

Fear of Recurrence

What is recurrence?

Recurrence is when the cancer comes back after it has been treated. A recurrence can happen in the same place where the cancer first began or it can come back in a different part of the body. You may worry about a recurrence of your cancer often. You may only think about it when you go in for check-ups, or maybe you don't worry about recurrence at all. Fear of recurrence is something that affects survivors differently.

It's perfectly understandable if you have fears of recurrence. No one wants to get cancer again. Living with some fears of recurrence, especially when you go back in for check-ups, is a common experience for many cancer survivors. However, fears of recurrence may get so overwhelming that they make it difficult to move on with your life and adjust to life after cancer. If you have fears of recurrence, it is possible to manage them either by yourself or with the help of a professional counselor.

Who worries about recurrence?

While recurrence is a concern for many survivors, some survivors are more afraid of it than others. You might think about recurrence more if you had a kind of cancer that was difficult to treat. You may be someone who is usually very calm and level headed when it comes to other things, but fears about the cancer coming back may be too much for you to handle.

There is no way to determine who will worry about recurrence and who will not. It doesn't matter how old you are, what cancer type you had, or how long you have been a survivor - anyone can experience fears of recurrence. That's why survivors may want to think about whether they have fears of recurrence and whether they need professional help to manage those fears.

What are signs that a survivor may have fears of recurrence?

Below are some symptoms that you might experience if you worry about recurrence:

- You think you might have cancer again when you have any aches, lingering coughs or headaches
- You notice the normal minor aches and pains in your body that never bothered you before cancer
- You are afraid to rebuild your life because you are too scared you might get cancer again

Don't forget that even though you had cancer, it's still possible for you to get common physical illnesses like a cough, cold or a common ache. Many aches and pains in your body are not related to cancer. But anytime you have concerns about your health, you should talk to your health care team.

Many oncologists operate by the two week rule: any pain or symptom that goes away in less than two weeks is not usually something to worry about. This does not mean that you have to wait two weeks to call your health care team when you have concerns about your health. Let your health care team help you understand what you are experiencing. A therapist, social worker or other member of your health care team can help you learn how to better manage your fears of recurrence. It's OK to live with some fears of recurrence and not seek professional help; however, any fears that are overwhelming and seriously interfering with your quality of life should be discussed with a professional counselor.

You might want professional counseling if:

- You constantly worry about recurrence
- You think about your cancer recurring before you go to bed at night and the first thing in the morning
- You go for more than a few weeks without sleeping well
- You don't feel hungry for days
- You don't want to spend time with your friends or continue your usual routines
- You can't concentrate at school or work

Why do some cancer survivors have fears of recurrence?

Cancer survivors probably live with more uncertainty about recurrence than people who have had other kinds of illness. Because cancer is such a difficult illness to treat, there is a chance that it might come back again. It's possible to treat recurrent or metastatic cancer, cancer that recurs in a different part of the body, but it's sometimes hard to cure recurrent cancer. If the cancer comes back again, you might worry that your cancer can't be cured. Remember that there are treatment options for people with recurrent cancer. There may be different treatment options that weren't available when you were treated last time. If a recurrence does happen, it is very important to maintain an honest and hopeful dialogue with your health care team to ensure the best medical care possible. In addition to fearing a recurrence that may be fatal, cancer survivors may worry about having to endure more treatment. Going through surgery, chemotherapy and radiation once is bad enough; thinking about going through it again may seem impossible. It might help if you try to maintain a positive attitude. Realizing that you survived treatment once and believing that you could endure it again may help ease your fears of recurrence.

When might fears of recurrence affect a survivor?

You may always live with some fears of recurrence. You may notice that over time, your fears of recurrence have decreased and you don't think about the cancer coming back as much. Some survivors find that their fears of recurrence go away as time passes. No matter how long it has been since you finished treatment, there may be certain moments during your survivorship when fears of recurrence affect you.

You may find that you worry more about cancer recurring:

- When you are due for check-up appointments
- When you have scans, blood tests or other medical procedures
- When you hear or read something about cancer that frightens you

It's perfectly normal to worry more about recurrence during these moments in your survivorship. These can be very scary experiences. Knowing when your fears of recurrence are usually the strongest can help you prepare to deal with them.

What can a survivor do to manage fears of recurrence?

Let yourself be afraid. It is normal to experience some fear about your cancer recurring. Telling yourself not to worry or criticizing yourself for being afraid won't make these feelings go away. Try not to feel guilty for having these feelings. Accept that you are going to experience some fear and focus on finding ways to help yourself manage the anxiety.

It may also help to remember that the fear usually lessens over time, and that you won't always feel so anxious. Be aware that your anxiety may temporarily increase at certain times, such as before follow-up care appointments, around the anniversary date of your diagnosis, or when a friend is diagnosed with cancer.

Express your feelings. Talking about your fears and feelings or writing about your thoughts in a journal can help reduce your anxiety. Talking and thinking about your concerns can help you explore the issues underlying your fear. Fear of recurrence might include fear of having to repeat cancer treatment, losing control of your life, or facing death.

Many cancer survivors find joining a support group to be helpful. Support groups offer the chance to share feelings and fears with others who understand, as well as to exchange practical information and helpful suggestions. The group experience can also create a sense of belonging that helps you feel less alone and more understood.

Be well informed. Most cancers have a predictable pattern of recurrence. While a doctor cannot tell you exactly what will happen to you, an oncologist familiar with your history will be able to give you specific information about whether, when, and where your cancer

might recur, as well as symptoms to look for. Knowing what to expect can help you stop worrying unnecessarily that every ache or pain means your cancer is back.

Get regular follow-up care. Every cancer survivor should receive regular follow-up care including doctor visits and, usually, a schedule of tests. You should also be told what symptoms to look for and report to your doctor. Good follow-up care can help ensure that a cancer recurrence is caught early. Thinking of yourself and your doctor as partners in charge of your health-care decisions can help you feel more in control.

Adopt a healthy lifestyle. Eating a well-balanced diet, exercising regularly, getting enough sleep, and reducing stress can help you feel better physically and emotionally. Doctors do not yet know why cancer recurs in some people but not in others, but avoiding unhealthy habits like smoking and excessive drinking may help reduce the risk of recurrence. Adopting a healthy lifestyle will also lower your chances of developing other health problems.

Reduce stress. Finding ways to reduce stress will help lower your overall level of anxiety. Experiment with different ways of reducing stress to find out what works best for you.

- ✓ Spend time with family and friends
- ✓ Spend time on hobbies and other activities you enjoy
- ✓ Take a walk, meditate, or enjoy a bath
- ✓ Exercise regularly
- ✓ Find time for humor-read a funny book or watch a funny movie
- ✓ Join a support group
- ✓ Avoid unnecessary stress-don't take on unnecessary responsibilities or commit yourself to tasks you don't have time for

Talk to a health care professional about your risk of recurrence:

Good communication between you and your health care team helps you get answers to your questions and feel more confident about the care that you receive. It's not always easy to say everything you want to say during an appointment. You might not be used to having to ask so many questions. It takes practice.

Here are some tips you can use to improve your communication with your health care team:

- Make a list of possible symptoms of recurrence you experienced and take them to your visit. Let the members of your health care team see your list so that all of you can make the most out of the time you have together.
- If you have concerns about recurrence in between appointments, give your health care team a call and let them know what they are. If it's not an emergency, you might even fax or mail in your questions and follow-up with a phone call.

- Let your health care team know if you are feeling sad or depressed. They can help you find ways to manage your feelings and suggest other professionals who can help you.

Talk to your friends and family and find out if they have similar fears:

Your friends and family may be afraid to bring up their worries because they don't want to upset you. You might tell them it is actually more helpful for you to talk with them about these fears, and that talking helps you feel less alone.

You can directly ask them things like:

- ✓ Do you worry about my cancer coming back?
- ✓ Do you worry more now about your own health?
- ✓ Are you afraid that I might die?

You may find that some of your family or friends can talk with you about these difficult and scary subjects. Some conversations might not feel comfortable. Many survivors have friends that are uncomfortable talking about cancer. Try not to be too disappointed in the ones who just can't talk about their fears.

Talk to a professional therapist if fears of recurrence overwhelm you:

Ask your health care team for a referral to a therapist who works with other cancer survivors. Most cancer centers employ oncology social workers who are specially trained to work with cancer survivors and their families. Even if you are not a patient at a cancer center, the oncology social worker may meet with you or refer you to someone else in the community. The Association of Oncology Social Work (AOSW) is also a good resource. <http://www.aosw.org> or Phone: (215) 599-6093.

It is important to interview the therapist to find out if he or she is the right professional for you. Speak honestly with the therapist and let him or her know your reasons for wanting to work with a therapist.

Examples of questions to ask the therapist:

- What type of education background do you have?
- What license do you have?
- What is your experience working with people with cancer?
- What do you understand about the emotional response to this illness?
- Do you take my insurance?
- Do you work with people who are anxious? Depressed?
- Do you know community resources for people with cancer?

Find a support group and discuss your fears with other cancer survivors:

Support groups provide a safe environment to share experiences with other survivors, learn new ways to handle difficult situations and talk about the emotions. You will see different styles of coping with stress and adjusting to life as a cancer survivor. If you are uncomfortable talking about certain subjects with your family or friends, a support group offers you a place to talk freely about what is important to you.

Some ways to find out more about support groups in your area:

- Ask your health care team for suggestions. Some cancer programs offer support groups for cancer survivors and their family members right in the clinic or hospital.
- Call a nearby cancer center or university hospital and ask about support groups.
- Call the American Cancer Society at 1-800-ACS-2345 (1-800-227-2345) and request a list of support groups and cancer centers in your area.

National Resources

AMC Cancer Information and Counseling Line

www.amc.org

Email: ciclhhelp@amc.org

Phone: 1-800-525-3777

Cancer information specialists and counselors take calls Monday-Friday, 8:30 a.m. to 5:00 p.m. (MST).

This counseling line is staffed by cancer information specialists and counselors who can talk to you about your concerns. In addition, they provide medical information, resource referrals, emotional support and short-term counseling at no charge. Services are available to survivors, caregivers, family members, or anyone with questions about cancer. Questions can also be submitted by email. This service is operated by the AMC Cancer Research Center. The research center's Web site has additional information about a variety of cancer topics, as well as links to other cancer sites.

National Cancer Institute (NCI)

www.cancer.gov

- Email: Send an email through the "Need Help?" section of Cancer.gov.
Phone: 1-800-4-CANCER (1-800-422-6237)
TTY for deaf and hard of hearing callers: 1-800-332-8615
English-speaking and Spanish-speaking information specialists answer calls Monday-Friday, 9:00 a.m. to 4:30 p.m. local time.
Online: Immediate online assistance is available (in English only) through *LiveHelp*, an instant messaging system for typing in questions and receiving responses from information specialists. You can access *LiveHelp* from the "Need Help?" section of the Cancer.gov homepage Monday-Friday, 9:00 a.m. to 10:00 p.m. (EST).

Cancer.gov, the National Cancer Institute Web site, provides accurate, up-to-date information on many types of cancer and the emotional challenges cancer can bring. You can use the site to search for information by cancer type or topic, and you can access information about managing emotional concerns and treatment-related issues. Information about financial and insurance matters is also included. You can learn how clinical trials work and search for a clinical trial in your area. This site has a detailed dictionary of cancer terms. Web site information and publications are available in Spanish.

CancerCare Web site at www.cancercare.org, or call 1-800-813-HOPE (1-800-813-4673) for information on telephone, online or on-site support groups.

Cancer Hope Network linking survivors: <http://www.cancerhopenetwork.org/>

Local Resources

Support groups and other support services for survivors and families

Gilda's Club- www.gildasclubseattle.org
(206) #709-1400
Cancerlifeline-
206 297-2500 or www.cancerlifeline.org

Works Cited

Lance Armstrong Foundation Survivorship Topics
www.livestrong.org