Getting Back on Track

Life after breast cancer treatment

Canadian Breast Cancer Foundation
ONTARIO

Princess Margaret Hospital
University Health Network
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Dear Reader,

When you were diagnosed with breast cancer, you understood that your life would no longer be the same. Yet, despite the initial fear and anxiety, you survived the diagnostic and initial treatment period. Whether you had help from family, friends, other patients, or you struggled on alone, you have made it through a very demanding and stressful period. Now you are beginning another phase. The intense treatment is over and your new life is beginning - you are going to get back on track.

Improved treatment has reduced the chance of breast cancer recurrence. There are more women than ever who have undergone successful treatments and are now flourishing in their own communities. They experience similar concerns about their post treatment life and the persistent and late side effects that can occur. It is inevitable that the health care providers that you have relied upon during the treatment portion of your journey fade from your day-to-day activities and you will be more on your own. But be assured that there is support from other survivors, your loved ones, and your health care team.

We have written this book to help address some of the normal concerns that one has during this transition from active care to the rest of your life. We also would like to share some remedies and coping skills that may help you get back on track.

We extend our sincere thanks and appreciation to our partner, the Canadian Breast Cancer Foundation – Ontario Region, for providing this book to you.

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Introduction

A guidebook for your journey

Congratulations! You’ve made it! Your active treatment for breast cancer is finally over and you can once again focus on moving forward with your life. Every woman will find her own pace, and this booklet can be a guide that may help along the way. Until now, your treatment has probably been a full-time job for you. You may have put many things on hold, and you may not have had time to sit down and think about what your breast cancer experience will mean to you.

This may be a particularly vulnerable time for you, and you may have many mixed feelings about what you’ve been through. One moment you may be thrilled that your active treatment is over. The next moment you may feel abandoned, or anxious that your cancer may recur, and you may feel a need to call your doctors and nurses for support. All these feelings are normal. Remember that you still have the support of your health care team.

Although this booklet may be the first place you check for information and for advice, it should never take the place of the real life support you have available from your health care team as well as your family and friends.
Inside this booklet

CHAPTER ONE
We look at changes in how you will relate to your doctors, nurses and other health professionals now that you have completed your active treatment for breast cancer. We consider your health care needs now and over the next few years so that you will know what to expect and when you should seek help if you need it.

CHAPTER TWO
We cover some of the physical side effects you may experience after your active treatment for breast cancer is over. Not all of the symptoms are the direct result of breast cancer or its treatments. Some are related to normal life events such as aging, or normal life experiences such as stress. In any event, by knowing what might happen and watching for early warning signs, you may be able to minimize or possibly even prevent problems and get help more easily if you need it.

CHAPTER THREE
We highlight the importance of a healthy lifestyle as you recover from your treatment. We look at ways to support healthy eating and physical activity and to set goals for a healthy fitness routine that will work for you.

CHAPTER FOUR
We examine some of the emotional, spiritual and social needs you may have as your active treatment for breast cancer ends and your life continues. We look at some of the personal issues you may face and how you might work through them on your own and with support from others.

CHAPTER FIVE
We cover some of the changes that may affect your relationships now that you have completed your active treatment for breast cancer. Your personal and professional relationships will be an important part of your coping strategy. We provide tips that might help you with relating to your family, friends and co-workers during this time.

CHAPTER SIX
We look at some of the practical and financial issues that you may face as you return to everyday life. We provide useful information about making the transition back into your regular daily activities and planning for the future after your breast cancer experience.

CHAPTER SEVEN
We pass along some tips on how to evaluate information about cancer that you may come across in the media or on the Internet such as news articles, research studies and descriptions of complementary and alternative medical therapies, so that you can better judge when that information is relevant to you.

APPENDIX
At the end of this guide you will find an appendix that lists the names and contact information for major organizations and websites that provide information for women who have experienced breast cancer in communities across Ontario.

We hope that this book will assist you and those who care about you with moving forward with your life.
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For what matters.
This chapter looks at changes in how you relate to your health care team now that you have completed your active treatment for breast cancer. Useful tips are provided so that you can identify when you need help and learn how to find it.

This chapter also discusses some of your health care needs now, and what you may experience and should watch for during the next few years.

What you may be feeling now

“During my breast cancer treatment I often dreamed about when it would all be over and when I would have my old life back. Now I wonder if that time will ever come. I feel alone and afraid. Will I still have the caring and support that my health care team provided me?”

Until now, doctors, nurses and other health care professionals have guided you on your cancer journey. From your earliest tests, through your diagnosis and your treatment, these professionals provided you with information and helped you make choices. You may have grown to trust them. You have shared your thoughts and feelings with them and likely made some friends along the way.

Now that your active breast cancer treatments are over, you are entering a new phase in your journey. You may be worried about your future and fear that you are losing the connection to your health care team. Even though your family and friends are willing to help, you may feel that you still need the expertise of health care professionals to guide you along the way.

At this point, you should be aware that some side effects of cancer treatment may not go away for some time after your treatment is over, and some side effects may surface even years later. This guide will help you learn about these effects and what you can do to minimize and possibly even prevent them.

You may not want to ask for any more time and attention from your busy health care team. You may feel that you shouldn't “bother” them because they must spend their time with other patients who need them more. That's not true. Your questions and concerns about the possible side effects of your cancer treatments and other cancer-related issues are equally important. Your health care team is still there for you.

What you need to know now

All of the health professionals who guided you along your way are still available to support you if you need them. In fact, most will encourage you to call them if you have any questions about treatment after-effects, new symptoms or other issues. Your health care team can also help you link with other trained professionals who are skilled in helping people who have experienced cancer adjust to life after treatment. It is really all about learning to live with and beyond cancer.

It's true you will see your health care team less often now that you have completed your treatment. Your visits to the hospital or cancer centre will become fewer and the location of your appointments may change. In addition, the size of your health care team may become smaller because you do not require active, hospital-based treatment; however, you will still need to attend followup and possibly other medical appointments. Your checkups will be shared among a number of different health professionals. You may not need to see all of these people regularly, but they will remain part of your followup care as needed.
You and your family doctor or nurse practitioner will be the primary coordinators of your care and will look after your overall health in partnership with your cancer care team. If needed, other health professionals will support you. As with your hospital-based treatments that likely involved many professionals, your continued active involvement in the management of your care will help to ensure that all of your health care professionals are well-informed about your care and your care needs. If you do not have a family doctor or nurse practitioner, please see the appendix for information on locating a family doctor.

After some period of time, you may need only regular followup with your family doctor or nurse practitioner. This followup may include annual mammograms and clinical exams, as well as other usual screenings such as cervical (pap smears) or colorectal screenings (dependent on age). You will likely have mammograms at the hospital where you had your surgery, or you may be seen at your cancer centre or at a local centre in your community. More information about follow up care is provided later in this Chapter in the section “Your new health care routine.”

YOUR NEW HEALTH CARE TEAM

The “star player” – you: You have learned how the health care system works and how you prefer to be treated. Being assertive and staying involved in your care will help you remain informed about your treatment and its potential late effects. You are the most important member of your health care team and should continue to be part of all decisions. Keep records about your care so that you can tell your health care providers about the treatments you have had and the side effects that you may have experienced or are experiencing. You should ask for and keep copies of all tests and results, if they are available to you, and share them with your doctor as necessary.

Your family doctor or nurse practitioner: Your family doctor or nurse practitioner will play a central role in monitoring your
overall health after treatment. You will need a family doctor or nurse practitioner who works closely with you, does an annual complete physical check up and manages your general health. Your family doctor or nurse practitioner will also help you keep track of your physical and emotional needs, and make sure that your health care is arranged in a timely manner. Make sure that your family doctor or nurse practitioner knows of all your additional medical appointments and receives all test results, copies of reports, recommendations and records of visits to specialists. *If you do not have a family doctor or nurse practitioner, please see the appendix for information on locating a family doctor.*

**Your nurse:** Nurses can be your most helpful guides within the health care system. Your nurse can help you with your physical, emotional and practical needs. Today, there are many different types of nurses who help patients and their families. Some nurses specialize in oncology (cancer treatment) and some work with family doctors.

It will be important to maintain your relationship with the oncology nurse or nurses who worked with you during your cancer treatment. Your oncology nurse can be a great source of information to you after your cancer treatment has ended. He or she can be available by telephone and can answer your questions regarding your followup care, provide support and direct you to helpful resources.

**Your oncologist(s):** You may continue to see one or more of your medical, surgical and/or radiation oncologists during different phases of your treatment and follow up.

**TIP:** Try to space your oncologist visits equally so that you receive breast examinations regularly during the year.

**OTHER POSSIBLE MEMBERS OF YOUR HEALTH CARE TEAM**

**Your social worker:** A social worker may be available in your community to help you with emotional and psychological support as you and your family continue with your activities of daily life. Often this period is described as adjusting to a “new normal.” A social worker can also be very helpful in understanding practical issues such as drug coverage benefits, disability benefits, social and community support options and financial support options. If you need to find a social worker near you, go to: www.oasw.org.

**Your physiotherapist and occupational therapist:** If you experience difficulties moving and using your arm as a result of surgery or radiation treatment, your family doctor, surgeon or radiation oncologist may suggest you see a physiotherapist or an occupational therapist. The physiotherapist or occupational therapist can provide you with information on how to get back into your activities of daily living and exercising after your breast cancer treatment. If you need to find a physiotherapist near you, go to: www.collegept.org. To find an occupational therapist near you, go to: www.coto.org.

**NOTE:** If your community does not have a physiotherapist or an occupational therapist that specializes in the care of women who have experienced breast cancer, ask your therapist to consult with a colleague in a cancer treatment centre or hospital who works with women who have experienced breast cancer.

**Dietitian:** A dietitian has the expertise to counsel you on matters of nutrition and diet. Attending an educational session or consultation with a dietitian can help you gain an understanding of healthy eating and diet, both of which are important for long-term health. If you need to find a dietitian near you, check with a hospital in which
you are a registered patient to see if there is a dietitian who sees patients; or, you can go to: www.dietitians.ca or consult with your family doctor.

Medical radiation technologist (MRT): An MRT has training in the field of medical imaging and specializes in mammography examinations. Their expertise will ensure that your mammograms are done with the best image quality so that the radiologist can review your pictures with all the fine details.

Psychiatrist: A psychiatrist is a medical doctor who can provide a mental health assessment of signs of depression, anxiety or post-treatment stress, and who can prescribe medications if needed. A psychiatrist requires a referral from a medical doctor. You can also speak with your nurse, social worker, family doctor or oncologist for help with issues related to your ability to cope.

Psychologist: A psychologist has training in psychology and provides psychological services but does not prescribe medication. A psychologist can help you cope with difficulties with your thoughts and feelings.

Support staff: Secretaries, booking clerks and others who contribute to your health care program will be important to you as you arrange, change and cancel your appointments. It is wise to check with your doctor or nurse to clarify which support staff person you should call.

Patient and family resource centres and/or libraries: You may still have questions and need information as you continue your journey. Your local hospital or cancer treatment centre will have a resource centre or library to assist you in finding answers to your cancer-related questions.

BREAST CANCER SURVIVORSHIP PROGRAMS

Many hospitals and cancer centres provide programs to help people with cancer at various stages of their treatment. Your hospital may have a special breast cancer survivorship program that will provide support to you and your family during your follow up over the next few years. This program will help you consider your overall needs for information, education and support, and help you find the appropriate followup clinics for dealing with late and persistent side effects of cancer treatment such as lymphedema, pain, fatigue, difficulty with physical and cognitive functions, osteoporosis, weight management, and social and emotional difficulties. Information on the ongoing physical side effects of treatments is provided in Chapter Two. Information on your emotional needs following treatment for breast cancer is provided in Chapter Four.

TALKING WITH OTHER PEOPLE WHO HAVE EXPERIENCED CANCER

You may wish to take advantage of other social supports offered through community organizations. These organizations often provide a range of programs such as support groups, social networking, online supports, and physical activity and coping programs. You may find it beneficial to become involved with the cancer community and learn from the wisdom of others who have experienced cancer. More information about reaching out in your community is provided in Chapter Five.

Caring Voices is a national, online social networking community for Canadians who have experienced cancer, including patients, caregivers, family members, friends and health care professionals. Through the use of real-time chat and online forums, Caring Voices provides current resources, peer support, and advice from peers, health care professionals and community experts. Caring Voices can even match people so that they can share their experiences with each other. Go to: www.caringvoices.ca. More information about Caring Voices is provided in the appendix. If you are a young woman, see the appendix for information on resources for young women who have had breast cancer.
What you can expect during the coming year

YOUR NEW HEALTH CARE ROUTINE

Health Canada* has recommended a series of tests and procedures for women who have been treated for breast cancer. These recommendations are based on the experience of thousands of cancer specialists who have provided follow up care to women with breast cancer over many years.

✔ Medical history and physical examinations

Since no single schedule will work for everyone, the timing of your examinations should be set by you and your doctor to suit your individual needs. In general, it is recommended that women who have had breast cancer visit their doctor or nurse every three to six months for the first three years after their active treatment has been completed, then every six to 12 months during years four and five and every year thereafter.

During each visit, your doctor or nurse will update your medical history and conduct a physical examination.

1. Medical history: Tell your doctor or nurse about any side effects of your treatment such as swelling or tenderness in your breasts, stiffness in your shoulder, or swelling in your arm or other areas of your body. If you are taking Tamoxifen, be sure to tell your doctor about any unusual vaginal bleeding.

2. Physical examination: The purpose of the physical exam is to look for recurrence of cancer. Your doctor or nurse may also check for side effects of cancer treatment, for example signs of lymphedema (swelling caused by a buildup of lymphatic fluid).

* More specifically, the Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer, which is part of Health Canada's Canadian Breast Cancer Initiative.

✔ Post-treatment mammography

It is recommended that you schedule a mammogram one year after the first mammogram that led to your diagnosis, but not until six months after radiation therapy. After that, you should obtain a mammogram every 12 months.

The purpose of your annual mammogram is to detect any local recurrence of cancer in one or both of your breasts.

NOTE: Additional tests to other parts of your body such as bone and liver scans, chest X-rays, etc. will not be carried out on a regular basis unless your doctor has concerns that your cancer may have spread.

✔ Coordination of care

For a while, you will continue to see some or all of the specialists who have been involved in your treatment such as your surgeon, medical oncologist and radiation oncologist. At some point in the future, one of these specialists or your family doctor may become the primary person who is responsible for coordinating your care.

No matter who is coordinating your care, all of the members of your health care team should keep you fully informed and let you know exactly what follow up arrangements have been made and who is responsible for carrying them out.

If you are receiving hormone-blocking therapy, you should talk with your oncologist about how often to schedule follow up visits.

✔ Genetic counselling

Talk to your doctor if there is a history of cancer in your family. More information about genetic risk and testing is provided in Chapter Four.
CHAPTER ONE
Working with your new health care team

LOOKING AFTER ALL OF YOUR HEALTH CARE NEEDS

"I was so into my treatment and recovery from breast cancer that I’d put off going to the dentist or seeing my eye doctor."

While you were being treated for breast cancer, you may have stopped looking after other aspects of your health. If so, now is a good time to book any overdue health care appointments. You may also want to make some changes to your diet and exercise habits that can help you work towards a healthy future. More information about diet and exercise can be found in Chapter Three.

CHARTING YOUR COURSE: SEEKING INFORMATION

"During my treatment, I got better at finding answers to some of my questions. I talked to my doctors and read books and articles."

Some women who have been through breast cancer treatment feel they can’t get enough information. After their treatment is over, they may have more time to think and often have questions about what has happened to them. On the other hand, some women would rather not focus on what has happened and prefer to let their health care team advise them as needed.

No matter what your approach, at times over the next year you may wish you had a personal advisor to help you. You may see articles about breast cancer in newspapers, magazines and online. Do not believe everything you read. You need to make sure that the information is from a credible source. If you are not sure, check with your family doctor or nurse practitioner; other members of your health care team; Willow Breast Cancer Support Canada at 1-888-778-3100 (toll free), www.willow.org, or info@willow.org; or the Canadian Cancer Society’s Cancer Information Service at 1-888-939-3333 or www.cancer.ca.

More information and tips about dealing with current issues are provided in Chapter Seven.

Ask the right questions
You may have many questions about the after-effects of treatments, ways to deal with emotional ups and downs, diet and exercise, or more practical issues such as returning to work. You can work with your family doctor or nurse as well as your oncology team to find answers to these questions. Remember, no question is trivial or stupid.

Some women keep a binder or notebook at home and write down their questions as they arise. You may be worried about a trip you’ve planned or how to juggle family demands when you return to work. You may wonder about physical symptoms such as aches or pains you weren’t expecting, a cough, change in vision, abnormal vaginal bleeding or a change in your sex drive.

Because of your cancer diagnosis, you will probably be more aware of changes than before. Keep in mind that many changes are temporary; they will often come and go and probably disappear within a week or so.

Check with your health care team if you experience any of the following:

✔ New pain that won’t go away
✔ A cough that won’t go away
✔ A lump in either breast, neck, armpit or above the collarbone
✔ Unusual changes at the site of your surgery or in the scar itself
✔ A tired feeling that won’t go away
✔ Loss of appetite
Weakness, tingling or numbness in arm, hand or leg

Swelling in the arm, shoulder, breast, chest, armpit, back, hand or fingers

Any new symptom that is unusual or severe and doesn’t go away, such as bone pain, shortness of breath or headaches

If you experience a new symptom that does not go away, keep track of your answers to the following questions:

• When did you first notice the symptom? For example, one week or one month ago.

• What is the symptom like? Can you describe the symptom?

• Is the symptom getting better or worse, or is it the same as when you first noticed it?

• What makes the symptom worse? What makes the symptom better?

• Does the symptom wake you up from sleep?

• If your symptom is pain, can you rate it on a scale from one to ten. (One is very mild pain and ten is the worst pain you have ever had.) More information on pain is provided in Chapter Two.

Before your appointment with your family doctor or nurse practitioner, review these questions, organize your thoughts, and write them down so that you can better remember them and ask your questions easily. You may want to bring your notes with you as well as a pen and paper so you can write information down.

Respect your doctor's time limits. If you have more than one symptom, discuss your most troublesome one first. Don't wait until your doctor is doing a physical exam or about to leave the examining room. Many people take notes or ask a friend along to help them remember everything that's discussed at an appointment.
In some cases, after the appointment you may wish to book another to discuss issues that you did not feel you had time to discuss. You may have questions that your family doctor or nurse practitioner can’t answer. In that case, check with your oncologist, your nurse or other members of your health care team or support network.

**NOTE:** Your doctors should be advised of any breast cancer-related medications you are taking such as Tamoxifen or Arimidex before they prescribe medication. Taking a complete list, prepared by your Pharmacist, of your current medications or bringing all of your current medications in your purse or a bag to any medical appointments will be useful for your doctors to ensure coordinated treatment and to reduce side effects.

Provide the best possible information to your family doctor
Keep up-to-date records of all the medical care you receive for cancer and other conditions. Doing so will assist with future decisions about your care that may depend on how you have been treated in the past. Most cancer clinics automatically send notes from your visits to your family doctor, but check or remind your health care team. If you move or go to several different doctors, you are the only one who will have your complete health history. Therefore, you are the key person who can ensure everyone is informed.

Make sure that you keep your family doctor or nurse practitioner up-to-date on the following:

- Any medications that you are taking (including over-the-counter medicines such as painkillers and laxatives, as well as nutritional supplements, vitamins, minerals, etc.). Your family doctor will need this information to avoid problems when prescribing any new medicines for you.
- Whether you are considering natural or herbal therapies. These therapies may affect your body in ways that your doctor needs to be aware of.
- When your next mammogram is due, if applicable.
- Which specialists are still following your care.
- Any fears or concerns you have, especially those that might affect your recovery.
- Any lifestyle changes such as quitting smoking, changing your diet or exercise routine, etc.
- How you feel. Are you experiencing any symptoms or changes that are worrying you?

What to expect over the next few years

> As I recovered, I became quite good at putting thoughts about my breast cancer experience out of my mind. But then I realized that was a mistake. I thought a lot about my experience and began to make it part of my life. After all, it is something that changed me; it made me the person that I am today.

As you move farther away from your breast cancer treatment and your regular life returns, you may find that it is easier to put it all behind you. You will probably become quite good at keeping fearful thoughts from your mind. On the other hand, you may find that you have more time to think about and reflect upon what has happened to you. During this time it will be very important that you follow your plan for long-term health and wellness.
Consider keeping a journal as you continue in your cancer recovery. Journaling can provide a way to express your feelings and document your journey. People who write journals feel better both mentally and physically. In fact, one study showed that women who had experienced breast cancer who wrote about all of their feelings reported fewer physical symptoms and fewer unscheduled visits to their health care team. Journaling has many benefits. It can help you:

- Identify your feelings and set goals
- Prepare for visits to your health care team
- Gain a new perspective on your experience
- Vent difficult feelings such as anger and hurt, and help you move on to more productive or happier thoughts

Get regular checkups. Ask your family doctor or nurse practitioner how often you should check in with her/him.

Go for all tests that are suggested to you. There are no regular breast cancer tests other than a routine mammogram and clinical examination. Your family doctor or nurse practitioner can tell you how often you should have other regular checkups.

Live a healthy life. Enjoy a balanced diet that is high in fruits, vegetables and whole grains, and low in fat and sugar. Do your best to get a healthy amount of rest and regular exercise, avoid tobacco smoke and recreational drug use, and if you drink alcohol, limit your consumption to one drink or less each day. Try to keep your stress level down. These actions will help you feel better. Above all, don’t be too hard on yourself! Do things you enjoy. Pleasure can be a powerful tool for health. More information about healthy living is provided in Chapter Three.

Above all, love and live life.
This chapter covers some of the physical side effects you may experience after your active treatment is over. If you watch for early warning signs, some of these problems can be treated before they get worse. By knowing what might happen, you may be able to minimize or possibly even prevent problems and also get help more easily if you need it.

What you may be feeling now

“I’m so very tired. My body has changed. I feel angry that my body has let me down!”

There is no doubt that your breast cancer treatment has been hard on you. Every part of you may feel drained. Your strength may be low and on some days you may have a hard time getting out of bed in the morning.

Your family and friends may think it is time for you to return to the way you were before you were diagnosed with breast cancer. You may not want to tell them that you still have some health issues and are not feeling quite like yourself. You too may feel that it is time to get back to your normal life. This will be a big task, however, and you may not be able to get there as quickly as you would like.

The treatment for your breast cancer was very powerful and has affected your whole body, especially if you had surgery, radiation, chemotherapy and/or hormone-blocking therapy. Some physical effects of this treatment may continue to affect you for a while as you heal. But take comfort. Over time, and by learning as much as possible about how to take charge of your health, you will feel well again.

What you need to know now

“I didn’t expect that after my treatment was over I would feel well again right away. I knew that I’d probably feel tired for a while, but I didn’t count on all these other annoying health problems! When will they end?”

YOUR RATE OF RECOVERY

Your rate of recovery will depend on the treatments you have received. For example, if you had both surgery and radiation, you may find that the skin damage from radiation will heal relatively quickly, but your surgical scar may take longer to heal. The side effects of your breast cancer treatment may continue for the next few months.

ACHES AND PAINS

“Whenever I feel an ache or pain, my first thought is that it has something to do with breast cancer. I worry that the cancer has come back.”

What is pain?
Not all women have pain with breast cancer, but some do. Usually pain is due to surgery, radiation, chemotherapy or hormone-blocking treatments. For example, you may have pain in your breast, chest area or under your arm from surgery or radiation, even after the area has healed. Some women have an overall body ache that begins several months after their chemotherapy treatment and may last up to one year or more. Unfortunately, there is no known treatment for this overall ache, but pain relievers may be used if the
pains is severe. Overall aching will usually go away on its own. The common side effects of hormone-blocking treatments include joint stiffness or joint pain.

No matter what kind of pain you have, it can be frightening and stressful. You may wonder what aches and pains are normal and when you should call the doctor. Call your family doctor if any of the following occurs:

- You experience any unusual ache or pain that starts gradually and becomes worse after a few weeks
- You have arthritis and your arthritic pain is worse than normal or interferes with your usual activities
- You experience any sudden severe pain

**What to do if you have pain**

Your first step will be to admit that you have pain. Although you may not want to worry your family or friends, you will need to ask for help and support from your health care team. Tell your health care team where the pain is and how it feels. Try to answer these questions:

- How long have you had your pain?
- Has your pain been getting worse, staying the same or getting better over time?
- What does your pain stop you from doing?
- Does your pain wake you from sleep?
- What are you usually doing when your pain starts and stops?
- Does your pain start up without any warning?
- Does your pain stay in one place or move around?
- Is the pain sharp, dull, hot, cold, burning, aching or throbbing?

- How bad is your pain on a scale of one to ten? (One is very mild pain, while ten is the worst pain you can imagine.)
- How long does your pain last?
- What makes your pain better and what makes your pain worse?

**NOTE:** Chronic, troublesome pain from surgery (especially in the area near the breast) is common, as is the experience of numbness in the underside of your upper arm. You may feel some tenderness to your skin as well as sensations of tightness, pulling, burning or a feeling of sudden electric jolts that might shoot down your arm or to another area of your chest. If you feel anything like this and need relief from the discomfort, you should let your family doctor know so the pain can be treated.

**Find out what helps relieve your pain**

Some women with pain choose to live with mild discomfort rather than take medication. That is perfectly fine; most of us do this often for a variety of aches and pains. However, if your pain begins to affect your daily life, there are ways of controlling it. Effective medications are available with few, if any, side effects.

**Over the counter, non-prescription pain relievers:** Analgesics such as Tylenol and non steroidal anti-inflammatories such as Ibuprofen, Motrin and Advil can be purchased in drug stores without a doctor’s prescription. Sometimes, these mild non-prescription drugs are all that you need. Always check with your family doctor before taking any medication, even over-the-counter pain relievers.

**Prescription pain relievers:** There are many different pain relievers that must be prescribed by your doctor. Non-steroidal, anti-inflammatory medications include Arthrotec and Celebrex. Narcotics or opioids may include Tylenol #3 (codeine),
Some women develop problems with their arm and shoulder area because of breast cancer treatment. These problems usually happen if lymph nodes have been removed from under the arm, or if radiation has been administered to the underarm lymph nodes and/or the shoulder area. Symptoms may include numbness, swelling and/or pain. You may also have tightness across your chest and stiffness in your arm and shoulder that can limit how you move.

It is normal to feel that you need to protect your shoulder on the side where you had surgery and/or radiation. However, even if this area of your body is sore or uncomfortable, you will need to regularly and gently exercise your arm. If pain slows down your rehabilitation, making it difficult to exercise and use your arm for daily activities, discuss the use of painkillers with your family doctor.

If movement is not restored, a condition known as “frozen shoulder” (painful stiffness of the shoulder that makes it difficult to lift your arm over your head) can occur. Preventing frozen shoulder is much easier than treating it. If you have not already received information on arm and shoulder exercises, ask your family doctor, physiotherapist or occupational therapist how to do them. If you have had breast reconstruction surgery, check with your plastic surgeon before you start any shoulder exercise.

If you are having problems with arm and shoulder movement that do not go away within three months after your breast cancer surgery, ask your doctor for a referral to a physiotherapist or occupational therapist for an assessment. If persistent pain is making movement difficult, your doctor may refer you to a rheumatologist, an orthopaedic surgeon or pain specialist.

LYMPHEDEMA

Your lymphatic system drains fluid and some waste materials from your tissues. A clear, colourless fluid called lymph passes through lymph nodes, where waste products are removed or broken down into smaller particles. The lymph fluid returns to the circulation system just before the blood enters the heart. Lymph nodes are
located throughout your body in places like your neck, under your arms and in your groin. If the lymph pathways are damaged, fluid and proteins can build up in your tissues. This fluid build up causes swelling called lymphedema.

Lymphedema is a problem for some women who are treated for breast cancer. For many of these women, lymphedema can become a chronic (lifelong) condition. Your chance of developing lymphedema will depend on the following:

- The extent of your surgical treatment
- The number of lymph nodes that have been removed
- The extent of radiation therapy
- Your weight

How to reduce your chances of developing lymphedema

Once you have had surgery and radiation, you are at risk for lymphedema on that side of your body for the rest of your life. Lymphedema may develop as late as 30 years following treatment.

Although lymphedema cannot be prevented, there are several things you can do that may reduce your chance of developing it.

1) Look after your skin. The most important thing you can do is avoid breaks in your skin that could lead to an infection (e.g., cuts, pinpricks, animal scratches). Follow these tips:

- Keep your skin clean and dry
- Apply moisturizer daily to prevent chapping
- Avoid cutting your cuticles. If you have manicures, make sure the person knows not to cut your cuticles.
- Protect exposed skin with sunscreen and insect repellent, and consider wearing long sleeves when outdoors
- Be careful with razors to avoid nicks and irritation

- If possible, avoid having an injection in the arm on the affected side of your body
- Wear gloves and long sleeves when doing any activity that may cause a burn or injury such as baking, washing dishes, gardening or using tools

If you do get a break in your skin, clean it well with soap and water, apply antibiotic ointment, and cover with an adhesive bandage or apply a liquid bandage after washing. Watch for possible signs of infection such as a swollen, red, painful area that is getting larger. See your doctor immediately for treatment, if necessary. If your doctor is not available, go to an urgent care centre or emergency department.

2) Avoid constricting your arm. By keeping the circulation flowing in your arm, you may avoid a backup of fluid that can overload your lymphatic system.

- Avoid tight fitting jewelry and tight or restrictive clothing on your arm.
- If you wear a bra, wear one that fits well, with wide straps and preferably without underwires.
- Avoid carrying heavy purses or bags with shoulder straps on the affected side.
- Offer your unaffected arm to take blood pressure.

3) Avoid extreme temperatures. Take care to avoid exposure to extreme cold or prolonged (more than 15 minutes) exposure to heat directly to the side of your body that you had your surgery and/or radiation on. For example, wear a coat and gloves in very cold weather, and avoid hot tubs and saunas.

4) Maintain a healthy body weight. If you are overweight, you have a greater chance of getting lymphedema. Try not to panic
if you are overweight. Talk to your family doctor or a dietitian about a plan for healthy eating and physical activity. A healthy diet and regular exercise program (like walking) will help. *More information about healthy eating and physical activity is provided in Chapter Three.*

5) **Maintain a healthy activity level and lifestyle.** Exercise may trigger lymphedema by increasing lymph production and by creating inflammation in your joints and muscles. Yet the majority of women who are at risk of lymphedema can safely perform aerobic and resistance exercises if they follow these guidelines:

- Increase the duration and intensity of your exercise very slowly and gradually. Don’t expect that you will return to your pre-treatment exercise level right away.
- Rest frequently during activity and avoid over exercising.
- Monitor the affected area during and after activity for any change in size, shape, texture, soreness, heaviness or firmness.

**NOTE:** Some women have also used compression garments when doing strenuous and repetitive exercises, but the benefits of this practice have not been fully researched.

Always check with your doctor before beginning any new form of exercise. *More information about safe physical activity if you have lymphedema is provided in Chapter Three.*

**NOTE:** Even if you do all these things, there is no guarantee that you will not develop lymphedema. These are general precautions that you should keep in mind.

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**Lymphedema warning signs**

Your best defense against lymphedema is to catch it early. Watch for these important warning signs:

- A feeling of tightness in the skin of your arm, armpit, shoulder and/or chest
- A feeling of heaviness in your arm
- Swelling/increase in the size of your arm, shoulder, breast, chest, armpit, back, hand or fingers
- Clothing or jewelry feeling tight on the affected side
- Aching or stiffness in the arm on the side of your surgery
- Pain or a feeling of congestion or blockage in your arm
- Any swelling or discomfort that does not go away within six to 12 weeks after surgery

You can check yourself by looking in the mirror with your arms up so you can compare the affected (surgery) side with the other side. If you notice a difference in size between your two arms, inform your doctor or nurse practitioner.

**What should you do if you have lymphedema?**

Unfortunately, there is no cure for lymphedema. However, it can be successfully managed with appropriate treatment. If you are diagnosed with lymphedema, you will need to continue to follow the guidelines above as well as learn the following methods designed to protect your arm from stress or injury:

- Manual lymph drainage, a hands-on technique that directs the flow of fluids away from the affected area
- Multi-layer compression bandaging and/or compression with either bandages or garments
- Special exercises to promote lymphatic flow
- Skin and nail care

*Note:* Some women have also used compression garments when doing strenuous and repetitive exercises, but the benefits of this practice have not been fully researched. Always check with your doctor before beginning any new form of exercise. *More information about safe physical activity if you have lymphedema is provided in Chapter Three.*

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**Getting Back on Track**

Life after breast cancer treatment

Princess Margaret Hospital

Canadian Breast Cancer Foundation – Ontario Region
Wearing compression garments will support your at risk arm, especially when exercising and travelling by air. More information about air travel is provided in the section “Air Travel” below. Sleeves should start at the wrist and end at the upper arm two fingers below the arm pit. A compression gauntlet or glove may also be worn. Compression garments should be replaced every four to six months, or when they begin to lose their stretch.

To ensure your compression garment fits well, always ask for a fitter who has received special training. A list of certified fitters can be obtained from the Lymphovenous Association of Ontario and local self-help groups such as Wellspring.

Financial assistance is provided for compression garments through the Assistive Devices Program of the Ontario Ministry of Health and Long-Term Care. More information about the Assistive Devices Program is provided at the Ontario Government’s website: www.health.gov.on.ca under the search term “Pressure Modification Devices,” or by calling 1-800-268-6021 (toll free).

Air travel. When you fly, the cabin pressure is less than the atmospheric pressure on the ground and may create some swelling. If you have been diagnosed with lymphedema, the American National Lymphedema Network recommends taking the following precautions when travelling by air:

- Obtain a well-fitted compression garment that includes a glove or gauntlet
- Put the compression garment on before your flight
- Leave the garment on for one to three hours after getting off the plane
- Move your limbs frequently during the flight to help prevent swelling
- Stand up and move around frequently during the flight and while waiting for your flight
- Avoid lifting and carrying heavy luggage
- Avoid using luggage with shoulder straps; use roller bags instead
- Wear loose-fitting, non-constrictive clothing
- Drink plenty of fluids and avoid alcohol, caffeine and salty foods during your air travel
- Wear a medical alert bracelet identifying that you have lymphedema. These can be ordered through medical identification companies such as the Canadian MedicAlert Foundation, go to: www.medicalert.ca/en/index.asp or Universal Medical ID, go to: www.canada.universalmedicalid.com.
- Ask your doctor if you should bring an antibiotic because of your increased risk of infection. If needed, your doctor will give you a prescription for this medication.

More information about lymphedema resources is provided in the appendix.

Your hospital or cancer treatment centre may have a Lymphedema Clinic to help women with managing lymphedema following cancer treatment.

FATIGUE

“I get tired really quickly just from doing normal things such as using the stairs or cleaning up the breakfast dishes. Sometimes I feel exhausted even if I don’t do anything. Even a good night’s sleep doesn’t help.”
What is cancer-related fatigue?
Of all the side effects of breast cancer and its treatment, fatigue is the one that women report most often. Cancer-related fatigue is an overwhelming sense of tiredness that seems more than you might expect as a result of your recent activity. Cancer-related fatigue can interfere with your daily functioning. Even sleep may not bring relief. You may have trouble paying attention when reading, watching television, even talking with family members. You may find that you are not able to do all of the activities you did before your cancer treatment.

Cancer-related fatigue is caused by a number of different factors such as:

• The fact that your body has been fighting a serious disease
• The physical effects of your treatment
• Changes in your hormones
• Infection or other illness
• Anemia (when you do not have enough red blood cells)
• Certain medications
• Pain
• Being less active
• Poor nutrition
• Sleep interruptions
• Being under stress emotionally and physically
• Being worried or sad
• Dealing with conflict
• Feeling tension among your family, friends and/or co-workers

What can you do about fatigue?
View your fatigue as a side effect of your cancer treatment and not think of yourself as being lazy. Your fatigue is different from the normal tiredness that everybody experiences and can affect the way you think as well as how you feel. There are things that you can do to manage your fatigue while you are healing.

It is normal to feel tired immediately following your treatment. If your fatigue does not go away in several weeks you should work with your doctor and health care team to better understand how to accommodate your reduced energy levels.

Your health care team can help you manage uncontrolled symptoms (such as hot flashes, pain, anemia and emotional distress) as well as helping you make adjustments to your work and lifestyle. These adjustments may help reduce your fatigue.

You can talk openly about your fatigue with your family, your friends and your co-workers, if you feel comfortable doing so. Don’t try to hide your tiredness. Try to understand your fatigue and learn about things that you can do to make it easier to cope:

• Eat well. Eat a varied diet of healthy foods from the four main food groups. Spread your calories throughout the day.
• Plan meals ahead and cook several portions and freeze them.
• Keep well hydrated, especially when exercising. Drink at least 1500 mL (about six cups) of fluid daily. If you find that your sleep is interrupted because you are getting up at night to go to the bathroom, limit your fluids for a few hours before bedtime.
• If you have trouble sleeping, limit caffeine containing drinks to four cups per day or less. This includes regular coffee, tea, iced tea and many soft drinks (check the labels). Do not drink caffeine four hours before going to bed.
• Go to bed at the same time every day and if you have trouble falling asleep then get up and do something boring (for example read the manual for your refrigerator or an old textbook). Seek help if there are problems that are affecting your sleep.

• Be as active as you can during and after your cancer treatment. Start slowly and progress gradually. Aim for 20 – 30 minutes per day of moderate physical activity. Physical activity has been shown to be the most effective thing you can do to combat fatigue. Use the stairs rather than an elevator, take short walks or do some light physical activity such as gardening or light housework. Check with your nurse, physiotherapist, occupational therapist or your family doctor about the best type of physical activity and how long and how often you should be active.

• Balance your energy. Save your energy for those things that need to be done and those that you enjoy the most. Be realistic about what you can do. Modify your work schedule and take rest breaks when possible.

• Pace yourself. If an activity is too tiring, divide it up into manageable stages and spread the stages over several days.

• Prioritize and plan your activity so that you have time to rest throughout the day. Eliminate unnecessary tasks by planning ahead and using shortcuts such as sending an email rather than writing and mailing a hand written letter or letting the dishes dry in the rack. To minimize fatigue and strain on your muscles, watch your posture and positioning as you do activities. Sit down to do a task when you can; it uses less energy than standing.

• Use diversions. Find and do activities you enjoy such as crafts, reading, watching movies or working on puzzles. Try relaxation techniques such as listening to music, reading, deep breathing, progressive muscle relaxation, guided imagery or meditation.

• Rest as often as you need to by taking short naps and breaks. Short periods of rest earlier in the day (before 3:00 p.m.) are better than long ones.

• Check with your hospital or cancer centre to see if they offer a fatigue management program.

More information about healthy eating and physical activity is provided in Chapter Three.

Mental fatigue
Mental fatigue is a type of fatigue that can cause you to experience a lack of mental clarity or a feeling of mental “fuzziness,” to sometimes feel forgetful, and to have trouble concentrating, finding words or speaking. At some point during your treatment or after, you may experience mental fatigue. This is normal and may have resulted from chemotherapy or other medications, as well as stress caused by a number of factors:

• Your diagnosis
• The decisions you are required to make
• Your breast cancer treatments
• The need to make plans and solve problems

To help you cope with mental fatigue, try the following:

• Plan activities that need thinking when you are most rested
• Ask questions, use notes and make lists
• Learn new information in small amounts
• Engage with activities in nature to restore your attention such as walking in the park, smelling flowers, bird watching, or playing with a pet. Choose activities that give you a sense of “being away” from worries and a renewed sense of hope.
• Increase your physical activity
If you are experiencing mental fatigue, the best thing you can do is to minimize your stress:

• Avoid doing too much all at once (multi-tasking)
• Stay involved in social activities such as visiting with friends, dining out, or going to the movies
• Check with your hospital or cancer centre to see if they offer a neurocognitive clinic or cognitive function program

More information about memory and attention problems as well as depression is provided in Chapter Four.

NOTE: If you are working outside the home and your symptoms of mental fatigue are interfering with your performance at work, you may need to speak with your employer about temporary modifications to your work responsibilities. More information on returning to work is provided in Chapter Six.

Practical ways for family and friends to help you
Your family and friends can help you reduce your fatigue. They may not even be aware that you are experiencing fatigue. To avoid misunderstandings, explain how being tired is affecting you. By including your family and friends, you will help them understand what you are going through. Ask them to be flexible with plans and take one day at a time. Consider who gives you support and who may drain your energy, and think about protecting your personal boundaries.

Here are some things that you may want your family and friends to do for you:

• Telephone you at a regular, agreed-upon time to see how you are doing
• Bring over your favourite food in a disposable container so you don’t need to worry about returning the dish
• Have someone you trust take over your care giving responsibilities while you take some time to be on your own or with your partner or a friend
• Take you for a short drive
• Call for your shopping list and make a special delivery to your home.
• Call ahead before visiting. Tell them not to be afraid to visit, but to be open to keeping the visit short.
• Help you celebrate holidays and the change of season by decorating your home or bringing flowers
• Help you help other members of your family who may need some support
• Drive you to appointments, etc.

Your hospital or cancer treatment centre may have a Fatigue Clinic to help women with managing fatigue following cancer treatment.
BREAST PROBLEMS

Any problems you experience with your breast will most likely be the result of your surgery or radiation treatment or both. Fortunately, they will probably go away quite quickly.

Side effects of surgery
Lumpectomy: For a while, the area of your breast where the lump was removed may feel numb and/or tender. You may also feel tenderness and/or shooting pains throughout your breast and into your underlying chest wall. These sensations will usually go away in a few months. However, in some women, tenderness and/or shooting sensations may last for years.

Mastectomy: If you have had your entire breast removed, you may feel some numbness in the skin along your incision site, under your arm and in the area around your breast, arm and shoulder (the axillary area). You may also feel mild to moderate tenderness and stiffness, and your chest wall, arm and axillary area may be sensitive to touch. This change in sensitivity has occurred because the fine nerves to your skin have been cut. This sensitivity can last for a while, but will usually improve as your nerves slowly heal. However, there may be an area of numbness that is permanent. If you choose to wear a breast prosthesis, this sensitivity may cause some discomfort. As nerves repair themselves, you may feel odd sensations such as itching, tenderness, or pins and needles.

Side effects of radiation
As with any treatment, radiation causes side effects. Your radiation side effects will depend on the daily dose of radiation you received, the total dose of radiation you received and the parts of your body that were treated.

You may not begin to heal until seven to ten days after your treatment has ended. In general, side effects caused by radiation will continue for two to three weeks after your treatment is completed. After that time, the side effects will gradually fade.
Common side effects of radiation therapy to the breast may include changes in skin colour, and redness and soreness of the skin and underlying breast tissue. Swelling (edema) or firmness (fibrosis) may also occur.

Skin problems: Irritation to your skin is usually the worst in the upper inner corner of the treatment area, on your nipple, in the crease area beneath your breast and along your lower underarm area, and sometimes your scar area. You will notice that your skin problems will begin to improve approximately two weeks after treatment is completed. In general, your skin problems should clear up by six weeks after treatment. You should follow specific skin care instructions from your health care team during these few weeks, especially if the skin has started to crack during your last week of radiation.

Some women who have had radiation to their breast as well as to the lymph nodes in the underarm area may continue to experience changes in skin colour on the front of the neck/shoulder and at the back of their upper shoulder. For women with a darker complexion or who are easily tanned, sometimes the skin on the breast remains darker than the normal skin tone, similar to a suntan. You may also notice that your nipple looks larger and is more sensitive.

You may need to use moisturizers and provide extra protection from friction for your skin and nipple. You should avoid exposing the treated area (e.g., neck or upper breast area) to sunlight. Cover the area with clothing and, once the skin is healed, use sunscreen with an SPF of 30 or more.

Caring for your skin
After radiation treatment is completed, skin soreness, dryness and itchiness can be treated with a variety of products and procedures that will be recommended by your health care team.

In general, dry, itchy or red skin that is intact may be relieved by taking these measures:

- Lubricating your skin as instructed by your health care team
- Avoiding exposure to sunlight that can cause additional irritation
- Using sunscreen, especially in the area above your collarbone. Use sunscreen with an SPF of 30 or more and apply often when outdoors.
- Protecting your skin from extreme temperatures and wind. Keep indoor temperatures cool.
- Bathing in cool or lukewarm water. Baking soda added to your bath may be soothing.
- Wearing loose-fitting, lightweight cotton clothing
- Drinking plenty of fluid each day to stay well-hydrated

TIP: You may wish to wear a cotton undershirt or vest and avoid bras with underwires. If you are going out, you may want to apply a non-stick dressing to the raw area to protect it from your clothes. Stay away from chlorinated pools until your skin has completely healed. Lake water and ocean salt water are safe if the bacterial count is low.

If an area of skin is blistered or cracked, avoid the use of any products, including an antiperspirant or deodorant. Do not shave under your arm until the sensitive area has healed.
For broken or cracked skin, you can apply a small, soft, clean cloth (a face cloth or gauze dressing) soaked in saline to the area three to four times a day (see below). Continue to do this until the area is healed.

**Recipe for a saline soak:**
- Mix four cups of water and two teaspoons of salt in a pot
- Boil the water and salt for ten minutes. (You can also boil the cloths with the solution and use as needed.)
- Let the water, cloths and salt solution cool down
- Pour into a jar that has been through the dishwasher or rinsed with boiling water, and cover it
- The jar of solution may be kept in the fridge or at room temperature
- Make a new solution everyday

**Instructions:**
- Wash your hands before using the solution
- Place a small, soft, clean cloth such as a face cloth in a bowl
- Pour the water and salt solution into the bowl until the cloth is wet
- Sit or lie down
- Expose the reddened, cracked or open area of your skin
- Gently squeeze the cloth to remove excess water
- Apply the cloth for 10 to 15 minutes to the reddened, cracked or open area
- Remove the cloth and leave the area exposed to the air to dry for another five to 10 minutes

**Swelling (edema):** Some women feel tightness, aching, or cramping in the muscle under the breast, against their rib cage. This sensation is caused by the muscle filling with fluid as part of the healing process. Sometimes these effects subside within a month following treatment, but they may take up to two to three years to subside. As your breast area softens, you may think you feel a new area of lumpiness where your surgery was performed. This has most likely been there from the beginning, but was disguised by the overall firmness of your breast. This lumpiness should also soften and become less tender with time.

Gentle exercise can relieve any discomfort you may feel during the healing process. Speak to your physiotherapist or occupational therapist about exercises and follow the care plans that are recommended by your health care team.

**Firmness (fibrosis):** This side effect may happen many months or years after the radiation is finished. Only a small number of women experience fibrosis. This is scarring of the breast tissue and may make your breast tissue feel harder than normal. Most women usually notice that the radiated breast is firmer than the opposite breast. The fibrosis is usually mild, and you may not even notice it.

**HAIR REGROWTH**

“Nothing was as bad as losing my hair. For me, it was almost worse than losing my breast. It’s so visible, so much a part of my image – so much of me. It’s hard enough to have had cancer and feel bad, but now I think I may look bad too!”

Hair loss is a temporary problem caused by some chemotherapy drugs. If your hair loss upsets you, it can help to remind yourself that your hair will grow back soon. How soon it grows back will depend on how fast your hair normally grows. A few weeks after...
finishing chemotherapy you’ll see soft fuzz. You may experience scalp tenderness with hair regrowth. Within a month, your hair will have started to grow in and will continue to grow at a rate of about one quarter to one half inch per month. As your hair regrows, it may be the same as it was before you had chemotherapy. On the other hand it may be thinner or thicker and curlier or straighter than your original hair. Your hair may also grow back a different colour.

Every woman has a different comfort level with her self-image. Some people choose not to cover their head or wear a wig. If you are more comfortable wearing a wig or head covering, do so for as long as you need to feel comfortable. Once your hair has grown back you can continue to style, colour or perm it as you wish.

DRY EYES

Some women experience dry eyes as a result of their breast cancer treatment and the medications that they may have been prescribed such as Tamoxifen. Dry eyes usually occur when your eyes do not make enough tears to keep them moist. You may notice a sandy or gritty feeling in your eyes; they may be watery or tired, and you may feel burning and the sensation of something in them. There are many types of treatment for dry eyes. All are prescribed by your doctor and could include any of the following:

- Tear replacement with eye drops made of artificial tears
- Ointment to keep your eye lubricated at night
- Sustained release "pellets" that contain artificial tears placed behind your lower eyelid
- Special contact lenses that have low water content. These can help prevent tears from evaporating and keep your eyes moist.

You may also find it helpful to wear glasses that are tight-fitting to decrease the evaporation of tears from your eyes. You could use a humidifier to increase humidity. Avoid smoky places and take care when using hairdryers. Dry eyes that are left untreated can lead to serious complications, so do check with your family doctor or nurse practitioner if you are experiencing dry eyes.

What to expect during the coming year

TREATMENT-RELATED MENOPAUSE

“Sometimes I think I blame too much on my hormones when what’s really causing me problems is the plain facts of my life. My breast cancer happened close to menopause, and now I wonder if what I’m feeling is menopause or the effects of my treatment and recovery.”

Menopause and growing older mean different things to every woman. In some ways, menopause can be positive - no more regular periods or worry about unwanted pregnancy, no more bloating or cramps. On the other hand, menopause can be upsetting because it means that you can no longer bear children and may represent the end of your youth. No matter what your view, there are things you can do to make menopause easier.

Menopause is a part of the natural aging process. As you get older, your body gradually produces less estrogen, which makes your periods become irregular, and after a while, the amount of estrogen becomes so low that your periods stop completely.

About half of women under 50 who are diagnosed with breast cancer will experience premature (early) menopause because of chemotherapy treatment. Other women may experience
menopausal symptoms because they have stopped taking hormone replacement therapy at the time of their breast cancer diagnosis. These symptoms can be quite upsetting for some women.

Am I really in menopause?
Menopause is a process, not just one event. After treatment for breast cancer, many factors affect your periods such as chemotherapy, hormone-blocking treatments (e.g., Tamoxifen), weight changes and stress. There is no medical test to see whether you are “really” in menopause – only time will tell. Some women start having their periods again quite quickly after breast cancer treatment, but for some, their periods don’t return for over one year, or not at all. Your doctor will not be able to tell you what will happen in your particular situation, as each woman is different.

Menopause caused by chemotherapy
Chemotherapy may have caused your periods to become further apart or even stop completely. During your treatment, you may have had symptoms such as hot flashes, night sweats and vaginal dryness. Once you have finished your cancer treatment, you may feel that chemotherapy-related menopause is just one more stress that you have to deal with. You may worry that this sudden menopause might make it harder for you to get well again. As you recover from your breast cancer treatment, you may have trouble distinguishing what symptoms are normal parts of menopause and what symptoms may be side effects of your treatment. This situation can be even more difficult if you are experiencing menopausal symptoms at a different time than other women your age.
NOTE: Your treatment-related menopause may be temporary and there is a chance that you may still be able to get pregnant. If you are sexually active with a male partner and do not want to become pregnant, keep using a birth control method even if your periods have stopped (but not the birth control pill, the estrogen patch or ring). If your period returns, it may begin in the first year after your treatment. However some patients get their period more than 12 months after their breast cancer treatment has ended.

Endocrine treatments
Some breast cancer cells require the hormone estrogen to grow. If your breast cancer was “estrogen-dependent,” you will be advised not to use hormone replacement therapy (HRT) to treat your menopause symptoms. If you have had to stop taking hormone replacement therapy, you may experience menopausal symptoms as a result of a dramatic drop in estrogen.

Your doctor may even prescribe a special endocrine therapy such as Tamoxifen or aromatase inhibitors as part of your breast cancer treatment. Endocrine therapy is the treatment of cancer with medication that interferes with the way the hormone estrogen works. Tamoxifen works by blocking estrogen receptors on breast tissue cells and slowing their growth. Luckily, Tamoxifen has estrogen-like benefits such as keeping bones strong and lowering cholesterol. Unfortunately, in some pre-menopausal and post-menopausal women, Tamoxifen sometimes produces side effects. For example, hot flashes may get worse or recur when Tamoxifen is added after chemotherapy. Lack of estrogen can also cause vaginal irritation and bladder problems in some women.

NOTE: If you are taking Tamoxifen and you notice that your leg becomes hot, red and swollen, notify your family doctor and oncologist, or go to your local emergency department. You may be developing a deep vein thrombosis (DVT). Also notify your doctor if you notice any unusual vaginal bleeding. You may need to be checked for the possibility of uterine cancer. Both DVT and uterine cancer are rare but known side effects of Tamoxifen.

If you have already completed menopause, your doctor may prescribe aromatase inhibitors. These medications block the enzyme aromatase that turns hormones called androgens into small amounts of estrogen in the body. Common side effects include joint stiffness or joint pain. For more information on pain management, see the section on pain at the beginning of this chapter.

You may be concerned that by lowering your estrogen you may raise your risk of heart disease. The benefits of preventing a recurrence of breast cancer will outweigh this risk. Seek as much information as you can about hormone-blocking therapy and talk with your doctor or nurse practitioner to develop a plan of action that will work for you. If you choose to see a natural or holistic health practitioner, make sure he/she is reputable, and refrain from using estrogen-containing preparations. More information about complementary/alternative medicine is provided in Chapter Seven.

Symptoms of menopause
Whether they are caused by treatment or come on naturally, menopausal symptoms are very different for each woman. Here are some short- and long-term changes you may experience:

- Changes in your periods
- Hot flashes and night sweats
- Tiredness and trouble sleeping
- Less interest in sex
If you are experiencing:

**Hot flashes and night sweats**
- Check with your family doctor. Non-hormone medicines such as the antidepressants venlafaxine (Effexor) and gabapentin (Neurontin) have been helpful in reducing hot flashes.
- Try avoiding alcohol and caffeine to see if it helps
- Wear layers of clothing made out of natural fibres such as cotton
- Splash cool water on your wrists
- Remember that these symptoms are probably temporary and may subside

**Sleeping problems**
- Try drinking warm milk, chamomile tea or relaxing herbal teas at bedtime

**Irritability or anxiety**
- Use relaxation techniques such as visualization, deep breathing, massage or acupuncture

**Vaginal dryness**
- Try a water-soluble lubricant, which can be helpful if applied just before having intercourse; non-hormonal lubricants include Astroglide and Replens
- Try vaginal moisturizers such as Replens and vitamin E. Vitamin E vaginal suppositories are also helpful, but use no more than 800 IU per day
- Consider that for some women, having sexual intercourse more often can decrease the dryness
- Wear cotton underwear

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**Vaginal bleeding**
Vaginal bleeding can have a variety of causes. It may be a sign that your period has returned, especially if the bleeding occurs for a few days every few weeks. If you were post-menopausal before your breast cancer treatment, or have not had your period for many months, vaginal bleeding could be a sign of a problem with the lining of the uterus. You should contact your family doctor and oncologist if you suddenly start to have unexpected vaginal bleeding.

**Living with menopause**
There are many things that you can do to help with menopausal symptoms. Because every woman experiences menopause differently, each woman will use different ways to cope.
Other herbal therapies for menopausal symptoms, specifically black cohosh and vitamin E, have not been shown to be effective in reducing menopausal symptoms in women who have had breast cancer. Note: Black cohosh should not be taken by women who have had breast cancer. Check with your doctor before starting any new therapy to relieve menopausal symptoms. More information about complementary/alternative medicine is provided in Chapter Seven.

OSTEOPOROSIS

Because you may have reached menopause earlier than normal as a result of your treatment, or because your hormone replacement has been discontinued, you may have a higher chance of developing osteoporosis, a disease that affects your bones and may cause them to break more easily. This bone loss affects one in four women over the age of 50 in Canada. The rate of bone thinning can speed up around the time of menopause with the loss of estrogen. Women who have been treated for breast cancer may be at higher risk for osteoporosis because their breast cancer treatment often includes the reduction of estrogen.

You can reduce your risk of developing osteoporosis by making sure you are getting enough calcium and vitamin D everyday in your diet through food sources and, if necessary, supplements. Health Canada’s recommendations for elemental calcium are 1,000 mg per day for adult women younger than 50 years of age and 1,200 mg per day for women 50 and over. Your intake of calcium should be spread throughout the day and can include high-calcium foods as well as supplements. For example, one 8-oz glass of milk contains 300 mg of calcium. Do not exceed 2,400 mg of calcium per day from food and supplements.

Most women who have had breast cancer should take additional vitamin D supplements. Most Canadians, in fact, do not get sufficient vitamin D through sun exposure and diet. Generally known for its role in promoting bone health, the effect of vitamin D on cancer risk and outcomes is not yet clear. New research

Bladder infections

- Drink lots of fluids (eight to 10 glasses a day)
- Wear cotton underwear
- Urinate frequently (especially after sex)
- Keep your genital area clean

Bladder control

- Try Kegel exercises to improve your bladder control. You can ask your family doctor or nurse practitioner how to do them or check in a book on women’s health.

Complementary therapies for menopause

While herbal therapies are available to relieve menopausal symptoms, many are not recommended for women who have had breast cancer, either because the therapies are not effective or there are concerns about their safety.

Some over-the-counter herbal products used to reduce menopausal symptoms contain phyto-estrogens in concentrated form. However, there is concern about the safety of concentrated phyto-estrogens for women who have experienced breast cancer. Phyto-estrogens are compounds, similar to estrogen, that are found in plants. Until more is known, women who have had breast cancer are advised to avoid using both herbal phyto-estrogens and concentrated soy components in pill or powder form.

NOTE: There are some estrogens that are placed directly into the vagina to reduce vaginal dryness. These include Estring (a ring placed into the vagina) and Vagifem (a vaginal tablet) and are prescribed by your doctor. You should always check with your oncologist before using them because it is not yet known how safe these products are for women who have had breast cancer.
in your body you are at a higher risk for developing heart disease or stroke. While your family history, age, gender and ethnicity can affect your risk of heart disease, there are other risk factors that you can control. The Heart and Stroke Foundation recommends the following steps to lower your risk of heart disease:

- Find out if you have high blood pressure or high blood cholesterol, and if you do, learn how to control them
- Maintain an ideal weight through healthy eating and physical activity. For more information about weight control, see Chapter Three: Healthy living after breast cancer treatment.
- Limit your consumption of alcohol and tobacco products
- Limit your stress

Chemotherapy-induced cardiotoxicity
It is possible that your treatment for breast cancer may have had some side effects on your heart. Chemotherapy-induced cardiotoxicity is a rare side effect in which damage to the heart muscle is caused by chemotherapy or Trastuzumab (Herceptin). This damage may make it difficult for your heart to pump blood throughout your body. Inform your health care team if you experience shortness of breath that won’t go away.

What to expect over the next few years

LONG-TERM PHYSICAL SYMPTOMS AND SIDE EFFECTS OF BREAST CANCER TREATMENT
As more and more women survive breast cancer and live longer, more active lives, doctors learn more about the long-term effects of cancer treatment. As our understanding increases, oncologists are better able to anticipate and respond to these changes.
PREGNANCY AND CHILDBIRTH

“...My husband and I had decided to have a baby, but I got cancer instead. When my treatment was over, I was told I could try again, but I found out that my ovaries had shrunk from the chemotherapy and I couldn’t take fertility drugs. To make matters worse, my periods became irregular and I noticed signs of early menopause.

Can I become pregnant?

If you were pre-menopausal and did not have a hysterectomy or oophorectomy prior to being diagnosed with breast cancer, it may still be physically possible to become pregnant. Even though your periods have stopped, you may continue to ovulate and could therefore become pregnant. However, it is recommended that you wait for at least two years after your breast cancer treatment before you attempt to get pregnant. It is also important to note that hormone-blocking treatments such as Tamoxifen should not be taken if you are pregnant or trying to get pregnant.

It is still unknown whether the hormone levels of pregnancy have an effect on the recurrence of breast cancer in women. Many fertile women go on to become pregnant after they have had breast cancer. If you would like to have a child after your breast cancer treatment is completed, you should discuss this with your health care team. Information on fertility-related resources is provided in the appendix.
This chapter outlines the importance of a healthy lifestyle as you recover from your treatment for breast cancer. It looks at ways to support healthy eating and physical activity, and to set goals for a healthy fitness routine that will work for you.

What you may be feeling now

“During my breast cancer treatment I put on a few pounds. My doctor told me to watch my weight but my friends and family tell me not to worry. Changing my diet and activity seems like such a challenge, especially now when I’m trying to get my life back together after treatment.”

Up until now you have spent most of your time dealing with your illness and its treatment. You may not have had time to even think about eating right, and you may not have had the energy to plan a physical activity program. This is perfectly normal. As you recover from your treatment and any lingering physical side effects begin to lessen, you can turn your thoughts to getting back to a healthy lifestyle that includes making sure you are eating right and being physically active.

What you need to know now

Some women may gain weight during treatment, even if they haven’t increased the amount of food they eat. Although losing weight may not be your first goal at the moment, now is a good time to pay some attention to setting lifestyle goals and eating for your long-term health. A healthy, well balanced diet may help reduce your risk of breast cancer recurrence, other cancers, obesity, heart disease and adult-onset diabetes. Physical activity may also help reduce your risk of breast cancer recurrence, and it will enhance your sense of well-being and have a positive effect on your overall health.

HEALTHY EATING AFTER TREATMENT FOR BREAST CANCER

Here are six recommendations that are important for everyone and will help you make healthy food choices after your treatment.

- Control your calories
- Eat more fruit and vegetables
- Eat more plant-based meals
- Eat more fibre
- Eat less fat
- Eat less sugar

1) Control your calories to achieve a healthy weight

Obesity is a serious problem in Canada. Not only is it linked to an increased risk of breast cancer, it also contributes to increasing your risk of heart disease, other cancers and adult-onset diabetes. Controlling your calories is all about consuming the right amount of calories for your height and physical activity levels.

What is a healthy weight?

Your Body Mass Index (BMI) is a measure of weight that takes height into consideration. BMI can be an important indicator of whether your weight is putting your health at risk. A BMI of 18.5-25 is a healthy weight range if you are under 65 years of age, while a BMI of 20-27 is a healthy weight range if you are 65 years of age and over.
Don't be too concerned if your weight has increased slightly during treatment. You can regain control by making some of the changes listed in this chapter to your dietary habits and level of physical activity. However, if you find your weight is above the healthy range for your height, you may want to have your family doctor or nurse practitioner refer you to a dietitian to develop a nutritional plan tailored to you.

2) **Eat seven vegetable and fruit servings per day**

You are probably already aware that it is important for your overall health to eat vegetables and fruit. These foods contain many vitamins, minerals and other nutrients that work together to promote health.

**What is a serving of vegetables and fruit?**

One serving of vegetables or fruit is one cup of leafy greens, one half cup of chopped vegetables or fruit, one whole piece of fruit or four ounces of juice. Getting your seven servings of vegetables and fruit each day is as easy as eating berries with breakfast, drinking vegetable juice and eating a large salad with lunch (counts as two servings), enjoying fruit as an afternoon snack and having two vegetables with dinner. Remember to eat vegetables and fruit in a variety of colours. Choose orange, dark green and red fruit and vegetables to get the most nutrients.

3) **Eat more plant-based meals**

In addition to fruits and vegetables, other plant-based foods include grains and legumes. Legumes such as dried peas and beans are a high fibre, low-fat source of protein. By choosing them for some meals instead of meat, you can increase your fibre and reduce your intake of saturated fat.
Never cooked with legumes before?
Try using canned red kidney beans in a vegetarian chili or canned lentils in soup. Check a vegetarian cookbook or magazine for ideas about how to cook with legumes. You can also find legume recipes online at www.pulsecanada.com or www.pea-lentil.com.

4) Increase your fibre to 25 grams per day

Eating lots of fibre will help control your hunger. It will also help keep your digestive system healthy and control your cholesterol and your blood sugar levels.

How can I get 25 grams of fibre?
You can get 25 grams of fibre by consuming seven servings of fruit and vegetables and five servings of whole grains per day. A serving of whole grains is one slice of whole wheat or multigrain bread, or half a cup of foods such as these:

- Barley
- Brown rice, wild rice
- Buckwheat
- Bulgur
- Corn
- Whole grain cereals (e.g. Shredded Wheat, oatmeal)
- Whole grain pasta

5) Limit your intake of fat

A high-fat diet can lead to weight gain and may increase your risk of breast cancer recurrence. It is important to keep your total fat intake moderate. It is also important to be aware of the different kinds of fat. Some fats are healthier than others.

Foods with healthier fat sources:
- Olive oil, canola oil
- Oil-based salad dressings using olive or canola oils
- Nuts (almonds, walnuts, peanuts)
- Fatty fish (salmon, sardines, herring)
- Avocado

Saturated fats are found mainly in animal products. These animal fats contribute cholesterol to the diet and should be consumed in moderation. An example of a moderate portion is a three-ounce serving of meat.

Foods with high levels of saturated fats:
- Red meats, ribs, organ meats
- Bacon, salami, bologna
- Eggs
- Full-fat cheeses, cream cheese
- Butter, ghee, lard
- Cream, whipping cream
- Sour cream, creamy salad dressings
- Mayonnaise, tartar sauce
- Ice cream

Trans (or hydrogenated) fats are created through a chemical process called hydrogenation that makes them remain in a solid form. These fats limit the body’s ability to regulate cholesterol and should be avoided as much as possible.
Foods with high levels of hydrogenated fats:
- Hard margarines
- Vegetable oil shortening
- Commercial pastries, croissants and cookies
- Non-dairy creamer
- Fried snack foods, like french fries and chips
- Other deep-fried, fast foods

How can I reduce the fat in my diet?
Most dairy products are available in low-fat forms. You can help cut your fat intake by using skim (0% fat) or 1% milk, low-fat yogurt and partly skimmed-milk cheeses. Trimming the fat off meats and removing the skin from poultry will reduce the fat. When you are eating higher fat foods, keep the portion size small and eat these foods less frequently.

6) Limit your intake of sugar
Sugar provides “empty” calories. This means it provides no nutritional value other than energy. Currently, researchers are investigating how dietary sugar affects the development of diseases such as diabetes. Reducing your intake of foods high in sugar can help you manage your weight.

Foods that contribute a high level of calories from sugar:
- Sugar, syrup, honey
- Jams and jellies
- Regular soft drinks, iced tea and fruit-flavoured drinks
- Regular jello, popsicles, slushies
- Regular chewing gum
- Candies, marshmallows
- Fruit canned or frozen in heavy syrup
- Burfi, halva*
- Chocolate bars, fudge*
- Cake, pastries, and donuts with icing or glaze*
- Cookies with cream filling or chocolate coating*

* These foods contain large amounts of both sugar and fat.

A word about vitamin supplements
The World Health Research Fund (WHRF) and the American Institute for Cancer Research (AICR) recommend that the best way to meet your nutritional needs is through the food products you eat and drink.

In some situations, however, certain supplements are a good idea. For example, most Canadians, including women who have had breast cancer, should take vitamin D supplements. Due to our low levels of sunlight in Canada, Health Canada recommends supplements of 200IU/day for people aged 19–50 years, 400 IU/day for those aged 51–70 years; and 600 IU/day for those aged 71 years or older. These amounts are in addition to the vitamin D you take into your body through the foods you eat. See the section on osteoporosis in Chapter Two for more information on vitamin D supplementation.

Always check with your family doctor before taking vitamin supplements, especially if you are considering taking higher-than-recommended amounts. Your doctor may also measure your vitamin D level to check whether you are getting enough vitamin D.
Setting goals for healthy eating

A good way to tackle these six recommendations is to write down exactly what you eat and drink for three days. Then compare your intake with the recommendations. This exercise will help you find any “trouble spots” in your diet. Here are some examples of things you may notice:

- Your total vegetable and fruit intake is only four servings a day.
- When you have meat at dinner, the serving is a six-ounce portion.
- You use higher-fat foods such as medium ground beef, regular mayonnaise, 2% milk.

Once you have a list of areas to improve, you can set your goals for change. If your list is long, you may want to set goals over a few weeks, instead of all at once. Make sure your goals are specific, so you can tell if you are succeeding. Here is a sample schedule for change:

**Week 1:**
- ✔ I will change from using 2% milk to skim milk.
- ✔ I will increase my vegetable servings at dinner by one serving.

**Week 2:**
- ✔ I will change from medium to extra lean ground beef.
- ✔ I will change from white to whole wheat bread.
- ✔ I will bring a piece of fruit to work for a snack each day.

**Week 3:**
- ✔ I will reduce my meat portion at dinner from six to three cooked ounces.
- ✔ I will change from regular to light mayonnaise.

**Week 4:**
- ✔ I will have a meatless meal at dinner once a week.
- ✔ I will change from white rice to brown rice.

**Week 5:**
- ✔ I will try cooking some new foods that include more legumes.

**DEVELOPING A NEW PHYSICAL ACTIVITY ROUTINE**

“Now that I’m finished my treatment, I can feel my energy levels beginning to return. I want to start a new physical activity program, but I’m not sure how far I can push myself.”

Physical activity is an important ingredient in the recipe for a healthy life. Often, women who have experienced breast cancer are fearful of being too active because they worry they may push themselves too far. In addition, the effects of treatment may have left them feeling tired, anxious, depressed and less inclined to exert themselves.

You need to know that at this point in your life, physical activity is extremely important. Physical activity may help reduce your risk of breast cancer recurrence. Physical activity can also provide these benefits:

- Improve your muscle and bone strength
- Help with managing your weight
- Help you regain your energy
- Help you feel better emotionally
- Enhance your independence
- Reduce the side effects of treatment
- Improve the quality of your life

Did you know that physical activity can reduce fatigue?

Fatigue is one of the most distressing and devastating effects of breast cancer treatment. One of the most important benefits of being physically active is that it can help you feel less tired. Physical activity through an exercise program can actually reduce the loss of
physical functioning caused by breast cancer treatment and, if the program involves aerobic exercises, it can even improve your lung capacity. This all adds up to less work for your body; as a result, you will feel less tired.

Even minimal physical activity is good for you, especially as you put treatment behind you. You will soon discover that physical activity can be empowering. It is something that you can have control over. It will also enhance your overall well-being.

**There is no better time than now to get active!**

Now that you have completed your active treatment and started to get back to a more regular routine, you may want to make a commitment or recommit to a healthy lifestyle. It will be natural for you to have some questions and fears as you begin a physical activity program, or re-engage in the physical activities you enjoyed before your diagnosis and treatment. You may worry that physical activity might cause damage or even a health problem such as lymphedema.

You may also wonder when you should start to become more active, how much you should take on and what your limits may be. You will need to find out what kinds of activities you can participate in. There are no hard and fast rules about physical activity after breast cancer treatment; with help you can develop a safe, effective physical activity program. Your health care team can help you identify any limitations that you should be aware of as you become more active.

Your return to activity after treatment should increase gradually. Keep in mind that your surgery and post-surgery treatment have taken a great deal out of you, and your progress will take time. You may want to keep a log to see how you are progressing. Be patient! You will soon feel stronger and less tired as a result.
Handling weights with care:
When using weights, use smooth and controlled motions. If you gradually increase the weights and repetitions, you won’t tire as quickly and will feel stronger when doing physical or recreational activities. Strength training also helps increase the amount of lean muscle in your body and can help prevent or fight against osteoporosis.

Dress for success:
Whether you exercise indoors or out, always wear clothing that is loose fitting, particularly on your arms, shoulders and chest, and is appropriate for the climate.

Avoid overdoing it:
You can avoid overheating by wearing light, breathable clothing and drinking plenty of water throughout your activity. If you feel tired, listen to your body and lower your intensity.

Do you have problems with shoulder mobility?
If you experience problems moving your arm and shoulder, ask your doctor or nurse practitioner to make a referral to a physiotherapist and/or occupational therapist. He/she can do a comprehensive assessment, provide recommendations to optimize your function and mobility, and work with you to develop an individualized exercise program.

Try a dance-based exercise program
Dance-based exercise programs can help you recover from the physical side effects of surgery and treatment, regain mobility and strength, and improve your general well-being. The therapeutic effects of dance can also help you cope with emotional stress. Once you’ve learned some basic moves you can do them at home.

A note about lymphedema and physical activity
If you have had axillary lymph nodes (in your armpit) removed, your shoulder and arm may have reduced mobility and lymph flow. In the
past, women who have had axillary surgery have been warned to avoid vigorous and repetitive upper body exercise. Recent research has questioned this recommendation and has shown that upper body exercise does not cause lymphedema, providing you start the exercises slowly and progress gradually. It is now thought that physical activity can help you regain your range of movement and enhance lymphatic flow in the arm and shoulder. Some women at risk for lymphedema use compression garments when doing strenuous and repetitive exercises, but the benefits of this practice are still being tested.

If you have lymphedema, it is suggested but not yet proven that you should avoid saunas and whirlpools. This is because the heat of the water can increase your circulation and bring more fluid into your arm. You should also wear your lymphedema sleeve during all physical activity, and if you feel fatigued or hurt, you should stop. Swelling, aching or a feeling of heaviness in your arm or other parts of your body may suggest that you are doing too much and trying to progress too fast.

In women with lymphedema, recent studies have shown that slow, progressive weight lifting resulted in reduced symptoms and increased strength and did not affect limb swelling. Always get your doctor’s or nurse practitioner’s approval prior to beginning a new physical activity program, and if you have questions, consider seeking the guidance of a physiotherapist or occupational therapist to help create a safe and effective physical activity program. Listen to your body and start on your own path to living a stronger, healthier life. More information about lymphedema is provided in Chapter Two.

A note about your body image and physical activity

Your treatments may have changed parts of your body temporarily or permanently, affecting your body image and the physical activities you feel comfortable participating in. There is no one way to decide how to get involved in physical activities when you are also adjusting to changes in your body image. For example, if you had mastectomy surgery and use a breast prosthesis, you may feel uncomfortable about wearing the prosthesis when swimming. Purchasing a swimsuit with pockets to hold the prosthesis so it won’t slip out, using a private shower/change cubicle if available, going with a friend who can support you, or deciding to start with another type of physical activity are all options you may want to consider.

For women who have had chemotherapy, it can often take several months for hair to fully grow in. You may want to participate in physical activities, but feel self-conscious or not sure about wearing a wig during these activities. For example, you may want to join an exercise program at a gym or community centre. Wearing a light hat or a scarf instead of a wig, going with a friend for emotional support, using a separate shower cubicle if available, or postponing this type of activity until your hair has fully grown in are all possible responses. Whatever you decide, finding the right way for you to engage in physical activities is important to your overall physical health and emotional well-being.

A STEP-BY-STEP GUIDE TO SETTING ACTIVITY GOALS

Here is a step-by-step process to help develop your own personal physical activity plan.

Step 1: Determine what activities interest you

Adding any type of physical activity, for example brisk walking, will give you health benefits. What are your favorites? Do you enjoy golfing, walking with friends, walking at home on a treadmill, dancing or gardening?

List some of the activities that you and your family, spouse, partner or friends enjoy doing together and that you can do over the next month:

1. 
2. 
3. 

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**Getting Back on Track**

**Life after breast cancer treatment**

**Princess Margaret Hospital**

74 Canadian Breast Cancer Foundation – Ontario Region

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**Step 2: Determine how much physical activity you should add**

- Write down the number of days a week you are currently active:
  
  I am currently active ________ days a week.

- Write down the number of minutes of a day you are currently active:
  
  I am currently active ________ minutes a day.

- Write down the level of your activity:
  
  I am usually active at a ______________________ level.
  
  (moderate/vigorous)

- Find the number of minutes you are active per day in the left column of the chart below.

---

**Minutes I exercise each day now**

<table>
<thead>
<tr>
<th>Minutes I exercise each day now</th>
<th>Towards the goal of being active at least five days a week for at least 30 minutes each day, the number of minutes I need to add each day.</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 10 minutes</td>
<td>20 - 30 minutes</td>
</tr>
<tr>
<td>11 - 20 minutes</td>
<td>10 - 20 minutes</td>
</tr>
<tr>
<td>21 - 30 minutes</td>
<td>0 - 10 minutes</td>
</tr>
<tr>
<td>30 minutes or more</td>
<td>Although you meet the recommended goal for exercise minutes, you can increase your health benefits by adding more exercise if you wish.</td>
</tr>
</tbody>
</table>

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- Write down the number of exercise minutes and days you need to add to your regular routine. You will use this number later to help you set an exercise goal.

  I need to add ________ days to my exercise program.

  I need to add ________ minutes of exercise.

---

**Step 3: Set a goal**

Write a goal for this next week by filling in the blanks below.

Starting on ______________________, (day of the week)

I am going to_______________________________________

(your physical activity choice) for ____________ minutes.

I am going to do this ________ days this week.

---

**Step 4: Make your goal a reality**

What do you need to do to meet this goal? Do you need to buy walking shoes or call a friend and ask them to start walking with you? Should you buy an exercise video or call your local fitness centre and sign up for a class? List these steps below:

1. 
2. 
3. 

---

**Step 5: Reward yourself!**

Write down how you will reward yourself if you meet your goal.

---

**EXAMPLE OF A WALKING GOAL**

“Starting on Monday, I am going to walk for 30 minutes. I am going to do this five days this week (Monday to Friday). I am going to phone my friend Kari to see if she will walk with me after work or at lunch time. If I can do this for two weeks I will buy myself a new pair of walking shoes.”
Keep fine tuning your fitness goals
As you achieve your fitness goals, it is important to raise the bar so that you continue to challenge yourself. You can even set goals that will help you start moving more and sitting less. For example:

- When I talk on the phone, I am going to walk around rather than sit in a chair.
- I am going to take the stairs when I can instead of getting on the elevator on the main floor.
- I am going to play outdoors with my children instead of watching TV with them.

What to expect over the next few years

This chapter has provided many tips about how to follow a healthy eating plan and how to increase your physical activity. If all these changes seem overwhelming, remember that every journey begins with a single step. By setting a few basic goals for eating and activity, you will soon find that you have taken charge of your diet and activity and are well on your way to a healthy lifestyle.
This chapter examines some of the emotional, psychological and spiritual needs you may have as your breast cancer treatment ends and your life continues. It deals with some personal issues you may face and how you might work through them on your own and with support from others.

What you may be feeling now

“My children want me to tell them that I’m cured, but I’m not sure what to say. Will I ever be rid of this dreadful disease?”

The past months have probably been an emotional time for you. You may find that emotional ups and downs might continue for a while longer now that your active treatment has ended.

While your family and friends may hope that things will return to the way they used to be, you may wonder if things will ever be the same. The truth is, your diagnosis and treatment for breast cancer have changed you and it is likely that you will need to find a “new normal.”

What you need to know now

“I’m the kind of person who likes to see results. I love to start a job and finish it. For the past few months, I’ve been working to get rid of this disease. When will I know that it’s gone for good?”

DOCTOR, AM I CURED?

In the modern world, we like to believe that there is a cure for every illness. If you have been treated for breast cancer, you will want to be told that you have been cured. Unfortunately, the reality of breast cancer is that there is no way to know that it is ever completely gone.

When breast cancer cells return after treatment, it is called a recurrence. There are three types of recurrence:

- **Local recurrence:** when breast cancer cells are discovered in the breast at the scar where the original surgery took place.
- **Regional recurrence:** when breast cancer cells are found in the area around the breast near the original surgical scar.
- **Distant recurrence:** when cancer cells are discovered in other areas of the body (sometimes also referred to as metastasis or secondary cancer). These cells probably spread from the original tumour before treatment and settled in another place in the body. They can be present for years without symptoms and then suddenly cause problems.

It may be hard to live with the knowledge that your cancer may come back, but keep in mind that all available measures have been taken to ensure that at this point in time there is no evidence of cancer in your body.

**What is my risk of recurrence?**

For many women with breast cancer, it is unlikely that cancer will recur. The chance that cancer will come back depends on many factors:

- The size (or grade) of the tumour
- Whether or not the tumour was estrogen-receptor or progesterone-receptor positive
Family risk

Approximately five to 10 per cent of women with breast cancer have an inherited predisposition for the disease. This means that in a small number of cases, a hereditary factor that has been passed down from parents to their children through generations may cause the members of the family to have a greater chance of developing certain types of cancer such as breast, ovarian and prostate cancer. Finding out whether you have a hereditary predisposition for breast cancer is complex and depends on many factors. Some of the factors that may suggest that a family has a hereditary predisposition include the following:

- Being from a family that has two or more close relatives who were diagnosed with breast cancer under the age of 50
- Having a family member who was diagnosed with breast cancer before 35 years of age
- Being from an Ashkenazi Jewish background
- Having a family member who was diagnosed with male breast cancer
- Having a family member who was diagnosed with invasive serous ovarian cancer
- Having many family members diagnosed with any type of cancer at a young age

If a woman with breast cancer does not have a strong family history of breast cancer, her sisters and daughters still have a slightly higher than average risk for the disease. They should discuss with their family doctor or nurse practitioner how often they should have a mammogram and physical examination.

Note: If you have had a form of breast cancer known as Ductal Carcinoma in Situ or microinvasive cancer there is only a very low chance that your cancer may come back. Death from this type of breast cancer is so rare that you can regard yourself as cured after your treatment is complete. In this case, you will need to be checked for new primary cancers, not cancers caused by your original tumour.
Genetic testing for breast cancer

Changes or mutations in two genes called BRCA1 and BRCA2 (Breast Cancer 1 and Breast Cancer 2) are involved in most cases of hereditary breast and ovarian cancer. Researchers are also searching for other genes that may increase a woman's breast cancer risk.

Genetic testing can help find out if a person has a mutation in the BRCA1 or BRCA2 genes. Having a mutation may increase the chance for other family members to get breast, ovarian and prostate cancer.

You may qualify for genetic testing depending on your family history of cancer (see above) or if you come from an Ashkenazi Jewish background. This type of testing is done in a special clinic with genetic counsellors, who will explain the benefits and limitations of testing and who will help you and your family understand the results. Not every family will be eligible for genetic testing, and genetic testing may not be the right choice for every family.

You will need to think carefully about a decision to have genetic testing. If you think there may be a hereditary link to your breast cancer and are interested in finding out, you will need a referral to a genetic counsellor through your health care team. More information about genetic counselling services in Ontario is provided in the appendix.

LIVING WITH THE FEAR THAT YOUR CANCER MAY COME BACK

“No matter how hard I try to put my fears aside, I often find myself worrying that my cancer will come back. Every ache and pain I feel scares me.”

Step 1: Think about your personal feelings

Some women think about their cancer experience everyday. Others think about it less often. Your approach will be your own and may change as time passes.

There is no reason to believe that there was something you could have done to prevent getting breast cancer or to blame yourself and think that you somehow “deserved” to get it. Your breast cancer is not your fault. You are not to blame. There was nothing that you could have done differently that would have completely eliminated your breast cancer risk.

Instead, it can help to try and focus on the positive. This can include having faith in the treatment you received and remembering how hard you fought to overcome breast cancer.

Step 2: Accept that it will be difficult

It is perfectly normal to fear that breast cancer will return. After a while, you may have fewer thoughts about breast cancer, but some anxiety may return. This anxiety may happen at times when you expect it, such as the anniversary of your diagnosis or before a medical checkup. You may also find that you become anxious at times when you don't expect it, for example significant moments such as weddings, birthdays, etc. If you feel overwhelmed at these moments, you may want to seek help from someone you trust. Talk to your family doctor, nurse or another member of your health care team about how you are feeling.

You may feel lonely and isolated after your breast cancer treatment is over. Your family and friends may think that it’s time for you to get back to your life again. They may not understand your fears or other concerns you may have. You may find that you do not want to upset them by talking about it. More information about “survivor loneliness” is provided later in this chapter in the section entitled sadness, depression and anxiety.
If you would like to talk to others who share the breast cancer experience, you may want to join a support group or seek out one-to-one peer support. More information about peer support is provided in Chapter Five: Reaching out: your social needs.

**Step 3: Take action!**

Even if you are worried about breast cancer recurrence, don’t let your worries prevent you from participating in regular followup and monitoring. Here are some things you can do:

✔ **Regular doctor’s followup**

As described in Chapter One, you and your family doctor, nurse practitioner or oncologist will need to work together on a plan for regular followup. This followup may include annual mammograms and clinical exams. Other tests are not usually required. It will be important to keep your health care team up-to-date on how you feel physically and to check with them about any changes in your health.

Many women find their regular followup appointments are very difficult emotionally. Not knowing whether your cancer may have come back can be very upsetting. It may help you to talk to another woman who has experienced breast cancer. Bring along this person or someone else you trust as well as a list of any questions you may have to your doctor’s appointments.

Call your family doctor or nurse practitioner if you have any concerns or a symptom that you are worried about such as the following:

- Any new lump in the breast area
- Steady and unusual pain in your legs or back
- A dry cough that does not go away
- A decrease in your regular amount of energy
Your family doctor or nurse practitioner should always be the first one you call, but you can also contact your oncologist, the nurse who works with your oncologist or any member of your health care team. If you are seeing more than one oncologist, try to spread out your appointments with them over time to make the followup more effective. This is also a good way to receive more regular clinical exams.

✔ **Annual mammograms**

A mammogram can detect any changes in your breast that might be signs of breast cancer. If you have been having your mammograms done through the Ontario Breast Screening Program (OBSP), you will no longer be eligible to participate because you have had breast cancer. Instead you will go to a diagnostic mammography centre for your mammogram at the hospital where you had your surgery, at your cancer centre or at a local centre in your community.

Be sure to go to a centre that is accredited (which means that it has met specific standards around quality) by the Canadian Association of Radiologists (CAR) Mammography Accreditation Program. If you are not sure about whether a facility is accredited or not, contact CAR at (613) 860-3111 or email: info@car.ca.

✔ **Be breast health aware**

Your breasts have probably changed as a result of your breast cancer treatment. You may have even lost a breast or both breasts. Getting used to how your body now normally looks and feels can help you be alert to any unusual changes. Changes to look for include the following:

- Changes to the size or shape of one or both breasts
- Unusual, steady pain in the breast or armpit area that does not go away over four to six weeks
- Swelling under the armpit or below the collarbone
- Nipple changes, including discharge, a change in the shape or position of a nipple, or a nipple that becomes pulled inward (inverted)
- Lumps or thickening
- Skin changes, including redness, irritation, rash or scaly skin
- Dimpling or puckering

If you find something that concerns you, report this change to your family doctor or nurse practitioner, who can find out what is causing the change.

**Step 4: Find a way to cope that works for you**

Every woman will develop her own special way of coping after her breast cancer treatment is over. Some women prefer to cope on their own while others like to talk about their experience. You will need to find what approaches will work best for you. Here are some ways to cope:

**Support groups**

You may have already joined a support group when you were going through treatment. If not, you may want to think about it now. There are many wonderful breast cancer support groups available in Ontario. You can join one, organize one, or even help to restart an old group. You will find that there are many other women who will want to share their experiences with you and learn what they can from you. More information about peer support is provided in Chapter Five: Reaching out: your social needs.

**Individual counselling**

You may choose to work directly with a counsellor such as a social worker, psychiatrist, psychologist, psychotherapist or religious or spiritual counsellor. Counselling may help you with all of the following:

- Recovering emotionally from breast cancer
- Increasing your confidence
• Improving your ability to cope
• Strengthening your relationships with others
• Improving your communication with others
• Becoming more aware of your own needs and how to meet them

Volunteering
Some women volunteer their time to help other women who are experiencing breast cancer. If volunteering is something you would like to do, there are many ways for you to contribute. You can spend as much or as little time as you want. Some volunteer positions may take many hours every week throughout the year, while others will require only a few hours during special times. The choice is up to you.

Here are some volunteer possibilities:
• Working with peer support programs for other women who have experienced breast cancer
• Driving patients to treatment
• Promoting education about cancer in schools, community groups and ethno-cultural organizations
• Volunteering at your local hospital
• Organizing or participating in fundraising and special events such as one of the many runs or walks for breast cancer

Volunteering is a good fit for some women, but it’s not for everyone. Some programs will ask you to wait for one or two years after the completion of your treatment before you begin volunteering. It is best to give yourself some time to recover before taking on any major time commitment.

Help for your partner and your family
If you have a partner or spouse, be alert to the possibility that he or she may also need help and support in dealing with the stress of breast cancer. In order to help you maintain a positive outlook, your partner may not have openly expressed his or her concerns. If your spouse or partner is a woman, she may have additional worries such as her own fear of developing breast cancer.

If you have children, no matter what their age they will also need support. They have been through a very difficult experience and may be afraid to tell you how worried they are.

More information about support groups and individual counselling options for spouses, partners and children is provided in the appendix.

For more on your relationship with your partner and your children, see Chapter Five: Reaching out: your social needs.

What to expect during the coming year

ADJUSTING TO THE LOSS OF YOUR BREAST

“After my surgery I kept dressing and undressing in front of the mirror. I’d try on all the clothes I’d worn before, and even with the prosthesis, nothing seemed to look the same.”

Healing your self-image
Your body image is about more than just your physical self. It also includes your overall sense of wholeness, how you feel about yourself and your appearance and how you relate to others. For many women, their breasts are important to how they feel as
a woman. If this is true for you, after breast cancer treatment you may find yourself feeling changed and less attractive. This experience may be even more complicated if you had negative feelings about your body before breast cancer.

Finding ways to look and feel better

• Accept that there are changes (negative and positive) to your body and how you feel as a person. If you can, talk to supportive and trusted friends and family about your feelings.

• Pay attention to the rest of your body and physical appearance in a way that makes sense to you. Try self-nurturing activities, such as getting a massage, a new haircut or a manicure, or doing yoga. Explore new styles of clothing that help you feel comfortable.

• Acknowledge and highlight parts of your body you feel comfortable with such as your smile, the colour of your eyes or the shape of your hands.

• Ask your partner or a friend to tell you what they think makes you attractive.

If you continue to struggle with your body image, consider professional counselling or peer support. You can find out what counselling resources exist in your community by asking your health care team, or contacting Willow Breast Cancer Support Canada at 1-888-778-3100 (toll free), www.willow.org or info@willow.org, or the Canadian Cancer Society’s Cancer Information Service at 1-888-939-3333 or www.cancer.ca.

If you choose to wear a breast prosthesis

A breast prosthesis is an artificial breast form that looks like a breast and is worn under clothing. The choice to wear a prosthesis is yours. If your entire breast has been removed you may choose to wear a full prosthesis. If only part of your breast has been removed you may choose to wear a partial prosthesis. You may also choose not to wear a breast prosthesis at all.

NOTE: Your health care team can advise you on when you can obtain a breast prosthesis. This decision usually takes place after the side effects from surgery and radiation have passed. While you are waiting, the Canadian Cancer Society can provide an information kit that includes a temporary breast prosthesis. Call the Canadian Cancer Society’s Peer Support Program at 1-800-263-6750 to request this kit.

There are many medical supply or specialty stores where you can buy a breast prosthesis. Some of these stores also sell special underwear and bathing suits with pockets stitched inside them to hold a prosthesis. Look for a vendor who has staff who are trained to measure and fit you properly. Be sure to ask the staff person who fits you about what to expect when wearing a breast prosthesis, how to manage the prosthesis when engaged in physical activities and exercises, and how to care for your prosthesis.

Funding to help pay for the cost of a breast prosthesis is available from the Ontario Assistive Devices Program (ADP). If you are interested, ask your nurse for an application form. The form is also available from vendors in Ontario that sell breast prostheses, from your local unit of the Canadian Cancer Society, by phoning ADP at 1-800-268-6021 (toll free), or go to: www.health.gov.on.ca/en/public/forms/adp_fm.sppx. Private health insurance plans may also provide coverage for special clothing or prosthetics.

Breast reconstruction

If you have had a mastectomy, you may want to discuss the possibility of breast reconstruction with your health care team.

There are three types of breast reconstruction. The first type of reconstruction uses an implant filled with silicone gel to recreate the breast mound. Another option is to build a breast using tissue “borrowed” from another part of the body. The final type of
reconstruction combines both techniques. The type of surgery you receive will be decided upon by you and your surgeon depending on your particular needs, your body and your treatment for breast cancer.

Breast reconstruction may enhance some women’s confidence and self-image after a mastectomy. It will not affect your treatment, follow-up care or post-treatment monitoring.

SADNESS AND DEPRESSION

Why am I still feeling so blue all the time? Everyone thinks I should be happy now that my treatment is finished, but I just can’t stop feeling sad.

It is common for many women to experience sadness or depression when they are first diagnosed and then again when their treatment is finished.

Sadness is a normal emotional response and all of us experience sadness at some point in our lives. Sadness can be a natural reaction to painful circumstances. It is normal to feel sadness and anxiety as you move through the treatment process and after treatment as well. Your feelings will be affected by your age, changes in your hormones resulting from treatment and your life situation. For example, menopause caused by your treatment can make you feel sad, and being tired can add to your sadness. If you don’t let yourself feel sad and grieve sometimes, you may not resolve these feelings.

Depression is different from sadness. Depression is a physical illness with multiple symptoms that can linger for weeks, months or even years.

Is it sadness or depression?

You may wonder if what you are feeling is sadness or if you are experiencing depression. If you are experiencing several of the following symptoms for more than two weeks, and they are making your life difficult, you may be dealing with depression:

- Sadness throughout the day, nearly everyday
- Loss of interest in or enjoyment of your favourite activities
- Feelings of worthlessness
- Excessive or inappropriate feelings of guilt
- Thoughts of death or suicide
- Trouble making decisions
- Fatigue (tiredness) or lack of energy
- Sleeping too much or too little
- Change in appetite or weight
- Trouble concentrating
- Aches and pains
- Feelings of restlessness or being slowed down

If you are experiencing a combination of these symptoms, talk to your health care team or counsellor. Depression can be treated with either medication or counselling, or a combination of both. You may be prescribed antidepressant medication by your family doctor or a psychiatrist that can help with depression and anxiety. Antidepressants can take four to six weeks to be effective and you may only need these medications for a short time. Your family doctor or psychiatrist will help you decide when these medications are not needed any more.
Talking about your feelings with your family doctor, nurse practitioner, psychiatrist or counsellor can also help you deal with depression. Counselling can be helpful either alone or in combination with medications. You should decide with your doctor what type of treatment is best for you.

The Canadian Association of Psychosocial Oncology offers a booklet entitled, *The Emotional Facts of Life with Cancer* on their website at: www.capo.ca/eng/more_information.asp. If you are not sure if you need professional support, completing the self-assessment questionnaire in this booklet may help you decide. A self-assessment questionnaire for family and caregivers is also provided.

**A note about Tamoxifen**

Some women question whether Tamoxifen causes depression. It isn't clear that Tamoxifen causes depression. Two major studies in the United States and Canada found that women who took Tamoxifen were not any more depressed than women who took sugar pills (or placebos).

If you do feel depressed or if you often feel frightened for no reason, short of breath or a tightness in your chest, you should ask for help from your health care team. You may need short-term counselling, medication or both.

**Survivor loneliness**

“Survivor loneliness” is a term used to describe what happens when someone has experienced a personal crisis such as breast cancer and struggles to find meaning. Sometimes women who have experienced breast cancer feel alone in their experience. If this sounds like you, you may want to talk to a therapist, join a support group or speak to other women who have experienced breast cancer through the Canadian Cancer Society’s Peer Support Program. Call toll free at: 1-800-263-6750, or visit www.cancer.ca, and search “peer support” or visit Caring Voices, a national online social networking community for Canadians who have experienced cancer, at: www.caringvoices.ca.

**YOUR SEXUALITY**

“When my husband and I get close, I feel him tense up when he goes to touch me near my breasts. He says there isn’t a problem, but I wonder how I can get him to open up about his feelings.”

For many women, breasts are a part of your body that are strongly connected with your sexuality. Like many women who have experienced breast cancer, after your treatment you may find sex and physical intimacy difficult. Adjusting to any changes in your appearance as a result of breast cancer surgery can be very challenging, and like some women, you may feel less attractive as a result.

You may even feel that because you have had breast cancer your body has betrayed you. Your surgery may leave you feeling violated. You may also worry about whether your current or future sexual partner(s) will find you desirable and attractive. These are all perfectly normal feelings.

There are also physical effects of breast cancer treatment that can affect your sexuality. Radiation can make your breast and nipple less sensitive to arousal. Menopausal symptoms caused by cancer treatment might lower your interest in sex. When your ovaries shut down, they stop making estrogen as well as testosterone, which is the hormone that causes sexual desire. The reduction in testosterone may make you less interested in sex.

If you have a partner you are probably both feeling fragile now. This is normal – you have been through a difficult time together. Your partner may not want to push your sexual relationship too far for fear of hurting you, or may even have the wrong idea that sex might
make your cancer come back. Don’t assume that your partner is not interested in you or finds you unattractive. Help your partner understand that their fears are mistaken. You will probably find that he or she has been much more concerned about losing you than about the loss or change of appearance of your breast.

Making love can be healing for both of you, but remember that reconnecting physically may take some time after breast cancer treatment, because of fatigue (tiredness) caused by chemotherapy and radiation that could continue for several weeks after treatment.

No matter what type of sexual relationship you have, it can help to start out with lots of closeness, hugging, massages and other things that you make you feel good. You may need to be more clear in telling your partner about your wants and needs. Sexual arousal may take more time, and it may be better to focus on natural pleasure rather than forcing yourself to return quickly to the level of sexual activity you experienced in the past.

Together you can explore new ways of enhancing sexual feelings and find other erogenous (sexually stimulated) parts of the body that are not tender or uncomfortable and feel good for you. If you continue to worry about your sexual life, you may want to seek professional help. Your health care team can help and may refer you to a specialist.

Things to keep in mind:

• No matter what kind of cancer treatment you have had, your ability to feel pleasure from touching will almost always remain.

• Good communication with your partner and health care team is the key to success. Don’t be afraid to talk about how cancer is affecting your sex life.

• Try to keep an open mind and explore new ways to feel sexual pleasure.
**Memory and Attention Problems**

Lately I’ve found it difficult to concentrate on anything. I sit down to read a book and my mind wanders. I can never remember where I put my sunglasses, and the other day, I forgot my neighbour’s name.

Women who have completed breast cancer treatment sometimes report that they feel mentally fuzzy or that they are more easily distracted and do not remember things as well as before. This can be the result of several factors working together.

Chemotherapy may affect your memory and attention, as can changes in estrogen levels because of menopause caused by treatment and/or the use of Tamoxifen. The stress of dealing with a life-threatening disease can also negatively affect your thinking abilities, and fatigue itself can make you less alert. In addition, your memory and attention may also be affected if you are experiencing pain, difficulties sleeping, anxiety and/or depression.

No matter what is causing your cancer-related “chemo-brain,” there are things you can do that will help. Make life easier for yourself by always putting often-used items in the same one or two places. Just like the rest of your body, the more you “exercise” your brain, the better it will work. Try to keep your brain active by learning new things. Try doing crossword puzzles or testing your memory by working on things you’d like to remember - like telephone numbers or family birthdays.

Keep participating in activities that you enjoy and that stimulate you mentally such as reading or socializing.

**Dating after breast cancer**

As a single woman, you may wonder about how you will behave when intimate situations arise in the future. It is up to you to choose when and how you tell a new sexual partner about your breast cancer experience. You may choose to tell them right away or you may want to wait some time until you feel ready.

More information about your social needs as a single woman who has experienced breast cancer is provided in Chapter Five: Reaching out: your social needs.

**If you are a lesbian or bisexual woman**

It takes a tremendous amount of courage to go through this, being a gay woman and experiencing breast cancer. It really does, it takes everything you’ve got.

If you are a lesbian or bisexual woman, your experience with breast cancer may be different than for a heterosexual woman. Some studies have shown that breast cancer patients who identify as lesbian tend to struggle less with body image and may have a stronger network of support. However, some lesbian and bisexual women who have experienced breast cancer may not receive the same level of support from providers when facing issues related to their sexual identity.

You may want to talk to your health care team about how your sexual identity has affected your breast cancer experience.

More information about your relationship with your partner is provided in Chapter Five: Reaching out: your social needs.
CANCER AND POST-TRAUMATIC STRESS DISORDER

Sometimes, people who experience a traumatic event develop psychological, emotional and even physical problems that are called Post-traumatic Stress Disorder (PTSD).

Some women with breast cancer have been known to experience PTSD. If you have PTSD you may have three types of symptoms:

1) **“Re-experiencing” symptoms such as:**
   - Powerful, repeated thoughts or memories about your breast cancer experience
   - Recurring nightmares or flashbacks in which you re-live parts of your treatment
   - Strong feelings of distress when reminded of your breast cancer

2) **Avoidance and emotional numbing symptoms such as:**
   - Avoiding thoughts, feelings, or conversations about your breast cancer experience
   - Avoiding places or people that remind you of your breast cancer experience
   - Having difficulties remembering important parts of your breast cancer experience
   - Having a loss of interest in important, once positive, activities
   - Feeling distant from others
   - Having difficulties with positive feelings, such as happiness or love
   - Feeling as though your life may be cut short

3) **Hyperarousal symptoms such as:**
   - Having a difficult time falling or staying asleep
   - Feeling more irritable or having outbursts of anger
   - Having difficulty concentrating
   - Feeling constantly “on guard” or like danger is lurking around every corner
   - Being “jumpy” or easily startled

If you think you might be experiencing PTSD, talk with your health care team or counsellor about your experience and any symptoms you have.

What to expect over the next few years

We have one woman who comes to our support group not for herself, but as a beacon of the future for those of us who are newly diagnosed. She was diagnosed with breast cancer more than 30 years ago. Her story is fascinating to us. We love to hear about her feelings and how she has dealt with the years of survivorship.

CREATING A “NEW NORMAL”

As you move into your life after breast cancer, you will become better at restoring a sense of purpose and wholeness. Eventually your breast cancer experience will move farther and farther into the past, and you will believe again that you are in good health. A certain level of trust and comfort will slowly come back as you enter the long-term stage of survival. Many women find that their lives
have improved in many different ways after breast cancer. They may feel more empowered, closer to their family and friends and stronger as a result of their breast cancer experience. They take the time to identify new priorities and live each day to the fullest.

**SPIRITUALITY/FAITH ISSUES**

“Breast cancer made me look beyond the everyday world for comfort and support. I realized for the first time in my life that there was something that was greater than us all, a power that would steer me through the rough times now and into the future.”

For many women, spirituality is that part of you that longs for meaning, integrity, beauty, dignity, love, acceptance and hope. Your spirituality or personal philosophy may include an awareness of your purpose and the search to find meaning in the events of your life. Many women who have experienced cancer go through a spiritual crisis or a test of faith as they struggle to understand their existence and to find meaning in their illness.

Many people find that their spirituality or personal philosophy helps them maintain health and cope with illness, trauma, losses and life transitions by integrating body, mind and spirit. The following suggestions might help you engage this aspect of yourself:

- Creative arts such as painting, music, poetry, dance
- Spending time in a natural setting
- Meditation

You may want to ask yourself the following questions:

- How has cancer changed me and how I see my life, my relationships, my hopes and dreams?
- What have I learned about myself that I didn’t know before?
- What has helped me stay hopeful?
- What has helped me live with breast cancer?
- What has helped me carry on?

Use your personal beliefs and/or faith as a tool for recovery. You may want to reach out to your spiritual leader, priest, pastor, rabbi, imam, minister, elder, priestess or other spiritual advisor for support. Whatever your spiritual, religious or other beliefs, it is important to have people by your side who will support you.
A poem for those affected by breast cancer:

WHAT BREAST CANCER CANNOT DO

Cancer is so limited...
It cannot cripple love.
It cannot shatter hope.
It cannot corrode faith.
It cannot eat away peace.
It cannot destroy confidence.
It cannot kill friendship.
It cannot shut out memories.
It cannot silence courage.
It cannot invade the soul.
It cannot reduce eternal life.
It cannot quench the Spirit.

ANONYMOUS

Reaching out: your social needs
This chapter covers some of the changes that may affect your relationships now that you have completed your active treatment for breast cancer. It also provides tips that might help you in relating to your friends, family and co-workers during this time.

What you may be feeling now

> Like many people, I have always found it hard to ask for help. While I was being treated for breast cancer, my friends and family were there for me in so many different ways. Now, I want them to know how much I appreciated their help and that I still need them.

As you move back into your everyday life after completing your active treatment for breast cancer, it may not be as easy as you thought it would be to face each new day. As you venture out into the “real world,” you may meet friends and neighbours who have not seen you for a while. They might ask you where you’ve been, or if they know about your diagnosis, they may have questions or feel uncertain about what to say to you. If you work outside of your home, you may find that your co-workers also have questions or uncertainties. Even if you live in a closely knit community where it is known that you have been treated for cancer, you may still wonder what people know and how much you should tell them.

You may find it difficult to describe your breast cancer experience over and over again. Some women find that it helps to share their experiences with people, but others don’t. If you do not wish to describe your experience, you may want to simply reassure people that you are fine now and thank them for their interest and concern.

Your experience with breast cancer may have brought you closer to your friends and family. Over the past several months, you might have come to appreciate the importance of your social support network. In other chapters we have talked about how your friends and family may feel that it is time for things to return to normal and for you to get on with the rest of your life. You may also feel that it is time to let your friends and family get on with their own lives. Even if you still feel lost and fearful at times, you may feel that you have already asked for enough help from them.

Sometimes supporters can find it difficult to let go. They may not want to let you get back to everyday life. They may feel that you are still fragile and need to be protected. It may be hard for you to loosen the strong ties that you’ve developed during your treatment for breast cancer. If this is the case, you may want to tell your friends and family that it is important for you to function on your own again.

What you need to know now

The immediate crisis of your diagnosis and treatment has passed. As you move into your “new normal” life, think about ways to reach out for help when you need it. If possible, talk openly with your friends and family about your feelings and your needs. Let them know how much you appreciated the help and support they gave you during treatment and that there will likely still be times when you want to ask for their help and support. For example, you may want to ask for help when you are feeling tired, frightened or insecure.
After your diagnosis and during treatment, you may have found that some of your friends and family avoided you or were there for you less than you would have liked. You might feel angry and hurt by their lack of attention, or you may now feel badly about your anger towards them. Although these individuals may not have been there for you during times of crisis, they might find it easier to be supportive now that you are returning to your everyday life.

Cancer is an illness that frightens people for many different reasons. For some people, cancer is a reminder of their own vulnerability. Others may associate cancer with the loss of a loved one and others may fear cancer because they have the wrong idea that it is always fatal.

By keeping the lines of communication open, you can support the sharing of feelings between you and your family or friends. Communicating may help strengthen your relationships and also mend any hard feelings that may have been caused if you feel that you have been avoided during your cancer experience.

It can be helpful to let your friends and family know that you still need them to be the friend or loved one that they have always been. You may also want to remind them that you care about them and are there for them too.

**Help your friends and family help you**

Many of us find it hard to ask for help. Here are some things that you can do that may make it easier for your friends and family to help you.

1) Know your situation: Take a look at your life and try to see what might be making things difficult for you. Have there been changes at home, new financial worries or emotional and physical concerns that you could use some help with?

2) Know yourself: What have you learned about yourself that could help you ask others for help? Do you fear a loss of control? Do you think that things won’t be done properly? Are you afraid to bother people?
3) **Know what needs to be done:** Decide what needs to be done to get your life back on track. Plan tasks and determine what needs to be done first. Then divide some of these tasks among your friends or family members. Think about their skills and interests. What do they like to do? What are they capable of doing? Be clear about what you need from them. Make sure to thank them for their help. Try not to take over if things don’t go the way you think they should.

4) **Let go:** By letting your friends and family help you, you will show them that you trust and respect them and also that you need them. With help, you can devote more time and energy to positive and enjoyable things in your life.

5) **Talk about things openly:** Be direct and honest. Tell your friends and family how you feel. State your feelings clearly. Talk about goals and dreams that you share and how you might achieve them.

6) **Provide feedback:** Let your friends and family know how you feel about their help and support. This may take courage, but providing both praise and constructive criticism when needed will strengthen your relationship and help your friends and family to better help you.

7) **Offer to help others:** There may be things that you can now do to help and support your friends and family.

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**What to expect during the coming year**

**YOUR RELATIONSHIP WITH YOUR PARTNER**

“My partner and I had been so focused on my treatment and recovery that when it was all over, it felt like we didn’t have anything to talk about anymore.”

Breast cancer affects you and your entire family, including your children and your spouse or partner. Open communication between family members is important at the best of times and it is essential now.

Look back over the past several months and, if you can, talk openly with your partner about what’s happened over this time and how you are both feeling now. Share your hopes and fears with each other and try to be honest about your experiences. Working out issues in your relationship can be an important part of the healing process and can actually help you heal.

**Try to be open-minded as you listen to your partner’s point of view:**

- Focus on your partner’s comments, not on what you plan to say in response
- Repeat what he/she says in your own words to clarify and to show your partner your understanding of what has been said
- Ask questions to better understand your partner’s concerns
- Acknowledge that his or her views matter to you
Communicating with your partner may not be as easy as you would like it to be and may not have been a regular part of your approach to each other. You may also be in a relationship where neither you nor your partner is comfortable discussing or thinking about these types of issues. If this is the case, you may want to connect with other important people in your life for support. You and your partner may also choose to seek the help of a counsellor.

No matter what your situation, your experience with breast cancer will have had some impact on your relationship. You may have been pleasantly surprised by your partner’s strength and support during this time and this may have confirmed or renewed your faith in a strong future together.

On the other hand, the experience may have uncovered issues that have become difficult to deal with during the last few months. Your partner may now feel that the breast cancer experience is over and that you both should go back to the way things were before your diagnosis. You may not be ready or able to do this, or you may find that you don’t want to return to the way things were before you were diagnosed.

If these kinds of issues arise, you may want to consider counselling. A counsellor can help you learn to cope and communicate in a positive and constructive way. Working through the impact of breast cancer together can help you grow closer.

If you are in a relationship with a woman, your partner may feel especially upset about your experience and concerned because this disease could affect her as well. She may also have experienced difficulty when relating to your health care team, who may or may not have appreciated her role in your life.

As lesbian or bisexual women, you and your partner might view issues of independence and equality in relationships differently than other couples. It is possible that your cancer may have challenged these values.

Open and honest discussion can help to resolve any issues you and your partner might be experiencing. When communicating with your partner, consider her point of view and let her know that you value and respect her. Be open and honest about how you are feeling and don’t be afraid to tell her how she can help.

**NOTE:** If you are concerned that your partner is not being valued by your health care team, you may want establish her relationship more strongly by assigning her power of attorney for health care. More information about legal matters is provided in Chapter Six: Returning to everyday life.

**YOUR RELATIONSHIP WITH YOUR CHILDREN**

If you have children, no matter what their age, they will also need help and support in dealing with the experience of having a parent with breast cancer. As you probably already know, as a parent, part of the challenge of breast cancer even after your treatment is finished is balancing your own needs with those of your children.

Your children’s reaction to the end of your treatment will depend on their age. Younger children may not understand your physical and emotional limits and will expect you to care for them and treat them as usual. Based on their own experience as children, illness for them usually means a brief period of sickness and a quick recovery.

Older children and teens will be better able to appreciate that it may take some time for you to return to full health and that some things may not be the same for a while. Older children and teens may also resent the fact that they will continue to have additional responsibilities that they accepted during your treatment.

Your children may not understand that although you may look and seem to feel better, you are still not back to normal. After your treatment, be honest with your children so they can understand
the changes that are happening to you and to them. How you communicate with your children will depend on many factors such as your own level of acceptance, your individual style of parenting and communication, and your children's ages and unique personalities.

Even after the crisis of diagnosis and treatment has passed, continue to communicate with your children. As you talk to your children, the following tips may help:

1) **Talk openly:** Consider your children's age level and explain the situation in a way they will understand. Be brief and honest in your discussion. Listen carefully, encourage feedback and let them know that they can ask you questions at any time.

   **TIP:** Let your children know ahead of time when your followup appointments are planned and that these are normal and to be expected.

2) **Be positive:** Acknowledge your children's strengths and encourage them to tell you how they feel about their lives and activities. If they are young, let them play and enjoy leisure activities. Have fun as much as you can.

3) **Cope with fear for the future:** Try to cope with your own fears first so that you do not overwhelm your children. Make sure they know that they will always be cared for.

**Provide your young children with roots and wings:**

**You can help your children feel more stable (roots) by providing the following:**

- A regular routine and family life that includes regular meals, bedtimes, school hours and after-school activities
- Information about what is happening with the family

**You can give your children independence (wings) by doing the following:**

- Allowing them to take time away from the family so they can nurture a sense of self
- Maintaining their regular interests or activities away from home
- Showing that you appreciate how well they are coping

**Adult children need support too!** Even if your children have grown up and are no longer living at home, they still care and may still be very concerned about you. Make sure you keep the lines of communication open and provide them with opportunities to help you even if they don’t live close by.

**IF YOU ARE SINGLE**

“As my partner and I split up, I decided to remain single. Now I’m wondering if that was the right decision, as I’m not sure if I can find someone who will be comfortable with the fact that I’ve had breast cancer.”

As a single woman, you may be worried about how breast cancer might affect your future. If you have been looking for a partner, you may be worried that breast cancer will alter your chances of meeting someone to share your life with. You may wonder what to tell a potential partner or lover about your health history and how he or she will respond to the news that you have had breast cancer.

Breast cancer is very common and many of us know someone who has had it. Although there’s no way to predict how someone will respond to learning that you have had breast cancer, you will...
probably find that most people are supportive and prepared to continue a relationship.

If you would like to begin dating, you may want to start some new and engaging activities that will help you meet people who share your interests. Many couples meet through their families, friends, co-workers, classmates or neighbours. Talk to the people you know – and tell them you’d love to meet someone new. Let them know what you’re looking for and talk to them openly about your hopes for the future. Try to relax and have fun as you develop new friendships and renew old ones.

Remember that you are in control of when and how you tell someone you are dating or interested in about your breast cancer.

Even if you choose to stay single, you may find yourself wondering if being on your own is still a good idea. Because your health has been threatened, you may feel afraid of facing your future alone. Nurture and build a support network that you can count on. Talk openly with your friends and family about your fears. If you have not already done so, consider joining a peer support group of other similar women who have been through the same experience.

If you are a young woman, information on resources for young women who have had breast cancer is provided in the appendix.

**Support Groups: Are They For You?**

“Something very special happened when I attended my first breast cancer support group meeting. I felt like a huge weight had been taken off my shoulders. Meeting others who had been through the same thing was just what I needed to help me cope.”
A breast cancer support group is usually made up of a group of women who gather together on a regular basis. Groups are often informal - such as several women who have experienced breast cancer and who decide to meet regularly to have tea or coffee together. Every support group will have a different blend of members - some may have women who have just finished their treatment, while other groups may include women who are at different stages of treatment or past their treatment by years or even decades. Some groups may be organized around specific themes or be focused on different stages of the breast cancer experience.

Keep in mind that peer support is different from professional counselling. Most peer support groups have rotating leaders from within the group who contribute to the group based on their own personal experience with breast cancer. The purpose of these peer-led groups is usually to help members manage daily living, cope with emotional and other issues and/or educate themselves.

Professional counselling groups are different than peer-led groups. The leaders of professional counselling groups usually have special expertise through training and education, and they may or may not have had breast cancer themselves. The group usually follows a format set by the leader, who guides and encourages members to set personal goals and move toward them.

As well as groups that meet together, you may also find support from your peers through telephone-based services such as Willow Breast Cancer Support Canada or the Canadian Cancer Society’s Peer Support Program. Another form of peer support can be found through web-based chat rooms such as Caring Voices (www.caringvoices.ca), where you can “chat” over the Internet with other women who have experienced breast cancer without having to leave your home or identify yourself if you don’t want to.

Information about these and other support groups in Ontario is provided in the appendix. If you are a young woman, information on resources for young women who have had breast cancer is provided in the appendix.

**Choosing the right support group**

When choosing to join a peer-led or professionally run support group, think about your own needs now and in the future. Different kinds of groups work for different people, and you are the only one who knows what is best for you. Are you looking for emotional support, or are you hoping to find information and strategies for dealing with ongoing physical health and lifestyle issues? Are you hoping to be inspired by meeting others in your situation, or are you looking for shared experiences and coping methods?

**Here are some of the benefits of participating in a breast cancer support group:**

- Learning more about cancer resources, including books, videos, websites, organizations and other current information
- Finding out about new ways to make it easier to cope with your recovery and ongoing medical procedures
- Gaining insight into your own experience with breast cancer
- Becoming more aware of your own needs
- Feeling more empowered or able to make choices
- Feeling less alone
- Feeling more in control of your situation

Another advantage of a support group is that you choose what you wish to share about yourself and your experience. Many women with breast cancer shield family and friends from what they are going through. Often, women will hide their emotions from family and friends. In a support group, you do not have to protect anyone and you may be able to open yourself up in a way that you have not been able to do before.
If you decide to join a support group, it is always a good idea to call ahead and speak with the group’s contact person. You can also ask to speak with other group members or request a printed or online description or history of the group. You could ask the group’s contact person the following questions:

• How many people attend the group’s meetings and what is the make up of the group (e.g., women who have experienced breast cancer, family members, age range, stage of cancer diagnosis, cultural focus, etc.)?
• How long is each meeting?
• How often does the group meet?
• Is there an established group of members who usually attend?
• How long has the group been meeting?
• Is it a peer-led group?
• If a professional leads the group, what is her/his experience or training?
• What is the format of group meetings?
• What kinds of subjects are discussed?

Each support group will have a different style. Look for a group that fits you.

**Starting your own breast cancer support group**

If you find that a suitable support group does not exist in your community, you might want to organize one yourself. This may be a very demanding but rewarding task. Although you will need to put your own energy and time into starting a support group, there are a lot of resources available to help you.

If you do decide to start a breast cancer support group, it can help to find others who have experienced breast cancer, supportive professionals, hospitals and other organizations who can work with you as a team. Willow Breast Cancer Support Canada has a support group training program with resources to assist you in developing your group and facilitation skills. For information on this program, contact Willow at 1-888-778-3100 (toll free), www.willow.org, or info@willow.org.

**Try something different**

If a traditional support group does not interest you, there are other ways to get together with women who have experienced breast cancer. You could organize a special event, fundraise, or try dragon boating. Dragon boating is a sport that involves the use of a large canoe-type boat with a crew of 20 paddlers, sitting two across, one steersperson in the stern and one drummer sitting high in the bow. Corporations, businesses, educational establishments and health facilities compete annually in these races and more and more women who have experienced breast cancer have been getting into dragon boating. There are dragon boat teams across Canada as well as in the United States, Australia and New Zealand.

**NOTE:** Always check with your doctor before starting a program such as dragon boating, especially if you have previous shoulder injuries. Ease into the activity slowly and progress gradually.
What to expect over the next few years

“As I moved farther away from my breast cancer experience, I wanted to be able to let go of some of the many supportive people and resources that sustained me. I did this gradually and after a while, I felt much more independent again.”

MOVING FORWARD ON THE PATH OF LIFE

Many women are transformed by their breast cancer experience in ways that they never expected. You may find that you possess strength that you never realized you had before your diagnosis. You may have a new sense of direction and be clearer about your life’s goals.

However there may be challenges as well. Your self-image may have changed, and you may feel more vulnerable than you felt before your diagnosis. No matter how well you have dealt with your breast cancer experience, there is no doubt that you are a different person than you were before.

Accepting what has happened to you may take time. Building a new approach to life will probably be a “work in progress” that may take many years. Don’t be afraid to take a look at how your life has changed and to begin the process of moving forward. Even if one step at a time may be all that is possible, your first step may be quite simply to decide that you are not going to stay where you are.

More information about how to cope with your emotional needs is provided in Chapter Four: Looking within: your emotional needs.
This chapter looks at some of the practical and financial issues that you may face as you return to your everyday life. It provides useful information about making the transition back into your regular daily activities and planning for the future after your breast cancer experience.

What you may be feeling now

“I want to get back to doing the things I used to do, but I’m not the same person that I was before breast cancer. My life is different – I’m worried that I won’t be able to keep my job, but if I don’t work, how will we pay all the bills?”

Your experience with breast cancer has probably led you to think about things you may not have worried about in the past. You may have concerns about your financial security and about other practical issues such as your health insurance, your employment or other daily commitments such as volunteer work. You may wonder how much you should tell the people who are involved in these activities about your experience with breast cancer.

What you need to know now

As someone who has experienced breast cancer, you still have the same basic rights to employment, health care and financial security that everyone else does. You do have a future and every reason in the world to think about it and plan what you want to do for yourself, your family, your children, vacations or retirement. You’re no different from anyone else, although like many others who have faced a serious illness or life changing event, you may have a better appreciation of what the “future” really means.

What to expect during the coming year

HELP WITH MEDICAL EXPENSES

Your ongoing care may involve medical and drug costs that are not covered by the Ontario Health Insurance Plan (OHIP) such as prescriptions for pain relief, other medications or creams for lingering effects of radiation. A number of sources may assist with these costs:

- Group Health Care Insurance through your employer or your partner’s employer
- The Ontario Drug Benefit Program
- The Trillium Drug Program
- Assistive Devices Program
- Veterans Affairs Assistance
- Non-Insured Health Benefits for First Nations People and Inuit
- The Interim Federal Health Program (for refugee claimants)

Your hospital or community social worker can provide information about these programs. You can also check the online document entitled, Coping with your Financial Concerns when you have Breast Cancer: A Guide to Resources and Services in the Province of Ontario, Willow Breast Cancer Support and Resource Services (2009) at: www.willow.org/pdfs/Coping_Ontario.pdf.
because you have had breast cancer it may be more difficult to keep or find a job, pay your bills and support yourself and/or your family. Even though studies have not shown that this is true, you may worry that if you place too much stress on yourself it will increase the chance that your cancer will return.

When thinking about returning to work, you will need to consider these issues:

- Physical limitations such as pain, lymphedema, problems with shoulder movement and function, numbness, and fatigue.
- Emotional issues such as anxiety, fear or depression.
- Cognitive (brain-related) issues such as lack of concentration, memory and attention problems, and mental fatigue.
- The timing of your return, for example a full-time or gradual return.
- The suitability of your work, for example concerns about repetitive and heavy lifting.

Tell your family doctor, nurse practitioner or your health care team about any concerns you have. They can link you with resources that can help you, such as return-to-work programs in your community, outpatient rehabilitation clinics with both physiotherapy and occupational therapy services, and other programs. For example, a physiotherapist may be able to provide exercises to help you reduce pain and regain your energy.

Paid employment can fill an essential need for many people who have experienced cancer. During your treatment for breast cancer, the employment situation may have changed for you or your partner. Continuing your employment or finding a new job may be a necessary financial step for you. As well as providing income, your job may provide important benefits such as health insurance.

If you are employed, your job may also be part of how you define who you are. It may be a key part of your social support network. Your co-workers may be supportive friends who care about you and what you’ve been through.

After treatment is completed, most women with breast cancer don’t miss a lot of work. Some women are able to continue working through their treatment, while others may need to take time off during treatment or later due to problems from the side effects of their treatment. Whatever your situation, you may worry that
DEALING WITH CO-WORKERS’ REACTIONS

There is no legal reason why you should tell anyone at work about your breast cancer unless it will interfere with your ability to perform your job or if you will need extra time off. The Ontario Employment Standards Act clearly states that employers are not allowed to ask for information about the diagnosis or treatment of an employee’s medical condition.

If you do make it known that you have been treated for breast cancer, keep in mind that sometimes people’s personal fear of cancer may result in attitudes that can lead them to treat you differently.

Your co-workers have probably been worried about you. They may fear that you are no longer healthy. Some may even worry that you are not able to do your share of the work and that they will be expected to take on more than they can handle. If you sense that this is a problem, use your judgment in responding to their concerns. Keep in mind that some of your co-workers may not want to talk openly about your experience. They may need time to become more comfortable and to adapt to your new situation.

More information about talking to others about cancer is provided in Chapter Five: Reaching out: your social needs.

How to talk to your employer

If you are experiencing some lingering side effects of treatment that limit your ability to do your job, you may want to speak to your employer. The following tips may help:

1) Provide your employer with a note from your doctor that explains your limitations and how long you might be affected by them. Medical notes only need to provide the following information:

- The duration or expected duration of the absence.
- The date the patient was seen by a health care professional.
• Whether the patient was examined in person by the health care professional issuing the certificate.

2) Work together to set goals that you know you can achieve.

3) If possible, ask for a change in your job responsibilities so they are a better fit for your current abilities.

4) Ask if you can work flexible hours so that you can take advantage of times when you feel more energetic.

5) Provide information about cancer through written or online materials or by asking someone in your health care team to speak with the staff of your workplace.

6) Ask co-workers for help when necessary and appropriate.

7) Make sure you know about your company’s policies on sick leave, disability leave, flexible hours and work retraining options.

**Employment discrimination**

There are provincial and federal laws that protect employee rights. However, in spite of these legal protections, you may find that your employer treats you differently from other employees. Workplace problems are sometimes reported by women who have experienced breast cancer. These include demotion, denial of promotion, undesirable transfer, denial of benefits and even hostility in the work place. Often this kind of discrimination is difficult to prove.

*More information about how to access provincial and federal employment standards is provided in the appendix.*

If you think that you are being treated differently at work because of your cancer history, you may want to try to work out an informal solution first. This may be difficult to do on your own, and therefore support from your health care team can be very important. Provide your doctor or nurse practitioner with specific information about the physical and emotional demands of your job. Be honest about your limits and your abilities. Ask your family doctor or nurse practitioner to write a letter to your employer outlining your short-term and long-term health situation.

Know your rights. Check out your employer’s procedures for settling employment issues. All employers must have policies in place that protect workers with disabilities. If you need to be accommodated in some way to help you work (such as flexible working hours in order to keep doctor’s appointments), be open with your employer and suggest alternatives based on medical information.

Keep written records of all relevant incidents at work. It can help to make written notes as events happen instead of trying to remember them later. Keep track of all performance reviews and positive comments about your work as well as any incidents or remarks that you consider discriminatory or damaging to your reputation.

**What to do if you believe you are experiencing or have experienced discrimination**

Discrimination due to a disability such as a breast cancer diagnosis should be reported to the Human Rights Tribunal of Ontario, which is committed to fairness, integrity and the rule of law. If you feel you have been discriminated against, the Tribunal’s Human Rights Legal Support Centre can help you file an application and even provide you with legal representation.

*For more information about the Tribunal visit their website: www.hrto.ca/hrto/. This website will provide you with rules of procedure, policies, forms and users’ guides.*

*If you choose to seek private counsel, you can find a labour lawyer through the Law Society of Upper Canada’s Lawyer Referral Service at: www.lsuc.on.ca/public/a/faqs---lawyer-referral-service/*
Legal aid

Legal aid is available to individuals with low incomes who may need help with a variety of legal issues such as employment rights, human rights, eligibility for Ontario Works and the Ontario Disability Support Program, employment insurance and government pensions.

Legal aid can provide three types of services:
- **Legal aid certificates** reimburse participating lawyers for some or all of the services they provide to clients for some types of legal problems.
- **Advice lawyers** can provide assistance, particularly in family law matters, and help with filing documents.
- **Community legal clinics** can provide assistance in areas of law that most affect individuals with low incomes.

More information about legal support is provided in the appendix.

If you are self-employed

Self-employed individuals face unique challenges during an illness such as breast cancer. It is likely that your work has been interrupted and you may have lost clients and contacts. You may also be facing financial challenges due to a loss of income and have no disability compensation.

Here are some tips that may help if you are self-employed:
- Acknowledge your limits. Remember that initially you may not be able to work at the same pace as you did before.
- Set goals that you know you can achieve.
- Try to ease yourself back into your work at a pace that suits you.
- Try to work flexible hours so that you can take advantage of times when you feel more energetic.
- If your clients ask, provide information about your cancer experience if you feel comfortable doing so, and/or refer them to written or online materials.
- Ask for help. For example, you may want to consider subcontracting some of your work, even for a brief time.

FINDING A NEW JOB

"Although my employer was sympathetic and supportive, I got the feeling that because I’d had cancer my chances of promotion had gone way down. I decided that it was time to find a new job and start fresh."

The same laws that protect Canadians against discrimination in the workplace also apply to hiring new employees. During interviews and on job applications, employers may ask only job-related questions. They are not allowed to ask about medical history, but they can ask for a medical certificate to verify your ability to perform the duties of the job. You can choose not to volunteer any information about your cancer history, and keep the focus on your current ability to do the job in question.

If you do choose to talk about your cancer experience, stress that you are fully able to do the job as described and that your medical history will not affect how you can perform your duties. Although it is not necessary, you could include information that will describe your condition and demonstrate your ability to do the job. You could also include your doctor’s name for reference and offer to provide a letter from your doctor if you wish.

Your resume is a place to focus on your skills and should not draw attention to periods of time during which you were not working due to treatment or recovery. If asked, be prepared to explain any gaps in your employment history.
OBTAINING FINANCIAL ASSISTANCE

If your illness has resulted in loss of employment and you have very little or no income and limited assets, you may be eligible for financial assistance through the Ontario Works Program. To obtain financial assistance, you must first complete a telephone interview to determine your eligibility. If you are eligible to apply for Ontario Works, you will be asked to arrange for an assessment at your closest Ontario Works office. You can request an appointment in your home or elsewhere in your community if it is difficult for you to visit an Ontario Works office.

During your appointment, you will be asked about your family size, income, assets, savings, expenses and housing costs, and you will have to provide identification such as proof of identity (e.g., birth certificate), your social insurance number, your health card and if necessary, your immigration status.

You will also have to provide financial information such as your shelter expenses (e.g., a copy of your mortgage or rental agreement), bank statements (e.g., recent bank statement for all your bank accounts), proof of assets and information about your previous employment (e.g., Record of Employment and/or your most recent pay stubs), information about other money you may be receiving such as a pension, a copy of your Canada Child Tax Benefit statement (if you have children under 18 years of age), and information about assets you may own (e.g., registered retirement savings plan).

If you are eligible, Ontario Works may provide immediate, emergency or short-term financial assistance or special funds for specific needs. If you are receiving Ontario Works, you may also be eligible for certain health benefits such as drug coverage benefits.

If your situation is such that you need to apply for long-term financial assistance, speak with a social worker or other social service worker to get more information about long-term income replacement options such as the Ontario Disability Support Program (ODSP) and Canada Pension Plan’s Disability Program. Both of these income replacement programs have eligibility requirements that you must meet. You can also obtain information on these programs by contacting the programs directly.

Community resources are available to help you determine which financial assistance programs you may be eligible for and to link you with a social worker or other social service worker to help you with applying for these programs. Visit www.211Ontario.ca, an online directory providing easy access to community, social, health and related government services in Ontario.

Additional information about financial assistance is provided in the appendix.

LIFE INSURANCE

If you are looking for life insurance coverage, you may want to use an insurance broker. Insurance brokers have access to different companies and can find the best package for you. It will be important to make them fully aware of your health history. Although every insurance company’s rules are different, some are more flexible than others.

In Canada, if you have had breast cancer, your pre-existing life insurance policy will be honoured for your lifetime if it is a whole-life policy and for the remaining amount of the term if it is a term (or temporary) policy. However, purchasing a new life insurance policy is a different matter. If you have been diagnosed with breast cancer, you will find that your eligibility for insurance policies will be different from someone who has not had breast cancer.

Women who have experienced breast cancer and who are applying for individual policies may be offered policies at a substandard or special class rate, which usually means more expensive monthly premiums (payments). Factors that may affect your eligibility and/or
your premium may include the type of diagnosis and treatment you received, the number of years since your diagnosis, your current health assessment and whether you are taking drugs to help prevent breast cancer recurrence. If you are charged an increased premium or your application is declined, find out if it would be helpful if you provided further information. You may also want to ask when you can apply again.

One option to consider is to apply for several small policies with different companies. However, in this case, work with a trained insurance broker to find the best combination of coverage possible. There are forms of individual life insurance called “guaranteed issue,” where no health assessment is made. These policies are designed specifically with uninsurable people in mind and are often quite expensive. These types of policies are usually provided to cover funeral expenses, not to provide asset or income protection.

**Critical illness insurance** is an insurance product that provides a lump sum cash payment if the policyholder is diagnosed with a critical illness. The most common critical illnesses that are covered are cancer and heart disease. Critical illness insurance is designed to provide financial assistance to cover expenses involved with specific conditions. However, most policies will provide money to the insured to use in whatever way they wish.

Your eligibility for critical illness insurance plans may depend on additional factors such as your family health history. The critical illnesses that are covered may vary slightly from company to company, so it is a good idea to consult with an insurance broker before purchasing any insurance product.
NOTE: If you are already covered by life insurance and other benefits such as short-term and long-term disability by your employer, you should keep in mind that if you change jobs, you will lose those benefits. However, should you leave your current work place, some insurance companies have a provision to convert your policy from group coverage to individual coverage without proving insurability. This change must be done within a specific time period (e.g., 60 days). Check with your insurance provider to find out if this is an option for you. Also, when considering employment opportunities, be aware of whether prospective employers provide group insurance benefits. Some workplace group insurance programs do not disqualify new employees on the basis of a pre-existing medical condition such as breast cancer; however, other programs may require that the policy be underwritten to determine a new rate.

If you are already insured, make sure you pay your premiums on time so your insurance does not lapse.

What to expect over the next few years

“My husband and I had always put money away for a “rainy day.” When I got breast cancer, I was tempted to cash it all in and go on a trip around the world. We checked with a financial advisor and decided to make some changes. We didn’t go on that world trip, but we do spend a little more of our money travelling to visit our grandchildren and going on one nice trip every year.”

FINANCIAL PLANNING

During the past year, you have probably focused much of your attention on your health and getting your life back on track again. You may want to now give some thought to your financial and legal affairs. There are many ways that you can get help doing this. If you have a lawyer, financial advisor and/or tax accountant, you should talk to them about what has happened and what has changed as a result of your breast cancer. Other potential sources of advice on financial and legal issues may include these:

- Friends and family with financial expertise.
- Your social worker at the hospital or treatment centre (for information and/or referral to outside agencies).
- Members of your breast cancer support group who may have gone through a similar experience.
- The Community Information Centre for your area.
  Go to: www.211Ontario.ca.

If you have debt and it is more than you can handle, speak directly to your creditors, your mortgage holder or your landlord. If you need help negotiating with your creditors, find out from your bank or your local community information centre. Go to: www.211Ontario.ca if credit counselling is available in your area. Be honest about your situation and remember that it is not your fault that you had breast cancer. You will probably find that most people you speak to will be sympathetic to your situation and want to be helpful.

LEGAL HELP

You will need to check with a lawyer if you write or change your will or transfer any assets you may have. As mentioned in Chapter Five, if you are in a lesbian relationship you may want to consider providing your partner with power of attorney for health care.
No matter what your legal needs, it will be important that you find a lawyer with relevant skills and experience. If you cannot afford a lawyer, you can contact Legal Aid Ontario to ask if financial assistance is available to help pay for a lawyer for your specific legal need. More information about Legal Aid is provided earlier in this chapter as well as in the appendix.

If your estate (all of your possessions, including your property, financial assets and debts) is modest, you can also obtain Ontario Will kits at local business supply stores. Power of Attorney kits are also available free from the Ministry of the Attorney General. A form for creating a living will is available through the website for the Joint Centre for Bioethics at the University of Toronto: www.jointcentreforbioethics.ca/tools/livingwill.shtml.

Your experience with breast cancer has probably helped you better appreciate the importance of securing your financial future from an employment, insurance and legal point of view. Although you have been focused on your recovery up until now, it will be wise to set aside some time to set goals and make a plan for the future.
This chapter will provide you with tips on how to evaluate information you read in the media or on the Internet such as news articles, research studies and descriptions of complementary and alternative medical therapies, so that you can better judge when that information is relevant to you.

What you may be feeling now

"Every time I see an article in the newspaper or a magazine about a new breast cancer treatment, I start thinking about my breast cancer experience all over again and worry that I might not be doing the things I should."

As your life goes on, your breast cancer experience will move further and further away from your everyday thoughts. You will become better at living with what has happened to you. There will be times, however, when you may come across an issue that interests you. You may read an article on the Internet about a new form of treatment, hear about current health care issues on the radio, or talk to a friend with breast cancer who is exploring an alternative product or approach. These experiences may make you wonder if you are currently doing the right things. You may ask yourself: is there more that I should be doing to reduce my risk?

What you need to know now

If you have questions about new treatments for breast cancer, Willow Breast Cancer Support Canada or the Canadian Cancer Society’s Cancer Information Service can provide you with the details of any new research findings reported in the press. You can contact Willow at 1-888-778-3100 (toll free), www.willow.org or info@willow.org, and the Canadian Cancer Society’s Cancer Information Service at 1-888-939-3333 or www.cancer.ca. If you have breast cancer issues that concern you, contact your family doctor or other members of your health care team. If you are part of a breast cancer support group, you may also wish to bring issues to the group’s attention and check to see what others have found out.

What to expect during the coming year

DEALING WITH INFORMATION REPORTED BY THE MEDIA AND ONLINE

Your breast cancer experience has been shaped by many factors. These include the level of support you have had, your financial situation, your ethnic and family culture, the community and society in which you live, and your spirituality. Cultures and societies in particular are influenced by media such as the Internet, TV, radio, newspapers, magazines and movies. These sources of information all compete for our attention. And, almost everyday, they have something new to tell us about health care and breast cancer. Unfortunately, information that is unclear or incomplete often raises false hopes and results in unrealistic expectations.

The news media like to present short bits of information that are easy to understand and make a quick impact, but they often don’t tell the whole story. For example, most of us have heard the statistic that one in nine Canadian women will develop breast cancer in her lifetime. If not interpreted correctly, this statement can give the impression that one out of nine women currently has breast cancer. This is not true. The statement actually means that if we followed
a group of 1,000 Canadian girl babies all through their lives, 111 of them (or one in nine) would be diagnosed with breast cancer at some point during their lifetime, which means by the time they reach the age of 90 years old.

Stay informed, but be cautious

It is natural that you and your family will be on the lookout for information about medical breakthroughs or promising results from clinical trials. Whether you actively search for this information or not, you will likely hear about new developments in breast cancer treatment and other new findings related to breast cancer. Always try to use your judgment and think critically. Don't be afraid to question the facts you read in the media and online. The media often play a “watch dog” role and will report on controversial studies that may go against established methods of treatment and practice.

The following points are useful to keep in mind when judging information about new medical treatments or breakthroughs:

1) Has the information been subject to complete scientific study and published in a peer-reviewed journal?
   
   • Valid new cancer discoveries are not usually announced first in the press. Significant advances are based upon studies in humans that have been published in medical and scientific journals and discussed at major medical meetings.
   
   • The peer review system is used by scientists to decide which research results should be published in a scientific journal. This system ensures that research is carefully checked by other qualified experts (peers) before it is made public. When research has passed the peer review process, it has passed the scrutiny of other scientists. Scientists do not draw their conclusions from just one paper or set of results. They consider
the context of other work and their own experience. It usually takes more than one research study for results to be accepted as good evidence.

2) Has the treatment or product been tested on humans?

- A large number of promising new treatments are announced each year; however, they are usually based on testing that has been done on animals. Out of the thousands of drugs that are investigated, only a very small number will be successful enough to be approved for use in humans.

- Sometimes studies are conducted on a very small number of participants. Remember that researchers need to study a large population over a long time to make sure that findings are not just the result of chance.

- Note whether the people in the study were a similar age, sex, and ethno cultural background as you. Studies done on people very different from you may not apply to you.

3) Who is responsible?

- Who conducted the study and who is funding it? Often, studies paid for by pharmaceutical or medical equipment companies will report results that are favourable to their product.

- Has the study been repeated by other investigators? If this is the only study of its kind, more research may be needed to confirm the results.

4) Other things to keep in mind:

- The environment is a popular issue in the media and a lot of information is reported about air pollution, electromagnetic radiation and harmful chemicals such as asbestos and radon that may cause cancer. When you read about a substance that carries some risk, even if scientific evidence has not yet proven a firm link, it is best to be cautious in your use of that substance. When in doubt, check with the Canadian Cancer Society’s Cancer Information Service (see appendix).

- The media often report about products (such as herbal supplements) or treatments that claim to prevent or even cure cancer. Before attempting to use these products, check with your health care team to verify if there is any truth to the media reports. More information about cancer fraud is provided below in the section about Project False Hope.

How to evaluate information on the internet

When you visit a website, consider the source of the information and critically view any material you find. Keep in mind that anyone can create a site and post whatever content they desire.

Below are some questions that can help you evaluate the quality of online health information.

- Who developed and maintains the site? Check the site’s URL (usually listed in a box labeled “address” near the top part of your screen). For example, the URL for Health Canada’s website is: www.hc-sc.gc.ca. The initials gc.ca indicate that the website is maintained by the Government of Canada. Some other common designations are “edu” for educational institution, “org” for non-profit organization “net” for network and “ca” for Canada.

You can also check for a link that says “Who We Are” or “About...”. If there is no information available about the purpose of the site or who owns or develops its content, it is wise to verify the accuracy of the information by checking with other reputable sites.

- Who pays for the site? Good websites are costly and many have outside sources of funding. This information should be clearly presented on the site. The source of funding can affect how the content is presented. For example, drug-company-sponsored information may focus only on products that the company produces.
• Where does the information come from? Sometimes information on websites is collected from other websites or from off-line sources. If this is the case, the original source should be clearly listed. Medical facts and figures should have references, and opinions or advice should be clearly labeled as such and set aside from information that is based on research results.

• When was the material produced? All health content should have a date on it, so you can tell when the material was written, when it was posted and when it was last revised.

• Does the site ask you for personal information? If so, check its privacy statement to ensure that your information will not be shared without your permission.

• Is there a way to contact the site? Credible websites always provide a way for readers to contact the site owners with problems, feedback and questions. If the site hosts chat rooms or other online discussion areas, the terms and rules of use should be posted.

NOTE: Check with your hospital or cancer centre, Willow Breast Cancer Support Canada, the Canadian Cancer Society’s Cancer Information Service, or the Canadian Breast Cancer Foundation - Ontario Region for information on credible Internet websites that provide information on breast cancer. You can contact Willow at 1-888-778-3100 (toll free), www.willow.org, or info@willow.org, and the Canadian Cancer Society’s Cancer Information Service at 1-888-939-3333 or www.cancer.ca or email the Canadian Breast Cancer Foundation - Ontario Region at: breastcancer@cbcf.org

**COMBATING CANCER FRAUD: PROJECT FALSE HOPE**

In Canada and throughout the world, many websites advertise miraculous treatments and cures that just don’t work. These sites lure people with false claims. The Canadian Cancer Society and the Competition Bureau of Canada worked in cooperation on Project False Hope, which is intended to identify and stop online health fraud. Project False Hope was set up to provide cancer patients and their families with information they need to recognize health fraud.

The Competition Bureau’s False Hope web page (www.competitionbureau.gc.ca/healthfraud) provides interactive tools that can help you learn to spot the signs of fraudulent online cancer treatments and cures.

*More information about Project False Hope is provided in the appendix.*

**THE RESEARCH PROCESS**

In Canada we are fortunate to have one of the top cancer research systems in the world. Across the country, cancer researchers are working to examine how cancer develops, risk factors, early detection and screening, treatment, quality of life and survivorship.

The search for better ways to control cancer begins with basic research in the laboratory and may involve animal studies or live human cells in test tubes. This laboratory work identifies new methods that are most likely to work and tests the safety and effectiveness of these new methods before they are tried on humans.

**Clinical trials**

Research studies that go beyond the laboratory and begin to test the results on people are called clinical trials. These trials are designed to answer specific questions about biomedical or behavioral methods, and include testing new treatments for people
with cancer or who are at risk for cancer. Clinical trials are the most important way of testing new methods for the better treatment and control of cancer.

Before a clinical trial can start, a research proposal must be approved by a Research Ethics Board that ensures that the research is carried out ethically. This means that researchers do not have any conflict of interest and the participants fully understand the risks and benefits of the trial and give consent to take part.

There are many different types of clinical trials:

- **Treatment trials** that test experimental treatments, new combinations of drugs or new approaches to surgery or radiation therapy.
- **Prevention trials** that examine how to prevent cancer through medicines, vaccines, vitamins, minerals or changes in lifestyle.
- **Diagnostic trials** that search for better tests or procedures that can be used to diagnose cancer.
- **Screening trials** that test the best way to detect certain cancers.
- **Quality of life trials** that explore ways to improve the comfort and quality of life for people with cancer.

During a clinical trial, information is gathered about how these procedures or treatments affect people, whether there are side effects or risks, how safe they are and whether they are better than standard methods (if standard methods exist). For example, new cancer treatments must prove to be safe and effective in scientific studies with a certain number of patients before they can be made widely available. Most of the standard treatments for cancer were first shown to be effective in clinical trials.

Evidence-Based Medicine

If you find yourself worrying about or “second-guessing” your breast cancer treatment, remember that medical professionals in Canada are very serious about their responsibility to use the best evidence they have available when treating patients.

There is no doubt that health care decisions are complex and difficult. When using evidence-based medicine to treat individuals with cancer, health professionals combine their own individual clinical expertise with external evidence about what has been proven to work. In addition, they consider the unique needs and wishes of their patients. When making decisions, health care professionals combine all these factors: the evidence available, their own expertise and their patients’ needs and wishes.

Complementary and Alternative Medicine (CAM)

During your breast cancer treatment you may have already thought about or tried complementary or alternative therapies. Now that you have completed treatment, you may wish to explore these therapies to prevent a recurrence.

What is complementary and alternative medicine?

Complementary and Alternative Medicine (CAM) includes a variety of different health care systems, practices and products that are not usually considered to be part of regular medicine. Although some
CAM therapies are backed by scientific evidence, many still need to be tested through well-designed, scientific studies to ensure that they are safe and work effectively.

Complementary and alternative medicines (CAM) include a range of therapies. When used in combination with conventional or regular medicine, these therapies are called complementary medicine; when used instead of conventional medicine, they are called alternative medicine.

Here are some examples of CAM therapies:
- Acupuncture
- Art Therapy
- Ayurveda
- Chiropractic
- Herbalism
- Homeopathy
- Hypnosis
- Macrobiotic Diet
- Massage
- Meditation
- Music Therapy
- Naturopathy
- Osteopathy
- Psychotherapy/Counselling
- Qigong
- Reiki
- Reflexology
- Therapeutic Touch
- Traditional Chinese Medicine
- Tibetan Medicine
- T’ai Chi
- Yoga

CAM also includes many natural health products such as:
- Herbal products
- Vitamin and mineral supplements
- Traditional Chinese, Ayurvedic and other traditional medicines
- Homeopathic preparations

Should you try complementary or alternative medicine (CAM)?

How you feel about complementary and alternative medicine may depend on your cultural, religious, ethnic and personal background and on what you have heard or read about CAM. Many women are attracted to these therapies because they seem more natural, less toxic and less intrusive compared to conventional medical treatments.

Be cautious when using CAM therapies. There is often not much information available about the safety and effectiveness of many complementary and alternative therapies. Some practitioners of CAM therapies may not be well-educated, qualified or even accredited by a licensing body. In addition, there have been reports about toxic substances contaminating natural health products, as well as side effects when they are given alone or with other medications. Some substances do not even contain the actual ingredients listed or list ingredients by different names. Remember that if your oncology health care team had sufficient evidence that any of these therapies would improve your chances of living longer, they would recommend them to all of their patients.

Take steps to protect your safety

Before you try an alternative approach or take any self-selected or over-the-counter product, including a natural health product, you should take steps to be sure it is safe. Ask yourself the following questions:
- Why should I take this product or try this approach?
- Is it safe for me?
- Are there side effects that I should be aware of?
- How much will it cost?
- Can I use it along with any other treatments I am taking?
- What are the benefits to me?
• Is this the best product or approach to achieve those results, or are there better alternatives?

• Is there evidence that supports the safety and effectiveness of this product or approach?

• Is the practitioner well-qualified to practice the therapy?

**Here are some additional tips that are important if you choose to seek complementary and alternative therapies:**

• Tell your health care team what you are doing and why, and especially if you notice
  - Unusual changes in body functions
  - Possible allergic reactions (swelling, hives, shortness of breath)

• Check with your pharmacist about any natural health product you intend to use. He/she may be able to provide further information and will also advise you on any possible drug interactions.

• If using natural health products, use products that are approved by Health Canada. Look for a DIN, NPN or DIN-HM on the label of medications. These are drug information numbers given to the product by Health Canada that verify they have been approved.

• Be cautious about health-related claims. Using the steps listed above, do some additional research to ensure that you fully understand the pros and cons of the product or approach before using it. Do not rely on company advertisements or package information, and don’t be afraid to check with your health care team.

• Be aware of any reactions or interactions with other drugs you are taking. Report any adverse reaction to your health care team.
NOTE: Always check the ingredients of any over-the-counter medicine or herbal preparation because some may contain estrogen. Inform your doctor right away if you notice any unexpected side effects or interactions with other medicines you are taking.

Don’t hesitate to keep your health care team informed

You are responsible for gathering and assessing information about complementary and alternative therapies, but you may be concerned that your health care team might abandon you if you make product or treatment choices that they do not recommend. Your doctor and health care team should support your right to look into and consider complementary and alternative therapies and encourage you to share your decisions about the use of these products and approaches with them.

For more information on complementary and alternative therapies, contact Willow at 1-888-778-3100 (toll free), www.willow.org, or info@willow.org, and the Canadian Cancer Society’s Cancer Information Service at 1-888-939-3333 or www.cancer.ca.

Conclusion

Moving forward

Thousands of women in Canada are living with a history of breast cancer. With time, you will find that the immediate crisis of your cancer experience will pass and it will become a part of your life experience. The impact of cancer can shift old roles and may force you to look at your life differently. You have been through a tough period, and now is the time for healing and restoring your health.

You play a large role in many aspects of your own health and wellness, and where you choose to go from here will be influenced by what you choose to focus on and the decisions you make. Hopefully, this booklet will be a guide that can help you find the right sources of information and advice.

Remember, you are not alone. You have been and will continue to be an essential partner in your own health care team. Ask for support if you need it – your health care team will always be there for you in addition to your friends, your family and your community.

Safe passage!
Appendix
Resources for breast cancer survivors

You may find that the process of getting back to your regular routine is complicated. Many women who have experienced breast cancer and their families and friends need assistance, support, guidance and information in order to become comfortable with their “new normal.”

In the following pages, you will find many different resources that can help you in your transition from your experience as a patient with breast cancer to an individual who is living life after breast cancer. This list contains province-wide and regionally focused organizations, websites, online communities and further reading so that you can tailor information resources and information to your own personal needs.

NOTE: These resources are provided as general information. Please remember that the views expressed in these resources and by the organizations listed in this section are not necessarily those of your doctors or other members of your health care team. While this listing is current as of the date of the printing of this booklet, it is not exhaustive. The resources listed below may have additional information on new or updated resources that may be helpful for you.

Province-wide support and information

**Willow Breast Cancer Support Canada**
Willow offers support and information to anyone affected by breast cancer, free of charge. When you call Willow, you will speak with someone who has had breast cancer. Willow’s peer support team offers empathetic and supportive listening and is experienced in answering a wide range of questions and concerns about breast cancer. Willow’s health librarian works with the peer support team to research your question(s) and send you a personalized information package.

  - Toll free phone: 1-888-778-3100
  - Web: www.willow.org
  - Email: info@willow.org

**Canadian Cancer Society, Cancer Information Service**
The Canadian Cancer Society’s Cancer Information Service is a national, bilingual, toll free service available to cancer patients, their families, the general public and health care professionals seeking reliable information about cancer and support organizations in their community.

  - Toll free phone: 1-888-939-3333
  - Email: cis@ontario.cancer.ca

**Canadian Cancer Society, Peer Support Program**
The Canadian Cancer Society’s Peer Support Program is a nationwide toll free service that matches patients and caregivers with trained volunteers who have had a similar cancer experience and understand what it’s like to live with and beyond cancer.

  - Toll free phone: 1-800-263-6750
  - Web: www.cancer.ca/ontario Search: peer support
Look Good, Feel Better Program
The Look Good, Feel Better Program helps women to cope with the appearance-related side effects of cancer treatment. The program offers free workshops and literature on skin care, makeup, hair loss and nail care. Their website includes information about the services and resources they provide across Ontario.
   Toll free phone: 1-800-914-5665
   Web: www.lgfb.ca

Lymphovenous Association of Ontario
Breast cancer survivors who have received surgery or radiation treatment to the lymph nodes are at a heightened risk of developing lymphedema. The mandate of the Lymphovenous Association of Ontario is to improve the quality of life for those living with lymphedema by raising awareness and providing education on lymphedema to patients, therapists and health care professionals across Ontario.
   Phone: 416-410-2250; Toll free phone: 1-877-723-0033
   Web: www.lymphontario.org
   Email: lymphontario@yahoo.com

211 Ontario
This online directory of services provides easy access to community, social, health and government services in Ontario. It can also direct you to your local Community Information Centre (select General Community Services, Community Information Centres).
   Web: www.211ontario.ca/

Regional resources and supportive care programs

HOW IS THIS LIST ORGANIZED?
The province of Ontario is made up of 14 geographic regions, each of which is served by a Local Health Integration Network (LHIN). The list below provides resources divided by region, including key local community support services and contact information for the Supportive Care Program of each Regional Cancer Program. This list is not exhaustive. To find out more about additional resources in your area, contact Willow Breast Cancer Support Canada, the Canadian Cancer Society’s Cancer Information Service, or the supportive care program at your cancer centre, affiliated hospital or community cancer clinic.

Your Regional Cancer Centre, or affiliated hospital or community cancer clinic, is where you have received treatment for breast cancer over the course of many weeks, months, or even years. You may still be taking medication as part of an ongoing treatment plan. Now that you are no longer visiting your cancer centre as regularly, you may be wondering what role your health care team will play in your care. While your family doctor or nurse practitioner will monitor your overall health and well-being, you will have follow-up appointments at your Regional Cancer Centre. You may also still want or need to access the supportive care services at your Cancer Centre.

Supportive Care (sometimes called Psychosocial Oncology) Programs offer a variety of services to individuals and families at the time they are diagnosed with cancer, during treatment at the Cancer Clinic and after treatment is over. Experienced professionals are available to talk with about your feelings and concerns around your breast cancer experience and to provide
information about support groups and other resources available in your community. The types of services that may be available, depending on the specific Supportive Care Program, include social work, physiotherapy, occupational therapy, and pain and symptom management, as well as the services of dietitians, pharmacists, spiritual care advisors and psychiatrists or psychologists.

**Erie St. Clair Regional Cancer Program**, within the Erie St. Clair Local Health Integration Network (LHIN)
The Erie St. Clair LHIN boundaries include all of the County of Lambton, Chatham-Kent, Essex County and the City of Windsor.

**Windsor Regional Cancer Centre**
(at Windsor Regional Hospital)
Web: www.wrcc.on.ca
Supportive Care Program
Phone: 519-253-3191 ext. 58652
Web: www.wrcc.on.ca/webpage.cfm?site_id=3&org_id=204

**Wellspring at the Hospice of Windsor and Essex County**
Wellspring at the Hospice of Windsor and Essex County offers programs at no charge for cancer patients at any stage of illness and their caregivers.
Phone: 519-974-7100
Toll free phone: 1-877-499-9904
Web: www.wellspring.ca/windsor-and-essex-county.html or www.thehospice.ca

**South West Regional Cancer Program**, within the South West Local Health Integration Network (LHIN)
The South West LHIN boundaries include all of Elgin County, Middlesex County, Oxford County, Perth County, the County of Huron, Bruce County and the Cities of London and Stratford.

**London Regional Cancer Program**
(at London Health Sciences Centre)
Web: www.lhsc.on.ca/About_Us/LRCP/index.htm
Supportive Care Program
Phone: 519-685-8622
Web: www.lhsc.on.ca/Patients_Families_Visitors/LRCP/Supportive_Care/index.htm

**Wellspring London and Region**
Wellspring London and Region provides a wide range of supportive care programs and educational services at no charge for people living with cancer and those who care for them.
Phone: 519-438-7379
Web: www.wellspringlondon.ca

**Wellspring Stratford Program**
Wellspring Stratford Program offers a range of free programs to meet the needs of people living with cancer and those who care for them.
Phone: 519-271-2232
Web: www.wellspring.ca/stratford-program.html

**Waterloo Wellington Regional Cancer Program**, within the Waterloo Wellington Local Health Integration Network (LHIN)
The Waterloo Wellington LHIN boundaries include the entire County of Wellington, the Region of Waterloo and the City of Guelph. This LHIN contains part of Grey County, which is split with the South West and the North Simcoe Muskoka LHINs.

**Grand River Regional Cancer Centre**
(at Grand River Hospital, Kitchener)
Web: www.grrrcc.on.ca
Supportive Care Program
Phone: 519-749-4370 ext. 5781
HopeSpring Cancer Support Centre
HopeSpring was created to assist people to move beyond the fear, confusion and frustrations surrounding a cancer diagnosis and treatment. It offers a variety of programs and services including personal and group support, a free wig boutique and an excellent resource centre.
  Phone: (Waterloo) 519-742-4673
  (Cambridge) 519-624-5855
  Web: www.hopespring.ca

Hamilton Niagara Haldimand Brant Regional Cancer Program,
within the Hamilton Niagara Haldimand Brant Local Health Integration Network (LHIN)
The Hamilton Niagara Haldimand Brant LHIN boundaries include all of Hamilton, Niagara, Haldimand and Brant. Also included are part of Halton (specifically Burlington) and roughly half of Norfolk County, which is shared with the South West LHIN.

Juravinski Cancer Centre
(at Hamilton Health Sciences)
  Web: www.jcc.hhsc.ca

Supportive Care Program
  Phone: 905-387-9711 ext. 64315
  Web: www.hamiltonhealthsciences.ca/sitemaker/websitefiles/jcc6978890/body.cfm?id=67

Wellwood Resource Centre (Hamilton)
Wellwood is a community-based, non-profit organization providing information, supportive care programs and peer support to people who have received a diagnosis of cancer, their families and caregivers and health care providers.
  Phone: 905-389-5884
  Web: www.wellwood.on.ca

Breast Cancer Support Services (Burlington)
Breast Cancer Support Services is a self-help organization offering a variety of free programs and services, including education and support for women and men with breast cancer.
  Phone: 905-634-2333
  Toll free phone: 1-800-465-1902
  Web: www.breastcancersupport.org

Wellspring Niagara (Thorold)
Wellspring Niagara offers a wide range of programs to people living in the Niagara Region. Its mission is to provide free social, emotional, psychological, informational and spiritual support to individuals living with cancer, their families and close supporters.
  Phone: 905-684-7619
  Toll free phone: 1-888-707-1277
  Web: www.wellspring.ca/niagara.html

Wellspring Stevensville Program
Wellspring Stevensville Program offers a range of free programs to meet the needs of people living with cancer and those who care for them.
  Phone: 905-684-7619
  Toll free phone: 1-888-707-1277
  Web: www.wellspring.ca/nc/centres/niagara/ways-wellspring-can-help/calendar-and-whats-on/stevensville-calendar.html

Mississauga Halton Central West Regional Cancer Program,
within the Mississauga Halton Local Health Integration Network (LHIN) and the Central West Local Health Integration Network (LHIN)
The Mississauga Halton LHIN boundaries were changed to include a southwest portion of the City of Toronto, the south part of Peel Region and all of Halton Region except for Burlington, which remains in the Hamilton Niagara Haldimand Brant LHIN. The Central West LHIN now includes all of Dufferin County, the northern portion of Peel Region, part of York Region and a small part of the City of Toronto.
The Carlo Fidani Peel Regional Cancer Centre  
(at Credit Valley Hospital, Mississauga)  
Web: www.cvh.on.ca/cancer/index.php

Supportive Care Program, Social Work  
Phone: 905-813-1100 ext. 6007  
Web: www.cvh.on.ca/cancer/index.php

Wellspring Halton-Peel (Oakville)  
Wellspring Halton-Peel serves individuals and families coping with cancer in the communities in and around the regions of Halton and Peel. The centre is also considered home to programs run by a number of other organizations offering cancer support in the region.  
Phone: 905-257-1988  
Toll free phone: 1-877-499-9904  
Web: www.wellspring.ca/halton-peel.html

Wellspring Chinguacousy (Brampton)  
Wellspring Chinguacousy serves individuals and families coping with cancer in the communities in and around the regions of Halton and Peel. The centre is also considered home to programs run by a number of other organizations offering cancer support in the region.  
Phone: 905-792-6480  
Toll free phone: 1-877-499-9904  
Web: www.wellspring.ca/chinguacousy-brampton.html

Toronto Regional Cancer Program, within the Toronto Central Local Health Integration Network (LHIN)  
The Toronto Central LHIN shares the City of Toronto with the Mississauga Halton, Central West, Central and Central East LHINs.

Princess Margaret Hospital (Toronto)  
Web: www.uhn.ca/pmh

Breast Cancer Survivorship Program  
The Breast Cancer Survivorship Program provides support to breast cancer patients of Princess Margaret Hospital and to their families and friends. The Program offers survivors the opportunity to participate in a comprehensive, reflective interview and create a survivorship plan. The Program also offers various late-effect clinics such as Lymphedema, Neurocognitive, Fatigue and the Function and Mobility clinic.  
Phone: 416-946-4501 ext. 2363 or ext. 4841  
Web: www.survivorship.ca  
Email: survivorship@uhn.on.ca

Ontario Cancer Institute/The Princess Margaret Hospital / University Health Network  
Healing Journey Program  
The Healing Journey program helps cancer patients and family members cope with the stress of cancer and its treatments. Dr. Alastair Cunningham, a psychologist, mind-body researcher and cancer survivor, leads the sessions. There are three levels to this program: Coping with Cancer Stress, Skills for Healing, and Steps towards a Spiritual Healing.  
Phone: 416-946-2062  
Web: www.healingjourney.ca

Odette Cancer Centre  
(at Sunnybrook Health Sciences Centre, Toronto)  
Web: www.sunnybrook.ca

Supportive Care Program  
(also called Psychosocial and Palliative Oncology Program)  
Phone: 416-480-4623  
Web: www.sunnybrook.ca/content/?page=3542
Wellspring Sunnybrook (Toronto)
Wellspring Sunnybrook offers a number of programs that have been developed in collaboration with the Odette Cancer Centre, as well as the regular roster of Wellspring support groups, coping skills sessions and expert-led educational presentations.
Phone: 416-480-4440
Toll free phone: 1-877-499-9904
Web: www.wellspring.ca/sunnybrook-toronto.html

Wellspring Odette House (Toronto)
Wellspring Odette House in Toronto offers programs that are free of charge and open to individuals and caregivers who are coping with any type and any stage of cancer. Programs include individual and group support, coping skills, expressive therapies, energy work and educational workshops and presentations.
Phone: 416-961-1928
Toll free phone: 1-877-499-9904
Web: www.wellspring.ca/odette-house-toronto.html

Wellspring at Women's College Hospital (Toronto)
Wellspring professionals at Women's College Hospital offer programs that are free of charge and open to individuals and caregivers who are coping with any type and stage of cancer. Services include peer support, financial counselling, discussion groups, cancer exercise programs, yoga, meditation and referrals to other support programs.
Phone: 416-323-6400 ext. 4240

Gilda's Club Greater Toronto
Gilda's Club provides a meeting place where men, women, teens and children living with cancer, as well as their families and friends, can join with others to build social and emotional support as a supplement to their treatment of choice.
Gilda’s Club offers support and networking groups, lectures, workshops and social events in a non-residential, home-like setting.
Phone: 416-214-9898
Web: www.gildasclubtoronto.org

Central Regional Cancer Program,  
within the Central Local Health Integration Network (LHIN)  
The Central LHIN boundaries include a northern section of the City of Toronto, most of York Region and part of Simcoe County.

Regional Cancer Centre  
(at Southlake Regional Health Centre, Newmarket)  
Web: www.southlakeregionalcancer.org  
For Supportive Care services, ask for a referral from a member of your health care team.

Wellspring at Doane House Hospice (Newmarket)  
Wellspring at Doane House Hospice offers programs at no charge for cancer patients at any stage of illness and their caregivers.  
Phone: 905-967-0259; Toll free phone: 1-877-499-9904  
Web: www.wellspring.ca/doane-house-hospice-newmarket.html or www.doanehospice.org

Wellspring at Matthews House Hospice (Alliston)  
Wellspring at Matthews House Hospice offers programs at no charge for cancer patients at any stage of illness and their caregivers.  
Phone: 705-435-7218  
Toll free phone: 1-877-499-9904  
Web: www.wellspring.ca/alliston.html

Central East Regional Cancer Program,  
within the Central East Local Health Integration Network (LHIN)  
The Central East LHIN boundaries include all of Durham Region, Kawartha Lakes, the Haliburton Highlands and Peterborough County. Central East also contains part of Northumberland County and the eastern City of Toronto (east of Warden, south of Steeles).

R. S. McLaughlin Durham Regional Cancer Centre  
(Lakeridge Health, Oshawa)  
Web: www.lakeridgehealth.on.ca/index.php?id=A21-7C&navID=listMenuRootV  
Supportive Care Program  
Phone: 905-576-8711 ext. 4703  
Web: www.lakeridgehealth.on.ca/article.php?id=AA2-9L&navID=listMenuRootV

Hearth Place Cancer Support Centre (Oshawa)  
Hearth Place Cancer Support Centre is committed to providing community support for patients and their families dealing with cancer. The Centre offers peer support, information, a resource centre, wellness programs and an ongoing lecture and discussion series.  
Phone: 905-579-4833  
Web: www.hearthplace.org

South East Regional Cancer Program,  
within the South East Local Health Integration Network (LHIN)  
The South East LHIN boundaries include all of Hastings County, Lennox and Addington, Prince Edward County, Frontenac County and the City of Kingston. This LHIN contains most of Northumberland County, as well as Leeds and Grenville, which is split with the Champlain LHIN. Lanark County is also split with the Champlain LHIN to accommodate the moving of the Perth Smith Falls hospital sites to the South East LHIN.
Cancer Centre of Southeastern Ontario  
(at Kingston General Hospital, Kingston)  
Web: www.krcc.on.ca/

Supportive Care Program  
Phone: 613-544-2631 ext. 2910  
Web: www.krcc.on.ca/patient_visitor/patient_visitor_supportiveCareProgram.asp

Breast Cancer Action Kingston  
Breast Cancer Action Kingston is a survivor-led, charitable organization, working to educate and support women and men living with breast cancer, their families and the community.  
Phone: 613-531-7912  
Web: www.bcakingston.org

Champlain Regional Cancer Program,  
within the Champlain Local Health Integration Network (LHIN)  
The Champlain LHIN boundaries include all of Renfrew County, the City of Ottawa, Prescott and Russell, and Stormont, Dundas and Glengarry. Split municipalities include Lanark County (to accommodate the moving of the Perth Smith Falls hospital sites to the South East LHIN) and part of Leeds and Grenville.

The Ottawa Hospital Cancer Centre  
Web: www.ottawahospital.on.ca/sc/cancer/index-e.asp

Psychosocial Oncology Program  
Phone: 613-737-7700 ext. 70148  
(or ask for Psychosocial Oncology Program Unit Coordinator)  
Web: www.ottawahospital.on.ca/sc/cancer/cancer-programs/support-e.asp

Breast Cancer Action Ottawa  
Breast Cancer Action is a charitable organization whose goal is to ensure that each person diagnosed does not feel they need to fight alone. From pre-operative information sessions, peer support and rehabilitative exercise classes, the mission is to make a significant and meaningful difference to the lives of people affected by breast cancer or with breast health concerns.  
Phone: 613-736-5921  
Web: www.bcaott.ca

Wellspring Ottawa (scheduled to open in 2011)  
Wellspring Ottawa will offer a range of free programs to meet the needs of people living with cancer and those who care for them.  
Web: www.wellspring.ca

North Simcoe Muskoka Regional Cancer Program, within the North Simcoe Muskoka Local Health Integration Network (LHIN)  
The North Simcoe Muskoka LHIN includes the municipalities of Muskoka, most of Simcoe County and part of Grey County.

Simcoe-Muskoka Regional Cancer Centre  
(Royal Victoria Hospital, Barrie)  
Web: www.rvh.on.ca  
For Supportive Care services, ask for a referral from a member of your health care team.

North East Regional Cancer Program, within the North East Local Health Integration Network (LHIN)  
The North East LHIN boundaries include the Districts of Nipissing, Parry Sound, Sudbury, Algoma and Cochrane. The North East LHIN also includes the eastern portion of the District of Kenora, which it shares with the North West LHIN.

Regional Cancer Program of the Hôpital Régional De Sudbury Regional Hospital  
Web: www.neorcc.on.ca

Supportive Care Program (also called Psychosocial Resources)  
Phone: 705-522-6237 ext. 2175  
Web: www.neorcc.on.ca/neorcc/DesktopDefault.aspx?TabId=193&TabIndex=303
BreastNorth.info
The website www.breastnorth.info was developed by the Breast Action Coalition – Sudbury to create a virtual community for breast health/cancer information and support. It contains information on a wide range of services available to residents living in Northeastern Ontario.
Web: www.breastnorth.info Email: breastnorth@hrsrh.on.ca

Wellspring at Warmhearts Palliative Caregivers
Sudbury/Manitoulin
Wellspring at Warmhearts Palliative Caregivers Sudbury/Manitoulin offers programs at no charge for cancer patients at any stage of illness and their caregivers.
Phone: 705-677-0077
Toll free phone: 1-877-499-9904
Web: www.wellspring.ca/warmhearts-palliative-caregivers-sudburymanitoulin.html or www.warmhearts.ca

Northwestern Regional Cancer Program,
within the North West Local Health Integration Network (LHIN)
The North West LHIN includes the Districts of Thunder Bay, Rainy River and most of Kenora.

Regional Cancer Care
(at Thunder Bay Regional Health Sciences Centre)
Web: www.tbh.net/programs_&_services/cancer_care.asp

Supportive Care Program
Phone: 807-684-7310; Toll free phone: 1-877-696-7223
Web: www.tbh.net/programs_&_services/cancer_care/supportive_care.asp

Wellspring at Hospice Northwest (Thunder Bay)
Wellspring at Hospice Northwest in Thunder Bay offers programs at no charge for cancer patients at any stage of illness and their caregivers.
Phone: 807-626-5570
Toll free phone: 1-877-499-9904
Web: www.wellspring.ca/thunderbay or www.hospicenorthwest.ca

Online communities
Online communities can be excellent places to search for support and information and to share stories and experiences with other breast cancer survivors. These communities may be especially helpful for individuals who live in remote areas or for people who aren’t able to leave their home for various reasons.

It is important to remember that information you receive from your peers in an online community should not replace the advice of your doctors, nurses, or any other member of your health care team.

Breast Cancer Action Nova Scotia
Breast Cancer Action Nova Scotia provides an international discussion forum for breast cancer and breast cancer-related subjects. It is an online, supportive community group with people from all walks of life and from all over the world.
Web: www.bca.ns.ca/forum/

Breastcancer.org (United States)
Breastcancer.org is a non-profit organization dedicated to providing reliable, complete and up-to-date information about breast cancer. It provides discussion boards, chat rooms and “ask the expert” online conferences to help women and their loved ones make sense of the complex medical and personal information about breast cancer, so they can make the best decisions for their lives.
Web: www.breastcancer.org/community/

Caring Voices
Caring Voices is an online community for survivors, which includes any person touched by a diagnosis of cancer. Features include a resource library, chats, forums and scheduled live events with medical experts, including doctors, nurses, social workers, dietitians, pharmacists and more.
Web: www.caringvoices.ca
Sharing Strength
Sharing Strength is an online resource and community for people facing a diagnosis of breast cancer. Features include discussion forums, bulletin boards and a place to post your own personal story and read the stories of others.

Web: www.sharingstrength.ca

Willow Talk
This online community was created to give you a place to find information, connect with others or share your story.

Web: www.willow-talk.org/

Canadian research and advocacy resources
Organizations in this section can provide you with current information about research in the field of breast cancer or with general information about diagnosis, treatment and side effect management. Many of these websites contain special information sections for patients.

Canadian Breast Cancer Foundation
The Canadian Breast Cancer Foundation is the leading national volunteer-based organization in Canada dedicated to creating a future without breast cancer. The breast cancer section of the Canadian Breast Cancer Foundation website contains up-to-date information on breast health and breast cancer compiled from a variety of current sources and reviewed by breast cancer experts, along with links to additional sources of information in each section.

Phone: 416-815-1313 (Toronto); Toll free phone: 1-866-373-6313
Web: www.cbcf.org/ontario
Web: www.cbcf.org/breastcancer/

Canadian Breast Cancer Network
The Canadian Breast Cancer Network (CBCN) is a survivor-directed, national network of organizations and individuals concerned about breast cancer, affected by breast cancer and for those at risk.

Toll free phone: 1-800-685-8820
Web: www.cbcn.ca/

Cancer Care Ontario (CCO)
Cancer Care Ontario is an agency created by the provincial government to oversee cancer care in Ontario. Background information about CCO is provided on this website along with links to the sites of the cancer treatment centres across Ontario.

Phone: 416-971-9800
Web: www.cancercare.on.ca; search: Breast Cancer

Cancer View Canada
Cancer View Canada connects Canadians to online services, information and resources for cancer control. It is an ever-evolving portal that brings together resources for cancer prevention, screening, treatment, and supportive, palliative and end-of-life care. The production of Cancer View Canada has been made possible through a financial contribution from Health Canada, through the Canadian Partnership Against Cancer.

Web: www.cancerview.ca/

Ontario Breast Cancer Exchange Partnership
The Ontario Breast Cancer Exchange Partnership (OBCEP) is a coalition of organizations working together to improve access to information and support for women and their families affected by breast cancer. The strategic direction of OBCEP is set by a Coalition of Stakeholders consisting of 36 cancer and breast cancer organizations across Ontario and over 70 Corresponding Members that are grassroots and breast cancer survivor-directed groups.

Toll free phone: 1-888-837-9071
Web: www.obcep.ca
Books and online resources

This section contains books, pamphlets and online resources organized by the following subject areas:

- Advocacy
- Bone Health
- Breast Reconstruction
- Complementary Therapies
- Family Doctor
- Fatigue
- Fertility
- Financial Concerns
- Future Planning
- General Breast Cancer
- Information
- Genetic Counselling Services in Ontario
- Individual and Family Counselling
- Inflammatory Breast Cancer
- Lesbian Women and Breast Cancer
- Life after Breast Cancer
- Lymphedema
- Menopause
- Nutrition and Weight Management
- Pain
- Parenting
- Physical Activity and Exercise
- Sexuality & Relationships
- Work Life
- Young Women

If you can't find books at your local or online bookseller, Cancer Centres have a variety of books and other resources available in their patient and family libraries. Call your Regional Cancer Centre to ask how to borrow reading material from them.

*Information on your Regional Cancer Centre is provided in the section “Regional Resources and Supportive Care Programs” above.*
NOTE: The resources listed below are provided as general information. Please remember that the views expressed in these resources are not necessarily those of your doctors or other members of your health care team. While this listing is current as of the date of the printing of this booklet, it is not exhaustive. The resources listed below may have additional information on new or updated resources that may be helpful for you.

ADVOCACY

Website
Cancer Advocacy Coalition of Canada
www.canceradvocacy.ca/

BONE HEALTH

Websites
Osteoporosis Canada
Osteoporosis Canada educates, empowers and supports individuals and communities in the risk reduction and treatment of osteoporosis.
Web: www.osteoporosis.ca; search: Breast Cancer, then select Secondary Osteoporosis

BreastCancer.Org (United States)
Breastcancer.org is a non-profit organization dedicated to providing reliable, complete and up-to-date information about breast cancer, including bone health information.
Web: www.breastcancer.org/tips/bone_health/

BREAST RECONSTRUCTION

Books
Living in the Postmastectomy Body: Learning to Live in and Love Your Body Again, by Becky Zuckweiler (Hartley & Marks, 1998)

Websites
The UHN Breast Restoration Program
Web: www.breastrestoration.ca

Myself Together Again (United States)
Web: www.myselftogetheragain.org

Willow Breast Cancer Support Canada
Web: www.willow.org/pdfs/reconstruction.pdf

COMPLEMENTARY THERAPIES

Websites
Health Canada
Health Canada’s website provides information on the safe use of natural health products.

National Centre for Complementary and Alternative Medicine (United States)
The National Institutes of Health’s National Centre for Complementary and Alternative Medicine provides a website with information on the results of scientific research on the diverse medical and health care systems, practices and products that are not generally considered part of conventional medicine.
Web: nccam.nih.gov
Project False Hope
The Competition Bureau’s Project False Hope web page features interactive tools to help you learn to spot the signs of fraudulent online cancer treatments and cures.
Web: www.competitionbureau.gc.ca/eic/site/cb-bc.nsf/eng/02745.html

Willow Breast Cancer Support Canada
Web: www.willow.org/pdfs/complementary.pdf

FAMILY DOCTORS

CPSO Doctor Search
The College of Physicians and Surgeons of Ontario (CPSO) provides a public registry of Ontario doctors that includes qualifications and practice information. You can search for family doctors who are accepting new patients in your area at www.cpso.on.ca/docsearch/

Health Care Connect
Health Care Connect is a program of the Ministry of Health and Long-Term Care to help Ontarians without a family health care provider find one. To register, call 1-800-445-1822, or register online at www.health.gov.on.ca/en/ms/healthcareconnect/public/default.aspx.

You must have a valid OHIP card to be part of the program. A nurse - called a Care Connector - will be assigned to help you find a health care provider in your area. Your Care Connector will be your main point of contact with the program. Your will receive contact information for your Care Connector by mail after you have registered for the program.

FATIGUE

Book

Websites
American Cancer Society (United States)
Managing Your Cancer Related Fatigue: Online course developed by the American Cancer Society
Web: ww2.cancer.org/docroot/MIT/content/MIT_2_4x_Fatigue_in_people_with_cancer.asp

American Cancer Society (United States)
Calculator for calories used with specific exercises. It also calculates your target heart rate at whatever percentage based on age.
Web: www.cancer.org/healthy/toolsandcalculators/calculators/app/calorie-counter-calculator

BreastCancer.Org (United States)
Breastcancer.org is a non-profit organization dedicated to providing reliable, complete and up-to-date information about breast cancer, including information on fatigue.
Web: www.breastcancer.org/tips/fatigue/

National Cancer Institute (United States)
Web: www.cancer.gov/cancertopics/pdq/supportivecare/fatigue/Patient

The Fatigue Symptom Inventory (FSI) is a 14-item self-report measure designed to assess the severity, frequency and daily pattern of fatigue as well as its perceived interference with quality of life.
Web: www.cas.usf.edu/~jacobsen/HANDOUT%5B1%5D.FSIFSI%202005.pdf
Your Bank to Energy Savings: Helping People with Cancer Handle Fatigue (Ortho Biotech 2004)
   Web: www.cshodgson.com/YourEnergyBank.pdf

FERTILITY

Book

100 Questions and Answers about Cancer and Fertility, by Kutluk H. Oktay, Lindsay Nohr Beck and Joyce Dillion Reinecke (Jones and Bartlett Publishers, 2008)

Websites

Assisted Human Reproduction Canada
   Web: www.ahrc-pac.gc.ca

Fertile Hope
   Web: www.fertilehope.org

Fertile Future
   Web: www.fertilefuture.ca

FINANCIAL CONCERNS

Income Replacement (Social Insurance) Programs in Canada

Employment Insurance
Phone: your local Service Canada office or contact toll free at 1-800-206-7218
   Web: www.servicecanada.gc.ca/eng/ei/menu/eihome.shtml

Canada Pension Plan - Retirement, Early Retirement and Disability Programs
Phone: your local Service Canada office or contact toll free at 1-800-277-9914
   Web: www.hrsdc.gc.ca/eng/isp/cpp/cpptoc.shtml

Income Replacement (Social Assistance) Programs in Ontario

Ontario Works
Phone: your local municipal government office, or look in the blue pages of your phone book for the office nearest you.
   Web: www.mcss.gov.on.ca/mcss/english/pillars/social/ow

Ontario Disability Support Program
Phone: 416-325-5666
Toll free phone: 1-888-789-4199
   Web: www.mcss.gov.on.ca/mcss/english/pillars/social/odsp/

DRUG COVERAGE PROGRAMS IN ONTARIO

The Ontario Drug Benefit Program
Through the Ontario Drug Benefit (ODB) Program, the Ministry of Health and Long-Term Care covers most of the cost of prescription drug products listed in the Ontario Drug Benefit (ODB) Formulary, as well as some exceptional cases. If you belong to one of the following groups of Ontario residents and you have a valid Ontario health card, you are eligible for drug coverage under the ODB Program:

- People 65 years of age and older
- Residents of long-term care homes
- Residents of Homes for Special Care
- People receiving professional services under the Home Care program
- People receiving social assistance (Ontario Works or Ontario Disability Support Program assistance)
- Trillium Drug Program registrants (see below)

Toll free phone: 1-866-532-3161
Web: www.health.gov.on.ca/english/public/pub/drugs/odb.html

income replacement (social assistance) programs in ontario

Ontario Works
Phone: your local municipal government office, or look in the blue pages of your phone book for the office nearest you.
   Web: www.mcss.gov.on.ca/mcss/english/pillars/social/ow

Ontario Disability Support Program
Phone: 416-325-5666
Toll free phone: 1-888-789-4199
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- Residents of Homes for Special Care
- People receiving professional services under the Home Care program
- People receiving social assistance (Ontario Works or Ontario Disability Support Program assistance)
- Trillium Drug Program registrants (see below)

Toll free phone: 1-866-532-3161
Web: www.health.gov.on.ca/english/public/pub/drugs/odb.html
The Trillium Drug Program
The Trillium Drug Program (TDP) is an annual provincial government co-payment program for residents of Ontario who have a valid OHIP card and spend a large part of their income on prescription medications. The TDP provides benefits for certain prescription drugs when the drug costs for a household exceed a set amount of the household’s income.

Toll free phone: 1-800-575-5386
Web: www.health.gov.on.ca/english/public/pub/drugs/trillium.html

Interim Federal Health Program
The Interim Federal Health Program provides temporary health insurance to refugees, protected persons and refugee claimants, as well as to their dependants in Canada who are not yet covered by a provincial or territorial health insurance plan.

Toll free phone: 1-888-242-2100
Web: www.servicecanada.gc.ca/eng/goc/interim_health.shtml

Non-insured Health Benefits for First Nations People and Inuit
The Non-insured Health Benefits Program (NIHB) is Health Canada’s national, medically necessary health benefit program that covers some health-related goods and services that are not insured by provinces and territories or other private insurance plans. NIHB provides coverage for benefit claims for a specified range of drugs, dental care, vision care, medical supplies and equipment, short-term crisis intervention mental health counselling and medical transportation for eligible First Nations People and Inuit.

Toll free phone: 1-800-640-0642
Web: www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/index-eng.php

Veterans Affairs Assistance
Veterans Affairs Canada (VAC) offers a range of health benefits, including medical, surgical and dental care, prescription drugs, and hearing and vision aids to qualified Veterans and their families. A Veteran’s VAC Health Identification card or VAC Health Identification letter identifies the benefits and/or services that he or she is eligible to receive in any province or territory in Canada.

Toll free phone: 1-866-522-2122
Web: www.vac-acc.gc.ca/clients/sub.cfm?source=Services/benefits/content

DRUG COVERAGE PROGRAMS IN CANADA

Breast Cancer Survivor to Financial Survivor!
Publication is expected in the spring of 2010. This booklet is being developed by the Canadian Breast Cancer Network to give breast cancer survivors some financial decision-making tools and options, new ways to evaluate and use their own assets, and information on the best strategies for negotiating the social benefits and disability systems. This booklet looks at how to manage assets such as RRSPs, and whether to borrow funds, mortgage or sell a house, cash in insurance policies, obtain job re-training or obtain part-time work, either in one’s pre-existing workplace or somewhere new. For more information call toll free at 1-800-685-8820
Web: www.cbcn.ca/en/

Coping With Your Financial Concerns When You Have Breast Cancer
Web: www.willow.org/pdfs/Coping_Ontario.pdf
FUTURE PLANNING

A Power of Attorney is a legal document that gives someone else the right to act on your behalf. The Ministry of the Attorney General has a Power of Attorney Kit that will help you appoint the person you want to make decisions for you in the event that you are no longer able to do so for yourself.

Phone: 416-314-2800 (Toronto)
Toll free phone: 1-800-366-0335
Web: www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf

GENERAL BREAST CANCER INFORMATION

These books and web resources offer a range of information about understanding your disease. Please search the books and websites for the information you are looking for that is not found on this list.

Books


Websites

BC Cancer Agency
Web: www.bccancer.bc.ca; search: Breast Cancer

Breastcancer.org (United States)
Web: www.breastcancer.org

Breast Cancer Network of Strength (United States)
Web: www.networkofstrength.org/
Canadian Cancer Society
Web: www.cancer.ca; search: Breast Cancer

Canadian Cancer Society, Cancer Information Service
Toll free phone: 1-888-939-3333
Email: cis@ontario.cancer.ca

Canadian Breast Cancer Foundation
Web: www.cbcf.org or www.cbcf.org/ontario

Canadian Breast Cancer Network
Web: www.cbcn.ca

Cancer.Net
Web: www.cancer.net; search: Breast Cancer

Dr. Susan Love Research Foundation (United States)
Web: www.dslrf.org/

Living Beyond Breast Cancer
Web: www.lbbc.org

Susan G. Komen for the Cure (United States)
Web: ww5.komen.org/

Willow Breast Cancer Support Canada
Phone: 416-778-5000; Toll free phone: 1-888-778-3100
Web: www.willow.org
Email: info@willow.org

GENETIC COUNSELLING SERVICES IN ONTARIO

Websites
Cancer Care Ontario, Cancer Genetics Testing and Counselling
Web: www.cancercare.on.ca/cms/one.aspx?pageId=10060

Genetic Counselling Clinics in Ontario
Web: www.mountsinai.on.ca/care/family-medicine-genetics-program/genetic-counselling-clinics

Genetic Resources Ontario
Web: www.geneticresourcesontario.ca/contact.htm

INDIVIDUAL AND FAMILY COUNSELLING

Websites
211 Ontario
Under the subject heading General Community Services, the 211 Ontario online directory provides information on how to contact your local Community Information Centre (CIC). Your local CIC will have information on the individual and family counselling services available in your community.
Web: www.211ontario.ca/; select General Community Services

Family Service Ontario
Family Service Ontario is an association of family service agencies that provide individual, couple and family counselling to help families cope with a wide range of emotional, psychological, social, physical and financial problems. This association provides a list of their accredited members, along with information on how to access the family service organization in your area.
Web: www.familyserviceontario.com; select Membership
INFLAMMATORY BREAST CANCER

Books

*Inflammatory Breast Cancer: A Patient’s Guide - Before and After Treatment*, by Verite Reily Collins (Anshan, paperback publication in March 2010)

Websites

Inflammatory Breast Cancer (IBC) Support
  Web: www.ibcsupport.org

Willow Breast Cancer Support Canada
  Web: www.willow.org/pdfs/IBC.pdf

LEGAL SERVICES

Websites

Legal Aid Ontario
Legal Aid Ontario gives low-income people access to a range of legal services tailored to meet their legal needs.
  Web: www.legalaid.on.ca/en/

The Law Society of Upper Canada’s Lawyer Referral Service (LRS)
For $6, the LRS will provide the name of a lawyer who will provide a free consultation of up to 30 minutes to help you determine your rights and options.
  Phone: 1-900-565-4577
  Web: www.lsuc.on.ca/public/a/faqs--lawyer-referral-service/

LESBIAN WOMEN AND BREAST CANCER

Books


Websites

The Making Us Visible Project: Access to Breast Health and Breast Cancer Services for Lesbian and Bisexual Women
  Web: www.sherbourne.on.ca/programs/breast.html

LIFE AFTER BREAST CANCER

These general works contain information about many of the topics on this list and others, including, nutrition, relationships, sexuality and work.

Books


*After Breast Cancer: Answers to the Questions You’re Afraid to Ask*, by Musa Mayer (O’Reilly, 2003)


Happiness in a Storm: Facing Illness and Embracing Life as a Healthy Survivor, by Wendy Schlessel Harpham (W.W. Norton & Company, 2005)

100 Questions & Answers About Life After Cancer: A Survivor’s Guide, by Page Tolbert and Penny Damaskos (Jones and Bartlett, 2008)

Picking up the Pieces: Moving Forward After Surviving Cancer, by Sherri Magee and Kathy Scalzo (Raincoast Books, 2006)

Pamphlets

Canadian Cancer Society, Life after Cancer  
Web: www.cancer.ca; search: Life after Cancer

Website

Willow Breast Cancer Support Canada  
Web: www.willow.org/pdfs/AfterTreatment.pdf

LYMPHEDEMA

Books


Lymphedema: Understanding and Managing Lymphedema after Cancer Treatment, by American Cancer Society (American Cancer Society, 2006)

Living Well With Lymphedema, by Ann B. Ehrlich, Alma Vinji-Harrewijn, and Elizabeth J. McMahon (Lymph Notes, 2005)

Overcoming the Emotional Challenges of Lymphedema, by Elizabeth McMahon (Lymph Notes, 2005)

Voices of Lymphedema: Stories, Advice, and Inspiration from Patients and Therapists, by Calina Burns, Ann B. Ehrlich and Elizabeth J. McMahon (Lymph Notes, 2007)

100 Questions and Answers about Lymphedema, by Nicole L Stout, Paula J Stewart and Saskia R J Thiadiens (available from the National Lymphedema Network, www.shop.lymphnet.org/main.sc)

Websites

Canadian Lymphedema Foundation  
Web: www.lymphovenous-canada.ca/

Lymphovenous Association of Ontario  
Web: www.lymphontario.org

Lymph Notes (United States)  
Web: www.lymphnotes.com

National Lymphedema Network (United States)  
Web: www.lymphnet.org/

Willow Breast Cancer Support Canada  
Web: www.willow.org/pdfs/Lymphedema.pdf

Manual Lymph Drainage

Several schools teach Manual Lymphatic Drainage (MLD). Check the websites listed below for a therapist near you:

www.vodderschool.com  
www.torontolymphocare.com  
www.klosetraining.com  
www.acols.com  
www.nortonschool.com/lymphedemacourse.html

You can also call the Lymphovenous Association of Ontario at 1-877-723-0033 (toll free).
MENOPAUSE

Books

100 Questions and Answers about Menopause, by Ivy Alexander and Karla A. Knight (Jones and Bartlett, 2005)


Websites

North American Menopause Society (United States)
Web: www.menopause.org; search: Early Menopause Guidebook

North American Menopause Society (United States)
Early Menopause Guidebook
Web: www.menopause.org/edumaterials/earlyguidebook.aspx

NUTRITION AND WEIGHT MANAGEMENT

Websites

American Institute of Cancer Research – Recipe Corner (United States)
Web: www.aicr.org; search: Recipe Corner

Dietitians of Canada – Calorie calculator
Web: www.dietitians.ca

Foodland Ontario – availability of fresh seasonal produce in Ontario
Web: www.foodland.gov.on.ca

Health Canada – Canada’s Food Guide
Web: www.hc.gc.ca; Search: Canada’s Food Guide

PAIN

Books


Pamphlets

Pain Relief: Information for People with Cancer and their Families, by Canadian Cancer Society
Web: www.cancer.ca; search: Pain Relief

Website

Cancer Pain
Web: www.cancer-pain.org

PARENTING

Books


How to Help Children through a Parent’s Serious Illness, by Kathleen McCue, with Ron Bonn (St. Martin’s Griffin, 1996)


APPENDIX

Websites
   Web: www.cbcf.org/ontario/whataboutmykids
Willow Breast Cancer Support Canada
   Web: www.willow.org/pdfs/Children.pdf

PHYSICAL ACTIVITY AND EXERCISE

Books

Websites
Renewed Strength
Renewed Strength provides strength and mobility training to men and women recovering from chemotherapy, radiation therapy and/or cancer surgery through specially designed DVD’s, videos and free classes.
   Web: www.renewedstrength.ca
SEXUALITY AND RELATIONSHIPS

Books

*Intimacy after Cancer*, by Sally Kydd and Dana Rowett (Big Think Media, 2006)

*No Less a Woman: Femininity, Sexuality and Breast Cancer*, by Deborah Hobler Kahane (Hunter House, 1995)

*Woman Cancer Sex*, by Anne Katz (Hygeia Media, 2009)

Website

Willow Breast Cancer Support Canada
  Web: www.willow.org/pdfs/Sexuality.pdf

WORK LIFE

Books

See the section Life after Breast Cancer above; many books listed there have chapters about returning to work.

Websites

Cancer and Careers
  Web: www.cancerandcareers.org

Ontario Human Rights Commission
  Web: www.ohrc.on.ca/en/issues/disability; search: Issues - Disability

Provincial and Federal Employment Standards and Rights

Ontario Employment Standards
  Web: www.labour.gov.on.ca/english/es/

Federal Employment Standards
  Web: www.hrsdc.gc.ca/eng/labour/employment_standards/index.shtml

Human Rights Legal Support Centre of Ontario
  Web: www.hrisc.on.ca/en/index.htm

Human Rights Tribunal of Ontario
  Web: www.hrto.ca/NEW/home.asp

YOUNG WOMEN WITH BREAST CANCER

Books


Websites

BreastCancer Now What?

Breastcancernowwhat.com was developed by young women with breast cancer, for young women with breast cancer, in hopes that it will provide young women with information, support, inspiration, hope and a sense of community.
  Web: www.breastcancernowwhat.ca/
I’m Too Young for This! Cancer Foundation
The I’m Too Young for This! Cancer Foundation was founded by young adult survivors for young adult survivors. The organization is a grassroots advocate for the next generation of cancer survivors and their caregivers in their late teens, 20s and 30s.
Web: i2y.com/

Nanny Angel Network
The Nanny Angel Network is a group of professional women comprised of nannies and board members who volunteer their time to provide quality, compassionate relief child care, at no cost, to mothers diagnosed with breast cancer, in treatment or in the early stages of recovery. Eligibility criteria include the following:
1) Being a mom diagnosed with breast cancer, currently in treatment or in the early phases of recovery;
2) Having a child or children under 12 years old; and
3) Living in metropolitan Toronto, Vancouver or Calgary.
Web: www.nannyangelnetwork.com/

Rethink Breast Cancer
Rethink Breast Cancer is a charity helping young people who are concerned about and affected by breast cancer through innovative breast cancer education, research and support programs.
Web: www.rethinkbreastcancer.com/

Willow Breast Cancer Support Canada
Willow Breast Cancer Support Canada provides a Young Women and Breast Cancer Resource List with information on books and websites for young women with breast cancer. The list includes websites on topics such as early menopause, fertility and pregnancy, and online community support, and has links to information related to helping children cope, breast reconstruction and sexuality.
Web: www.willow.org/pdfs/YoungWomen.pdf

Young Adult Cancer Canada
The mission of this organization is the help every young adult dealing with cancer in Canada by providing inspiration, information and support.
Web: www.youngadultcancer.ca/

Young Survival Coalition: Young Women United against Breast Cancer (United States)
Young Survival Coalition (YSC) is an international organization dedicated to the critical issues unique to young women and breast cancer. YSC works with survivors, caregivers and the medical, research, advocacy and legislative communities to increase the quality and quantity of life for women aged 40 and under who are diagnosed with breast cancer.
Web: www.Youngsurvival.org
References

This section provides information on the books and articles that were consulted in the preparation of this booklet.

Chapter 3. Healthy living after breast cancer treatment: diet and physical activity


Chapter 4. Looking within: your emotional needs


Pelusi J. Sexuality and body image. AJN. 2006; 106(3) Supplement.

Rosedale M. Survivor loneliness of women following breast cancer. Oncology Nursing Forum. 2009; 36(2).


Chapter 5. Reaching out: your social needs


Chapter 7. Reading between the lines: understanding current cancer-related issues


Cancer Care Ontario. Position paper on complementary therapies. Toronto (ON); Cancer Care Ontario (no date).


References


The Canadian Breast Cancer Foundation

As the leading national volunteer-based organization dedicated to creating a future without breast cancer, the Canadian Breast Cancer Foundation works collaboratively to fund, support and advocate for relevant and innovative breast cancer research; meaningful education and awareness programs; early diagnosis and effective treatment; and a positive quality of life for those living with breast cancer.

For more information about the work of the Foundation’s Ontario Region, please contact us or visit us online.

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Toronto, ON M5C 2N8
Phone: 416-815-1313
Toll free: 1-866-373-6313
Fax: 416-815-1766
www.cbcf.org/ontario
e-mail: info@cbcf.org
Your active treatment for breast cancer is finally over and you can once again focus on moving forward with your life. Every woman will find her own pace, and this booklet can be a guide that may help along the way.

*Getting Back on Track: Life after breast cancer treatment* is a booklet for women who have completed active breast cancer treatment. Friends and family may also find this booklet useful.