



Managing the Fear of Cancer Recurrence

What Is Fear of Cancer Recurrence or Progression (FCRP)?

After cancer, some uncertainty and worry that the disease might return is natural, as is anxiety raised by reminders of cancer, like follow-up appointments and tumor marker tests. However, if this worry becomes severe and debilitating we call it fear of cancer recurrence (FCR). For people with more established cancer the fear may be about cancer progression (FCP). We refer to both as FCRP.

About 1 in 4 people with cancer report moderate-to-severe FCRP, and up to 3 in 4 some anxiety about recurrence. Relatives as well as patients are affected.

Normal cancer-related anxiety is usually worst in the first year after cancer and usually lessens over time.

Sometimes, FCRP is high or grows over time, leading to:

- Avoiding previously enjoyed normal activities
- High levels of distress, difficulty in planning, indecisiveness
- Sleep disruption
- Inability to move on with your life and put cancer behind you
- Over-protectiveness of the former cancer patient
- Disruption of relationships, loss of interest in sex, altered appetites, weight changes and moodiness

If you experience any of the above and repeatedly think about cancer returning and what might happen, then you may have FCRP.

Why Does FCR Happen?

Cancers are often chronic, sometimes life-threatening, illnesses that can recur. Sometimes, natural worry becomes uncontrolled fear that gradually dominates everything else, interfering with normal life. People are most likely to be affected if they:

- Are newly diagnosed for the first time
- Are young, and have dependents, particularly young children
- Have a previous history of anxiety, depression or similar common mental health complaints
- Underwent prolonged and repeated difficult treatments or had severe reactions to treatments

- Felt the disease or treatments badly affected how they thought about themselves
- Had a poor relationship with their oncologist, or were otherwise dissatisfied with their treatment
- Are socially isolated or have few friends or others who can offer them support
- Are a person who doesn't cope well with life difficulties generally
- Has had recurrence or progression of the disease

How Can I Manage FCRP?

FCRP is generally classed as moderate or severe:

- Raised uncertainty – such as when waiting for a test result or if someone else is diagnosed with cancer, or occasional thoughts about cancer, which cause temporary anxiety about cancer recurrence that soon passes is normal, part of the adaption process and not considered to be FCRP
- Having regular thoughts or being pre-occupied about cancer recurrence or progression, treatment or other aspects of cancer, with or without deeper feelings of anxiety suggests moderate FCR
- Severe FCR can appear as uncontrolled worry about recurrence/ progression, anxious thoughts, emotional distress and interference with daily life. People cannot plan or move on in their lives, and can feel no confidence in the future



Dealing with FCR requires balancing a sensible awareness of the risk of recurrence with a plan to monitor your health while building wellbeing. To do this the following may help:

1. When uncertain, some people prefer more information, others prefer less. If you prefer more information, then talk with your oncologist about recurrence or progression. What is the probability of recurrence? What proportion of patients with your stage and type of cancer have a recurrence? When is it most likely to happen? What should you look out for? If progression, then what changes should you anticipate and when, and what can you do to maintain wellness? Your oncologist can give you some facts about this. Knowing this will help you better judge the risk of recurrence. If your oncologist is unavailable, seek a second opinion. You may call **HKU Jockey Club Institute of Cancer Care (JCICC)** for adviser
2. Place the focus of your attention outside. Avoid monitoring your body for "signs of cancer". Remember aches and pains have happened all your life before cancer and continue to happen after cancer too, maybe more frequently as treatments can leave long lasting effects on the body. Don't assume each pain means cancer
3. Adopt a healthier lifestyle:
 - Stop smoking – this is the single most important thing if you are a smoker
 - Significantly reduce and limit your alcohol intake. Ideally, quit all together, but if not have no more than one drink every third day
 - Diet - reduce or eliminate red meat. Replace with vegetable protein, such as tofu, beans, parsnips, fish and white meat. Make fruit and vegetable 80% of your diet. Eat a wider variety of foods. Eat some traditionally fermented products daily (yoghurt, kimchee, sauerkraut, tempeh, kombucha or kefir), eat more nuts and whole grains, such as red or black rice
 - Do regular, daily exercise. Join a programme, group or do it with family/friends. Try to do some vigorous exercise every day. Walk as much as you can, especially in the countryside
 - Reduce your stress as much as possible
 - Do the above step-by-step. Enroll your family to help achieve these

4. Learn to relax at will. To do this, you need to practice deep relaxation:
 - Make a set time and place each day where you will not be disturbed for 30 minutes that has a comfortable chair/sofa
 - Switch off your phone
 - Sit/lie, remain still and systematically relax each muscle in your body
 - Allow your mind to drift – just observe what happens. Don't judge or try to control your thoughts. Rather, just witness how your mind behaves
 - Remain awake but fully relaxed. When finished, slowly move and resume normal activities. Keep relaxed. This helps prevent stress and anxiety. The more you practice, the better you will get at relaxing.
5. Cancer forces many people to rethink what is important in life and report it being a very positive thing when they look back. So reassess your plans. What is important to you now? Make those things your priorities. Plan how to achieve them
6. Name your fears. What do you need to do to face each one? Are there people who can help you? Talk to them, family, friends, and professionals. Find out what your options are if you don't know. Make whatever arrangements are needed
7. Keep the lines of communication open. Maintain honest two-way communication with your loved ones, doctors and others after your cancer diagnosis. You may feel particularly isolated if people try to protect you from bad news or if you try to put up a strong front. If you and others express emotions honestly, you can all gain strength from each other

If you need further help, talk to your oncologist, doctor or call **HKU Jockey Club Institute of Cancer Care Hotline 3917 9606** and talk to one of the JCICC support staff who can assess and recommend further help.

