

# The Emotional Facts of Life with Cancer



A GUIDE TO COUNSELLING AND SUPPORT  
FOR PATIENTS, FAMILIES AND FRIENDS

*The Emotional Facts of Life with Cancer: A Guide to Counselling and Support for Patients, Families and Friends* is the first initiative in a unique partnership between the Canadian Association of Psychosocial Oncology (CAPO) and TransCanada PipeLines Limited. Collaborative, meaningful community partnerships are an integral part of TransCanada's community investment program.



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# INTRODUCTION

## **Purpose of the guide**

The purpose of this booklet is to help you understand how professional counselling and support can help you cope with cancer. Very often, we are not aware of how deeply a disease affects the human spirit and emotional health. The information contained here is intended to lighten the burden of people who are living with cancer, and their families, by describing what psychosocial support can offer. In this way, we hope to give realistic and useful information about getting help with the emotional distress that is a normal part of the experience of having cancer.

## **How to use this guide**

For patients at any stage of your experience with cancer, this guide will help you to understand whether the help of a professional might be of value, and to see how others have been helped in turning their personal health crises into a chance for hope and healing. For families, caregivers and friends—some advice and information is aimed directly at your experience, and can guide you to the help that you may need. The guide will help you to understand and anticipate the emotional distress issues faced by people living with cancer. It will also remind you that emotional distress is very much a part of the experience of those who love and care for someone with cancer.

We have organized this guide to help you with some of the questions, concerns and common situations you may face. The guide will introduce you to the support provided by professionals who specialize in dealing with cancer. It gives an overview of how counselling works, its benefits, and the unique needs of cancer patients and their families.

A note of explanation about our terminology: we have used the

word “patient” to describe the person with cancer, although this term may also apply to people who are long-term survivors or people not in active treatment. When we use the term “family” we do not limit it to the relatives of the patient, but also include a range of relationships: parent, spouse, relative, same-sex partner, friend or caregiver.

### **Author’s note**

Thirteen years ago I received my cancer diagnosis, while I was an architecture student on a work term in Toronto. In my doctor’s office, I was the model of strength and optimism because I thought that’s what he wanted to hear. Outside the office I struggled with loneliness, depression, the futility of asking “why,” the financial stress. I didn’t have the language (or the courage) to say, “I’m having trouble coping. Is there someone I could talk to about how I am dealing with this?” Even though I had lots of friends, I didn’t feel like they understood because, after all, how many students have any real inkling of what it’s like to have cancer.

I wish I’d known at the time about counselling services available for cancer patients. I suspect that counselling services—and patients’ attitudes—have come a long way since I was diagnosed. Patient support resources have become increasingly integrated into cancer centres as more compassionate approaches to health care become acceptable and desirable. More and more of us know that asking for trained professional help is not a sign that we are weak or crazy; it means we are human.

The difficult reality is that a cancer diagnosis can be as devastating emotionally as it is physically. It is my hope that this book will give all cancer patients and families the know-how to reach out for support when it’s needed.

# What is Professional Support?

**“A lot of people** have the view that psychologists and psychiatrists are not too far from being witch doctors. They don’t understand what counsellors actually do. The job of the counsellor isn’t to solve patient problems. Instead, talking to counsellors may suggest directions that cancer patients can explore to find their own way through difficulties.

I was one of those classic men who don’t have any problems and won’t ask for help. During my treatment for prostate cancer I’d been able to cope really well. But suddenly, months later, with the hospitalization of my wife it seemed everything was falling apart, and I got hit with depression very seriously. One day my oncologist asked me how things were going. I said to him, “Sometimes I have some pretty black days,” and he turned around and came back with a counsellor. I realized then there was help at hand, and I was ready for it, because the black days were really black.

It was a real shock to me to get to the point where I had to admit I needed outside help. I’d always prided myself on being able to discipline myself to get things done—I had finished my Masters degree in one year, and my PhD in three—I was always able to set ridiculous schedules and get things done. My black days started with the realization that the things that got me that far in life simply weren’t working any more. I was trying to use that attitude of self-discipline to stay healthy, but I still felt rotten and realized I couldn’t handle it, and was fortunate to find a counsellor who could get me to start accepting help.”

—Ed Schwarz, prostate cancer patient



## **Professional Support Resources**

### **What is psychosocial oncology?**

The word “psychosocial” may seem intimidating, but it may help to break down what it means. The root of “psycho” means relating to the mind or the psyche, and the “social” part is about the relationships people have with family and with society. “Oncology” means the branch of medicine that deals with cancer. In other words, psychosocial oncology is a specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of very human needs that can improve quality of life for people affected by cancer.

### **Why do counsellors for cancer patients require special training?**

Psychosocial oncology professionals are trained to help you with your fears and strong emotions. They are specially trained to deal

with cancer patients because the physical effects of cancer are uniquely difficult, and nearly impossible to separate from the emotional distress they cause. For instance, counsellors may deal with issues associated with brain tumours such as depression, anger and changes in personality. They are also experienced in addressing the identity, self-esteem and body issues often associated with the disfigurement caused by surgical treatments for head and neck, breast and other cancers. Their training gives them insight into the social issues faced by individuals with varying social networks for coping with cancer: people who live on their own, recent immigrants, people of all ages, from children to the elderly, and people of different sexual orientations.

Another key aspect of their training is as problem-solving navigators. This role often includes helping patients and families through available information, acting as a gateway to personalized needs such as support groups, financial resources, books and information. Many cancer patients find the overwhelming quantity of information in some areas to be just as daunting as the lack of information in others (particularly in hard-to-talk-about areas such as sexuality and cancer). Counsellors are knowledgeable about what information is available, and can help you determine what additional information you might need and when. For instance, they may be able to point young mothers to information on how to talk to children about cancer, or recommend a video on sexuality for a prostate cancer patient.

Counsellors are also experienced in helping patients and families with practical issues such as financial resources. They can give you a sense of what financial help may be available, and help fill out forms to meet the complex eligibility criteria required for many financial support applications.

## **Types of Counselling**

Counselling is part of an integrated team approach to treating patient needs in a holistic way. Different individuals may be available for counselling depending on the services in the community and your level of need. Most cancer centres offer individual counselling by psychologists, psychiatrists, social workers and chaplains, as well as pain and symptom management nurse and physician specialists.

Counsellors do much of their work one-on-one with patients, but



they also work with families. Some departments offer group counselling, or peer support groups led by a trained professional. Dieticians who will customize a nutrition plan to your individual needs may also work as part of the counselling team. Advanced practice nurses with specialized knowledge and skill related to cancer also provide counselling.

The counsellors in settings where cancer treatments are given are required to have specific psychosocial oncology training. Counsellors understand the physical and biological aspects of cancer treatment, and their specific impact on your overall well-being.



## **The Counselling Process**

If you've never had an experience with professional counselling, you may wonder how it works. Most counsellors use a fairly well defined three-stage process. The first stage involves exploring and identifying concerns. The next stage is about understanding how these concerns relate to your life, how you think, and your life history. The third stage focuses on taking action about your concerns, or learning to live with them in a different way. Here's a little more detail on what happens at each stage.

### **Exploration**

You begin counselling by telling your story. Cancer may be changing many things in your life. You may be able to cope with

some of them; others may be beyond your coping ability. The stress of cancer may affect your personal relationships, your sense of self. You may have other worries, and as you struggle to deal with these changes, intense emotions may surface. The exploration process helps you become aware of all the issues you are dealing with and their place and importance in your life.

## **Understanding**

The next stage of counselling is to understand how you feel, think, react and behave in relation to your concerns. Getting a sense of both what is working and what is not can help you to regain a sense of control. Practical issues are often easier to understand and resolve than deeply felt internal ones. However, examining and working through your feelings and behaviours promotes a clearer understanding of what is positive and health promoting for you, and what is not.

## **Action**

After issues become clearer, you may decide if, when and where to take action to reduce difficulties or regain control in a situation that may seem overwhelming. Action can take many forms. Here are a few examples:

- Making a list of questions to ask your doctor
- Taking an active part in treatment decisions
- Accepting help and asking for support from family and friends
- Setting achievable goals and planning how to reach them
- Re-establishing a sense of meaning and purposefulness in life
- Learning new skills to cope with your fears and stresses
- Changing patterns of living or relationships that are unsatisfying

## **Counselling and Confidentiality**

All health professionals in Canada are bound by a code of ethics and legislation that guarantees confidentiality. Confidentiality means that your discussions with a counsellor will not be shared with others. The exceptions occur when patients threaten to harm themselves or others, or when incidents of child abuse are disclosed. In these cases health professionals are legally bound to ensure that people are protected. This may require informing authorities.

## **Finding Counselling Resources**

The trained professionals who provide a range of services to cancer patients are often located in the Psychosocial Oncology or Supportive Care and Counselling Services departments of cancer centres, hospitals and clinics. The counselling services are usually free of charge, as they are considered a core service in cancer care.

Sometimes newly diagnosed patients receive a new patient information package. It may provide information services, including ways to get psychosocial support (which may be called a number of different things: psychosocial oncology, counselling, professional support, social work). Your family doctor, oncologist or oncology nurse may also fill you in on what kinds of services are available, and make a referral on your behalf, especially if your emotional distress is visible to them. However, many people don't show outward signs of distress, so don't be afraid to self-refer, as only you know what you are going through inside.

Patients and families can self-refer by directly calling the cancer centre, clinic or hospital to ask for an appointment. Everyone, cancer patients as well as their family members, is entitled to receive support in coping with cancer at their centre. If it is not convenient for you to go to your cancer centre, counselling can sometimes happen by telephone. There may also be private practitioners in your area, to whom you can be referred by your family physician, and the cost may be covered by provincial health insurance or extended health insurance plans.

## **Programs Offered by Psychosocial Resources**

Programs and seminars that are geared to the needs of people living with cancer may be available to you. These programs may include general seminars on coping with cancer, smoking cessation, sexuality, care for the caregiver, stress management, and how to talk to children about cancer. Some offer sessions for children and teens who have parents with cancer, retreats for patients, meditation and relaxation therapy programs, art therapy, workshops and therapeutic play for children who have a family member with cancer, etc. Some programs focus on the needs of people with a specific type of cancer, such as breast or prostate cancer. You need to talk with the health professionals who are involved in your care, and they will guide you on the programs available.

# Do I Need Professional Support?

## SELF-ASSESSMENT QUESTIONNAIRE FOR PATIENTS

The following questionnaire may help you determine whether you might benefit from professional counselling. Every patient experiences some of these symptoms; there are no right or wrong answers.

*During the past two weeks:*

1. *I have felt anxious or worried about cancer and the treatment I am receiving.*

Not at all   1   2   3   4   5   All the time

2. *I have felt depressed or discouraged.*

Not at all   1   2   3   4   5   All the time

3. *I have been irritable or unusually angry and I have not controlled it well.*

Not at all   1   2   3   4   5   All the time

4. *My sleeping habits have changed.*

Not at all   1   2   3   4   5   Very much

5. *I have experienced a change in my appetite.*

Not at all   1   2   3   4   5   Very much

6. *I have had difficulty concentrating at work or at home, or on routine things such as reading the newspaper or watching television.*

Not at all   1   2   3   4   5   Very much

7. *Cancer and its treatment have interfered with my daily activities.*

Not at all   1   2   3   4   5   Very much



8. *Cancer and its treatment have interfered with my family or social life.*

Not at all    1    2    3    4    5    Very much

9. *Cancer and its treatment have interfered with my sexual life.*

Not at all    1    2    3    4    5    Very much

10. *Pain and discomfort have caused me to limit my activities.*

Not at all    1    2    3    4    5    Very much

11. *Cancer has caused physical, emotional or financial hardship for me.*

Not at all    1    2    3    4    5    Very much

12. *Cancer and its treatment have caused changes in my physical appearance and this concerns me.*

Not at all    1    2    3    4    5    Very much

13. *I have had difficulty coping with the stress I have experienced.*

Not at all    1    2    3    4    5    Very much

14. *My quality of life during the past two weeks has been:*

Excellent    1    2    3    4    5    Very poor

**If you find that many of your answers are in columns four or five, you may be experiencing significant distress and should consider discussing your feelings with a counsellor.**

## SELF-ASSESSMENT QUESTIONNAIRE FOR FAMILY AND CAREGIVERS

The following questionnaire may help you as a family member or caregiver to determine whether you might benefit from professional counselling.

1. *I feel anxious or worried about my loved one's cancer diagnosis/treatment.*

Not at all   1   2   3   4   5   All the time

2. *I feel depressed or discouraged.*

Not at all   1   2   3   4   5   All the time

3. *I have been irritable or unusually angry and I have not controlled it well.*

Not at all   1   2   3   4   5   All the time

4. *My sleeping habits have changed.*

Not at all   1   2   3   4   5   Very much

5. *I have experienced a change in my appetite.*

Not at all   1   2   3   4   5   Very much

6. *I have had difficulty concentrating at work, home or school, or on routine things such as reading the newspaper or watching television.*

Not at all   1   2   3   4   5   Very much

7. *My loved one's diagnosis/treatment interferes with my daily activities.*

Not at all   1   2   3   4   5   Very much

8. *My loved one's diagnosis/ treatment interferes with my family or social life.*

Not at all   1   2   3   4   5   Very much

9. *My loved one's diagnosis/ treatment interferes with sexual life.*

Not at all   1   2   3   4   5   Very much

10. *My loved one's diagnosis has caused financial hardship to our family.*

Not at all   1   2   3   4   5   Very much

11. I have difficulty keeping up with my caregiving activities.

Not at all    1    2    3    4    5    Very much

12. I have difficulty coping with the stress that the entire family is experiencing.

Not at all    1    2    3    4    5    Very much

Everyone experiences some of these symptoms, to varying degrees, part of the time. If you find that many of your answers are in columns four or five, and you are having difficulty dealing with your situation on your own, you may be experiencing significant distress. Please do not hesitate to discuss your feelings with a psychosocial oncology counsellor.

*Based on tools developed by the Tom Baker Cancer Centre Department of Psychosocial Resources and Northwestern Ontario Regional Cancer Centre Supportive Care Program, with permission (partly derived from the Functional Living Index: Cancer and from the EORTC Core Quality of Life Questionnaire).*

## COMMON QUESTIONS

### How common is emotional distress in cancer patients?

Between 35 percent and 45 percent of all cancer patients\* experience significant emotional distress (including depression). The number reaches 70 percent for palliative care patients.\*\*

### How common is emotional distress in families and caregivers?

Several studies\*\*\* have found that family members experience as much, if not more, distress as the patients. Family members typically experience fear of loneliness, a sense of helplessness, lifestyle disruption and uncertainty. Family members struggle with the possibility of death of their loved one, alternatively trying to avoid thoughts of death.

## **What is the cost of counselling?**

Because the services of a psychosocial professional are seen as an essential part of the care of cancer patients, caregivers and families, there is usually no direct cost when services are sought at a cancer treatment facility.

## **I am living in a small town and support services are not available. What should I do?**

Even though you live in a small town, you can still access the services at your cancer centre or hospital clinic on your follow-up visits. On your next visit you may want to arrange to meet a counsellor who can help evaluate your needs and recommend professionals or support services in your community. A number of options may be available in your area, such as:

- Peer support groups
- Counselling from a family doctor
- Employee Assistance Programs (EAP)
- Telephone Peer Support or Telecare Programs
- Counsellors and psychologists in private practice in your area
- Programs run by Community Health Agencies
- Hospital-based social work programs

## **Does going to a counsellor mean I'm mentally ill?**

Many people feel there is a stigma to seeking counselling or that it means that they are mentally ill or weak. Going to a counsellor means neither—it means you are rallying the supports you need to cope with difficult situations for which no other experience in your life will have prepared you. It is helpful to think of seeking support as a sign of strength; you have recognized your difficulties and need to do something about them. Counselling is a way of helping you to find solutions and maintain control over the things you can control. There will likely be times when emotional distress is a normal reaction to your situation, but it doesn't mean that reaching out for the help you need is a sign of weakness.



## **Why doesn't my regular oncologist provide this support?**

A comedian once described cancer as a "team sport." A psychosocial counsellor is part of the team along with oncologists, nurses and other health professionals. Each has specialized knowledge and skill and all work together to help you meet physical and emotional needs. Counsellors focus specifically on the emotional and psychological impact of cancer, whereas treatment is the main area of your oncologist's expertise.

## **Who should I talk to, and what do I say if I think that I want counselling?**

It's often easiest for patients and family to talk with someone they know, such as a family doctor or oncologist. The words are often difficult to find because many people become quite emotional about asking for this sort of support. It may help to use very simple words: "There are things that I need to talk about with a counsellor," "I am feeling overwhelmed, I'd like to talk to somebody."

Very often people need emergency support during a time of crisis. For instance, you may feel left hanging with emotionally difficult conclusions after a conversation with a doctor, and not know where to go or what to do. In this case it is best to go directly to the psychosocial oncology department, whose staff have experience in crisis intervention and usually have someone available to provide counselling if you find yourself distraught and in need of help.

## **How do I make arrangements for family members to get counselling?**

Like patients, family members can usually arrange their own appointment without a referral from another doctor. Often family members are told when they bring a patient for help that the same support is available for them, and they can assess whether it would be beneficial.

# The Unique Emotional and Social Needs of the Cancer Patient

**“ For me,** my counsellor-led support group is a place to go and say, ‘Cancer stinks.’ A place where I can openly express my feelings about this horrific disease and not keep them bottled up and wreaking havoc within me. It’s a place where you talk about the what-ifs. Most people don’t like talking about death. Spouses and family members can’t or won’t deal with the possibility that you may not be around in the foreseeable future. They don’t want to deal with any more pain, and don’t understand why you want to keep reliving this disease.

I’m constantly hearing you have to be positive. But you can’t ‘pretty up’ this disease. You have to face it, deal with it, and you have to think about it.

When I’m faced with depression, sleeplessness, anxiety, the last thing I need is a pep talk. Intellectually I know that feeling positive is good for your mental health and yes, I will get there. But for now, I need a place where I can allow myself to feel miserable, and down, and depressed, a place where I’m not protecting those around me from cancer. A place to deal with the tough issues that come with cancer. ”

—*Rosa McDonald, breast cancer patient*



## How Counselling Helps Patients

The greatest benefit of psychosocial care is that patients and families may experience a significant improvement in quality of life. Without emotional support, people can struggle unguided with issues of their own mortality, with complex questions about quality and quantity of life, and with the burden of coping with treatments and suffering, both physical and emotional. Through counselling, you may be better equipped to enjoy a fulfilling and productive life.

The experience of cancer can have the effect of putting a magnifying glass over one's life: it tends to bring out the good, amplifying the strong supportive bonds with friends and family. However, the impact of the illness can also exaggerate the difficulties of everyday life, related, for instance, to marital problems or to family communications issues. These may add to the considerable anxiety of living with the cancer itself.

Patients who receive emotional support are better equipped to cope with the relationship problems and the fear, depression and anxiety that are a normal part of dealing with cancer. Counselling can help to ease tensions within the family, and help with the complicated task of getting financial aid, making it easier for the person to get on with the important job of coping with the disease and its treatment.

For many people, one of the greatest benefits of counselling is that it is an opportunity to have their problems given individual attention. Counsellors have a deep sensitivity to the fact that the life of every person with cancer is unique. Counselling work is about tailoring an individualized approach to each situation.



## The Unique Needs of the Cancer Patient

Supportive needs often fall into five main categories: informational; psychological (needs related to emotions and coping); social (communicating with people); practical and financial; and spiritual (relating to belief and the need for hope).

### Informational Needs

One goal of psychosocial support is to make sure that individuals and families have access to accurate information to answer whatever questions they have. Counsellors can recommend good information sources and advise on how to evaluate and use available information, including:

- Weighing the benefits and side-effects of treatment before you make decisions
- Getting information about your illness and managing side-effects, and learning about things you can do to help healing
- Pointing to other resources that may help you cope—complementary therapies and other types of support that may be available and useful to you and your family, such as peer support groups, community resources, palliative care, etc.

### Psychological Challenges

Counselling can help to confront some of the psychological challenges of a cancer diagnosis, including:

**Dealing with Fear.** Many individuals experience fear and constant or intrusive thoughts—about having the disease, fear of losing independence and control, fear of cancer spreading or recurring, fear of pain, of the unknown, of dying. Helping patients manage fear (and all its emotional and social consequences) is one of the most important jobs of psychosocial professionals.

**Managing Anger.** People often find themselves angry about having the disease, at not getting clear answers, at delays and obstacles in the health care system.

**Opening Up.** Counselling offers a place to express all emotions, positive or negative. Many patients feel the need to express themselves fully, and to be in touch with feelings to face their individual situations. This process may also involve re-evaluating life values and the importance of certain goals.

**Guilt.** Feelings of guilt may emerge for many reasons: about the cause of illness, about not being able to look after other family

members, about the impact on children, if hereditary elements are found.

**Depression.** Depression can be related to the effects of the cancer or its treatment, a normal response to coping with the emotional distress around cancer, or already present and amplified by the condition.

**Stress.** Counselling about stress may involve recognizing signs such as physical tension or panic attacks, and developing appropriate stress-reducing techniques—meditation, relaxation, coping skills, exercise programs, leisure pursuits.

**Identity and Self-Image.** You may need to adjust to dramatic issues of identity and self-image brought on by cancer and its treatment (such as loss of hair or disfigurement), or to your changing role within the family unit, or your identity as it relates to your ability to work. A sense of loss can be lessened through identifying and grieving what may have been altered or lost through the cancer experience.

**Fatigue.** Fatigue is the most common symptom associated with cancer and its treatment, and can be caused by physical factors, such as pain or chemical changes associated with the disease or its treatment, or nutritional problems associated with weight loss or diminished appetite. It can also be the result of emotional factors such as worry and anxiety; or of other factors—trying to do too much when your energy reserves are depleted. The health care team, including counsellors, can help you manage fatigue with a self-care plan that allows your body to restore its vigour by limiting energy expenditures, attending to good sleep habits, arranging help with exhausting tasks, maintaining a mild exercise program, and practicing quiet times of meditation.

**Anxiety.** Counselling can provide an opportunity to talk about death and dying and help to find ways of reducing fears and alleviating anxiety.

## **Social Issues**

Counselling can help to deal with some of the difficult social dimensions of a cancer diagnosis, which include:

**Communication Issues.** How to talk to children about cancer, and how to deal with their reactions; communication with elderly parent or family members with a different cultural heritage.

**Addressing Family Issues.** Discussions of how the family can be

supportive, and involving them in counselling if useful.

**Changes in Relationships.** Dealing with changes in other people's attitude toward you, especially close relationships; dealing with changes in sexual feelings, changes in relationships, anxiety about fertility, problems with sexual functioning, and the need for information.

**Other Communication Issues.** Planning how to talk to your employer and co-workers; how to develop a good working relationship with your physician.

## **Practical and Financial Issues**

Some people may experience a change in lifestyle because of a lower income, or have to deal with out-of-pocket expenses for medications, supplies, transportation or accommodation. Support may take the form of advocacy, referrals, assistance in reorganizing finances, exploring and applying for financial assistance, solving transportation and accommodation problems, and providing information. Counsellors can also provide guidance on practical issues such as living wills, do not resuscitate orders (DNRs), power of attorney, and insurance.

## **Spiritual Questions**

Spiritual beliefs may range from organized religion to less formal systems of belief. Spiritual needs often become more important in the lives of cancer patients. People who don't regularly belong to various faith communities often seek out spiritual support at different times of need. For many cancer patients, faith gives both hope and meaning to lives in the turmoil that is typical to life with cancer. Issues of spirituality often surface in the counselling process, or can occur with a chaplain, who is often part of the counselling team. Spiritual needs often include:

- The need to find meaning in the experience
- Exploring feelings about death and dying
- The search for hope and appreciation for life

## **Changing Needs**

Needs vary at different stages of your illness.

**Diagnosis.** Counselling during diagnosis may help with the shock, anxiety, fear and sense of loss of control, help you adjust to

becoming part of a complex health system and prepare you for what lies ahead.

**Treatment.** Throughout treatment, fear and anxiety usually dominate patients' emotions. Counselling can prepare you for the treatment and its side-effects, including your emotional responses. Very often conversations cover pain and symptom management, how to decide about which treatment option is best for you, the use of alternative or complementary treatments and relaxation strategies such as meditation, relaxation and imagery, and may involve consultation with a dietician to suggest a plan of care. Counsellors may also become involved to help patients with fears about stressful medical procedures (needles, enclosed places) that may interfere with treatment.

**Survivorship.** The time after treatment ends, and subsequent "survivorship," present their own unique set of challenges for the person with cancer. After treatment, individuals may feel "dropped" from the system, ill-prepared for the transition between the intensity of care and treatment and the return to "everyday" life. At this time counselling may help you to reflect on the idea of being in remission, and the emotional and practical challenges of this transition.

**Recurrence.** Recurrence of cancer can be accompanied by a sense of hopelessness, a dread of further treatment and side-effects, distress and an escalation of the fears that the person feels upon first diagnosis.

**End of life.** Many people at the end stage of their illness begin to grieve, and have a sense of mourning their own deaths that may be accompanied by depression and acute sadness. Counselling can ease the heavy burden of this spiritual pain. It can give guidance on how to accomplish the things that will contribute to a sense of a meaningful life, whether it is through coming to terms with suffering, reviewing the meaning of one's life or helping to ease communication with family members and loved ones. Occasionally unresolved emotional issues can result in intractable physical pain, sometimes called "soul pain," or "psychic pain," which must be looked at in both its emotional and physical dimensions as part of the holistic treatment of patient needs.

# The Benefits of Counselling for Family and Caregivers

**“In November 2001**, my partner Lou received a cancer diagnosis. He died in February of 2002. During those four months he spent half the time in the hospital and the rest at home. The physical demands were far beyond what I had imagined, but the emotional demands were the most exhausting. The day after Lou died I connected with the chaplain at the cancer centre, who suggested that I might want to meet with a counsellor.

I was paralyzed in all sorts of ways. For example, the first day I tried to go back to work, I saw someone in the hall who I'd known for years, and realized I couldn't remember her name. Had I not gone through counselling, I would probably still be sitting at home. Counselling was a way of beginning to be able to talk about my experience, to tell and retell my story. It helped me to heal, and to make me as functional as possible.

I experienced a lot of irrational guilt, which was really debilitating. I couldn't have talked about those issues to anyone else. When I tried, it was counterproductive. In counselling there is safety and the freedom to be completely open. It's invaluable to talk to someone who can say with some authority, you're not losing your mind, and this is something that other people have gone through. I was able to arrive at a point where now it's manageable, most days. Though I have many wise and supportive friends and family, I needed that professional perspective. Being able to talk to someone who professionally understood was a real godsend.”

—*Scott McCormack,*  
*caregiver and partner of a cancer patient*







## **Emotional Distress in Family and Caregivers**

The emotional distress experienced by family and caregivers can be just as intense or even more intense than the patient's. Nearly half of all caregivers experience some form of depression, as well as physical and emotional exhaustion brought on by the intensity of providing care. Professional counselling can lessen this distress, from the early stages of diagnosis and treatment, right through grieving and bereavement in the case of loss of a loved one.

## **Benefits of counselling for family and caregivers**

Many family members consider one of counselling's biggest advantages the fact that they can express pent-up feelings and emotions which are often tightly under control when they're with the patient or other family members. Often, families and caregivers feel helpless when faced with the serious illness of a loved one. They aren't sure what to do, what actions or words are

appropriate. Professional support helps to overcome these feelings of helplessness, to give strategies to cope with feelings, and a realistic idea about what can and cannot be done in any given situation.

Often families and caregivers want to be very positive, caring and upbeat. This can place further strain on the family, as it allows no room for the sadness that is a very real part of everyone's experience of cancer. Family members and caregivers often react to their own distress by trying to be proactive; however, if their ideas don't mesh with wishes of the patient this can be a source of tension. The lack of meaningful communication can leave the patient feeling misunderstood and angry, and the family member feeling unappreciated and isolated. Counselling can be useful to work out some of these issues and ease family tensions, and play a very important role in aiding communication between patient, caregiver and family.

### **The importance of care for the caregiver**

Counsellors recognize that care for the caregiver is integral to the care of the patient. Often caregivers need emotional support and counselling to be effective in their changing roles. Taking on the role of caregiver introduces a range of challenges, which have to do with self-management, sexuality, role changes, physical exhaustion, and emotional distress. Often the spouse or partner experiences higher levels of distress than the patient, yet may not feel entitled to these feelings. It is important to acknowledge that caregivers and family have very different stresses and needs than patients. While the person with cancer must focus on getting well and is the focus of attention, the caregiver must deal with everything and bear the burden of both the emotional and practical disruption. The enhanced responsibilities of running a home, dealing with financial pressures, taking care of children, acting as a source of information for family and friends, and maintaining a career are just a few aspects of this juggling act.

Professional counselling can provide strategies to achieve meaningful communication within the family, validating the role and needs of each family member. Very often caregivers need permission to take care of themselves, and counselling can underline the importance of caring for the larger human environment to best care for the patient.

## Helping the Family to Cope

Family and caregivers face many unique situations in which counselling can help to manage their emotional distress, including:

### **Young children with a parent with cancer**

Children can benefit from counselling either directly—with individual or group counselling—or indirectly, where parents seek out counselling to come to terms with how cancer in the family might affect their lives. Often we find it difficult to talk to children about a parent’s cancer, torn between the instinct to protect them and the desire to be honest. Counselling can help parents evaluate the amount of information that a child is able to absorb, and also help children come to terms with their fears and emotions. Counsellors may be able to point parents to appropriate resources, including material for parents to read with their children.

Children, like all the people who love and count on you, should know if you are suffering from cancer. If loved ones are denied this information, they may not understand the changes in your physical and mental state. Children are very attuned to changes, whether they are discussed or not, and often become anxious when they sense something is wrong but don’t understand what is happening.

Children may be affected by the fear of the unknown that is part of a cancer diagnosis, and by the strains that cancer places on everyday life—how other children and siblings react, the strains on marriages and financial situations that children invariably pick up on. Just as every family is different, each child will react differently, and counselling can respond to these unique needs.





### **Adult children with parents with cancer**

Adult children of parents with cancer often find themselves in the predicament known as the “sandwich generation,” simultaneously looking after ill parents but also trying to raise their own families—and are often torn between the two.

### **Children with cancer**

When children are diagnosed with cancer, particularly tough emotional issues emerge for their parents: the tragedy of watching a child suffer, the sense of unfairness that a child with cancer is out of the natural sequence of things, a sense of guilt that they cannot bear the burden of suffering in their children’s place. Parents often feel deep angst at bringing children for treatment, knowing it is the right thing to do medically but feeling intense anxiety at causing their children pain. Parents must also cope with the effects throughout the family: the extra demands of time it places on stretched families, the consequences of how other children in the family react, the strain it can put on relationships and finances.

### **Grief, mourning and bereavement**

It is natural to grieve the death of a loved one before and after their passing. When the grief occurs in anticipation of death, it is called anticipatory grief; mourning and bereavement occur after.

Bereavement support for family and caregivers is an important part of the work of psychosocial counsellors.

## SOURCES

- Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. *J National Cancer Institute* 1993; 85: 365-376
- \*\*\*Blanchard CG, Albrecht TL, Ruckdeschel JC. The crisis of cancer: psychological impact on family caregivers. *Oncology*. 1997 Feb; 11(2): 189-94
- Bonevski B, Sanson-Fisher R, Girgis A, Burton L, Cook P, Boyes A. Evaluation of an Instrument to Assess the Needs of Patients with Cancer. *Cancer* 2000 88 (1) 217-225
- Department of Psychosocial Resources, Tom Baker Cancer Centre. Counselling & Support for patients, families and friends. Feb 2002
- \*\*\*Farrell B, Ervin K, Smith S, Marek T, Melancon C. Family Perspectives of Ovarian Cancer. *Cancer Practice* 2002 10(6) 269-276
- Finkelstein DM, Cassileth BR, Bonomi PD, et al. A pilot study of the functional living index-cancer (FLIC) scale for the assessment of quality of life for metastatic lung cancer patients. *Am J Clin Oncol* 1988; 1: 630-633
- \*\*Portenoy RK, Thaler HT, Kornblith AB, et al. Symptom prevalence, characteristics and distress in a cancer population. *Qual Life Research* 1994, 3:183-189
- \*\*\*Vachon M. Psychosocial needs of patients and families. *J Palliat Care* 1998 14(3) 49-56
- \*Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The Prevalence of Psychological Distress by Cancer Site. *Journal of Psycho-Oncology* 2001 10(1) 19-28

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