



the Physicians of Oncology Hematology West

Survivorship: Next Steps to Take After Treatment

After a cancer diagnosis, a person's priorities regarding relationships, career, or lifestyle may change. Some people with a history of cancer, called cancer survivors, say that they appreciate life more and have gained a greater acceptance of self. At the same time, some survivors also become anxious about their health and are uncertain of how to cope with life after treatment, especially when frequent visits to doctors stop. Once your active treatment is complete, you may wonder, "What happens next?" The transition to this phase of survivorship is unique for each person. Community programs such as 'A Time to Heal' can guide you through this phase; the 12 week program is offered for patients with all cancer types, and their caregivers, three to four times annually.

Life as a Cancer Survivor

Surviving cancer or "survivorship" can be defined in different ways. Two common definitions include:

- Having no disease after the completion of treatment
- The process of living with, through, and beyond cancer. Meaning your cancer survivorship began at diagnosis

When treatment ends, people often expect life to return to the way it was before the diagnosis. The next few months will be a time of transition and change as you discover what is "normal" for you now.

Surviving Cancer: What to Expect

Finishing cancer treatments can be both exciting and challenging. Many survivors have mixed emotions, including relief that their treatment is over, as well as anxiety about the future. After treatment, the "safety net" of regular, frequent contact with the health care team ends. Physical problems such as psychological problems, sexual problems, and fertility concerns may arise. Many survivors feel guilty about surviving, after having lost friends or loved ones to the disease. Some survivors are uncertain about their future, while others experience discrimination at work or find that their social network feels inadequate.

Fear of Recurrence

Fear of recurrence (cancer that comes back after treatment) is common among most cancer survivors. It may lead a person to worry over common physical problems, such as a headaches, coughs, and joint stiffness. It is hard to know what is "normal," and what needs to be reported to the doctor. Discussing the actual risk of recurrence with your doctor and the symptoms to report can often lower your anxiety. Maintaining a regular schedule of follow-up visits can also provide a sense of control. Although many cancer survivors describe feeling scared and nervous about routine follow-up visits and tests, these feelings may ease with time.

Relationships

When active treatment is over, some survivors need different types of support than they had before. Some friends may become closer, while others distance themselves. Families can become overprotective or may have exhausted their ability to be supportive. Relationship problems that may have been ignored before cancer can surface. The entire family is changed by the cancer experience in ways they may not be aware of. Recognizing and working through these changes are needed to help you get the support you need, and some people find that counseling helps. Open and ongoing communication helps with adapting to life and shifting relationships after cancer. There are many supportive community groups for patients and their families that can be attended. These are often diagnosis specific, meaning the people in attendance have same or similar diagnoses. You may want to consider attending a support group to share your experience with others who have had similar experiences. You may need to try more than one group to find a “fit” that’s right for you.

Getting Back to "Normal"

Returning to a regular work schedule is one way of getting back to a normal routine. Many patients who took time off for treatment return to work, some others have worked throughout treatment. Rarely do the after effects of treatment prevent you from returning to your current occupation.

Although many survivors can be as productive as they were before treatment, some find they are treated differently or unfairly. During and after treatment, it may be helpful to anticipate questions from coworkers, and decide how to answer these questions in advance. Coworkers may want to help but do not know how. It may be up to you to start the conversation and set the limits. When and how you choose to discuss a diagnosis is a personal decision.

Long-Term Side Effects of Cancer Treatment

A “late effect” is a side effect that occurs months or years after treatment. Many people who have received treatment for cancer are at risk for developing late effects. The types of late effects a person experiences vary based on the cancer treatments he or she received. The monitoring for and treatment of late effects is an important part of care after cancer treatment. All cancer survivors should continue to receive follow-up care after treatment to diagnose and manage any late effects.

Examples of Late Effects

Because late effects are caused by cancer treatments, nearly any type of treatment can cause late effects. Some of the more common late effects are described below. If you are concerned about a particular late effect, please talk with your doctor.

Heart problems: These are most often caused by radiation therapy to the chest and/or chemotherapy, especially if the drug doxorubicin was used. People age 65 or older, and those who received higher doses of chemotherapy have a higher risk of heart problems including inflammation (swelling) of the heart muscle, congestive heart failure, or heart disease. Contact your primary doctor if you experience any unusual swelling, water retention, chest pain, or shortness of breath.

Lung problems: Chemotherapy and radiation therapy to the chest may damage the lungs. Cancer survivors who received both chemotherapy and radiation therapy may have a higher risk of lung damage. Some of the drugs that are more likely to cause lung damage include bleomycin, carmustine, prednisone, dexamethasone, and methotrexate. The late effects may include the following:

- Decreased lung function or a change in how well the lungs work
- Thickening of the lung lining or inflammation of the lungs
- Difficulty breathing

Endocrine (hormone) system problems: For women, chemotherapy and radiation therapy may damage a woman's ovaries, causing hot flashes, sexual problems, osteoporosis (thinning of the bones), and early menopause. There are treatments that can help with these side effects if needed.

Men and women who receive radiation therapy to the head and neck area may have lower levels of thyroid hormones, requiring medication to return these levels to normal.

Both men and women are at risk for infertility from cancer treatment. Pregnancy should be avoided for at least 3 months after treatment is completed. If you have questions about family planning we can assist you with a referral to a reproductive specialist.

Bone, joint, and soft tissue problems: Cancer survivors who have received chemotherapy, steroid medications, or hormonal therapy may develop osteoporosis or joint pain. You can lower your risk of osteoporosis by not smoking, eating foods rich in calcium/vitamin D, participating in regular physical activity, and limiting the amount of alcohol you drink.

Brain, spinal cord, and nerve problems: Chemotherapy and radiation therapy can cause long-term side effects to the brain, spinal cord, and nerves. These late effects can include:

- Hearing loss from high doses of chemotherapy, especially with drugs like cisplatin
- Risk of stroke, for those who have had high doses of radiation treatment to the head
- Nervous system side effects, such as peripheral neuropathy, (numbness, tingling or pain) often seen in the hands or feet.

Learning, memory, and attention difficulties: Chemotherapy and high doses of radiation therapy to the head may cause these problems. These symptoms may or may not improve over time. Keeping your mind active with activities such as crossword puzzles may be helpful.

Dental and vision problems: Cancer survivors should have regular check-ups with a dentist and an ophthalmologist (eye doctor).

- Chemotherapy and radiation therapy to the head and neck area may affect tooth enamel and lower saliva production causing a dry mouth. Gum disease may develop as a result of radiation therapy.
- Steroid medications may increase the risk of eye problems, such as cataracts (clouding of the eye that affects vision).

Emotional difficulties: Cancer survivors often experience a variety of positive and negative emotions, including relief, a sense of gratitude to be alive, fear of recurrence, anger, guilt, depression and anxiety, and isolation.

Cancer survivors, as well as caregivers, family, and friends may experience post-traumatic stress disorder. Each person's post-treatment experience is different. For example, some survivors struggle with the emotional effects of the cancer, and others say that they have a renewed outlook on life because of the cancer. You may find community support groups to be of benefit if you are experiencing emotional difficulties. There are also many distress management professionals in the area who work specifically with cancer patients and survivors.

Fatigue: Fatigue is the most common side effect of cancer treatment, and it often continues after treatment. Fatigue may be caused by the effects of treatment or may have no known cause. Research suggests you may experience varying levels of fatigue for up to one year following treatment. Exercise has been shown to be of benefit. If you are experiencing fatigue, talk to your nurse or doctor, as they may have some additional suggestions to help with fatigue.

Secondary Cancers: A secondary cancer is a different type of cancer that appears after the original cancer diagnosis. According to the National Cancer Institute (NCI), cancer survivors have a 14% higher risk of developing a new cancer. The development of a secondary cancer is thought to be from previous cancer treatments, such as chemotherapy and radiation therapy. Chemotherapy and radiation therapy can also damage bone marrow stem cells and increase the chance of either myelodysplasia (a blood cancer where the normal parts of the blood are either not made or are abnormal) or acute leukemia.

Screening for Late Effects

It is important to talk with your doctors about appropriate tests based on your cancer history. Finally, keep a copy of your treatment summary to share with other physicians involved in your health care.

Follow-Up Care after Cancer Treatment

After your treatment ends, you will continue to have follow-up visits with your oncologist. Ongoing health needs are not the same for everyone. Follow-up care is individualized based on

the type of cancer, the type of treatment received, and your overall health. Generally, people return to the oncologist for follow-up appointments every 3 to 4 months during the first 2 to 3 years after treatment, and once or twice a year after that.

Follow-up care will involve regular checkups including physical exam and lab tests, and may include imaging procedures such as X-rays and CT scans.

Follow-up care is important because it helps to identify changes in health. The physician will address any ongoing problems related to cancer treatment, recommend tests to check for recurrence or to screen for other types of cancer, and check for physical and psychosocial effects that may develop months to years after treatments ends.

After treatment care may also include medications for issues related to cancer therapy, such as yearly infusions for osteoporosis.

In addition to seeing your oncologist for care related to your cancer diagnosis, you should continue to see a primary care doctor for other medical care. Your primary care doctor will manage things such as colds, blood pressure, and other health concerns.

Regular visits to the dentist and eye doctor are also recommended.

If you have a port (or other IV access device), you will need to schedule appointments for routine flushes every 4 weeks.

Congratulations on finishing your planned treatment. We know this is a time of celebration but may also be a time of worry and concern. Please know we will continue to be here to support you and answer your questions; your case manager is available for any questions, concerns and any referral needs. Life beyond cancer treatment is different for each person. We encourage you to stay active in getting the information and support you need.

Survivorship Resources

Local/Regional:

- A Time to Heal www.mytimetoheal.org
- Leukemia Lymphoma Society www.lls.org
- American Cancer Society acs.org
- YMCA Livestrong metroymca.org

National:

- American Institute for Cancer Research www.aicr.org
- Cancer and Careers www.cancerandcareers.org
- CancerCare www.cancercare.org
- Cancer Financial Assistance Coalition www.cancerfac.org
- Cancer Support Community www.cancersupportcommunity.org
- Job Assistance Network www.askjan.org
- Journey Forward www.journeyforward.org
- MyOncofertility.org www.myoncofertility.org
- National Coalition for Cancer Survivorship www.canceradvocacy.org
- National Cancer Survivors Day Foundation www.ncsdf.org
- Patient Advocate Foundation www.patientadvocate.org
- National Cancer Institute: Office of Cancer Survivorship
<http://dccps.nci.nih.gov/ocs/office-survivorship.html>