

[TRACK 8: SURVIVOR STORIES: END OF LIFE ISSUES]

[Narrator]

Another important area where we need to use good decision-making skills is on end-of-life issues. You have a legal right -- and a moral right -- to decide what kind of medical treatment you want -- or don't want -- if you become seriously ill. Making these decisions ahead of time and putting them in writing in a legally valid document will help make sure that your health-care team and family follow your wishes if you are not capable of communicating when the time comes. Listen to how Ruth took care of this decision.

Ruth, 75 years old

[Ruth]

I'm 75 years old. I was recently diagnosed with early-stage breast cancer. I haven't had too many health problems, other than heart problems and a mild stroke two years ago. Turns out my chances with my breast cancer are very good, but I'm still worried about having another stroke. George and I have been married for 52 years now and he depends on me for so much. If I have another stroke, a bad one, he'd have to make some hard choices if I couldn't decide for myself. I've already told him that I wouldn't want to be kept alive by machines. But, I know it would be hard for him to tell the doctors to take me off life support. So, I decided to put my wishes down in writing, so he won't ever have to make that choice.

[Ruth]

I called the social work department at my local hospital and asked the social worker for some information about a living will. She suggested I use a document called "Five Wishes" from an organization called Aging with Dignity. She gave me their phone number and Internet address. When I called them, they were very helpful and sent me a copy of the "Five Wishes" form. I felt a sense of relief when I received that form -- it gave me a way to take care of something very important to George and me. I took out a sheet of paper and started listing what's important for maintaining my quality of life. Then I asked myself some hard questions. First of all, who would I want to make health-care decisions for me if I couldn't make them for myself? I wrote down my husband, but then I thought about my oldest daughter, Annie, and a couple of my closest friends. So, I wrote down their names, too, and reasons why I should or should not choose each person. It's too important a decision to make all at once, so I put this sheet of paper away and re-read it a few days later. I added some new reasons that I thought about to the list and crossed off other ones. After this, I felt pretty comfortable with my decisions.

[Ruth]

The next question from the "Five Wishes" is what kind of medical treatment I would want if I became seriously ill or were dying. Do I want life support treatments, like being put on a respirator, or would I want to be resuscitated -- have my heart started again if it stops? Do I want blood transfusions, or kidney dialysis, or to be given food by tubes? What about antibiotics if I get pneumonia? There's a complete list of questions in this "Five Wishes" document -- many you could never think of on your own. My social worker told me that the "Five Wishes" document is a legal document in the state where I live. So, my answers are very important and I know my wishes will be carried out.

[Ruth]

First, I needed to talk with George and our daughter, Annie, about my decisions. At first they were uncomfortable -- these things are not easy for people to talk about. They kept telling me that my

cancer was caught early and I shouldn't be worrying about what might not happen. But I knew we would all feel better once we talked about it and knew we had a plan together. So, I told them what I had to say was very important and that they should listen to what I had decided and why I had arrived at my decisions. I told my husband that I would like Annie to be my health-care agent. After all, she has had some training in healthcare and is comfortable in hospitals and talking with doctors. I also told George that I honestly think it would be too hard for him to make these kinds of decisions. I knew his feelings might be hurt... maybe they were. Well, we were all nervous about talking about these questions. But, I'm certain we all felt better knowing what to do -- not knowing would be much worse.

[Ruth]

Annie had some questions about my answers on the form. So, we finished it up and agreed that George and I would go discuss the document with our lawyer and then give a copy of it to all of my doctors and the hospital where I get treated, so that it can become a permanent part of my medical record. I have to say that this whole experience has really helped all of us feel so much closer. And, now we can look to the future feeling a lot more secure.

[Narrator]

You can obtain a copy of the "Five Wishes" document by calling 1-888-5-WISHES (1-888-594-7437), or on the Internet at www.agingwithdignity.org. "Aging with dignity" is one word in the Internet address. Keep in mind, too, that "Five Wishes" is only one example of a document for making sure that your wishes at the end of life are followed. Each state has a form of its own and your lawyer, doctor, or hospital can assist you with finding copies.

[Narrator]

Once you have made your mind up on important questions about your medical care, you may need to get prepared to solve other challenges or problems that may come up.

[Social Worker]

We know that we often find solutions to a bigger problem when we break the bigger problem into smaller pieces, and then work on the smaller problems first. When working with cancer survivors, I find it also helps to think about other major problems we've had in our lives and to think about how we solved them -- what we did right, and what we could have done better. Previous problem solving can offer a blueprint for how to deal with current problems.

[Narrator]

Doris is a good example of this. She lives in a small town and feels very lucky that all of her children have stayed nearby, instead of moving away like the children of so many of her friends. Listen to how Doris and her children dealt with a major family problem.

Doris, 78 years old

[Doris]

I've lived with my cancer for a long time, and I recently had my fourth recurrence. My cancer is now very advanced, and the only treatment left is experimental. I've talked to my health-care team. They've told me that the side effects of the treatment are pretty serious. My doctor says he's not sure it will help me very much. After all of the surgery and chemotherapy I've had, I just don't want to go through chemotherapy again -- especially if it has little chance to help me. I realize I'm going to die sometime in the near future and I've made my peace with that. I'm very

religious and count on God to get me through.

[Doris]

The problem is my three children. They don't like the idea of me just "giving up." They make me feel like I'm letting them down. My oldest son even acts like he's mad at me. The other day he told me that I should think about my grandchildren -- didn't I want to live to see them grow up? Well, I was just heartsick at this. I adore my grandchildren and if it was possible to live long enough to see them raised, you can be sure I'd do anything to make it happen. I was so upset after our conversation. For several days afterwards, I even thought about changing my mind. But, I've just got to be realistic now.

[Doris]

I decided I needed some help to solve this problem -- that I needed to talk to someone outside the family. I thought about my minister and how helpful he was when my husband, Ed, died five years ago. I called him and asked if he could meet with me. We had a long talk and he helped me understand the problem better -- that my children were afraid of losing me, too, and that I need to help them prepare for my death while at the same time living as fully as we can and spending time -- good time -- together. He said we are experiencing what is called "anticipatory grief" -- we are grieving the fact that we are going to lose one another and that we need to talk about these feelings. I also told him that I did not want to become a burden on my family -- that I had always been fairly independent, and that my children have their own lives to lead. At the same time, I knew I couldn't get through this without the help and support of my children.

[Doris]

So, we decided on a plan that has several steps. I called the local hospice and went and met with them. Since our town is so small, I already knew two of the women who worked there, and they have been very kind to me. They described their services. They are what is called a "home care hospice." They provide care so you can stay in your home. They also told me about how I select the hospice Medicare benefit that covers nursing care and medications, including medications for pain, if I should need them. They said they would get in touch with my doctor about a referral. I know my doctor will agree. She works part-time with the hospice program.

[Doris]

The people at the hospice also agreed to help me set up a meeting with my children. The hospice nurse, social worker, and pastoral counselor would all be present to help me explain my choice and what we can expect. And, what role my children will need to play.

[Doris]

The next part of my plan was to get my children together to tell them about my final decision. My birthday was coming up -- my 79th! I sent a note to each of my children asking them to come to my house on Thursday evening for an early birthday dinner. I asked them not to bring any presents. At first, my daughter objected -- she said it would be easier if they just took me out to our favorite restaurant for a celebration. "Thank you," I said, "but no." I wanted them to come to my house.

[Doris]

They were all able to come, and we had a nice meal together. I had cooked many of their favorite dishes. When dinner was over, I said I wanted to tell them about the best birthday present they could give me. What I wanted was their blessing about my choice to forego any more treatment for my cancer. I said that I wanted them to help me have the best quality of life that I could

possibly have in whatever time I had left.

[Doris]

Then, I told them that I had chosen to enter a hospice program and that I would like all of them to come with me to a meeting there. I said I knew that they were afraid of losing me, and that I felt the same way about leaving them. But, I also reminded them that together we had faced difficult times in the past -- when their father died -- and that we would face the future in the same way -- together. I also said that we had other decisions that we needed to make and that I would ask each of them to help me with specifics, like getting my legal and financial affairs in order... and making funeral arrangements. I told them that I did not want to become a burden to them. We talked about what services the hospice could offer, including what they called "respite services" where I could enter the hospital for several days if my children were unable to help me during a short time. They all said we would never need to use the respite option, but I still wanted them to know that was available to us.

[Doris]

We did cry a little, and at times the conversation was hard. But, we were finally able to talk fairly openly about my situation and clear the air. We seemed like we were working together as a family again. I must say, it was a very good birthday indeed.

[Narrator]

Doris is obviously a very brave and strong person. But, the key point here for all cancer survivors is that, if you can set your goals and are willing to put some effort into it, you can find ways to overcome a seemingly large obstacle by overcoming all the small ones, one at a time. Doris did this by identifying the problem, getting the facts, thinking it through carefully, and carrying out her plan. She and her family also took the time to think about how they had solved previous problems. This experience served them well.