

[TRACK 7: LIVING WITH HOPE]

[Narrator]

Ever since you were diagnosed with cancer, you may have found yourself living with the ever-present reminder of how insecure you feel about your future. From that first moment you are told that you have cancer, your immediate future becomes defined, at least in part, by the period of weeks or months between diagnostic tests and checkups. Even though survivors are living longer than ever before, it's not surprising that many feel that their futures are cast in a gray zone of uncertainty.

[Narrator]

But, to a certain extent, living with uncertainty is what all of us do as we go about our daily activities. You don't have to have a diagnosis of cancer or other life-threatening disease to feel uncertain about the future. The terrorist events of September 11, 2001, for example, made many of us feel less secure. Suddenly, we sensed that there's a degree of uncertainty about the future that wasn't there before that tragic day. Some people think of a diagnosis of cancer as its own form of biological terrorism. Like terrorism, cancer is an unexpected and dreadful intruder in the lives of many people. This includes the person who receives a cancer diagnosis, as well as his or her family, friends, and colleagues. These situations can change your life and make you feel uncertain in ways that can be disturbing and confusing. These feelings can make you wonder if there is any satisfactory way to reduce your fear of death or cancer recurrence, or of being stigmatized—that is, being thought of or treated differently by the people in your life—just because of your cancer diagnosis. You may wonder if there is any way to overcome your feelings of sadness or loss.

[Linda]

A diagnosis of cancer puts fears about an uncertain future and feelings of our lives being out of control squarely in front of us. Cancer knocks us off balance. One cancer survivor I work with said it this way: Cancer patients crave “feeling normal” and try to work the gray areas of living with uncertainty into daily living. It becomes normal—a “new normal”—to live with the stress of cancer survivorship.

[Linda]

Cancer does not represent a single crisis in our lives, but a sequence of crises. For many survivors, this sequence begins with the “first-alert” system that our bodies use to tell us that something has gone wrong. It might be a symptom that nags at us and tells us that something is just not right. It may take us a while to admit that there really could be something wrong. And, it may take even longer for us to get around to going to see a doctor about it.

[Linda]

For some people, the diagnosis takes some additional time for tests and more tests, and draws out the uncertainty. For other people, the diagnosis can be made fairly quickly. In any case, actually getting the diagnosis of cancer starts a whole other sequence of crises—the crisis of decision-making about treatment; the crisis of surgery, radiation, and/or chemotherapy; the crisis of dealing with changes in the way your body looks or functions; the crisis of ending treatment and wondering what may happen next; and the crisis of recurrence, if that is our destiny.

[Linda]

With each crisis comes increased anxiety and fear. These fears and anxieties are a very basic part of being human. They are part of cancer survivorship. They can be managed and become the “new normal” that many survivors feel. Let’s begin that process together.

[Linda]

Along with the many uncertainties that go with a diagnosis of cancer, there are also many fears. I hear them daily from cancer survivors and their caregivers. The three fears I hear most often are: the fear of death; the fear of cancer recurrence; and, the fear of being stigmatized as being “different” by the people in your life because of your cancer diagnosis.

[Linda]

Although a fear of dying is a very natural part of life for most people, we, as a society, do not deal with it naturally and honestly. Most people who receive a diagnosis of cancer—no matter how good their prognosis may be after treatment—feel the reality of their own mortality, perhaps for the first time. The reality becomes an immediate concern, not just something in the far-off future. We might think of the diagnosis as starting the clock that counts down our remaining days. For these reasons, it is very important to give voice not only to our fears about death and dying, but also to our hopes for what we would wish our process of dying would be if we were given a choice. Cancer survivor and author Arthur Frank captured these feelings well in his book, *At the Will of the Body*, when he wrote: “The ultimate value of illness is that it teaches us the value of being alive...illness and, ultimately, death remind us of living. Death is no enemy of life.....illness restores the sense of proportion that is lost when we take life for granted. To learn about value and proportion we need to honor illness, and ultimately, to honor death.”

[Narrator]

It is very important for survivors and people close to them to recognize how difficult it is to resume a positive, life-oriented, and future-focused outlook after experiencing the fear of death brought about by a cancer diagnosis. Getting to a place where you can “honor our life and honor our death,” as described by Arthur Frank, is a process that may begin with a diagnosis of cancer. For some people, that may take years. The secret is not how long it takes, but learning that healing can begin when we talk about it with others—a friend or loved one, another survivor, a health-care professional, a spiritual leader—someone who can listen with an open heart to our fear of death and help us put it into perspective in our life. There are many wonderful resources available to people with cancer and their caregivers to help with this process. Those resources for additional reading are listed in the Resource Booklet that accompanies this program.

[Linda]

The second fear that health-care professionals hear about is the fear of cancer recurrence. It may be the most common and consistently felt emotion that people with cancer experience. This fear is felt with a mixture of anxiety and depression that may come and go over time. A woman I work with who is a breast cancer survivor described her fear of recurrence this way: “Every time I go for a checkup, I get afraid that they might find something. I don’t feel that way between checkups. But the fear of the cancer coming back must be somewhere in the back of my mind, and it bubbles up to the surface right before and during

my checkups. My fear is probably less now than it used to be, but I keep expecting I'm not going to feel afraid, because I don't feel that way on a day-to-day basis. It always surprises me that I do feel afraid."

[Linda]

This sense of uncertainty can give rise to a range of reactions from mild worry and anger, to panic, and even thoughts of suicide. Many survivors find it somewhat comforting to know that the intensity of worrying about recurrence tends to fade the longer you go without symptoms that remind you of the initial diagnosis. The uncertainty that many survivors have about every little ache or pain goes away as their routine checkups show that these aches and pains are not related to the cancer. Some survivors adjust so well over time that they describe their feelings regarding a fear of recurrence as being like background music at a restaurant or on an elevator. They get used to living with it to the point where they hardly even notice it. If something happens to draw their attention to it, though, they may find that they become aware of the fear again, and it can become rather annoying and even worrisome. Being aware of when your anxious or worrisome thoughts are becoming overbearing is a key to making the adjustment to living with, but not being overwhelmed by, these nagging fears.

[Linda]

If you feel that you would be uncomfortable discussing your fears about recurrence openly in a support group, or if you find that the passage of time and reassuring checkups are not enough to relieve your anxiety, you may want to arrange a few sessions with a social worker or other health professional who can assist you in resolving these feelings. If you don't feel comfortable doing that, it's good to know that there are many other options for getting support. You can find a list of organizations that offer direct services for how to deal with these emotions more privately, through teleconferences, and over the Internet in the Resource Booklet that accompanies this program.

[Linda]

It's hard to imagine in this day and age, when people talk openly about almost anything, that there still exists a stigma around people who are diagnosed with cancer. A stigma, which literally means "a mark on the body of disgrace or reproach," is as old as the disease itself. Many people may think of a diagnosis of heart disease or diabetes as "bad news." But, many people with cancer feel "marked" by the disease. This may be because cancer or cancer treatment can change the appearance of your body. You may feel "marked" by surgical scars, the loss of hair from chemotherapy, or the loss of body parts. The notion that cancer could, in some way, represent a defect or lessening of your identity and abilities does not go away easily. We live in a society that celebrates health and beauty. Those of us with scars or other signs of illness can feel like they're on the outside looking in. We must realize that many people still regard cancer as a death sentence, and may in some way feel that people diagnosed with the disease are "victims" rather than "survivors." Returning to the workplace presents another set of stigma issues to deal with. Many cancer survivors report being treated differently by employers and colleagues as well after their diagnosis and treatment.

[Narrator]

To lose the stigma of cancer, survivors have to make themselves visible to others who may be afraid to confront their own fears about cancer. At a time in your life when you want to be treated like everyone else, or more importantly, the same way as you were treated before you were diagnosed, the reality is that your life after cancer *is* different. Allowing other people to impose a stigma on you could confirm your

own worst fears about having cancer. Keeping a positive attitude in the face of any such stigma is a challenge that survivors must confront head on.

[Narrator]

With all this discussion about living with fear and uncertainty, the good news is that studies show that cancer survivors are among the most resilient people when it comes to their ability to recover emotionally and regain their optimism. And they can learn to be hopeful about the future. The distinction between optimism and hopefulness is an important one for survivors who are living with uncertainty and fear. Optimism emphasizes the positive aspects of any given situation. Hope, on the other hand, can be defined in many ways and is an essential experience of the human condition. It functions in different ways in families and across cultures, but universally it is a way of feeling, a way of thinking, a way of behaving, and a way of relating to the people in your world. Hope is a necessary element for healthy coping that can help you avoid despair. Hope is also a reflection of the desire to make life under stress bearable. It is important to think about the ways in which you hope, and to be direct with family, friends, and professional caregivers about what is most helpful to you. Never let anyone tell you that there is nothing further to hope for, or that there is no hope. There is *always* something to hope for. You, as an individual, have the right to determine what you hope for and when and how you hope.

[Narrator]

Over many decades, cancer survivors have discussed their fears and their hopes, their feelings of anxiety and uncertainty. Cancer survivors have shared these emotions with each other in support groups, in waiting rooms, over the telephone, and now through listservs and other social networking sites on the internet. With few exceptions, they report that the act of openly acknowledging their fears is, in itself, a way of gaining a sense of control and maintaining a sense of hopefulness.

[Narrator]

Cancer survivor, Ellen Stovall, sees that the path to dealing with uncertainty begins with good communication between you and all the people from whom you seek support.

[Ellen Stovall, Cancer Survivor]

With communication comes understanding and clarity; with understanding, fear diminishes; in the absence of fear, hope emerges; and in the presence of hope, anything is possible.

This is the end of the Cancer Survival Toolbox program entitled "Living Beyond Cancer." You may also want to listen to other Cancer Survival Toolbox programs such as "Communicating," "Making Decisions," or "Negotiating." If you need more information about cancer survivorship issues, feel free to call the National Coalition for Cancer Survivorship toll free at 1-888-650-9127 or visit the NCCS website at www.canceradvocacy.org.