**Advance Directives, “The Conversation,” and Health Care Agents**

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We must talk with our loved ones and doctors about our wishes and aspirations at the end of life and how we want to be treated.

More than two out of three U.S. adults have *not* completed an advance directive. This is a shockingly low number, given the stakes, and it underscores a paradox of American life. Americans are fascinated by death and dying—as we can see from the TV news and films that emphasize fatal accidents and murders—yet conversations about death and dying and what people want at the end of life are typically rare.

**Why Are We So Tongue-Tied When Talking About Death and Dying?**

While our attention is drawn to death and dying, actually talking about how to achieve a good death is taboo, even as we rubberneck at death at every opportunity. Why are we so reticent and tongue-tied?

Several reasons: First, parents don’t want to cause their kids anxiety and discomfort. Second, children are reluctant to raise such an intimate topic with their parents for fear of somehow tempting the gods to bring it about. And third, doctors are taciturn on the subject because death signifies that they have failed to save their patient, and no one likes to admit failure. But this lack of conversation leads to adverse outcomes for everyone.

Conversations about death and dying must become routine if we are going to achieve our goal of making it easier for people to attain peaceful and good deaths.

The difference between a hard death and a good death often depends on whether the patient has talked with their loved ones about what they want at the end of life. We should not be discussing a sick or injured person’s end-of-life wishes for the first time when they are in an ICU. That is too late.

**Advance Care Planning**

Advance care planning is the process of preparing for health care in the future, should we lose the ability to talk for ourselves. It includes completing an advance directive, deciding the treatments we would want or not want, deciding on a health care agent, and sharing our values and preferences with loved ones and doctors.

Studies have shown that patients who have participated in advanced care planning are more likely to be satisfied with their care and have care aligned with their wishes.

**Advanced Directives**

One essential way to be prepared is to have an advance directive. An advance directive is a legally valid form that allows patients to choose the type of medical care they wish to receive at the end of life when they can no longer speak for themselves.

An advance directive has three parts: selecting a health care agent or proxy, deciding on the care we want at the end of life, and deciding on what happens to our body after death: organ donation and disposal of the body (conventional burial, green burial, cremation, natural organic reduction, alkaline hydrolysis, or medical school donation.)

The consequences of not creating an advance directive include increasing the probability that we will die in an ICU in a hospital hooked up to tubes and ventilators, unable to speak and alone.

It is worth filling out an advance directive if only as a loving gift to those we cherish. Those loved ones will yearn for our guidance when we are near death, and they have to make difficult decisions on our behalf about how our life should end.

At the end of life, not having an advance directive and not having had “the conversation” can lead to overly aggressive medical interventions that might be futile and even do more harm than good. And, of course, no advance directive means that our loved ones are left struggling on their own, wondering what we would have wanted.

**Including Our Goals of Living**

Often advance directives involve a checklist where we indicate, for example, that we don’t want our life extended if we are in a persistent vegetative state. This is of limited value. What an advance directive should include is our goals of living to clarify what is meaningful to us. Concerns often revolve around being able to communicate easily with loved ones, the ability to toilet and bathe, incontinence of both urine and stool, the ability to enjoy food, and mobility.

For example, what level of physical functioning is acceptable to us with life-prolonging interventions? Perhaps being bedridden and having to use a bedpan is acceptable, but anything worse than that (for example, being bedridden and needing diapers) is not. What about mental functioning? Being able to recognize and talk with loved ones is acceptable, but perhaps being able to recognize loved ones but unable to communicate is unacceptable.

**DNR Litmus Test**

Dr. Eleanor Tanno, a doctor and educator who specializes in helping people complete their advance directives, says there is one question your family should be able to answer about your advance directive: “I would want to live as long as I could still (describe what is most important to you).” Dr. Tanno says this is one of the most critical questions to define your end-of-life wishes. It is so critical that she has termed it your “Do Not Resuscitate (DNR) Litmus Test.”

It is more important to understand our personal values and goals—our goals of care—rather than understand medical treatments. For example, we might tell our family, “In the event of a terminal illness, I do not want heroic measures.” But it’s hard to know what heroic measures mean exactly. The answer, says Dr. Tanno, is that you do not need to know medical treatments but rather understand your personal goals. In other words, these conversations are about values, and one way to name those concretely is to create your DNR Litmus Test.

The Litmus Test is where you think about which basic activities still represent a quality of life for you. Your health care agent can then subject your likely medical outcomes to that test. In other words, you ask yourself, “My life would be worth living as long as I could still (describe what is most important to you).”

For example, my life would be worth living as long as I could still:

* Recognize my spouse, grandchildren, and other members of my family
* Talk to my family
* Take myself to the bathroom (i.e., not be incontinent)
* Get out of bed
* Walk
* Swallow
* Feed myself
* Taste food
* Use a cell phone
* Read books
* Recognize my friends and talk with them
* Live on my own (i.e., not in a nursing home)

The Litmus Test helps to uncover what activities are critical to the quality of your life. What are the minimum activities that make you who you are and what you value? Are they physical activities, social activities, cognitive activities, or all of them? It’s important to discuss your Litmus Test with your health care agent as they will be the one applying this knowledge to your medical care if you cannot talk for yourself.

**Dementia and Adding a Dementia Provision to Your Advance Directive**

When a person gets Alzheimer’s or other dementia, they face the terrifying prospect of becoming a dysfunctional and different person and devastating their family. Advanced dementia can bring hellish consequences to patients and loved ones alike.

People suffering from this insidious disease have their personalities, characters, and memories eviscerated. The disease impacts not only the brain but the entire nervous system. Some may rage at their loved ones (after a lifetime of being gentle and affectionate), while others may be reduced to childlike dependence (after a lifetime of being self-confident and strong).

The Alzheimer’s Association says Alzheimer’s cannot be cured and that one in three seniors dies with (and many from) Alzheimer’s or another form of dementia. The organization also notes that improving health through exercise and nutritious eating can lower the risk of dementia.

Patients with dementia are as likely as any other patient to be given harsh medical treatments in which doctors assume that the goal of care is to prolong the quantity of life by as much as possible. Shockingly, nine out of every ten patients with dementia have at least one medical procedure in the last week of their lives, like hip or knee replacement, cardiac pacemaker implantation, mechanical ventilation, or feeding tubes.

**Extending the Lives of Dementia Patients May Be Irrational**

Advanced medical technology can now extend the lives of patients with dementia almost indefinitely, but this is both hideous and irrational. It is hard to imagine a patient seeing themselves in the future suffering from end-stage dementia and wanting a life-prolonging and painful treatment. Most of us would shake our heads in horror and say, “No thanks, just let me die peacefully, swiftly, and naturally.”

Doctors should not automatically assume that everyone with advanced dementia wants their lives extended as much as possible and wants to receive aggressive medical treatments to keep them alive as long as possible, with no thought given to their quality of life. If a patient with advanced dementia documented their wishes earlier in their lives (when they still had decision-making capability) for a gentle, dignified, and peaceful death, then that ought to be respected. Such documentation would be in the form of a dementia provision added to their advance directive.

It should be possible for patients to articulate in writing their wishes for treatment, feeding, ventilation, antibiotics, and other interventions should they later suffer from advanced dementia. Every person has the right to say they are not willing to experience significantly reduced mental and emotional function—and eventually become a different person—because of Alzheimer’s or other dementia.

**Some Patients With Advanced Dementia Would Rather Be Dead**

Some people with advanced dementia would rather be dead than suffer through the end stages of their disease—unable to walk, incapable of feeding themselves, unable to recognize loved ones, their mental and emotional faculties largely destroyed, incontinent of urine and stool, and with major personality and behavior changes.

Life-prolonging treatments under these circumstances are neither rational nor wise. If a patient has advanced dementia, the best approach is to let the person die naturally and not do anything to impede that happening while providing as much comfort as possible.

Patients with dementia usually suffer a glacially slow decline, and every patient will draw the line differently where they will cross a watershed status that is no longer acceptable to them and where they no longer want to receive life-prolonging interventions. It is crucial to document in your dementia provision (part of your advance directive) where you want to draw the line so that your caregivers, health care agent, and medical providers know what you want.

**Deciding the “Line” and Finding a Peaceful Exit Plan**

The way to achieve a peaceful and dignified death with Alzheimer’s and other dementia is to articulate in writing and in conversations with loved ones what our “line” is, past which we do not wish to live. For example, our line might be where we no longer recognize our spouse and grandchildren. At that point, our medical providers and loved ones can implement a peaceful exit plan.

Many people with dementia don’t do this planning and consequently suffer horribly through many years of anguish and misery from this devastating disease. Patients are subject to painful medical interventions, with their character and personality destroyed and their mental, physical, and emotional abilities brutally stolen from them.

We need to help people determine—in advance of the loss of decisional capacity due to dementia—the point at which they would like to forgo treatments and allow a natural death. Both patients and doctors must understand the importance of documenting one’s preferences before mental capacity is lost. Doctors should embrace the legal end-of-life wishes of their patients with dementia who have proclaimed their desire to forgo treatments or voluntarily stop eating and drinking (for those still capable).

The dementia provision must be executed at a time when the patient is fully competent and then must be advocated for by the patient’s family to ensure it is honored.

**Selecting A Health Care Agent or Proxy**

A crucial part of our advance directive is selecting who will be our health care agent. Our health care agent (also called health proxy, medical advocate, surrogate, or medical power of attorney) is the person we appoint to speak for us if we are unable to make medical decisions because we are too ill or unconscious.

Our health care agent should know us well, know our values, and be able to carry out the wishes expressed in our advance directive. If we don’t appoint a health care agent, then there is a higher chance we will receive treatments to prolong our life rather than allow a natural death.

We should choose someone who is assertive when it comes to talking with doctors, especially if the doctors tend to be authoritarian and overbearing. We also want someone comfortable with the responsibility of representing us, who knows us and our end-of-life wishes well, and who has the ability to make tough decisions on our behalf.

Another skill our health care agent will need is the strength to stand up to others who may try to intimidate them, such as an estranged or emotionally detached sibling who flies in from far away and suddenly and vehemently disagrees with what is in our advance directive.

Doctors are familiar with this troubling experience. After spending years neglecting the dying person, a relative suddenly appears in the ICU and wants to take over, ordering the doctors to “do everything possible” to save the patient, even though that isn’t what the patient wants. Our health care agent must have the backbone and fortitude to deal with this kind of unwelcome challenge.

It is not okay when family members insist on aggressive treatments for patients who are actively dying and who have made it clear in their advance directive that they don’t want to be overmedicalized near the end of their lives. A vital responsibility of a health care agent is to make sure older patients who are weak and in declining health are protected from harsh, aggressive, futile treatments.

Our next of kin may not always be the best person to be our health care agent. They may not have the competence to represent you assertively and accurately, and may be too timid to stand up to doctors who forcefully recommend a treatment inconsistent with your advance directive.

If we fail to pick a health care agent and no family member is willing to come forward and make a decision, then doctors will default to doing everything they can with all the pain and suffering that goes with it.

**The Limits and Weaknesses of Advance Directives**

Advance directives aren’t a complete solution because sometimes they get ignored and sometimes patients change their minds. But even if they are not working as well as we would like, the process of completing an advance directive is helpful because it can help to stimulate and promote family members thinking about, and hopefully talking about, how they want their lives to end.

The essential part of advanced care planning is not completing an advance directive and ticking check-boxes but the in-depth conversation, stimulated by filling out an advance directive, between patients and their health care agents, their loved ones, and their doctors about the patient’s goals and values.

Advance directives are often vague concerning the steps between being healthy and being dead. They tend only to cover issues that arise if we are close to death. They deal with extreme circumstances, such as what to do if a loved one has a terminal illness or is in a persistent vegetative state (PVS), but what about all the steps before that?

**Even Highly Detailed Advance Directives Are Inadequate**

Even a highly detailed advance directive will never cover all the medical situations (and the myriad possible nuances and distinctions) we might find ourselves in, so having an ongoing conversation with our health care agent, our loved ones, and our doctor is important. Such conversations will better prepare all of those people to make decisions on our behalf when we can no longer speak for ourselves.

If our health care agent and doctor have had multiple conversations with us about what matters to us, they will be much better armed to make the right decision on our behalf when difficult decisions need to be made.

**“The Conversation”**

As already noted, when difficult decisions have to be made at the end of a patient’s life, advance directives are often of limited use because the medical issues are much more complicated and nuanced than the over-simplified advance directive anticipated.

Nevertheless, everyone should complete an advance directive because they can encourage ongoing conversations with loved ones about what we want at the end of life. This can help our health care agent represent our views more accurately when we can no longer speak for ourselves.

Advance care planning for the end of life is not a task we can do one time and consider it done and finished and off our plate. It isn’t enough to complete our advance directive, select our health care agent, file that information away, and think the job is done. It isn’t. The key to effective and successful advance care planning is to use our advance directive as a starting point for an ongoing conversation with our loved ones and doctors about how we want to achieve a good death.

An advance directive is a tool to help us convey to our family and medical providers how we want to be cared for and treated at the end of life, but they can become outdated, get lost, or be interpreted incorrectly. For those reasons, advance directives should be considered a starting point for ongoing dialogue and conversation with our doctors and loved ones.

Our goals and priorities may change as we get older. For example, an unacceptable treatment, such as being intubated, may, over time, not seem so bad. An ongoing conversation with loved ones can reveal these shifting priorities. We want our caregivers to know what our current priorities are.

**Conversations about Dying Can Produce Significant Benefits**

Having “the conversation” isn’t about deciding on ventilators, feeding tubes, and pacemakers. It is about sharing what is most important to us with someone who cares about us.

Conversations about what we want at the end of our lives must happen between patients and doctors and between patients and their loved ones and caregivers. Patients who discuss their preferences with their doctors and loved ones will likely suffer less in their last weeks and days of life than those who do not.

Dr. Atul Gawande writes in his book *Being Mortal*, “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.”

**How to Get the Conversation Started**

People don’t have the conversation because they fear death and are terrified by the notion that life will be over for them. They deal with this dread by avoiding any discussion of death and dying. But one easy way to start the conversation is to discuss advance directives. For example, if your heart stops, do you want CPR? Do you want to be on a ventilator?

The Conversation Project, cofounded by renowned Boston Globe columnist Ellen Goodman, recommends that end-of-life conversations should begin ideally in good health and suggests the following ways to start it:

* I need your help with something.
* Remember how Aunt Paula died? Do you think it was a good death or a hard death? How would you like yours to be different?
* I was thinking about what happened to Grandpa, and it made me realize…
* I need to think about the future. Will you help me?

Given that we are all going to die at some point, who has the primary responsibility to get these death and dying conversations started? Medicare requires primary care physicians to ask about end-of-life care decisions during the annual wellness visits. But the responsibility can’t just be dumped on family doctors. All doctors who work with chronically ill patients should be talking about the end of life. And, of course, family members need to talk with each other, too.

**Doctors Are Reluctant to Talk About Death**

Doctors, as a general rule, are hesitant to talk about death. They are often not trained to do so, don’t know what to say, are scared of death themselves, fear legal repercussions from ornery and conflicting family members, and worry that their prognoses might be wrong. And occasionally, they can be paternalistic, thinking they know better than the patient what is good for them. For those doctors, they must learn to give the choice of how to die to their patients and not arrogate to themselves control over that decision.

Not only doctors but also a patient’s friends and family must grasp that it is morally wrong to hide information from patients for fear of upsetting them and, therefore, risk delaying or impeding the creation of end-of-life directives. Patients cannot make sound health decisions if they are not fully informed.

**Ways to Supplement an Advance Directive (POLST, MOLST, and DNR)**

An advance directive gives a rough sense of how we want to be treated in a few medical circumstances, but it is not a doctor’s order, and it is unavoidably hazy in many situations we might find ourselves in.

As we become sicker and closer to death, it is wise to supplement our advance directive with other tools, such as a do-not-resuscitate (DNR) order and a physician order for life-sustaining treatment (POLST), both of which are signed by doctors and therefore carry considerable authority and thus likely to be honored by hospitals and other medical providers.

POLST and MOLST (“medical order for life-sustaining treatment”) are identical and refer to a detailed doctor’s orders of medical treatment to be allowed or prohibited. For a patient with an incurable disease, frail health, or within a year or two of dying, having a POLST or MOLST is vital.

A DNR order is signed by a doctor when CPR is not in accordance with the patient’s wishes, but it is only good for a particular admission at a particular time. If a patient wants to remain DNR, regardless of the facility or institution they are in, then it is wise to ask your doctor to fill out a POLST or MOLST.

The POLST/MOLST is a one-page, double-sided, usually bright pink form that describes a patient’s preferences regarding treatments like ventilators, CPR, and feeding tubes. EMTs, paramedics, and other first responders are legally required to do everything they can to keep a person alive unless there is a signed doctor’s order saying not to. POLST.org provides state-specific POLST forms.

A “Do Not Resuscitate Order” or DNR (also called Allow Natural Death or AND) directs your medical care team not to give you CPR (cardiopulmonary resuscitation) if your heart stops beating. If you don’t want your chest aggressively compressed (and your ribs likely broken), your heart electrically shocked, and tubes inserted down your throat to keep you breathing, then you need a DNR.

Choosing “full code” as opposed to “no code” (or DNR) means that you want to be kept alive regardless of the cost in pain or suffering.

**Put Your Paperwork Where It Can Be Found Easily**

It takes a prolonged effort to complete an advance directive, dementia coda, POLST/MOLST form, and DNR, and all that effort will be wasted if no one can find them. So, give all your completed forms to your loved ones, health care agent, and doctors.

Ask your doctors to upload all these documents, including your advance directive, into their electronic medical system so that they become part of your chart and can be easily accessed by a new doctor you might be seeing. I also recommend registering your completed forms online with the U.S Living Will Registry or MyDirectives.com so they can be accessed from anywhere.

**Have an Exit Strategy**

Author and hospice doctor Samuel Harrington argues in his book *At Peace: Choosing a Good Death After a Long Life* that we should each consider an exit strategy. By that, he means an illness for which we will decline treatment. When aggressive medical treatment like surgery results in complications and inadequate benefits, we should consider passive care, then hospice care, and then an exit opportunity.

We each need to visualize an exit option and identify an exit strategy, such as discontinuing routine medications to shorten the dying process. Creating a vision of a peaceful, pain-free death is the first step in avoiding endless and frequently painful medical treatments. Dr. Harrington writes, “Exit strategies include sepsis, the respiratory failure of pneumonia (with morphine for comfort), a sudden arrhythmia, dehydration, low blood sugar, or a metabolically induced coma.”

Of course, delirium, seizures, uncontrollable pain, hallucinations, extreme agitation, feelings of despair, and other scary symptoms might still happen even for a patient with an exit strategy. Dr. Harrington writes, “Even under the best of circumstances, the process of dying is messy, intense, unappealing, and unpredictable.”

But having an exit strategy significantly increases the chances of a peaceful and dignified death characterized by control, comfort, acceptance, and loving goodbyes.

Having “the conversation,” preparing an advance directive, and finding (and talking with) a health care agent tell your loved ones what you want at the end of your life. This is crucial to achieving a good death.

Advance care planning handout April 2023