

# Aftereffects of Cancer Treatment

The day that treatment ends, a new chapter in life begins. You may have left cancer behind and are continuing your life with few or no lingering problems. Or you may have entered an unexpected and confusing new phase of the cancer experience. This phase does not focus on battling cancer itself. Instead, the new challenge is about identifying, understanding and living with the unexpected or unwelcome aftereffects of cancer or cancer treatment on your body, emotions and life.

## What will survivors learn in this document?

This document provides an introduction to understanding aftereffects of cancer and cancer treatment and how they may affect your life.

Because the aftereffects of different kinds of treatment are difficult to describe in one document, we do not provide extensive details on the specific physical, emotional and practical problems. However, the information in this document will help you be aware of the possibility of aftereffects so you can keep track of your symptoms and talk about them with your family and your health care team.

All survivors can benefit from this information. However, it is written for adult survivors who have completed treatment either recently or in the last several years. Ideas on how survivors currently in treatment can use this information are given later in this document.

## What are aftereffects?

Aftereffects can be described as long-term or late effects of cancer treatment.

**Long-term effects** develop during treatment, are lingering or chronic (do not go away) and continue after treatments are over. Many long-term effects improve or resolve with time, such as anemia, fatigue and anxiety (feeling worried). Some long-term effects are permanent, such as limb loss, some types of limb weakness or nerve damage.

**Late effects** are delayed and can surface months to years after treatment ends. Usually, the earlier these problems are identified, the easier they are to treat. Some late effects are long-lasting or permanent, such as certain types of heart disease or lung disease, lymphedema (swelling in a limb due to blockage of the lymph system), osteoporosis, depression and second cancers.

There are three different categories of aftereffects:

- **Physical** (such as scarring or fatigue)
- **Emotional** (such as anxiety or depression)
- **Practical** (such as problems with employment or health insurance)

Aftereffects can range from very mild to very serious and will vary from one survivor to the next. Doctors cannot always predict which aftereffects, if any, will occur, or how serious or long-lasting they will be. You may not suffer any significant aftereffects at all.

If aftereffects do occur, this does not mean that your health care team gave you the wrong treatment. Aftereffects are sometimes an unavoidable and difficult part of cancer survivorship.

However, experiencing aftereffects does not mean that there is no hope in maintaining a high quality of life. Treatment can help you manage aftereffect symptoms and continue to live a full and happy life.

## **Why have some survivors never heard of aftereffects of cancer treatment?**

The idea of aftereffects may be new to you. Much less is known about aftereffects than about side effects during treatment; however, ongoing research is actively exploring this area. Not all health care professionals talk to newly diagnosed survivors or those undergoing treatment about what to expect after treatment ends. When you don't know what to look for, new symptoms can be very confusing and even frightening.

Some survivors may think they are “going crazy” because they didn't expect or don't understand their physical or emotional symptoms. If you feel this way, you are not alone. The truth is that something is causing these symptoms, and the cause may or may not be related to your cancer history. You need to report your symptoms to your health care team and undergo proper evaluation. Your symptoms may be easily treatable, even if they are related to aftereffects of cancer treatment. Aftereffects of cancer are real, and if you are experiencing symptoms, you deserve help in learning how to understand and manage them.

## **Cancer treatments and aftereffects**

The most common treatments today for treating cancer are surgery, radiation and chemotherapy. These treatments may be given as stand-alone treatments or, more commonly, in some combination with one another. These anticancer therapies may result in a cure, remission, disease control without remission or symptom management (palliation), depending on the particular type of cancer, the stage of disease at the time of diagnosis and other factors.

The purpose of the following short descriptions of cancer treatment is to explain in a very simple way why aftereffects can occur. Not all cancer survivors will experience these aftereffects. Learning about them may be scary. However, when you learn what the possible effects are, you can know what to expect and feel more confident in reporting any symptoms to your health care team right away. Medical attention can minimize problems associated with these aftereffects.

## **Why does surgery cause aftereffects?**

Surgery as a cancer treatment means having cancerous tissue removed from the body. The goals of surgery are to confirm the presence of cancer cells by taking a sample of tissue (biopsy) and then to help eliminate the cancer by removing as much of the tumor as possible. Sometimes surgery is used to reduce the size of a tumor (to “debulk” the tumor) before using other therapies to eliminate the cancer, or to implant a device for administering treatment.

Damage to healthy tissue can result from the growth of a tumor, which damages or kills normal cells as it grows. Damage may also occur when healthy tissue surrounding the tumor is removed during surgery to make sure that all of the cancer cells are removed. Surgery can damage muscles, bones, nerves and organ systems, depending on what part of the body is operated on.

A few examples of possible aftereffects of surgery:

- Scarring at the incision site
- Lymphedema (swelling of upper or lower limbs)
- Problems with movement or activity
- Nutritional problems (for example, if part of the bowel is removed)
- Cognitive problems such as memory loss
- Changes in sexual function and fertility
- Ongoing pain
- Psychological effects of physical changes, even if the physical changes are not visible to others (for example, feeling self-conscious about a scar from surgery, even if that scar is usually hidden by clothing)

Although aftereffects can still occur, the risks of aftereffects of surgery have been reduced over the years. For many types of cancer, less extreme and less radical surgery is now used, which results in less scarring than years ago. Newer methods limit the damage to normal tissues, and reconstructive surgery now helps reduce noticeable physical changes from surgery. Even when a radical approach is needed, advances in surgical technique and technology have dramatically reduced the damage and resulting long-term effects associated with these procedures.

## **Why does chemotherapy cause aftereffects?**

Chemotherapy is the use of certain groups of medicines that can kill or stop cell growth and cell reproduction. Chemotherapy medicines can be given as an oral tablet, by injection or through the vein (an IV).

These medicines circulate throughout the entire body through the bloodstream. Because most of these medicines do not make a distinction between cancerous cells and non-cancerous cells, they can damage healthy cells that normally divide quickly. This can cause systemic effects (effects that happen throughout the body). This damage to healthy cells is the reason for side effects.

The side effects experienced depend on which cells are affected. Many of these medicines interfere with rapidly growing cells of the body like the gastrointestinal lining, hair, skin and nails. This is why survivors receiving these medicines experience temporary side effects such as mouth sores, upset stomach (sometimes with vomiting), hair loss and skin rashes. As the non-cancer tissues repair themselves, the side effects improve or resolve.

Aftereffects happen when organs are damaged by high doses of or repeated exposure to chemotherapy. How long the aftereffects last depends on many factors, including if and when the damaged organs can repair themselves. Not all chemotherapy medicines cause the same aftereffects. Some aftereffects are related to specific medicines, and some happen as a result of the combination of chemotherapy with other treatments, such as radiation.

Some examples of possible aftereffects of chemotherapy

- Fatigue
- Early or premature menopause
- Infertility
- Changes to the heart
- Reduced lung capacity with difficulty breathing
- Kidney and urinary problems
- Neuropathy (numbness, tingling and other sensations in certain areas of the body, especially the hands and feet)
- Muscle weakness
- Cognitive problems such as memory loss or inability to focus
- Osteoporosis
- Changes in texture and appearance of hair and nails
- Secondary cancers

## **Why does radiation therapy cause aftereffects?**

Radiation therapy is the use of x-rays in a series of planned treatments. The x-rays are directed at a tumor located in a specific area of the body using a variety of techniques. Radiation can be administered either externally (on the surface of the skin) or internally (inside the body), and in high or low doses. The total dose of radiation that can be safely administered is well known, and the types of aftereffects that occur with certain radiation dose levels are also fairly well known. Aftereffects occur because of permanent damage to normal cells or structures of the body that are either right in or close to the area being exposed to radiation (the “field” or “radiation port”).

When external radiation is given, the area where the tumor is located must be clearly marked so that radiation is delivered directly to the tumor. Sometimes tiny dots are tattooed on the skin around the tumor to clearly mark its location. If there are vital organs, such as the heart, lungs or liver, in the radiation field, lead blocks are used to shield these organs from radiation. These techniques help minimize radiation damage to

normal tissues surrounding the cancer, as well as ensure that treatment is directed to the same location each time.

However, healthy tissue can still be damaged. Some rays in the intended field may scatter and expose surrounding tissues and organs to small doses of radiation. Or, depending on the position of the tumor, it may be necessary to include some healthy tissue and organs in the field in order to ensure complete treatment of the cancer.

In contrast to chemotherapy, which is systemic, radiation is local and causes aftereffects only in the area of the body that was exposed to the radiation (known as local effects). Some radiation aftereffects are similar to those caused by chemotherapy. However, some examples of aftereffects that are specific to radiation include:

- Cataracts (if radiated near eyes)
- Permanent hair loss (if scalp is radiated over certain dose levels)
- Dental decay, tooth loss, receding gums (if radiated near mouth)
- Loss of tears and ability to produce saliva (if lacrimal or salivary glands in the face are radiated)
- Problems with thyroid and adrenal glands (if neck radiated)
- Slowed or halted bone growth in children (if bone radiated)
- Decreased range of motion in the treated area
- Skin sensitivity to sun exposure (in area of skin that was radiated)
- Problems with the bowel system (if abdomen radiated)
- Secondary cancers (in area radiated)
- Infertility (if ovaries or testes were directly radiated)

## **What are some emotional aftereffects of treatment?**

After treatment, you may continue to have strong feelings regarding your illness and treatment, or you may experience new emotions. Feelings about the cancer experience may even surface months or years later.

Some common emotions and concerns you may experience after treatment:

- Anger
- Fear
- Sadness or depression
- Anxiety
- Uncertainty about the future
- Concerns about pain or fatigue
- Concerns about body image

Sometimes you may not know how to describe the feelings you are having. If you think that you are supposed to be grateful and happy, you may try to ignore unpleasant emotions. Even though you may be physically able to return to your normal daily activities or work, you may find that you aren't very interested or that you have trouble concentrating. You may worry all the time or just have a general feeling of uneasiness or

unhappiness. These emotions can affect how you communicate with your family and friends, and those relationships may suffer.

You may experience all, some or none of these emotional aftereffects. You may also have thoughts, feelings and reactions that are not mentioned. Asking for help from your family, health care team or mental health professionals can help you manage your emotions. Your concerns and feelings are important and deserve attention and appropriate treatment as soon as they are noticed.

## **What are some practical aftereffects of treatment?**

You may have practical problems with every day life activities. Some problems may start during treatment and continue after treatment is finished. Other problems may surface months after treatment is completed, especially if physical and emotional aftereffects develop.

Some practical areas where problems may surface:

- Difficulty working due to physical or emotional aftereffects
- Changes in relationships with family, friends or co-workers
- Difficulty getting health or life insurance
- Difficulty communicating concerns with your health care team
- Financial stress
- Employment discrimination

These are just a few examples, but all areas of your life can be affected.

## **When do survivors need information on aftereffects?**

- **Recently diagnosed survivors**  
If you have recently been diagnosed, you can use this information to discuss your treatment options with your health care team. Once treatment is started, you can ask about what you can expect from different treatments and how your life may change during and after treatment.  
You may feel scared and even overwhelmed when learning about the possible aftereffects of treatment, but knowing what to prepare for can help you choose the treatment that is right for you. Talk about your concerns and fears with your health care team. Be honest and direct, and ask your health care team members to help you understand the possible changes to your life and what you can do to prepare for them.
- **Survivors who have recently completed treatment**  
If you have recently completed treatment or are a few years out from treatment, you should talk to your health care team about a follow-up plan that identifies possible aftereffects and their symptoms. Knowing what to look for can help you get treatment early and possibly reduce the severity of some aftereffects. You can

also reduce the stress of not knowing how to manage symptoms by talking to your health care team and using community resources.

- **Long-term survivors**

If you received treatment many years ago, you may be living with aftereffects that are much more difficult to manage. In the past, treatments for many types of cancer were more toxic or were given in much higher dosages, so greater damage to healthy tissue may have occurred. You may have longstanding symptoms that have not been evaluated or treated, either because the risk of aftereffects was not understood when you were treated or because effective treatments were not available. In addition to physical aftereffects, you may also be dealing with emotional and practical changes. You may be frustrated by the lack of information on aftereffects.

Keeping a record of unexpected or unexplained emotions and practical problems can help you talk with your health care team and family about how past cancer treatments may be affecting your physical and emotional health. The Cancer Survivor's Health Journal included in the Live Strong Survivorship Tools can help you keep a record of your concerns.

## **What information do childhood cancer survivors and older survivors need?**

- **Childhood and adolescent cancer survivors**

There is a growing body of research on the aftereffects experienced by survivors who were diagnosed and treated as children or adolescents. In fact, there is more information available on children than on adult survivors. This document focuses on adults; however, resources are given in the Additional Resources document for further reading on aftereffects for survivors who received cancer treatment as children. The more complete information available on aftereffects of childhood cancer may be useful in understanding your own symptoms and for discussing these symptoms with your health care team. Keep in mind, though, that some of this information does not apply to adults, even adults who had the same type of cancer and the same type of treatment.

- **Older survivors**

Older survivors may have age-related changes in normal function and other illnesses (heart disease, for example) that affect their recovery from cancer treatment as well as their risk of certain aftereffects. Keeping a record of symptoms, known medical conditions and medications is very important when talking to your health care team members about physical changes. The Cancer Survivor's Health Journal included in the Live Strong Survivorship Tools can make this record keeping easier.

## **Why do some survivors know so little about aftereffects?**

- During treatment survivors and their health care teams usually focus their attention on treating the cancer. Aftereffects may never be discussed until symptoms show up after treatment.
- Communication problems may prevent health care team members and survivors from easily understanding each other.
- There is relatively little scientifically-proven information about aftereffects in adults.
- There are only a few guidelines for physicians on providing follow-up care.
- Primary care doctors who don't specialize in oncology may not be aware of the aftereffects for certain treatments.
- Doctors may not want to burden or frighten survivors with possible aftereffects that may or may not occur.
- Cancer treatment is an emotional experience. Survivors may not be ready or willing to talk about possible aftereffects while going through treatment.
- Survivors may not know how to record or report their symptoms.

## **How can survivors work with their health care teams to manage aftereffects?**

Even though talking about aftereffects can be upsetting, you have a right to know what is happening to your body. Knowing what to expect helps you to make decisions that are right for you, plan for the future and regain a sense of control over your life. Talking with health care team members is an important way for you to learn about possible aftereffects of specific treatments. This communication also helps to educate health care team members about important quality of life issues that can affect you. Much of what health care professionals know about survivorship topics comes directly from survivors themselves.

Health care team members should help you in the following ways:

- Provide information and resources on your specific type of cancer
- Describe risk factors and potential aftereffects
- Help you understand and manage aftereffects
- Help you understand which doctors you should see for routine follow-up visits or if certain symptoms or problems develop (oncologist, general practitioner, etc.)
- Create a follow-up health plan when treatment ends. This plan will help you:
  - Know what symptoms to look for
  - Know how to reduce the risk of certain aftereffects
  - Understand your risk of secondary cancer
  - Know how often to see your health care team

You can work with your health care team in the following ways:

- Keep a record of your symptoms and discuss them with your health care team
- Ask questions when you don't understand something
- Follow any agreed-upon treatment plans for aftereffects
- Read about aftereffects on your own and bring that information to your health care team visits

Remember that even if you are no longer seeing your cancer health care team, you can discuss these issues with any health care professional.

## **Will all doctors know how to diagnose and treat aftereffects?**

After you finish treatments, you will probably see your oncologist for a while to watch your health. If you notice any new physical or emotional symptoms, talk to your oncologist. Decide with your oncologist if you need to make an immediate appointment or if you can discuss and evaluate your symptoms at the next scheduled visit.

If you are no longer seeing your oncologist, talk to your primary care provider (PCP) about symptoms that you notice. Not all doctors will know about aftereffects, so you may need to see an oncologist (preferably the one who treated you) or request a referral to a specialist who may have more knowledge about life after cancer treatment. This is especially important if you see a health care professional who you think does not take your concerns seriously or who does not think you need any special attention for your symptoms.

In most cases, even if you are being followed by a primary care provider for your non-cancer medical needs, it is helpful to have occasional follow-up visits with the oncologist who treated you. Your oncologist will usually know the most about your treatment and what aftereffects to look for. Some survivors have difficulty with health insurance companies when they want to see their original oncologists for aftereffects symptoms.

Talking with other long-term survivors who have similar challenges can also be helpful and reassuring. By sharing information, you can learn from their experiences and find ways to manage your own challenges.

The process of getting long-term follow-up care is not always easy. When your concerns are not acknowledged, you may be very frustrated. You will have to be active and determined in asking for the help you need.

## **Are there long-term follow-up clinics for survivors?**

Many young survivors who were treated when they were children or adolescents continue to have access to pediatric long-term follow-up clinics. At this time, there are very few long-term follow-up clinics for adults. Several national cancer advocacy groups, including the Lance Armstrong Foundation, are working to bring more awareness to the aftereffects of treatment and the need for long-term follow-up care for adults.

## **Managing Aftereffects**

Living with aftereffects of cancer treatment can be difficult. However, when you are aware that aftereffects can happen and seek help with symptoms early, you increase your chance for successful treatment and a better outcome.

Understanding that cancer aftereffects are possible can help motivate you to:

- Change unhealthy behaviors (for example, stop smoking, improve diet)
- Be aware of symptoms that may be signs of a problem
- Seek a diagnosis when problems are noticed
- Get treatment as soon as possible

## **Works Cited**

Lance Armstrong Foundation Survivorship Topics  
[www.livestrong.org](http://www.livestrong.org)