

Fear of Recurrence

Fear of recurrence, the concern that cancer will come back after treatment, is common among survivors. Although having some concerns about recurrence is natural, too much worrying can affect your quality of life. Understanding how to manage fear of recurrence can help you feel more confident and secure about survivorship.

Fear of Recurrence: Detailed Information

This information is meant to be a general introduction to this topic. The purpose is to provide a starting point for you to become more informed about important matters that may be affecting your life as a survivor and to provide ideas about steps you can take to learn more. This information is not intended nor should it be interpreted as providing professional medical, legal and financial advice. You should consult a trained professional for more information. Please read the Suggestions (<http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Emotional-Effects-of-Cancer/Fear-of-Recurrence#s#s>) and Additional Resources (<http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Emotional-Effects-of-Cancer/Fear-of-Recurrence#a#a>) sections for questions to ask and for more resources.

Recurrence of cancer (also called recurrent cancer) is when cancer comes back--usually after treatment is done and a period of weeks or months during which there were no signs or symptoms of the disease. Remission of cancer can be temporary or permanent. If remission is temporary, cancer recurs (relapses) either in the same place where the disease first began (primary site) or in different places in the body (metastases). Fear of recurrence is the experience of worry and concern that cancer might come back. It affects each survivor differently.

Who worries about a recurrence of cancer?

There is no way to determine who will worry about recurrence and who will not. It doesn't matter how old you are, what type of cancer you had, or how long you have been a survivor. However, understanding the possible causes of fear and what you can do about it may help you feel more secure and better able to manage these types of concerns.

Cancer survivors probably live with more uncertainty about recurrence than people who have had other kinds of illness. This may be because cancer is generally difficult to treat, and there is a chance that it could recur.

Fear that cancer could return is both a normal and common concern for cancer survivors who have completed treatment and are in remission. The American Cancer Society estimates that at least 70% of survivors experience this type of fear. No one wants to get cancer again.

Sometimes, a fear of recurrence results in positive actions. For example, it can motivate you to find new information, seek needed support, or to schedule follow-up health care appointments. Fear of recurrence often inspires new healthy living behaviors such as an exercise routine and healthy eating habits.

When does fear of recurrence become a problem?

Even very calm and level-headed individuals may sometimes feel that the fear of a cancer recurrence is too much to handle. However, this fear should not become so overwhelming that it is difficult to move on with your life.

While the return of cancer is a concern for many, some may be more troubled by it at certain times than others. Many survivors feel unprotected, helpless, and more at risk when active cancer treatment is done. It might be of greater concern to those who have had a type of cancer that was difficult to treat. There may be strong concerns if side effects or aftereffects from the treatment continue long term. In addition, there can be a concern that the medical team is no longer monitoring and watching for cancer as closely as during treatment.

For some, even common physical illnesses such as coughs, colds and viruses can raise strong concerns. The good news is that many aches and pains will most likely not be related to cancer. However, always contact your health care team if you have concerns, feel that something is wrong, or experience symptoms that are new or different.

Some oncologists operate by a “two-week rule.” If any pain or symptom does not go away in two weeks, it should be checked. However, this does not mean that you should wait two weeks to call about concerns. Let your health care team help you understand what you are experiencing. If a fear of recurrence becomes overwhelming or begins to interfere with your quality of life, a member of your health care team can help.

The following are signs that fears about cancer may be a problem:

- Any minor aches, coughs or headaches bring a strong fear that cancer has recurred.
- There is an unwillingness to rebuild and return to a full life due to fears.
- Recurrent is a constant worry.
- Thoughts about cancer recurring happen before you go to bed at night and the first thing in the morning.
- There are long-term sleeping problems (more than a few weeks).
- Little or no appetite continues for days.
- There is no desire to spend time with friends.

- There is no interest in continuing usual routines.
- There is an inability to concentrate at school or work.

Recurrent or metastatic cancer (starts in one part of the body and spreads to a different part of the body) can be treated, but it is sometimes hard to cure. Treatment options for people with recurrent cancer may be different. In some cases, the new treatment method may not have been available at the time of the last treatment. Keeping in mind that you went through treatment once and know that you can do it again may help ease some fears about recurrence.

It is perfectly normal to worry more about recurrence at specific times in your survivorship. Knowing when your fear of recurrence is usually the strongest can help you be prepared to deal with it. You may find that you worry more about cancer recurring when:

- It is time for follow-up health care appointments
- Scans, blood tests or other medical procedures are scheduled
- When you hear or read something about cancer that frightens you

What can be done to deal with the fear of cancer recurrence?

You might find that beginning a conversation about your fears can be helpful for loved ones and friends. Some may be afraid to bring up their worries because they don't want to upset you. However, talking with them may help them, and you are likely to feel less alone. Together, you may be able to come up with a plan to face these fears.

Talk with your friends and loved ones about your concerns.

You can start a conversation by saying something such as:

- “Sometimes, I worry about my cancer coming back and what might happen if it does...”
- I wanted to tell you that because I would like to have your support and help when I am feeling afraid.
- I wonder if the fear of my cancer coming back might be bothering you, too.
- What things have you thought about that we can do to help cope with this worry?”

Some friends and family members may be uncomfortable talking about cancer. If that is the case, it is very important to remind yourself:

- You have done nothing wrong by bringing up the subject – the other person may be responding to his or her own experience and fear of cancer.
- It may be that the other person does not know how to discuss the subject.
- Although the response is not what you wanted to hear, it may be that this person is doing the best he or she can right now.
- You may be able to return to the conversation at a later time.

Find a cancer support group.

Support groups can provide a safe environment to share experiences with other survivors. You can also learn new ways to handle difficult situations and have a chance to talk about emotional issues that only survivors may understand. These groups can offer an opportunity to learn different styles of coping with fear and ways of adjusting to life as a cancer survivor. If you are not comfortable talking about certain subjects with your family or friends, a support group will offer a place to talk freely about what is important to you. Each support group is unique so you may want to try more than one to find the best one for you.

Talk with a professional therapist if fear of recurrence overwhelms you.

If family and friends are not able to help you with concerns, your health care team or a licensed counselor may be an important source of support. Ask 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.

Keep in mind that, no matter how long it has been since you finished treatment, there may be certain occasions when the fear of cancer recurrence affects you. With time, you are likely to find that your concerns and the level of fear may lessen.

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Fear of Recurrence: Suggestions

The suggestions that follow are based on the information presented in the Detailed Information (<http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Emotional-Effects-of-Cancer/Fear-of-Recurrence#d#d>) document. They are meant to help you take what you learn and apply the information to your own needs. This information is not intended nor should it be interpreted as providing professional medical, legal and financial advice. You should consult a trained professional for more information. Please read the Additional Resources (<http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Emotional-Effects-of-Cancer/Fear-of-Recurrence#a#a>) section for links to more resources.

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

- A doctor cannot tell you exactly what will happen to you. However, based on your particular situation (including the type of cancer you had, the treatment you had, how long it has been since you had cancer, and your health history), your doctor can talk with you about how likely or unlikely it is that the cancer will come back.

- Tell your doctor about signs or symptoms that you are worried about. You can also ask for a list of signs and symptoms that you should be watching for. Being armed with information may give you confidence and a sense of control over your fear.

Prepare for a discussion with your doctor about the risks of recurrence.

It may not always be 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.

The following are things you can do to prepare for your health care appointment:

- Make a list of signs and symptoms that concern you 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.
- Ask them to tell you about the signs and symptoms that you should be watching for.
- If you have concerns about recurrence in between appointments, let them know what they are.
- You can email, fax or mail in your questions and follow-up with a phone call to the nurse or doctor.
- Let your health care team know if you are feeling anxious or depressed.
- If needed, ask for a referral to other professionals who can help you.

During times when the fear of recurrence is bothering you, it may be helpful to:

- Talk to a health care professional about your level of risk for recurrence
- Discuss your concerns with loved ones and trusted friends
- Talk to a professional therapist if the fear feels overwhelming
- Join a cancer support group and discuss your concerns with other survivors

Explore ways to learn about cancer support groups in your area such as:

- Ask your health care team for suggestions. Some cancer programs offer support groups for cancer survivors and their family members in the clinic or hospital.
- Call a nearby cancer center or university hospital and ask about support groups.
- Visit **LIVESTRONG** Navigation Services online at [LIVESTRONG.org/Get-Help](https://www.livestrong.org/Get-Help), or call 1.855.220.7777 for information on support groups.
- Contact a nonprofit organization to request a list of support groups and cancer centers in your area, such as the American Cancer Society online at www.cancer.org or call 1-800-227-2345.

Recurrence: Additional Resources

LIVESTRONG Navigation Services

LIVESTRONG.org/Get-Help

Online: Complete an intake form through the LIVESTRONG website.

Phone: 1.855.220.7777 (English and Spanish)

Navigators are available for calls Monday through Friday, 9 a.m. to 5 p.m. (Central Time). Voicemail is available after hours.

LIVESTRONG offers assistance to anyone affected by cancer, including the person diagnosed, loved ones, caregivers and friends. The program provides information about fertility risks and preservation options, treatment choices, health literacy and matching to clinical trials. Emotional support services, peer-to-peer matching and assistance with financial, employment and insurance issues are also available. To provide these services, LIVESTRONG has partnered with several organizations including Imerman Angels, Navigate Cancer Foundation, Patient Advocate Foundation and EmergingMed.

Cancer Hope Network

www.cancerhopenetwork.org

Email: info@cancerhopenetwork.org

Phone: 1-877-HOPE NET (1-877-467-3638)

This number is answered Monday-Friday, from 8:00 a.m. to 5:30 p.m. (EST). Voicemail is available after hours.

Cancer Hope Network is a not-for-profit organization that provides free and confidential one-on-one support to cancer patients and their families. They offer support by matching cancer patients or family members with trained volunteers who have already undergone and recovered from a similar cancer experience. You can submit your request by phone or by email. A volunteer will try to contact you within 24 hours.

U.S. Institutes of Health - National Cancer Institute (NCI)

www.cancer.gov

Online assistance is available in English or Spanish through the *LiveHelp* instant

Online: messaging system. This service is available Monday-Friday, 9:00 a.m. to 11:00 p.m.(EST).

Email: Send an email through the “Need Help?” section of the website
1-800-422-6237

Phone: TTY for deaf and hard of hearing callers: 1-800-332-8615
Information specialists answer calls Monday-Friday, 9:00 a.m. to 4:30 p.m. local time.

The National Cancer Institute's website provides accurate information about the challenges cancer can bring. You can search for information by cancer type or topic. You can find information about treatment, financial and insurance matters. You can also learn how treatments in development work and search for a clinical trial in your area. This site also has a good dictionary of cancer terms, drug information and other publications. Cancer information specialists can answer your questions about cancer and help you with quitting smoking. They can also help you with using this Web site and can tell you about NCI's printed and electronic materials. The knowledgeable and caring specialists have access to comprehensive, accurate information on a range of cancer topics, including the most recent advances in cancer treatment. The service is confidential, and information specialists spend as much time as needed for thorough and personalized responses.

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