

## [TRACK 2: SURVIVOR STORIES: 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 effects 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 this 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, sometimes referred to as "long-term survival."

[Linda]

The extended stage of survival starts when you complete your initial 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 may continue to remind 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. Alisha wondered if I was 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 lots 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 visualize her future in the world 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]

Before your treatment ends, it is important to discuss with your doctor what to expect when you make this transition, which may include how to cope with change and uncertainty. When you talk about the end of treatment, a Treatment Summary will be helpful to better understand what treatment you received, and a Follow-Up Care Plan will help you and your health care team coordinate your care moving forward. If you and other members of your medical team know what treatment you had, any issues with that treatment, and new issues to monitor in the future, you will be better prepared to deal with your new health care needs. The Treatment Summary and Follow-Up Care Plan should be shared with your primary care doctor or other members of your health care team. You should also keep copies for yourself.

Request a transition 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? A list of more questions to ask as you transition off active treatment can be found in NCCS's *Teamwork* booklet, which is listed in the Cancer Survival Toolbox resource booklet.

Another free program, called Journey Forward, can help you work with your health care team to coordinate your follow-up care. The free software helps you and your health care team create a customized Treatment Summary and a Follow-up Care Plan based on your individual treatment. It also makes it easier to organize the information that is outlined in this section. Learn more about Journey Forward at [www.canceradvocacy.org](http://www.canceradvocacy.org), or by calling 888.650.9127.

[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 "survivor" or "survivorship" clinic. This type of clinic is staffed by experts who understand the specific issues of survivors who have completed their initial treatment or are returning to their primary care providers for follow-up. While a number of these specialty clinics are already available for children and young adults who received treatments as children, very few of these clinics have been available for survivors of adult cancers. Fortunately, this trend is changing as the numbers of cancer survivors increase, and their needs for a new model of specialized care can no longer be ignored. We should soon see survivorship care and clinics available in many more healthcare settings.

[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!