

Counselling and Support for People with Cancer, Families and Friends

CancerCare Manitoba
Revised May 2002

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OUR MISSION

CancerCare Manitoba

CancerCare Manitoba is charged by an act of the legislature of Manitoba with responsibility for cancer prevention, detection, care, research and education for the people of Manitoba.

As a centre of choice, CancerCare Manitoba is dedicated to excellence in cancer care, to enhancing quality of life for those living with cancer and blood disorders, and to improving control of cancer for all Manitobans.



Department of Psychosocial Oncology

- *Enhance the psychological, social, emotional and spiritual well-being of people affected by cancer;*
- *Generate new knowledge about the psychosocial effects of cancer and share our knowledge and expertise with others;*
- *Assume leadership for the coordination and equitable access to psychosocial resources in Manitoba;*
- *Ensure services are effective and delivered in an efficient and fiscally responsible manner; and*
- *Provide a stimulating and supportive environment for our staff, colleagues and associates.*

WHAT IS THE DEPARTMENT OF PSYCHOSOCIAL ONCOLOGY?

The Department of Psychosocial Oncology is made up of social workers, psychologists, psychiatrists, and others who are specially trained to help you and your family cope with the emotional, psychological and social stresses which often arise as a result of cancer and its treatment.

The name of our department may sound confusing; however, the following pages explain how we can help you adjust to the diagnosis and prepare yourself for living with cancer.

Some forms of cancer may be readily cured with little disruption to you or your family. At other times, cancer may require major adjustments by you and those close to you. People who have been diagnosed with cancer often describe their experience as an emotional roller-coaster. You may feel as if your life has been turned upside down, and that the future seems uncertain.

At this time, talking about your feelings, worries, hopes and fears is often more helpful than keeping them inside. Experience and research show there are many practical steps you can take to cope with a difficult situation and regain a sense of control. A professional counsellor can provide a safe and confidential place to talk and can help you turn a personal health crisis into a chance for hope and healing.

Just as you are more than a collection of cells, coping with cancer is not merely a matter of coping with physical illness. Fear and the changes demanded of you can feel overwhelming. Treatments for some types of cancer may continue for long periods and may have side effects that tax your coping abilities.

A sense of loss of control, anxiety, sadness and anger are all normal responses. It is not just your physical body that goes along for tests, check-ups, surgery, chemotherapy, or radiation treatments. These experiences have a profound effect upon feelings and emotions.

It makes sense to take care of your anxieties and emotional well-being by reaching out for help when you need it.

The purpose of this booklet is to help you understand the role counselling services may play in your overall cancer treatment program. Counselling is part of the care provided at both CancerCare Manitoba Units (MacCharles and St. Boniface) and is offered at no cost by the Department of Psychosocial Oncology.

We hope that this booklet will be useful to you on your journey in dealing with cancer.

COUNSELLING CAN HELP YOU

Cope with Reactions to Cancer

- anger at having the disease
- fear of cancer
- changes to your body
- anxiety about treatment
- fear of cancer recurring
- anger at not getting clear answers
- loss of control
- feelings of guilt
- wondering if life will ever seem normal again
- adapting to side effects (e.g. fatigue)

Address Family Issues

- family relationships
- how the family can be supportive
- role changes within your family
- talking with children
- helping children cope with changes/fears
- intimacy and sexuality

Explore Personal Issues

- assess relationships, career or leisure pursuits
- clarify values, goals and priorities
- make the most of your life
- explore the meaning of cancer
- explore spiritual issues

Confront Practical Issues

- obtain information about financial resources
- plan how to raise issues with your doctor
- plan how to talk to your employer and co-workers
- solve transportation and accommodation problems
- obtain information about other resources

WHAT IS COUNSELLING?

You may be unfamiliar with counselling and may wonder how talking can help. There is a well-defined process in counselling which takes place in three stages:

1. **Exploring** and identifying the concerns.
2. **Understanding** these concerns in relation to you, how you think and feel and your life history.
3. **Taking action** with regard to the concerns, or learning to live with them in a different way.

Exploration

Counselling begins by telling your story; focusing on the issues you have identified. Cancer may be changing many things in your life. You may talk about your coping successes as well as events you fear may be beyond your ability to cope. The stress of cancer can alter your personal relationships. How your family and friends are dealing with your illness may be a major cause of concern for you. There may be other worries. As you struggle to deal with these changes, strong emotional issues may surface. The exploration process helps you to become aware of all the issues that you are dealing with as well as their place and importance in your life.

Understanding

When concerns have been identified, the next stage of the counselling process is to understand how you feel, think, react and behave in relation to each of them. Understanding what things are working for you and what things are working against you helps to bring a sense of control to the situation.

Practical issues are often easier to understand and deal with than deeply felt internal ones. However, examining and working through your feelings, thoughts and behaviours enables you to reach a clearer understanding of what is positive and health-promoting for you and what is not.

Action

Once issues have become clearer, you may want to decide on a course of action. Action can take many forms. Here are just a few examples:

- Learning new skills to cope with the stresses you experience.
- Changing patterns of living or relationships that are unsatisfying.
- Making a list of questions to ask your doctor.
- Taking an active part in treatment decisions.

- Facing fears and talking them over.
- 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.

You will be treated with respect, caring and understanding. We are here to support you in your efforts to deal as effectively as possible with all the changes that a cancer diagnosis may bring.

A PATIENT'S POINT OF VIEW

When I first became a patient of CancerCare Manitoba, I did not know counselling services were available to all patients. I thought a doctor's referral was needed. Later I learned I could ask to see a counsellor.

At first when I was diagnosed with cancer I had many issues. There was the shock of the word "CANCER", dealing with the treatments, possible disfigurement and the fear of death. I was introduced to the term "recurrence".

Who could I share my feelings of anger and fear with? Who could help me learn to handle the emotions I was experiencing? It was with a sense of relief, mixed with apprehension, that I made my first counselling appointment.

I felt sadness at having cancer, anger at and fear of the disease itself, grief over the temporary hair loss, and the permanent changes to my body. I was also anxious about my treatment and angry at the doctors for not being able to give me hope and encouragement. Counselling is helping me get in touch and deal with these feelings.

I also had to come to terms with the fact that my life would never be quite the same. I could not go back, only forward, taking responsibility for some necessary changes.

In counselling I am free to explore family issues, which consume energy needed for recovery and healing. Most importantly it is helping me clarify personal issues such as how I want to use the rest of my life and what my values, goals and priorities are. Exploring these issues helps me regain control over my life.

In a confidential setting I have the freedom to discuss my personal concerns. Through counselling I am learning: to accept all my feelings without judging them, to be more open in any relationships, to be more at ease with myself and others, and to bring more joy into my life. I would encourage any patient to meet with a counsellor at least once while in treatment. You will not be asked to change who you are. Instead you will be helped to become more yourself.

SOME QUESTIONS FREQUENTLY ASKED

Q. Do I need a referral in order to see a counsellor?

A. No. Any patient of CancerCare Manitoba, their family members or loved ones can phone the Department of Psychosocial Oncology and request an appointment with a counsellor.
(MacCharles Unit 787-2109; St. Boniface Unit 235-3141)

Q. Can the counsellor facilitate referrals to other agencies or self-help groups?

- A. Yes. Our Department keeps in close contact with Community programs and staff are knowledgeable about other agencies and self-help groups. We will gladly facilitate referrals and make connections.

Q. When should I consider seeing a counsellor?

- A. Timing is an important element in counselling. Normally counselling works best when the individual is in control of initiating the counselling contact.

Some people like to talk things over during the initial stages of the diagnosis, whereas others may feel too overwhelmed and prefer to wait until events have settled down. Most frequently, people make contact with a counsellor when they are adjusting to a situation of change.

Q. Is there a charge for these sessions or a limit on their number?

- A. No. CancerCare Manitoba recognizes the importance of counselling and covers the cost. The appropriate number of sessions is negotiated between you and your counsellor.

Q. What if my diagnosis is terminal?

- A. Staff at CancerCare Manitoba are committed to talking with people with cancer in an open, honest and caring way. Should medical treatments fail, this information will be gently communicated by the physician, who will then suggest a further plan of action. Having plans in place for pain control, support for you and your family, and additional help in the home can relieve some of the concerns and worries you have. Psychosocial Oncology staff can assist you with all of these areas.

Q. Will I be able to discuss spiritual issues with my counsellor?

- A. Yes, counsellors are ready to discuss the meaning and significance of living. When a crisis such as critical illness occurs, it is normal for a person to feel a need to make sense of living, of being ill, and of dying.

We will also help you connect or reconnect with a pastoral care worker or spiritual counsellor, if you wish.

Q. Sometimes I feel as if no one is really listening to my questions and concerns. How can counselling help?

A. Your counsellor can help you to clarify your concerns, identify where the problem may lie and, if appropriate, act as an advocate on your behalf in the health care system. Some patients are so polite that they hesitate to speak up when problems arise. It is important that there be a clear understanding between people with cancer and CancerCare Manitoba staff. The ability to communicate clearly and effectively is a skill that can be learned.

Q. What does confidentiality mean in counselling?

A. Confidentiality means that you can meet with a counsellor and be assured that the contents of the discussion will not be revealed without your consent, unless required by law. Psychosocial Oncology staff must communicate their involvement with you to other health care team members to ensure you receive quality care. However, the details of discussions are not shared without your consent.

Although all thoughts and feelings can be openly discussed in counselling, there are limits to confidentiality. In cases where a person with cancer threatens actual harm to him/herself or others, or when incidents of current child abuse are disclosed, the counsellor is under ethical and legal obligation to ensure that people are protected, which may require informing relevant authorities.

Q. Is it appropriate for me to talk about cancer to my children and other loved ones?

A. Most of the time, yes. A diagnosis of cancer affects the entire family. Your children and the people who love you and count on you should know when you suffer from an illness as serious as cancer. When loved ones are denied this information, they can't understand why you might look or feel so sick, or why you might have to reduce your activities. When people (especially children) can't understand what is happening and yet feel that something is really wrong, they typically become very anxious. When loved ones learn only much later that a parent, a relative, or a friend suffers from cancer, their reaction is often one of sadness and/or anger. Unless children are too young to understand, they should be informed in an age-appropriate way of a person's cancer and reassured that they are doing the best they can to deal with the illness. If you are not sure about how to talk to your children or your loved ones, please talk to us!

WOULD I BENEFIT FROM COUNSELLING?

Many people find it a challenge to adjust to and cope with a disease like cancer. You may find it interesting to answer the following questions to help you determine whether you might benefit by discussing your concerns with one of our professional staff. The following are some common concerns people experience surrounding their illness. There are no right or wrong answers; this is a

way for you to examine your own feelings.

During the Past Two Weeks:

1. I have felt anxious or worried about cancer and the treatment I am receiving.
1 2 3 4 5
Not at All All the Time
2. I have felt depressed or discouraged.
1 2 3 4 5
Not at All All the Time
3. I have been irritable or unusually angry and I have not controlled it well.
1 2 3 4 5
Not at All All the Time
4. My sleeping habits have changed.
1 2 3 4 5
Not at All All the Time
5. I have experienced a change in my appetite.
1 2 3 4 5
Not at All 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.
1 2 3 4 5
Not at All All the Time
7. Cancer and its treatment have interfered with my daily activities.
1 2 3 4 5
Not at All Very Much
8. Cancer and its treatment have interfered with my family or social life.
1 2 3 4 5
Not at All Very Much
9. Cancer and its treatment have interfered with my sexual life.
1 2 3 4 5
Not at All Very Much
10. Pain or discomfort has caused me to limit my activities.
1 2 3 4 5
Not at All All the Time
11. Cancer has caused physical, emotional or financial hardship for me.
1 2 3 4 5

Not at All

Very Much

concentrating on the task at hand, and feeling tension build up in our bodies. Usually a build up of tension can be sensed in areas such as the neck, back, throat, chest and stomach. When stress is extreme, "panic attacks" and short periods of breathlessness may be experienced. Tightness in the chest may be another indication of intense anxiety. Excessive stress can interfere with our ability to cope and adversely affect overall health. Muscular tension resulting from stress can increase sensations of pain you may feel.

Reducing your level of stress may be particularly valuable to you at this time. The Department of Psychosocial Oncology offers help through a variety of stress-reducing techniques. These may include:

- relaxation training;
- talking through your fears;
- improving coping skills and problem solving;
- hypnosis and imagery techniques;
- changing patterns of behaviour that repeatedly lead to frustration and distress;
- beginning a suitable program of regular exercise in consultation with your physician;
- engaging in leisure pursuits such as arts, crafts, or gardening which are relaxing to you.

The exact methods used are determined between you and your counsellor, according to your preferences and physical ability.

The Department offers a weekly Introduction to Relaxation and Mind/Body Approaches Group. In addition, Department Clinical Staff and the CancerCare Manitoba Resource Centre have relaxation tapes for your use.

If stress is something you are concerned about, you can arrange an appointment to speak with one of our counsellors by calling the Department of Psychosocial Oncology. (MacCharles Unit 787-2109; St. Boniface Unit 235-3141)

FATIGUE AND OTHER TREATMENT SIDE-EFFECTS

Cancer treatment, like all medical treatments, has some side-effects. These vary widely and depend on the type of cancer you have and the treatment(s) you are receiving. Many can be controlled or significantly reduced with medications and/or skills which can be learned. Others may require a change in how you do things.

Some side-effects are relatively common. For example, most people complain of fatigue at one time or another. The exact causes of fatigue are not yet well understood. It includes the disease, treatment, emotional demands, activity/sleep patterns, and physical changes. Cancer and its

treatment can be very demanding physically, emotionally, socially and psychologically, and may contribute to feelings of being tired, drained, and worn-out. These concerns should be discussed with your doctor and nurse; often they can suggest ways or prescribe medications that can help reduce the fatigue. If it requires re-organizing how you do things, then our counsellors can help you consider the options so you can make the best decision for you and your family.

Some people with cancer experience other side-effects. Various forms of relaxation training and guided imagery are available to help in the relief of pain and anxiety and to help you cope with treatment side-effects.

Whether or not we can help you directly, we can, in collaborating with members of your health care team, assist you to understand the side-effect(s), how it is affecting you and ways to cope with it.

CANCER AND SEXUALITY

When first confronted by the reality of cancer, your thoughts probably focused on survival. As time passes, however, you may start to wonder, "How normal can my life be?" Perhaps you wonder also, "What about my sexuality now?" or "Can I be sexually active?"

We believe sexuality is an important part of the quality of everyday life. Feelings about sexuality affect our zest for living, our self-image, and our relationship with others.

Just as you have the right to know whether your treatment will affect your nutritional appetite, your physical comfort, or your possibilities of returning to work, you also have the right to know how your treatments might affect your sexuality.

The Department of Psychosocial Oncology offers services to help you and your partner maintain good sexual feelings. At this time, when you are probably feeling in need of intimacy, it is often helpful for you to continue to be sexually active in ways that are right for you.

One of the most important points to remember is that pleasurable sexual activity is always possible regardless of the physical circumstances or medical history. This may seem surprising to you, especially if you have been feeling unwell, depressed, and unhappy with how your body looks. Perhaps, because of these feelings you have been sexually inactive for a while. Nevertheless, it is true that regardless of the effects of the cancer treatment, the ability to feel pleasure from touching almost always remains.

Sometimes cancer treatments can interfere with your interest in sexual activity. If you are female, you may experience pain with intercourse, vaginal dryness, or concerns regarding fertility. Perhaps treatment has put you into sudden menopause. If you are male, you may be having

difficulties in getting or maintaining an erection. Counselling may help you develop strategies for dealing with these problems. Sometimes counselling can help prevent the development of sexual problems in the future.

Sometimes there is more than one cancer treatment available. In such a situation you may wish to discuss with a physician which treatment will best maintain your sexual functioning or preserve your fertility. Clarifying your feelings about changes in sexual functioning or possible loss of fertility can sometimes help determine what choice of treatment is right for you.

It is our experience that when cancer impacts on sexuality, counselling and discussion of the problem often helps to maintain good sexual health.

SUPPORT GROUPS

Many people find it helpful to meet with others in similar circumstances in a group setting. Research has shown that participation in a support group can be effective in diminishing the psychological distress associated with the cancer experience, both for people with cancer and their loved ones.

Our Department provides, and collaborates with others, in providing a variety of support groups, some that are time limited and some that are on-going. Examples are a group for younger women with breast cancer, a group program for bereaved children, a group for learning relaxation techniques, and a group for children who have a family member with cancer (Kids Can Cope).

There are many support groups for people with cancer both within and outside Winnipeg. Our Department makes every attempt to stay informed about these programs. Information about these programs is available by calling our Department.

INFORMATION AND THE INTERNET

CancerCare Manitoba maintains a Web Site at www.cancercare.mb.ca. The Web Site has information about programs and services of CancerCare Manitoba and the Department of Psychosocial Oncology. It also has some starting links to cancer information sites on the Web.

CancerCare Manitoba and the Department of Psychosocial Oncology has available a computer at the MacCharles Unit and training for those wishing to access information on the Internet. Information about the program can be obtained from the Department of Psychosocial Oncology.

READING LIST

The following readings have been useful for some people with cancer, their families and friends. This list is an introduction and is not exhaustive. Much of the material can be found in the CancerCare Manitoba Libraries at both units. Additional information is available from the Hope Breast Cancer Information and Resource Centre (788-8080). If you would like information related to a specific type of cancer, you may consult with the librarian or volunteer.

American Cancer Society Booklet - *Sexuality and Cancer. For the Man Who Has Cancer and His Partner.* (1997)

American Cancer Society Booklet - *Sexuality and Cancer. For the Woman Who Has Cancer and Her Partner.* (1998)

Bombeck, Emma. *I want to grow hair, I want to grow up, I want to go to Boise: Children Surviving Cancer.*

An American author of children's literature compiled enchanting stories of children living with cancer and coping with friends, family, school and social engagements. This book is comic in style and will likely be appreciated by children who can independently read its fine print and 174 pages.

Boulden, Jim. *Saying Goodbye - Coloring Book.*

A useful tool for approaching grief issues with children. It provides an opportunity to read about death, dying, funerals and change. This book creatively conveys a message, while promoting reflection through the use of written exercises and coloring pages.

Buckman, Robert. *I Don't Know What to Say: How to Help and Support Someone Who is Dying.*

This book is helpful to any friend or family member of someone who is dying.

Burns, David. *Feeling Good.*

Best-selling guidebook to self-help for depression and anxiety through cognitive therapy.

Canadian Cancer Society Booklet - *Helping Children Understand: A Guide For a Parent with Cancer.*

Canadian Cancer Society Booklet - *Taking Time - Support for People Living with Cancer and People Who Care About Them.*

Cunningham, Alastair. *The Healing Journey.*

Dr. Cunningham is a senior scientist at Cancer Care Ontario. He is also a cancer patient. This book presents information and is a guide for people who wish to address a diagnosis of cancer as not just a biological disease, but also as a psychological and spiritual crisis.

Dollinger, Malin. *Everyone's Guide to Cancer Therapy.*

A diagnosis of cancer triggers many questions that demand straight-forward answers. A volume such as this provides information that is helpful in making informed decisions.

Frank, Arthur. *At the Will of the Body: Reflections on Illness.*

A thought-provoking and insightful account of one person's experience of surviving cancer.

Garrett Garrison, Judith and Sheperd, Scott. *Cancer and Hope.*

Here is a guide to emotional survival for someone who has cancer. Provides medicine for the spirit.

Hessell, Jenny. *Nobody's Perfect.*

A colorfully illustrated and sensitive look at a child's understanding of death. The format is a story version of a young boy's experience with the death of a classmate to illness.

Jevne, Ronna Fay and Levitan, Alexander. *No Time for Nonsense - Self-Help for the Seriously Ill*

This book describes the most common problems that people with a chronic or life-threatening illness run into, including physical, emotional, and practical difficulties. The authors give their ideas about the skills and attitudes that they have seen others use that have promoted their sense of health and well-being.

Johnson, Judi and Klein, Linda. *I Can Cope.*

This book has a positive message. It is about learning to live with cancer and being healthy despite a cancer diagnosis.

Lerner, Michael. *Choices in Healing.*

Dr. Lerner provides a balanced and scholarly review of many of the most widely known complementary methods in cancer.

LeShan, Lawrence. *Cancer as a Turning Point, and You Can Fight for Your Life.*

Dr. LeShan is a psychologist who, through this book, provides insight and inspiration for anyone living with cancer. He includes many case histories which add meaning to his message.

McCue, Kathleen. *How to Help Children Through a Parent's Serious Illness.*

Provides reassurance, insights and very practical advice to parents and families when a parent is seriously ill.

Murcia, Andy and Stewart, Bob. *Man to Man.*

Personal stories which help couples who face the cancer challenge to do so with hope and understanding.

Ontario Breast Cancer Exchange Project. *A Guide to Unconventional Cancer Therapies.*

Available from R & R Bookbar

14800 Yonge Street, Unit 106, Aurora, ON L4G 1W3

For information call: 1-416-480-5899

Rondo, Theresa. *How to go on Living When Someone You Love Dies.*

This author's goal is to provide insight on resolving and understanding grief, speaking to children, resolving unfinished business, taking care of yourself, planning funeral and bereavement ceremonies, and utilizing practical and psychosocial support services.