

[TRACK 5: SURVIVOR STORIES: 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 and can occur even after your treatment is over. 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*; it is also available at www.canceradvocacy.org/toolbox. If you continue to experience 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 enough to deal with, but so is recovery after treatment..It’s normal to need some help even if you are a long-term survivor.

[Joan]

As an oncology nurse, the emotion I usually talk about first with survivors is anxiety. Anxiety is a common reaction to both the diagnosis of cancer and also the end of treatment. 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. Having a roadmap to manage your care moving forward may help you deal with anxiety. With a Follow-Up Care Plan, you can work with your medical team to make sure you are being followed appropriately, and know when to expect tests or screening. Journey Forward is a free program that can help you and your health care team create a written Follow-Up Care Plan to share with your primary care physician and/or other doctors you may see. Information on this resource is listed in the Resource Booklet that comes with this program.

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, especially if they focus on longer-term survivor issues. 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.