

## Emotional Effects of Cancer

Living with cancer is an experience that can affect every aspect of your life. Not only is your body affected, but also your mind and your spirit. You may experience many emotional reactions to all of these changes. When cancer treatment ends, the emotional effects may continue or new emotions may surface.

There is no “standard” emotional response to cancer survivorship. Each survivor is different, as is each experience. Most likely you will experience a mix of emotional reactions, some of which may even be positive. For example, you might feel satisfaction in deepening personal relationships or confidence in finding strengths within you.

On the other hand, some of your emotional reactions might be uncomfortable or confusing, and at times you may feel overwhelmed by conflicting feelings. If this is how you feel during your journey through cancer, you are not alone. Many cancer survivors say that managing their feelings can be just as difficult as dealing with their medical issues.

Changes in emotions or mood are common throughout the cancer experience. For example, at diagnosis, you may have felt afraid, sad and worried. Perhaps you felt more confident after you decided on a treatment plan. During treatment, you might have had many changes in your mood. Many cancer survivors describe the treatment time as an emotional roller coaster—some days are “up” while other days are “down.”

After treatment ends, many survivors are surprised to find that they continue to have changes in their emotions or mood. For some, completing active treatment brings a time of great emotional distress. Many survivors describe the time after treatment as one of the most emotional—and unusual—periods of their lives. You may have similar reactions as you adjust to life after cancer treatment. Understanding what some of these emotions are can help you manage them and feel confident about survivorship.

### What will survivors learn from this document?

This document provides an overview of the emotional effects that survivors sometimes face when treatment ends. Although many different experiences and many different points of view are represented, no single document can cover all the emotions that are experienced by cancer survivors. As you read about emotional aftereffects, keep in mind that you may have none, some or all of these concerns. Or you may experience these emotions more or less strongly than other survivors. Even though you may not experience all of these emotions, chances are you will recognize at least some of them at some point in your survivorship.

## **Why are emotional effects sometimes confusing after treatment ends?**

Perhaps you expected to be thrilled and feel relieved. You may indeed feel this way when treatment ends. However, you may be surprised to find that you also have uncomfortable feelings and unanswered questions. Is the cancer gone for good? Will I face more side effects from the cancer or the treatment? I've made it through treatment—shouldn't I feel completely happy? What is going to happen now?

You may be surprised by the mixture of feelings you have when treatment ends and the process of moving on with life begins. This can happen for several reasons.

- **Feelings about your experience with cancer are suddenly coming to the surface.** Until now, you may have put your energy into managing the crisis of diagnosis and treatment. Your focus was on finding a health care team, choosing among treatment options, and just getting through the treatments. You may have put off paying attention to your feelings about the cancer experience until now.
- **You may not have been prepared for emotional effects.** You may have read and heard a lot about the physical and practical aspects of cancer and what you might expect to happen. But you might not have read or heard as much about any emotional stress that you might experience. Emotional effects are frequently overlooked in discussions of important side effects of treatment and survivorship.
- **People around you may not understand the emotional stress that completing treatment can bring.** Family members, friends and even your health care team may be ready to celebrate your victory of beating cancer. They may expect you to get back to normal and “get on with your life.” Acknowledging fears or sadness when others are celebrating your success can be difficult.

Emotions often surface unexpectedly. Knowing what some of these emotions are can help you understand what you are experiencing and help you find ways to manage your reactions.

## **What are some emotional effects associated with the end of treatment?**

When treatment ends, you might feel excited about your future, relieved that treatment is over, and ready to move on with your life. Or you might feel worried about the future, angry that you had cancer, or embarrassed that you had to rely on others for help and support. Many people have mixed feelings. You may have none, some or all of the feelings and reactions listed below. You also may have thoughts, feelings and reactions that are not mentioned.

Knowing about some of the most common emotional effects may help you understand and manage your feelings. Noticing the difference between some of these emotions (for example, sadness vs. guilt) is not always easy. Use the resources in the Additional Resources document to help you learn more about them.

Some common emotions are:

### **Fear of recurrence**

Will the cancer come back? Fear of recurrence is one of the most common concerns for survivors. You might feel especially worried about the cancer coming back if you continue to have symptoms or if you have aftereffects from the treatment. You may also feel at risk because:

- You are no longer actively taking treatments. This may make you feel helpless against a possible recurrence of cancer.
- Your medical condition is not being watched as closely by your health care team during follow-up as it was during active treatment.

### **Anxiety (Feeling worried or nervous)**

Some survivors say that the time right after treatment ends is one filled with insecurity and anxiety. You may feel that something bad is about to happen. Perhaps you feel that the threat of cancer coming back is constantly hanging over your head. Follow-up appointments, symptoms of common illnesses (like a cold), questions about how the cancer experience will affect your future—all of these may cause you to feel anxious.

### **Worries about self-image or body image**

If you experienced physical changes, you may sometimes worry about how you look to other people. You may feel differently about your body after you have had cancer and treatment. Your sense of who you are and how others see you can be challenged as you try to adjust to post-treatment survivorship.

### **Sadness or depression**

Sadness is a feeling of unhappiness, unrest or mental suffering that can be caused by an unexpected change, stressful situations or a loss of some kind. Sadness may be the most surprising of all the post-treatment emotional effects. However, feeling sad is a common response, especially in the early months after treatment ends. While you were focusing your energy on your diagnosis or treatment, you may not have had a chance to “let down” and really think about the changes that were happening in your life. You might have experienced losses that are painful and hard to accept. Feeling sad is a normal response as you try to adjust to any changes or disruptions that have happened.

Depression is something different than sadness. Just as with sadness, depression may be caused by stressful situations or unexpected change or loss, but it may also be caused or made worse by chemical changes in the brain. The sadness that comes with depression lasts for a longer amount of time and may be very strong.

Some symptoms of depression include:

- Long-lasting changes in eating habits
- Loss of interest in activities you usually enjoy
- Problems with sleep
- Feelings of hopelessness, helplessness or despair
- Inability to experience joy
- Problems with concentration
- Suicidal feelings

Depression is a real and treatable medical problem. If you have any of these symptoms, or other symptoms that are keeping you from feeling like yourself or feeling good, talk to a mental health professional and your health care team right away.

### **Grief and loss**

Losing someone or something that is important naturally causes pain and sadness. Grief is the natural human response to loss. Grief is more than simple sadness or depression because it happens over a long period of time and usually includes emotions such as denial, anger and acceptance. Survivors and their families may face many types of losses as a result of the cancer experience, such as the loss of a job or career, the loss of financial or emotional security, the loss of physical function or health, or the loss of an important goal or lifelong dream. Understanding and managing grief is a process that may happen over a long period of time and can include a wide range of thoughts and feelings.

### **Guilt**

Guilt is another emotional effect of cancer that can surprise you after completion of your treatment. Guilt is a feeling you experience when you think you are to blame for something. You may think that something you did caused your cancer. You may feel guilt because you survived while others did not, or you may worry that you have placed too much of a burden on loved ones. Whatever the cause, guilt is a complex emotion that can be difficult to acknowledge and express.

### **Uncertainty**

You may feel unsure about different aspects of your life. The condition of your health can be a primary area of concern. You may find yourself becoming nervous as your follow-up appointments or important anniversary dates (such as the date of diagnosis or the date of completing treatment) get closer. You might worry more than usual about your

health—there may be no such thing as “a simple cold” or “only a headache.” You and your family may find it hard to make plans for the future. Even though uncertainty affects different people in different ways, all cancer survivors live with some uncertainty about their future.

### **Anger**

Anger is a feeling that can have various levels, from mild irritation or frustration to rage or fury. Challenges in many areas of your life can bring up anger. You may feel cheated out of the chance to have a normal life. You may struggle with physical or emotional aftereffects of treatment. You are most likely to feel anger when you are reminded of what you have lost because of cancer. Physical, financial, spiritual, emotional or social distress can also lead to anger.

### **Emotional numbness**

The sensation of being drained, worn out or just unable to feel anything because of overwhelming experiences is common among survivors. After the stress of treatment, you may feel unable to manage anything more. You may “shut down” all of your feelings in order to protect yourself. If you often find yourself thinking “I just don't care” or “It doesn't matter,” then you may be experiencing emotional numbness.

### **Spiritual distress**

The ability to make sense out of life's experiences is important to your sense of well-being. You may look for different ways to understand your cancer experience, especially if your treatments were difficult or your illness was seriously life-threatening. Sometimes understanding why things happened the way they did can be hard. The search for meaning often begins at diagnosis and can continue for many years after treatment is over. The question “Why me?” may be hard to resolve, especially if you are living with uncertainty about your health and your future. The picture of your life the way it is now may be very different from the way you thought it would or should be. You may experience spiritual distress as you redefine your values and goals and search for what now gives your life its quality and meaning.

## **Are these emotions and symptoms normal?**

Having some emotional effects some of the time is normal and common during survivorship. However, feeling depressed, worried, stressed or overwhelmed most of the time is a sign that you need help managing your emotions. You should talk with a mental health professional or your health care team about the cause and treatment choices for any emotional effects if they are very intense, last a long time or interfere with your daily activities.

## **Will all cancer survivors experience emotional effects?**

You may have all, none or only a few of these feelings and reactions. Every survivor will feel and respond differently. Knowing that these emotional reactions are common and sometimes expected can be a starting point for living well and accepting your feelings after treatment.

You may be at higher risk for emotional distress if:

- You have ongoing or long-term effects that are related to cancer or cancer treatment such as, but not limited to:
  - Osteoporosis
  - Fatigue
  - Insomnia
  - Chronic pain
  - Cognitive problems (problems with thinking or concentration)
  - Sexual dysfunction
  - Infertility
- You have memories of difficult experiences during your treatment that are very upsetting for you
- You have a previous history of emotional distress
- You do not have enough social and emotional support
- You are experiencing problems in your relationships with family and friends
- You are experiencing problems with practical matters such as employment, insurance or money

## **What are some situations that might lead to emotional distress?**

You and your family may be dealing with a broad range of issues, including physical, social, emotional, financial and spiritual challenges. Believing the myth that you can just pick up your life where you left off makes living with these challenges even more difficult, and it increases the struggle to deal with uncomfortable emotions.

Examples of situations that may lead to emotional distress include:

- Making plans for your future and your family's future
- Difficulty doing the things you used to do (for example, planning and cooking meals, walking around the block or working at your job)
- Adapting to disabilities or to an awareness of being different
- Facing prejudice, fear or discrimination as a result of your health history
- Adjusting to new relationships with friends, co-workers and even your health care team
- Worrying about when to tell—or when not to tell—others about your cancer experience
- Asking yourself the question “Why me?”
- Feeling stress in your relationship with your family

- Dealing with financial problems as a result of your cancer experience
- Feeling that you cannot live up to the expectations of others that you should go back to your life as it was before cancer
- Understanding that your experiences and emotional reactions may be different from those of family and friends

## **What are some signs that you may be experiencing emotional effects?**

Emotions can trigger reactions in your body, in your behavior and in the way you think about things.

Some physical reactions might include:

- Crying often
- Feeling tired (fatigue)
- Feeling generally “under the weather”
- Difficulty sleeping
- Feeling tense or “jittery”
- Change in eating habits

Some reactions in your behavior might include:

- Avoiding people or things that remind you of your cancer experience
- Needing a lot of reassurance from family and friends that you're doing OK
- Lacking confidence in yourself
- Withdrawing from people and normal activities
- Feeling irritable and moody much of the time
- Overreacting to situations
- Having problems communicating with others

Some reactions in the way you think about things might include:

- Not being able to forget about your cancer experience
- Increased watchfulness or caution about your health
- Not being able to concentrate or pay attention
- Difficulty making decisions
- Getting angry or frustrated easily

## **Will the emotional aftereffects ever go away?**

Researchers are just now beginning to study and learn more about the long-term emotional effects of the cancer experience. Their work shows that, over time, most survivors can adjust in positive ways to the stresses of cancer and its treatment.

Emotional reactions to cancer can change over time. Your feelings at the beginning of your journey with cancer may be very different from those you have at the end of treatment or beyond. Gradually, as you adjust to or accept the cancer experience and allow yourself to become comfortable with your feelings, many of the emotional effects will become less intense and happen less often. Memories of the distress of diagnosis and treatment usually begin to fade. You may see that other life events become more important and the cancer experience becomes less important.

Even so, reminders of your experience with cancer can bring up emotional effects for years after treatment has ended. Examples of reminders might include:

- Sounds, tastes or smells that remind you of treatment
- Routine medical appointments
- Hearing about another person's cancer experience
- Anniversary events (such as the date of diagnosis or the date of completing treatment)
- Important events with family or friends (graduations, birthdays, holidays)
- Ongoing health problems because of adverse aftereffects of treatment
- Times of crisis or unusual stress in your life

## **Can strong emotions cause cancer to come back?**

Researchers have studied the relationship between emotions and cancer extensively. There is no convincing evidence that emotions can cause cancer. However, there is research supporting the idea that taking a positive approach to treatment and playing an active role in your care can improve both your physical and mental sense of well-being.

## **Why is paying attention to emotional aftereffects important?**

Paying attention to your feelings, especially uncomfortable feelings, can be hard when you and others may have wanted and expected to just get on with life. Yet paying attention to your emotional reactions after treatment has ended is important for many reasons.

Expressing emotions instead of keeping them inside lowers stress and promotes mental and physical health. Ongoing stress can affect your hormones and your immune system, and this may slow down the healing process. There is evidence that social support as well as professional mental health support can improve the quality of life for cancer survivors.

Paying attention to your feelings can also help you:

- Make room for more positive feelings to come out—such as courage, self-confidence, hope and gratitude
- Live more fully—in mind, body and spirit
- Communicate better with family, friends and health care team members
- Maintain good relationships with family and friends
- Develop strengths that can help you manage other stress in your life
- Gain awareness and understanding of your experiences

Cancer brings changes that are not always for the worse and may bring about healthy personal growth. The cancer experience and your emotional responses to it can become important resources as you face your future.

### **Works Cited**

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