Hope and Good Dying
What Do Chaplains Have to Offer when Cure is “Off the Table”?

Carol Taylor, PhD, RN
Georgetown University School of Nursing and Health Studies
Kennedy Institute of Ethics
taylorcr@georgetown.edu
Making All Things New:
Co-Creation, Transformation, Resilience and Hope

Hope...
Sometimes that’s all you have when you have nothing else.
If you have it, you have everything.
Mercy

• “Spreading the Gospel means that we are the first to proclaim and live the reconciliation, forgiveness, peace, unity, and love that the Holy Spirit gives us.”
  — Pope Francis, The Church of Mercy
"A year later," Palin said, "I gotta ask the supporters of all that, 'How's that hopey, changey thing working out for ya?" "

February 7, 2010
“Dying in America Is Harder Than It Has To Be”
Dying in America, IOM report, Sept. 17, 2014

• The American health care system is poorly equipped to care for patients at the end of life.
• Despite efforts to improve access to hospice and palliative care over the past decade, the committee identified major gaps,
  – a shortage of doctors proficient in palliative care,
  – reluctance among providers to have direct and honest conversations about end-of-life issues, and
  – inadequate financial and organizational support for the needs of ailing and dying patients.
Suicide Rate on the Rise

• The age-adjusted suicide rate in the U.S. jumped 24% between 1999 and 2014. Led by an even greater rise among middle aged white people, especially women. The Washington Post, Friday, April 22, 2016
Causative Factors

• Economic recession
• More drug addiction
• “Gray divorce”
• Increased social isolation
• Rise of the Internet and social media
Dear Mildred,
We have moved to Washington State to live with our daughter. Both of us are sick and cannot take care of ourselves. In July I had back surgery and Steve had a prostate operation. We are 78 and 80 years old, so we are not healing too fast. Both of us have to walk with walkers. Miss my home in New Jersey so much. If ill health won’t kill me depression will. And it’s no picnic living with my daughter. I think all she wanted out of me and pop is the money for the sale of my house. I’m sorry I ever gave her power of attorney. She says I should be glad I have some one to take care of us. And we don’t appreciate what’s being done for us. Hope you’re in good health.
Love and Blessings
Ann and Steve
p.s. new address on envelope
Today’s Outcasts

• More than 5 million Americans are living with Alzheimer’s disease.
• 1 in 3 seniors has Alzheimer’s disease.
• In 2013, 15.5 million family and friends provided 17.7 billion hours of unpaid care to those with Alzheimer’s and other dementias – care valued at $220.2 billion.
Why I Hope to Die at 75

An argument that society and families—and you—will be better off if nature takes its course swiftly and promptly

By Ezekial Emanuel, The Atlantic, October 2014
Do You Know These Women?
Two women captured our hearts.
Both were dying of brain cancer.
Both taught us to cherish life—that nothing is greater than the human spirit.

• Brittany Maynard, 29, fought for the right to die with dignity. On Saturday, November 1, 2014, Maynard, who suffered from terminal brain cancer took her last breath. She had moved to Oregon to end her life under that state’s Death with Dignity Act.

• Lauren Hill, 19, fought for a dream—to play in a college basketball game before she dies. Her cause was infectious as she conveyed a never-give-up spirit [CNN News, Nov. 6, 2014].
Emerging Voices

NPR host Diane Rehm emerges as key force in right-to-die debate

My Own Life, Oliver Sacks on Learning he has terminal cancer

February 17, 2015

February 19, 2015
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.]
• Diane Rehm
  – http://www.washingtonpost.com/local/npr-host-diane-rehm-emerges-as-a-key-force-in-the-right-to-die-debate/2015/02/14/12b72230-ad50-11e4-9c91-e9d2f9fde644_story.html
  – http://thedianerehmshow.org/shows/2015-02-17/the_latest_in_the_debate_over_aid_in_dying

• Oliver Sacks
  – http://www.nytimes.com/2015/02/19/opinion/oliver-sacks-on-learning-he-has-terminal-cancer.html
  – Gratitude
Dr. Paul Kalanithi
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.

Realizing ourselves... Becoming true

• 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. (Rahner, K. 1971, How to receive a sacrament and mean it. Theology Digest, 19, 229)
During the winter it was good the seed remained hidden in the earth, but in spring, if it does not bud it rots.

(Illich, I. (June 1955). The American Parish. *Integrity*, 5-16.)
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
  3. Need for forgiveness

• Erikson’s last developmental stage: ego integrity vs despair
Spiritual Care

- Care that enables individuals to meet basic spiritual needs: (1) need for meaning and purpose, (2) need for love and relatedness, and (3) need for forgiveness.

- 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.]
Francis’s Year of Mercy

• Jesus' attitude is striking: we do not hear the words of scorn, we do not hear words of condemnation, but only words of love, of mercy, which are an invitation to conversation. "Neither do I condemn you; go, and do not sin again." Ah! Brothers and Sisters, God's face is the face of a merciful father who is always patient. Have you thought about God's patience, the patience He has with each one of us? That is His mercy. He always has patience, patience with us, He understands us, He waits for us, He does not tire of forgiving us if we are able to return to Him with a contrite heart. "Great is God's mercy," says the Psalm.

— Angelus on March 17, 2013
Francis’ Year of Mercy

• God's mercy can make even the driest land become a garden, can restore life to dry bones (cf. Ez 37:1-14). ... Let us be renewed by God's mercy, let us be loved by Jesus, let us enable the power of his love to transform our lives too; and let us become agents of this mercy, channels through which God can water the earth, protect all creation and make justice and peace flourish.

— Easter Urbi et Orbi message on March 31, 2013
Visualize the plant that most represents your state of being at this time
Or perhaps something like this?
“Spreading the Gospel means that we are the first to proclaim and live the reconciliation, forgiveness, peace, unity, and love that the Holy Spirit gives us.”

— Pope Francis, The Church of Mercy
The Church as a Field Hospital
The Church as a Field Hospital

• “This is the mission of the Church: to heal the wounded hearts, to open doors, to free [people], to say that God is good, God forgives all, that God is our Father, God is tender, that God is always waiting for us ... ".
Spiritual Care and Engendering Hope

Mark’s Story
• **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.]
Six Circles of Hope
J. Donald Schumacher

- Hope for a cure;
- Hope for a sudden and long remission of disease;
- Hope for a pain-free existence;
- Hope for the resolution of interpersonal relationships;
- Hope for self-forgiveness; and
- Hope to be remembered well.
Ultimately, 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 opposite of hope is called despair, but despair is really just a another name for meaninglessness. To suffer without any sense of meaning abject hopelessness (Sulmasy 2002)
Belgian Cardinal Danneels in an address entitled “Where do I find hope” in December 13, 2001 (origins, vol. 31, pp. 445ff) writes:

- “How in our fearful times can we remain hopeful? Hope is not located somewhere at the edge of human existence: It is its heart. If it is hit, the person dies.” He offered two ways to exercise hope. First is prayer, which involves “suspending oneself between the past and the future... To pray is to consult one’s memory and to feed it. But prayer is also to look forward with a burning heart to the days to come.” Second is engagement. “Hope never materializes when people do not engage themselves, or do not make decisions or choices.”
• Cole Sear in the movie The Sixth Sense was on to something when he said "I see dead people everywhere...And they don't know they're dead." These are people without hope...
Healing Presence...
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 grown and to change.

*Healing is the integration of self. People move from a sense of brokenness to a sense of wholeness.*  
*C. Puchalski*
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. (Miller, E.J. & Cutshall, S.C. 2001. *The art of being a healing presence. A guide for those in caring relationships.* Willogreen Publishing.)
Joseph Cardinal Bernardin, A Sign of Hope

• As Christians, we are called, indeed empowered, to comfort others in the midst of their suffering by giving them a reason to hope. ...We are to do for one another what Jesus did: comfort others by inspiring in them hope and confidence in life. As God’s ongoing, creative activity in the world and the love of Christ make it possible for us to continue to live despite the chaos of illness, so too our work in the world must also give hope to those for whom we care. Our distinctive vocation in Christian health care is not so much to heal better or more efficiently than anyone else; it is to bring comfort to people by giving them an experience that will strengthen their confidence in life. The ultimate goal of our care is to give to those who are ill, through our care, a reason to hope.
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.
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.

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).
"Every day, every moment, you make choices on how to act or respond. Through these acts, you have the power to positively influence. As John Quincy Adams sagely said, 'The influence of each human being on others in this life is a kind of immortality.' So I ask you: What will be your act of courage? How will you influence your environment? What will be your legacy?"