

## [Track 5: Survivor Stories: To Treat or Not to Treat]

[Narrator]

We make choices every day – from when to get up in the morning to what to wear, what to eat, what book to read, and so on. Yet when it comes to deciding about treatment – the need for treatment, what type of treatment to choose, or when to stop treatment – how we decide can be very different.

In the Cancer Survival Toolbox program called “Making Decisions,” we learn there are three types of decision-makers. The first lets others make decisions for him or her; the second makes decisions after looking at options and talking with others; the third makes decisions with as little input from others as possible. Much of this has to do with how much control we want or feel we can have. We also can change our styles of decision-making depending upon our circumstances.

One of the most difficult decisions may be whether to continue or stop cancer treatments. Is the treatment no longer controlling my cancer? Would a clinical trial or experimental drugs be worth trying? Is the treatment success rate high enough that it's worth it to me to live with the symptoms I'm likely to face as result of the treatment? Will I be “giving up” by asking to stop chemotherapy or radiation? Do I want to be kept alive with the help of technology and machinery?

An equally difficult task is deciding who will make the decision to stop. Will it be my doctor, a family member, or me, the person with the disease?

Let's listen in on a support group where the discussion focuses on stopping aggressive treatment. It's important to note that stopping treatment does not mean there is nothing else to be done. Good palliative care and symptom control are essential at this time.

[Female #10]

My doctor said the cancer's now in my liver and bones. She can't offer me any treatments that will cure the cancer, but she promises she'll make me as comfortable as possible. I'm 75 and have had a wonderful life, but my husband is not ready to let me go. He wants me to keep trying anything that might give us some more time. I know how hard it is for him to take care of me and watch me suffer. We can't even talk about my dying without having a fight. So I just want my doctor to decide when enough is enough, and I know that she'll make the best decision for me.

[Male #6]

When my grandfather died of cancer in the 1950s, everything seemed so sad, yet simple. He went to the hospital, had surgery, was diagnosed with cancer, and stayed there until he died. The doctor could only try and make him comfortable, as there weren't any other options. But he died in so much pain.

Now I have the same type of cancer. While my first course of treatment didn't cure the cancer, it kept it under control for many years and I had no pain. But the cancer's back, and being in pain is my main fear. My doctors say they can keep trying new therapies, but I'm so tired of feeling sick all the time. I want help deciding when to stop all the experimental treatments, but the final decision will be mine.

[Male #7]

Whoa! No one is making any decisions about my life except me! I'm going to keep trying anything and everything till they take me out kicking and screaming! I still have a lot of life to live, and I

have three kids who need me around as long as possible. There is always a new treatment down the road, so I just need my doctors to keep things under control long enough to find it.

[Female #11]

I already stopped radiation. It just wasn't working. My big question now is whether or not I want to be hooked up to any machines in the hospital if I can't breathe on my own, or if I should get antibiotics for an infection if it just prolongs my dying? The quality of my life is very important to me...more so than how long I live. I also know I can change my mind at any time. I'm glad my family has told me they will support whatever choice I make.

[Linda]

You've all discussed very different ways to deal with continuing or stopping treatment. All of you are right because each of your decisions, even if you've decided that someone else will make decisions for you, reflect who you are now. What's important to notice is that what unites all these different decisions is that each of you has control over your situations in one way or another.

Here are some other things I've learned: Refusing machines and technology or anything that prolongs your life or your suffering is not an act of neglect, but rather can be an act of love and respect. It is your choice. Accepting technology and medicines or anything that prolongs your life because you want to fight every step of the way is also your choice. Discussing your goals for care and your choices and responsibilities with your family, doctor, and hospice team is best done sooner rather than later. Make sure your wishes are known and have them in writing if possible. Also, keep in mind that you can change and adjust your goals at any time. Experiencing fears and doubts about having made the right choice is natural. And, having your symptoms treated is your right.