**End-of-Life Care:**

**Ensuring Your Wishes Are Known**

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February 27, 2024

The difference between a bad death and a good death often depends on whether people have taken the time to think through how they would like to die, made sure to put their thoughts in writing, and discussed their thinking with their loved ones and doctors.

Today, we’ll explore why clarifying your thoughts, writing them down, and talking with your loved ones and doctors about your end-of-life preferences are crucial. These discussions can reduce pain and suffering and ensure dignity and peace of mind for you and your family.

My parents and three brothers never did any of these things, and it explains why they all had bad deaths.

We’ll discuss three key steps: first, selecting **a health care agent** who can advocate for you; second, completing **an advance directive** to document your wishes; and third, **initiating** **conversations** with your family and doctors about your end-of-life preferences.

**Step One: Selecting a Health Care Agent**

A critical component of an advance directive is choosing your health care agent, also known as your health proxy, medical advocate, surrogate, or medical power of attorney. Your health care agent is authorized to make medical decisions on your behalf if you cannot do so yourself.

Your health care agent must know you well, understand your values, and be willing to follow your advance directive. If you prefer a dignified natural death, your health care agent can ensure you are not subjected to aggressive, futile medical interventions that do more harm than good. When recovery is no longer possible, emphasis will shift to comfort care. Adhering to your advance directive, your health care agent will opt for a Do Not Resuscitate (DNR) order or Allow Natural Death (AND) order and stop interventions like CPR and mechanical ventilation.

Having a health care agent who has documented authority, combined with a knowledge of your desires, maybe the only way to prevent an over-zealous and invasive treatment program that prolongs suffering and reduces quality of life.

If, on the other hand, your advance directive asks that doctors pursue all available intensive treatments, regardless of your quality of life and functional status, then your health care agent will do their utmost to fulfill that request.

**QUESTIONS AND COMMENTS**

**Step Two: Prepare an Advance Directive**

As I’ve said, every person must have a health care agent who will speak knowledgeably and compassionately on their behalf. But that health care agent must be equipped with the tools to be effective. The primary tool they need is an advance directive.

An effective advance directive goes beyond mere medical instructions. It articulates our aspirations for life, helping to define what makes life meaningful to us. Every person will value life’s pleasures differently, but a list might include engaging in meaningful conversations with loved ones, going to the toilet without needing help, enjoying meals, and retaining mobility.

When our loved ones and doctors understand our values and what we consider an acceptable quality of life, they are better equipped to make decisions that align with our desires. Imagine framing the quality of our life through the lens of everyday joys and abilities that we hold dear. Our health care agent is then empowered to evaluate potential medical outcomes against these benchmarks to ensure our care is consistent with our personal definition of a life worth living. Consider what aspects of life you find indispensable:

* The joy of recognizing and interacting with your partner, family, and friends
* The ability to communicate with loved ones
* The independence to manage personal care and avoid incontinence
* The simple pleasure of feeding yourself
* The engagement in cherished activities like reading, and
* The autonomy of living in your own home rather than in institutional care.
* Each of you will have other items to include in such a list.

By explicitly documenting these criteria in your advance directive, you enable your health care agent to make informed decisions that honor your values and preferences. This clarity helps safeguard your dignity and ensures that your care truly reflects what you consider critical to your quality of life. You are describing a minimum quality of life where it would still be worth it to keep living. Anything less than your minimum, and you want your health care agent to stop pursuing aggressive medical interventions.

Completing an advance directive can seem daunting at first. However, many resources are available to guide you. For a comprehensive understanding and step-by-step assistance, the following websites are helpful:

* *For residents of Maryland*, the Attorney General’s office provides a dedicated portal with state-specific information and forms at [Maryland Health Care Directives](https://www.marylandattorneygeneral.gov/Pages/HealthPolicy/AdvanceDirectives.aspx).
* ***MyDirectives.com***: A digital platform for creating, storing, and sharing advance directives, available at [mydirectives.com](http://mydirectives.com).
* ***AARP***: Offers extensive resources on health, legal, and end-of-life planning, accessible at [aarp.org](http://aarp.org).
* ***Compassion & Choices***: Provides information and support for end-of-life care decisions, including advance directives, at [compassionandchoices.org](http://compassionandchoices.org).
* ***The Conversation Project***: An initiative aimed at helping people talk about their wishes for end-of-life care. Visit [theconversationproject.org](http://theconversationproject.org) for tools and tips on starting these important discussions.
* ***Final Exit Network***: <https://finalexitnetwork.org/advance-directives-for-dementia/>

**QUESTIONS AND COMMENTS**

Despite the profound importance of advance directives, only about 40 percent of Americans have completed them, with the figure dropping to around 20 percent in communities of color. We must strive to increase these shockingly low numbers.

The legal field is increasingly acknowledging the duty of doctors and hospitals to review and follow advance directives, with legal consequences becoming more pronounced for those who fail to comply. This shift is evidenced by the growing number of lawsuits alleging wrongful prolongation of life, which emphasize the critical need for adherence to patients’ end-of-life wishes as expressed in their advance directives. Such legal trends underscore the increasing importance of respecting patient autonomy and the documented preferences regarding their care.

Preparing an advance directive takes time and reflection, but the peace of mind it brings you and your loved ones is invaluable. It’s a precious gift to your children and survivors, who won’t be left wondering what you may have wanted.

If you have a serious illness, I recommend supplementing your advance directive with a POLST or [MOLST form (Medical Orders for Life-Sustaining Treatment)](https://www.umms.org/bwmc/patients-visitors/for-patients/advance-directive-molst). While an advance directive allows you to make decisions about your *future* medical care, the POLST/MOLST form is a form for *right now*. Signed by a doctor, it contains medical orders about CPR and other life-sustaining treatments you want or don’t want. See <https://polst.org/>

**QUESTIONS AND COMMENTS**

**The Special Case of Alzheimer’s and Other Dementia**

Alzheimer’s and other dementia present special issues. A stunning 45 percent of older adults die suffering from dementia. Some of them may appear happy, even though earlier, with a clearer mind, they had set limits to continuing treatments.

For many of us, the prospect of enduring the late stages of dementia is intolerable, but each person’s tolerance for such decline varies, making it imperative to define and document the point at which life-prolonging treatments are no longer desired. People should have the right to refuse to endure the profound mental and emotional decline characteristic of advanced dementia.

The key to ensuring that one’s end-of-life wishes are honored, even in the grip of advanced dementia, is having a dementia provision or coda as part of your advance directive. Compassion & Choices offers a comprehensive model for such a provision, available at their website: [Compassion & Choices Dementia Values Tool](https://www.compassionandchoices.org/dementia-values-tool). This provision enables individuals to explicitly state their preferences regarding treatments, nutrition, ventilation, antibiotics, and other medical interventions should they face advanced dementia.

**QUESTIONS AND COMMENTS**

**Step Three: Crucial Conversations with Health Care Agents, Loved Ones and Doctors**

A health care agent can learn only so much from an advance directive and dementia coda. Doctors might also ignore them, or they might get lost, or be made irrelevant if the patient’s preferences change. Perspectives on certain treatments, like intubation, may shift with time or changing health conditions.

Thus, you must supplement the written document with conversations. Advance directives alone cannot guarantee that end-of-life wishes will be respected. Even a highly detailed advance directive will never cover all medical situations, so having an ongoing conversation with your health care agent is essential.

These discussions ensure that those making decisions on your behalf are fully informed of your values and preferences, enabling them to act in your best interest even in situations not explicitly covered by your advance directive.

At a time of stress, when doctors may instinctively fall back into a treatment-at-all-costs mindset, your health care agent may need to be able to recollect seeing and hearing you talk clearly about your wishes and your values. No written document can be as powerful as the human connection provided by a face-to-face exchange.

**QUESTIONS AND COMMENTS**

Normalizing conversations about death and dying is essential if we want more people to experience peaceful and dignified deaths. To begin these crucial discussions, consider using relatable starting points. For example:

* Reflect on a personal experience: You might say, “Remember Aunt Sarah’s death? Would you consider her death peaceful or difficult? How would you envision a different end for yourself?”
* Invoke family history: You might say, “Thinking back to Grandpa’s final days, what are your thoughts on how it was handled? How might we approach such situations differently?”
* Express vulnerability and seek support: You might say, “I’ve been contemplating the future and its inevitabilities. Could we talk about it together?”

Dr. Jessica Zitter, an ICU physician, frequently encounters the profound implications of the absence of these conversations. She witnesses patients sustained by medical technology—breathing machines, feeding tubes, dialysis, antibiotics—despite grim outlooks for recovery or a return to their previous way of life. Dr. Zitter often reflects on how many of these patients might have preferred not to be maintained in such subhuman states if only they had communicated their wishes to a loved one or a doctor. Surveys consistently reveal that few people desire such an existence, yet in the absence of explicit directives, medical professionals like Dr. Zinner often feel compelled to continue life-sustaining treatments.

I recommend writing a letter to your health care agent to supplement your advance directive and conversations. I have a handout to show you what I mean and give you a template or model.

**QUESTIONS AND COMMENTS**

**Keeping Documents and Conversations Current and Available**

Preparing an advance directive and conversing with your health care agent are not one-time actions. Advance directives should be updated regularly, and conversations should be ongoing.

It is also vital that those dealing with you at the end of your life know where to find your advance directive and dementia provision. They must be readily available, so distribute copies to your family, health care agent, and doctors. Encourage your doctors to integrate your advance directive into their electronic medical records to ensure continuity of care across different providers. Additionally, consider registering your documents with platforms like the U.S. Living Will Registry or MyDirectives.com to ensure their accessibility.

**QUESTIONS AND COMMENTS (LAST CHANCE) *Describe handouts***

Let me end by telling you again why having an advance directive, a dementia coda, and conversations about death and dying are so essential.

Patients who engage in open dialogues with their doctors and loved ones about their end-of-life preferences will likely experience less suffering in their final weeks and days. Dr. Atul Gawande, in his book *Being Mortal*, highlights the profound impact of these discussions. He notes, “People who had substantive discussions with their doctor about their end-of-life preferences were far more likely to die at peace and in control of their situation and to spare their family anguish.”

Regular, thoughtful conversations about end-of-life preferences can help families and health care agents form a clear understanding of how a patient wishes to spend their final days. Dr. Gawande writes, “If end-of-life discussions were an experimental drug, the FDA would approve it.”

Initiating conversations about illness, aging, and dying while we are relatively healthy is crucial. Even brief expressions of our wishes, such as “Do everything you can to keep me alive as long as possible,” or “I never want to be on a mechanical ventilator,” or “Prioritize my comfort, even if it means using morphine,” provide invaluable guidance for your health care agent.

In this program today, we’ve navigated the critical terrain of end-of-life planning, from articulating our wishes for the final chapter of our lives to the pragmatic steps of drafting advance directives and dementia coda, appointing a trusted health care agent and engaging in what Dr. Gawande aptly describes as “the hard conversation.”

These actions are profound expressions of love and respect for our families. They are a gift to our children, providing a roadmap for achieving what many of us hope for—a good death that resonates with our values and allows us to live fully, right up to the end. Thank you.

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**I have** **the following handouts for you**:

1. My prepared remarks (the document you are reading)
2. Letters to my family describing how I want to die (labeled Appendix I)
3. Advance Care Planning (advance directives and living wills)
4. Hospice

I have other handouts for you relating to other aspects of death and dying. If you’d like to see any of them, please send me a request via email, and I’ll happily send them to you. My email is [christopher.n.palmer@gmail.com](mailto:christopher.n.palmer@gmail.com). I have also posted them on my website, [www.ChrisPalmerOnline.com](http://www.ChrisPalmerOnline.com).

1. Legacy letters (also known as ethical wills) to my family (labeled Appendix II)
2. 50 Ways to Improve Your Life, and Thus Your Death
3. Decluttering and Death Cleaning
4. How to Write a Memoir
5. How to Age Well
6. Funeral Planning
7. A letter to my family describing some ideas for my burial and memorial service (also known as a death will.)
8. Green Burial handout.
9. Live Well to Die Well

***Author bio*:**

Chris Palmer is an author, speaker, wildlife filmmaker, conservationist, educator, professor, and advocate for reform in aging, death, and dying.

He serves on the Board of Montgomery Hospice and Prince George’s Hospice and as Vice President of the Board of the Funeral Consumers Alliance of Maryland and Environs. Chris also serves on the Advisory Council for the Maryland Office of Cemetery Oversight and on the Board of the Bethesda Metro Area Village (BMAV). Within BMAV, he founded and leads the aging, dying, and death group.

He is a trained hospice volunteer and was formerly a Board member of the Green Burial Association of Maryland. He frequently gives pro bono presentations and workshops on aging, death, and dying issues to community groups.

He has written ten books. The latest, to be published by Rowman & Littlefield on October 1 this fall, is *Achieving a Good Death: A Practical Guide to the End of Life*. Proceeds from all his books fund scholarships for American University students.

Conversation About Dying Talk by Chris Palmer