

[Track 2: Survivor Stories: Choices and Control]

[Narrator]

Perhaps one of the hardest things about dying is deciding when and how to have necessary, and frequently difficult, conversations. Our dying and death are not ours alone. Family, friends, co-workers, and our healthcare team all share our experience to some extent. Yet, many people are unfamiliar with death. Their only framework may be television or the movies, where death is portrayed in unrealistic ways.

If you are employed, it will be necessary to tell your employer and co-workers when you can no longer return to work. This may bring about a change in the relationships you previously had with your work friends. You may find they become uncomfortable around you. They may be inexperienced with dying and death, and they don't know what to do or say, so they stop calling or visiting. At the same time, as your disease progresses, you may find you don't want many visitors, or that you want to be with only a special person or two. Withdrawing from the outside world is a normal part of dying, but it can also be a loss.

Some family members may also become uncomfortable around you, and you may have to help them. This can seem like an added and unfair burden, but if you wish to have contact with them, you can find ways to put them at ease. Saying something like the following might help: "I may look different, but I'm still the same person, and I want our relationship to stay the same as it's always been for whatever time I have left."

There are important conversations you will need to have with your family and your doctor and healthcare team. These conversations usually revolve around your treatment options, and your wishes and desires as the end of your life nears. Some individuals are reluctant to have these conversations because it means dealing with or facing death. Family members and even doctors or your healthcare team may not bring up the subject. Dying and death are often hard to talk about. Some suggestions for such conversations are provided later in this program.

You also need to consider your legal affairs, such as making certain that your will is updated, and that you have advance directives, including a living will and health care proxy, that will take effect if you can no longer make decisions about your treatment or if you become comatose. Another essential document is a durable power of attorney, a legal document that lets you appoint someone you trust, often called a health care agent, to make decisions about your care. Examples include "Five Wishes" or state-specific forms found at www.caringinfo.org. Perhaps a family member or close friend or lawyer can assist you in getting these advance directive documents in order. There is more information about these topics in the *Cancer Survival Toolbox* program entitled "Living Beyond Cancer".

Advance directives work best when you and your family talk with each other and with your doctor about what your future holds. It is particularly important to discuss whether or not you want life-sustaining measures, such as a breathing machine, intravenous fluids, or a feeding tube. This is a good time for everyone in the family to talk about what they would want for themselves at the end of life, which could make it easier for you to talk about it as well.

There are several factors that make these conversations difficult. First, each person's death is unique, so it may not be possible for doctors to tell you how you will die, or to give you an exact estimate of the time you have left or when you might reach a point when you can no longer make decisions for yourself. Also, some doctors are reluctant to talk about end of life concerns because they are afraid it will take away a person's hope.

A second factor is that you and your loved ones might not reach the same conclusions at the same time. In the “Topics for Older Persons” *Cancer Survival Toolbox* program, we met Doris, who was ready to enter hospice but her family wanted her to keep fighting. Doris knew she was dying, but her sons weren't ready to let her go. She found a creative way to help her children understand what she needed and what her wishes were. She used her birthday celebration as the time for a discussion about hospice, and asked her children to give their blessing as a way of showing their love for her.

Another factor is that the frequency and styles of family communication differ widely. Some families have open communication where most things are discussed with family members, and even with close friends. Other families are quite private, and there are topics that are never or rarely discussed. In these families, personal privacy is highly valued, and family members know what is acceptable and what communication channels are appropriate. In many families, there are mixed communication styles. Culture also can play a big role. In some cultures, families are expected to tell each other everything; in others, health matters are kept private. Perhaps the way you talked about serious issues in your family are different from how they were discussed in your partner's family. There are also age differences in communication. For example, compare your grandparents' saying about “airing dirty laundry in public,” with today's teenagers' texting or social networking activities.

In our society, talking openly about someone dying is not common. We read about death in newspapers, see reports on television, and watch action movies where people die. Yet, when it comes to talking about our own death or the death of a loved one, we don't know when or how to approach the topic. We fear we will say the wrong things, upset our loved ones, or give a message that death is near.

Books and articles urge us to have these difficult conversations early, before they are needed. Few of us do that. As a result, we might get to a point where the conversation can't be delayed any longer, but we are at a loss as to how to begin. One thing that has been created to assist people with communicating their wishes regarding treatment at the end of life is a form called POLST. POLST stands for Physician Orders for Life Sustaining Treatment. POLST is a physician order which is recognized and honored across treatment settings. It is portable which means that it goes with the patient. It provides direction or orders for a range of medical treatments such as orders for code status; this means whether or not you want to have cardiopulmonary resuscitation done. It also allows for choices regarding nutrition, hydration, intubation, mechanical ventilation, and antibiotics. The POLST is for anyone who is seriously ill and is choosing to limit medical interventions. POLST does not replace an Advance Directive but is intended to complement it. More information on POLST and Advance Directives can be found in the Resource Booklet that accompanies the Toolbox.

Sometimes others – a family member, a social worker, nurse, or faith leader – can assist us. Let's listen to Betty's story about talking with her mother, whose physical condition was getting worse.

[Betty (Female #5)]

My mom had had a serious heart problem, plus her cancer for a long time. Each time she was hospitalized, I would try to broach the topic of what her wishes might be in the future. She and I have been very close my whole life, and the only topic we couldn't seem to discuss was the thought of losing each other. As her condition got worse, it seemed more and more important that we talk.

One of the issues was that my mother was a private person. Like many older African-American women, she was a woman of strength. She didn't believe in being emotional or shedding tears. She never complained and seemed to take things in stride. She'd always been a source of support for me, and it was hard for me to deal with changing our roles.

I finally talked to my brother about the need for us to talk to our mother about dying. He was fairly matter-of-fact and said he would be part of the conversation. I felt it might be helpful to use a document called "Five Wishes," which covered what my mother would want during her final days and hours and for her funeral. One afternoon when we were all together, my brother brought up the topic in a way that said we needed to get this done. Surprisingly, my mother didn't object. The three of us went through all of the questions. We documented her answers and had two neighbors sign as witnesses. I felt much better and I think my mother did, too. I tried to understand why my brother was able to bring about the discussion when I hadn't been able to. Looking back, I believe it was because he approached it in a straightforward matter – as something that needed to be done. That allowed my mother to remain in control, and the conversation never became emotional. Mother died suddenly a few months later. We followed all of her wishes. I often think of that conversation as a gift from my brother.

[Narrator]

Justina, a hospice chaplain, tells us why she thinks communication is so important when we are facing the end of life.

[Justina (Female #6)]

My father was diagnosed with late-stage colon cancer when I was 14 years old. At the time my younger brothers and I really didn't understand how serious it was, especially because he was determined to extend his life as long as possible through experimental treatments. He and my mother were very close, and they talked about decisions that had to be made at each stage of his illness. Maybe because we kids were so busy with our own lives, or maybe because they thought they could protect us from the hurt, we didn't really sit down and talk about what might happen if the treatments stopped working or how we felt about it.

When he died of complications in the hospital, it came as a really big shock. It took me a long time to get over the anger I felt at not having a chance to say goodbye. We told each other we loved one another all the time so it wasn't that I missed the chance to do that, but I always wished that we had talked more about our family, what he meant to us and ways that he would always be with us in our hearts.

When I work with families now, I encourage them to bring up the subject of death and talk about ways of staying close, even in the face of loss. It's hard to face sadness together, but it's almost always better than facing it alone.

[Narrator]

The Cancer Survival Toolbox program on "Communicating" has a number of helpful tips. Remember it is important to use "I" messages when we express ourselves. A simple request like "I have something I've been wanting to talk about, but haven't known quite how to bring it up," can open up a difficult topic. "Checking the message" – repeating what you think the other person said – is another important communication skill. When expressing strong feelings of anger, sadness, or guilt that are common reactions to loss, sometimes it can help to sit quietly first and gather your thoughts. Then, begin with the statement, "I am aware that I am feeling..." An example is, "I am aware that I am feeling really angry at cancer," or, "I'm aware I am missing all the really fun things we used to do."

Every family is unique, and good communication can make the most of your family's strengths. If your family is having trouble talking about loss or the end of life, help is available. Social workers in many healthcare settings – hospitals, cancer clinics, visiting nurse associations, and hospice and palliative care programs – are trained to provide just this kind of help. There are also some very helpful guides such as the Caring Conversations web site (caringinfo.org) listed in the Resource Booklet.

We can always find reasons not to do things that make us uncomfortable. The time isn't right. We don't have the necessary documents. We don't want to discourage our loved one or take away their hope. We don't want to give up hope ourselves. The list goes on and on. But eventually, if we wait too long, the time for the conversation can be lost.