

**CHOICES:
BEGINNING CRITICAL CONVERSATIONS
TOWARD THE END OF LIFE**



**Written by Gardner Yenawine
In Consultation With
David Almond
Richard Dutton
John Kirk
Graham McSwiney
Aarne Vesiland
James Young
Roger Wells**

Copyright © 2015

**You are welcome to copy, reference, and distribute this booklet in its entirety as long
as proper credit is given to the authors**

Preface

Dying well is about living well. It is about an event that should be planned, organized, and often entrusted to those likely to be our “community” at the end of life. Dying is about developing and maintaining healthy, trusting relationships with people we will depend on for support toward the end of our lives.

Clearly these subjects—dying and death—can be difficult. There may be great reluctance to launch the relevant conversation and often even greater reluctance on the part of involved family to willingly come to the table. When/if they do, there can be significant disagreement that may, at any point, threaten to derail the conversation.

The need to shed light on the issues to be discussed, the necessary plans to be laid, and the concrete steps to be taken must be understood and addressed if good quality of life is to be realized through the end and, when at the end, we are to “die well.”

Purpose

First, this primer is designed to encourage and support crucial conversation and planning within families and also with the surprisingly wide circle of people likely to influence our experiences as we age into the last life stage and approach death.

Secondly, this primer can help individuals and organizations to structure courses and workshops for making this important discussion a reality in appropriate community forums, at kitchen tables, in places of worship.

Introduction: David’s Invitation

“Dear _____,

I am on a journey, an end-of-life journey. The events along the way and their timing are not precisely predictable at the moment. I am concerned about how my journey affects each of you. I am interested in having one- on-one conversations so that you can share with me your concerns and feelings, I can share mine, and we can talk about how our concerns and feelings affect each other and what to do about that. Some of you may not want to do this. That’s okay. If you wish to try this, I suggest, during the week of February 6 and thereafter, we try to find convenient times for each of you to do what you want to do about this. I have few preconceived notions about this suggestion. At the moment, I am content and eager to see how the journey unfolds and then concerned about how its related events may affect you.

*Lots of love,
David”*

David was a member of our men’s discussion group, which was initiated out of a desire and need to speak of our personal concerns associated with aging. When David shared the fact that he was receiving palliative care at Dartmouth-Hitchcock Medical Center, our group naturally began to talk personally about end-of-life issues. As David’s journey progressed, he generously shared his experiences and feelings; the result was an ever-deepening exploration of our individual and shared concerns, issues, hopes, and

intentions related to the challenges and opportunities that arise as we approach the end of life and death.

Before his death, David spoke gratefully of his life, his appreciation of what it truly meant to “live in the moment,” and, especially, his end-of-life experiences with the people he loved, as well as the fullness of his connection and conversations in response to his invitation to meet and talk. He reported total acceptance of his circumstances and died peacefully and comfortably. Seemingly his only regret was that he had waited so long to connect and talk. His advice: “Do it now. Don’t wait until you are in palliative or hospice care.”

Background

Out of our group’s discussions, four domains of vital concern emerged: **Legal, Medical, Spiritual, and Community**. Some issues clearly belong in one or another of these domains; others overlap and seem less distinctly characterized by just one domain. In large part, as a legacy to our shared experience with David, we developed an outline of topics within those four domains. We then offered a workshop entitled ***End Of Life: A Discussion Among Friends*** at Colby-Sawyer College’s adult education program, “Adventures in Learning.” On the first day of registration the course filled, with a long queue of people wishing to participate should it be offered again. We have offered the course four additional times and, still, the waiting list is long.

Chapter 1: Course Objectives

Objectives of our structured workshop:

- To identify critical domains of life experiences that challenge people as they enter and move through final stages of life, namely, **LEGAL, MEDICAL, SPIRITUAL, and COMMUNITY** domains;
- To prompt reflection and conversation about challenges associated with those domains;
- To inform and guide those conversations with the help of experienced professionals well-grounded in each of the four domains;
- To empower participants to initiate conversation and planning with their families and with other stakeholders who may influence the final stage of life and the time of death.

Chapter 2: Course Structure

The class consisted of five two-hour sessions. Enrollment was limited to 24 participants. Tables to provide writing surfaces were arranged in a modified circle with the hope that all involved could see and hear whoever was speaking. During the first hour of each session, experts (two minimum, three maximum) presented key issues for consideration along with recommended action steps, and illustrative personal stories. Presenters were encouraged to have prepared “key points” documents for distribution at the conclusion of the session. **The importance of sharing real life stories cannot be overstated. These stories made the subject matter inspiring, motivational, and compelling. They drew people into the conversation.** To illustrate, a true sample story is included below for each of the four domains.

The second hour of each session provided time for questions, answers, and open discussion. We assumed that some participants would be reluctant to speak up in a large group, so both hours of the fifth session were devoted to open discussion. During the first hour of this final session, participants were asked to gather in groups of four or five around separated tables for facilitated discussion. This second hour provided opportunities for summary presentations of small group discussions and overall wrap-up. Given the overlapping nature of some issues, e.g. legal with medical, all of the expert presenters were encouraged to participate at all five sessions of the class.

Class Composition: Moderator/Facilitator, Scribe, Presenters, Participants

Responsibilities Include:

- Moderator, who welcomes and convenes the session, manages time, ensures adherence to “communication ground rules,” encourages full and open communication, stresses the importance of confidentiality (not of content but of who says what)
- Scribe, who takes session notes
- Presenters, who are topic experts experienced in both subject matter and specific knowledge of challenges and planning needs of seniors, their families, as well as their legal and healthcare resources, spiritual advocates, and legal representatives
- Participants with a willingness to share topic-related stories, personal concerns, and questions with presenters and each other

“Ground Rules”

Participants are strongly encouraged to:

- Make every effort to attend all sessions (because of the sensitivity of the subject matter, the comfort of participants, and the continuity of discussion)
- Accept and respect widely diverging points of view on the subject matter
- Protect the time so that all who wish to speak, can
- Avoid repeating comments that have already been made
- Assure that one person is speaking at a time, as recognized by the moderator
- Protect the confidentiality of WHO says what

Chapter 3: Session Notes

The following notes provide some understanding of the topics to consider in the four domains of life experience that we found to be essential. A few cautions:

- These notes should be viewed as opinions rather than facts.
- The notes should be shared to prompt critical conversations.
- The notes cannot and do not reflect the full range of issues associated with the topic of discussion.
- Variations in laws, customs, religious practices, and personal preferences determine personal relevance, right/wrong, good/bad, legal/illegal.

Legal Considerations

S and G are in their mid-nineties, enjoying good health, and living independently in a somewhat isolated home they built 30 years ago. Suddenly G begins rapidly losing memory and is advised to stop driving. S has had little driving practice. Further, G has always kept the books and paid the bills. Family members, near and far, agree that Mom and Dad are unable to manage the rapidly approaching winter living where they do. This decision sets into motion others that well-intentioned sons make, resulting in relocation to a retirement community near one son, loss of the car, and loss of time to prepare for a move, i.e., a loss of independence. S and G blame themselves for their failure to plan and for their sudden loss of control of a most enjoyable life.

- Durable Powers of Attorney – Financial/Medical
- Wills
- Trusts
- Tax plans
- Determining one's capacity to make rational decisions
- Delegating responsibility for the management of finances/check writing
- Accessibility of personal information/essential documents/records/contact numbers, pins and passwords
- Conflict resolution
- Mediation

Medical Considerations

Mr. B was 95, of sound and very strong mind, but quite frail. He required nursing home care and had been in a facility for several years. His Advanced Directives clearly stated that, should he suffer any life-threatening illness, he wished everything be done to preserve his life. His children were clearly aware of his desire and were not comfortable challenging it. One morning, Mr. G was found displaying the symptoms of extensive pneumonia, which examination quickly confirmed. He was unresponsive and obviously struggling to breathe, despite administration of oxygen. With his children's concurrence, Mr. G was transferred to a hospital ICU where all measures possible, short of intubation and mechanical ventilation, were undertaken, despite his continuing deterioration. He suffered mightily for his final five days, as did his children, who recognized their father's wishes to have "everything done" were not adequately informed by the specific situation as his life was ending.

- Myth of immortality
- America's historic medical model centered on cure from diagnosis to death
- Pain and suffering versus the commitment to sustaining life at all costs
- Impacts of medical/physician specialization
- Blending the biologic disease model with the palliative care model focusing on symptom management, patient comfort, quality of life, and shared, team-oriented responsibility for decision-making
- Roles of nursing, social work, spiritual advising
- Hospice

- Treatment of chronic life-threatening or life-ending illnesses
- Care prior to arrival and in the Emergency Room
- Availability/accessibility of medical records including DNR (do not resuscitate/"comfort measures only") orders in emergent circumstances
- Determination of "near-death," "death," "permanently unconscious" conditions

Spiritual Considerations

M was diagnosed with terminal cancer. Immediately following the diagnosis, she and her family enlisted the considerable resources provided by hospice care. M, a very concrete, here-and-now person who was not part of any spiritual or religious community, had trouble imagining what might follow death and expressed her fear of dying and leaving behind what she knew and valued. Because M had enrolled in hospice care early, she had time to establish meaningful relationships with her hospice nurses and felt comfortable discussing her fears with them. M eventually found peace with dying and what might come after death.

- Definition of "spiritual" life
- Distinguishing spiritual life from religious life
- Helping resources
- Ethical will
- Grief
- Experiencing the loss of future
- Collecting and sharing "Life Stories"
- Prayer/pastoral care
- Timing for hospice care

Communal/Community Considerations

After living with cancer for many years and, at times, heroically battling its progress, T was hospitalized and terminally ill. As death approached, her dedicated team of nurses *assumed* she wanted to die in the comfort of her own home with family and close friends. Every effort was being made to accomplish this objective. Then, unexpectedly, the patient vehemently expressed her wish to stay right where she was in the hospital; her genuine desire was for her family's final memories to be of her when she was well at home, doing what she loved most, tending a lovely garden, not dying. Once her wishes were understood, they were honored.

- Defining "dying well/good death"
- Encouraging family dialogue
- Identification of the challenges and opportunities associated with the last stage of life and death
- Demystifying administrative details of dying
- Support services for primary caregivers
- Options for home care
- Identifying and coordinating the missions and work of community institutions
- Legacy Gifts
- Understanding the nature of grief and grieving
- Depression and suicide – rights and responsibilities

- Euthanasia
- Funeral and memorial services

Chapter 4: Glossary of Terms

(Caution: Definitions vary from state to state; New Hampshire is used as an example.)

Advance Directive: A legal document that allows you to control decisions about end-of-life care if you become unable to make those decisions for yourself. In NH, it is a two-part set of instructions. First, you delegate who you want to make decisions for you should you become incapacitated. Second, you can decide what medical treatments you want or don't want should you be near death or permanently unconscious without reasonable hope of regaining consciousness. You can alter or cancel your advance directive orally or in writing at any time.

Durable Power of Attorney for Health Care: This gives the legal right (Power of Attorney) to someone you designate to make medical decisions for you if you become unable to make those decisions for yourself. You are allowed to select more than one person; however, the first name listed generally has primary responsibility for making any decisions.

A **Living Will** is a part of New Hampshire's advance directive form where you can instruct your doctor or healthcare provider on what life-sustaining treatment, if any, you want to have if you are near death or permanently unconscious, without hope of recovery. In this section of the form, you can choose, for example, to state that even if all other forms of life-sustaining treatment (such as respirators to help you breathe or dialysis) are removed, medically administered pain relief, nutrition, and hydration should continue to be given (or not).

Witness: For an advance directive to be valid, it needs to be signed either in the presence of two witnesses (both over the age of 18), or the directive has to be notarized. A lawyer is not needed but can be helpful in answering any questions.

Near Death: NH defines "near death" as an incurable condition caused by injury, disease, or illness, which is such that death is imminent, and the application of life-sustaining treatment would, to a reasonable degree of medical certainty, only postpone the moment of death. It takes two physicians, or one physician and one nurse practitioner, in agreement, to certify that someone is near death.

"Capacity" to make healthcare decisions means that a person has capacity if he or she can understand the significant risks and benefits of healthcare decisions. An advance directive gets activated only when a doctor determines that the patient is incapacitated. It is important to know that patients can regain capacity, and, when that happens, they regain the right to make their own healthcare decisions.

DNR stands for Do Not Resuscitate. If you stop breathing or your heart stops beating, medical staff normally perform CPR to try to restart your heartbeat or breathing. A DNR order is a medical order that says medical staff should not attempt to resuscitate you in this situation. You can include a DNR order in your advance directive, or a DNR order can be made separately.

Life-Sustaining Treatment includes any medical procedures or interventions that use mechanical or other medically-administered means to sustain, restore, or supplant a vital function that, in the written judgment of the attending physician or nurse practitioner, would serve only to artificially postpone the moment of death for a person who is near death or is permanently unconscious.

Medically administered nutrition and hydration, sometimes called artificial nutrition and hydration, is a medical intervention that delivers nutrition and/or fluids via a tube passed through the nose and into the stomach, through a tube surgically placed directly into the stomach, or through a vein. NH now considers medically administered nutrition and hydration to be life-sustaining treatment.

Curative Medicine is medical treatment with the goal focused on cure, usually physician-directed.

Palliative Medicine is care focused on pain- and symptom-management with the goal of patient comfort, usually team-directed with participation of patient, family, doctors/nurses, palliative and/or hospice care people.

Hospice is a Medicare entitlement available in the likely final six months of life as determined by a physician or nurse practitioner.

End of Life is an extended process that could include diagnosis, treatments, palliative care, hospice, death, and the grieving process.

THE END OF LIFE: A DISCUSSION AMONG FRIENDS

Reading and Resources List

- Alexander, Eban III. Proof of Heaven: A Neurosurgeon's Journey into the Afterlife. New York: Simon and Schuster, 2012.
- Bailey, Sue, and Flowers, Carmen. Grave Expectations: Planning the End Like There's No Tomorrow. Kennebunkport, ME: Cider Mill Press, 2009.
- Baltins, Andris. Love Letters: Reflections on Living With Loss. Minneapolis: Syren Book Co., 2007.
- Beresford, Larry. The Hospice Handbook: A Complete Guide. Canada: Little, Brown and Co., 1993.
- Brody, Jane. Guide to the Great Beyond: A Practical Primer to Help You and Your Loved Ones Prepare Medically, Legally, and Emotionally for the End of Life. New York: Random House, 2009.
- Byock, Ira. Dying Well. New York: Berkley Publishing, 1997.
- Byock, Ira. The Best Care Possible: A Physician's Quest to Transform Care to the End of Life. New York: Berkley Publishing, 2012.
- Byock, Ira. The Four Things That Matter Most: A Book About Living. New York: Simon and Schuster, 2014.
- Callahan and Kelley. Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying. New York: Simon and Schuster, Inc., 2012.
- Cassell, Eric J. The Nature of Suffering and the Goals of Medicine, Second Edition. New York: Oxford University Press, 2004.
- Church, Forrest. Love and Death, My Journey Through the Valley of the Shadow. Boston: Beacon Press, 2009.
- Coste, Joanne Koenig. Learning to Speak Alzheimer's. New York: Houghton Mifflin Harcourt Publishing Co., 2004.
- Gawande, Atul. Being Mortal. New York: Henry Holt and Co., 2014.
- Halifax, Joan. Being With Dying: Cultivating Compassion and Fearlessness. Boston: Shambhala Publications, 2008.
- Heffner, John E., and Byock, Ira. Palliative and End of Life Pearls. Philadelphia: Hanley and Belfus, Inc., 2002.
- Jacoby, Susan. Never Say Die: The Myth and Marketing of the New Old Age. New York: Vintage Books, 2012.

- Lattanzi-Licht, Marcia, Miller, Galen W., and Mahoney, John J. The Hospice Choice: In Pursuit of a Peaceful Death. New York: Fireside, 1998.
- Longaker, Christine. Facing Death and Finding Hope: A Guide to the Emotional and Spiritual Care of the Dying. London: Doubleday, 1998.
- Mace, Nancy L., and Rabins, Peter V. The 36 Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Related Dementias, and Memory Loss. NY: Grand Central Life and Style, 2012.
- McCullough, Dennis. My Mother, Your Mother: Embracing "Slow Medicine," the Compassionate Approach to Caring for Your Aging Loved Ones. New York: Harper Collins, 2008.
- McFadden, Susan H., and McFadden, John T. Aging Together: Dementia, Friendship, and Flourishing Communities. Baltimore: Johns Hopkins University Press, 2011.
- Neal, Mary C. To Heaven and Back: A Doctor's Extraordinary Account of Her Death, Heaven, Angels, and Life Again: A True Story. Colorado Springs: WaterBrook Press, 2012.
- Newmark, Amy, and Geiger, Angela T. Chicken Soup for the Soul: Living with Alzheimer's and Other Dementias. Cos Cob, CT: Chicken Soup for the Soul Publishing, 2014.
- O'Kelly, Eugene. Chasing Daylight: How My Forthcoming Death Transformed My Life. New York, NY: McGraw Hill, 2006.
- Okun, Barbara, and Nowinski, Joseph. Saying Goodbye: How Families Can Find Renewal Through Loss. New York: Berkley Publishing, 2011.
- Oliver, Mary. New and Selected Poems. Boston: Beacon Press, 1992.
- Rachels, James. "The Morality of Euthanasia," Matters of Life and Death. Edited by Regan, Tom, et al. New York, NY: Random House Inc., 1992.
- Remen, Rachel Naomi. Kitchen Table Wisdom: Stories That Heal. New York, NY: Berkley Publishing, 1997.
- Sabatino, Charles. Eight Advance Care Planning Lessons That Took Me Thirty Years to Learn. American Bar Association, Bifocal, Vol. 34, No. 6, July/August, 2013.
- Simonds, Phillip. Learning to Fall: The Blessings of an Imperfect Life. New York, NY: Bantam Books, 2003.
- Snyder, Lisa. Living Your Best Life with Alzheimer's. North Branch, MN: Sunrise River Press, 2010.

Sporborg, Nancy. It's Not About the Hike: Two Ordinary Women on an Extraordinary Journey. Peterborough, NH: Bauhan Publishing, 2011.

Taylor, Natalie. Signs of Life: A Memoir. New York, NY: Random House, 2012.

Verhey, Allen. Christian Art of Dying: Learning from Jesus. Grand Rapids, MI: Willia B. Eerdmans Co, 2011.

Wanzer, Sidney, and Glemullen, Joseph. To Die Well: Your Right to Comfort, Calm, and Choice in the Last Days of Life. Philadelphia: Da Capo Press, 2008.

Helpful Web Sites:

Aging With Dignity
Caring Connections
Compassion and Choices
Fresno Buddhist Temple
Funeral Wise
Good Funeral Guide
Healthy New Hampshire
Hospice Directory
The Conversation Project