretend I am without fear. But my predominant feeling is one of gratitude. I have loved and been loved; I have been given much and I have given something in return; I have read and traveled and thought and written. I have had an intercourse with the world, the special intercourse of writers and readers. Above all, I have been a sentient being, a thinking animal, on this beautiful planet, and that in itself has been an enormous privilege and adventure. [Sacks, O. February 19, 2015. My Own Life. The New York Times.]

And now, weak, short of breath, my once-firm muscles melted away by cancer, I find my thoughts, increasingly, not on the supernatural or spiritual, but on what is meant by living a good and worthwhile life — achieving a sense of peace within oneself. I find my thoughts drifting to the Sabbath, the day of rest, the seventh day of the week, and perhaps the seventh day of one’s life as well, when one can feel that one’s work is done, and one may, in good conscience, rest. [Sacks, O. (August 14, 2015). Oliver Sacks: Sabbath. Sunday Review, New York Times.]

Paul Kalanithi
Kalanithi’s diagnosis is both a death sentence and an opportunity—albeit an unwanted one—for the kind of introspection that many of us claim to want but that never seems possible unless forced by tragedy. His decision to go to medical school, he writes, was an effort “to forge relationships with the suffering, and to keep following the question of what makes human life meaningful, even in the face of death and decay.” Krug, N. January 9, 2016. An affirmation of life in the face of death. Book World. The Washington Post, C1, 4.

My brother arrived at my bedside. “You’ve accomplished so much,” he said. “You know that, don’t you?” I sighed. He meant well, but the words rang hollow. My life had been building potential, potential that would now go unrealized. I had planned so much, and I had come so close. I was physically debilitated, my imagined future and my personal identity collapsed, and I faced the same existential quandaries my patients faced. The lung cancer diagnosis was confirmed. My carefully planned and hard-won future no longer existed. Death, so familiar to me in my work, was now paying a personal visit. Here we were, finally face-to-face, and yet nothing about it seemed recognizable. Standing at the crossroads where I should have been able to see and follow the footprints of the countless patients I had treated over the years, I saw instead only a blank, a harsh, vacant, gleaming white desert, as if a sandstorm had erased all trace of familiarity. Kalanithi, P. 2016. When breath becomes air. New York, Random House, pp. 120-121.