

Managing Psychosocial and Family Distress after Cancer Treatment



UHN

Information for cancer survivors

Read this pamphlet to learn:

- What psychosocial distress is
- What causes distress
- What you can do
- Where to get more information

Patient Education

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What is psychosocial distress?

Facing a serious illness such as cancer can be very stressful. You and your family may feel confused or distressed, and may not know what help and support there is available.

Cancer survivors can experience a wide range of feelings including:

- Fear
- Anxiety
- Sadness
- Anger
- Numbness (no feelings)

It is important to remember that these feelings are all normal and that you are not alone in having to deal with your feelings.

What causes distress?

Going through cancer treatment can be very hard for people. The effects of cancer are life-changing experiences and can affect your emotions and mood.

There is no right or wrong way to feel or react – everyone is different and people’s emotions can change over time. These changing feelings and emotions are part of the process for many people as they deal with their cancer.

Distress can be more pronounced at different times in the cancer journey. For example, you may have greater distress because you have fear of cancer coming back as you transition from active treatment, such as chemotherapy, to the follow-up phase of care.

Usually, it takes some time after cancer treatment to regain confidence and get used to these changes. Most patients report less distress about a year after cancer treatment ends.

What can I do?

After cancer, some people think life is not so much about “getting back to normal,” but more about finding what a “new normal” is for you.

After treatment, it is helpful to take things as they come and focus on adapting to change. Cancer can be life changing, and while recovery is very much possible, it is important to remember that it will take time to get back to the way things were, or to find a new “normal” that’s right for you.

During this process of change and recovery, there may be times when you may need the help of your family and friends to cope with the difficult emotions you’re experiencing. But there are things that you can do yourself to help you feel better.

If you are feeling afraid, anxious, angry or stressed, here are some things you can try:

Communicate.

- Stress and tension can often be released by talking to someone. How much you talk about your cancer depends on your personality and the people around you.
- Some people avoid talking about their fears, and worries while others feel more comfortable speaking to family and friends. There is no “normal” amount of communication. Unless you want to, you do not have to have to keep your thoughts or emotions to yourself just because you are finished treatment.
- The simple act of talking may help you to better understand your own feelings. If you live alone or don’t have a social network, talk to your family doctor or hospital staff about being connected to a support group offered by Gilda’s Club or Wellspring.
- There isn’t one right way to communicate about cancer. You may find that instead of talking to someone, it helps to keep a journal or a diary where you can freely express your feelings and emotions.

Exercise.

- Exercise is a good way to reduce stress and enjoy life more.
- By getting your muscles moving, you can help yourself focus on things other than cancer.
- Exercise can also reduce:
 - ✓ pain after treatment
 - ✓ insomnia
 - ✓ fatigue

This can further help reduce stress in many people.

- Exercise does not always mean going for a jog or lifting weights. Walking, taking the stairs or doing light housework are also good ways of exercising and can help manage your worries or anxieties.
- The Lebed Healthy-Steps class offered at ELLICSR is a fun program that does stretches and dance moves set to music. It is a healing exercise program designed to help you thrive. To attend the classes, call Barbara at 416-505-5578.

Use meditation and relaxation.

- Yoga, meditation and relaxation are some techniques that may help you lower stress by quieting your mind. Focused breathing, hypnosis, or imagery may also help.
- Princess Margaret Cancer Centre offers private, individually guided relaxation sessions that are available to all patients, free of charge. For more information, call Occupational Therapy at 416-946-4501 extension 5580.

Be creative.

- If talking about your feelings directly is not working for you, take up an old hobby or try a new activity that might give you a way to release your emotions.
- Art, music, or dance can give you the chance to express yourself in a different way.

Practice Problem-Solving Coping Steps

1. Define the problem.
2. Recognize how you feel about the problem. Accept your feelings.
3. Relax and try not to think about solutions for awhile.
4. Consider all possible solutions.
5. Try to imagine how other people might solve the problem or how to obtain information to solve the problem.
6. Evaluate pros and cons of each solution.
7. Arrange the solutions in a list with the least practical to the best.
8. Make a choice.
9. Briefly consider if there is another way to think about the original problem.

Get professional help.

Talk to your doctor about getting help from a professional counselor to help manage your distress.

If you are:

- having trouble concentrating
- being nervous or restless
- feeling or looking tense
- worried about "losing control"
- feeling uneasy and that something bad is going to happen
- having headaches
- being cranky or angry with others
- feeling tired or fatigue
- trouble sleeping or restless sleep

Know what to look for. Getting help is not a sign of weakness.

It is normal to have negative feelings when you have had cancer. Many people say they want to have the freedom to give in to their feelings sometimes. Remember, it is normal to have some bad days and it is healthy to accept your emotions as they come.

Some people believe that they got cancer because of something they did or did not do. Blaming yourself can cause extra stress and anxiety, and is not helpful to your recovery. Do not blame yourself. Remember, cancer can happen to anyone.

If you have fear of cancer coming back, here are some things you can try:

1. Keep a record of your appointments.

Go to all your medical follow-up appointments. Follow-up care means seeing a doctor for regular checkups. At these visits, your doctor will look for side effects from treatment and check if your cancer has come back.

It is important for your long-term health that you go to all these appointments, even if the hospital brings back unpleasant memories. Knowing what to expect after cancer treatment can help you and your family make plans, lifestyle changes, and important decisions.

2. Be informed.

Learn about your cancer. Some people want to know about the risk of cancer for their family. Others want to know what symptoms of recurrence to look out for.

Talk to your doctor and ask any questions you may have about your cancer experience. Having more knowledge may give you with a greater sense of control over your life.

3. Share your feelings.

People have found that when they share strong feelings like fear, anger or sadness, they are more able to let go of them. Some people talk to friends or family, other cancer survivors, or a counselor.

Wellspring (www.wellspring.ca/downtownTO) and Gilda's Club (www.gildasclubtoronto.org) offer programs that can help you connect with other survivors.

Even if you prefer not to talk to others, you can still sort out your feelings by thinking about them or writing them down.

4. Focus on Wellness.

Try to be hopeful. Sometimes this means looking for the good even during a bad time. Try to use your energy to focus on wellness and what you can do now to stay as healthy as possible. Eat healthy and avoid alcohol and other sedatives.

You can find the Canadian guidelines for healthy eating on this website:
www.hc-sc.gc.ca

ELLICSR Kitchen offers 2 classes on eating healthy.

1. From Plant to Plate is run by a chef and dietician who are joined by guests from local farms, restaurants, and other health and food focused organizations. Here you will learn how food is grown, and how to prepare your food.
2. The Survivor's Kitchen: Cooking for Health class is run by a chef and dietician who provide advice and great recipes to keep you eating healthy.

For more information about these classes and recipes visit
ELLICSRkitchen.ca.

5. Look at what you can control.

Put your life in order. Be involved in your healthcare by being informed and keeping your appointments. You can make changes to your life such as eating healthy and exercising. Some people have a schedule they follow every day.

These things can help you gain more control over your life and feel better.

How do I prepare for my appointment with my doctor?

If your feelings are too overwhelming or you cannot enjoy your everyday life anymore, you can talk to your doctor.

Before you see your doctor, take time to think about how distress is affecting your life.

Ask yourself these 5 questions and write some notes below:

1. Keep a diary every day for at least a week before your appointment with your doctor. Write down any differences in your mood and how you are sleeping.



2. How does this distress affect you emotionally (feeling sad, blue, anxious)?

3. How does your distress affect you physically (fatigue, difficulty functioning at work, daily activities)?

4. How does your distress affect how much you enjoy your life (doing social activities)?

5. In the past week, what have been the major triggers of my distress (examples: family, chores, emotions, fears, etc.)

Take this booklet with you when you go to see your doctor. Talk to your doctor about your answers. Let your doctor know how you feel. Only your doctor can help with some causes of your distress.

What can I expect after seeing my doctor?

Your doctor will talk to you about different options that may help.

Where can I find more information?

American Cancer Society

Website: www.cancer.org

Topic: Distress

Canadian Association of Psychosocial Oncology

Website: <http://capo.ca/docs/bookletREVISED.pdf>

Canadian Cancer Society

Website: www.cancer.ca

Topic: Life after Cancer

Canadian Mental Health Association

Website: www.cmha.ca

Gilda's Club

Website: www.gildasclubtoronto.org

Oncolink

Website: www.oncolink.org

Topic: Adjustment to Cancer - Anxiety and Distress

Princess Margaret Hospital

Website: www.theprincessmargaret.ca

Topic: Psychosocial Distress

Wellspring

Website: www.wellspring.ca

Remember

- ✓ Communicate.
- ✓ Exercise.
- ✓ Use meditation and relaxation.
- ✓ Keep a record of your appointments.
- ✓ Be informed.
- ✓ Share your feelings.
- ✓ Focus on wellness.
- ✓ Look at what you can control.