

Life After Cancer

A Cancer Survivorship Newsletter



The Gorilla in the Room: Fear of Cancer Recurrence

There are over 18 million cancer survivors in the United States and this number is expected to rise. Advances in oncology have led to improved survival but despite this achievement, patients still face a trajectory marked by emotional and physical distress associated with diagnosis and treatment.

The fear of cancer recurrence is fear, worry or concern about cancer returning or progressing. The fear of cancer recurrence (FCR) can be a dominant and highly common symptom after cancer for both patients and caregivers and is one of the most common unmet needs reported by patients. In a national survey of cancer survivors, almost 80% reported some FCR as a concern.

The fear of cancer recurrence is a critical target for optimal survivorship care. Low grade FCR is common and may be adaptive as it alerts patients to recognize the warning signs of recurrence and to adopt healthy behaviors. However, FCR can also be associated with worse quality of life, poor adjustment, and high levels of anxiety and depression. Approximately 7% of patients experience severe and disabling FCR. People with severe FCR report constant and intrusive thoughts about cancer, interpretation of mild and unrelated symptoms as a sign of recurrence, a conviction that cancer will return regardless of actual prognosis, and an inability to plan for the future due to worry that cancer may return and disrupt their plans. Depending on their coping strategy, they may over monitor for signs of cancer activity, constantly search online for information related to their cancer and its treatment/prognosis, overuse health services to receive assurance, and/or fearfully avoid screening and follow-up. When severe, FCR can be clinically significant, and is unlikely to improve without clinical intervention.

FCR can become worse in certain situations including around clinic visits and scans (scanxiety), treatment anniversaries, and seeing others develop cancer or experience progression/recurrence. This is worse in adolescents and young adult cancer survivors and is not confined to patients but affects caregivers as well.

Risk factors for higher levels of FCR may include:

- Later cancer stage at diagnosis
- Younger age (<60 years)
- Prior diagnosis of recurrence
- Lower levels of social support
- More clinician visits
- Self-identification as a cancer patient
- For females – having children regardless of their ages
- Prior health issues including anxiety disorders or depression
- More physical symptoms or pain



To date, there remains no consensus as to how FCR should be measured and severity categorized and there is no reliable consensus for treatment of FCR.

Screening for FCR with any method is recommended at the end of treatment and during follow up, when cancer survivors have less contact with the healthcare system. It is important to talk about FCR rather than expecting to adopt “a positive outlook.” Medical providers can be helpful if they effectively communicate the prognosis, the most likely signs and symptoms of a recurrence (as well as those not likely to be related to cancer), recommended behaviors to reduce risk (such as smoking cessation and exercise), and standard follow-up schedules.

For mild symptoms of FCR, it may be helpful to access educational materials (pamphlets, information sheets, etc.) concerning FCR and strategies to manage or seek assistance or to use internet-delivered interventions.

For moderate symptoms, patients can be referred for brief cognitive behavioral therapy-based intervention. The skills that work best for managing fear of recurrence include reframing uncertainty about one's health, scheduling time for worry during the daytime, eliciting the relaxation response using deep breathing and meditation, and developing healthy behaviors that can affect clinical outcomes, including sleep, physical activity, nutrition, and smoking. Certain positive psychology strategies, such as creative expression, humor, and gratitude notes/journaling, may also be useful for managing fear of recurrence.

For severe symptoms, patients may be referred for face-to-face evaluation by a psycho-oncologist to be replaced by psychiatrist, psychologist, or APNs to assess symptoms and provide support and/or medication/therapy.



These are some ideas that have helped others deal with uncertainty and fear and feel more hopeful:

- **Be informed.** Learn what you can do for your health now and about the services available to you. This can give you a greater sense of control.
- **Coexist with your fears of cancer recurrence** – rather than fighting it.
- **Be aware of your fears, but don't judge them.** Practice letting them go. It's normal for these thoughts to enter your mind, but you don't have to keep them there. Some people picture them floating away or being vaporized. Others turn them over to a higher power to handle. However you do it, letting them go can free you from wasting time and energy on needless worry. When you're triggered, stop what you're doing and implement some kind of coping mechanism, whether that's taking five deep breaths, going for a walk, or calling a friend to distract you.
- **Express your feelings of fear or uncertainty with a trusted friend or counselor.** Being open and dealing with emotions helps many people feel less worried. People have found that when they express strong feelings, like fear, they are better able to let go of these feelings. Thinking and talking about your feelings can be hard. But if you find cancer is taking over your life, it often helps to find a way to express your feelings.
- **Take in the present moment rather than thinking of an uncertain future or a difficult past.** If you can find a way to feel peaceful inside yourself, even for a few minutes a day, you can start to recall that peace when other things are happening – when life is busy and confusing.
- **Use your energy to focus on wellness and what you can do now to stay as healthy as possible.** Try to make healthy diet changes. If you are a person who smokes, this is a good time to quit. Start an exercise program.
- **Find ways to help yourself relax.** Our psychosocial team can provide you with a list of resources and apps to explore guided imagery, breathing exercises, and meditation.
- **Be as physically active as you can.**
- **Control what you can.** Some people say that putting their lives back in order makes them feel less fearful. Being involved in your health care, getting back to your normal life, and making changes in your lifestyle are among the things you can control. Even setting a daily schedule can give you more power. And while no one can control every thought, some say they've resolved not to dwell on the fearful ones.

In the end, it is helpful to acknowledge the cancer diagnosis and what you have been through and recognize that you are not alone in this journey and there is help available if you need it. And let's not forget the caregivers who traverse this cancer path with you and can experience the same fears and worries.

Protect your health and learn more by speaking to your healthcare team or visiting our website at: <https://cinj.org/survivorship>.

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