

# *Getting Back on Track*

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## **Life After Treatment**

The M. Lau Breast Centre



**Princess Margaret Hospital**  
University Health Network

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**Special thanks to:** Willow Breast Cancer Support and Resource Services, Community and Patient Education Committee, and the Patient Education Department of Princess Margaret Hospital and Princess Margaret Hospital Foundation.

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**Funding:** This project has been funded by a grant from the Canadian Breast Cancer Foundation – Ontario Chapter.



## Introduction

### A Guidebook for Your Journey as a Breast Cancer Survivor

*Congratulations!! You've made it!* Your treatment for breast cancer is finally over and you are about to begin your journey as a breast cancer survivor. There is no right or wrong way to travel your breast cancer journey. Every woman will find her own pace at which to move forward. The authors of this booklet have brought this information together to guide you – to provide a roadmap that may help you along the way. Until now, your treatment has probably been a full time job for you. You have put a lot on hold and you may not have had the time to sit down and think about what your cancer experience will mean to you.

This may be a particularly vulnerable time for you. You probably have many mixed feelings to sort out. One moment you're thrilled your treatment is over and you never want to see another doctor or medical waiting room again. The next moment you feel abandoned or anxious that your cancer may recur and you want to call your doctors and nurses for support. **This is normal.** Remember that you still have the support of your health care team. This booklet may be the first place you check for information, and it will help you decide when to seek further advice and guidance, but it should never take the place of the real life support you have available from your medical team and your friends and family.

This booklet has been developed for breast cancer patients who have completed their treatment. It focuses on issues that may arise once your treatment is over.

*In Chapter One* we look at changes in how you relate to your doctors, nurses and other health professionals now that you have completed your 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. We also provide useful tips to help you work effectively with your health care team.

*In Chapter Two* we cover some of the physical side effects you may experience after your treatment is over. Not all of the symptoms experienced by breast cancer survivors are the direct result of their breast cancer or its treatment. Some are related to normal life events such as aging, or normal life experiences such as stress. In any event, if you watch for early warning signs, some of these problems can be treated before they get worse.

*In Chapter Three* we stress the importance of a healthy lifestyle as you recover from your treatment. We look at ways that you can eat well and adopt a healthy fitness routine that will work for you.

*In Chapter Four* we examine some of the emotional, spiritual and social needs you may have as your breast cancer treatment ends and your life continues. We look at some issues you may face and how you may work through them on your own or with support. Your relationships will be an important part of your coping strategy.

*In Chapter Five* we cover some of the changes that may affect your relationships now that you have completed your treatment. We provide tips that might help you relate to your friends, family and co-workers in the best possible way.

*In Chapter Six* we look at some of the practical and financial issues that you may face as you return to your everyday life. We provide useful information about making the transition back into the working world and how to plan for the future after your breast cancer experience.

*In Chapter Seven* we pass along some tips on how to deal with current cancer-related issues you may come across in the newspaper, on radio, TV, or the Web, take a look at how the media present health care issues and research information and provide you with some tools that will help you judge when the information is relevant to you.

At the end of the guide you will find an appendix which includes the major organizations and websites that provide information, services and support to people with breast cancer. We have focused on groups and websites that provide information on the range of resources that exist in the community.

We hope that this book will assist you and those who care about you in your journey as a breast cancer survivor.



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## Chapter 1

# Working With Your New Health Care Team

### **Chapter Outline:**

This chapter looks at changes in how you relate to your doctors, nurses and other health professionals now that you have completed your 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. We also provide useful tips to help you work effectively with your health care team.

## What You May be Feeling Now

*During my breast cancer treatment I often dreamed about when it would be over and 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 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 probably learned to trust them. You have shared yourself with them and may have made some friends along the way.

Now that your breast cancer treatment is over you are entering a new stage in your journey. It is perfectly normal to worry about your future and you may not want to give up the connection to your health care team. Even though your family and friends may be willing to help, you may feel that you need the expertise of health care professionals to guide you along the way.

You may not want to ask for any more time and attention from your health care team. You have seen how busy they are dealing with the many other patients who are undergoing active treatment. You may feel that you shouldn't "bother" them because they should be spending their time with others who may need them more. That's not true. 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 tell you to call them if you have any questions about treatment after-effects, new symptoms or other issues. They can also help you link with other trained professionals who are skilled in helping cancer survivors move into their life after treatment.

**However... a few things will change now that you have completed your treatment.**

**You will see your health care team less often.**

You will still need to have medical appointments, but these visits will become fewer because you don't require active treatment. Now your check-ups will be shared among your surgeon, radiation oncologist, medical oncologist (or the clinical associates working with them) and your family physician. You may not need to see all of these professionals regularly, but they will be available if you need them.

**Note:** After five years, you will probably need medical follow-up with only one oncologist and your family doctor. This follow-up will include annual breast imaging and clinical exam. Other tests are not usually required.

**The size of your team will become smaller.**

You will not see as many health professionals as you did during active treatment.

**Your family doctor will coordinate your care.**

He/she will look after your health in partnership with your breast health team. If needed, other medical professionals and social workers are there for you.

**Your relationship with team members may change.**

Your nurse may become a more important source of information after your cancer treatment ends. Your Nurse Case Manager will be available by telephone and at your follow-up clinic visits.

**Note:** Find out who your Nurse Case Manager is. She/he can help steer you in the right direction so that you get the help you need.

**Where you go for your health care appointments may change.**

You will likely have mammograms at the hospital where you had your surgery.

## You and Your New Health Care Team

### **1. The “Star Player”—You**

You have learned a lot about how the health care system works and how you like to be treated. You are the most important member of your health care team and should continue to be part of all decisions.

### **2. Your Family Doctor**

You will need one family doctor who works closely with you, does an annual complete physical check-up and manages your general health. He/she will also need to help you keep track of your physical, emotional and social needs, and make sure that your health care is arranged in a timely manner. You will need to make sure that he/she is aware of all your medical appointments and the results of any tests. If you can, you should ensure that a copy of all reports and visits to specialists are sent to him/her.

### **3. Your Registered Nurse**

Nurses can be your most helpful guides within the health care system. They can help you meet your physical, emotional and practical needs. Today, there are many different types of nurses who help patients and their families. The key nurses that you will relate to now will probably be the nurses who work with your family doctor and perhaps an oncology nurse.

At Princess Margaret Hospital, your Nurse Case Manager will be a key contact for you. Your Nurse Case Manager works together with your oncologist. If you forget who your Nurse is, you can call your oncologist’s office to find out.

### **4. Your Oncologist(s)**

You may continue to see your medical, surgical and/or radiation oncologists. Each oncologist will do a physical examination that relates to the treatment he/she gave you. You should try to space your oncologist visits equally so that you receive breast examinations regularly during the year.

## **5. Your Social Worker**

A social worker is available to help you with your psychological and social well-being and help you and your family resume your daily life.

## **6. Your Physiotherapist and Occupational Therapist**

If you experience difficulties with arm movement as a result of surgery to remove lymph nodes, your family doctor or surgeon may suggest you see a physiotherapist or an occupational therapist. These professionals can help you to improve your arm movement and help you get back to your daily life.

## **7. Your Peer Support Group**

You may wish to take advantage of local support groups that are available in your community. For a complete list of these groups, check with your social worker or Willow Breast Cancer Support and Resource Services.

## **8. Other Members of Your Health Care Team**

**Dietitian:** A health care professional with the expertise to counsel you on matters of nutrition and diet.

**Medical Radiation Technologist (MRT):** A health care professional who does mammography exams.

**Patient Flow Coordinator:** An individual who works in the Breast Clinics at Princess Margaret Hospital and will continue to book your appointments as needed.

**Psychiatrist:** A physician who provides psychiatric evaluations and interventions and who also can prescribe medication.

**Psychologist:** A health care professional with a doctorate in Psychology who provides psychological services but does not prescribe medication.

**Support staff:** Secretaries, booking clerks and others that contribute to your health care program.

**Volunteers:** People who volunteer their time to work at the Breast Centre Patient Family Resource Centre. Volunteers can help you find

information you need or show you how to use the computer in the centre. Volunteers also help in clinics with charts and recording weights.

## What to Expect during the Coming Year

### Getting Back to a Health Care Routine

*I was so into my treatment and recovery from breast cancer that I'd forgotten about going to the dentist or seeing my eye doctor.*

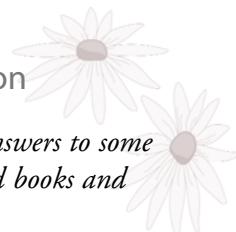
Now is the time to start a new health care routine that will last for the rest of your life. While you were being treated for breast cancer, you may have forgotten about other aspects of your health. When was the last time you went to the dentist or had a Pap test? Did your weight change? If so, you may need to ask your family doctor or a nutritionist/dietitian about a plan that includes healthy eating and exercise. Over the next year, try to take a “holistic” or complete approach to all your health care needs.

### 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 have 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 style, at times over the next year you may wish you had a guide to help you. You may see articles about breast cancer in the



newspapers, in magazines and on the Internet. **Do not believe everything you read.** You need to make sure that the information is from a responsible source. If you are not sure, check with your health care team or the Canadian Cancer Society's Cancer Information Service. Chapter 7: Dealing with Current Cancer-Related Issues also provides tips on dealing with current issues.

See also Appendix 1: Resources for Breast Cancer Survivors for a listing of useful websites and tips on how to evaluate them.

### **Asking 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 concerns or more practical issues such as returning to work. You will need to work with your family doctor and nurse as well as your oncology team to find answers to these questions. **Remember, no question is trivial or stupid.**

You might want to keep a notebook at home and write down your 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, changes in your body such as a cough, change in vision, abnormal vaginal bleeding or a change in your sex drive.

For each new symptom, record your answers to the following questions:

1. When did you first notice the symptom? For example, one week or one month ago.
2. What is it like? Can you describe it?
3. Is it getting better or worse, or is it the same as when you first noticed it?
4. What makes it worse? What makes it better?
5. Does it wake you up from sleep?
6. If your symptom is pain, can you rate it on a scale from 1 to 10. (1 is very mild pain and 10 is the worst pain you have ever had.)

Before your appointment with your family doctor, review these questions and organize your thoughts so that you can ask your questions easily. Bring your notes with you as well as a pad and paper so you can jot the answers down.

You will need to 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 the appointment.

You may have questions that your family doctor can't answer. In that case, check with your oncologist, your nurse or your cancer support group.

**Note:** You do not need to check with your oncologist about new medications prescribed by other doctors unless it is a hormone. On the other hand, other doctors should be advised of any breast cancer-related medications such as Tamoxifen before they prescribe medication. Taking a list of your current medications to any medical appointments will be useful for your doctors to ensure coordinated treatment and reduce side effects.

### **Providing 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 because future decisions about your care may depend on how you have been treated in the past. Notes from your clinic visits should be automatically sent to your family doctor. If you move or go to several different doctors, you are the only one who will have your complete health history.

Make sure that you keep your family doctor up to date on:

- ✓ Any medications that you are now taking (including over-the-counter medicines such as painkillers, laxatives, as well as nutritional supplements, vitamins, minerals, etc.) Your family doctor will need this information to avoid problems when prescribing a new medicine for you.

- ✓ Whether you are considering herbal therapies. Herbs may affect your body the same way drugs and medications do.
- ✓ When your next mammogram is due (if applicable).
- ✓ Which specialists are still following you.
- ✓ Any fears or concerns you have, especially those that might affect your recovery.
- ✓ Any lifestyle changes such as if you quit smoking, changed your diet or exercise routine, etc.
- ✓ How you feel. Do you have any symptoms or changes that are worrying you?

## What to Expect Over the Next Few Years

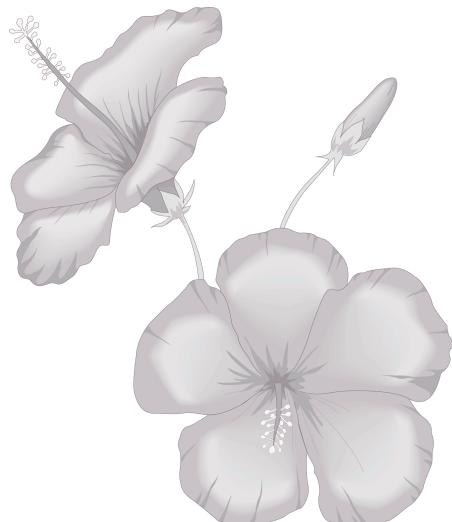
*As I recovered, I became quite good at putting thoughts about my breast cancer experience out of my mind. But then I realized that was a mistake. I thought a lot about my experience and began to make it part of my life. After all, it is something that changed me; it made me the person that I am today.*

As you move farther away from your breast cancer treatment and your busy 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 stick to your plan for long-term health care.

**Get regular check-ups.** Ask your family doctor how often you should check in with him/her.

**Go for all tests that are suggested to you.** There are no regular breast cancer tests other than a routine mammogram. Your family doctor can tell you how often you should have other regular health maintenance checks.

**Live a healthy life.** Eat well. Do your best to get a healthy amount of rest and regular exercise, avoid smoking and recreational drug use and use alcohol in moderation. 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.



## Chapter 2

# After Treatment Is Over: Ongoing Physical Side Effects

### **Chapter Outline:**

This chapter covers some of the physical side effects you may experience after your treatment is over. If you watch for early warning signs, some of these problems can be treated before they get worse.

By knowing what to expect, you will find it easier to get help 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 your body may feel drained. Your strength is down and you may have a hard time getting out of your bed in the morning.

Your family and friends may think it is time for you to return to the way you were before. You may not want to tell them that you still have some health problems. You may feel that it is time to get back to your normal life as quickly as you can. This will be a big job 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 it has affected your whole body. There are some physical effects of this treatment that may continue to affect you for awhile as you heal. But take heart! Over time, and by learning as much as possible about how to take charge of your health, you will find that you will soon feel well again.

## What You Need to Know Now

*I didn't think 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?*

### Short-Term Physical Symptoms and Side Effects of Breast Cancer Treatment

There are side effects of your breast cancer treatment that may be bothering you now and will continue for the next few months. This is because some parts of your body heal more quickly than others. Your skin and the mucous membranes inside your mouth and stomach will

heal faster than any changes to the tissues under your skin. Your muscles will take longer. Finally your blood vessels, nerves, and sweat glands will be the last to complete the healing process.

If you have had radiation therapy you may find that it will slow down the healing response in the area where it was given.

## Aches and Pains

*Whenever I feel an ache or pain, my first thought is that it has something to do with my 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 their pain is because of their surgery, radiation or chemotherapy treatment.

For example, you may have pain in your breast from your surgery even after it has healed. Some women have an overall body aching that begins several months after their chemotherapy treatment and may last for up to one year or more. Unfortunately, there is no known treatment for the overall aching, but pain relievers are often used if the pain is severe.

Overall aching will usually go away on its own.

No matter what kind of pain you have, it can be frightening and stressful. You may wonder what are normal aches and pains and when you should call the doctor. You should let your family doctor know about any unusual ache or pain that starts gradually and becomes worse after a few weeks. If you have arthritis and your arthritic pain is more than normal or if it interferes with your usual activities, let your doctor know. You should also report any sudden severe pain.

### **What to Do if You Have Pain**

Your first step will be to actually admit that you do have pain. Although you may not want to worry your family, you will need to ask for help and support from your health care team. You will need to tell them where the pain is and how it makes you feel. It may help to think of answers to these questions:

- How long have you had the pain?
- Has it been getting more severe, is it stable or getting less over time?
- What does the pain stop you from doing?
- Does your pain wake you from sleep?
- What are you usually doing when it starts and stops?
- Does it start up without any warning?
- Does it stay in one place or move around to other spots in your body?
- Is it sharp, dull, hot, cold, burning, aching or throbbing?
- How bad is your pain on a scale of 1 – 10? (1 is very mild pain, 10 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 to the area near the breast) is common. This type of pain may feel like a numbness in the under part of your upper arm. You may also feel some tenderness to your skin as well as sensations of tightness, a pulling, burning or a feeling of sudden electric jolts that might even 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 it can be relieved.

### **Find Out What Helps Relieve Your Pain**

Some women with pain choose to live with mild discomfort rather than taking medication. That is perfectly fine – most of us do it every day for a variety of aches and pains. However, if your pain begins to affect your daily life, there are ways of controlling it. Today, medications are more effective with fewer side effects, if any.

*Non-prescription pain relievers:* Analgesics such as Tylenol and non-steroidal anti-inflammatories such as Ibuprofin, Motrin and Advil can be bought in drug stores without a doctor's prescription.

Sometimes, these milder non-prescription drugs are all that you may need. Always check with your family doctor before taking any medication, even non-prescription pain relievers.

*Prescription pain relievers:* There are many different pain relievers that are available only with a prescription from your doctor.

Prescription non-steroidal anti-inflammatory medications include Arthrotec, Vioxx and Celebrex. Narcotics or opioids are different and include Tylenol #3 (codeine), Morphine, Dilaudid or Percocet. The amount and type of prescription medication you take will depend on your personal needs. You may feel some drowsiness or nausea especially when you first use them. For most people, these side effects will go away after a few days.

**Note:** If you take opioids you will probably notice a change in your normal bowel routine and may need a regular laxative or stool softener to prevent constipation.

*Non medicinal forms of pain relief:* These types of pain relief can be helpful on their own and to supplement medication. They include meditation, relaxation training, therapeutic touch and yoga.

Many people worry about getting addicted to painkillers (or opioids). Your body will get used to taking pain medication, but it is extremely rare for people to have a problem stopping the medication when taken as prescribed. Studies show that addiction usually happens when people take drugs to deal with stress or emotional issues. It usually does not happen when opioids are taken regularly to provide pain relief in an amount that is suited to your own needs. If you worry about addiction, don't hesitate to talk it over with your health care team.

## Arm and Shoulder Problems

*I was surprised that it was my arm that caused me more trouble than my breast. I didn't know about the arm problems that can develop from breast cancer treatment!*

A lot of women don't know that problems can develop with their arm and shoulder area because of breast cancer treatment. These usually happen if you have had lymph nodes taken from under your arm or if you have had radiation to your breast, armpit/axilla and the surrounding area. Your symptoms may include numbness, swelling and/or pain. You may also have tightness across your chest and stiffness in your arm and shoulder. These can limit movement and may cause pain.

It is normal to feel that you need to protect your shoulder on the side where you had surgery and possibly radiation. Even if this area of your body is sore or uncomfortable you will need to exercise your arm gently and often. If mobility 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 this condition is much easier than treating it. If you have not already received information on these exercises, ask your family doctor, physiotherapist or occupational therapist how to do them.

If you are having ongoing problems with arm and shoulder movement, 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 or an orthopaedic surgeon.

### **What is Lymphedema?**

Lymphedema is a health problem that may happen because of breast cancer surgery and radiation treatment, sometimes not until many months or years after treatment is finished. It is a swelling that develops when there is a build-up of lymph fluid in the soft tissues of your arm between the skin and muscles. Your lymphatic system drains waste material from your tissues. A clear, colourless fluid called lymph passes through regional lymph nodes where it is filtered. If the lymph pathways become congested, damaged or even blocked, proteins can build up in your tissue.

Although most cases are quite mild, lymphedema may make you feel uncomfortable, affect your self-image and interfere with your regular

activities and the clothes you wear. It is not a sign of breast cancer recurrence but it may be a painful reminder of your breast cancer experience.

In some cases, lymphedema can affect your whole arm or only part of it, such as your hand and fingers, your forearm or your upper arm. Lymphedema can also affect your chest, shoulder and the area of your back behind your shoulder.

It is not completely understood why lymphedema happens to some women and not to others. Anyone who has had lymph nodes removed for breast cancer treatment or has had radiation to the axilla (the underarm area) may develop lymphedema. Surgery or radiation can damage or narrow the lymphatic vessels and reduce drainage. You may also get lymphedema if you hurt your arm, get an infection in your arm or are overweight.

Although it doesn't happen often, some women may not realize that they have very mild lymphedema until an injury to the arm such as an infection causes it to flare up and create swelling. Usually it is treated only if your symptoms are bothering you.

### **How to Reduce Your Chances of Developing Lymphedema**

Even though lymphedema cannot be prevented, we do know enough about the lymphatic system and how the condition develops to be able to recommend some things you can do that may reduce your chance of developing it.

#### **1. Look after your skin**

Healthy skin is your body's best defense against infection. Since an infection in your affected arm may make it swell, you need to try to avoid any injury to your skin.

- Keep your skin clean and well moisturised.
- Try to avoid breaks in your skin that could lead to infection (e.g. cuts, pinpricks, pet scratches and avoid cutting your cuticles).
- If possible, avoid having an injection, blood taken or a treatment such as acupuncture in your arm, neck, shoulder and back on the

side of your body that had the surgery.

- Wear gloves when doing any activity that may cause injury such as housework, gardening or hobbies.
- Use an electric razor if you need to shave your armpit.
- Avoid burns and sunburns. Wear long oven mitts, use sunscreen and keep your arms protected from the sun by wearing long sleeved shirts.
- Wear insect repellent to avoid bug bites.
- Try to avoid extremes of heat (e.g. hot tubs and saunas). Avoid sunbathing.
- Avoid harsh detergents that may irritate your skin.



If you do get a break in your skin, clean it well with soap and water and put a bandage on to protect it.

## **2. Improve the circulation in 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 jewellery and tight or restrictive clothing on your arm.
- Wear a bra that fits well with wide straps.
- Squeeze a soft foam ball occasionally.

## **3. Maintain an ideal body weight**

If you are overweight, you have a greater chance of getting lymphedema and it may be more difficult to control if it does develop.

- Talk to your family doctor or a dietitian about a plan for healthy eating and exercise. (See also Chapter 3: Healthy Living After Breast Cancer Treatment.)

## **4. Exercise carefully**

In the past, women were told that they should not do things that cause

stress on their arm such as rowing, tennis, golf, etc. There is no real proof that these activities may cause lymphedema and unfortunately, there are no clear guidelines about what is safe and what is not. Moving your arm and contracting the muscles as you do exercise will help move fluid through your arm.

- Increase your exercise gradually and watch your response. If your arm aches afterward, you may have overdone it and you should rest. Lie down and elevate your arm.
- Do some form of aerobic activity (e.g. swimming, walking, biking, dancing, light aerobics). Aerobic activity has many different health benefits. (For more information, see Chapter 3: Healthy Living After Breast Cancer Treatment)

**Note:** Even if you do all these things, you may still develop lymphedema. We do not know enough about the problem yet to be able to give clear guidelines. These are general precautions that you should keep in mind. Don't panic if you are overweight or if you get a cut, infection or block the flow of blood to your arm. You do not need to make drastic changes to your lifestyle. Common sense is the rule and a healthy diet and regular exercise program (even walking) will help.

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

- A tense feeling in your armpit.
- A feeling of heaviness in your arm.
- Swelling or an increase in the size of your fingers.
- Numbness around the incision (this may be due to surgery).
- Weakness, aching or stiffness in the arm where the lymph nodes were removed.
- Pain or a feeling of congestion or blockage in your arm.

It is normal to have swelling and discomfort after your surgery but this usually goes away within 6 – 12 weeks. If these symptoms don't go away, you should talk to your oncologist.

You can check yourself by doing a “Stemmer sign” test. Pinch the skin on your arm or hand that is worrying you and then compare it to your other arm. When swelling accumulates your skin may seem thicker and it will be more difficult to pinch. You can also measure your arm with a tape measure and compare it to the size of the same area in your other arm. (Note: Your “dominant” arm or the one you use most is usually slightly larger.) If you have more than an inch or 2.5 cm difference it may mean that you have lymphedema. Let your doctor know and ask if you can be referred to a lymphedema clinic.

### **How Lymphedema is Treated**

You will probably be asked to elevate your arm on several pillows and keep it as straight as you can, especially at night. Lymphedema is also treated by using compression garments called “lymphedema sleeves”. These sleeves control the flow of fluid in your arm by wrapping it tightly. Good compression garments should be custom-made and fitted by someone who has received special training. Some sleeves start at the wrist and end at the upper arm. Others include the shoulder and fasten with a strap around the upper torso. A “compression gauntlet”, especially one that includes your wrist, can be used if your hand is swollen. Compression garments should be replaced every 4 to 6 months, or when they begin to lose their stretch.

### **If Lymphedema Happens to You**

Fortunately, there are things that will make your life easier if you develop lymphedema. Most of these involve protecting your arm from stress or injury.

- Moisturise your skin often.
- Keep your hand and arm extra clean but don't use harsh soaps as they may irritate your skin.
- Protect your hand and arm from cuts or injuries that may break the skin by using protective gloves when cooking, cleaning or working in the garden. Use a thimble when sewing.
- When manicuring your nails be careful that you don't draw blood by cutting your cuticle.

- Avoid acupuncture in your arm, neck, shoulder and back on the affected side.
- Exercise your arm, but do not overtire it.
- Avoid rigorous, repetitive movements such as scrubbing, pushing and pulling.
- Rest your arm in an elevated position (higher than your heart if possible) especially at night.
- Avoid extreme temperature changes when bathing or washing the dishes. Don't take extremely hot baths or use hot tubs or saunas.
- Try to avoid cutting or burning your hand or arm and if you do, treat the injury right away.
- When possible, avoid needles and taking blood pressure from your affected arm.
- Maintain a healthy body weight (see Chapter 3: Healthy Living After Breast Cancer Treatment).
- Wear a compression sleeve for any vigorous activity or air travel.

An area of your body with lymphedema will have a harder time fighting infection. You should watch for signs of infection in your arm such as fever, redness, swelling, warmth or tenderness. Infection and inflammation can become worse very quickly. Call your family doctor right away if you think your arm may be infected. You may need to start antibiotics immediately even at any early sign of trouble. Your oncologist may order special tests to ensure that any arm swelling is not due to a blood clot or recurrence of cancer in the armpit.

*Lymphovenous Canada* is an organization that can provide resources on how to handle lymphedema. For more information, see Appendix 1: Resources for Breast Cancer Survivors.

# Fatigue

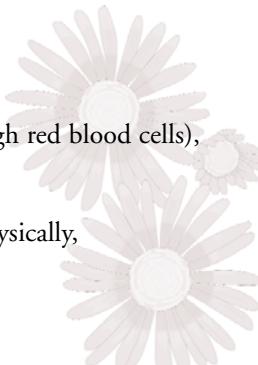
*I'm so very tired. I get tired really quickly just from doing normal things such as cleaning up the breakfast dishes. Sometimes I feel exhausted even if I don't do anything. Even a good night's sleep doesn't help.*

## What is Fatigue?

Of all the side effects of breast cancer and its treatment, fatigue is the one that women report most often. Fatigue is exhaustion in your whole body that is more than a normal feeling of being tired. It should gradually decrease over time and should go away in several weeks or sometimes months or longer. Your fatigue may be a sign of other medical problems. Fatigue that persists or increases should be discussed with your family doctor.

We don't really understand what causes fatigue, but there are many things that make it worse:

- 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,
- anaemia (when you do not have enough red blood cells),
- being less active,
- being under stress emotionally and physically,
- being worried or sad,
- dealing with conflict and
- feeling tension among your family, friends and/or co-workers.



## Living with Fatigue

It will take time for your fatigue to go away. Try not to get frustrated, there are things that you can do to make it easier to cope:

- Eat well. Eat healthy foods from the four main food groups. Eating many small meals over the day might make you feel better. (See Chapter 3.)
- Pace yourself. Use smooth, fluid movements rather than jerky ones. If your 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 paper plates or letting the dishes dry in the rack.
- Rest as often as you need to by taking short naps and breaks. Short periods of rest are better than long ones. Naps can help as long as they don't cause you to have trouble falling asleep at night. Rest before you feel tired so that you can extend your energy level longer over the day.
- Sitting whenever possible promotes better posture and takes about 50% less energy than standing for an activity.
- Improper work heights can make you tired, so organize your work areas and adjust them if necessary. The best working height for tabletops is two inches below your bent elbow. Raising the height of your bed can make bed-making easier. Store items in the area where they are used the most and within easy reach.
- Use aids such as long handled dustpans, sponges and dusters, jar openers, trolleys or adapted cutting boards to save time and energy.
- Relax. Nervous strain and anxiety use up your energy. Minimize stress by making realistic goals for what you can accomplish. Try different methods of relaxation until you find the one that reduces your stress.
- Exercise if you can. Take short walks or do some light physical exercise such as gardening or light housework. Check with your nurse, physiotherapist, occupational therapist or your family doctor about the best type of exercise and how long and how often you can do it.
- If you are feeling stressed, try to figure out what is causing it. Ask

your family, friends or health care team to help you work out some ways to cope.

- Follow a regular sleep routine and stick to it.
- Keep a record of how you feel each day. If you can, stop doing the things that make you feel tired or do them less often. Keep doing things that make you feel good.
- Try not to waste your energy. Work within your fatigue level. Spread your work evenly over several days rather than concentrating it all on one day. Learn to delegate heavy tasks to others whenever possible and limit your visits and activities when you are tired.
- Do things that take your mind off how tired you feel. These might be reading, listening to music, going to work, taking car rides, meditating or taking naps.
- Make sure your body temperature feels right. When you are too hot or too cold, it puts added stress on your body and you may get tired more quickly.
- Ask for and accept help when people offer it.
- Try to keep up your social life. Do the things that you really want to do and that make you happy. If you feel deep sadness or hopelessness, talk to your health care team or consult with a support service such as Willow Breast Cancer Support and Resource Services. (See Chapter 4 for more information about depression following breast cancer treatment and Appendix 1: Resources for Breast Cancer Survivors.)

Talk to your family and friends about your fatigue. They may not be aware of it. To avoid misunderstandings, explain how it is affecting you. Make a list of things you'd like them to do. For example, you could ask for their help to clean the house, do the laundry, go shopping and drive you where you need to go. 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.

## **Practical Ways for Family and Friends to be Helpful**

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

1. Telephone you to see how you are doing.
2. Bring over your favourite food in a disposable container so you don't need to worry about returning the dish.
3. Watch your children while you take some time to be on your own or with that special someone.
4. Take you for a short drive.
5. Call for your shopping list and make a special delivery to your home.
6. Call ahead before visiting. Don't be afraid to visit, but keep the visit short.
7. Help you celebrate holidays by decorating your home or bringing flowers.
8. Help other members of your family who may need some support.
9. Drive you to appointments, etc.

## Breast Problems

*My poor breast, the focus of all I've been through! When all was said and done it actually caused me the fewest problems!*

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

## Side Effects of Surgery

**Lumpectomy:** For a while, the area in your breast where the lump was removed may feel numb and tender. You may also feel tenderness and 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 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 the area around it. You may also feel mild to moderate tenderness and stiffness and the area may be very sensitive to touch. This is 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. There may often be an area of numbness that is permanent. If you choose to wear a breast prosthesis, this hypersensitivity 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, there are risks involved in the use of radiation. The brief high doses of radiation that damage or destroy cancer cells can also hurt normal cells. When this happens, your body will respond by starting to heal the damage. You may not begin to heal until 7 – 10 days after your treatment has ended. Common side effects of radiation therapy to the breast may include changes in skin colour, redness and soreness of the skin and underlying breast tissue. Edema or fibrosis may also occur.

**Skin Problems:** Irritation to your skin is usually the worst in the upper inner corner of the treatment field, on your nipple, in the crease beneath your breast and along your lower underarm area. You will notice that your skin problems will improve one week after treatment and should be almost totally cleared up by six weeks after treatment.

Some women who have had radiation to their breast as well as their axillary nodes may continue to experience changes in skin colour on the front of the neck and at the back of their upper shoulder. Sometimes the skin on your breast remains darker than your normal skin tone, similar to a suntan and the pores may appear larger. You may also notice that your nipple looks larger and is more sensitive. You may need to use moisturiser and provide extra protection from friction. When exposed to sunlight you will need to use sunscreen.

**Edema (Swelling):** Sometimes women feel a tightness, aching or crampy feeling in the muscle under the breast, against their rib cage. This is because the muscle fills with fluid as part of the healing process. It will take longer for this tenderness or swelling to go away. Sometimes these effects subside within the month following treatment, but they may also take even 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 been there from the beginning, but was disguised by the overall firmness of your breast. This should also soften and become less tender with time. Very few women are left with permanent swelling. Gentle exercise can relieve this discomfort. Speak to your physiotherapist or occupational therapist about exercises and follow the care plans that are recommended by your health care team.

**Fibrosis (Firmness):** A very few women experience fibrosis. This is scarring of the breast tissue and may make your breast tissue feel harder than normal. After many years most women usually notice that the radiated breast is firmer than the opposite breast.

Your skin soreness, dryness and itchiness can be treated with cornstarch, aloe vera gel or hydrocortisone cream. If an area is blistered or cracked, avoid the use of any of these products including an antiperspirant or deodorant. Do not shave under your arm until the sensitive area has healed.

Dry, itchy or burned intact skin may also be relieved by:

- Avoiding sunlight exposure, which can cause additional burning.
- Lubricating your skin with an oil-based moisturiser such as Vitamin E cream.
- Drinking at least eight glasses of fluid each day.
- Protecting your skin from extreme temperatures and wind. Keep indoor temperatures cool.
- Using sunscreen, especially in the area above your collarbone. Keep sunscreen with an SPF of at least 15 in your purse and apply often when outdoors for the rest of your life.

- Bathing in cool or lukewarm water. Cornstarch, baking soda, oatmeal or soybean powder added to your bath may be soothing.
- Wearing loose fitting, lightweight cotton clothing.

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

For especially sensitive and raw areas, you can also apply a cloth soaked in saline 3 to 4 times a day (see below). Continue to do this until the area is healed.

#### **Recipe for a Saline Soak:**

Mix 4 cups of water and 1 teaspoon of salt in a pot.

Boil the water and salt for 10 minutes. (You can also boil J-cloths with the solution and use as needed.)

Let the water, J-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 every day.



#### **Instructions:**

1. Wash your hands before using the solution.
2. Place a clean, soft cloth such as a face cloth or J-cloth in the bowl.
3. Pour the water and salt solution into the bowl until the cloth is wet.
4. Sit or lie down.
5. Expose the reddened, cracked or open area of your skin.

6. Gently squeeze the cloth to remove excess water.
7. Apply the cloth for 10 to 15 minutes to the reddened, cracked or open area.
8. Remove the cloth and leave the area exposed to the air to dry for another 5 to 10 minutes.

## Hair Regrowth

*Nothing was as bad as losing my hair. For me, it was even 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 have to look bad too!*

Hair loss is a temporary problem so take comfort in reminding yourself that your hair will grow back eventually. How soon will depend on how fast it normally grows. A few weeks after chemotherapy is finished, you'll see soft fuzz. You may experience scalp tenderness with hair loss and regrowth. Within a month, your hair will have started to grow in and will continue to grow at its normal rate which is about one quarter to one half inch per month. Your new hair may be the same as your old hair. On the other hand it may be thinner, thicker and curlier or it may be straighter than your original hair. It may also grow back a different colour.

Every person has a different comfort level with his or her public image. Wear your wig or head coverings for as long as you need to feel comfortable. Once your hair has regrown 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 drugs 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 include:

**Tear replacement** with eye drops made of artificial tears.

**Ointment** to keep your eye lubricated at night.

**Sustained release ‘pellets’** that contain artificial tears can be placed behind your lower eyelid.

**Special contact lenses** that have a low water content 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 evaporation of tears from your eyes. Use a humidifier to increase humidity. Avoid smoky places and take care when using hairdryers.

If dry eye is left untreated it can lead to serious complications. Check with your family doctor if you are experiencing any symptoms.

## 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 are 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 monthly emotional ups and downs, no more bloating or cramps. On the other hand, it may upset you because you can no longer have children and may represent the end of your youth. No matter what your view, there are things you can do to make it easier.

Menopause is a part of your natural aging process. As you get older, your body will gradually produce less estrogen which will make your periods become irregular and after a while, the amount of estrogen will become so low that your periods will 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 experience menopausal symptoms because they have had to stop taking hormone replacement therapy at the time of their breast cancer diagnosis. These symptoms can be quite upsetting for some women.

### **Menopause Caused by Chemotherapy**

Chemotherapy may have caused your periods to have 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 your treatment is over, your periods may start again and your cycle will return to normal. However, there is also a chance that your periods may become irregular or even not return although your doctor will not be able to tell you this for sure.

Once you have finished your cancer treatment and the crisis of your diagnosis and treatment are over, 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 knowing what are normal symptoms of menopause and what may be side effects of your treatment. You may feel out of sync because you are dealing with a normal life event at a different time than your friends.

**Note:** Your treatment-related menopause may be temporary and there is a chance that you may still get pregnant. Keep using a birth control method (**but not the birth control pill**) even if your periods have stopped. If your periods do start again, it will probably happen in the first year.

### **Menopause and Hormonal Treatments**

Hormone replacement therapy (HRT) is a common way to treat menopause symptoms. If you were prescribed HRT your doctor will probably tell you not to continue to take it, including hormone creams. This is because it is thought that most breast cancers need estrogen

to grow and there is a concern that HRT may cause the return of a previously diagnosed tumour. Because you have had to stop your hormone replacement therapy, you may experience menopausal symptoms as a result of a dramatic drop in estrogen.

Your doctor may even prescribe an *anti-estrogen* therapy such as Tamoxifen which 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. But unfortunately in a few pre and postmenopausal women, it sometimes produces unwanted 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.

You should not worry that by lowering your estrogen you may raise your risk of heart disease. The benefits of preventing a recurrence of breast cancer will outweigh the risk. Seek as much information as you can about hormone therapy and work with your doctor 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. (See Appendix 1: Resources for Breast Cancer Survivors for information on the Canadian Naturopathic Association. See also Chapter Seven for information on Complementary Therapies.)

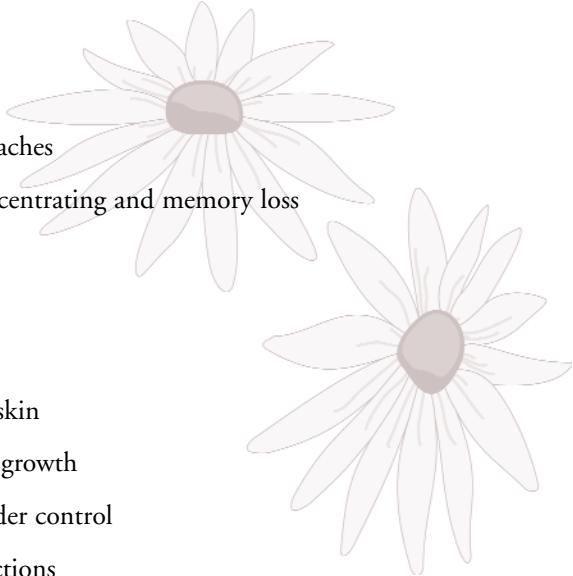
### **Symptoms of Menopause**

Whether they are caused by treatment or come on naturally, menopausal symptoms are very different for each woman. Some short and long term changes you may feel are:

- changes in your periods
- hot flashes and night sweats
- tiredness and trouble sleeping
- less interest in sex
- mood swings, sadness and irritability
- anxiety



- breast pain
- headaches
- joint and muscle aches
- difficulties in concentrating and memory loss
- weight gain
- vaginal dryness
- skin dryness
- thinning of your skin
- hair loss and hair growth
- some loss of bladder control
- urinary tract infections



## **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.

### **If you are experiencing:**

#### **Hot flashes and night sweats**

- Check with your family doctor. There are non-hormone medicines such as venlafaxine (Effexor-HR) which have been proven to reduce hot flashes.
- Check to see if avoiding alcohol and caffeine may help.
- Wear clothing in layers that is 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**

- Some women drink warm milk, chamomile tea or teas that contain valerian at bedtime.

## **Irritability or anxiety**

- Use different relaxation techniques such as visualization, deep breathing, massage or acupuncture.

## **Vaginal dryness**

- Water-soluble lubricants are helpful if they are applied just before having sex; non-hormonal lubricants include Astroglide and Replas.
- Try vaginal moisturisers such as Replens and Vitamin E.
- Having sex more often decreases the dryness.
- Vitamin E vaginal suppositories are helpful, but use no more than 800 IU per day.
- Wear cotton underwear.
- Estring is a product that can be prescribed by your doctor. It is a ring that can be inserted into your vagina to provide a low dosage of estrogen and may help to reduce vaginal dryness. Although it is probably safe for women with breast cancer, you should check with your oncologist before using.

## **Bladder infections**

- Drink lots of fluids (8 – 10 glasses a day).
- Wear cotton underwear.
- Urinate frequently (especially after sex).
- Keep your genital area clean.

## **Bladder control**

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

## **Diet and Menopause**

A well-balanced diet, which is low in fat and high in fibre, is always a good idea for everyone. Phyto-estrogens may help if you have had breast cancer and are having problems with menopause. Phyto-estrogens are compounds, similar to estrogen, that are found in plants. Soybeans are rich in them and have a positive effect on bone density and coronary artery reactivity. Phyto-estrogens are also found in flaxseed, tofu and miso. Always check with your doctor before trying them because their safety for women who have had breast cancer is still being studied.

## **Complementary Therapies for Menopause**

Many women also use different herbal therapies to relieve their menopausal symptoms. Unfortunately, there has not been much research into their effectiveness and safety, so again, you should check with your doctor. When choosing herbal supplements, always look for products that list all the ingredients. It is best to put your faith in medical research, not in package claims.

## **Osteoporosis and Cardiovascular Disease**

Because you may have reached menopause earlier than normal as a result of your treatment or because hormone replacement has been discontinued, you may have a higher chance of developing osteoporosis, a disease which affects your bones and may cause them to break more easily. This bone loss affects one in six 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 reduction of estrogen.

Women who have had breast cancer should receive a complete assessment for osteoporosis. If you are in Toronto, you can ask your doctor to refer you to the Osteoporosis Clinic at the Toronto General Hospital (416-340-3890) for a bone density scan and counselling about your nutrition and lifestyle.

You can combat your risk of osteoporosis by making sure that there is enough calcium in your diet through food sources and if necessary, calcium supplements. The current recommendations for elemental calcium are 1,000 mg per day for adult women younger than 50 and under and 1,500 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.

Check with your doctor to find out if you should be taking additional Vitamin D supplements. It is recommended that you get 400 IU of Vitamin D in the summer and 800 IU between November and March. One 8-oz glass of milk contains 110 IU of Vitamin D. Weight-bearing exercise like walking will also help keep your bones strong. Before starting any new exercise program, consult with your family doctor to make sure it is safe for you.

Early menopause may also lead to coronary artery disease, a disease which affects your heart. Estrogen protects arteries, so when you have less estrogen you are at a higher risk for developing cardiovascular disease. It is important to maintain a healthy weight, avoid smoking and get regular exercise.

## 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 and fuller 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've noticed signs of early menopause.*

### **Can I become pregnant?**

Yes, it is still physically possible to become pregnant. Even though your periods have stopped, you may continue to ovulate and can 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 still unknown whether the hormone levels of pregnancy have an effect on the recurrence of breast cancer for women with a previous breast cancer. If you would like to have a child after breast cancer, you should discuss this carefully with your health care team. The final decision will be yours.



## Chapter 3

# Healthy Living After Breast Cancer Treatment: Diet and Exercise

### **Chapter Outline:**

This chapter stresses the importance of a healthy lifestyle as you recover from your treatment for breast cancer. We look at ways that you can eat well and adopt a healthy fitness routine that will work for you.

## What You May be Feeling Now

### Getting Back to Your Normal Weight

*My weight was a problem before I had breast cancer. Now it's an even bigger one! When I went on Tamoxifen I put on twenty pounds before I knew it. Everyone tells me not to worry and maybe I shouldn't. Losing those extra pounds 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 an exercise program. This is perfectly normal. As you recover from your treatment and your lingering physical side effects begin to lessen, you can turn your thoughts to getting back to a healthier lifestyle that includes eating right and getting some exercise.

## 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. Exercise will provide you with a feeling of control and enhance your sense of well-being, whether you lose weight or not.

### Healthy Eating After Treatment for Breast Cancer

Here are five recommendations that will help you eat healthy after your treatment.

#### **1. Control your calories to achieve a healthy weight**

Obesity is a serious problem in North America. Not only is it linked

to increased risk of breast cancer; it also contributes to heart disease and adult-onset diabetes.

### **What is a healthy weight?**

Your Body Mass Index or BMI, is a measure of weight that takes height into consideration. It can be an important indicator of whether your weight is putting your health at risk. You should try and aim for a BMI of 20-25 if you are under 65 years, and of 20-27 if you are over 65 years.

### **Body Mass Index**

Find your height in feet or in centimetres in the appropriate chart for your age. The weight in the same line is your healthy weight range.

If you want to know your exact BMI, the formula is:

Weight (kg) ÷ Height (m<sup>2</sup>)

#### **Body Mass Index 20-25 for Women under 65 years**

Height	Weight
5' 0" (152 cm)	101-128 lb (46-58 kg)
5' 1" (155 cm)	106-132 lb (48-60 kg)
5' 2" (158 cm)	110-136 lb (50-62 kg)
5' 3" (160 cm)	112-141 lb (51-64 kg)
5' 4" (163 cm)	117-147 lb (53-67 kg)
5' 5" (165 cm)	121-150 lb (55-68 kg)
5' 6" (168 cm)	125-156 lb (57-71 kg)
5' 7" (170 cm)	128-159 lb (58-72 kg)
5' 8" (173 cm)	132-165 lb (60-75 kg)
5' 9" (175 cm)	134-169 lb (61-77 kg)

## Body Mass Index 20-27 for Women 65 years and over

Height	Weight
5' 0" (152 cm)	101-136 lb (46-62 kg)
5' 1" (155 cm)	106-143 lb (48-65 kg)
5' 2" (158 cm)	110-147 lb (50-67 kg)
5' 3" (160 cm)	112-152 lb (51-69 kg)
5' 4" (163 cm)	117-158 lb (53-72 kg)
5' 5" (165 cm)	121-163 lb (55-74 kg)
5' 6" (168 cm)	125-167 lb (57-76 kg)
5' 7" (170 cm)	128-172 lb (58-78 kg)
5' 8" (173 cm)	132-178 lb (60-81 kg)
5' 9" (175 cm)	134-182 lb (61-83 kg)

## 2. Try to limit your fat intake.

Although the connection between fat intake and breast cancer is unclear, it is believed that high fat intake can increase your risk for heart disease. In addition, high levels of fat in your diet will make you gain weight.

### Some examples of high fat foods:

- regular beef, pork or lamb
- regular hard cheeses
- ice cream
- deep-fried foods
- chocolate



- fried snack foods like French fries and chips
- nuts and seeds
- pastries and croissants

**Other items used to add flavour can also add a lot of fat, such as:**

- butter, margarine and oil
- regular salad dressing
- cream and whipping cream
- sour cream
- mayonnaise
- tartar sauce

### **Does the type of fat matter?**

Yes. Try to avoid using saturated fats and hydrogenated fats (like those found in hard margarine and in fried snack foods). Instead, use olive oil and canola oil, which are better for both breast health and heart health.

### **How do I reduce fat in my diet?**

These days it's quite easy to purchase most dairy products in a lower fat form. You can help cut your fat intake by using:

- skim or 1% milk
- yogurt with 2% fat or less
- 1% sour cream
- partly skimmed milk cheese, like mozzarella or cheddar

Trimming the fat off meats and removing the skin from poultry will also help. Serving yourself smaller portions of high fat foods such as fatty cuts of meat and full fat dairy products will reduce your fat intake.

### **3. Eat at least five to ten vegetable and fruit servings per day.**

We've all known for years that it is important for your overall health to eat your vegetables and fruits. Fruits and vegetables contain many vitamins, minerals and other nutrients that may work together to promote health.

## **What is a serving?**

One serving is one cup of leafy greens, one half cup of chopped vegetables or fruit, one whole piece of fruit or 4 ounces of juice. Getting your five servings is as easy as: juice with breakfast, salad with lunch, fruit as an afternoon snack and two vegetables with dinner. Remember to go for colour. Choose orange, dark green and red fruits and vegetables to get the most nutrients.

## **4. Eat more plant based meals.**

Legumes such as dried peas and beans are a high fibre, low fat source of protein. By choosing them often instead of meat you can increase your fibre and reduce the saturated fat.

### **If you have 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. On the Internet, there are some recipes using legumes at [www.pea-lentil.com/recipes/](http://www.pea-lentil.com/recipes/) or at [www.5aday.gov](http://www.5aday.gov) under Recipe Box.

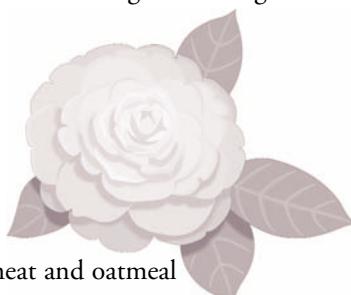
## **5. Increase your fibre to 25 grams per day.**

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

### **How can I get 25 grams?**

You can get 25 grams of fibre by consuming five servings of fruit and vegetables and five servings of whole grains. A whole grain serving is one slice or 1/2 cup of foods such as:

- barley
- brown rice
- corn
- whole wheat bread
- whole grain cereals like Shredded Wheat and oatmeal



## **Setting Goals**

A good way to tackle these five recommendations is to write down exactly what you eat and drink for three days. Also make a note of any exercise you do. Then compare your intake with the recommendations. This will help you find any 'trouble spots' in your diet. Some examples of things you may notice are:

- Your total vegetable and fruit intake is only 3 servings a day.
- When you have meat at dinner it is a 6 ounce cooked portion.
- You use higher fat foods such as medium ground beef, regular mayonnaise, 2% milk.
- You do not exercise enough.

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:

- |               |  |
|---------------|--|
| <b>Week 1</b> | ✓ I will change from using 2% to using skim milk                           |
|               | ✓ I will increase my vegetable servings at dinner by one serving.          |
|               | ✓ I will walk for 15 minutes three times a week.                           |
| <b>Week 2</b> | ✓ 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.                       |
| <b>Week 3</b> | ✓ I will reduce my meat portion at dinner from six to three cooked ounces. |
|               | ✓ I will change from regular to light mayonnaise.                          |
|               | ✓ I will increase walking to 20 minutes four times a week.                 |

- 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 increase walking to 30 minutes four times a week.

## Developing a New Fitness Routine

*Now that I'm finished my treatment, I can feel my energy levels beginning to return. I want to start a new exercise program but I'm not sure how far I can push myself.*

Exercise is an important ingredient in the recipe for a better, healthier life. Not only does it help you control your weight and decrease the risk of disease, it can also make you physically stronger, improve your psychological and emotional well-being and enhance your independence.

Now that you have completed treatment and begun to get back to a more regular routine, you may want to make a commitment to a healthier lifestyle and improving your self-image. Exercise will be the key to your self-improvement plan. It will be natural for you to have some questions and fears as you begin an exercise program. You may worry that exercise might cause damage or even a health problem such as lymphedema or that it may be too late to even start.

You may also wonder when you should begin to exercise, how much you should take on and what your limits may be. You will need to find out what kinds of activities you should participate in. Although there are no hard and fast rules about exercising after breast cancer treatment, it is possible to develop a safe, effective exercise program.

Even minimal exercise is beneficial to you, especially as you put treatment behind you. You will soon discover that one of the important secrets of those who exercise is that exercise is an empowering activity. It is something that you can have full control over. It will produce noticeable effects and benefits almost immediately.

There are many types of exercise that can match your various interests and responsibilities and you should strive to incorporate a variety in your exercise plan. You may also want to consider exercising with other people who can help motivate you and keep you on track.

It has been shown that breast cancer survivors who regularly work up a light to moderate sweat on an exercise bike, on a stair climber or in any other aerobic activity not only get into better physical condition, they also feel much less fatigued and less depressed or anxious. The sooner you return to exercise the better you'll feel. Exercise will also help you get back your life and regain a sense of control and may help with pain relief. A routine that is progressive with measurable milestones will give you a sense of accomplishment and confidence.

Your return to activity after treatment should be gradual. If you have had axillary lymph nodes removed, your shoulder and arm may have reduced mobility and lymph flow. By exercising you will help to regain your range of movement and enhance lymphatic flow.

Aerobic training is an important form of exercise that helps large muscles such as your legs. Strength and muscular training are also important to cancer survivors. Your exercise program should include elements of all these and should also help to increase your flexibility and range of motion. When using weights, handle them with care and use smooth and controlled motions. If you gradually increase the weights, you won't tire as quickly and will feel stronger when doing physical or recreational activities. It also helps increase the amount of lean muscle in your body and can help prevent or fight against osteoporosis.

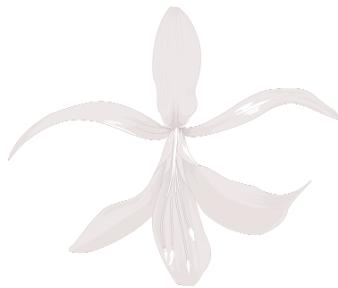
Find a place to exercise that is clean, comfortable, and free of obstacles. Wear clothing that is loose fitting, particularly on your arms, shoulders and chest, and is appropriate for the climate in which you are exercising. You can avoid overheating by wearing cool clothes and drinking plenty of water throughout your workout. If you feel tired, listen to your body and either lower your exercise intensity or stop altogether. Always warm up before and cool down after your exercise session and always stretch when you are done.

If you have lymphedema, avoid saunas and whirlpools. You may also have to limit the number of repetitions you do during your exercise program. You should also wear your lymphedema sleeve and if you feel fatigued or hurt, you should stop. Swelling, aching or a feeling of heaviness in your arm may suggest that you are doing too much and trying to progress too fast. Keep in mind that your surgery and post-surgery treatment have taken a great deal out of you, and your progress will take time. Be patient! The results will come.

Always get your doctor's approval prior to beginning an exercise program and if you have questions, seek the guidance of a physiotherapist or occupational therapist to help create a safe and effective exercise program. Listen to your body and start on your own path to living a stronger healthier life.

### **Try a Dance-Based Exercise Program**

Dance-based exercise programs can help you recover from the physical side effects of surgery and treatment as well as help you regain mobility, strength and general well being. Its therapeutic effects can also help you cope with emotional stress. Once you've learned some basic moves you can do them at home.



## Chapter 4

### Looking Within: Your Emotional Needs

#### **Chapter Outline:**

This chapter examines some of the emotional, spiritual and social needs you may have as your breast cancer treatment ends and your life continues. We look at some issues you may face and how you may work through them on your own or with support.

## 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 little while has probably been an emotional time for you and you may find that these emotional ups and downs continue for a while. Your family and friends may think you are cured and you may just want to get on with your life. You may wonder if things will ever be the same again. The truth is, you will never be the same person you were before. 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 this 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 gone.

When breast cancer cells return after treatment, this is called a **recurrence**. Cells may be discovered in the area around the breast (local or regional recurrence) or in other areas of the body (metastasis). These cells probably escaped from the original tumour before treatment and settled in another place. They can wait for years and then suddenly cause problems.

It may be hard to live with the knowledge that your cancer may come back, but try to remember that all available measures have been taken to ensure that at this point in time there is no evidence of any cancer in you. If you still have difficulties though, talk to your family doctor. There are lots of things you can do that will help.

## **What is My Risk of Recurrence?**

For many women with breast cancer, recurrence is very unlikely. The chance that your cancer will come back depends on many things. For example, the characteristics of your cancer (tumour size, grade, receptor and nodal status), the treatment you received and the length of time that has passed since your diagnosis will all have an effect on your risk.

There are no special diets, vitamins or exercises that are definitely known to reduce your risk of recurrence. Keep in mind that every year, more and more women survive breast cancer and live longer and healthier lives. In fact the survival rate for breast cancer is the highest it's been since 1950. When you hear statistics, you will need to keep in mind that their value is limited. They are about groups of people and you are an individual.

**Note:** If you have a form of breast cancer known as *Ductal Carcinoma In Situ* or *microinvasive cancer* there is a very low chance that your cancer may come back. Death from these types of breast cancer is so rare that you can regard yourself as cured. You will need to be checked for new primary cancers, not cancers caused by your original tumour.

## **Family Risk**

Although most women who are diagnosed have no known risk factors, about 5 to 15% of women with breast cancer do have an inherited predisposition for the disease. In other words, in a small number of cases, breast cancer happens more often to women who are from the same family. If you do not have a strong family history of breast cancer, your sisters or daughters have a slightly higher than average risk and they should follow the same guidelines for mammography as anyone else. Nevertheless you may worry about their risk. You may feel guilty about having breast cancer, especially if you have a daughter. This may be stressful for you and your family.

If there is a strong family history of cancer or if you come from Ashkenazi Jewish background, you and your family may qualify for genetic testing. This type of testing is done in a special clinic with counsellors who will explain the pros and cons of testing and who will

help you and your family understand the results and their implications. Genetic testing can tell if there is a gene mutation that may increase the chance of others in your family getting breast cancer long before the cancer actually develops. Not every family can or should have genetic testing.

Genetic testing has advantages and disadvantages. One advantage is that it can reduce uncertainty about developing cancer and define a person's risk level. A disadvantage is that no matter what the results are, they may cause depression, anxiety or feelings of guilt. If you and your family do have testing, you will need to think about the decision carefully and go for any genetic counselling that is available.

**Note:** Sometimes women think their family is at risk when they are actually not. If you think there is a familial link to your breast cancer you should discuss this with your health care team.

## Living with the Fear Your Cancer Will 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 every day. Others try to put it out of their mind. Your approach will probably fall somewhere in the middle and may change as time passes.

It won't help to think that there was something that you could have done to prevent your breast cancer or to blame yourself and think that you somehow "deserved" to get it. Don't think that way. This is not your fault. You are not to blame. There was nothing that you could have done differently.

### **Step 2: Accept that it will be difficult**

It is perfectly normal to fear that breast cancer will return. After a while, your thoughts about breast cancer should become less, but some anxiety may return at the anniversary of your diagnosis, before your medical

check-ups and during special times such as weddings, birthdays, etc. If you find that you are worrying all the time, then you may need to seek some help. Talk to your family doctor or nurse.

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. You may not want to upset them by talking about it. If this happens, you might want to join a support group or seek out one-to-one peer support.

### **Step 3: Take Action! Make a plan for early detection**

You are now a breast cancer survivor and your health care team will work with you on a plan to make sure that if your cancer does return it will be discovered as early as possible. You will be more carefully watched and checked than the average woman. Your body will be monitored for changes and any warning signs of cancer and other diseases so that they are detected as early as possible when you have the best chance of successful treatment.

Don't let your worries keep you from following early breast cancer detection guidelines. There are things that you can do to make sure that if cancer returns, it is found as early as possible:

#### **✓ Regular Doctor's Follow-up**

As described in Chapter One, you and your family doctor or oncologist will need to work together on a plan for regular follow-up and monitoring. It will be important to keep your family doctor up to date on how you feel physically and check with him/her often about changes in your health.

Many women find their regular follow-up appointments very difficult emotionally. Not knowing whether your cancer has come back can be very distressing. It may help you to talk to someone who has already been through a similar experience. 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.

Never worry about calling your family doctor if you have any concerns or a symptom that you are worried about such as the following:

- any new lump that persists,
- persistent and unusual pain in your legs or back,
- a dry cough that does not go away, or
- a decrease in your regular amount of energy.

Your family doctor should always be the first one you call, but you can also contact your oncologist, your Nurse Case Manager or any member of your health care team. If you are seeing more than one oncologist, try to spread out your follow-up appointments with them over time to make monitoring more effective. This is also a good way to have more regular clinical exams.

#### ✓ **Annual Mammograms**

A mammogram can check out any changes in your breast that might signal breast cancer. You should always try to have your mammogram done at the same location. Be sure to go to a centre that is accredited (passed a special set of tests) by the Canadian Association of Radiologists (CAR) Mammography Accreditation Program. If you are not sure about this, ask.

If you have been getting your mammograms at an Ontario Breast Screening Centre, you will no longer be able to go there because you have had cancer. Instead you will be sent to a diagnostic mammography centre for your mammogram, probably the one where you had your pre-surgery mammogram and ultrasound.

#### ✓ **Monthly Breast Self Exam (BSE)**

Although it is a good idea to check your breasts regularly, we are not sure if breast self-examination really makes a difference. Some women who have had breast cancer find it hard to check their breasts. Don't feel guilty if you decide not to, but if you do, you should try to do it every month. Ask your family doctor or the nurse at your health clinic to give you a complete teaching session in BSE.

It may help to tell yourself that you are not looking for lumps. This is your doctor's job. You are checking your breasts so that you know what is normal and will notice any change. If you do, you should report this change to your family doctor who can check it. The best time to start doing BSE is right after a doctor's visit when you know everything is all right. Always try to do it on the same date every month.

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

Every woman will develop her own special way of living with breast cancer. Some women "go it alone" while others like to talk about their experience. You will need to find what method will work best for you.

#### **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 for women today. You can join one, organize one, or even help to bring one back to life. You will find that there are other women out there who will want to share their experiences with you and learn what they can from you. For more information on support groups, see Chapter 5: Reaching Out: Your Social Needs.

#### **Individual Counselling**

You may choose to work directly with your own counsellor such as a social worker, psychiatrist, psychologist or chaplain. The goal of your counselling will be to help you recover from breast cancer so that you can get your confidence back and regain control of your life.

#### **Volunteering**

Some women volunteer their time by helping other women who are experiencing breast cancer. If volunteering is something you would like to do, there are many ways for you to contribute your talents and the time you spend can be as much or as little 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:

- Work with peer support programs for other survivors.
- Drive patients to treatment.
- Promote education about cancer in schools, community groups, ethnic organizations and workgroups.
- Organize or participate in fundraising and special events such as Dragonboat Racing.



Volunteering works for some women, but it's not for everyone. Some programs will ask that you wait 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**

Your partner or spouse may need help and support. He/she is also dealing with the stress of breast cancer. Partners may need to express their concerns and tension and may not want to worry you. Lesbian partners have added worries such as struggling with their own fear of breast cancer.

If you have children, they will also need support. They have been through a very difficult experience and may be afraid to tell you how upset they are. There are support groups and individual counselling options available for spouses, partners and children. (See Appendix 1: Resources for Breast Cancer Survivors.)

## **What to Expect During the Coming Year**

### **Adjusting to 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**

For many women, their breasts are an important part of how they feel as a woman. After breast cancer treatment, many women feel changed and not attractive any more. If you are feeling this way, there are things you can do that will make you feel better about how you look.

Wearing a prosthesis is up to you. If your entire breast has been removed you can wear a full prosthesis. If only part of your breast has been removed you can use a partial prosthesis. Special underclothing and bathing suits with pockets are available at most medical supply or specialty stores. If possible, talk to other women about how they have managed.

Funding is available from the Ontario Assistive Devices Program (ADP) to help pay for the costs of breast prostheses. Ask your nurse for the form you need. You will also need to ask your oncologist to complete the medical section of the form. There are many places where you can obtain a prosthesis and special clothing such as special shops that will measure and fit you properly. These shops will also know about the ADP. Private health insurance plans may also provide coverage for special clothing or prosthetics.

## **Find Ways to Look and Feel Better**

- Pay attention to the rest of your body according to what makes sense to you. For example, think about your hair, make-up, clothing or accessories. Get a manicure or a massage. Wear clothes that make you feel comfortable.
- Acknowledge the parts of your body you feel comfortable with such as your smile, the colour of your eyes or the shape of your hands.
- Ask someone else (a partner or a friend) to tell you what they think makes you attractive.

If you continue to feel badly about your body image, you can seek professional or group counselling. Counselling services are available through your family doctor, a breast cancer support group, Willow Breast Cancer Support and Resource Services' peer support, or your community or hospital social worker.

If you have had a mastectomy, you may also want to discuss the possibility of reconstructive surgery with your doctor.

## Depression

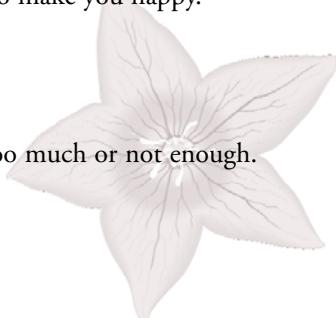
*I don't understand why I'm feeling so blue all the time.  
Everyone thinks I should be happy now that my treatment  
is finished. I just can't stop feeling sad.*

Many women become depressed when they are first diagnosed and then again when their treatment is finished. This is common. You have been through a hard time. These feelings will be affected by your age, changes in your hormones, and your life situation. For example, early menopause can make you sad and fatigue can exaggerate your sadness.

It is normal to feel sadness as you move through the treatment process. If you don't let yourself feel sad and grieve sometimes, you may not resolve these feelings.

You may wonder whether you are feeling sadness or true depression. Are you experiencing any of the following?

- A feeling that you cannot cope.
- A strong feeling of helplessness and hopelessness.
- Sluggishness.
- A hard time concentrating.
- Problems remembering things.
- Attacks of panic.
- Less pleasure in things that used to make you happy.
- Overeating or not eating enough.
- Less interest in sex.
- Sleep problems such as sleeping too much or not enough.



If any of these things are happening to you, talk to your family doctor or a counsellor so you can find out if you need extra help.

You may not want to take medication, but antidepressants can help with depression and anxiety. Antidepressants can take 2 – 3 weeks to be effective. You may only need these medications for a short time. Your family doctor can prescribe antidepressants or you may be referred to a psychiatrist. In addition to medication, talking about your feelings with your family doctor, psychiatrist or counsellor is an important part of the process that will help you feel better. Your family doctor or psychiatrist will help you decide when the antidepressants are no longer needed.

Some women question whether Tamoxifen causes depression. However, it isn't clear that the depression is caused by the Tamoxifen. Two major studies in the United States and Canada found that women who took Tamoxifen were no more likely to be depressed than women who took sugar pills (or placebos). Some women on Tamoxifen have had anxiety attacks. If you often feel frightened for no reason, short of breath or tightness in your chest, you should ask for help from your health care team. You may need short-term counselling, medication or both.

## Your Sexuality

*When my husband and I are intimate, I feel him tense up when he goes to touch me. He says there isn't a problem, but I wonder how I can get him to open up about his feelings.*

Your breast is a part of your body that is very strongly connected to sexuality. Like many women who have been through breast cancer treatment, after your experience you may find sex and intimacy difficult. Because you have had breast cancer you may feel your body has betrayed you. Your surgery may leave you feeling violated because it has changed the way you look. You may feel less attractive. This is perfectly normal.

There are other reasons why you may be feeling this way. Radiation can make your breast and nipple less sensitive to arousal. Treatment-related menopause might be lowering your interest in sex. When your ovaries

shut down, they stop making estrogen as well as testosterone which is the “hormone of desire”. The reduction in testosterone may make you less interested in sex.

You and your partner are probably both feeling fragile now – 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 wrongly think that sex might make your cancer come back. You may misinterpret this as a lack of interest, but in reality your partner has probably been much more concerned about losing you than about the loss of your breast. Making love can be healing for both partners, but reconnecting physically may take time after breast cancer.

No matter what type of sexual relationship you have, start out with lots of closeness, hugging, massages and other things that you feel comfortable with. You may need to be more direct in expressing your wants and desires to your partner. Arousal may take more time, but focusing on natural pleasure rather than pressure will usually please both of you. Together you can explore new ways of heightening sexual feelings and find other erogenous zones that are not tender or uncomfortable. If the uneasiness and worry don't fade, you should seek the help of a counsellor. Your family doctor, community or hospital social worker can help and may refer you to a specialist for further counselling.

## 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 reading glasses and the other day,  
I forgot my neighbour's name.*

Women who have completed breast cancer treatment sometimes report that they feel fuzzy or are losing their mental sharpness. This is the result of several factors working together. Changes in estrogen levels because of menopause or the use of Tamoxifen can make it hard to remember things. So can the stress of dealing with a life-threatening disease. Fatigue can make you less alert, and chemotherapy may also affect your short-term memory.

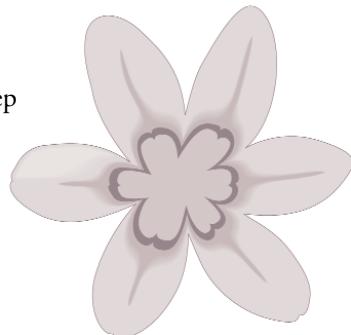
Fatigue, anxiety and depression can also have a strong effect on your memory. Memory is also affected by how often and how long you use it and other brain functions. No matter how old you are you can still grow new brain cells. Just like the rest of your body, the more you “exercise” your brain, the better it will work. So keep your brain busy; keep learning new things; consider doing crossword puzzles or test your memory by working on things you’d like to remember—telephone numbers or family birthdays.

## 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 or PTSD. PTSD is usually diagnosed when someone persistently relives a traumatic event in their thoughts, feelings and even dreams for more than one month. The individual may also try to completely avoid anything that is related to the traumatic event and appear to be “numb” in their response to everyday life.

### **The symptoms of PTSD are:**

- Difficulty falling asleep and staying asleep
- Irritability or outbursts of anger
- Difficulty concentrating
- Hyper-vigilance (excessive watchfulness)
- Jumpiness/easily startled



Some women with breast cancer have been known to experience PTSD. If you think you are one of these, you should talk with your social worker, psychologist, psychiatrist, peer support group or family doctor about your experience and any symptoms you have. You can help your health care team understand you better and plan your treatment by sharing this information about yourself.

## 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 and are able to do anything you set your mind to. A certain level of trust and comfort will slowly come back as you enter the long-term stage of survival. Many people in fact find that their lives have improved after breast cancer. 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.*

Many cancer survivors go through a spiritual crisis or a test of faith. Fear can overpower and paralyse you. Anger can make you lash out at others and yourself. You may ask “Why?” or “Why me?”. You may begin to doubt your faith and feel you are weak. You may be afraid of what you will face in the future.

All of us need to understand our existence to find meaning in our illness. When faced with cancer, a sense of hope can provide you with direction. Keeping that hope can help steer you through the uncomfortable side

effects of treatment and lead you into your new life as a breast cancer survivor. Your spiritual and religious beliefs and relationships with others are part of that hope.

Use your personal faith or beliefs as a tool for recovery. It is as important as any medicine or surgery. Reach out to your spiritual leader, pastor, rabbi, priest, chaplain, peer support group or friend for support. Whatever your 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* ⇐



## Chapter 5

### Reaching Out: Your Social Needs

#### **Chapter Outline:**

This chapter covers some of the changes that may affect your relationships now that you have completed your treatment for breast cancer. We provide tips that might help you relate to your friends, family and co-workers in the best possible way.

## What You May be Feeling Now

*Like most 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, but that I still need them.*

As you move back into your everyday life, you may find that although you feel ready to take on the challenges each new day brings, it may not be as easy as you'd thought. As you venture out into the "real world", you may meet friends and neighbours who have not seen you for a while. They may ask you where you've been. If you work outside of the home, you may find that your fellow workers may not know what to say to you. Even if you live in a closely-knit community where it may be known that you have been treated for cancer, you may still wonder what people know and what 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 are one of those who is not comfortable talking about it, 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 may have come to appreciate the importance of your social support network. In Chapter One of this booklet we talked about how your friends and family may feel that it is time to get back to normal and 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 though you may still feel lost and fearful, you may think that you have already asked for enough help from them.

You may also find that some of your helpers can't 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 difficult for you to loosen the strong ties that you've developed during your treatment for breast cancer.

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 treatment crisis has passed. As you move back into your “new normal” life, think about how you can find your own way of knowing when and how to reach out for help. If possible, talk openly with your friends and family. Let them know how much you appreciated the help and support they gave you during treatment but that there will still be times when you may want to ask for their help and support, for example, when you’re tired. When your energy is low, you may feel frightened and insecure. Your friends and family can help you recognize when you may be doing too much.

Cancer is still feared by some people. It may remind them of bad experiences they have had in the past. After your diagnosis and during treatment, you may have found that some of your friends and family avoided you. You may feel angry and hurt by their actions and then regret your anger towards them. Although these individuals may not have been there for you during times of crisis, it may be easier for them to be supportive now that you are returning to your everyday life.

Let your friends and family know that you need them to be the friend or loved one that they have always been. Tell them that you care about them and are there for them.

### **Help Your Friends and Family Help You**

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

- 1. Know your world:** Take a look at your life and try to see what may be making things difficult for you. Are there changes at home, financial worries or emotional and physical concerns that may be causing stress?
- 2. Know yourself:** What do you know about yourself that will help you ask others to help you? Do you fear a loss of control, do you think that things won’t be done right? 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 decide which need to be done first. Then divide some of them among your friends or family members. Think about their skills and interests. What do they like to do? Make it very clear what you need from them. Make sure you thank them for their efforts. 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 that you need them. With help, you can devote more time and energy to positive and enjoyable things.
- 5. Talk about things openly:** Be direct and honest. Tell your friends and family how you feel. State your feelings clearly. Talk about goals that you share.
- 6. Provide feedback:** Let your friends and family know how they're doing. This may take courage, but providing both praise and constructive criticism when necessary will strengthen your relationship and create a better sense of team.
- 7. Offer to help others:** There may be things that you can do to help your friends and family. Let them know that you are there for them.

## 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, I felt like we didn't have anything to talk about anymore.*

Look back over the past several months and if you can, really talk with your partner about what's happened over the past little while. Share your fears with each other and try to be honest about your experiences.

Working out issues and feeling comfortable together again can be an important part of your healing process.

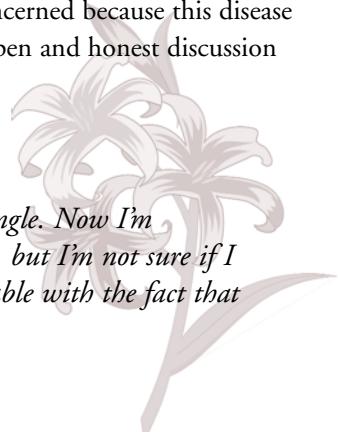
This may not be as easy as it seems. In some cultures this type of dialogue may not be a regular part of your approach to each other. You may also be in a relationship where you or your partner may not be comfortable discussing and thinking about these types of issues. If this is the case, you may want to link with other women, or women of similar culture 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 some impact on your relationship. You may have been pleasantly surprised about your partner's strength and support during this time and may have renewed your faith in a strong future together. On the other hand, the experience may have uncovered issues that have become even harder to deal with during the last few months. Your partner may now feel that the breast cancer experience is all over and that you both should go back to the way things were before. You may not be ready to do this. If these kinds of issues arise, you may need to seek professional counselling.

Breast cancer can happen to any woman, regardless of her sexual orientation. If you are in a lesbian relationship, it may be easier for you because your partner may be more sensitive to some issues about breast cancer. On the other hand, it may be difficult. Your partner may feel especially upset about your experience and concerned because this disease could affect her as well. Now is the time for open and honest discussion to resolve these issues.

## If You are Single

*After my divorce, I decided to remain single. Now I'm wondering if that was the right decision, but I'm not sure if I can find a partner 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 mate, you may be worried that breast cancer will alter your prospects. What will you tell a potential lover about your health history?

Breast cancer has become so common that most of us know someone who has had the disease. Although there's no way to tell how anyone will respond to breast cancer, you will probably find that most people are supportive and prepared to continue a relationship.

Try to start some new and interesting activities that will help you meet people who may have the same interests as you. Many couples are introduced to each other by their families or friends, co-workers, classmates or neighbours. Look to the people you know – and tell them you'd love to meet someone new. Your social network has resources for you to tap. Let your friends know what you're looking for and talk to them openly about your hopes for the future. Relax and have fun as you develop new friendships and renew old ones. Be honest about your breast cancer, but don't feel that you have to discuss it until you are ready.

Even if you want to stay single, you may wonder 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 to your friends and family about your fears. If you have not already done so, consider joining a peer support group of other women who have been through the same experience.

## 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 —

simply a group of women who have experienced breast cancer and who meet 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 around mixed concerns that find focus over time.

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 and Resource Services, the Canadian Cancer Society's *CancerConnection*, newsletters, or web-based chat rooms.

Keep in mind that peer support is different from professional counselling. Peer support groups have leaders who contribute to the group from their own personal experience. Their purpose is to help members manage daily living, cope with emotional and other issues and educate themselves. Professional counselling groups are different. Their leaders usually have special expertise gained through training and education. The group usually follows a format that is set by the leader who guides and encourages members to set personal goals and move toward them.

Support groups are often run by a hospital or organizations such as the Canadian Cancer Society, Wellspring or Gilda's Club of Greater Toronto.

### **Choosing the Right Peer Support Group**

When choosing a peer support group, you will need to think about your own needs now and into 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 who are coping well? Whatever your reasons for seeking support now, your needs may change over time.

If you decide to join a peer support group, call ahead and talk with the group's contact person. You can also speak with other group members and ask for printed materials with a 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. survivors, 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 peer support group will have a different personality. Look for a group that fits you.

To find out what support groups are available in your area, contact Willow Breast Cancer Support and Resource Services. You can also visit the Wellspring or Willow websites for a complete list of cancer support groups. (See Appendix 1: Resources for Breast Cancer Survivors.) If you live outside of Toronto you can call Willow or visit their website as well as call the Canadian Cancer Society or the public health department in your community to find out what groups exist in your area.

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

available for you. If you do decide to go ahead, find other survivors, supportive professionals, hospitals and other organizations who can work with you as a team. Information on how to set up a support group is available from a number of sources such as Willow Breast Cancer Support and Resource Services.

### **Try Something Different**

If a traditional support group does not interest you, there are other ways to get together with breast cancer survivors. For example, Wellspring offers yoga for people living with cancer and Mount Sinai Hospital has a quilting group especially for women who have had breast cancer. You could organize a special event, fundraise, or try Dragon Boating. This sport involves the use of a large canoe-type boat with a crew of 20 paddlers, sitting two abreast, one steersperson in the stern and one drummer sitting high in the bow. Traditionally, corporations, businesses, educational establishments and health facilities compete annually in these races and recently, breast cancer survivors have become involved. There are teams across Canada as well as in the United States, Australia and New Zealand.

## **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.*

### **Stepping Back onto 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 now have a new sense of direction and be very clear about your life's priorities. However there may be challenges to getting on with life again. Your self-image may have changed, and you may now feel that you are more vulnerable than you were before. (See Chapter 4 for a discussion of how to cope

with emotional needs.) No matter how well you have dealt with your experience, there is no doubt that you are a different person than you were before. You may find that these changes in you create challenges to becoming independent again.

Accepting what has happened to you may take time. Building a new approach to life will probably be a “work in progress” that will take many years. Don’t be afraid to take a look at how your life has changed and begin the process of moving forward. Your first step will be quite simply, to take that first step.



## Chapter 6

### Returning To Everyday Life

#### **Chapter Outline:**

This chapter looks at some of the practical and financial issues that you may face as you return to your everyday life. We provide useful information about making the transition back into the working world and how to plan 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 made you think about things you may have not worried about in the past. You may have concerns about your financial security and about other practical issues such as your health insurance and whether your job is safe. You may wonder how much you should tell the people who handle these affairs for you.

## What You Need to Know Now

The secure foundation that you have worked so hard to build is still strong. As a breast cancer survivor 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 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 or cortisone cream for lingering effects of radiation. There are a number of sources that may assist with these costs. These include:

- Group Health Care Insurance through your employer
- The Ontario Drug Benefit Program

- The Trillium Drug Program
- Interim Medical Coverage for Refugee Claimants
- Assistive Devices Program
- Veterans Affairs Assistance

For information about these programs, contact your hospital social worker. You can also check the online document *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, 2001 which is available on the Willow website (See Appendix 1: Resources for Breast Cancer Survivors).

## Returning to Work

*Although I tried not to miss too much work because of my breast cancer treatment, I found that when I went back full time, I didn't have the same level of energy and my powers of concentration were down. To make matters worse, I didn't have a very understanding boss and I didn't get the support I needed to get back on track.*

Work fills an important need for many cancer survivors and continuing your work will be an important psychological (and financial) step for you. As well as providing income, it may provide important benefits such as health insurance. Your employment is also part of how you define who you are. It may be a key pillar 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 even able to continue working through their treatment and others need to take time later due to problems from the side effects of their treatment. Whatever your situation, you may worry that because you have had breast cancer it may be more difficult to keep your job, pay your bills and support your family. You may worry

that if you place too much stress on yourself it will increase the chance that your cancer will return.

Discuss what's possible with your family doctor. There are many support services available that will help make working easier for you. For example, you may need help from a physiotherapist who can provide exercises to reduce pain and improve your fatigue. Occupational therapists are available to assess your work environment and recommend modifications that will maximize your independence. Check with your family doctor to see if your working hours should be reduced or if there are some work restrictions you need because of temporary pain or stiffness in your shoulder.

### **Dealing with Co-workers' Reactions**

There is no legal reason why you need to tell anyone at work about your breast cancer unless it will interfere with your ability to perform your job or if you need extra time off. If you do make it known, you will need to prepare yourself for the reactions from your co-workers. Sometimes, the fear of cancer can result in attitudes that may make you feel as if you are being treated differently.

It may help to put yourself in your co-workers' position. They could be worried about you. They may fear that you are no longer healthy. Some may even worry that you are not able to pull your share of the load and that they will be expected to take on more work. If you sense that this is a problem, you will have to use your judgement in dealing with it. For example, some of your co-workers may not be comfortable talking openly about your experience and your positive outlook for the future. They may need time to understand that everything will be fine.  
(See also Chapter 5 for more about relationships)

### **How to Talk to Your Employer**

If you are experiencing some lingering side effects of treatment such as fatigue or arm problems that limit your ability to do your job, you may need 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 may be affected by them.

2. Work together to set goals that you know you can achieve.
3. If possible, ask for a change in your job responsibilities.
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 materials or by asking someone in your health care team to speak with the staff.
6. Do not feel embarrassed about asking co-workers for help.
7. Make sure you know about your company's policies on sick leave, disability leave, flexible hours and work retraining options.

### **Employment Discrimination**

Although discrimination is rarely a problem today for breast cancer survivors, in the past, many breast cancer survivors returned to work and found that their job opportunities were limited. That is because, years ago, long-term medical treatments made it difficult for employers to manage when a worker had cancer and many found ways to exclude and even fire cancer patients. Today, treatments are shorter and less invasive. Most breast cancer survivors can expect to lead healthy and productive lives. There are also provincial and federal laws that protect employment rights.

Even with these changes and legal protections, you may find that your employer treats you differently from other employees. Workplace problems that are sometimes reported by cancer survivors 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.

If you think that you are being treated differently at work because of your cancer history, you should try to work out an informal solution first. Many employees have difficulties doing this on their own. Support from your doctor will be very important. Provide him/her with specific

information about the physical and emotional demands of your job. Be honest about your limits and your abilities. Ask your doctor 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 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 carefully written records of all relevant events. 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 damaging to your reputation.

## 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 establish your ability to perform the duties of the job. Your best bet is 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 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's not necessary, you could include information that will describe your condition and illustrate your

ability to do the job. Include your doctor's name for reference and offer to provide a letter from your doctor.

Your resume should focus on your skills and not draw attention to gaps in time during which you were in treatment or recovery. You should be prepared to explain any blank stretches of time.

## Income Replacement in Ontario

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 income replacement through the Ontario Works Program. This social assistance program is available for Ontario youth aged 16 and 17 years and adults aged 18 years and over in financial need. You will need to call for an appointment to arrange a financial assessment at your closest Ontario Works Office. If you are too unwell, you can request an appointment in your home. You will be asked about your savings, income and expenses and will have to provide identification, proof of shelter expenses, proof of assets and information about your previous employment.

Ontario Works can also provide immediate, emergency and short-term financial assistance and special funds for specific needs. For more information about Ontario Works, call your local Ministry of Community and Social Services Office, your local municipality or visit the website: [www.gov.on.ca/CSS/page/services/ontworks.html](http://www.gov.on.ca/CSS/page/services/ontworks.html)

## Life Insurance

If you are looking for life insurance coverage, you should use an insurance broker and make sure they are fully aware of your health history. Although every insurance company's rules are different, some are more flexible than others. Insurance brokers have access to different companies and can look for the best package for you.

In Canada, if you have had breast cancer, most **pre-existing** life insurance policies 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 may find that you are not eligible or that the eligibility criteria for you will be different.

Breast cancer survivors applying for individual policies will likely be offered policies at a *substandard or special class rate*, which usually means higher premiums. Factors that may affect your eligibility may include the type of diagnosis and treatment you received, the years since your diagnosis, your current health assessment and whether you are taking prevention drugs. If you are charged an increased premium or your application is declined, find out if you should provide further information. You should also ask when you should apply again.

Another option might be to apply for small policies with several companies, i.e. several insurance policies of \$10,000 each. Life insurance offered by businesses or banks such as mortgage insurance can add further protection. There are forms of individual life insurance, called “guaranteed issue,” where no health assessment is made. You should ask companies about these policies.

**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 benefits. However, should you leave your work, some insurance companies do have a provision to convert your policy from group coverage to individual coverage without proving insurability. This must be done within a specific time period. Check with your insurance provider to enquire if this applies to you.

If you are already insured, make sure you pay your premiums on time so your insurance does not lapse. If you have daughters, you should also encourage them to get life and disability insurance while they are young and healthy, in case your diagnosis of breast cancer affects their options.



# 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 traveling 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 or tax accountant, you should talk to him/her about what’s happened and what has changed as a result of your breast cancer. Other sources of advice include:

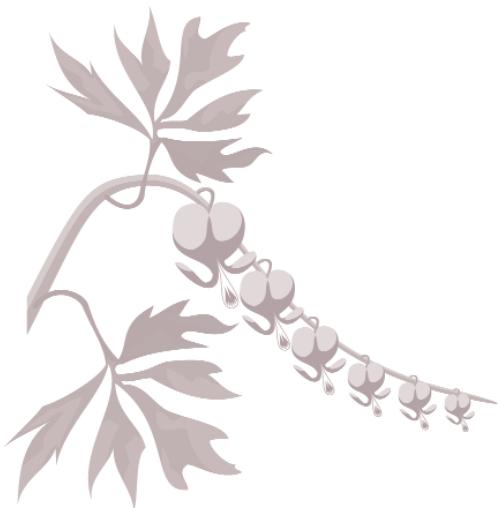
- friends and family with financial expertise
- your social worker at the hospital or treatment centre
- members of your breast cancer support group who may have gone through a similar experience
- The Community Information Centre for your area

If you have debt and it is more than you can handle, you should speak directly to your creditors, your mortgage holder or your landlord. Find out from your bank if credit counselling is available in your area. Be honest about your situation and remember that there is no need to feel guilty about it. It is not your fault that you had breast cancer. You will probably find that these people are sympathetic and want to be helpful.

**Note:** Willow Breast Cancer Support and Resource Services have a Benefits Information Counsellor with whom you can make an appointment to receive a free consultation on the issues raised in this chapter.

## Legal Help

You will need to check with a lawyer if you write or change your will or transfer your assets. It will be important that you find a good lawyer with skills and experience. If you feel you can't afford a lawyer, find out if you qualify for the Ontario Legal Aid Plan. If your estate is modest, you can also obtain Ontario will kits at local business supply stores. Power of Attorney kits and forms for creating a legal will are also available free from The Office of the Public Trustee and Guardian. Forms for creating a living will are available through your hospital social worker.



## Chapter 7

### Dealing With Current Cancer-Related Issues

#### **Chapter Outline:**

This chapter provides tips on how to deal with current cancer-related issues you may come across in the newspaper, on radio, TV, or the Web. We take a look at how the media present health care issues and research information and provide you with some tools that will help you judge when the information is relevant to you.

## What You May be Feeling Now

*Every time I see an article in the newspaper or a women's magazine about a new breast cancer treatment I start thinking about what happened all over again and worry that I might not be doing the things I should.*

As you get on with the rest of your life, 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. Every once in a while though, you will come across an issue that may worry you. You may see an article in the newspaper about a new form of treatment, you may hear about hospital cutbacks on the radio or you may talk to a friend who has just been diagnosed and is exploring non-traditional forms of treatment. These bits of news may make you wonder if you are doing the right thing. You may ask yourself: Did I get the best possible type of treatment? What if I need an expensive type of treatment in the future and the funds are not available? Is there more that I should be doing to prevent a recurrence?

## What You Need to Know Now

Your health care team is available to answer any questions that you may have about new treatments and issues that may concern you. Don't hesitate to contact your family doctor or your oncologist if you have questions. 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 been able to find out. Willow Breast Cancer Support and Resource Services can search for the full details of any new trial reported in the press.

## What to Expect During the Coming Year

### Dealing with Media Reports

In today's fast-paced modern world, the popular press plays a big role in providing us with information almost as soon as it becomes available. TV, radio, newspapers, magazines and now, the World Wide Web all compete to be the first to tell us what's new and almost everyday there is something new about health care and breast cancer.

The news media like short bits of information that are easy to understand and make a quick impact, but they often don't tell you 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. This statement gives the wrong impression that one out of nine women have breast cancer. This is not true. The statement actually means that if we followed a group of 1000 Canadian girl babies all through their lives, you would find that 111 of them (or one in nine) would be diagnosed with breast cancer *at some point during their lifetime.*

### **Media Controversies**

It is natural that you and your family will look for information about medical breakthroughs. And you will hear about new developments in the treatment of breast cancer. However, you will need to use your judgement about the facts you read. The media often play a "watch dog" role and will report on studies that may go against established methods of treatment and practice. Always question what you read in the media, and especially on the Web.

The following points are useful to keep in mind when judging news stories:

1. A large number of promising new treatments are announced each year; however they are usually based on testing that has been done on animals. From thousands of drugs that are investigated, only a very small number will be successful enough to be approved for use in humans.
2. Who is funding the research? Often, studies paid for by pharmaceutical or medical equipment companies will report results that are favourable to their product.
3. New valid cancer discoveries are rarely announced first in the press. Significant advances are based upon studies in humans that have been published in medical journals and are discussed at major medical meetings.

### **The Research Process**

In Canada we are fortunate to have one of the top cancer research systems in the world. Our search for better cancer treatments begins with basic research in the laboratory that sometimes involves animal studies or live human cells in test tubes. This laboratory work identifies the new methods most likely to work and will test the safety and effectiveness of these new methods before they are tried on humans in clinical trials.

Research studies that go beyond the laboratory and begin to test the benefits of treatments in people are called clinical trials. These trials test new treatments for people with cancer or who are at risk for cancer. Their goal is to test methods that may prevent the development of cancer in high-risk people, to find better ways to treat the disease and to improve the quality of life for cancer patients. Clinical trials are the most important way of testing new methods for the better treatment and management of cancer.

During a clinical trial, much more information is gathered about how a treatment affects patients, whether there are side effects or risks, how safe the new treatment is and whether the new treatment is better than the standard one. 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.

Today, more funds than ever are being devoted to breast cancer research in Canada and as a result, The National Cancer Institute of Canada has established the Canadian Breast Cancer Research Initiative. Its objective is to fund a broad range of cancer research in Canada on prevention, early detection, diagnosis, treatment, supportive care and palliation for individuals affected by breast cancer. This research includes fundamental laboratory investigations, clinical trials, health care research and epidemiological, psychosocial and behavioural studies. The ultimate goal is the prevention, cure and eradication of breast cancer.



## Complementary Therapies

*When my treatment was finished I did a lot of reading about non-traditional ways to help fight breast cancer. I changed my diet and learned how to meditate. I'm not sure if it's really making a difference, but I know it makes me feel more in control. At least I'm doing something.*

During your breast cancer treatment you may have already thought about and may have even tried complementary therapies. Now that you have completed treatment, you may feel that you want to do more to help prevent a recurrence. Many women turn to complementary therapies that are usually not provided by medical doctors.

Examples of complementary therapies that may help you include:

- ✓ herbal preparations
- ✓ therapeutic touch
- ✓ reflexology
- ✓ homeopathy
- ✓ acupuncture
- ✓ traditional Chinese medicine
- ✓ Qi Gong
- ✓ T'ai Chi
- ✓ Yoga
- ✓ Massage and reflexology
- ✓ Reiki
- ✓ art therapy
- ✓ hypnosis
- ✓ meditation
- ✓ music therapy
- ✓ psychotherapy/counselling



### **Should You Try Complementary Therapies?**

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

Unfortunately, there is not much information known about the effectiveness of many complementary therapies. There are many reports of toxic substances contaminating them, 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 call them by different names.

Always treat herbal preparations as though they are drugs and watch for reactions and side effects. We really don't know if these methods work because not enough research has been done to test how safe they are or even whether

they have any effect. Although many doctors feel that these therapies do not provide any benefit, they will not object if their patients try them as long as there is no evidence that they do any harm. However, not enough research has been done to be sure that no harm really is being caused. For example, although research has suggested that vitamin A may reduce the chance that a cancer cell will form, two large studies showed that vitamin A supplements increased the risk of lung cancer in smokers.

The Government of Canada is in the process of developing regulations for complementary therapies, but until these are in place, it is very important that you check with your oncologist or family doctor before you decide to use any form of treatment. You will need to ask:

- Is it safe for me?
- Do the benefits outweigh the possible harms?
- Can I use it along with any other treatment I'm receiving?
- Am I comfortable with the principles on which it is based?
- What are the possible side effects?
- Will it interact with food, alcohol, or other drugs?

#### **Personal considerations:**

- Am I willing to spend the time and money for the therapy I have chosen?
- Do I have confidence in the provider of the therapy?
- How long should I take the therapy, and how will I know if it is working?

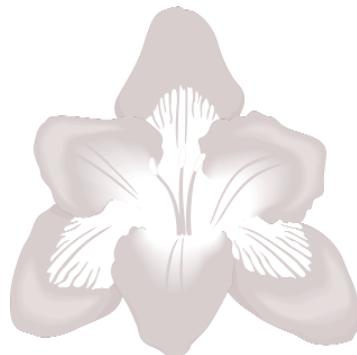
Before starting one of these therapies, find an expert in that form of therapy and arrange to speak with them and ask him/her to supervise your progress. You should also advise your doctor of your plans.

**Note:** Always check the ingredients of any medicine or herbal preparation with your doctor because some may contain estrogen. Inform your doctor right away if you notice any unexpected side effects or interactions with other medicines.

#### **Tell your doctor right away if you notice:**

- Unusual changes in body functions.
- Possible allergic reactions (swelling, hives, shortness of breath).

For more information on complementary therapies, please call the Canadian Cancer Society's Cancer Information Service or Willow Breast Cancer Support and Resource Services. (See Appendix 1: Resources for Breast Cancer Survivors.)



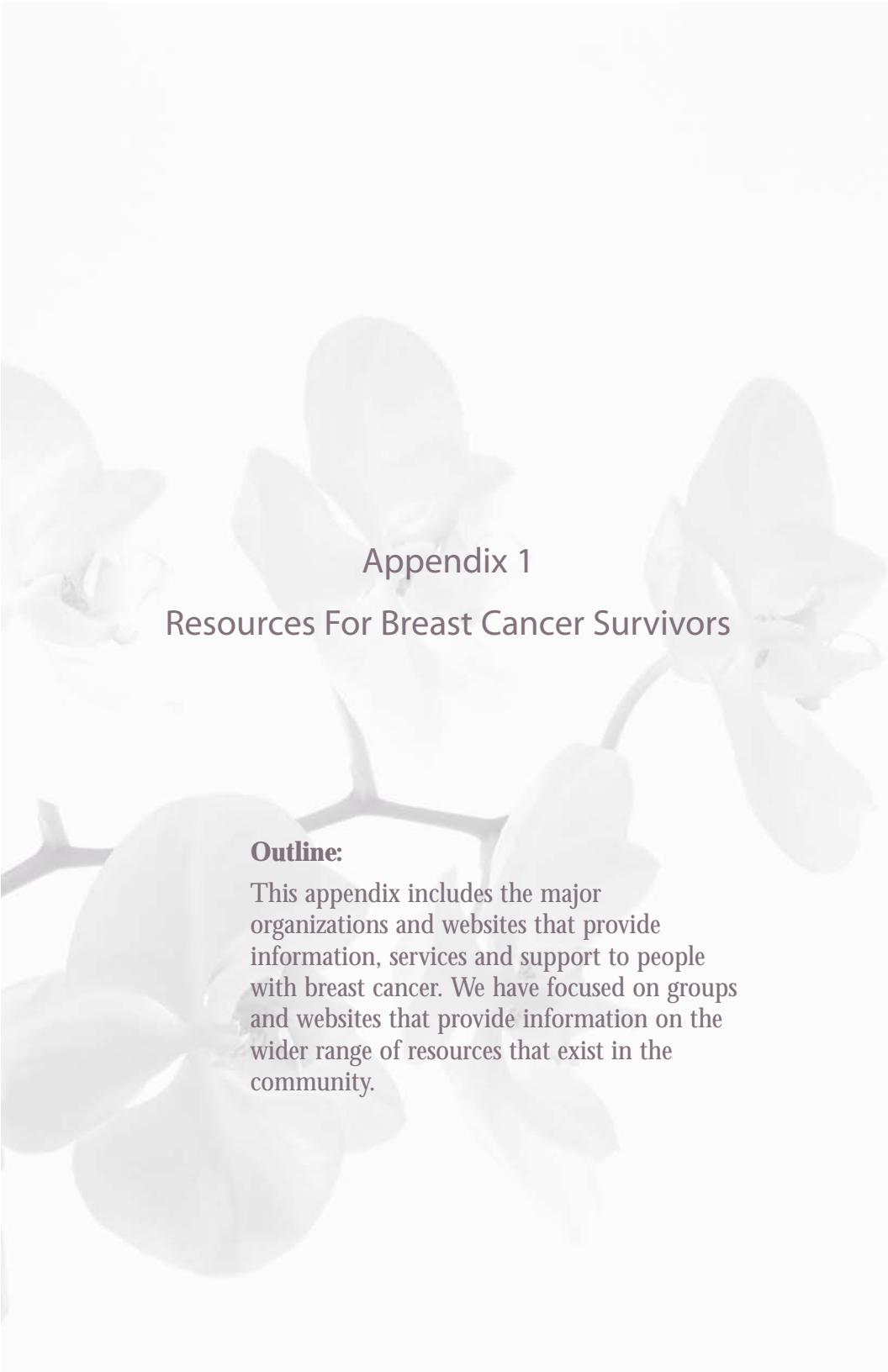
## Conclusion

### Moving Forward

Thousands of women in Canada are living with a history of breast cancer. With time, you will find that the crisis of your cancer experience will pass and it will become a part of your life. The impact of cancer can shatter old roles and senses of identity and force you to look at your life differently. You've been through a tough period, but now is the time for healing and restoring your health. Remember, you are not alone. This booklet will be a reference that you can refer to as needed to help guide you towards the right sources of information and advice. Never be afraid to 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 1

# Resources For Breast Cancer Survivors

### **Outline:**

This appendix includes the major organizations and websites that provide information, services and support to people with breast cancer. We have focused on groups and websites that provide information on the wider range of resources that exist in the community.

## Appendix

**Disclaimer:** The views expressed by these resources reflect the opinions of their providers and authors and not necessarily those of your physician or health care team.

**Note:**

1. This listing is current as of the date of the printing of this booklet.
2. Organizations, agencies and websites that provide services and information in languages other than English and with a specific cultural focus are identified with the following icon:

Organizations that Provide Information, Services and Support to Breast Cancer Survivors

**The Breast Cancer Society of Canada**

National Office  
401 St. Clair Street  
Point Edward, Ontario N7V 1P2

Toll Free: 1.800.567.8767

**Breast Cancer Support for Immigrant Women – Toronto (OISE)**

Phone: 416.515.8423

**Canadian Breast Cancer Foundation**

National Office  
790 Bay Street, Suite 1000  
Toronto, Ontario M5G 1N8

Tel: 416.596.6773 Toll-free 1.800.387.9816

**Canadian Breast Cancer Network**

Suite 602, 331 Cooper Street  
Ottawa, Ontario K2P 0G5  
Tel: 613.230.3044 Toll Free: 1.800.685.8820

**Canadian Breast Cancer Research Initiative**

10 Alcorn Avenue, Suite 200

Toronto Ontario M4V 3B1

Tel: 416.961.9406

**Canadian Cancer Society**

National Office

10 Alcorn Avenue, Suite 200

Toronto, Ontario M4V 3B1

Tel: 416.961.7223

**Canadian Naturopathic Association**

1255 Sheppard Ave. East

North York, Ontario M2K 1E2

Tel: 416.496.8633

**Cancer Care Ontario**

620 University Avenue

Toronto, Ontario M5G 2L7

Tel: 416.971.9800

**Chinese Medicine and Acupuncture Academy of Toronto**

Tel: 416.695.2131

**Chinese Medicine and Acupuncture Association of Canada**

154 Wellington Street

London, Ontario N6B 2K8

Tel: 519.642.1970

**Dragonboat Team – Dragons Abreast – Toronto**

Jane Campbell at 416.486.8291

**Gilda's Club of Greater Toronto**

110 Lombard Street

Toronto, Ontario M5C 1M3

Tel: 416.214.9898

**Healing Journey Program**

Ontario Cancer Institute/The Princess Margaret Hospital/

University Health Network

Room #10 – 502B, 610 University Avenue

Toronto, Ontario M5G 2M9

Tel: 416.946.2062

**Interlink Community Cancer Nurses**

620 University Avenue Suite 701

Toronto, Ontario M5G 2C1

Tel: 416.599.5465

**International Academy of Homeopathy**

Toronto, Ontario

Tel: 416.481.8816

**Ismaili Women Cancer Support Network**

Tel: 416.491.9320 (Shamira)

**Lymphovenus Canada**

8 Silver Avenue

Toronto, Ontario M6R 1X8

**Ontario Breast Cancer Information Exchange**

2075 Bayview Avenue

Toronto, Ontario M4N 3M5

Tel: 416.480.5899

**Wellspring**

Toronto Office

81 Wellesley St. E.

Toronto, Ontario M4Y 1H6

Tel: 416.961.1928

**Willow Breast Cancer Support and Resource Services**

785 Queen Street East

Toronto, Ontario M4M 1H5

Tel: 416.778.5000

**Useful Websites for Breast Cancer Survivors**

**Note:** This is a partial list of Canadian breast cancer resources found on the World Wide Web. These websites provide a range of services including chat rooms, links to community support organizations and specific medical information. As you visit them, they will lead you to many other websites around the world. You will need to use your common sense and evaluate the health information that you find on the web. As you read information you should keep the following points in mind:

**Content:** Does the information appear to be correct and up to date? Is it balanced and unbiased and appropriate for the intended audience? Is the source of the information referenced? Are copyright statements included?

**Credibility:** Is the sponsoring organization clearly identified? Do they include their e-mail address or contact information? Is the site's revision date posted and recent? Is the organization non-profit and is any commercial sponsorship clearly disclosed?

**Important Note:** Never take anything you read anywhere as a recommendation for a personal treatment plan for you. Web-based information should never override your doctor's advice. Speak to your health care team before taking any product, changing your lifestyle or beginning or discontinuing any course of treatment. If you suspect that you are ill or may have a medical emergency, contact a doctor, a health professional or call 911 immediately.

**A Word About Chat Rooms:** Web-based message boards, email, chat services, and other interactive features offer opportunities for breast cancer survivors to share knowledge, experiences, and other helpful information. Since most "conversations" are public, the experience is best when people follow certain guidelines. Remember that your expression, and voice tone are invisible to members, so it's helpful to understand basic online etiquette.

**Be succinct:** Stay on topic and collect your thoughts before communicating them publicly in writing.

**Respect the opinions of others:** Part of what makes a good web community is the ability to see different points of view. Sometimes you may have to agree to disagree.

**SPAM:** Don't "spam" the boards with multiple postings. Inappropriate messages, like advertising unproven "miracle cures" or products for sale will be removed.

**Respect others:** This is really the bottom line. "Do unto others as you would have them do unto you." This includes not using profanity or engaging in conduct that would be deemed inappropriate in face-to-face situations.

**Contact the moderator:** If you have questions or concerns about the web community guidelines, you can contact the moderator.

## Canadian Sites

**Note:** This list is based on the current list provided on the Willow website <http://www.willow.org> and the Ontario Breast Cancer Information Exchange website <http://www.tsrcc.on.ca/obciep>.

Bayview Support Network <http://www.tsrcc.on.ca>

Located at the Toronto-Sunnybrook Regional Cancer Centre, the Bayview Support Network is a self-help group created by cancer patients and survivors to ensure that cancer patients and their families do not have to face their illness alone. Their website offers information about the programs and support groups they offer, highlights from their newsletter, and personal stories from cancer survivors.

Breast Cancer Action <http://www.bcaott.ca>

Located in Ottawa, Breast Cancer Action is a survivor-directed group dedicated to developing programs to educate, counsel, and support women and men living with breast cancer, their families, and the community-at-large. Their website provides information about ongoing programs and special events and a list of suggested readings.

Breast Cancer Action Kingston [www.brcanactionkingston.com](http://www.brcanactionkingston.com)

Breast Cancer Action Kingston is a survivor-led, independent, charitable organization, working to educate and support women and men living with breast cancer, their families, and the community. Their website provides information about the group's programs and services. It also has a listing of the resources they have available in their resource centre, and highlights from their newsletter.

Breast Cancer Centre of Hope [www.cancercare.mb.ca/Hope/default.htm](http://www.cancercare.mb.ca/Hope/default.htm)

Provided by Cancer Care Manitoba, this website includes information on resources for patients and families, prevention and screening, calendar of events, statistics and research information.

### Breast Cancer Society of Canada

[www.bcsc.ca](http://www.bcsc.ca)

The Breast Cancer Society of Canada's mandate is to fund breast cancer research on the prevention, detection, and treatment of breast cancer. Their website offers a history of the organization, a description of the research they fund and a listing of upcoming events.

### Canadian Breast Cancer Foundation

[www.cbcf.org](http://www.cbcf.org)

The Canadian Breast Cancer Foundation is a charitable foundation dedicated exclusively to the support and advancement of breast cancer research, education, diagnosis, and treatment. Their website provides information about the organization, a listing of the research and education grants they have awarded, newsletter highlights, and text from the booklet, *Mammograms: What Every Woman Should Know*.

### Canadian Breast Cancer Network

[www.cbcn.ca](http://www.cbcn.ca)

The Canadian Breast Cancer Network is a survivor-directed, national network of organizations and individuals joined to ensure an independent voice for Canadians affected by breast cancer. Their website provides background information about the organization, highlights from their newsletter, and their position statements on current issues related to breast cancer, including environmental chemicals, genetic testing, and induced abortion.

### Canadian Breast Cancer Research Initiative

[www.breast.cancer.ca](http://www.breast.cancer.ca)

The Canadian Breast Cancer Research Initiative funds a broad range of breast cancer research in Canada. Research announcements, details about the grants they have awarded, and breast cancer statistics are posted on their website. Also included are summaries of the information packages they produced on six complementary therapies: 714-X, essiac, green tea, hydrazine sulfate, iscador, and vitamins A, C, and E.

## **Canadian Cancer Society**

[www.cancer.ca](http://www.cancer.ca)

The Canadian Cancer Society is a national, community-based organization whose mission is to eradicate cancer and enhance the quality of life of people living with cancer. Their mission is supported through research, education, patient services, and advocacy for healthy public policy. This website provides a description of the services they offer across Canada, information about the research funded by the National Cancer Institute of Canada, and a listing of upcoming events. Direct links are available to their provincial offices' websites.

### **Canadian Women's Health Network**

[www.cwhn.ca](http://www.cwhn.ca)

The goal of Canadian Women's Health Network is to improve women's health and health services. Their site includes information about the organization, newsletter articles, and a comprehensive listing of Internet resources related to women's health.

### **Canadian Health Network**

[www.canadian-health-network.ca](http://www.canadian-health-network.ca)

The Canadian Health Network (CHN) is a national, bilingual Internet-based health information service funded by Health Canada. Their website provides excellent resources from health information providers across Canada and features 26 Health Centres focused on major health topics including breast cancer. To date, there are links to more than 10,000 Internet-based resources on the CHN site.

## **Canadian Naturopathic Association (CNA)** <http://www.naturopathicassoc.ca>

The Canadian Naturopathic Association is a not-for-profit professional association representing the interests of naturopathic doctors and promoting naturopathic medicine throughout Canada. Their website includes information about naturopathic doctors, suppliers of natural remedies for professional use, and the provincial naturopathic associations.

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 with links to the sites of the cancer treatment centres across Ontario.

Clinical Practice Guidelines from CMA

[www.cma.ca/cmaj/vol-158/issue-3/breastcpq/index.htm](http://www.cma.ca/cmaj/vol-158/issue-3/breastcpq/index.htm)

A peer-reviewed Canadian consensus document with detailed guidelines on many aspects of breast cancer treatment. Published in 1998 as a special supplement to the Canadian Medical Association Journal. (Available in English and French.)

Federation Nationale des Cancer de Lutte Contre le Cancer (FNCLCC)

[www.fnclcc.fr/](http://www.fnclcc.fr/)

This site is run by the French organization FNCLCC. It offers scientific professional and consumer information through well over 100 French language documents about breast cancer.

Fondation Québécoise du Cancer

[www.fqc.qc.ca](http://www.fqc.qc.ca)

The Fondation Québécoise du Cancer is a non profit organization dedicated to cancer control in Quebec. This French language site provides background information about the Foundation and links to the French language sites related to cancer and its treatment centres in Quebec.

The mission of Gilda's Club (founded in memory of comedienne Gilda Radner) is to provide a meeting place where men, women and children living with cancer and their families and friends can join with others to build emotional and social support. The Gilda's Club website provides information about the Club and its resources.

### Inflammatory Breast Cancer

[www.bestiary.com/IBC/](http://www.bestiary.com/IBC/)

This site was written by Pete Bevin and Menya Wolfe and is run privately by Mr. Bevin. It contains information about inflammatory breast cancer, recommends books and tells patient stories.

### Interlink Community Cancer Nurses

[www.interlinknurses.on.ca](http://www.interlinknurses.on.ca)

Interlink Community Cancer Nurses is a non-profit community-based agency in Toronto which enables adults and children with cancer and their families to access the care and support which they require at all stages of their illness. It also acts as a specialized resource to health care professionals in meeting clients' needs. Their website provides information about Interlink, their mandate, mission and beliefs that inform their nursing practice.

### International Academy of Homeopathy

[www.homeopathy.edu](http://www.homeopathy.edu)

This website provides detailed information for professionals who wish to be trained in homeopathy. It also provides a schedule of monthly lectures in Toronto.

### Look Good, Feel Better Program

[www.lgfb.ca](http://www.lgfb.ca)

To assist women to cope with the side effects of cancer treatment, The Look Good, Feel Better Program offers free workshops and literature on skin care, make-up, hair loss, and nail care. Their website includes information about the services and resources they provide. A Canada-wide listing of workshop locations is also provided.

### Lymphovenous Canada

[www.lymphovenous-canada.ca](http://www.lymphovenous-canada.ca)

Lymphedema can occur as a result of breast cancer surgery or radiation, particularly when lymph nodes are removed. The purpose of this site is to link people in Canada (not just breast cancer survivors) with health care professionals and support groups in their communities and around the world. Information posted is about the latest developments in research and treatment in this area.

## Ontario Breast Cancer Information Exchange (OBCIEP)

[www.tsrcc.on.ca/obciep/default.htm](http://www.tsrcc.on.ca/obciep/default.htm)

The Ontario Breast Cancer Information Exchange Partnership (OBCIEP) is a coalition of organizations committed to ensuring that information about breast cancer is available to all people in Ontario. Their website includes comprehensive breast cancer information, a bulletin board and links to other Canadian and American websites about breast cancer.

- Quebec Breast Health Network (QBHN)/ Réseau Québécois pour la Santé du Sein (RQSS)

[www.simbolique.ca/rqss](http://www.simbolique.ca/rqss)

The Quebec Breast Health Network is a charitable foundation dedicated exclusively to the support and advancement of breast cancer research, education, diagnosis, and treatment. Their French language website provides information about their organization as well as resources about breast cancer.

- Réseau d'Échange d'Information du Québec sur le Cancer du Sein (REIQCS)

[www.reiqcs.org](http://www.reiqcs.org)

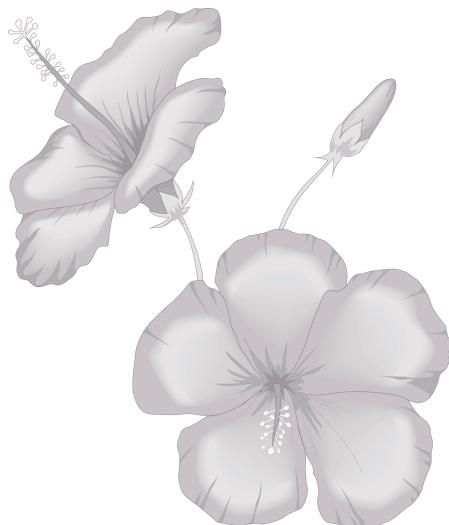
Réseau d'Échange d'Information du Québec sur le Cancer du Sein is a sister organization of the OBCIEP and is mandated to respond to the informational needs of the people in Quebec. One of the few websites available in French, it provides a description of the REIQCS and services and resources they provide. Full text of their journals and bulletins is also provided.

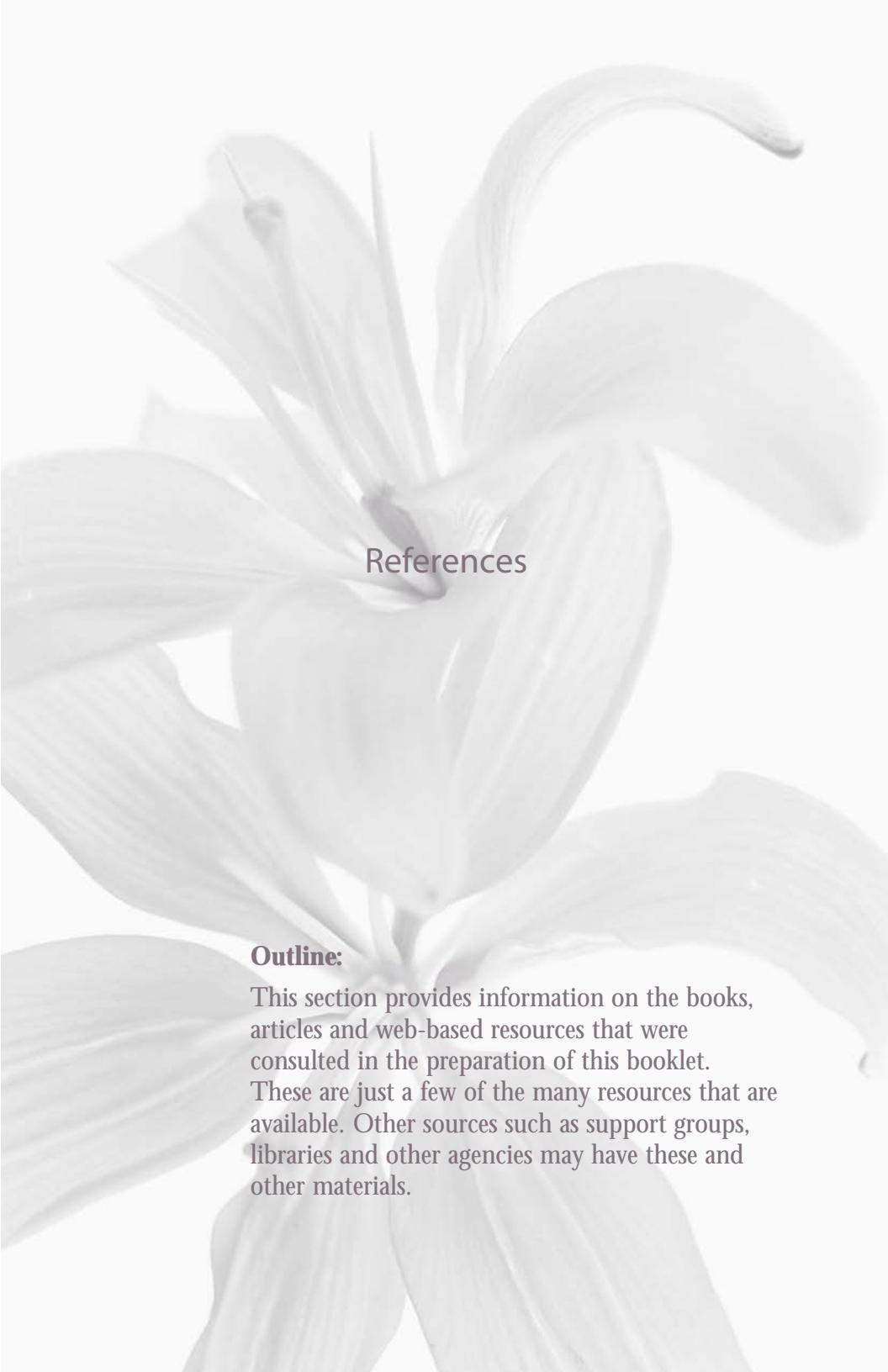
## Wellspring

[www.wellspring.ca](http://www.wellspring.ca)

Wellspring is a support centre for people and their families living with cancer with locations in Toronto, London and Oakville. Their website provides background information about the organization including the services, programs, and support groups they offer.

Willow's toll-free line enables them to provide support and information, by breast cancer survivors, to anyone with concerns about breast cancer, anywhere in Canada, free of charge. Willow's website provides background information about the organization, a comprehensive listing of Ontario support groups and other Canadian breast cancer agencies, as well as publications such as *Coping With Your Financial Concerns When You Have Breast Cancer* and newsletters.





## References

### **Outline:**

This section provides information on the books, articles and web-based resources that were consulted in the preparation of this booklet. These are just a few of the many resources that are available. Other sources such as support groups, libraries and other agencies may have these and other materials.

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