



How to Talk Plainly About End-of-Life Wishes

By Meredith Whitmore

While discussing end-of-life care can be uncomfortable for most, understanding how to broach the subject and preparing for what issues to plan for will ease the stress of the final days.

HERE'S A QUESTION we are not asked often but should consider: If someone were to ask your family members, friends and healthcare providers what your end-of-life wishes are, would any of them know the answer?

End-of-life matters are a conversation 95 percent of people in the United States say they want to have, and 92 percent say they believe is very important. Yet, only 32 percent of Americans have actually approached the subject with the people they believe they want to be involved in such decisions.¹ What's more, only 37 percent have put their end-of-life wishes in writing for friends and family to access when needed.²

Conversely, what are your friends' and family members' hopes and desires for how they want to spend their final years and months? Would you be able to help them live their final season in comfort, with gladness and even with peace? If you don't have the answers to any of these questions — and even if you are avoiding the topic altogether — statistics show you are clearly not alone. But, as more people understand the basics of advance care planning, the statistics can change for the better.

In his seminal book on end-of-life matters, *Being Mortal:*

Medicine and What Matters in the End, Atul Gawande, MD, MPH, writes, "You may not control life's circumstances, but getting to be the author of your life means getting to control what you do with them."³ Thankfully, there are ways to make this difficult conversation and all of its resultant logistics more approachable.

When to Discuss End-of-Life Wishes

The best time to discuss your beliefs and values regarding your or a family member's end-of-life care is well before a health crisis strikes. Working through such matters early reduces anxiety, emotional exhaustion and other stressors. (If you doubt this, imagine attempting to prepare a detailed, well-considered plan for anything, in addition to navigating a long-term emergency or difficulty.) Thinking through and discussing things beforehand allows ample time to address issues carefully so end-of-life plans can be most beneficial and peaceful for all.

And, lest anyone believe advance care planning is only for older people, it's not. No one knows when they could face illness or grave injury. And, no one knows when their loved

ones will, either. Whether you are a young mother, a middle-aged empty nester, a grandparent or a single young person, having some idea of how you want your end-of-life choices to be handled is invaluable for you and others should something devastating occur.

The common reluctance to address this issue is more than understandable, though. Talking about end-of-life choices and wishes is something that can elicit sorrow and angst, among many other feelings. Any time we are reminded of mortality, whether it's our own or a loved one's, the threat or reality of lingering illness, or the pressing matters of managing finances, estates and legal matters, we can feel overwhelmed. And, for good reason. But it's even more uncomfortable for everyone not to discuss it.

Because so much rests on having an end-of-life dialogue, it is something we will all want to face despite any discomfort. And, we won't regret doing so. Without it, relationships, emotions and finances could be unnecessarily strained, and you will not receive the type of care you hope for. The lives of everyone involved can be made less stressful and even more enjoyable because simple preparations are in place for the future to mitigate grief, crises, uncertainties and frustrations when the final season ushers in.

Preparing for the Discussion

If you feel nervous about talking about such an important subject, understand that not everything rides on one conversation. End-of-life decisions and wishes are typically discussed — and even discovered — through a series of conversations over time. So, when you begin the discussion, you do not necessarily have to have everything planned out that moment. It's often a process. And before you begin, you might want to prepare yourself first.

For some people, writing their thoughts in letter or outline form is helpful for organizing the points they want to make. For others, role-playing with a trusted friend, spiritual advisor or therapist can be helpful. No matter the method, the point is to give yourself a chance to understand and shape your thoughts, desires and emotions.

To begin, ask yourself what concerns you most about addressing the subject with loved ones and healthcare providers. If you can identify these things, you can begin to better understand and address them in productive ways.

And give yourself grace if you feel anxious. This is a difficult subject for virtually everyone.

Some Main Points to Consider

Advanced end-of-life care planning touches on multiple aspects of a person's social, familial, spiritual and healthcare worlds. While there are many facets to consider, here are some main points to discuss and prepare for. Of course, you may add additional questions or thoughts, if necessary. But, this list gives you a place to start.

People Involved in My Care

- Who will be my primary beneficiary?
- Who will be my primary caretaker?
- Who will have power of attorney, if necessary?
- What kind of bedside manner do I hope for in a physician? (On a more humorous note, would I prefer Dr. House or Nurse Nightingale? To each his or her own!)
- What do I want my healthcare providers to know about me personally, if anything? What about my other caretakers?
- How do I want hospice or other healthcare providers to interact with me? For example, do I want them to chat jovially with me? Say only the minimum? Not ask questions about my personal life?

The best time to discuss your beliefs and values regarding your or a family member's end-of-life care is well before a health crisis strikes.

Medical Treatment

- What types of medical treatment do I want, and when? For example, strictly palliative or more aggressive?
- What about obtaining a do-not-resuscitate order?
- How much do I want to know about my medical condition? Should doctors tell me everything, or do I want to be unaware of much?
- How much should my friends and family know about my condition? How should they interact with me regarding a diagnosis?
- What is important to me with regard to dignity and comfort in my care?

Legal and Financial Affairs

- Who do I want to receive my most cherished possessions, and how will they obtain them?
- Who is handling my will?
- Who will be given what from the estate?
- Are my taxes and other financial affairs in order?
- Do I want a living will?
- Which charitable or for-profit organizations do I want to donate my vehicles, home and other assets to?

Spiritual

- How will my faith traditions be carried out during my last days and at my memorial service or funeral?
- Do I want a spiritual leader of my faith to visit me and carry out rites or ceremonies?
- What type of service do I want to commemorate my life? Favorite music to be played, for example? A poem or passage of scripture to be read?
- Do I not wish to have a memorial service or funeral?

Breaking the Ice

While a single conversation is rarely sufficient, the first one regarding end-of-life decisions can at least broach the subject and lessen initial discomfort. Find a time to mention things when the people you are discussing it with are not hurried or distressed. You might approach by saying something simple such as, “I need your help with something I’ve been considering,” or “I’ve been thinking about the future and could use your insight.”

Significant family life events such as a wedding, funeral or retirement party can also serve as a springboard to mention your desires. You could also bring it up while preparing or revising a will or working on estate planning. Holidays, although they can be stressful for some, might also serve as an opportunity since the family is often together. And, if another friend or family member is facing end-of-life decisions, that opens the door to conversation as well.

Because your thoughts about end-of-life care could evolve over time, be sure to amend your verbal or written plans should a significant change occur. Keeping your loved ones apprised is important, and they might appreciate it as well. You could even ask, should they have their own plans, whether they have new ideas.

Anticipating Disagreement and Resistance

It’s important to consider the possibility that you and a loved one or healthcare provider could disagree on

something while discussing end-of-life wishes. Or, perhaps more common, it’s possible you’ll be met with deflection or other resistance.

For example, a common way people deflect advance care planning when it feels uncomfortably negative is to say, “We don’t need to do that. We’ll be able to handle it all.” Or, “You can beat it if you get sick.” It’s helpful to consider how you will respond. Saying something as simple as, “I want to be prepared anyway,” or, “This will be useful because it will relieve stress and help us to invest in one another, instead of scrambling for a plan when the time is shorter.”

Or, if you are approaching a loved one to discuss a plan for their own care, they might respond with hostility or passivity. “I don’t want to talk about it,” “I don’t need anything special” or “It’s too painful to think about” are common responses from resistant loved ones. A helpful way to address these comments might include saying, “We care about you and want you to be comfortable. It’s more painful for all of us not to discuss it in the long run, because we won’t know what to do.” Or, perhaps, “We understand your frustration. It’s a difficult topic. We still want to help you plan because we want to know we are making the best, most helpful decisions for you when the time comes.”

If healthcare providers disagree, perhaps a social worker, counselor, chaplain, mediator or other official can help to ease the friction and help foster better understanding between parties.

It’s Never Too Early

It’s never too early to begin the discussion. Professional advance planning services such as Five Wishes⁴ are also available for those who want a prescribed directive approach and helpful checklists. Remember, few ever regret the planning, even if initiating the discussion was uncomfortable. An advance care plan is worth the awkwardness of the first conversation. ■

MEREDITH WHITMORE is an English professor and freelance journalist in the Northwest.

References

1. The Conversation Project. The Conversation Project National Survey, 2018, and the Conversation Project Starter Kit. Accessed at theconversationproject.org and theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConvoStarterKit-English.pdf
2. Djulio, B, Hamel, L, Wu, B, and Brodie, M. Serious Illness in Late Life: The Public’s Views and Experiences. Kaiser Family Foundation, 2017. Accessed at www.kff.org/other/report/serious-illness-in-late-life-the-publics-views-and-experiences.
3. Gawande, A. *Being Mortal: Medicine and What Matters in the End*. New York: Metropolitan Books, Henry Holt and Company, 2014.
4. Five Wishes. Accessed at fivewishes.org/five-wishes/who-we-are.