

Beyond Cancer – Moving On

Today, people with cancer have a better chance at living a normal life than ever before in history. In fact, there are more than 10 million survivors – people who have, or are living with, cancer – in the United States right now. For them, cancer has become a chronic (on-going) health problem, such as high blood pressure or diabetes.

As hard as having cancer can be, many survivors feel that the experience led them to make important changes in their lives. They now take time to appreciate each new day. They also have learned how to take better care of themselves and to value how others care for them. Many volunteer and share their experience with others going through cancer or work to help improve cancer research, treatment and care.

Still, cancer is a major event and changes your life, including your relationships with others. It's normal to notice changes in the way you relate to family, friends, and other people that you are around every day – and the way they relate to you.

This document offers information on some of the differences you may experience once your treatment ends and practical advice for moving forward.

When Treatment Ends

The end of cancer treatment is often a time to rejoice. You are probably relieved to be finished with the demands of treatment and are ready to put the experience behind you. You may expect life to return to the way it was before you were diagnosed with cancer.

But it can take time to recover. You may have permanent scars on your body, or you may not be able to do some things you once did easily. You may find that others think of you differently now – or you may view yourself in a different way. You may have emotional scars from going through so much. You may also feel sad and worried that cancer will come back.

While many cancer survivors felt they had lots of information and support during their illness, many also feel everything changed once treatment stopped. You may miss your health care team and feel as if your safety net has been pulled away. It's also normal to feel somewhat cut off from other people – even family and friends. You may also feel that only others who have had cancer can understand your feelings.

Your family may have trouble adjusting to the end of your treatment, too. They may expect you to take back your old duties – the things they did while you were sick – before you are ready. Survivors often say that they didn't realize how much time they needed to recover. In fact, your recovery will probably take much longer than your treatment did.

Your “ New” Normal

The first few months after cancer treatment ends are filled with changes and adjustments for most survivors. It’s not so much “getting back to normal” as it is finding out what’s normal for you now. Whatever you decide, it’s important to do what’s right for you and try not to compare yourself with others.

Worrying about cancer coming back is one of the most common fears among survivors, especially during the first year after treatment. For some, the fear is so strong that they no longer enjoy life, sleep well, eat well or even go to follow-up visits. They notice every ache and pain and wonder if it is cancer. While it’s important to listen to your body and go to your doctor regularly, it’s also important to try to live each day to the fullest.

Knowing what to expect after cancer treatment can help you and your family make plans, lifestyle changes, and important decisions for the future. Getting involved in decisions about your medical care and lifestyle can help you regain some of the control you may have felt you lost during cancer treatment. People who feel more in control of their own lives often also feel and function better than those who do not.

Many survivors often feel the need to understand what having had cancer means to their lives now. In fact, many find that cancer causes them to look at life in new ways. They may reflect on spirituality, the purpose of life, and what they value most. For them, life after cancer has new meaning or they look at things differently now.

Your new “normal” may include making changes in the way you eat, the things you do and your sources of support. You might also find that going through a crisis like cancer gives you renewed strength. Being an active partner with your doctor and getting help from other members of your health care team is often the first step in regaining control over your life and moving forward.

Follow-Up Care

Follow-up care means seeing a doctor for regular medical checkups. Just like everyone, people who have cancer must get regular checkups for the rest of their lives, even after treatment ends.

However, you will need to have follow-up care related to your cancer in addition to care for any other conditions you may have. Depending on where you live, it may make more sense to get follow-up cancer care from your family doctor, rather than your oncologist. For specific concerns, you may want to see a specialist.

Discuss your options with the doctors who have been taking care of you. They can help you decide how to make transitions in care.

Keep Records

Always tell any new doctors you see about your history of cancer. The type of cancer you had and your treatment can affect decisions about your care in the future. They may not know about your cancer unless you tell them.

Ask your oncologist for a written summary of your treatment. In the report, he or she can suggest what aspects of your health need to be followed. Then, share this summary with any new doctors you see, especially your primary care doctor, as you discuss your follow-up care plan.

Here's a list of the most important information your doctors will need to know:

- The date you were diagnosed
- The type of cancer you were treated for
- Pathology report(s) that describe the type and stage of cancer
- Places and dates of specific treatment, such as:
- Details of all surgeries
- Sites and total amounts of radiation therapy
- Names and doses of chemotherapy and all other drugs
- Key lab reports, X-ray reports, CT scans and MRI reports
- List of signs to watch for and possible long-term effects of treatment
- Contact information for all health care professionals involved in your treatment and follow-up care
- Any problems that occurred during or after treatment
- Information about supportive care you received (such as special medicines, emotional support and nutritional supplements)

Cancer Follow-Up Visits

Your follow-up care depends on the type of cancer and type of treatment you had, along with your overall health. It is usually different for each person who has been treated for cancer.

At your first follow-up visit, talk with your doctor about your follow-up schedule. In general, survivors return to the doctor every three to four months during the first two to three years after treatment, and once or twice a year after that.

TIP: Check your health insurance plan to see what follow-up care it allows. Some insurance plans pay for follow-up care only with certain doctors and for a set number of visits. For those individuals without insurance, call 301-754-7195 to learn about Holy Cross Hospital's Financial Assistance Program.

At each visit, your doctor will look for side effects from treatment and check if your cancer has returned (recurred) or spread (metastasized) to another part of your body. Your role is to make sure you mention all aspects of your current health status, such as:

- New symptoms
- Pain that troubles you

- Physical problems that get in the way of your daily life or that bother you, such as fatigue, trouble sleeping, sexual problems, or weight gain or loss
- Other health problems you have, such as heart disease, diabetes or arthritis
- Medicines, vitamins or herbs you are taking and other treatments you are using
- Emotional problems, such as anxiety or depression, that you may have now or that you've had in the past
- Changes in your family's medical history, such as relatives with cancer

Make sure you also write down anything else you might want to know more about, such as new research or side effects.

Remember: Just because you have certain symptoms, it doesn't necessarily mean the cancer has come back. Symptoms can be due to other problems that need to be addressed.

Other Follow-Up Services

Home care, occupational or vocational therapy, pain management, physical therapy, and support groups also are considered follow-up care.

Complementary and Alternative Care

Some people also seek complementary and alternative medicine approaches to prevent illness, reduce stress, prevent or reduce side effects and symptoms, or control or cure disease. An approach is generally called "complementary" when it is used in addition to treatments prescribed by a doctor.

When it is used instead of treatments prescribed by a doctor, it is often called "alternative." Research has shown that more than half of all people with a history of cancer use one or more of these approaches.

Some common methods include imagery or relaxation techniques, acupressure and massage, homeopathy, vitamins or herbal products, special diets, psychotherapy, prayer, yoga and acupuncture.

TIP: Before using any of these methods, talk to your doctor or nurse. Some complementary and alternative therapies may interfere with medicines prescribed by your doctor.

Your Family's Cancer Risk

Three out of every four American families will have at least one family member diagnosed with cancer. Yet it's important to know that most cancer is not passed down through families. Only about 5 to 10 percent of the most common cancers (such as breast, colon and prostate) are inherited.

If you think your cancer may be inherited, you may want to talk to a genetic counselor. He or she can help answer questions and those of your family. The genetic counselor also can help you and your doctor decide on the medical care that you and your family might need if a genetic link is found.

Genetic testing can determine whether the cancers that occur in your family are due to genes or to other factors.

TIP: For your convenience, genetic services are available through Holy Cross Hospital. Call 1-855-HCH-HOPE to learn more.

Late and Long-Term Side-Effects

Some have described survivorship as being “disease-free, but not free of your disease.” What you experience with your body may be related to the type of cancer you had and the treatment you received. It’s important to remember that no two people are alike, so you may experience changes that are very different from someone else’s, even if that person had the same type of cancer and treatment.

Long after your treatment ends, however, you may find that you are still coping with its effects on your body. It can take time to get over these effects. Some of the most common long-term problems that survivors report are:

Fatigue. Feeling tired or worn out is one of the most common complaints during the first year of recovery.

Memory and Concentration Changes. One in four people with cancer reports having problems paying attention, finding the right word or remembering new things after chemotherapy. This condition is sometimes called “chemo brain.” These effects can begin soon after treatment ends or they may not appear until much later.

Pain. Some people have a lot of pain after treatment, while others have less. Everyone is different. After cancer treatment, you may feel:

- Pain or numbness in the hands and feet from nerves injured by chemotherapy or surgery
- Pain in your scars from surgery
- Pain in a missing breast or limb. While doctors don’t know why this pain occurs, it is real. It’s not just
- “in your mind.” This is sometimes called phantom pain.

Lymphedema or Swelling. Some types happen right after surgery, are mild, and don’t last long. Other types can occur months or years after cancer treatment and can be quite painful. These types also can develop after an insect bite, minor injury or burn.

Nervous System Changes (Neuropathy). Sometimes cancer treatment can damage your nervous system, producing sudden, sharp stabbing pain, tingling, burning, weakness or numbness. Most people first notice symptoms in their hands or feet. Sometimes these symptoms can be made worse by other conditions, such as diabetes, kidney failure, alcoholism and malnutrition. Symptoms can improve over time, but it may take up to a year or more.

Mouth or Teeth Problems . Radiation or surgery to the head and neck can cause dry mouth, pain in your mouth and gums, cavities, infections, loss of taste and jawbone problems. Certain types of chemotherapy may cause these problems, too. Some problems may develop months or years after your treatment has ended.

Trouble Swallowing. People who have had radiation therapy to the head, neck, breast or chest or those who have had surgery involving the larynx also may have this problem.

Changes in Weight and Eating Habits. Some survivors who have had certain kinds of chemotherapy or medicines have problems with weight gain. Breast cancer survivors, for instance, also often lose muscle and gain fat tissue. Other survivors are left with no desire to eat, and they lose weight, including muscle.

Bladder or Bowel Control Problems. This loss of control can happen after treatment for bladder, prostate, colon, rectal, ovarian or other cancers.

Menopause Symptoms. Some treatments may cause early menopause and the loss of fertility.

Depression and Anxiety. After treatment, you may still feel angry, tense or sad. In some cases, cancer treatment may have added to this problem by changing the way the brain works. For most survivors, these feelings go away or lessen over time. But if painful feelings do not get any better, and get in the way of daily life, seeing a physician or therapist can help.

If you experience any of these side effects, at any time in your cancer journey, make sure you talk to your doctor or nurse. There are many techniques and approaches that can make them go away, or at least reduce their impact on your life.

Developing a Wellness Plan

After cancer treatment, many survivors want to find ways to reduce the chances of their cancer coming back.

Some worry that the way they eat, the stress in their lives or their exposure to chemicals may put them at risk. Cancer survivors find that this is a time when they take a good look at how they take care of themselves.

This is an important start to living a healthy life.

When you meet with your doctor about follow-up care, you should ask about developing a wellness plan that includes ways you can take care of your physical, emotional, social, and spiritual needs. If you find that it's hard to talk with your doctor about these issues, it may be helpful to know that the more you do it, the easier it becomes. And your doctor may suggest other members of the health care team for you to talk with, such as a social worker, clergy member or nurse.

There are a number of steps you can take to help yourself on the road to recovery, as outlined below.

Lifestyle Changes

Here are some examples of changes you may want to think about to reduce your risk of cancer coming back:

Quit smoking. Smoking can increase the chance of getting cancer at the same site or another site.

Cut down on alcohol. Drinking alcohol increases your chance of getting certain types of cancers. Experts recommend that men have only two drinks a day and women have only one.

Eat healthy foods. Talk with your doctor or a nutritionist to find out about any special dietary needs that you may have. Then try to follow these guidelines:

- Eat at least five to nine servings of fruit and vegetables daily.
- Include beans in your diet.
- Eat whole grains (such as cereals, breads, and pasta) several times daily.
- Choose foods low in fat and salt.

Get to and stay at a healthy weight.

Exercise and stay active. Staying active after cancer lowers the risk of recurrence and leads to longer survival. Moderate exercise (walking, biking, swimming) for about 30 minutes every—or almost every—day also can:

- Reduce anxiety and depression
- Improve mood and boost self-esteem
- Reduce fatigue, nausea, pain and diarrhea

Talk with your doctor before you begin any exercise program.