Article Series Maintaining Connections

Hard Conversations About End-of-Life Care

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When you're living with cancer, there may come a time when you need to face difficult conversations about the future — especially around treatment, end-of-life care, and the kind of support you want.

You might wonder: *What if the treatment stops working? Who will make decisions for me if I can't? How will my loved ones be affected?*

While these conversations may seem scary, it's important to remember they aren't just about dying, they're also about how you want to live. How do you want to

spend your time? What matters most to you? Who do you want by your side?

Advanced care planning is an ongoing process that can happen at any life stage. It's the process of reflecting on your values, goals, and beliefs about medical care, talking through your wishes with your family or healthcare team, and putting those wishes in writing through advance directives, which are written instructions that tell others what medical care you want if you can't speak for yourself.

While you may assume your loved ones already know what your best interests are, research shows that's not always the case. In one study, participants were asked to predict which end-of-life decisions a loved one might make, and they guessed wrong almost one in three times. Having your documents in place and discussing your values with loved ones ahead of time can help them make the right decisions if you are unable to make them yourself.

You may find that the more direct you are about hard conversations, the more others come to appreciate your clarity and the less anxious you feel about it. One study of older adults found that advance planning was associated with better quality of care at the end-of-life.

You can find a useful guide and workbook on advance planning from the National Institute on Aging. Here are six simple Microsteps to help get you started.

Taking five minutes to finish this sentence: "What matters most to me is . . . "

You might write your answer in a journal, on a sticky note or in a phone app. Your answer might be attending a child's wedding, being able to walk your dog, feeling well enough to go to church, being able to keep working or visiting with grandchildren. No matter how big or small the idea is, be sure you jot it down.

Writing on an index card before your next medical appointment: "Can we talk for five minutes about advance care planning?"

Bring it with you and hand it to your doctor if it feels hard to say aloud. This takes the pressure off and ensures your doctor helps you start the medical side of the conversation.

Creating a planning folder for important healthcare and other documents.

You can use a simple folder and include items such as an advance directive, power of attorney, or estate planning forms. You can learn more about these documents and why they are important on the National Institute on Aging website. Sharing the folder with a loved one may be a useful way to start a difficult conversation.

Downloading and printing an advance directive document for your state.

It starts with a simple online search for “advance directive [your state] PDF”. Your search should turn up a government agency with the correct document for your state. Print it and put the document in your folder, and fill it out when you’re ready.

Saying out loud to yourself: “If I can’t speak for myself, I’d like ____ to help.”

This exercise may help you think about one or two trusted people who could serve as your health care representative.

Setting a yearly reminder on your calendar to update your advanced care wishes.

Add an event like “update my wishes” to your calendar. For digital calendars you can easily set this up to remind you yearly, but for physical you’ll need to make sure to carry it across each year. Having this calendar slot makes reviewing your documents an easy-to-remember annual habit.

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