

## Table of Contents

Ellen Stovall, Cancer Survivor

[Narrator] Robert O’Gorman

Linda, Oncology Social Worker

Alisha, early 20s

Kevin, early 30s

Sarah (Sex therapist), around 50

Jim, late 60s/early 70s

Mark, early 50s

Rose, around 50

Alexa, around 40

Lyrio, around 60

Marguerita, around 35

Elena, mid-40s

Joan, Oncology Nurse

Kathy, early 40s

Mary, early 30s

## Transcript: Living Beyond Cancer

**Narrator: Robert O’Gorman**

[Alisha]

When I was younger, I expected that my first couple of years out of college would be all involved in starting life as a real adult. My cancer diagnosis and treatment changed all that. Now that I’m done with my therapy, I realize I’m a cancer survivor, and it’s a whole new world.

[Kevin]

One thing I have learned – and really come to appreciate so much –is how important the bond between survivors can be. Sure, we’re all individuals and our types of cancer and treatment histories may be different. But, we’ve all faced the same big life-and-death questions that most other people have not. Talking with other survivors is such a life-affirming experience for me.

[Jim]

My surgeon told me that it might take a year or more after my surgery for prostate cancer before I’d be ready to start sexual relations with my wife again. Even then, I still needed help – and got it from a specialist in erectile dysfunction.

[Mark]

Since my cancer surgery, some things have had to change permanently in our family. Now, my wife and our kids do most of the chores I used to do around the house. I feel so dependent... almost useless. When I’m really frustrated, I get mad at them for no reason. I don’t mean to. I just want to get back to normal.

[Rose]

You know, I was expecting to feel really relieved—happy—when I finished my cancer treatment. During all those long months of feeling sick, I just kept thinking about how good I would feel when I was all done with it. But, when that day actually came, I was really surprised...I didn’t feel excited at all.

[Lyrio]

For me, it was always good to know that everybody at the clinic was watching out for me during my treatment. I felt so alone when my treatment ended.

[Marguerita]

Some people at work are always complaining about all these little things, like traffic or the weather. And, I am thinking about cancer and all the people fighting it. Sometimes I just want to just stand up and scream, “Don’t you know how lucky you are? What are you complaining about!”

[Kathy]

Knowing that we had some options to choose from in settling our financial plans and that we could pick the ones that were best for us made me feel a lot more secure.

[Mary]

All my plans for going back to school and then starting my own business were falling right into place for me. I couldn’t believe how lucky I was. But, with my cancer diagnosis, everything stopped. At the time, I thought that I would just be putting things on hold. But now, I just don’t know.

[Ellen Stovall, Cancer Survivor]

Welcome to this program of the *Cancer Survival Toolbox*<sup>®</sup> entitled, *Living Beyond Cancer*. If you have been treated for cancer, you probably have clear memories of the day you received your last treatment. If you were treated with chemotherapy in a clinic hospital, or doctor’s office, you probably remember the feelings you had as the nurse completed your treatment for the very last time. If you were treated with radiation therapy, you may remember getting up from the radiation table hoping never to feel that cold, hard surface again. When you left the hospital, you may have been praying that you would never have to undergo another painful surgery or procedure, or smell the strong odors that remind you of sickness. Maybe you remember putting on a happy or brave face as the staff brought out balloons, or a cake, or a graduation certificate to celebrate your last treatment. After all, this was the end of your cancer therapy that you were looking forward to for so long, right? Treatment was difficult, to say the least, but now it was finally over! That moment may have filled many of us with joy—we were ready to celebrate and get on with our lives. Others of us, though, weren’t quite so sure just how we were feeling. Were we happy and relieved to be finished with treatment? Or, anxious and afraid that we were now on our own? Were we feeling insecure about not seeing our health-care team so often? Or, were we ready to bolt out the door and never return? Maybe we were feeling a combination of all these feelings. That would only be natural, since we still had questions that nobody could answer for us. What would happen to us now that our treatments were over? Will we be able to keep the cancer from coming back? What does life beyond cancer look like?

[Ellen Stovall, Cancer Survivor]

Hello, everyone. My name is Ellen Stovall, and I, too, am a cancer survivor. Yes, a cancer...survivor. That powerful phrase describes all of us who have been diagnosed with cancer at some time in our lives. There are now about 10 million of us. And, about half of us—5 million people—have survived more than 5 years after our diagnosis. The National Cancer Institute recently estimated that about 14% of us—about 1,400,000 survivors—have lived more than 20 years beyond our diagnosis. That means that there are many of us who are surviving and living relatively normal lives years after our original diagnosis of cancer. Encouraging news, for sure. The end of the story? Not exactly.

[Ellen Stovall, Cancer Survivor]

In this program of the *Cancer Survival Toolbox*, we will talk about a number of important issues that are specific to life beyond the diagnosis and initial treatment of cancer. While support and resources are increasingly available to help people who are being treated for cancer or suffering from the side effects of these treatments, much less attention is focused on long-term survivors. But, the reality is that we don't simply change from being a "sick patient" one day to being a "well survivor" the next day. Cancer survivorship is a day-to-day, on-going process that begins with your diagnosis and continues through the rest of your life. The people on your health-care team—your doctors, nurses, social workers and mental health professionals—are some of your best allies in addressing your physical and emotional needs as a cancer survivor. Today, there are many excellent research programs that explore new ways to help survivors and their families adjust to changing needs. Many survivors have found that participation in this research provides an effective way to better understand and address their own ongoing survivorship needs. The Resource Booklet that accompanies the Cancer Survivor Toolbox lists ways to find out about research opportunities that may help you with your adjustment to survivorship. After all, survivorship does not look or feel the same for each of us. Here are some examples of how different our needs might be.

[Narrator]

Survivorship may extend for months, years, and even decades. Some survivors continue on maintenance therapy, which is similar to long-term treatments for other chronic diseases, like diabetes and heart disease. Other survivors will live for many years with metastatic cancer, while others will never experience their cancer again.

[Narrator]

Some survivors may have completed treatment within the past few months or even the past few years, while others were treated decades ago. Obviously, day-to-day survival issues will depend on your own individual situation.

[Narrator]

Some survivors may experience a recurrence of their original cancer, or they may be diagnosed with a second malignancy. Others may discover that their cancer treatments have damaged parts of their bodies, such as their heart, lungs, or kidneys.

[Narrator]

Some survivors recover from the effects of treatments with little difficulty and feel almost normal within a few short months. Other survivors take much more time to recover physically from the trauma of treatment.

[Narrator]

And, finally, while many survivors will recover physically, they may still have difficulty recovering from the emotional or social traumas that can result from cancer and cancer treatment. These challenges can be more difficult to deal with than the medical problems. Linda is an oncology social worker who's seen a spectrum of cancer survivorship.

[Linda]

Surviving cancer is more complicated than simply being sick or well...having cancer, or being cancer-free. Instead, it's a continual process of survival that's constantly changing. There may be times when the joy you feel about survival far outweighs any anxieties you may have. Then, there will be times when your fears and uncertainties seem to take over your life, and you wonder if you'll ever feel normal again. These changes might involve family and friends who are trying to adjust to your experiences after cancer, but often don't—or can't—understand what you're feeling. Many survivors face challenges in school or at work. You may have to fight **against** discrimination and fight **for** the chance to recover at your own pace. And, you may need to deal with intense feelings, like anxiety, anger, uncertainty, unresolved grief, and loss.

[Linda]

On the positive side, many survivors find themselves reevaluating their lives and changing their priorities. They might experience a new zest and appreciation for life, and try to make sense out of painful experiences. Many survivors have done this by getting involved in volunteer work and cancer advocacy in their communities, and by helping other cancer survivors directly.

[Narrator]

We hope that this program of the *Cancer Survivor Toolbox* will introduce you to some new skills to help you adapt to your life after cancer. The goal is to help **you**, a cancer survivor, be as healthy as possible within your personal circumstances.

[Narrator]

This program contains 6 sections on issues that are important to survivors.

Section 1 is Living With After Effects, in which we will look at the physical effects of cancer and its treatment, and what kind of records you need to keep.

In Section 2, Intimacy, we will explore the important topics of sexuality and fertility, and how close relationships might be affected.

In Section 3, Family Communication, we will talk about the experiences and challenges of survivorship that affect more than the survivor alone.

Section 4 focuses on the Emotional Aspects of Cancer, specifically in recognizing and dealing with anxiety, depression, grief, and distress.

Section 5 provides helpful information on Getting Your House in Order through health directives, wills and trusts, power of attorney, and financial planning.

Our program will conclude with Section 6, Living With Hope While Dealing With Uncertainty, with thoughts about advocacy, getting involved, giving back, and maintaining.

Let's begin by looking at how life beyond cancer can affect our bodies physically.

## Section 1: Living With After Effects

[Narrator]

The same factors that make cancer treatments so good at destroying cancer cells can be not-so-good, and sometimes quite damaging, to normal, healthy cells. You may have experienced some of the consequences of this kind of damage. For example, it's not uncommon for chemotherapy or radiation therapy to damage normal cells lining the throat, stomach, and bowels. This damage can result in side effects, like nausea, vomiting, diarrhea, or constipation. Hair follicles damaged by cancer treatment may stop producing hair, resulting in hair loss and baldness, and possibly the loss of your eyelashes and eyebrows. Parts of your body that normally make different kinds of blood cells may be harmed by cancer or cancer treatment. If this happens, your body makes fewer blood cells, and you may become pale and weak with a condition called anemia, or you may bruise easily, or catch infections. These kinds of side effects occur most often, and are most noticeable, while you are still receiving treatment.

[Narrator]

But now that you're done with your treatment, you probably have a lot of questions. As your hair grows back, will everything else start returning to normal, too? Or, does it take time to recover from the physical consequences of cancer and its treatment? How soon can you put this all behind you and start feeling like "your old self" again? And, does this recovery process ever end?

[Narrator]

This first section of our program will focus on what happens to your body after you finish your initial course of treatment, how you recover physically, and what you may need to know about keeping track of your health in the months and years after cancer. We'll begin with the first months after the completion of treatment. This period of time is sometimes called the "extended stage of survival." Then, we'll talk about the years that will hopefully follow, which is sometimes called the "permanent stage of survival."

[Linda]

The extended stage of survival starts when you complete your first course of treatment and lasts for approximately 1 to 3 years. This is an intermediate or transitional time, when survivors walk a fine line between the land of the "sick" and that of the "well." In this stage, you may not feel quite like a "patient" anymore because you are no longer being treated for cancer. But, you may not feel safe enough or confident enough to call yourself a "survivor." The medical world calls this time "remission," when the cancer appears to be totally gone. Some survivors who have a high risk for the disease coming back may continue to take some form of medicine, called maintenance therapy, during remission.

[Linda]

Many survivors describe their feelings during remission in a number of ways, such as: feeling untethered or not being anchored; being in limbo; living in a constant state of "watchful waiting"; or feeling anxious and fearful about the cancer coming back—will it happen again?

[Linda]

Some health-care professionals and cancer survivors call this “neutral time,” that is, a period of remission when you may feel uncertain and may worry a lot about your health. That’s completely understandable. In the first place, you can’t be sure that the cancer really is gone. And then you may not feel sure about how to look for hints or signs that the cancer may be returning. This uncertainty can be very stressful, especially since it comes at a time when many survivors expect, or at least hope, to feel only relief and joy once their treatments are finally over.

[Narrator]

During the extended survival stage, you may also need to deal with other health-related issues. Besides looking for signs of cancer, you may be living through lingering side effects from your original treatments. These side effects may include a lack of energy, weight loss or weight gain, or numbness in your fingers and toes. While these types of side effects are usually temporary and go away on their own over time, they might keep on reminding you that you have been sick. Although only time will tell, these lingering side effects will usually disappear within a few months. Some survivors, though, have to learn how to live with permanent changes in how their bodies look or function. These changes might include the loss of a breast, a leg, or other body part, or a change in body function, as with a colostomy. They could also include scars, radiation “tattoos,” or damaged sexual organs. Some survivors may need extra help adapting to these changes. So, referrals from your oncologist to a rehabilitation specialist or mental health counselor may be helpful. Just remember that not everyone has the same side effects, nor do the side effects go away at the same rate. Your doctors and nurses can help you monitor your progress. And other cancer survivors can help you understand what life after cancer looks like.

[Narrator]

With that in mind, let’s hear from two survivors, Alisha and Kevin, who met in the waiting room during follow-up visits to their oncologists.

[Alisha]

When I was younger, I expected that my first couple of years out of college would be all involved in starting life as a real adult. You know, thinking mostly about really big things, like what kind of job I would get, where I would live, what it would be like to be for me and my friends to finally be on our own. But, first my diagnosis of Hodgkin’s disease—it’s a cancer of the lymph nodes—and then my treatment changed all that. I finished a full course of chemotherapy a while ago and had my last radiation treatment 3 months ago. So, now, I realize I’m a cancer survivor, and it’s a whole new world.

[Kevin]

I’m proud to say I’m a 9-year cancer survivor. One thing I have learned -- and really come to appreciate so much -- is how important the bond between survivors can be. Sure, we’re all individuals and our types of cancer and treatment histories may be different. But, we’ve all faced the same big life-and-death questions that most other people have not. Talking with other survivors is such a life-affirming experience for me. You connect on everything from major issues to pretty specific questions about treatment side effects. Since I got my diagnosis of Hodgkin’s disease when I was 21, just like Alisha, I think I had a pretty good idea of what kinds of questions she might have. At that stage in life, you’re concerned about how you look and how your friends and other people see you. Alisha asked me lots of questions like, how long did it take for my hair to grow back? Did it look and feel normal? Or, did it grow back a different color and texture? Another issue was weight. Was I really thin when I finished my treatment? How long

did it take to put on some weight again, so I didn't look sick anymore? What did I eat? Could I exercise? Another question she had was about bruising. Did I bruise easily, and, if so, what did I do about it?

[Alisha]

Since I was planning on starting a new job, I needed to know what to expect. Would I keep on feeling really tired or would I get my energy level back? I asked Kevin if he had anemia from his therapy and whether he needed treatment to boost his red blood cells. I had experienced "chemobrain" and was worried that it might affect how I could work. How soon could I expect to start thinking clearly again? I knew that my white blood cell count was low, which could lower my resistance to infections. Since this new job would require me to work with a lot of people all day long, I wanted to know if I'd risk getting lost of colds. So, I asked Kevin if his doctor told him to stay away from large groups of people or children to avoid catching colds or the flu after he finished his cancer treatment. Had he gotten many infections? And, how long did it take for his white blood cell count to get back to normal?

[Alisha]

I also wondered about the numbness in my fingers and toes. I asked Kevin if he had experienced that, and how long it took to go away. Finally, even though it's a personal kind of question, I wondered what Kevin's doctors and nurses had told him about the possible effects of his treatment on whether he could have children in the future.

[Kevin]

I really felt good talking with Alisha about her questions. It's perfectly normal to feel worried about these things. It's also important to remember that, though many of us face the same questions no matter what type of cancer we survived, we each recover at our own pace. So, I suggested other ways for Alisha to get answers from other people, too. For me, that starts with my doctors and nurses. I found that it really helps to write down your questions between checkups so you'll remember to ask them all your questions. I also told her about the books, listservs, Web sites, and specialty clinics I had either accessed or heard about from other people. Maybe these would help her, too.

[Narrator]

Simply talking to someone who's "been there"—a veteran survivor—helped Alisha deal with her anxieties, feel a bit more secure, and start visualizing a future beyond tomorrow. She's starting to see the world of the permanent stage of survival in which Kevin and other long-term survivors live. It's difficult to describe just when this stage begins. It tends to evolve gradually over a period of years. You eventually begin to think less about cancer and feel more secure about the future. You start feeling comfortable in your body again, or you feel like you have adapted to changes that you must live with.

[Narrator]

While most survivors who recover from cancer go on to live relatively healthy lives, this by no means minimizes the challenges that other survivors face. These challenges may be of four kinds: recurrence, second malignancy, organ damage, or emotional and social issues.

[Narrator]

The first challenge involves the possibility of cancer recurrence. Some long-term survivors experience a recurrence of their original cancer and need more treatment. This might involve the same type of therapy that initially controlled the disease, but often a different kind of treatment, is needed. This is often an excellent opportunity to ask your doctor whether participating in a clinical trial would be one of the best options for you to consider at this time.

[Narrator]

In contrast to recurrence of the original cancer, some survivors may face the challenge of “second malignancy”—development of a new and entirely different kind of cancer than they had before. Second malignancies require different types of treatment from the first form of cancer. The earlier a secondary malignancy is caught and treated, the greater the chance for a successful outcome. There are more and more long-term survivors who have experienced second malignancies and have been successfully treated.

[Narrator]

A third challenge may come in the form of organ damage. Some long-term survivors find that their cancer or cancer treatments have damaged some parts of their bodies, such as their hearts or lungs, ovaries or testicles, bone marrow, or nervous system. It may take some extra effort on your part to find a health-care provider who has experience working with long-term survivors and who can make referrals to the appropriate specialists for diagnosis and treatment.

[Narrator]

And a fourth challenge involves a variety of emotional and social issues. While many survivors will recover physically, they may have difficulty recovering from emotional or social traumas that may result from their illness and treatment. These traumas are often more difficult for some survivors to deal with than the medical problems. We will hear more about these types of issues later in this program.

[Kevin]

Surviving cancer is more complicated than simply being either sick or well—either having cancer or being cancer-free. Cancer survival is a continual process that requires you to take the best possible care of yourself.

[Kevin]

There's one part of being a long-term survivor that I wanted to make sure Alisha knows about. I've survived nine years without a recurrence of cancer—that's very encouraging. But I'm still cautious about keeping track of my health. Since my original cancer has not recurred yet, it most likely will not come back this late. But, I know I'm still at risk for developing other medical problems related to my prior treatment.

[Narrator]

You're probably wondering what you can do to stay as healthy as possible after being treated for cancer. Right now, there is little known about how to prevent some of the late effects of cancer. This means that

it's extremely important that you learn how to monitor your health and have regular checkups, as Kevin just said, to catch any changes that you are unsure about. We are also learning more each year about the value of exercise, healthy nutrition, stress reduction, and screenings. Check with your health-care team for the latest information and specific recommendations in these areas. Meanwhile, here are a few suggestions that may help you develop your own personal plan for life after cancer.

[Narrator]

Request an exit interview with your doctor and nurse if you are just completing your treatments, or make a separate appointment if you are a longer-term survivor. Have them help you create a monthly or yearly follow-up plan. Some questions for you to discuss might be: How often do you need to be seen and by whom? What medical or diagnostic tests need to be done and how often? What are the possible risk factors that are specific to you?

[Narrator]

Get the name and phone number of someone you can call if you become anxious or have questions. In addition to the numbers of all your doctors, you will want the numbers for your oncology nurse and social worker. They are often much easier to contact than your doctor. They can frequently answer many of your questions, and can help recognize symptoms that may need further attention. They also can refer you to support groups or other community resources that offer continuing support to survivors who are no longer receiving treatment or who are on maintenance therapy.

[Narrator]

Ask your doctor or nurse to make photocopies of your medical records for you. These would include surgery, pathology, and x-ray films and reports. Also include details of all cancer treatments, such as the names and doses of all chemotherapy drugs, and the amount and location of radiation therapy. Have them list any problems that may have occurred during therapy, and what to expect now that you are finished. Make sure you have all the medical summaries from your health-care team. Many survivors have found it helpful to create their own personal summary that describes their diagnosis and treatment history.

[Narrator]

Keep track of your medical history. As you collect photocopies of your medical records, you will probably find it helpful to create your own system to save and organize your medical records. This could be a large envelope, a pocket file, or a binder with labeled sections to organize photocopies of your records. You could, for example, have separate sections for your prior diagnosis; your treatments, which should include dates and doses; lingering effects, like fatigue or numbness; risk factors, like thyroid dysfunction and infertility; and your follow-up plan. This way, you will be able to provide a detailed account of your medical history no matter what health-care provider you see in the future. This is especially important with today's medical climate where people change insurance plans so frequently, or if you move to other parts of your community or to another state.

[Narrator]

You may be able to be seen by health-care professionals at a long-term follow-up clinic, sometimes called a “late effects” or “survivor” clinic. This type of clinic is staffed by experts who care for long-term survivors and who understand the specific issues of this group. While a number of these specialty clinics are available for children and young adults who received treatments as children, very few of these clinics are available for adult cancer survivors at this time. We hope this will change soon.

[Narrator]

With increasing numbers of survivors living many years after their initial diagnosis, we are learning that continued support, accurate information, and accessible healthcare are all crucial for those who are fortunate to be long-term survivors. As a matter of fact, their lives depend on it!

## Section 2: Intimacy

[Narrator]

Intimacy, sexuality, and fertility issues are often neglected topics for cancer survivors. At the time of treatment, the focus is on achieving cure or control of the disease. But, during and after treatment, cancer survivors may experience changes in their desire to be close to other people, their levels of sexual desire and ability to enjoy usual sexual activities, and sometimes in their ability to have children.

[Narrator]

Intimacy involves sharing yourself with another person in more ways than through sex. Holding hands, touching, hugging, and caring deeply about another person, as well as sharing feelings, hopes, dreams, fears, emotions, and religious values are all aspects of an intimate relationship. If you were involved in a relationship as you went through treatment, that relationship may have become stronger through the course of your treatment. In some cases, however, a relationship will not last because of the stress of treatment or because of other issues that surface during or after treatment. Your feelings about life may change, and this may affect your intimate relationships.

[Narrator]

Whether you were involved in a relationship during treatment or not, you may become involved with someone new in the future. Think about when, and how, you will share the fact that you have had cancer. Talking about your cancer history is personal and can be very important, especially early on in a new relationship. You may want to consider waiting until you and your partner have had a chance to get to know one another and feel comfortable with each other before discussing your cancer experience in depth. Once you have established good communication skills and feel comfortable being with, and talking with, each other, it may be easier to talk about your cancer experience. When you do decide to share this information, don't assume that your partner will react in any particular way. If you are defensive or confrontational, you might frighten your partner. Television shows and movies have portrayed cancer as a painful, traumatic, and often fatal disease. An unfortunate, but normal, response to hearing the word "cancer" is to be afraid and to believe that the person with cancer will die. Be open to helping your partner understand the effect your cancer history has had on your health and on the way you lead your life now.

[Narrator]

Some types of cancer, like cancers of the breast, prostate, urinary tract, uterus, ovary, vagina, cervix, or testicles, are associated with obvious changes in sexuality. However, it's important to keep in mind that any type of cancer can affect sexuality. Sexuality is more than just the physical acts involved in intercourse. Human sexuality is a reflection of how we see ourselves both as individuals and in relation to others. It includes how we feel about our bodies, our need for touch, our libido or level of interest in sexual activity, communicating our sexual needs to a partner, and the ability to enjoy sexual activity. Sexuality is complex and involves many factors, including the desire for emotional intimacy. For some people, the ability to have children can affect their sexuality. A cancer diagnosis, and the treatments that follow, can affect sexuality in many ways. As a cancer survivor, you have probably experienced physical, emotional, psychological, and spiritual changes in your life. Any of these can have an impact on your sexuality and your desire for intimate contact with others. Additionally, the use of some medications, fatigue, or emotional stress can lead to a loss of the desire for sexual activity.

[Narrator]

Many survivors who experience pain, discomfort, discharge, or bleeding during their first attempts at sexual activity after cancer treatment assume that they can no longer enjoy sexual activity. This is not true. Different positions, various types of lubrication, more attention to foreplay, improved communication between partners, and talking with a sex therapist can help survivors deal with problems encountered during sexual activity. Let's focus on the different challenges that affect women and men who are cancer survivors. Sarah is a sex therapist who works with cancer survivors.

[Sarah]

The most common sexual problems that women face after cancer treatment are the lack of interest in sexual intimacy, pain during intercourse, the inability to achieve orgasm, and problems with lubrication. Women need both of the hormones, estrogen and testosterone, to maintain interest in sexual activity. Hormonal treatment for cancer that changes levels of estrogen or testosterone can change libido, which is another word for level of sexual desire. Too little estrogen can cause vaginal dryness, which can interfere with sexual intercourse. If your cancer is not sensitive to levels of estrogen in the bloodstream, your doctor may prescribe estrogen replacement therapy to increase estrogen levels and improve vaginal lubrication. If your cancer is sensitive to estrogen, as some forms of breast and ovarian cancers are, you can take estrogen in the form of a cream, vaginal pill, suppository, or through an estradiol ring inserted into the vagina. These forms of estrogen therapy can help with vaginal lubrication without increasing the levels of estrogen in your body's circulatory system.

[Sarah]

In addition to hormonal treatment, several good lubricants can be used to overcome vaginal dryness. Generous amounts of a water-based lubricant, such as K-Y jelly, Replens, Astroglide, Hydra-Smooth or other brand should be applied to the labia, vagina, penis, or vibrator to ease penetration, prevent pain, and minimize the risk of injury to the vaginal wall. This can be turned into sexual foreplay, so that it becomes a source of pleasure for both partners.

[Sarah]

For women with diminished sexual arousal, doctors can prescribe different types of medications, like Viagra, to increase interest in sexual activity. Women who have experienced painful intercourse after treatment for surgery may have been involuntarily tensing the genital muscles during foreplay. This makes penetration more difficult, causing pain, which, in turn, further increases fear, anxiety, and muscle tensing, and may consequently lead to avoidance of sexual activity entirely. Cancer survivors who find that their sexual activity is no longer comfortable may need to change positions, add lubrication, and practice muscle relaxation exercises. Additionally, they could use this as an opportunity to learn about other sexual positions and techniques that they might enjoy. A woman who experiences pain during intercourse may want to try positions where she is on top or side by side, so that she can control the angle and depth of penetration. Generous use of lubrication will also help minimize discomfort.

[Sarah]

Women who have been treated with certain forms of surgery or radiation need to know that these treatments can cause the vagina to become narrower and less flexible. This is called vaginal stenosis. Women who are at risk for vaginal stenosis need to use vaginal dilators to make sure that the vagina

remains open. Even if these women do not plan to have sexual activity in the future, it is still important to use vaginal dilators to keep the vagina open and flexible for future vaginal examinations by their health-care providers.

[Narrator]

Among men, erectile dysfunction, sometimes referred to as impotence, is a common physical and emotional problem following treatment for prostate cancer. Many affected men become depressed about the loss of sexual function and about not being able to meet the sexual needs of their partners. These men should know that there are many different ways to approach the problem. Let's hear about Jim's experience.

[Jim]

After my surgery for prostate cancer, my wife and I wondered about how soon we would be able to start having intercourse again. We spoke with the surgeon who said we could start as soon as I felt physically up to it. He wanted us to be aware, though, that it could take up to a year or more for erections to return to normal or to the firmness they had been prior to surgery. We tried when I thought I was ready, but we were extremely disappointed our first few attempts. So, we decided to get help from a specialist in erectile dysfunction. He provided me with some medication that might help make the erections more firm while my body was adjusting and recovering. This was very helpful. It took away some of the worry I was having about performance. My wife was also happier with the results. I learned that it's important not to be afraid to ask for the help you need.

[Narrator]

Erectile dysfunction may be related to damage to the nerves or the blood vessels supplying the penis, and it could also relate to the stress and emotions that men with prostate cancer frequently experience. A doctor who specializes in treating erectile dysfunction can determine the cause of the problem and suggest ways to treat it. Most doctors who specialize in erectile dysfunction are urologists, but there are a few general practice doctors who are certified in treating erectile dysfunction. A good resource is [www.impotencespecialists.com](http://www.impotencespecialists.com), where you can get a referral to a specialist in your geographic area.

[Sarah]

There are several types of medicines that can be taken to induce an erection. Some, like Viagra, Cialis or Levitra, are taken in pill form. Other medicines are rubbed on the penis to relax blood vessels, or inserted or injected into the penis or urethra to cause an erection. Some men may not be able to take Viagra or similar medications because these may interfere with other medications these men are already taking or because of some other medical condition unrelated to their cancer. Any doctor who treats a man for erectile dysfunction must know about all the medicines that person is taking, including over-the-counter and herbal medicines, so that potentially harmful chemical interactions between these medications can be avoided.

[Sarah]

There are also different types of penile implants and other devices to help men achieve and maintain an erection. If psychological or emotional factors contribute to the problem, talking with a licensed sex

therapist can be helpful. The American Association of Sex Educators, Counselors, and Therapists provides a listing of certified sex educators and counselors by state. Men whose maintenance therapy for prostate cancer involves the use of hormones will need to talk with their doctors about options for preserving sexual function.

[Sarah]

Treatment of testicular cancer may involve surgical removal of a testicle. This treatment does not make a man sterile as long as he has one functioning testicle. However, some men are bothered by their appearance after this surgery, and this can affect their ability to achieve and maintain an erection. Men who are thinking about having a testicular prosthesis implanted, either at the time of the original surgery or at any time afterward, should know that many experts do not recommend testicular implants for cosmetic reasons. Additionally, surgical fees for this procedure are high, and most public and private insurance plans will not pay for it. After the problems with silicon breast implants among women, testicular implants are not generally offered in the United States. Some companies are making saline-filled implants that could be more readily available.

[Sarah]

Men who have had lymph nodes removed from the perineal area and groin may have experienced damage to the nerves that control ejaculation. If so, they may still experience the sensations of sexual activity and ejaculation, but without the release of fluid during ejaculation. Men who have had their prostate gland or seminal vesicles removed, or who have had radiation therapy after prostate cancer, may also experience orgasm with little or no fluid being released. The absence of fluid will not affect their ability to have an orgasm. In some cases, the semen is produced but flows into the bladder rather than moving into the penis. This is called retrograde ejaculation. The feelings of ejaculation are not affected, but no fluid is released. The semen and sperm will eventually be carried out of the bladder with the urine, which might look cloudy. For men considering sperm banking, sperm can be harvested using methods other than ejaculation.

[Sarah]

Treatment for colorectal cancer may involve surgery that closes the anus. This means that anal intercourse will no longer be possible for survivors who received this treatment. Affected partners would need to explore other methods of sexual activity and intimacy to enhance their relationship.

[Sarah]

All cancer survivors whose sexuality, and specifically sexual organs, have been affected by cancer or cancer treatment can benefit from taking time to explore sensations in other areas of the body. The areas of the nipples, inner thigh, ears, neck, and face are all very sensitive to stimulation. Try different types of touch, from a light touch using the fingers, a piece of silk, or a feather, to a deeper, massaging type of touch, until you discover techniques that work for you and your partner.

[Sarah]

It's also possible that sexual function may be affected in ways that are not directly related to the sexual organs. For example, survivors who get short of breath during physical activity need to plan ahead for

sexual activity. Survivors who use supplemental oxygen should make sure that they have enough oxygen in the tank and that the tubing is long enough to allow them to move around freely during sexual activity. These people may find breathing easier if they lie flat on their backs. Positions that involve either sitting upright or standing may be more comfortable, since they allow the lungs to fully expand and take in more oxygen with each breath. These people should be sure to tell their partners if they are getting short of breath. If so, they should take a rest or slow the pace of their activity until they no longer feel short of breath.

[Sarah]

Survivors who have a colostomy, ileostomy, nephrostomy or ileal conduit will probably want to empty the pouch before any sexual activity. Some people with colostomies find that irrigation and replacement of the pouch with a patch device available from ostomy supply companies enhances self-image, too. Concerns about odor might be minimized by placing odor-reducing tablets or sprays in the pouch. All clamps and valves should be closed and secured.

[Sarah]

Survivors who have conditions that make their bones fragile, like multiple myeloma or bone metastases, may be concerned about the possible impact of sexual activity on their bones. Careful positioning may make sexual activity possible, comfortable, and safe even for these people. Generous use of pillows, rolled towels, and blankets can provide for comfort and support. Any survivor who experiences pain at any time during sexual activity should tell his or her partner immediately, and check if the affected part of the body can be moved without pain. They should contact their doctor right away if there is redness or swelling at the site of the pain, or if the pain does not go away in a reasonable time.

[Sarah]

Finally, anyone who is sexually active, whether they have cancer or not, should take precautions against sexually transmitted diseases. Any exchange of body fluids between people creates a risk of transmitting an infectious disease. The best protection against sexually transmitted diseases is to **always** use a latex condom, which can be used with water-based lubricants, such as K-Y jelly. These should be used for oral sex, vaginal intercourse, or anal intercourse. Before performing oral sex on a woman, a dental dam or plastic wrap should be placed over the woman's vulva to prevent possible transmission of infection. When performing oral sex on a man, the use of flavored condoms or topping a regular condom with flavored, water-based lubricant can diminish the taste of the barrier.

[Narrator]

Your doctor, oncology nurse, or social worker may have talked to you about fertility issues before you started treatment. Survivors who do not want to have children should practice an effective method of birth control. Survivors who knew before their cancer treatment that they would want to keep their options open were probably offered the chance to bank sperm, or to freeze embryos, ovarian tissue, or eggs. If you did not do any of these things before treatment, and you later decide that you do want to have children, there are things you should consider. First, you may want to talk with a reproductive endocrinologist or a fertility specialist. New techniques are constantly being developed to treat infertility. In some cases, men whose sperm counts were close to zero immediately after treatment have been able to father children years later because their bodies were able to begin producing sperm again.

[Narrator]

Second, many doctors recommend that you wait a year after completing treatment before attempting to have a child. This gives your body time to recover from the stress of cancer treatments and any effects of chemotherapy that might be passed on to a child. In the meantime, be sure to use effective birth control when you do have sex.

[Narrator]

Third, you may want to consider other options. If you find that you are not able to become pregnant or to father a child after treatment, and it is important to you to have a family, you might be able to use donor sperm, a donor egg, a donated embryo, a surrogate mother, or you might choose to adopt a child. A doctor or other fertility expert, a social worker, other family counseling experts, and adoption experts can help you explore various options for creating a family.

[Narrator]

Some health-care professionals may not be comfortable in approaching issues of intimacy, sexuality, or fertility. On the other hand, a growing number of doctors, nurses, social workers, and other providers are not only comfortable talking about sexuality and intimacy, but they have developed a great deal of expertise in it. Sometimes, all that's needed for a survivor to make his or her concern known is to simply bring up the question. Many people have a hard time talking freely about intimacy or sex. But, it is important, and is probably not as hard to do as, say, talking about life-and-death decisions—which most survivors have already done at least once or twice since their cancer diagnosis. If you don't feel comfortable with the provider you have, ask for a referral to another provider with the expertise you need. You may also benefit from the array of educational materials available from many organizations in written, video, CD, audiotape, and Internet-based formats. Ask your doctor, nurse, social worker, or other cancer survivors you meet about materials they found to be most valuable.

[Narrator]

In summary, the desire for intimacy is a basic human trait. It brings joy to our lives and allows us to give joy to others in a variety of ways. Physical sexual activity is one aspect of intimacy, as are touching, talking, crying and laughing. Cancer and cancer treatment do not change the need for intimate contact with other people even though the effects of cancer and cancer treatment may change the way survivors express intimacy and sexuality. Survivors may find that using survival skills, such as finding information, communicating, negotiating, solving problems, and making decisions, which are found in earlier *Toolbox* programs, helpful as they explore new ways of expressing intimacy and sexuality in current and new relationships.

### Section 3: Family Communication

[Narrator]

Mark is 50 years old and was diagnosed with kidney cancer about a year and a half ago. He is married and has two teenage sons and a teenage daughter. Let's hear what he says about the impact of his diagnosis on his family.

[Mark]

Since my cancer surgery, some things have had to change permanently in our family. Before, we all knew what our jobs around the house were. Everything went pretty smoothly. My wife and I both work outside the house, and at home, we had different things to take care of. I kept up with the cars and things that needed to be done around the house. I also paid the bills and managed the finances. My wife took care of all the shopping and kept everybody organized. Our teenage kids concentrated on their school work, sports, and summer jobs. Since I've had cancer, my wife and our kids have had to do a lot of my share. My sons take turns cutting the grass and doing the yard work. But, they can't really handle the harder maintenance jobs. My daughter is now in charge of getting the cars serviced on schedule and has to drive me to doctor appointments sometimes. My wife is working overtime to help make ends meet. I feel so dependent...almost useless. Sometimes, when I'm really frustrated, I get mad at them for no reason. I don't mean to. I just want to get back to normal.

[Narrator]

A family is a social system. Change in one part of the system causes change in the other parts. A cancer diagnosis for one family member can change the ways the entire family communicates and gets along. Sometimes, the change can have long-lasting effects on all family members. Many researchers have found that some of the most difficult problems that cancer survivors face are the reactions of the people closest to them—their family members, friends, and co-workers. To learn more about communication skills, you can listen to Program 1 of the *Cancer Survival Toolbox*, entitled "Communicating." Linda, the social worker, sees how a cancer diagnosis affects individuals and their families.

[Linda]

Families can take all different forms. They don't have to be bound by blood or legal relationships. In times of trouble, we usually think of families as a refuge...a place of support. Even the word "home" has special significance for most people in times of stress. Stress is an expected part of family life, but cancer puts extraordinary stress on families. For some families, the challenge of cancer can offer the chance for personal growth and can actually strengthen bonds within the family. But extreme and prolonged stress can have a negative effect on even the strongest and closest families.

[Linda]

During the initial cancer crisis, families face many new and often tough challenges. Family members need to find the right kinds of information to help make treatment decisions. They must decide who to tell about the diagnosis and what to tell them. As we heard from Mark, family members may need to take on new responsibilities, at least for a while. They may also have to make tough financial decisions. They

have to find ways to support one another emotionally and manage their fears and uncertainties. Each of these changes requires family communication.

[Linda]

Open communication and the expression of feelings within the family are crucial to creating a healing environment and for helping each other gain the strength necessary to deal with the long-term effects of cancer. Remember that, while separate cancer crises may come and go, cancer itself is a long-term illness. You will need to maintain or develop good communication skills so your family can adapt over the long haul. And, you need an understanding of what kinds of factors create communication barriers, so you can overcome them.

[Linda]

For example, family members may have differing views about cancer and its treatment. They, too, are frightened and concerned for their loved ones: Is the cancer really gone? Will it come back? They may think the treatment is not aggressive enough—or that it's too aggressive. Sometimes, they may disagree with the doctor's recommendations. Good communication and getting answers to their questions can help family members feel more secure. But, the cancer survivor has to have the final word about health-related issues. Family disagreements and undue pressure about treatment and about the health habits of the cancer survivor only add to the stress level of the whole family.

[Linda]

Serious illness can often intensify the strong relationships that already exist within a family. It also may intensify existing family problems. For example, if a child is not doing well in school, his or her grades are not likely to improve when an additional family problem, like cancer, comes up. Likewise, marital or financial problems often get worse when someone in the family develops a serious illness. Substance abuse, including excessive use of alcohol, use of illegal drugs, misuse of prescription drugs, as well as eating disorders, may also become more severe for a family member or the cancer survivor when new problems arise. This can be especially hard these days, since so many families are already stretched by the demands of taking care of both young children and elderly relatives.

[Linda]

Sometimes, existing problems do seem to “self-correct” for a short time as everyone focuses on an immediate cancer crisis. Eventually, however, the increased stress will probably take its toll. If someone in your family has a personal problem or is caught up in destructive behavior, do all you can to get them to seek counseling or go together for family therapy so that your family doesn't get overwhelmed. If a loved one will not seek help, seek counseling without them so you can get help in managing your own responses to the ongoing family problem and to any new crisis.

[Linda]

I always talk with cancer survivors about specific ways to avoid common barriers to family communication. First, keep cancer in perspective. Cancer can be treated, controlled, or managed. Don't let the negative myths and fears about cancer get in the way of family communication. The cancer

survivor and his or her family members need accurate and honest information about cancer, its treatment, cancer recovery, as well as long-term survival, including recurrences and possible second cancers.

[Linda]

Second, periodically review the ways in which family roles and activities have changed or may need to change. For example, will you need to delay or cancel a vacation or family event this year? Have finances changed, and, if so, what does that mean for your family? On the other hand, talk about things that have remained the same or don't need to be changed. It's important to remind each other of the love you have for one another, the value of family time, and the need to continue special activities and celebrations that keep you together as a family.

[Linda]

If family roles have changed, are the changes temporary or more permanent? One suggestion I often make is to change assignments or responsibilities among family members, when possible, every few months. This way, nobody becomes too burdened by any one task or responsibility. It usually helps to avoid having all of the personal care tasks fall on only one person. Consider asking teenager in the family and close family friends to share the care. For example, a teenager who drives could take you to doctor's visits or other appointments. This will enable the teenager to learn more about your treatment and progress, and will also provide an opportunity for private and meaningful conversation between the two of you.

[Linda]

If you worked before your cancer diagnosis and treatment, talking with your boss about your employment situation every few weeks or months can be very important. Will your employer need to make changes so you can return to work? Or, will you need to find a different type of work that is better suited to your energy level and recovery process? Keep in mind that you have rights in the workplace.

[Linda]

Some people use their experience with cancer as an opportunity to evaluate many fundamental aspects of their lives. Some will be eager to return to their original jobs and activities, but others will want to explore new options.

[Linda]

A third suggestion for avoiding barriers to communication—think about and plan exactly how you are going to go back to work and other outside activities. Many friends, neighbors, and co-workers will be curious about your illness and prognosis. Most will ask questions because they care about you and want to be supportive. Some people, however, are simply interested in the drama of a serious illness, or they like to gossip. Don't feel like you have to share the details of your health with everyone who asks. You and your family may want to practice answers to difficult questions so that when other people ask, you will have your answers ready.

[Narrator]

Keeping lines of communication open between you and your family, friends, and your boss, are all important for helping you discover your life beyond cancer. Listen to Mark's experience on an issue that might seem relatively minor, but can be a continual stumbling block for many survivors.

[Mark]

What I find most difficult in communicating with some acquaintances is that they think things are actually worse than they are, especially since I haven't had been able to return to work yet. This one woman from work always asks me how I am. When I say "I'm fine," it's like it's never a good enough answer for her. She'll lean in close, lower her voice, and ask, "How are you, really?" You know what? I'm really not interested in sharing a lot of details with her. I resent her being so nosy.

[Narrator]

Discussing and even practicing different kinds of responses with close family members might help Mark come up with a simple statement that will stop people from asking these kinds of questions. Sometimes, you just have to be blunt.

[Linda]

You might simply ask, "Why don't you believe me when I tell you 'I'm fine'?" Or sometimes, humor does the trick. You could ask, "What are you doing, writing a book about me?" Or, you may need to be clear that you are beyond discussing the cancer. What you want to talk about is the future or how things are going at work. The responses should be ones that you are comfortable saying. Take time to think about and talk through responses to these kinds of questions, so that you are prepared when you need to be.

[Linda]

A fourth suggestion for avoiding barriers to communications—avoid family burnout. We usually think of burnout affecting an individual person who's been under a lot of stress coping with a physically or emotionally difficult situation over a long time. Burnout sets in when that person finally reaches the point at which he or she is completely wiped out... drained of the energy and motivation needed to keep on coping. The same thing can happen to a family that's been coping with a stressful situation, like caring for a family member with cancer, over a long time. Family burnout can occur during the initial cancer crisis and over the duration of treatment that may extend for many months or even years. The signs of burnout range from physical symptoms, like fatigue and exhaustion, frequent headaches, or sleeplessness, to behavioral and psychological symptoms, such as being quick to anger, feelings of being unappreciated, and being unable to make decisions. Sometimes symptoms lead to "escapist" behavior, and an individual may start using alcohol or drugs to avoid the overwhelming feelings of stress. Sometimes, stress can lead to domestic violence. Problems like this demand professional help.

[Linda]

Two major clues to burnout are increased cynicism and feelings of being indispensable. You or your loved ones may become cynical about the treatment plan or about the health-care team. Or, you may start feeling despair that the situation will never get better. This cynicism may be linked to anger, and you may be directing your angry feelings about the situation or your sense of hopelessness at family members, your friends, or your doctor. On the other hand, family members may direct their anger and

frustration at the family member with cancer. If this is happening, it needs to be addressed directly. Your social worker is a good resource for issues like this.

[Linda]

Feeling indispensable is another sign of burnout. A family member who believes that he or she always has to be involved in caregiving – no matter how tired or stressed out they are. They may set aside their own personal goals, gratification, or even health so that they can always be around to help their loved one. Some people call this the “martyr” complex when one person sacrifices personal well-being for the family’s sake. It is very important that all family members take care of their own health. This means eating right, exercising, and taking time to relax and get enough rest. If not, the “martyr” may suffer burnout and could become resentful. And you may begin to feel smothered by a loved one who is so worried about you that they want to do everything for you. They need to know that part of your survivorship involves getting back to being independent.

[Linda]

The entire family, including the family member with cancer, should try to continue outside interests, hobbies, sports, and exercise programs as much as possible. If not, this can be an area of family conflict. Sometimes family members feel like the individual with cancer isn’t trying hard enough to get back to normal, or that they should be getting on with life, not dwelling on the illness.

[Linda]

On the other hand, family members can become overprotective, and some even have difficulty giving up the caretaker role. You may feel you’re ready to return to work... that it would be helpful to feel productive again. Your spouse or partner may worry that it will be too much for you, or that you’ll have a setback if you return to work or other activities too soon. If this creates a conflict, you may want to meet jointly with your doctor, oncology nurse, or physical therapist to discuss what level of activity might be optimal for you.

[Linda]

A final suggestion for avoiding barriers to communication—work at becoming better at asking for what you need. This applies to you, the survivor, as well as to family members who need to ask assertively for what they need. At times of serious illness and increased tension, many people put their own needs on hold and feel that it would be selfish to ask for something they personally want, or that it would be wrong to keep up with their own personal interests. After a while, this denial of personal needs can become the family norm, and resentment builds up. **Do not** assume that other family members know what you think, feel, or need. They are involved in the same situation and may not have taken your needs into account. Similarly, you may have overlooked their needs and concerns. Eventually, you and your family will return to normal, but it will be a “new normal.” Living with a diagnosis and history of cancer does change some things, but not all change is bad.

[Linda]

In fact, managing a serious medical condition over an extended period of time frequently leads to a higher level of functioning for the entire family. Families often draw closer together and can handle minor

problems and stresses more easily. They may be able to communicate with each other more directly. They may get to know one another better and be able to recognize and acknowledge one another's strengths and weaknesses and provide support as needed.

[Linda]

Good family communication skills can be learned, but you may need to get some specific training for dealing with cancer-related communication issues. If your family doesn't have the communication skills it needs, help is available. Talk with someone from your health-care team, attend mutual support groups or community programs specific to cancer-related problem-solving, or seek some individual or family counseling.

[Narrator]

We've covered a lot of ground in this section. To learn more about communication skills, listen to Program 1, "Communicating", in the *Cancer Survival Toolbox*. You can find more information on workplace discrimination in Program 5, "Negotiating," in the *Toolbox*.

## Section 4: Emotional Aspects of Cancer

[Narrator]

Alexa, Marguerita, Lyrio, and Elena are all survivors who have been meeting together in a support group for over a year. Some of them began to meet in the hospital clinic when they were receiving radiation treatment, and they have continued to meet. Rose has recently completed her treatment and just joined the group.

[Rose]

You know, I was expecting to feel really relieved—happy—when I finished my cancer treatment. All during those long months of feeling sick, I just kept thinking about how good I would feel when I was all done with it. But, when that day actually came, I was surprised... I didn't feel excited at all. Just the opposite. Now, I feel kind of let down and sad.

[Alexa]

Rose, I know what you mean. I felt that way, too, for a long time... like, will the cancer come back if I'm not taking any medicine?

[Lyrio]

For me, it was good to know that everybody at the clinic was watching out for me during my treatment. I felt so alone when I stopped going. I felt very confused by these mixed feelings. I have to thank everybody in this group for helping me through it. People who haven't been through it just don't get it sometimes.

[Marguerita]

That's so true! You know what really bothers me? Some people at work are always complaining about all these little things, like traffic or the weather. And, I am thinking about cancer and all the people fighting it. Sometimes I just want to just stand up and scream, "Don't you know how lucky you are? What are you complaining about!"

[Elena]

At my job, all these young people have so much energy and are so slim. Here I am...I don't have energy to do much of anything. I can't seem to take off all the weight I put on with the medicines. I started meeting with my social worker for some counseling, and that has been a big help.

[Narrator]

What these group members are describing are actually very common emotional reactions of cancer survivors. Cancer has an impact on our lives in many ways: physically, emotionally, and socially. Some of the effects of the diagnosis or treatment are short term, others may continue for a long time.

[Narrator]

The emotional distress that cancer causes can take many forms: anxiety... anger... depression... frustration ... are all quite common. In fact, researchers have found that about one-third of the people with a cancer diagnosis experience anxiety or depression serious enough to require professional help. Cancer specialists use a short questionnaire, called a “distress thermometer,” to help them measure the emotional impact of cancer on survivors. You can find a copy of this questionnaire in the Resource Booklet that comes with the *Cancer Survival Toolbox* and is available on the *Toolbox* Web site. If you are experiencing emotional distress from your cancer, it is very important to know that help is available, and to go get the help you need. Cancer is difficult to deal with—it’s normal to need some help during your most stressful times.

[Joan]

As an oncology nurse, the emotion I usually talk about first with survivors is anxiety. Anxiety is a common reaction to the diagnosis of cancer. The most basic form of anxiety is the feeling of fear. Fear can be important for self-preservation, because it alerts us to danger and allows us to get ready to respond. Anxiety can focus your energy, so that your body, mind, and spirit can react effectively to get you through the challenges you face. Many survivors find that they cope quite well. They can respond as needed during diagnosis and treatment, and when they need to make decisions. Sometimes, however, for many different reasons, anxiety reactions can make it hard to relax and enjoy your health after your treatment ends. Mental health researchers still have not identified all of the factors that cause anxiety reactions, but some biological factors, such as changes in hormones, may be involved.

[Joan]

The symptoms of fear and anxiety include a rapid heartbeat, shortness of breath, sweaty palms, agitation, or a sense of panic. Some of these effects may also be caused by certain kinds of medical treatments. For example, some medicines that are prescribed for respiratory or other conditions can cause feelings of agitation or restlessness that are similar to anxiety. It is also important to be aware that people who stop taking certain medications and other substances, like nicotine, can develop these symptoms, too. Talk with your doctor if you experience these symptoms.

[Joan]

Your doctor can assess your physical symptoms and can help you decide on the best way to manage them. Medical factors do not account for all anxiety symptoms that occur during or following cancer treatment. Therefore, your doctor may refer you to other members of the health-care team who can talk with you about nonmedical causes of anxiety and ways you can reduce or manage uncomfortable feelings. Some cancer support groups also address these issues.

[Narrator]

Some cancer survivors find themselves getting anxious about their annual medical checkups or tests. The fear that cancer can come back is common, even years after a diagnosis. This is very understandable, and there are many effective ways to deal with this anxiety. Oncology nurses, social workers, and wellness programs are available to help assess your anxiety symptoms and teach you stress-management techniques. You can learn most of these techniques, such as focused breathing, progressive muscle relaxation, and guided imagery, in a few sessions. Some focused breathing and relaxation exercises are included later in this program. You can listen and practice them on your own to get an idea of how well these techniques can work for you. Other techniques, such as biofeedback training, yoga, and meditation, take more time to learn, but are effective in helping both survivors and caregivers take control of their anxiety symptoms.

[Narrator]

There are other people, too, such as clergy or certified massage therapists, who can also help you deal with spiritual or physical causes of anxiety. If you find that a single technique helps you control anxiety, but you still need more help, talk with your doctor about combining medicine, counseling, and relaxation training to get the added relief you need. Your health-care provider can help you to find people and programs in your community that can help. All you usually need to do is ask and they will respond.

[Narrator]

Now, let's talk about depression. Most people have felt at least mildly depressed at some time in their lives. Depression is a common reaction to cancer, in caregivers as well as survivors.

[Joan]

As an oncology nurse, I often hear people say they're sad or "feeling down," or just "have the blues." Some survivors feel isolated during or after treatment, because they feel that other people don't really understand what they've been through. Survivors may feel angry about their situation. These feelings are a normal and expected reaction to the stress of having cancer. Cancer and its treatment can lower your self-esteem by affecting the way you lead your life or by changing the way your body looks and how you feel about these changes. Additionally, chemotherapy and some of the medicines used to treat side effects can also cause mood changes. These mood changes and feelings of depression usually get better as you get further away from your diagnosis and treatment. Sometimes, however, symptoms of depression may continue or go away only to come back and take you by surprise, even after you finish your cancer treatment.

[Joan]

A less common disorder, which mental health specialists call "major depression," involves difficulty concentrating, trouble sleeping, loss of appetite, and loss of pleasure in your usual activities. People with major depression may also have feelings of extreme sadness, guilt, and hopelessness. The good news is that there are many effective treatments for this kind of depression. Be sure to talk with your doctor about taking care of these feelings.

[Joan]

Individual or family counseling can also be helpful. In counseling sessions, a trained mental health professional can listen to your concerns and help you identify new ways of thinking about, and dealing with, the stresses that may be causing your depression. Some survivors find that short-term use of antidepressant medication helps relieve their symptoms. Support groups are also an excellent resource. They provide an opportunity to meet and talk with other survivors who understand what you are going through. These groups can give you suggestions and emotional support to help you get through tough times. If you're feeling depressed, don't wait to ask for help. Talk with a member of your health-care team, and they can help you to find the right source of help for you.

[Narrator]

Another emotional concern for many cancer survivors is grief. You may be surprised that grief is included in this program for survivors of cancer. Many people think of grief only as a reaction to a death. But, we can actually feel grief after any kind of loss. This is important, because, as you know, there are many losses that can come with cancer. When they first heard their diagnosis of cancer, some survivors describe feeling that they lost their sense of who they were as a healthy, well person. Other survivors react to the loss of hair, or the fact that their cancer surgery changed their bodies and the way they feel about their bodies. The loss of a breast or other body parts, and the loss of sexual drive that can follow certain surgeries, are significant losses that can be emotionally painful. There's more to grief, as Linda, the social worker, can tell us.

[Linda]

Many survivors have gotten so used to coping with lots of changes, big or small, that they don't allow themselves time to deal with the natural feelings of sadness or anger that accompany losses. Too often, people close to these survivors don't either. Often, friends and caregivers are trying so hard to say only positive things that they may not even want to think about anything negative. So, they may not recognize that survivors might be feeling angry or sad. You might even find yourself feeling that you can only think or say positive things.

[Linda]

However, experts agree that it is helpful to let out your feelings of grief so that you can get past these feelings and start to enjoy the positive feelings and experiences in life again. Support groups, individual and family counseling sessions, and retreats all offer you ways to express your feelings. You can probably find a social worker or other mental health specialist nearby to help you. Most major cancer treatment centers have social workers who offer counseling services. If you live a distance away from your treatment center, your doctor may be able to refer you to a social worker in your local community.

[Narrator]

For some people, it's easier to write thoughts and feelings down on paper than to say them out loud. Many survivors have found that keeping a journal to write down their thoughts and feelings about loss or grief can be quite helpful. It's a very private way to let these feelings out. Reading about other survivors' experiences can also be helpful, because they may have experienced the same thoughts and feelings that you have. There are many books, magazines, and Web sites, written by and for survivors that can provide help. Some of these are listed in the Resource Booklet that comes with this program. Most

important of all is allowing yourself to grieve when you have experienced loss. Making the effort to express your feelings, and finding that other people support you, is just as helpful in coping with loss and grief as it is in celebrating the gains and successes that are all a part of the cancer experience.

[Narrator]

You've already lived through cancer treatment, with its many physical and emotional distresses. As you're learning now, survivorship can have its own share of challenges that can be distressing, too. One lesson that many people say they have learned through cancer is the importance of asking for, and accepting, help. Many survivors, whose usual way of dealing with life situations is to work it out all by themselves, say that cancer taught them that they don't have to go it alone. This can be a difficult lesson to learn. Many of us have a hard time asking for help. However, just as it is crucial to see a doctor when you have a physical problem, it's crucial to get help from a mental health professional who understands when the emotional distress of cancer is affecting your well-being.

[Narrator]

Don't hesitate to ask for help if you or a member of your family are having problems. If you feel you need more support, have problems in family communication, or have financial worries that are causing you stress, talk with someone. There are so many effective treatments and strategies available to help improve the quality of life of survivors and their loved ones that there is no reason to be uncomfortable for one minute more.

[Narrator]

The next portion of this program is a brief demonstration of focused breathing and muscle relaxation exercises that you can try. As you may find, sometimes a few simple changes can make a big difference in how you feel. If you would like to find out more information about this and other techniques or programs like it, contact the social worker or nurse at your local hospital or check out the resources in the booklet that comes with this *Cancer Survival Toolbox*.

[Narrator]

Here's how Joan, an oncology nurse, helps survivors learn focused breathing and imagery exercises. Why not practice along.

[Joan] (with relaxing background music):

First, find a comfortable place to sit and relax. It's best to stretch out on a couch or bed. If you're sitting in a chair, you may be most comfortable stretching your legs out and crossing them at the ankles. Rest your hands comfortably on your lap or at your sides. To begin focused breathing, take a slow, deep breath. Then, blow the air out gently through your lips. As you let the breath out, allow your body to settle in and let all your muscles relax. This is called a "cleansing breath," because it can help you start cleansing your body of stress. Next, allow your eyes to gently close. With your eyes closed, focus your thoughts on a spot in the middle of your forehead. Now, breathe in slowly through your nose... notice that the air feels cool. Let the cool air in. Now, as you blow the air out gently through your lips, notice it feels warmer. Imagine as you breathe in that the cool, clean air is bringing in replenishment. As you

breathe out, imagine that you are letting out your stress. Focus on each breath. Notice that your chest rises as you let the cool air in—and notice how your chest relaxes as you breathe the air out.

[Joan]

Continue to breathe in and out in this comfortable way. In your mind, scan your body for any areas of remaining stress. Imagine that the cool air is flowing right to those spots where there may still be some stress. Now, imagine that the flow of cool air releases that stress, so that, as you breathe out, the stress flows right out of your body

[Narrator]

Now, Joan will begin the progressive muscle relaxation. This exercise will take a couple of minutes. She will give you instructions to tighten various muscle groups around your body, to feel the tension, and then release the tension. If you feel discomfort in any muscle group, simply imagine yourself tensing and then relaxing the muscles instead of actually doing this.

[Joan]

After your focused breathing exercises, stay in your relaxed position. Starting with your feet, curl your toes under to tighten the muscles in your feet, feel the tension hold it for the count of 1, 2, 3, 4, 5, now release.... and just let the tension flow out through the bottoms of your feet.

[Joan]

Now, your calves. Tighten the muscles in your calves. Feel the tension and hold it for the count of 1, 2, 3, 4, 5. Now release.... and just let the tension flow out through the bottoms of your feet.

[Joan]

Now, the muscles in your thighs, tighten the muscles, feel the tension hold it for the count of 1, 2, 3, 4, 5. Now release.... and just let the tension flow out, down your legs and out through the bottoms of your feet.

[Joan]

Now, the muscles in your pelvis and buttocks. Tighten the muscles, feel the tension hold it for the count of 1, 2, 3, 4, 5. Now release.... and just let the tension flow out.

[Joan]

Now the muscles in your stomach and abdomen, feel the tension hold it for the count of 1, 2, 3, 4, 5. Now release.... and just let the tension flow out.

[Joan]

Now, your hands. Squeeze your hands into a fist. Feel the tension in your hands and your arms. Hold it for the count of 1, 2, 3, 4, 5. Now release.... and just let the tension flow out through the palms of your hands.

[Joan]

Now, your shoulders. Squeeze your shoulders up toward your ears, feel the tension. Hold it for the count of 1, 2, 3, 4, 5. Now release.... and just let go of that tension.

[Joan]

Now, the muscles in your face. Squeeze your face muscles, tighten the muscles. Feel the tension. Hold it for the count of 1, 2, 3, 4, 5. Now release.... and just let go of any remaining tension.

[Joan]

Now, just focus again on your breathing. Notice how relaxed your body feels as you allow it to be supported by the couch or the chair. As you breathe in, say, "I am," and as you breathe out say, "relaxed." Again breathing in, say, "I am" and out, say "relaxed." And when you are ready, you can open your eyes slowly and continue on, enjoying this feeling of being relaxed.

## Section 5: Getting Your House in Order

[Narrator]

Kathy is a 42-year-old woman. She recently completed treatment for colorectal cancer that included surgery and chemotherapy. She now has to return to her treatment center for follow-up every 3 months. Listen to her new experiences in cancer survivorship.

[Kathy]

Having cancer started me looking at life in a whole new way. Before cancer, I didn't really think about the possibility of dying. I'm young, and things like that just don't happen to someone like me. Oh, I didn't think I would live forever. But I sure did think I had plenty of time to take care of my will and other things like that. My husband and I would always say, "Yeah, we need to do that," but put it off another day.

[Narrator]

The change Kathy is describing is very common among cancer survivors and people who have experienced a life-threatening event. Kathy now wants to "get her house in order."

[Kathy]

I have three small children, a husband, elderly parents. They all depend on me. I work outside the home to help support our household. My husband and I want to see our children go to college and have some of the things in life that we didn't have. I don't want my family to suffer if something happens to me. My cancer diagnosis and treatment made this very clear to me.

[Kathy]

My husband and I realized that we needed information about what we had to do. The cancer center where I received my treatment had a series of workshops on estate planning. Some of the topics they covered were advance health directives, making a will, power of attorney, financial planning, and life insurance. We went to a few of the workshops and got a lot of good information that helped us start our planning. Now that we've started to take care of a lot of these things, I have a sense of freedom...that my family will be taken care of even if I'm not here. This really took a load off my mind. I can relax a little more now.

[Narrator]

Kathy and her husband realized that they needed to plan for their personal futures now that they've taken care of their financial future. They learned that one way to plan for your personal future is through the use of advance health directives.

[Narrator]

Advance health directives are legal documents that you sign to instruct your family and doctors about what your choices for future medical care would be in situations where you would not be able to speak for yourself. One of the most important choices is about stopping—or not even starting—life-saving or life-sustaining treatments in the event of a health crisis. Every state has laws recognizing advance health directives. The two most recognized types of advance health directives are a durable power of attorney for healthcare and a living will.

[Narrator]

The durable power of attorney for healthcare lets you name someone who knows your wishes and can speak for you if you become unable to do so. In this situation, this person becomes your “agent” and will have the legal right to make health-care decisions for you. Your agent can be any adult, like a family member or a close friend. He or she does not have to be a lawyer. You may write down in the durable power of attorney the types of medical care you would wish to have. The more specific you are, the more likely you will receive the care you want. You can get a form for an advance health directive in many places, like the treatment center you have been going to, bookstores, or on the Internet. Power of attorney is a document to authorize someone to make financial decisions for you. This is similar to the durable power of attorney we just discussed. When you give a power of attorney to someone, you permit that person to manage your finances. You should talk with a lawyer for help in preparing the documents that will best express your wishes in regards to your financial matters.

[Narrator]

A second form of advance health directive, a living will, is a statement that tells your physician and family that you do not want your life prolonged by medical procedures if you are near death without any chance for recovery. Living wills are not considered as effective as a durable power of attorney. That’s because a piece of paper is less able than an agent to serve as your advocate and ensure that your wishes are carried out.

[Narrator]

A will is a written document that spells out your wishes for taking care of your responsibilities after you die. For example, a will usually explains how you would like your property to be distributed. It also names a legal guardian, the person you want to take care of your children who are still minors, and names an executor, the person who sees that the instructions in your will are followed.

[Narrator]

Each state has laws that list the requirements that a will must meet in order to be valid. It is important that you know what these requirements are. A lawyer can be very helpful in this. If you feel that you cannot afford a lawyer, many states have legal aid agencies that can help answer your questions. Your cancer center or hospital social worker can help you contact a legal aid society. Or, you may be able to talk with someone at your local community center about this.

[Narrator]

A will can distribute money you plan to leave for your heirs in the form of a trust. A trust is a financial relationship in which one party holds title to property for the benefit of another party. There are many

kinds of trusts depending upon the goals and purposes to be accomplished. Trusts may legally protect your assets, but they can be very complex. You should talk with a lawyer to help determine if a trust is best for you and to draw up a trust if you decide to do that.

[Narrator]

Kathy and her husband also had to take care of some other financial issues during Kathy's treatment phase.

[Kathy]

I was very sick for awhile. So sick that I had to stop working. I took a medical leave from work. At first, I took all of my sick time and vacation time. After that, I was able to go on disability. My husband had to take about 3 months off from his job to take care of me and our children. He was able to get that much time off because of what is called the Family and Medical Leave Act. This Act means that your job is safe while you're off from work because of emergency reasons. But, you don't get paid. Money got very tight for us. We used to rely on my income to pay for private schools for our kids and to help with care for my elderly parents. But now, we needed help. The social worker at my cancer center told us about some possible sources of extra money for us. We talked with a financial counselor for additional advice.

[Kathy]

The financial counselor suggested that we look at some other options. She said we could use our life insurance plan to get some money to pay for expenses during treatment. She also told us about companies called "viaticals" that will either buy your life insurance policy from you and give you money right away, or base a loan on your life insurance policy. We met with people from a couple of these companies so we would have a better idea of what they offer and what it would cost.

[Kathy]

I also had a small life insurance policy that we could use to tide us over during this really tough time. We found out that, because of the Americans with Disabilities Act passed in 1990, we could not be denied a loan or other financial service just because of my cancer history. This meant that we didn't have to worry about being able to apply for a loan while I was sick. This all may seem like a lot to think about. But, knowing that we had some options to choose from and that we could pick the ones that were best for us made me feel a lot more secure.

[Narrator]

For more information about financial concerns, you can listen to the "Finding Ways to Pay for Care" program in the *Cancer Survival Toolbox*. Let's hear from another survivor whose cancer diagnosis created a career challenge for her. Mary is 32 years old and has completed treatment for cancer that included surgery, radiation, and chemotherapy. Unlike Kathy, Mary does not have a spouse, children, or elderly parents to worry about. But, she is facing major career issues that may affect her happiness and financial future.

[Mary]

When I was first diagnosed with cancer, I had been thinking about a major career change. I am a graphic designer at a big design firm. I kind of fell into this line of work and found that I really love it ...and am good at it. I was getting ready to make the decision to leave the firm, go back to school, and then start my own graphic design business. Everything was falling right into place for me. But, with my cancer diagnosis, everything stopped. At the time, I thought that I would just be putting things on hold. But now, I just don't know.

[Mary]

I found out that, with my diagnosis, it's not easy to change health insurance. Private insurance is either nearly impossible to get or it's so expensive that I couldn't afford to pay for the insurance while I took time off from working to go back to school. Even just trying to change jobs might be real hard to do now. Once they hear that you've been off from work with cancer, employers may wonder whether you'll be able to stay on the job after they hire you. I know I'm lucky just to have a job, especially one that I really enjoy. But, I can't help feeling locked in and frustrated that I may have a hard time getting on with my career.

[Narrator]

Mary was able to get help through an organization called the National Coalition for Cancer Survivorship. This organization provided her with valuable information on how to avoid discrimination based on a cancer diagnosis. Some of the tips included: Ask a job counselor for help with résumé preparation and job interviewing skills; Apply only for jobs that you are able to do; If possible, look for jobs with state or local governments or large employers; Keep your legal rights in mind; Do not lie on a job or insurance application; When interviewing for a job, do not volunteer the information that you have or have had cancer unless it directly affects your qualifications for a job; During a job interview, do not ask about health insurance until after you have been given a job offer; If you have to explain a long period of unemployment during cancer treatment, explain it in a way that shows your illness is past, if possible, and that you are in good health and are expected to remain healthy; Keep the focus on your current ability to do the job in question.

[Narrator]

Cancer survivors today have new state and federal laws that require employers to treat survivors based on their individual abilities and not on their cancer history. Survivors should be aware of their legal rights and be willing to advocate for fairness in the work place. Having looked at all her options, Mary has returned to school. She was able to get some insurance through a school program and through the state's cancer insurance program. She feels that she has the information and tools to go out into the work place after her schooling. And, she knows how to avoid discrimination and hopefully live out her career dreams that will provide her with many years of fulfillment.

## Section 6: Living With Hope While Dealing With Uncertainty

[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 *a/ways* 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, and over the telephone. 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.