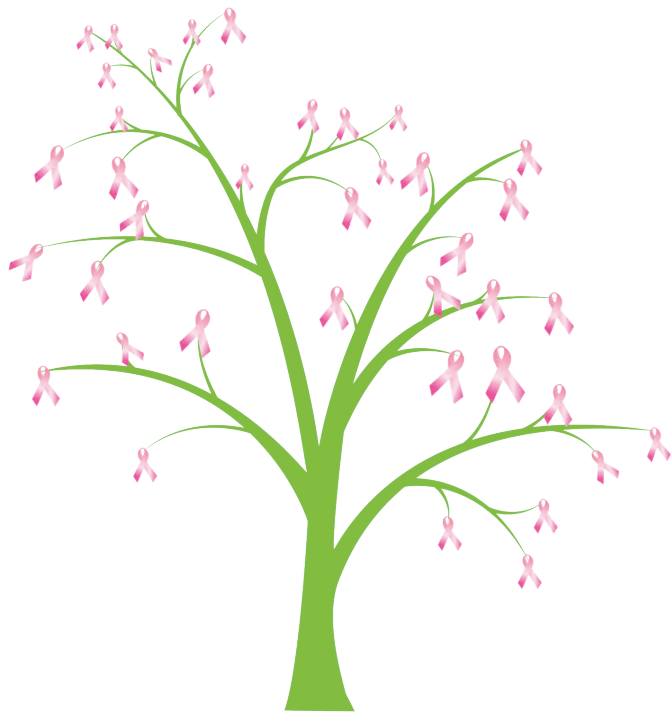


# Your Journey

a guide for women diagnosed with  
breast cancer



# Dedication

This comprehensive resource and video have been developed by the Lymphedema Working Group convened in November 2012 to develop enhanced education materials and information for breast cancer patients including diagnosis, treatment and adjustment to post-treatment life. The Lymphedema Working group hopes that this resource provides you with the information and support you need as you make your way through your unique breast cancer journey.



# Special Thanks

The Lymphedema Working Group consisted of representatives from the Ministry of Health; Regional Health Authorities (RHAs) and agencies that provide lymphedema services, supports, education and prevention; and patients who had recently engaged in the system to receive lymphedema treatment in the province. The Working Group would like to thank other breast cancer survivors in the province for thoughtfully contributing to the development of this resource.





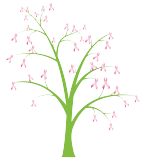
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# Introduction

***Courage is like love; it must have hope for nourishment.***  
***Napoleon Bonaparte***

It is very likely that you never imagined sitting across from your physician and hearing the words, “You have breast cancer.” But in Canada, an estimated one in nine women will have a similar experience at some time in her life. It is important for you to know that you are not alone. Women, just like you, contributed to the development of this resource binder and video. Their strength, wisdom and spirit are accompanying you on this journey.

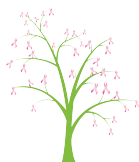
Upon hearing your diagnosis you probably felt an endless array of emotions - from fear, anger and sadness to hopefulness, determination and everything in between - but most certainly you felt overwhelmed. Many women in your position want to know everything about this disease and what lies ahead; the information available is plentiful. In preparing these resources we asked women who had already been through this journey about the information gaps that they experienced. The purpose of this binder is to fill these gaps and bring as much information as possible together in a comprehensive resource covering diagnosis and treatment, as well as the adjustment to your post-treatment life. In addition, there will be places for you to make your own notes, record questions to ask your health care team and store additional documents like lab results and your own research. But you do not have to read this binder from start to finish. Rather, you can refer to specific sections as they relate to you or when you need them.

“...without a moment's hesitation she tells me I have breast cancer. Time stands still for that moment. I sat in my vehicle and cried...no, I sobbed...it was beyond crying.”

“At that point my brain shut down, she talked, I didn't quite hear, in my head I thought, whoa, everything was distorted, slow down.”

The video has two purposes: to connect you with the experience of other women who were once in your shoes; and to demonstrate certain exercises and techniques that are important to your recovery. As a resource developed for Saskatchewan women, it will include information on how to find supportive services across the province. The intent is that every woman in Saskatchewan that is diagnosed with breast cancer receives this binder at the earliest possible entry point to services and that it provides these women with information, support and hope.

If you need help with understanding any of the information in this resource binder, please contact any of the support groups listed on page 118 or contact HealthLine at 811.



# Your Unique Journey

***In the midst of movement and chaos, keep stillness inside of you.***

**Deepak Chopra**

No two people are alike and no two women with breast cancer are totally alike. The course that you take through the diagnostic tests, treatment and recovery will be totally unique to you. While it would be nice if the diagnostic course were as simple as detecting a lump or suspicious findings on a mammogram and moving to biopsy and confirmation, your own path might be much more convoluted than this. Even given a positive mammogram, you could be faced with inconclusive biopsy results, MRIs, repeat biopsies and more, each with a wait time for results when time seems to be of the essence.

In terms of treatment, the classic, 'surgery, chemotherapy then radiation' course simply does not apply to every woman. Some go through complete courses of chemotherapy before surgery. Others need no radiation at all. For some, a lumpectomy or other breast conserving surgery followed by radiation is the perfect choice and may be perceived as an easier course of treatment. The implications of radiation need to be carefully considered however, as this can amount to an equally difficult road. The removal of lymph nodes is a procedure normally done at the time of surgery. However, removal of a large number of axillary (underarm) lymph nodes or the use of sentinel lymph node biopsy to potentially minimize the number of lymph nodes removed are variations that may also exist. Not every woman is suitable for sentinel node biopsy. Complicating all of this will be decisions about reconstruction at the time of surgery, shortly after, delayed until after all other treatments are done, or not at all.

"Only by talking to other women did I realize that there is no real 'standard' way of going through all this, which was comforting, being that I could not find my 'path' in the literature."

Many women have reported that their journey has been difficult, confusing and challenging as they moved through a complex health system sometimes described as a maze. Additionally they have reported that they need to be patient - patient with the system, patient with health care providers and patient with themselves - but not complacent. Taking hold of any portion of this journey, with gusto, will improve your mental and physical well being. At the same time,

there is great wisdom in knowing to expect the unexpected, being able to embrace uncertainty, and to find some peace, therein. To quote Chopra, again, *“Relinquish your attachment to the known, step into the unknown, and you will step into the field of all possibilities.”*

## Being Your Own Advocate

It is overwhelming, to say the least, but you need to first come to understand your particular breast cancer as thoroughly as possible and then consider all the options as you lead your care team through decisions on your treatment. Being your own advocate is a delicate blend of becoming as informed as possible, listening to your instincts and asserting yourself, when necessary.

### Tracking Your Journey

One way you can begin this process is by keeping track of your journey – write down every step, every appointment, test and piece of information your doctors give you – ask questions and keep asking questions until you understand. You can use this binder for this purpose (see sample tracking sheets), use multi-colored file folders, an on-line app or calendar or electronic files (scanning results and saving them on a data stick) or develop your own method. However you do it, take all this with you to every appointment. Examples of headings you can use for your own files are:

- Notes, Questions and Miscellaneous
- Chemo and Side Effects
- Blood Work (some women track their blood work so that they can determine when their immune system is the most compromised)
- Pathology Report (you will refer to this often)
- Operations and Tests
- Alternative or Complementary Treatments
- Support
- Food Journal

“It is important to have a tracking system set up asap because once you get into the side effects you don’t have the energy or stamina to get organized.”

The most important time to start writing things down and asking questions is at that very first appointment (or phone call from your doctor) when breast cancer is either strongly suspected or confirmed. If you were too overwhelmed at the time to ask questions, call back or schedule an appointment to go over the details. At each stage there are key questions to be asking (examples appear later in this



binder). You may need to sign a release form in order to have copies of your test results available to you. If you want your spouse or partner to have access to these reports, should you be unable to request them, you will have to sign a release so he/she can have access to these reports. Ask at your cancer treatment center about their policy.

## Understanding Your Cancer

Becoming knowledgeable about breast cancer is essential and helps you to know what questions to ask. Knowledge and information about breast cancer is constantly changing and advancing and therefore health care providers may have varying levels of expertise and opinion regarding your diagnosis, treatment and situation.

Becoming your own breast cancer expert will help you to sift through any conflicting information you receive and help you facilitate a connection among members of your health care team. “Your health care team” is referred to frequently in this binder but in reality, you will rarely, if ever, meet with all team members at the same time. Get to know the services provided by each team member so you can ask for the services you feel you need when you need them. It is much easier to reach out to them in the future, if you know how they can help. Please see page 25 for a list of health care providers that may be included on your health care team.

“My attitude went from, ‘poor me’ to ‘researcher’ quite quickly. Cancer could not and would not ever be an excuse for making a poor choice. Knowledge is power.”

Take your own research with you to every appointment. In doing your research, it is likely best to avoid blogs that are not associated with a credible resource. A number of reliable resources will be listed at the end of this binder.

Breastcancer.org provides access to a phone app that includes a glossary of terms, medical illustrations, helpful explanations and personalized research articles relating to a specific diagnosis. This app can walk you through your pathology reports and other diagnostic tests, which can be useful information when you and your doctor are deciding on the treatment that is right for you. This app can be found at:

<http://www.breastcancer.org/symptoms/iphone-app-breast-cancer-diagnosis-guide>

The Canadian Cancer Society has a national toll-free Cancer Information Service that can be accessed at: **1-888-939-3333 (TTY 1-886-786-3934)**, Monday to Friday from 9 AM to 6 PM (EST). You can also email your questions to: [info@cis.cancer.ca](mailto:info@cis.cancer.ca) or visit the Support/Services section of their web site: [www.cancer.ca](http://www.cancer.ca).

## Support

Other women with breast cancer can be a tremendous source of information and support. Don't be afraid to call someone you know who has been down this

road; in most cases they will be more than happy to help you navigate past obstacles they encountered. They will be your best source of information on all those 'deviations from normal expectations' you may encounter. Local breast cancer support groups can also help you to connect with women in your community. These will be listed at the end of this binder. Additionally, call HealthLine at **811** or go to [www.healthlineonline.ca](http://www.healthlineonline.ca) to connect to supports.

The Canadian Cancer Society can also connect you with peer support. These volunteers are screened and trained to provide you with emotional support, to listen and to use their own experiences to provide you with practical information. Call the toll-free number on page 11. They are usually able to match you with a volunteer within 48 hours.

Being your own advocate does not mean that you have to go it alone. When your doctor is talking about your breast cancer and treatment it is hard to take in all the information. Having a friend, partner, spouse or other support person with you at appointments will give you an additional set of ears and someone to talk with about your decisions ahead. You do not have to choose someone from your family or someone with a medical background but the person you choose has to be someone with whom you feel comfortable and trust. You may opt to have someone with you for your treatments or you may prefer to be alone because that is what makes you comfortable. Whatever helps you get through treatments is the way to go. This is a time in your life in which you come first. You may learn that the family member or friend you least suspected is the person that helps you the most.

Being on the receiving end of help and support may be a very new role for you but one that is worthwhile exploring. There are some practical, day-to-day things that a support person can do for you while you give your full attention and energy to your treatment and getting your rest. Some of these may include getting groceries or prescriptions, doing household chores, preparing meals, looking after children, driving to appointments or being the designated person to organize a schedule of the offers of support that you receive. Many will be grateful for having something to do for you. You and your loved ones will need to be open and accepting of these changes and you will need to give yourselves a bit of time to adjust to your new roles.

"I am really struggling asking for help – I am so used to being independent...yet I need to let go of the idea that I can do everything myself. Wow, there are so many wonderful people around me now...so much love....so much caring."

## Upholding Your Rights

*You have the right to have all the information you need to make the best choices for you. Find out how long it will take for tests/procedures/appointments to be booked and how long it will take for you to receive the results.*

There may be times when you do not feel confident with the accuracy or completeness of your diagnosis or comfortable with the treatment recommendations your doctors are giving you and you want a second opinion. It is your right to ask for a second opinion, whether after diagnosis or before any part of your treatment starts. It is also your right to ask for a different oncologist if you feel that differences of opinion or difficulties with your relationship are a detriment to your progress. This is sometimes an uncomfortable thing to do but it can be very helpful in the long run. If the second opinion supports your original diagnosis or treatment plan, you will be able to proceed with more confidence. If the second opinion differs, then this signals a time for more discussion and information gathering. Family, friends, or the health region's Quality of Care Coordinator/Client Representative can help you with this process if you need support.

If you have a concern that has not been adequately addressed by your health care providers, you can contact your regional quality of Care Coordinator/Client Representative. Each health region has a quality of care coordinator/client representative who can answer questions or concerns about access to quality health services, ensure you are aware of your rights and options, and collect feedback to recommend changes and improvements to enhance the quality of health services.

While you do not want to unnecessarily delay beginning treatment, making sure you are making the right decision for you is imperative, whether the issue is diagnosis, surgery options, adjuvant treatments like chemotherapy, radiation or hormone therapy or questions about the timing of reconstruction.

## Telling Family and Friends

One of the first decisions you will need to make is how to share your diagnosis with family and friends. There is no one right way, so take some time to think about what will work for you. You might feel some pressure to share your diagnosis, but it is important that you wait until you are ready. Be as clear as possible about your feelings, the reasons for telling others and

"We knew that social media is a place where we could all participate in writing, informing and updating progress to all our family and friends. We decided to keep this as factual, honest and open as we felt comfortable with."

what you expect from them. Most of all, you need to be prepared for a wide range of reactions. Not everyone is comfortable talking about cancer and some people may begin to act differently around you; some awkward or distant and others overly helpful. Just remember that this is new to them as well. With time, you and your loved ones should become more comfortable talking about all aspects of your condition and treatment.

Some women choose to share their news with their immediate family only. Others feel the need for close friends or workmates to be informed. You do not have to disclose your news to everyone at the same time, right away or in the same manner. Bringing your whole support system together to tell them as a group is one way to do this. Others find it more comfortable allowing key people to act as a relay system for getting the word out more gradually. Multiple phone calls can be emotionally draining when you have a large family so sending a carefully worded group email can be very effective. Using a web-based blog is one energy-saving way to keep friends and family up to speed on your progress. Regardless of how you go about it, your own honesty and openness could lead to sources of support that you had not imagined.

You need to set the tone for your journey ahead by being clear about your hopes and desires and what you will need from others. Some women shut down completely for a while. Others will choose to be strong. Over time, you will find a balance between these extremes and between autonomy and accepting support. You can let them know if you have fears about becoming a burden, but you may need to request their support from time to time. Keep the lines of communication open.

### **Talking to Your Children**

It may be difficult to talk to your children about your cancer diagnosis but the literature tells us that children can be amazingly resilient and cope well with a parent's illness. How much you tell them will depend on their age and maturity level. The calmer you are, the less frightened they are likely to be. This is not to say that you have to hide your emotions. Allow them to ask questions. Your honesty will give them permission to be open with you about their fears and concerns.

"We let our kids know that it's okay to talk about it with a friend, that this wasn't a secret. We felt it was important for them to reach out to their friends, too."

It's important that your children hear this news from you, as soon as possible after your diagnosis, and that they do not overhear you talking about it. Be clear about the fact that you have breast cancer and what lies ahead in terms of tests

and treatments. It might be helpful to let them know some ways that they can be helpful to you. It may be wise to contact their teachers or close friends' parents, as well, to open lines of communication about how they are coping away from home.

More information about talking to family and friends about your diagnosis can be found at:

**<http://www.cancer.org/treatment/understandingyourdiagnosis/talkingaboutcancer/talking-with-friends-and-relatives-about-your-cancer>**

## Questions to Ask at Diagnosis

What type of breast cancer do I have? What other tests need to be done to confirm or define my cancer? When is an MRI ordered and why?	
How do I get a copy of my pathology report? Who can explain this report to me? Do I need another appointment to do this?	
What is my cancer's stage? What does that mean? How does this affect my treatment options, long-term prognosis and chances of survival?	
Has the cancer spread to my lymph nodes or other organs? What does this mean? How does this impact my chances of survival?	
What are my treatment choices? What do you recommend and why?	
What is your position on incorporating alternative or complementary treatments?	
What is the goal of my treatment?	
How much experience do you have treating this kind of cancer?	
Do I need to decide on my treatment right away or can I think about it and get more information?	
This is such a big decision. How do I get a second opinion?	
What chance is there that my breast cancer will come back after treatment?	
How can I get in touch with other women who have had breast cancer? Are there support groups?	
Where can I get more information?	
Should I be using birth control? What type? What happens if I get pregnant	

during treatment?	
Is it possible to carry a pregnancy to term and have a healthy baby after I have been treated for breast cancer?	
If my fertility is affected by treatment, what are my options?	
Should I think about genetic testing?	
Are there any clinical trials you think are suitable for me and why?	

**Taken in part from:** *Questions to Ask about Breast Cancer: A workbook for women*. Canadian Cancer Society, 2006

**More questions available at:** The American Cancer Society, [www.cancer.org](http://www.cancer.org)

## Sample Tracking Sheet

It is important to remember that this tracking sheet does not necessarily represent the order through which you will proceed. Some of the categories will not apply to you. You may want to rearrange this sheet or add your own categories.

Dates of mammograms, dates results received	
Findings and implications	
Plans for being away from work, forms to complete, dates these are done & submitted, child care arrangements	
Topics for research you want to do	
Dates of biopsies, MRIs, ultrasounds, x-rays and other tests, dates results received	
Findings and implications	
Dates of blood work, dates results received	
Findings and implications	
Dates & times of appointments, which doctor/clinic, location	
Complete diagnosis including hormone receptor status, HER2 protein status, stage, grade, locations in the breast, node involvement, locations elsewhere	
Treatment options being considered, pros, cons, benefits, risks	
Treatment decisions made	
Surgery dates & times, kind of surgery	
Results of surgery, including the number & type (sentinel or axillary) of lymph nodes removed	
Discharge instructions	
People available for support post surgery & through treatment, names, phone numbers, when available & for what	



Post surgery progress, dates drains removed, dates for home care/wound care	
Who to call for concerns or specific complications, phone numbers	
Medications: name, dosage, schedule	
Side effects & management plan	
Chemotherapy plan & schedule	
Side effects & management plan	
Radiation plan & schedule	
Side effects & management plan	
Alternative or complementary treatments utilized & schedule	
Effects & benefits	
Plan for any preventative surgery	
Plan for any reconstructive surgery	
Date referral to physical therapy sent, appointments and for what purpose	
Exercise & physical therapy plan, your progress	
Dates of classes or educational sessions you want to attend	
Support groups, contact numbers, dates & times of meetings	

**The American Cancer Society has a number of comprehensive tracking sheets for various aspects of your treatment that you can download, print and add to your binder including:**

- Questions to Ask My Doctor About Breast Cancer
- Medicine List
- Daily Pain Diary
- Chemotherapy side Effects Worksheet
- External Radiation Side Effects Worksheet (general symptoms & radiation to chest sections)

To find these go to: [www.cancer.org](http://www.cancer.org). Click on "Find Support & Treatment"

There you will see two sections: Find Support & Treatment Topics; Treatment Tools. Under Treatment Tools you will find all of the above tracking sheets.



# About Breast Cancer

***Any fool can know. The point is to understand.***

**Albert Einstein**

Because there are so many forms and varieties of breast cancer it is difficult to look at it as just one disease. While they all start with uncontrolled and abnormal growth of cells in the breast that develop into tumors and invade breast tissue, their differences are important to determine as they will impact your treatment options. Tumors can either be benign (non-cancerous) or malignant (cancerous). Benign tumor cells stay in one place in the body and are generally not life threatening. Malignant tumor cells are able to invade the tissue around them and can metastasize (spread) to other parts of the body via the lymphatic system.

There are a number of risk factors for breast cancer including being female, having a family history of breast or ovarian cancer, never having given birth or having your first pregnancy after age 30, beginning menstruation early, reaching menopause later than average, taking hormone replacement therapy for more than five years, dense breasts and more. Breast cancer risk also increases with age. While people with a mutation of the BRAC1 or BRAC2 gene are at increased lifetime risk for developing breast cancer, only a small number (probably less than five percent) of breast cancers are a result of a defect or mutation of an inherited gene. Most breast cancers are a matter of cells getting 'mixed up messages,' behaving abnormally and then growing uncontrollably.

A detailed resource on the risk factors and causes of breast cancer can be found at:  
<http://www.bccancer.bc.ca/PPI/TypesofCancer/Breast/default.htm#Causes>

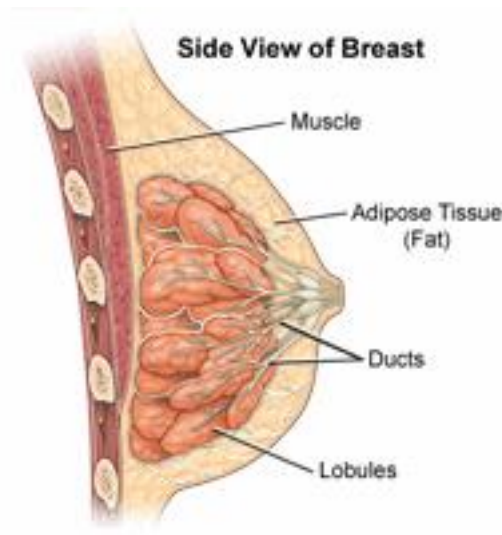
**Content credit for this section:** *Understanding Treatment for Breast Cancer: A guide for women.* Canadian Cancer Society, 2006 and *Breast Cancer: Understanding your diagnosis.* Canadian Cancer Society, 2007

**Other resources for more detailed information on topics in this section:**

- American Cancer Society, [www.cancer.org](http://www.cancer.org)
- Breastcancer.org
- BC Cancer Agency, [www.bccancer.bc.ca](http://www.bccancer.bc.ca)

## Anatomy of the Breast

Breast cancer can begin in either the lobules of the breasts (milk-producing glands) or the milk ducts (passages that drain milk). Breast tissue is made up of these lobules and ducts, as well as fat and lymph tissue, and covers a large area up to the collarbone and including the underarms. Breast tissue is connected to underlying pectoral (chest) muscles and bones. Lobular and ductal are the two most common types of breast cancer.



## Diagnostic Testing, Staging and Monitoring

You were likely alerted to the possibility of breast cancer following your own self-exam, a clinical breast examination done by your doctor or nurse practitioner, or a routine mammogram. Tools your doctor may use for diagnostic testing include: history and physical exam, diagnostic mammogram, ultrasound, biopsy and ductography (galactogram). For staging and ongoing monitoring purposes your doctor may use lymph node biopsy, blood chemistry testing, bone scan, liver ultrasound, chest x-ray, magnetic resonance imaging (MRI), hormone receptor testing and Human Epidermal Growth Factor Receptor 2 (HER2) status testing.

### ***Diagnostic Mammogram***

This is a specialized mammogram that uses extra compression to provide a clearer image of the area of concern. These magnified views help your doctor investigate very small areas of abnormality and help to determine if a biopsy is necessary. If you have dense breasts, you should consider this option and

discuss it with your physician. The resource list beginning on page 113 will support you in presenting this option to your health care team.

### ***Ultrasound***

Ultrasound is often used following a diagnostic mammogram to help determine if a solid lump or a mass is present, as opposed to a fluid-filled lump, which would more likely be a cyst. Cysts are most often benign but a solid lump or mass would be a strong indicator for a biopsy to see if cancer cells are present.

### ***Biopsy***

A biopsy is usually necessary to make a definitive diagnosis of cancer. In a biopsy, cells are removed from the breast and examined under a microscope. There are several ways of doing a breast biopsy:

- **Fine Needle Aspiration** uses a thin needle to remove fluid or cells from the lump. It is used when the lump can be felt through the skin or when the needle can be guided to the correct spot with the assistance of a mammogram or ultrasound. This procedure is quick but could be uncomfortable if your breasts are sensitive. Fluid being removed confirms that the lump is a cyst and generally no more tests will be required.
- **Core Needle Biopsy** involves a needle being inserted through a small cut in the breast to remove one or more samples of breast tissue. This can be done following a fine needle aspiration that confirms suspicious cells or when no lump or mass is present. Local freezing is used and mammogram or ultrasound guides the placement of the needle. You may have some breast tenderness or bruising for a short time afterward.
- **Surgical Biopsy** of a breast lump or suspicious breast tissue can be done two ways: incisional (take a sample of the lump); or excisional (remove entire lump). This can be performed in a doctor's office with local anesthetic (freezing) or in a hospital outpatient department under general anesthetic (patient asleep) as day surgery. No overnight stay would be required.
- **MRI-Guided Biopsy** is used when the area of concern is not clearly visualized on a mammogram or ultrasound. The MRI is used to identify the site for biopsy and a needle is used to withdraw the samples. Sometimes, a titanium marker will be left in the breast to make future surgery easier, if necessary.

Further laboratory tests on the biopsy sample are ordered when the breast tissue removed is found to be positive for cancer cells. These tests help your doctor learn more about your cancer.

- **Hormone Receptor Status** testing is done to determine if the cancer cells have certain hormone receptors. Breast cancer cells that have these receptors need estrogen and progesterone hormones to grow. If the biopsy sample has these receptors the tumor is called *hormone positive*. Knowing the hormone receptor status of the tumor helps to predict how the tumor will behave and whether or not the cancer is likely to respond to hormone therapy. Hormone-positive tumors are more common in post-menopausal women.
- **Human Epidermal Growth Factor Receptor 2 (HER2)** testing looks for the cancer gene that controls the HER2 protein. HER2 is a protein on the surface of the breast that promotes growth. Some breast cancer cells have a lot more HER2 than others. If the tissue has too much HER2 protein or too many copies of the gene that controls it, the tumor is called *HER2 positive*. HER2-positive breast cancers behave differently than other breast cancers and need specific treatments.

### ***Galactogram (ductography)***

Galactography is a procedure used to investigate the causes of discharge (bloody or clear) from the nipples and to identify the location of ductal lesions. In the galactogram, images of the breast ducts are taken using x-ray and x-ray dye.

### ***Blood Tests***

Blood tests may be ordered to see if the different types of blood cells in your body look normal and if they are normal in number. This shows your doctor how well your organs are working and may suggest whether or not there is cancer or if the cancer has spread. Blood urea nitrogen (BUN) and creatinine levels assess kidney function; alanine aminotransferase (ATL) and alkaline phosphatase assess the liver; and alkaline phosphatase also tests for bone health. A complete blood count (CBC) assesses white cells, red cells and platelets.

### ***Magnetic Resonance Imaging (MRI)***

An MRI can be ordered for a variety of reasons. Being that the MRI examines the breast tissue by taking very thin, cross-sectional images of the breast, it can help to distinguish a cancerous tumor from scars or detect small lesions that cannot be visualized using a mammogram or ultrasound. MRIs are sometimes

ordered when the biopsy returns inconclusive results or when, despite a negative biopsy, other serious concerns are still present. The MRI can help to determine the stage of your breast cancer and can be used to assess other parts of your body for potential cancer.

**For additional information on Diagnosis:**

*Breast Cancer: Your Path to Diagnosis.* Canadian Breast Cancer Foundation, [www.cbcbf.org](http://www.cbcbf.org)

**The Saskatoon Health Region's Breast Health Centre** at the Saskatoon City Hospital has a series of pamphlets available on these diagnostic issues including: Core Needle Biopsy; Wire Localization; Galactography; Breast MRI and MRI-guided Biopsy; and more (306-655-8686), [www.saskatoonhealthregion.ca](http://www.saskatoonhealthregion.ca).

## Interpreting Pathology Results

Once you have a definite diagnosis of cancer and your health care team has all the information it needs, the cancer will be given a stage and grade. This information is critical to making treatment decisions.

### Stages

The cancer stage describes the tumor size and gives information about whether it has spread beyond the place it started to grow. In the earliest stages of breast cancer, cancer cells are found only in the milk ducts or lobules. This is called *in situ cancer*. When in situ cancer is diagnosed before the cells have spread to the surrounding tissue there is no risk of them spreading after they have been removed. When cancer cells spread out of the duct or lobule it is called *invasive cancer*. It can still be treated effectively if diagnosed early.

One method of staging breast cancer is called tumor-node-metastasis staging (TNM). TNM provides a very extensive and detailed set of criteria for determining stage.

Information on TNM can be found at:

<http://www.cancer.ca/en/cancer-information/cancer-type/breast/pathology-and-staging/staging/?region=ab>.

"I want women to know that regardless of your stage, there is hope. Just talk to other women with breast cancer. Don't let your prognosis define you."

The following breast cancer staging system is simpler and more frequently used. It describes five stages:

Stage	Description
0	There are two kinds of stage 0 breast cancer: Ductal carcinoma in situ (DCIS) – abnormal cells are in the lining of a milk duct and have not spread outside the duct. Lobular carcinoma in situ (LCIS) – abnormal cells are in the lining of a lobule.
1	Tumor is 2 cm or smaller and the cancer has not spread outside of the breast.
2	Tumor is 2 to 5 cm, or cancer has spread to the lymph nodes, or both.
3	Cancer has spread to the lymph nodes and may have spread to nearby tissues such as the muscle or skin.
4	Cancer has spread to distant parts of the body.

**From:** *Breast Cancer: Understanding your diagnosis.* Canadian Cancer Society, 2007

### Grade

To determine the grade of a tumor the biopsy sample is examined under a microscope. A grade is given based on how the cancer cells look and behave when compared to normal cells (differentiation). This will give your health care team an idea of how quickly the cancer may be growing. There are three grades:

Grade	Description
1	Low Grade – slow growing, less likely to spread
2	Moderate grade
3	High Grade – tend to grow quickly, more likely to spread.

**From:** *Breast Cancer: Understanding your diagnosis.* Canadian Cancer Society, 2007.

Grade 1 tumors are said to be well differentiated (compared to normal cells). Grade 2 tumors are moderately differentiated and Grade 3 tumors are poorly differentiated. Again, more complex grading systems are found in the literature. Most notably the Bloom-Richardson–Nottingham Modification Grading System can be found at:

<http://www.cancer.ca/en/cancer-information/cancer-type/breast/pathology-and-staging/grading/?region=ab>.

### Keeping Track of Your Results

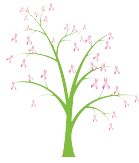
It is recommended that you request copies of your pathology results for your own files. This will assist you as you make your way through the treatment decision



process. It will help you to understand what is being recommended and why your treatment path is different from that of other women. It is important that you ask questions about these reports and gain a thorough understanding of your particular condition. If at any time you are still unclear about your pathology reports and what they mean, you can call the Canadian Cancer Society's toll-free Cancer Information Service at: **1-888-939-3333 (TTY 1-886-786-3934)**, Monday to Friday from 9 AM to 6 PM (EST). You can also email your questions to: **info@cis.cancer.ca** or visit the Support/Services section of their web site: **www.cancer.ca**. The provincial HealthLine may also be able to help you understand reports. Call **811** or go to [www.healthlineonline.ca](http://www.healthlineonline.ca).

**Breastcancer.org** has some very helpful tools to use including a ***Pathology Report Checklist***, available at: [www.breastcancer.org/symptoms/diagnosis/path\\_checklist](http://www.breastcancer.org/symptoms/diagnosis/path_checklist). This tool will help you keep your results together in one place and provide you with a format for asking your doctor questions about these reports.





# Surgical Options

*It is the surgeon's duty to tranquilize the temper,  
to beget cheerfulness, and to impart confidence of recovery.*

Sir Astley Paston Cooper

You will not be alone in your battle with breast cancer. In addition to your friends and family, you will have a health care team that will guide you at every stage of your journey. It is sometimes confusing to negotiate among all the team members with their different areas of expertise and determine who to go to when different concerns come up. The key is to ask, "What issues can I come to you for?" often and become your own care navigator.

## Your Health Care Team

Depending on your treatment plan, where you are treated, your doctor and you and your family, your health care team may include:

<b>Surgeon</b>	A doctor who performs biopsies or surgery.
<b>Surgical Oncologist</b>	A surgeon who has received specific training in treating cancer by removing lumps or tumors from the body.
<b>Radiation Oncologist</b>	A doctor who specializes in treatment of cancer using radiation.
<b>Radiation Therapist</b>	A therapist who helps plan and deliver your treatment and supports you in managing your side effects from radiation.
<b>Medical Oncologist</b>	A doctor who specializes in the treatment of cancer using different medications such as chemotherapy drugs.
<b>Oncology Nurses</b>	Nurses with special education and experience in chemotherapy, radiation, oncology and community nursing.
<b>Social Worker</b>	A health care professional who can help you and your family cope with cancer and its treatments.
<b>Registered Dietitian</b>	A dietitian has received special education on nutrition and can advise you on your diet.
<b>Physiotherapist</b>	A therapist who helps with the physical recovery, improvement and maintenance of your overall fitness and health.

<b>Plastic Surgeon</b>	A doctor who specializes in reconstructive surgery to reduce scarring or disfigurement, or to improve appearance.
<b>Complementary Therapists</b>	This could include professionals in yoga, massage, reiki, body talk, meditation, Traditional Chinese Medicine, Ayurvedic science, hypnosis, shiatsu, music therapy or acupuncture.

**In part from:** *Breast Cancer: Understanding your diagnosis.* Canadian Cancer Society, 2007.

## Developing Your Treatment Plan

There are many aspects to cancer treatment and numerous treatment options available depending on your particular circumstances, desires and beliefs. Based on the results of the diagnostic tests and other factors such as: your age; your general state of health; whether you've been through menopause; the stage and grade of your cancer and your hormone receptor status, your health care team will be providing you with information and recommending courses of action for you to consider. As much as time will allow, you need to take your time in making these decisions.

Western society has come a long way since the time when people simply did what their doctors directed them to do. Modern biomedical ethics upholds the notion that people have a moral right to direct the course of their own medical care and to be given full information in order to make appropriate medical decisions. Most people consider many factors in their medical decisions, including their own values and the views and desires of their family. Having a sense of control and maintaining quality of life are likely greater factors in treatment decision-making than ever before. While you have a great deal of autonomy in these matters, it is a burden that your health care team hopes to share with you. You may need to do a bit of soul searching about your values, particularly in relation to the question, "What is my goal for treatment?" You will be given many facts and data to consider and well reasoned recommendations to consider. While you thoughtfully consider these, you also need to pay attention to your intuition and how your decisions are sitting with you. Combine your intellect and your intuition to make the best decision for you.

Surgery is the most common treatment for breast cancer and it may be combined with other treatments such as chemotherapy or radiation therapy. The main goal of surgery is to completely remove the tumor from the breast. This can be done in two ways: breast-conserving surgery or mastectomy.

It should be noted that if you have had chemotherapy prior to your surgery, to reduce the size of the tumor, this will have an impact on your recovery from surgery. You will be in a somewhat depleted state heading into surgery, so your recovery might be a bit slower. You need to do everything you can to conserve your energy so that you can be as strong as possible heading into surgery.

## Breast-Conserving Surgery

In breast-conserving surgery the tumor and some of the tissue around it are removed, allowing you to keep or conserve as much of your breast as possible. Some lymph nodes may also be removed.

### Lumpectomy

A lumpectomy consists of removing the breast tumor and a small amount of healthy tissue surrounding it; enough to ensure that the edges or margins of the area are clear of cancer cells. Radiation therapy almost always follows a lumpectomy to ensure that any residual cancer cells in the breast are destroyed. If chemotherapy is in your treatment plan, this will occur before radiation. In a small percentage of women cancer can recur in the breast treated with lumpectomy and radiation (ranging from 9% to 14%). Recurrence would be treated with a mastectomy.

### Other Breast-Conserving Surgery

Your surgeon may recommend other breast conserving surgeries such as:

- Wide local excision
- Partial mastectomy
- Segmental mastectomy
- Quadrantectomy

These types of surgery are all very similar, except for how much breast tissue is removed. With the lumpectomy, the least amount of breast tissue is removed. In a quadrantectomy, the tumor and about a quarter of the breast is removed. After any of these surgeries, the tumor and the additional breast tissue are examined under a microscope. If cancer cells are found at the edges of the removed tissue (the margins), the surgeon may have to perform a **re-excision** – the removal of more breast tissue to ensure that all the cancer cells are removed.

### When Breast Conserving Surgery is Not Recommended

Lumpectomy or other breast-conserving surgery with radiation is not for every woman. Radiation cannot be given twice to the same breast. If you have had

radiation previously to the treated breast you will likely not be able to have breast-conserving surgery. If you have multiple tumors or extensive cancer in the breast, mastectomy is likely a better option. At times when the tumor is large in relation to the size of the breast, mastectomy may yield better results. If the surgeon has had to do repeated re-excisions, mastectomy may be the final outcome. Any condition for which radiation is contraindicated such as lupus, vasculitis or pregnancy, will limit your ability to have breast-conserving surgery. Committing to the daily schedule for radiation is difficult for some women for a variety of reasons. Finally, some women feel that they would have greater peace of mind with a mastectomy.

At times breast-conserving surgery is thought to be an easier option than mastectomy but this is not always the case especially when you consider the impact of radiation therapy, which is often underestimated. This will be discussed in more detail below.

## Mastectomy

When breast-conserving surgery followed by radiation is not the best treatment option, or is not desired by the woman, a mastectomy may be recommended. Radiation is sometimes required after mastectomy. When the tumor is greater than 5 centimeters or there are multiple tumors; when clean margins were not achieved; or when cancer cells are found in more than four lymph nodes. There are two types of mastectomy: total mastectomy and modified radical mastectomy.

### **Total Mastectomy**

A total mastectomy removes the entire breast, the nipple and some skin. The lymph nodes, nerves and muscle in the chest are left in place. This is also called a simple mastectomy. Women with multiple or large areas of localized ductal carcinoma are good candidates for total mastectomy. This procedure is used for women wanting a prophylactic (preventative) mastectomy instead of breast-conserving surgery or when a non-affected at risk breast is removed in order to eliminate any chance of cancer occurring in that breast.

### **Modified Radical Mastectomy**

A modified radical mastectomy removes the entire breast, the nipple, some skin and some of the lymph nodes in the armpit. Nerves and muscles are left in place. Women with invasive cancer are good candidates for a modified radical mastectomy as it allows for the examination of lymph nodes to determine if cancer cells have spread beyond the breast.

Another type of mastectomy, called a **radical mastectomy**, removes the entire breast, the nipple, skin, some of the lymph nodes in the armpit, some nerves and the muscles in the chest. This type of mastectomy is seldom done any more. Subcutaneous or nipple-sparing surgery is also done infrequently.

### **Skin Sparing Mastectomy**

A skin sparing mastectomy can be performed if you are considering immediate reconstructive surgery. It is done as a total mastectomy but as much skin as possible is retained to be used in reconstruction.

### **Prophylactic Mastectomy**

There are a number of reasons that you would consider having a mastectomy for prevention rather than a treatment. It could be that you have a very strong history of breast cancer in your family or you have tested positive for the BRCA1 or BRCA2 gene. Perhaps you have had breast cancer in one breast and fear a new cancer occurring in the other breast. If you have been diagnosed with lobular carcinoma in situ you are at increased risk of developing invasive cancer. The presence of clusters of micro calcifications in your breasts or having dense breasts might cause you to consider a preventive mastectomy especially if these conditions require you to endure multiple biopsies over time. If you have had radiation to the chest before the age of 30 you are at increased risk for breast cancer over your lifetime. Finally, some high risk women who have developed lymphedema after their first mastectomy with axillary lymph node removal decide on a prophylactic mastectomy on the other side to reduce the risk of both cancer recurrence in the other breast and lymphedema. Most women who undergo a prophylactic mastectomy opt for reconstructive surgery at the same time.

While a prophylactic mastectomy can dramatically reduce the risk of breast cancer (according to some studies up to 90 %), it is a very serious, life changing decision that must not be made lightly. It is important that you discuss the risks and benefits of prophylactic mastectomy with all of the members of your health care team and carefully make this decision together. While some women who request a prophylactic mastectomy find their surgeon in agreement with their decision, others have encountered reluctance. If you feel this is the right choice for you, you may seek a second opinion at any time or summon the support of the other members of your health care team when making this important decision.

### **Lumpectomy Versus Mastectomy**

There are some circumstances in which either a lumpectomy or mastectomy are equally appropriate options. Your doctor may have a difficult time recommending

one over the other in these cases and the choice will be yours. As previously mentioned, lumpectomy can be equally as effective in cases where there is only one tumor that is less than 4 centimeters in size and where clear margins were achieved in surgery. However, lumpectomy is almost always followed by several weeks of radiation therapy, which can be challenging to manage for a variety of reasons. Lumpectomy with radiation may not be the easier option depending on how well you tolerate the radiation treatments.

Only you can decide how important it is to keep as much of the breast as possible or how important it is to you to have symmetrical breasts (although reconstruction can be provided post lumpectomy). Another factor to consider is your own level of anxiety about cancer recurrence following lumpectomy and radiation. You will need to consider all these factors in your decision. Talking to your family or other support people will likely be of some help. Talking to other women who have been in this predicament can also provide you with first hand knowledge, experience and perspective.

More information on this topic can be found at:  
[www.breastcancer.org/treatment/surgery/mast\\_vs\\_lump](http://www.breastcancer.org/treatment/surgery/mast_vs_lump).

Reading through this more detailed information might help you clarify your own desires and facilitate a decision you feel comfortable with.

There may also be the occasion when your doctor is strongly recommending a lumpectomy or other breast-conserving surgery but, for a variety of reasons, you would prefer a mastectomy. Again, as with other treatment decisions, it is important for you to discuss the risks and benefits of a lumpectomy versus a mastectomy with all of the members of your health care team and carefully make this decision together. If you feel this is the right choice for you, you may seek a second opinion at any time or summon the support of the other members of your health care team when making this important decision. Without unnecessarily delaying your treatment, take your time in making these important decisions. Resist being rushed into making any decision with which you are not comfortable.

## Prophylactic Ovary Removal

Women who are at high risk for breast and ovarian cancer sometimes choose preventative surgical removal of the ovaries and fallopian tubes to reduce their risk. High risk for ovarian cancer and breast cancer sometimes go hand in hand.



Prophylactic removal of the ovaries reduces the risk of ovarian cancer and the risk of breast cancer in pre-menopausal women. However, this surgery reduces your estrogen levels and may cause you to experience menopausal symptoms such as hot flashes, difficulty sleeping, depression, and reduced sex drive. Reduced estrogen also has an impact on heart and bone health.

## Breast Reconstruction Surgery

The issue of breast reconstruction carries with it an additional set of decisions that you will be making at a time when you are likely feeling quite overwhelmed. Again, doing a little bit of reading, a little bit of soul searching about your own values and beliefs and being prepared with questions for your surgeon will go a long way. For many women, especially those with early stage breast cancer, having breast reconstruction at the time of the cancer surgery is possible. Have this conversation with your surgeon when discussing your surgery options. You will want to discuss the type of surgery (breast-conserving or mastectomy) and the likelihood of needing chemotherapy and/or radiation therapy. In the best-case scenario, the discussion about reconstruction includes both your cancer surgeon and a plastic surgeon.

If you decide against reconstruction, proceeding with surgery and other treatments becomes a bit more straightforward. This does not negate your ability to have reconstructive surgery at a later date if you change your mind. Decisions about breast prostheses do not have to be made at this time.

### Immediate Versus Delayed Reconstruction

If you decide that you do want reconstruction, the next question to tackle is when. What is the best timing for reconstruction given your unique set of circumstances? *Immediate reconstruction* is done at the same time as your cancer surgery. This requires coordination between your surgeon and a plastic surgeon. The plastic surgeon uses tissue taken from another part of your body or uses an implant to build a new breast. *Delayed reconstruction* is done after you have healed from your original cancer surgery and other treatments, like chemotherapy and radiation, are complete. This could be six to twelve months after your original surgery.

There are a number of factors to consider when determining the timing of reconstruction. For women in Stage 1, and sometimes Stage 2, immediate reconstruction is more possible because the likelihood of needing radiation is reduced at these stages. The key here is determining if there is lymph node

involvement, which is often not known until after the cancer surgery when tissue and lymph have been examined microscopically. Sentinel node biopsy might make the situation clearer ahead of surgery for women who are eligible for this procedure. For those who are not, these results will come a week or more after surgery. If the tumor is larger than 5 centimeters or it has spread to the lymph nodes, radiation therapy is likely. Women opting for a lumpectomy or other breast-conserving surgery are also likely to require radiation following surgery. Many surgeons will advise against immediate reconstruction if radiation is likely because radiation (and some chemotherapy) is known to cause unwanted changes in a reconstructed breast (decreased size and changes in colour, texture and appearance). Some of the literature indicates that the reconstructed breast can inhibit the radiation from effectively reaching its target. Most of the literature suggests that the decision about immediate reconstruction for women with Stage 1 or Stage 2 breast cancer is the most complicated and difficult.

The decision for women with Stage 3 or Stage 4 breast cancer is a little more clear-cut. At these stages, lymph involvement is more likely and courses of chemotherapy and radiation are most often required. Most surgeons will recommend delayed reconstruction for these individuals for the reasons mentioned above. Additionally, healing from reconstruction could delay chemotherapy and radiation. Reconstruction could also make the detection of recurring cancer more difficult.

In either case, discussions with your surgeon are needed before you and your health care team reach a decision about reconstruction and its timing. Talking with other women who have had breast reconstructive surgery would also be helpful. Below is a guide you can use for these discussions.

### **Questions to ask your surgeon about breast reconstruction:**

[www.breastcancer.org/treatment/surgery/reconstruction/questions-to-ask](http://www.breastcancer.org/treatment/surgery/reconstruction/questions-to-ask)

### **Types of Reconstruction**

For women who have had a mastectomy or breast-conserving surgery, breast reconstruction can create a more balanced appearance. While having your breast reconstructed may make you feel better about your appearance, it's important to be realistic. A reconstructed breast won't look exactly like your original breast and it won't have the same sensations as your original breast.

There are a number of breast reconstruction methods. It's important to understand the difference and talk to your health care team so that you can make



an informed choice on what is best for you. Your health care team should be able to show you pictures of reconstructed breasts and the different method used to construct them.

If your nipple and areola (the coloured tissue around the nipple) have been removed, it is also possible to have them reconstructed using tissue from other areas of your body. Sometimes tattooing is an alternative to reconstruction with tissue.

There are two main types of breast reconstruction and each type uses different techniques:

- ***Breast Implants***

The most common implant is a shell filled with saline (sterile salt water) or silicone gel. It is placed under the skin and muscle of the chest wall. Having an implant inserted is done in one operation.

If your skin and chest wall tissues are tight and flat you may need the tissue-expander method of implant. With this method, an expander implant (an empty bag with a small valve like a balloon) is placed under the skin and muscle of the chest wall. Small amounts of saline are injected into the shell's valve using a very small needle inserted through the skin. Many visits to the doctor are needed to stretch the skin and fully expand the breast implant to the size of the opposite breast. After the skin has stretched enough, the expander implant is usually removed in a second operation and a permanent implant is put in its place. Sometimes, expander implants are left in place as the final implant.

The implant method is a fairly simple technique. You can have it done as an outpatient which means you will not have to stay overnight at the hospital.

The possible problems or side effects with breast implants are:

- Infection
- Implant may get hard over time and the breast may lose its shape
- Scar tissue may form around the implant
- Small risk of leak or rupture

- ***Tissue Flap Techniques***

In tissue flap techniques, a section of skin and fat, and often muscle, is moved from the abdomen, back or other areas of the body to the chest area to shape a breast. There are four different tissue flap techniques:

- **Transverse Rectus Abdominus Myocutaneous (TRAM) Flap**  
Skin, fat and muscle (with its own blood supply) from the lower abdomen are tunneled under the skin up to the chest to form a breast. The effect on the abdomen is similar to a tummy tuck. The advantage of this technique is that the reconstructed breast is made of natural tissue and has a more natural feel than an implant. The possible problems or side effects of TRAM Flap technique include:
  - Scars on your abdomen and on the reconstructed breast, which never completely go away
  - Infection and bleeding after surgery
  - Buildup of fluid where the tissue was taken
  - Longer operation and recovery time than implant surgery
  - Possible weakness of the abdominal wall
  - The tissue in the area not surviving if there is a poor blood supply to the reconstructed breast
- **Latissimus Dorsi (LATS) Flap**  
Skin, fat and muscle (with its own blood supply) from the upper back are tunneled under the skin and turned to the front to form a breast. An implant is added in women who need a larger breast. The reconstructed breast is made of natural tissue and has a more natural feel than an implant. This technique also adds fullness to the lower part of the breast, where it is most needed to produce a natural looking breast. The possible problems or side effects of a LATS Flap technique include:
  - Scars on your back and on the reconstructed breast, which never go completely away
  - Infection and bleeding after surgery
  - Buildup of fluid where the tissue was taken
  - Skin taken from the back may be a different colour and texture than skin in the breast area
  - Longer operation and recovery time than implant surgery
  - Less muscle strength on the side of surgery
  - The tissue in the area not surviving if there is a poor blood supply to the reconstructed breast.
- **Free Flap**  
Skin, fat, muscle and blood vessels are removed from one area of the body (for example, the abdomen or buttocks) and placed under the skin on the chest to create a breast. The free flap method isn't used very often

and needs a plastic surgeon who is skilled in microsurgery to reconnect tiny blood vessels to the flap in the new breast location.

The advantage of the Free Flap method is that more of the muscle is left in place than with other flap methods, which may mean that strength can be recovered faster. Possible problems or side effects of the free flap technique are the same as other flap techniques. There is also more scarring in the area where the flap is taken.

- **Deep Inferior Epigastric Perforators (DIEP) Flap**  
Skin, fat and blood vessels, but not muscle, are removed from the abdomen and placed under the skin on the chest to form a breast. This method is not used very often and needs a plastic surgeon who is skilled in microsurgery to reconnect the tiny blood vessels to the flap in the new breast location.

The advantage of the DIEP Flap method is that the muscle is left in place, which may mean that strength can be recovered faster. Possible problems or side effects of the DIEP Flap technique are the same as other flap techniques. There is also more scarring in the area where the flap is taken.

**Source credit:** *Understanding Treatment for Breast Cancer: A guide for women.* Canadian Cancer Society, 2006

## Lymph Node Removal

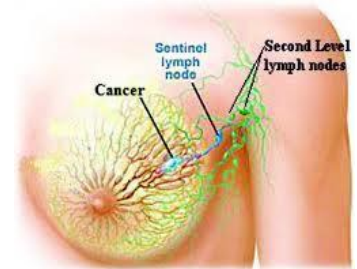
Lymph nodes work like small filters throughout the body filtering extra body fluids, abnormal cells and dead cells from infections. Large collections of lymph nodes are most commonly found in the armpits, groin and neck. If you have lymph nodes removed you should ask your doctor how many were taken as this may have implications for your risk of developing a complication called lymphedema, which will be discussed later.

### **Axillary Lymph Node Dissection**

In an axillary dissection, a number of lymph nodes are removed from under the arm by making a separate incision or cut. It may be done either at the same time as the breast surgery or later on. After being removed, the lymph nodes are examined under a microscope to see if the cancer has spread. Knowing this will help with planning the rest of your treatment.

## Sentinel Lymph Node Biopsy

Axillary dissection may potentially be avoided if a sentinel node biopsy is completed, providing the surgeon with more in-depth information about the extent of node involvement. In this newer procedure, the surgeon injects a blue dye or a radioactive substance, or both, into the breast. The lymph nodes that pick up the dye or the radioactive substance first (the sentinel nodes) are the ones that are draining the breast of fluids that may contain cancer cells. If cancer is found when the nodes are examined under a microscope, more lymph nodes will need to be removed. If cancer isn't found, the rest of the lymph nodes are left in place.



Not every woman is eligible for sentinel lymph node biopsy. The presence of multi-focal tumors, for example, is an exclusion criterion for most cancer centers. The incidence of lymphedema from axillary dissection ranges from 25% to 61%. The incidence of lymphedema following sentinel lymph node biopsy is 3% to 8%. You should be prepared with this information and ask your doctor if you are eligible for sentinel node biopsy and if your surgeon is trained in this procedure. You can ask to be transferred to a surgeon trained to do sentinel node biopsy.

**Content credit for this section:** *Understanding Treatment for Breast Cancer: A guide for women.* Canadian Cancer Society, 2007

**For more detailed information on the topics in this section:**

- Breastcancer.org
- BC Cancer Agency, [www.bccancer.bc.ca](http://www.bccancer.bc.ca)

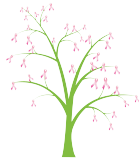
## Questions to Ask About Surgery

What are my options for removing my cancer?	
What is the difference between breast-conserving surgery, lumpectomy and mastectomy?	
Given my situation, would you recommend one surgery over another? Why? How much of my breast will be removed?	
What are lymph nodes and what do they do? Will you remove any lymph nodes? If so, why?	
If lymph nodes are removed, what side effects might I have?	
Is sentinel node biopsy an option for me? Are you trained in sentinel node biopsy? If not, can I be transferred to a surgeon who is?	
Will I need to be in the hospital? If yes, for how long?	
Will I need to take time off work? How much?	
What can I expect after surgery?	
What will my breast look like after surgery? What will my scar look like?	
Will I need nursing care at home? What community resources are there to help me after surgery? Who arranges this?	
Will I need more treatment after surgery? If yes, what kind and why?	
What other tests will I have prior to and following surgery?	
What do I need to know in order to decide about breast reconstruction surgery? Is it an option for me? When do I have to make this decision?	

Can I have reconstruction at the time of my cancer surgery? If not, why not? What do you advise?	
What kinds of breast reconstruction are there? What kind is best for me?	
What will my breasts look and feel like after reconstructive surgery?	
Will I have normal feeling in my breasts after reconstruction?	
Will I need a breast form or prosthetic? If so, where can I get one?	
When can I wear a bra?	
Can you recommend a mental health professional that I can see if I start to feel overwhelmed, depressed or distressed? Is support available for my family members, especially my children?	
Is there a class on all of this that I can take either before or after surgery?	

**Taken in part from:** *Questions to Ask about Breast Cancer: A workbook for women.* Canadian Cancer Society, 2006

**More questions available at:** The American Cancer Society, [www.cancer.org](http://www.cancer.org) (Find Support & Treatment section, Questions to Ask My Doctor About Breast Cancer)



# Non-Surgical Options

*We look for medicine to be an orderly field of knowledge and procedure. It is not.*

*It is an imperfect science, an enterprise of constantly changing knowledge, uncertain information, and fallible individuals, and at the same time, lives are on the line.*

*The gap between what we know and what we aim for persists. And this gap complicates everything we do.*

Atul Gawande

Your health care team may suggest additional adjuvant therapy after your surgery. The goal of adjuvant therapy is to destroy any cancer cells that may have been left behind after surgery or that escaped from the tumor and travelled to other parts of the body.

Chemotherapy, radiation therapy, hormonal therapy and biological therapy, alone or in combination, are all treatments that can be used after surgery to give you the best chance of recovery from breast cancer. In some cases, radiation therapy or chemotherapy may be given before surgery to shrink the tumor and make it easier to remove.

All treatment methods can damage healthy cells and lead to side effects but it's difficult to know if and when they might happen to you. Everyone reacts differently to these treatments and whether or not you have side effects will depend on many factors such as your general physical health and your treatment schedule. Side effects tend to come on gradually but are cumulative and can often last well beyond the point when your treatments end. In most cases, the damage to healthy cells is temporary and the side effects will go away as the cells repair themselves.

## Questions to Ask about Non-Surgical Options (general)

What is chemotherapy? What is radiation therapy? Will I need them? How will they help me?	
Will chemotherapy or radiation therapy improve my chances of survival? How?	
What are the short-term and long-term effects of these treatments? Are there any potentially permanent effects?	
How soon after surgery will I start treatments?	
What are clinical trials? How can I find out about clinical trials in my area?	
What are complementary and alternative therapies? How can I get more information on them? What are your views on utilizing these therapies?	
What if I choose not to have treatments?	

**Taken in part from:** *Questions to Ask about Breast Cancer: A workbook for women.* Canadian Cancer Society, 2006

**More questions available at:** The American Cancer Society, [www.cancer.org](http://www.cancer.org) (Find Support & Treatment section, Questions to Ask My Doctor About Breast Cancer)



# Chemotherapy

Chemotherapy treats cancer by using drugs to weaken and destroy cancer cells at the original cancer site and cells that may have broken away and spread to other parts of the body. Chemotherapy is considered a *systemic* treatment, which means that it affects the entire body as it circulates through the blood stream. Chemotherapy is used to treat early-stage invasive breast cancer to get rid of any cancer cells that were left behind following surgery and to reduce the risk of recurrence. Chemotherapy is also used to treat advanced-stage breast cancer to destroy or damage the cancer cells.

## ***Chemotherapy Drugs***

There are many different chemotherapy drugs and they are often used in combination to treat various kinds of cancers. The stage of your cancer, your hormone receptor, HER2 and lymph status, and other aspects of your general health will determine the specific combination of drugs for you. You may be able to take chemotherapy drugs orally (by mouth) at home. If you are receiving them directly into a vein, you will need to go to the hospital or treatment center. Here are some common combinations of chemotherapy drugs:

AC: Adriamycin & Cytosan

AT: Adriamycin & Taxotere

CMF: Cytosan, Methotrexate & Fluorouracil

FAC: Fluorouracil, Adriamycin & Cytosan

CAF: Cytosan, Adriamycin & Fluorouracil

The FAC and CAF combinations use the same drugs but different doses and frequencies. Your doctor may give you only one medicine at a time, as well.

**A comprehensive listing of chemotherapy drugs can be found at:**

[www.breastcancer.org/treatment/chemotherapy/medicines](http://www.breastcancer.org/treatment/chemotherapy/medicines)

## ***Chemotherapy Port***

Most chemotherapy drugs can be administered through a regular intravenous (IV) needle inserted into a vein at the start of each treatment. However, your doctor may recommend having a chemotherapy port inserted that remains in until you are finished all of your chemotherapy treatments. A chemotherapy port, or port-a-cath, is a small device that is implanted under your skin to allow easy access to your bloodstream. In addition to being used to deliver you chemotherapy drugs, it can be used to take blood or to receive transfusions. Some chemotherapy drugs can only be delivered using a port and a port is handy when you are having several treatments and are good to use with people

who have fragile veins. Discuss the most appropriate placement for this port (in the arm that was operated on; in the arm that was not operated on) with your health care team prior to the procedure.

A port is usually inserted in an outpatient clinic a few days prior to starting chemotherapy. A local anesthetic (freezing) is used to minimize any pain or discomfort during the procedure. During insertion, a small round metal or plastic disc is placed under your skin through an inch-or-two-long incision. This may be located on your upper chest or occasionally your upper arm. This port is then attached to a tube that is threaded into one of the large veins near your neck. After your port is in place, you will notice a slight protrusion on your skin over the port. The port has a resealing rubber center called the septum which makes it okay for you to bathe and swim without being concerned about anything getting into your port.

### ***What to Expect at the Cancer Treatment Centre***

The routine at cancer treatment centers will vary but this is generally what you can expect:

- Blood pressure, pulse, temperature, respiration (breathing rate), height and weight are recorded. Your height and weight are used to help calculate the doses of your drugs by the medical oncologist
- If you do not have a port, an IV will be inserted
- Usually blood is drawn for red and white blood cell counts
- At times you will be given other medicines, either by mouth or in your IV or port, to prevent nausea or any allergic-type reactions
- You might also be given some fluids that help the chemotherapy drug work more effectively
- After double-checking your name, medicine and dosage, the nurse will start the infusion, which can take several hours to complete. You might also have some chemotherapy drugs to take by mouth
- When the infusion is done, the nurse will take out the IV and take your blood pressure, pulse and breathing rate again

- Your doctor or the nurse will go over any side effects and how to manage them. You will usually be given some medicine for nausea. Make sure you have the number to call in case you have any severe side effects. Ask your doctor which side effects you should report right away.

You may be able to drive yourself to and from your chemotherapy appointment, but fatigue is a common side effect so it might be better if someone drives you. You should plan to take it easy for the remainder of the day and you might find yourself needing a nap quite often. It will also be important to drink plenty of fluids after your treatment as some of the chemotherapy drugs can make you quite dehydrated.

### ***Side Effects of Chemotherapy***

The side effects of chemotherapy depend mainly on the specific drugs you receive and the dose. In addition to feeling tired or weak, you may bruise or bleed easily or be at risk for infection. Hair loss is a common side effect but not all drugs cause hair loss. Changes in appetite, diarrhea, nausea and vomiting, and mouth sores are all possible side effects but they can often be controlled with other medicines. Tingling or numbness in the legs and feet can be severe enough to cause you to lose your balance easily and fall.

For advice on managing side effects you can call The Canadian Cancer Society's Cancer Information Service at: **1-888-939-3333 (TTY 1-886-786-3934)**, Monday to Friday from 9 AM to 6 PM (EST). You can also email your questions to: **[info@cis.cancer.ca](mailto:info@cis.cancer.ca)** or visit the Support/Services section of their web site: **[www.cancer.ca](http://www.cancer.ca)**.

If the chemotherapy drugs you are taking affect the ovaries, your menstrual periods may become irregular or stop completely while you have the treatment. This may bring on symptoms related to menopause such as hot flashes and dry vaginal tissues. These tissue changes can make intercourse uncomfortable and can make you more prone to bladder or vaginal infections. Depending on your age, the type of drugs and the dose you are taking, your periods may not start again.

If you are of childbearing age, it is important to practice birth control during chemotherapy, even if your periods stop. Although pregnancy may be possible during treatment, it is not a good idea because chemotherapy drugs can be harmful to a developing fetus. Discuss birth control choices with a member of your health care team.

Some chemotherapy drugs can affect your ability to become pregnant after treatment. It is important to discuss this possibility with your health care team if you plan to have children in the future. You might want to look into having your eggs preserved for future use. Whether or not infertility occurs, and how long it lasts, depends on your age, the type of drugs and the dose you are taking.

**Some content in this section from:** *Understanding Treatment for Breast Cancer: A guide for women.* Canadian Cancer Society, 2006

**For more detailed information on chemotherapy:**

- [www.cancer.org](http://www.cancer.org)
- [www.breastcancer.org](http://www.breastcancer.org)
- [www.cancer.ca](http://www.cancer.ca)

The American Cancer Society web site ([www.cancer.org](http://www.cancer.org)) has a comprehensive **worksheet for tracking your side effects** for you to use between your treatment cycles. It is recommended that you make copies of these sheets and put them in this binder so that you can track your symptoms and be able to report them clearly to your doctor at your next chemotherapy session. You can find these at:

**[www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/toolstomonitortreatment/index](http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/toolstomonitortreatment/index)**

Tracking sheets for medicines you take at home and pain tracking sheets are also available.

## Questions to Ask About Chemotherapy

Do I need chemotherapy? Why?	
What are the benefits and risks of chemotherapy?	
What are my options regarding the drugs I can take? How many drugs will I be taking at one time?	
How will chemotherapy be given? How often will chemotherapy be given?	
Where will chemotherapy treatments be done and who will give it to me?	
What are the possible side effects? When might they start and how are they usually managed?	
Are there any side effects that I should report immediately?	
Who do I contact in the evening or on the weekend? What is the phone number to call?	
Will these drugs cause me to gain or lose weight?	
Will I lose my hair? If so, how soon? Where can I find a good wig or head covering? Are wigs/head coverings covered by health insurance?	
Are there special instructions to follow while I am receiving chemotherapy or after the treatment is finished?	
Will I need help with daily activities during treatment?	
Will I need to take time off work or adjust my work schedule?	
Will I have to pay for any of the treatment?	
Will I go into menopause because of this treatment? What can be done to manage these symptoms if this happens? Does it reverse after	

treatments are done?	
What are the chances that the cancer will come back? How will we know it's working? What will we do if the treatment doesn't work?	
Will I be able to have children after these treatments? Will I be able to breastfeed?	
Is there anything I should be doing to prepare for chemotherapy?	
Will I need blood transfusions or any other supportive treatments?	

**Taken in part from:** *Questions to Ask about Breast Cancer: A workbook for women.* Canadian Cancer Society, 2006

**More questions available at:** The American Cancer Society, [www.cancer.org](http://www.cancer.org) (Find Support & Treatment section, Questions to Ask My Doctor About Breast Cancer)

# Radiation Therapy

Radiation therapy is a very effective way to destroy cancer cells that have been left behind after surgery, but depending on the size of the tumor and other factors, radiation can also be used after mastectomy. Radiation therapy uses a certain kind of energy beam (radiation) from x-rays, gamma rays, electrons and other sources to destroy the DNA in cancer cells that cause them to reproduce.

Radiation destroys healthy cells but it affects cancer cells more; stopping them from growing and multiplying. There are two ways to deliver radiation:

- From a machine that directs a beam at the body from the outside
- Pellets or seeds of material that give off radiation beams from inside the body

Radiation beams from a machine outside the body can be directed at the body from many angles so that the breast, chest wall, armpit and surrounding lymphatic system can be treated. This is the most common method of radiation therapy for breast cancer. In cases of metastatic (advanced or Stage 4) cancer, where cancer has spread to other parts of the body, radiation can be used to shrink and control areas where cancer has spread, in addition to the breast.

Your health care team will decide on the treatment schedule for you. Some schedules are five days a week for five to seven weeks. Treatments generally take about 30 minutes. Radiation, according to some studies, reduces the chance of cancer recurring by 70%.

## ***Preparing for Radiation***

In order for the external radiation to be directed at the correct and same spot each treatment, you will likely get some small dots marked on your body. At some centers these are tattooed on, while at others, oil based skin markers or dye are used. During the process of mapping the places to put these spots, you could be holding your arm in an awkward position for an extended period of time (the same position in which you will be holding your arm during the actual treatment). It is advised that you do some gentle stretching of your arm and shoulder prior to and after both the mapping and treatment session to prevent tightness and muscle soreness and to preserve the range of motion in your shoulder. The exercises noted later in this binder and demonstrated on the video can be used for this purpose. If you are post-surgical, it might also be helpful to take pain medication before you go to the mapping and treatment sessions.

### **Side Effects of Radiation**

The side effects of radiation come on gradually through the course of your treatments and linger for four or more weeks after treatments are completed. In addition to skin reactions, some of the common side effects of radiation include armpit discomfort, chest pain, heart problems, lowered white blood count and lung problems. The skin and tissue in the area being radiated could become less elastic as it heals, causing long-term tightness or scar tissue in the chest, armpit or shoulder areas. During radiation therapy your body uses a lot of energy for healing. You may find that it makes you very tired and that resting doesn't make you feel better. Resting is important but watch that you don't become too inactive. Too much rest can make you feel more tired.

Radiation therapy can cause skin changes where the radiation has passed through the skin. Skin in the treatment area may become red, dry, swollen, tender and itchy. Sometimes the skin becomes moist and 'weepy,' especially where there are skin folds. The nipple and the fold under the breast can be very sensitive or sore. Most skin changes will go away a few weeks after treatment has ended. Your skin will be checked regularly and your treatment team will make suggestions for your care. During or after treatment, you may find that your treated breast has changed in size or shape. It may also feel slightly firmer. While these changes are possible, they are quite rare.

#### **Skin care tips can be found at:**

[www.breastcancer.org/treatment/radiation/skin/care](http://www.breastcancer.org/treatment/radiation/skin/care)

#### **10 Key Points about radiation therapy can be found at:**

[www.breastcancer.org/treatment/radiation/10\\_points](http://www.breastcancer.org/treatment/radiation/10_points)

The American Cancer Society web site ([www.cancer.org](http://www.cancer.org)) has a comprehensive **External Radiation Side Effects Worksheets** that you can use while receiving radiation therapy. It is recommended that you make copies of these sheets and put them in this binder so that you can track your side effects and be able to report them clearly to your doctor at your next radiation therapy session. You can find these at:

[www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/toolstomonitortreatment/index](http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/toolstomonitortreatment/index)

**Some content in this section from:** *Understanding Treatment for Breast Cancer: A guide for women*. Canadian Cancer Society, 2006.

#### **For more detailed information on chemotherapy:**

- [www.cancer.org](http://www.cancer.org)
- [www.breastcancer.org](http://www.breastcancer.org)
- [www.cancer.ca](http://www.cancer.ca)



## Questions to Ask About Radiation Therapy

Do I need radiation therapy? Why?	
What are the benefits and risks of radiation therapy?	
What types are there? What type will I be given?	
What is radiation therapy like? Will it hurt?	
How will the radiation therapy be given? How often will it be given? How long will each treatment take?	
Where will the treatment be done and who will give it to me?	
What are the possible side effects? How are these usually managed? Are any of the side effects permanent?	
Are there any side effects that I should report immediately? What is the number to call on evenings or weekend?	
Before treatments, should I do (or avoid) anything in particular, such as not eating?	
Are there any special instructions to follow while I am receiving radiation therapy or after the treatment is finished?	
What do I need to know about taking care of my skin during treatment? Is it okay to use perfume, deodorant or lotions? Specifically what lotions should I be using? Will there be scarring?	
How long will it take for the treatment area to heal?	
Will I need help with daily activities during treatment?	
Will I need to take time off work or	

adjust my work schedule?	
Will I have to pay for any of the treatment?	
What should I do to get ready for radiation therapy?	
What kind of exercises should I do and how often?	

**Taken in part from:** *Questions to Ask about Breast Cancer: A workbook for women.* Canadian Cancer Society, 2006

**More questions available at:** The American Cancer Society, [www.cancer.org](http://www.cancer.org) (Find Support & Treatment section, Questions to Ask My Doctor About Breast Cancer)

# Hormone Therapy

The growth of some breast cancer cells is affected by estrogen, one of the female hormones in the body. Hormonal therapy medicines are systemic (whole body) treatment for hormone receptor-positive breast cancers. This therapy slows the growth and spread of breast cancer in two ways:

- Lowers the amount of estrogen in the body
- Blocks the action of estrogen on breast cancer cells

Because these drugs target estrogen, they are sometimes called anti-estrogen therapies. About 80% of breast cancers are estrogen receptor positive and 65% are also progesterone-receptor positive. About 13% of breast cancers are estrogen-receptor positive and progesterone-receptor negative. Only 2% of breast cancers are estrogen-receptor negative and progesterone-receptor positive. If a cancer is either estrogen or progesterone-receptor positive, it is said to be hormone–receptor positive.

Hormone therapy medications can be used to lower the risk of early stage hormone-receptor positive breast cancer from recurring and to shrink or slow the growth of advanced stage or metastatic hormone-receptor positive breast cancers. They can also be used to lower the risk of hormone-receptor positive breast cancer from developing in women who are at risk but have not yet been diagnosed with breast cancer. It should be noted that hormone therapy used for cancer treatment is not the same as hormone replacement therapy (HRT) used for the treatment of menopausal symptoms.

## ***Hormone Therapy Drugs***

Three kinds of drugs are used in hormonal therapy:

- aromatase inhibitors, drugs that prevent or inhibit estrogen from being produced
  - Arimidex (anastroxole)
  - Aromasin (exemestane)
  - Femara (letoxole)
- SERMs (Selective Estrogen Receptor Modulators)
  - Tamoxifen
  - Evista (raloxifene)
  - Fareston (toremifene)

- ERDs (Estrogen Receptor Downregulators)
  - Faslodex (fulvestrant)

Ovarian treatments are also used. Surgery to remove the ovaries and fallopian tubes, or drugs such as Zoladex (goserelin), that stop the ovaries from functioning as they normally would may be used.

### ***Side Effects of Hormonal Therapy***

Hormonal therapies do have side effects but they are usually milder than the side effects of chemotherapy and radiation therapy. Side effects will depend mainly on the specific drug or type of therapy used. Some serious side effects, such as blood clots, are possible but rare. Your health care team can tell you more and will help you make the best choices for you.

All types of hormonal therapy may lead to varying degrees of menopausal-like symptoms such as irregular menstrual periods, hot flashes, vaginal discharge or irritation. The symptoms usually stop when your treatment stops but sometimes menopause is permanent. The effects of having your ovaries removed are likely to be more severe than if you'd gone into menopause naturally. If you are premenopausal, it is possible that you could become pregnant – even if your periods stop – while you take anti-estrogen drugs. Talk to your health care team about birth control that doesn't affect your hormones (such as condoms or diaphragms).

**Hormone Therapy Side Effects Comparison Chart:**  
[www.breastcancer.org/treatment/hormonal/comp\\_chart](http://www.breastcancer.org/treatment/hormonal/comp_chart)

**Some content in this section from:** *Understanding Treatment for Breast Cancer: A guide for women*. Canadian Cancer Society, 2006

**For more detailed information on chemotherapy:**

- [www.cancer.org](http://www.cancer.org)
- [www.breastcancer.org](http://www.breastcancer.org)
- [www.cancer.ca](http://www.cancer.ca)

## Questions to Ask About Hormone Therapy

What is hormonal therapy?	
Will I need hormonal therapy? Why?	
What are the benefits and risks of hormonal therapy?	
What type of hormonal therapy will I be given?	
How will it be given? How often? Over what period of time?	
What are the possible side effects and long-term effects? How are they managed? Are there any permanent effects?	
Will I gain or lose weight?	
Are there things I should do or not do while having this treatment?	
Will hormonal therapy affect my usual activities? If so, how and for how long?	
Will I have to pay for any of the treatment?	

**Taken in part from:** *Questions to Ask about Breast Cancer: A workbook for women.* Canadian Cancer Society, 2006

**More questions available at:** The American Cancer Society, [www.cancer.org](http://www.cancer.org) (Find Support & Treatment section, Questions to Ask My Doctor About Breast Cancer)

# Targeted Therapies

Targeted cancer therapies are treatments that target specific characteristics of cancer cells such as a protein that allows the cancer cells to grow in a rapid or abnormal way. Targeted therapies are generally less likely than chemotherapy to harm normal healthy cells. Some targeted therapies are antibodies that work like the antibodies made naturally by our immune systems. These types of targeted therapies are sometimes called immune targeted therapies, immunotherapy or biological therapies.

## ***Drugs for Targeted Therapies***

There are currently six drugs being used for targeted therapy. Each has a slightly different mechanism of action in the body. These kinds of therapies are fairly new and are still undergoing study.

Herceptin (trastuzumab)	Tykerb (lapatinib)
Avastin (bevacizumab)	Perjeta (pertuzumab)
Afinitor (everolimus)	Kadcyla (T-DM1)

One of the more common drugs used, trastuzumab (brand name: Herceptin), is a targeted therapy that shows great promise for women whose breast cancers have an excess of the HER2 protein. The HER2 protein promotes tumor growth. Trastuzumab appears to work by interfering with one of the ways that breast cancer cells divide and grow and by stimulating the body's natural immune system to help destroy the cancer cells. It is given by injection and may be used with chemotherapy.

## ***Side Effects of Targeted Therapy***

Some women may be at increased risk of congestive heart failure while taking trastuzumab. It's important to talk to your health care team about the risks and benefits of this drug. Side effects of targeted therapy will vary. Some women experience flu-like symptoms, such as fever, chills, body aches, nausea, vomiting or loss of appetite. Side effects may also include a rash or swelling where the drugs have been injected. Talk to your health care team about how you can manage any side effects from biological therapy.

## Questions to Ask About Targeted Therapies

What is targeted therapy?	
What are the benefits and risks of targeted therapy?	
What type of targeted therapy will I be given, and why?	
How will it be given? How often? Over what period of time?	
What are the possible side effects and long-term effects? Are any of them permanent? How are they managed?	
Are there things I should do or not do while having this treatment?	
Will targeted therapy affect my usual activities? In what way? For how long?	
Will I have to pay for any of the treatments?	

**Taken in part from:** *Questions to Ask about Breast Cancer: A workbook for women.* Canadian Cancer Society, 2006

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# Clinical Trials

A clinical trial is a type of research study. Clinical trials help find new methods for diagnosing, treating, managing and preventing cancer. They are important because they show us what does and does not work in medicine. They answer important scientific questions and lead to future research. Through past clinical trials, doctors have developed new methods of surgery that are easier on the patient, found new and more effective drugs for specific types of cancer and found treatments that have fewer side effects. Cancer treatments that are in use today were first developed and tested in clinical trials. Many people who have cancer now live longer and also enjoy a better quality of life because of improvements to care made through clinical trials.

## *Types of Clinical Trials in Cancer Research*

**Cancer treatment trials** look for better ways to treat cancer and help improve cancer care. If a new or improved drug or treatment method is proven to be safe and works well, it can be made available to the public. Trials are the only reliable way to find out if new drugs and new methods of surgery or radiation are better than the cancer treatments currently being used. Studies may look at new types of treatment, such as gene therapy; how to combine therapies; or whether an existing drug can be used in a new way.

**Cancer prevention trials** look for ways to reduce the risk of developing cancer or prevent it from coming back. This may include using drugs, or making changes to lifestyle (for example diet or activity levels).

**Cancer screening trials** test the best ways to detect cancer, especially in its early stages.

**Quality-of-life trials** study ways to improve the comfort of people living with cancer or help them cope with the disease. These trials may study ways to reduce or manage nausea, fatigue, depression, pain and other problems caused by cancer or its treatment.

## *Phases of a Clinical Trial*

Before a clinical trial is launched, pre-clinical studies are carried out in the laboratory. Treatments that show promise in cell studies are then tested on laboratory animals. Only when the pre-clinical studies suggest that the new treatment is likely to be safe and effective in people can Health Canada approve



the treatment for further testing in clinical trials with people. Trials are carried out in four phases. Each phase is designed to answer specific questions.

- **Phase I Trials** look at how safe a treatment is and what the best dose of the medication is. Phase I trials are riskier than the later phases because this is the first time the new drug or therapy is being tested on humans. For this reason, Phase I trials usually involve only a small number of people with cancer (15 to 30). The first patients will receive a low dose of the treatment and are watched very closely. If there are no side effects or if the side effects are minor, the next group of patients will receive a higher dose. This continues until the doctors find the dose that works best with an acceptable level of side effects.
- **Phase II Trials** test how well new drugs or therapies work once they have been proven to be reasonably safe in Phase I. Usually a small group of people (fewer than 100) get the same treatment in this phase of a clinical trial. The goal is to find out how effective the treatment is and which types of cancer it might be used to treat. Researchers continue to collect information about side effects. Because the researchers know which side effects are most likely to occur from the Phase I studies, they can deal with them right away if necessary.
- **Phase III Trials** involve large groups of people (hundreds or thousands). In Phase III trials researchers compare treatments. They compare new treatments with the standard treatment. This means that everyone in the trial gets treatment. Researchers also gather more information about side effects that the new treatment may cause. Some Phase III trials are used to find out whether the new treatment is as effective as the standard treatment, with fewer side effects.

If a new drug or treatment proves to be safe and effective in Phase II trials, it can be submitted to Health Canada for approval. Once the treatment is approved, doctors can recommend it to all their patients. Some Phase II trials will study a new treatment even after it has been approved. Researchers may want to investigate new ways of using it and improving it. For example, they may want to try to reduce how often a medicine is given (dosing) or look for ways to lessen the side effects, while maintaining effectiveness.

- **Phase IV Trials** watch for long-term risks and benefits of the treatment and possible rare side effects. They may also look for added benefits of the

treatment. For example, a new drug may have been approved because it reduces the chance of the cancer coming back; however researchers want to see if this also means that the treatment helps people live longer.

### ***Trial Design***

Different methods are used to compare treatments. Patients taking part in a study are put into groups. Which patients go into which group is determined by chance, much like flipping a coin. This is called randomization. Patients are put into either a group taking the new treatment (called the experimental group) or a group taking a standard treatment (called the control group). Each of these groups is called a study arm.

- **Randomized Trials** – A computer will assign patients at random to each of the study arms so that all groups have a similar mix of patients of different ages, sex and states of health. If one group does better than the other group, it's likely because of the treatment, as the two groups are the same in many ways.
- **Controls in Trials** – The control group is a very important part of a trial. Researchers compare the new treatment to the standard treatment (received by the control group) to see if the new treatment is more effective or has fewer side effects. Without a control group, researchers would not be able to tell if the improvements in the patients were due to the new treatment or to chance.
- **Blinded Trials** – In a blinded trial, the researcher will know whether you are in the control group or the experimental group but you will not. This is because knowing what treatment you are getting can affect how you feel; more positive or more negative. This could influence the results of the study and make the research less reliable. In a double-blind trial, neither the patients nor the researchers working with them know which treatment group the patients are in or what treatment they are getting. This is done so that the researchers are not consciously influenced to expect or report better results for patients receiving the new treatment.
- **Open and Closed Trials** – Open trials are studies that are still looking for patients to take part. Closed trials are no longer accepting new participants. Once a closed trial is completed and the information has been analyzed, researchers will submit the results for review and publication in a medical journal.

### ***Finding Out What is Available and Appropriate for Me***

If you are thinking of participating in a clinical trial, talk to your doctors or another member of your health care team. They should be aware of which clinical trials are being done in your area and help you find out if you are eligible.

You can do your own research into clinical trials at:

- [www.cancerview.ca](http://www.cancerview.ca)
- [www.canadiancancertrials.ca](http://www.canadiancancertrials.ca)
- [www.breastcancer.org/treatment/clinical\\_trials](http://www.breastcancer.org/treatment/clinical_trials)
- [www.nih.gov/health/clinicaltrials](http://www.nih.gov/health/clinicaltrials)

### ***Implications of Participating in a Clinical Trial***

Research has shown that women are most influenced to become involved with clinical trials based on their perception of the risks involved. As such, it will be important for you to clearly understand the risks and benefits of any clinical trial you are considering.

#### **Possible Benefits**

- You may receive treatment that is not otherwise available which might be safer or more effective than current treatment options.
- Even if you do not receive the new treatments being tested, you can be sure that you will receive the best standard cancer treatment available.
- You may benefit from the extra follow-up care provided for participants.
- You take an active role in a decision that affects your life. This can be personally empowering and give you a sense of control.
- You have a chance to help others and to improve how cancer is treated.

#### **Possible Risks**

- New treatments under study are not always better than, or as good as, the standard ones.
- There may be unexpected side effects that may be more than those caused by standard treatments. Your trial team will carefully watch your reactions during the study.
- The new treatment may not work for you even if it helps others. This is true for all treatments, even the ones that are currently used as standard treatments.
- Being in a trial may take more time than standard treatment would or it may be inconvenient. You may need to have more tests or take extra medications.

You will be required to give informed consent before taking part in a clinical trial. You will receive a printed informed consent form that outlines key facts about the study in plain language. The form should include details about the treatment, tests and any potential benefits, risks or side effects of the treatment. It should explain everything you are required to do. If you agree to take part in the study, you will be asked to sign the consent form and you will be given a copy. Even after you have given consent, you can leave the trial at any time. You do not have to give a reason. If you are receiving the new treatment in the trial, you may not be able to continue but will be given the best standard treatment available for your type of cancer. Personal information will still be kept private and confidential.

## Questions to Ask About Clinical Trials

Why is this study being done?	
Why do researchers believe the new treatment being tested may be effective?	
Has the treatment been tested before?	
Who is funding the study? Who has reviewed and approved it?	
What is the standard treatment for the type of cancer I have?	
What is likely to happen in my case, with or without this new research treatment?	
What are the possible short-term and long-term risks, side effects and benefits to me of this new treatment or approach?	
How do these risks and benefits compare with the risks and benefits of standard treatment?	
What kinds of treatment, medical tests or procedures will I receive during the study?	
How do they compare with what I would receive if I do not take part in the study?	
How often and for how long will I receive the treatment?	
How long will I need to remain in the study?	
Where will my treatment take place?	
How will I know if the treatment is working?	
Who will be in charge of my care?	
Will I be able to see my own doctor?	
Will there be follow-up after the study? For how long?	
Will the study require extra time, work	

or expenses on my part?	
If I need to travel, will my expenses be paid back?	
What does my family need to know about the treatment? Can they help?	
Can I talk to other people who are in this study?	
What support is there in the community for me and my family?	

**Resource credit for this section:** *Clinical Trials: A guide for people with cancer.* Canadian Cancer Society, 2007

## Complementary and Alternative Options

Complementary and alternative medicine (CAM) includes a wide variety of therapies, botanicals, nutritional products and practices. These forms of treatment are used in addition to (complementary) or instead of (alternative) standard treatments; it is important to make this distinction. For example, a complementary therapy can be choosing care from a naturopathic doctor or using herbal medicine together with conventional cancer treatment. An alternative therapy is deciding to not use conventional care and only use these other therapies for cancer. However, in the community, complementary and alternative therapies are used in an effort to prevent illness, reduce stress, prevent or reduce side effects and symptoms, or control or cure disease.

Conventional cancer treatments are those accepted and widely used today to treat people in the Canadian health care system. These are treatments that are backed by scientific research, proving that they improve outcomes and quality of life for people with cancer. Conventional treatments are approved by Health Canada and include surgery, chemotherapy, radiation and other therapies that focus on interfering with the cancer's ability to grow and spread.

Mainstream medicine has come a long way in accepting the use of non-conventional therapies in conjunction with conventional medicine for cancer care. More and more integrative cancer care centers are being developed that utilize a comprehensive, holistic approach to treating people with cancer. At these centers, complementary therapies are offered along with conventional treatments by a team of health professionals from both fields. Mainstream medicine, however, does not consider non-conventional therapies as curative. Rather non-conventional therapies are seen as a means to help ease some of the symptoms of conventional treatment such as pain and nausea and to help the client better cope with cancer, its treatments or side effects. Mainstream medicine does not feel that the non-conventional therapies that claim to cure cancer have been through rigorous enough testing using scientific methodology to make these claims.

There was a time when the scientific community outright rejected and ridiculed non-conventional healing approaches but this has shifted over the years. The National Library of Medicine's database contains over 40,000 articles on alternative and complementary medicine with over 1,600 articles on herbal medicine alone. Meditation, yoga, massage, Ayurveda, energy work, herbal and nutritional approaches are increasingly being investigated and embraced as tools



for healing. This is, in part, due to a greater acceptance of a more holistic definition of health as more than just the absence of disease, but rather, balance among the physical, mental, emotional and spiritual aspects of an individual's life.

The purely alternative healing community and the conventional medicine community will likely always be at odds. The mainstream community will likely always be skeptical of the research methodologies and claims made by alternative approaches. The alternative community will likely always be skeptical of mainstream research that is funded by pharmaceutical companies or other for-profit entities. It comes down to individuals making a personal decision. The answer is not the same for everyone. What should be the same for everyone is a sound process for coming to a safe informed choice, which includes:

- Understanding the differences between conventional, complementary, integrative and alternative approaches to cancer treatment
- Finding out as much as you can about all the therapies you are considering, both conventional and non-conventional, holding them all up to equal scrutiny
- Being open with your health care team about your desire to either integrate non-conventional therapies with conventional or utilize alternative therapies entirely so that honest discussions can be had.

It's important you inform your health care team about any non-conventional therapies you are using and to request that they work cooperatively with these other care providers. If using alternative therapies alone, you do take the risk of delaying treatments whose efficacy is more clearly documented in the research literature than the alternative methods. It will be important to maintain contact with your oncologist in case you decide you want to have conventional treatment later on. Your oncologist can monitor your progress, even if you are using alternative therapies.

**For more information on integrative cancer care go to:** Inspire Health Integrative Cancer Care at [www.inspirehealth.ca](http://www.inspirehealth.ca)

"I wish I'd had more courage to insist that he talk to the "other side." I think he would have – I just didn't have the confidence to insist."

### ***Acupuncture and Traditional Chinese Medicine***

Traditional Chinese Medicine (TCM) is a broad range of medicine practices sharing common theoretical concepts that were developed in China over 2,000

years ago. It includes some forms of herbal therapy, acupuncture, massage, exercise, and dietary therapy. Acupuncture and herbal therapy are likely the most commonly used by westerners. TCM is mainly concerned with the identification of functional entities which regulate digestion, breathing, aging, and other functions. While health is perceived as harmonious interaction of these entities and the outside world, disease is interpreted as a disharmony interaction.

TCM herbs sold in Canada are governed by Health Canada rules for all natural health products. The use of such herbs while being treated with conventional treatments is generally not recommended because of the risk for drug interactions. For this reason, many cancer surgeons will ask you to discontinue the use of your herbs two to three weeks prior to surgery. Talk to your doctor if you wish to continue taking TCM herbs through cancer treatment.

Acupuncture is based on the belief that qi (pronounced chee), or vital energy, flows through your body along a network of channels called meridians. Qi is said to affect your spiritual, mental and physical health. Studies have found that acupuncture may help treat nausea and vomiting caused by chemotherapy. You may also find it useful for easing some types of cancer-related pain, hot flashes, fatigue and anxiety. The most common acupuncture method uses very thin, disposable, stainless steel needles inserted through your skin at certain points on your body. The needles are left in place for a short time (30 to 45 minutes). Sterile needles are particularly important when you have cancer because chemotherapy and radiation therapy can weaken your immune system. Acupuncture is generally thought to be safe. It may not be a good idea if you have low white blood cell or platelet counts or if you have lymphedema. Talk to your doctor before starting acupuncture treatments.

### **Aromatherapy**

Aromatherapy is the practice of using essential oils, mostly from plants, to change your mood or to improve your health. The use of essential oils goes back thousands of years by various cultures for bathing, cosmetic and medicinal purposes. Aromatherapy is thought to work through scent receptors in your nose, which send messages to your brain and affect heart rate, blood pressure and breathing. Essential oils are usually rubbed into your skin or absorbed from bath water. They can be inhaled through the air if the oil is put into steaming water, diffusers or humidifiers.

Essential oils may help to lower stress, tension and anxiety; promote a sense of calm or well being; lessen pain; ease nausea; and promote sleep. A few side

effects of essential oils have been reported including skin reactions and breathing problems, but generally they are considered safe.

### **Art Therapy**

Art therapy is based on the idea that being creative can be healing and can help you express fear, anxiety or hidden emotions to lower stress. You may find art therapy helpful for dealing with your fears and emotions about cancer. An art therapist will encourage you to express feelings or emotions such as fear, anger or isolation through painting, drawing, sculpting or other types of artwork. You will then talk about your feelings and emotions as they relate to your art.

### **Ayurveda**

The practice of Ayurveda dates back to India more than 5,000 years. The word, Ayurveda, comes from two Sanskrit words, Ayus, meaning life, and Veda, meaning knowledge or science. Therefore, Ayurveda is usually translated to mean the science of life. The guiding principle of Ayurveda is that the mind exerts the deepest influence on the body and freedom from sickness depends upon contacting our own awareness, bringing it into balance and extending that balance to the body. This kind of balanced awareness creates higher states of health. Ayurveda includes meditation, yoga, and techniques (diet, herbs, cleansing, massage and daily and seasonal routines) to rid the body of ama, toxic residue from undigested food, ideas, emotions and information from the environment that is thought to cause illness by blocking subtle circulatory channels called srotas, similar to the TCM concept of meridians.

Contrary to western medicine's depiction of cancer in terms of invasions and battles, Ayurveda views cancer cells as elements of the mind-body system that have lost their memory of wholeness so the patterns of intelligence that maintain healthy boundaries in the physiology have become distorted and fragmented. The renegade cells, having forgotten their true purpose in life, become insensitive to the needs of other cells, destroying their environments and eventually themselves. Ayurvedic treatments surround the cancer patient with a healing environment that supports their inner exploration and visualization of wholeness. Meditation is used for this purpose and to calm anxieties and worries. Integration of mind and body is facilitated through yoga and yogic breathing exercises.

Ayurvedic therapy includes education on nutrition and panchakarma (a series of therapeutic treatments that cleanse the body) detoxification therapies to encourage the release of deep-rooted stress. Herbs are used for both

detoxification and rejuvenation, as well as to treat nausea or other physical side effects of treatments. Visualization and aromatherapy are also used. Ayurveda is commonly used in conjunction with western medicine because it is believed that the ancient wisdom of the sages, which we now know is supported by quantum physics, can be very complementary to modern medical science. Ayurvedic physicians in North America are usually western trained physicians who have taken additional training (often in India) in Ayurveda. Other practitioners are certified to teach the principles of Ayurveda and guide people in adopting a more balanced, healthy lifestyle.

### **Biofeedback**

Biofeedback is a type of mind-body therapy used to improve quality of life. It uses simple machines to teach you how to control certain body functions such as heart rate, blood pressure, temperature, sweating and muscle tension. Using biofeedback can help your muscle strengthening exercises be more effective. Research has shown that biofeedback can also be helpful if you are trying to regain urinary and bowel function after cancer surgery and for easing some types of chronic pain. Biofeedback is thought to be safe and non-invasive, however a trained and qualified professional should teach you to use the machines, interpret changes and watch you closely while using this therapy.

### **Diet and Pharmacological Treatments**

A number of dietary approaches have been described in the complementary and alternative literature that support general health and are promoted as having anti-cancer and cancer treating properties. These include:

- |                       |                          |                       |
|-----------------------|--------------------------|-----------------------|
| • Anti-oxidants       | • Co-Enzyme Q10          | • Vitamin E           |
| • Gerson Therapy      | • Gonzalez Regime        | • Lycopene            |
| • Melatonin           | • Vitamin D              | • Pomegranate         |
| • Probiotics          | • Soy                    | • Tea                 |
| • Vitamin C High Dose | • Modified Citrus Pectin | • Dietary Supplements |

The National Cancer Institute has downloadable information sheets (PDQs) on each of the above topics as they relate to cancer prevention or treatment at:

[www.cancer.gov/cancertopics/pdq/cam/topics-in-cam/patient/page5](http://www.cancer.gov/cancertopics/pdq/cam/topics-in-cam/patient/page5)

Similarly, a number of pharmacologic agents are also identified in the complementary and alternative literature that have been shown to have positive effects in the treatment of cancer. These include:

- 714 X
- Cancell/Cantron/Protocol
- Hydrazine Sulphate
- Newcastle Disease Virus (NDV)
- Antineoplastons
- Cartilage (bovin & shark)
- Laetrile/Amygdalin

Handouts on these topics can also be found on the National Cancer Institute website at:  
[www.cancer.gov/cancertopics/pdq/cam/topics-in-cam/patient/page6](http://www.cancer.gov/cancertopics/pdq/cam/topics-in-cam/patient/page6)

## **Energy Medicine**

Energy medicine (or biofield therapy) focuses on the energy fields that are said to flow within and around your body. Energy medicine is based on the belief that changing the energy fields with gentle pressure or placing the hands in or through your energy fields can affect healing and wellness. Common forms of energy medicine include healing touch, Reiki, Body Talk and therapeutic touch. These therapies have mainly been used to erase symptoms of cancer or side effects of treatments such as anxiety, fatigue, pain, nausea or vomiting. Energy medicine is generally considered safe and few side effects have been reported. However, these therapies are not regulated in Canada.

## **Guided Imagery**

Guided imagery (or visualization) is a type of mind-body therapy. You close your eyes and imagine scenes, sounds, smells or other sensations to help your body relax or to improve your health and well-being. There are many different types of guided imagery. For people with cancer, a common method is to imagine your body fighting and beating cancer. Guided imagery may help you reduce some of the side effects of cancer treatments including nausea and vomiting, and lower anxiety and pain during medical procedures. Studies have also shown that guided imagery can ease tension, stress and fatigue. Imagery techniques are thought to be safe when done by a trained mental health practitioner.

## **Hypnosis**

Hypnosis is a state of relaxed and focused attention in which you are helped by positive suggestions from a therapist (hypnotherapist). Hypnosis is a medically accepted type of mind-body therapy. During hypnosis, the therapist leads you into a deeply relaxed state in which you feel separate, but still aware, of what is going on around you. Your therapist will then use suggestion to help you in different ways to gain control over certain symptoms or change some behaviour.

Several studies have shown that hypnosis can help with anxiety, depression and mood in people with cancer. Hypnosis and relaxation may also be helpful in

reducing chemotherapy-related nausea and vomiting and ease pain. Most side effects of hypnosis don't last very long. Side effects may include fatigue, anxiety, confusion, fainting and dizziness. Serious reactions may include seizures, lasting psychological problems and bringing back memories of earlier trauma. It is important to have hypnosis done by a trained professional.

### **Massage Therapy**

Massage is the treatment of the muscles and soft tissues in your body. Massage therapy has been used to help ease muscle soreness as well as stiffness, pain, anxiety and stress. It can also improve your circulation and promote relaxation and a sense of well-being. Generally, gentle massage can be adapted to meet the needs of people with cancer. There is evidence that massage can help people with cancer both physically and emotionally. Research has shown that it can help you lower stress, anxiety, nausea, pain, fatigue and lessen problems with sleeping.

There are many kinds of massage, such as reflexology, Thai massage, deep tissue massage and lymphatic massage. Talk to your doctor about what type of massage is safe for your type of cancer. Deep tissue massage may not be safe if you have osteoporosis, a bleeding disorder, cancer that has spread to the bone or bone problems during your cancer treatment. It is important to have massage done by a registered massage therapist experienced with cancer.

### **Meditation**

Meditation is used to relax your body and calm your mind. It involves focusing your attention and letting go of thoughts that normally occupy your mind. You can use focused breathing, repeat certain words or phrases (a mantra) or focus on an object to get yourself into the "gap" between your thoughts. There are many different types and styles of meditation. Meditation may be done while sitting or lying down. There are also moving forms of meditation such as tai chi, qigong, walking meditations, kundilini meditations and aikido. Meditation can be self-directed or guided by a trained professional.

Meditation can help you lower anxiety, stress, blood pressure, chronic pain and insomnia. It may help improve your quality of life and help you feel more in control and grounded. Problems rarely occur with meditation but some people may become disoriented or anxious. Talk to your doctor before starting any type of meditation that involves moving your joints and muscles such as qigong or martial arts.



## **Music Therapy**

Music therapy is a creative outlet that promotes healing and enhances quality of life. It can help encourage emotional expression, promote social contact and ease your symptoms. During music therapy you listen to music or use musical instruments under the guidance of a music therapist. There is evidence that music therapy can help you lower pain and relieve nausea and vomiting caused by chemotherapy. It may also help you ease stress and give you an overall sense of well-being. Some studies have found that music therapy can lower your heart rate, blood pressure and breathing rate.

## **Tai Chi & Qi Gong**

Tai chi (pronounced *ti chee*, & *chee gong*) are ancient Chinese martial arts that combine slow body movements, meditation and breathing exercises to improve your health and well-being. When doing these practices you move your body deliberately and gently, while breathing deeply and meditating. Many practitioners believe that they help energy, or qi, flow throughout the body. Like most moderate exercise they can improve your stamina, muscle tone, agility and flexibility. The breathing exercises may help lower your stress. Early research has shown that these practices improve quality of life in breast cancer survivors. If you suffer from muscle or bone problems, talk to your doctor before starting these activities.

## **Yoga**

Yoga is a form of exercise that uses a series of stretches and poses, breathing exercises and meditation. There are many different types of yoga. Lyengar and Hatha are two popular types of yoga. Some studies have found that yoga is helpful for people with cancer who have problems with sleep. Other research has shown that yoga can be used to control blood pressure, heart rate, breathing, metabolism and body temperature. Yoga may improve your physical fitness and well-being, lower your stress and help you feel more relaxed.

Talk to your doctor before starting any kind of therapy that requires movement of your joints and muscles. Side effects from yoga are rare and some yoga postures are hard to do. Overstretching joints and ligaments can cause injury. Yoga may not be a good idea if you have bone metastases and are at risk of fractures. Look for a yoga teacher with some training in working with people with cancer.

## Questions to Ask About Complementary and Alternative Options

Is it safe?	
What resources do I have available to me?	
How involved do I want to be?	
How do my choices of therapies work together?	
How will I know that it's helping me?	
What are the qualifications of the therapist?	
Is my doctor willing to work with a complementary or alternative therapist?	
Is the product or supplement regulated by Health Canada?	

**Content credit for this section (in part):** *Complementary Therapies: A guide for people with cancer.* Canadian Cancer Society, 2009





# Post-Surgical Issues

*Scars have the strange power to remind us that our past is real.*

Cormac McCarthy

## What To Expect

### *Stages of Healing*

The progress of your healing will depend on a number of variables including the extent of your surgery and your general level of health and fitness before your surgery. If you have had chemotherapy prior to surgery you will be in a more depleted state so healing will likely progress at a slower pace. Generally the healing process is divided into three stages:

- Immediately after surgery until your drain is removed (usually five to seven days, but it could be significantly longer in some women)
- Five to seven days after surgery (or after your drain is removed), up to six weeks after surgery
- Over 6 weeks post-surgery

As you progress through these stages you will be increasing your activity level accordingly. The suggestions for activity and exercise are only guidelines; you will need to tailor these to your own individual needs and circumstances. The most important issues with regard to activity and exercise relate to your surgical drain. While you are encouraged to begin to move your affected arm as normally as possible within the limits of your pain, please note the following warning:

**Until your surgical drains have been removed, do not raise the affected arm above 90 degrees (straight out from your shoulder) when doing household activities or the recommended exercises.**

**Do not lift anything more than one kilogram (about 2.5 pounds) for the first two weeks after surgery and more than four kilograms (about 10 pounds) for another four weeks after surgery (week six after surgery).**

**Do not lift anything over your head for the first six weeks after surgery.**

### ***Immediately After Surgery***

You may have your surgery in a day surgery or outpatient department of the hospital and be home by the end of the day or you may have your surgery, stay overnight in the hospital and go home the next day.

It is usual to feel some pain or discomfort across your chest and shoulder right after surgery. It is important to get control of your pain right away, so do not hesitate to ask for the pain medication that your doctor has ordered for you. Once you are home you will either use a prescription for pain from your doctor or a non-prescription pain reliever.

After your surgery you may feel numbness, tingling, burning, a sense of tightness or weakness. These sensations may disappear within six months to one year after surgery. Sensations may be diminished near the operated area and the inner part of your upper arm since nerves were affected during the surgery. If you have reduced sensation under your arm, you should only use an electric razor to shave your underarms to prevent cuts and infection.

You may also feel a bit of nausea because of the anesthetic. You can request medication to help your stomach feel more settled. You will have an IV running initially until you are able to tolerate fluids orally. You will likely have a small amount of solid food before you leave the hospital. As your appetite returns you can begin to have small, frequent meals when you are back home.

### **Arrange for a friend or family member to take you home and stay with you for at least the first 24 hours.**

In the first few days at home after surgery, your biggest concerns will be keeping your dressings dry, taking care of your drain and starting to move again. As soon as you are able, begin to do your own care like grooming, eating and dressing, using very gentle movements. Walk around your home, or your neighbourhood (accompanied), as much as your energy will permit but do not overdo it. Pay attention to your posture as you move and sit. Do some deep breathing to get your lungs moving again (about 5 deep breaths through your nose) every hour while you are awake. You can begin the gentle “drain in” exercises that are noted later in this binder.

### ***Dressings And Drains***

Your incision will be covered with dressings which will likely be changed before you leave the hospital. Underneath the dressing, stitches, staples or adhesive strips will be holding your incision closed. You may also have a drain in place to remove fluid from the surgical site. Pay attention to how the nurse is doing your dressing change and ask questions in case you have to do your own dressing

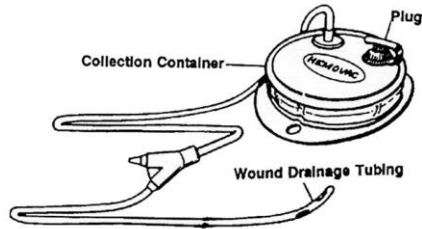
change, or reinforce it, at home. **It is important to keep your dressings dry.** Every health region's procedures are a little different when it comes to Home Care nursing. In some cases, the Home Care nurse will come to your home but in other cases you will need to go to a Treatment Centre for dressing changes.

You should be given instructions at discharge about the care of your incisions and dressings and how to use the drain. If you have a bit of drainage coming through your dressing you can reinforce it with a bit of gauze taped in place. Be careful about the type of tape you use with your dressings; if you have an allergy to latex be sure to let the nurses know. A tensor bandage can be applied for more support and comfort. Latex free tape can be purchased in most drug stores. Unless you have dissolvable stitches, the stitches or staples will be removed either by your doctor or the Home Care nurse. The Home Care nurse will also remove your drain.

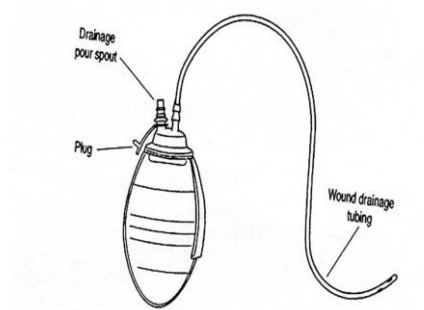
The day after surgery you should be able to have a bath or shower. If you have a shower you must be very careful to not get your dressings wet. Position yourself so that the stream of water is directed away from your incision and dressing. Having a shallow tub bath might be easier to manage but **do not soak your incision** before the drains have been removed and the incision is completely healed.

The doctor may have inserted one or two of the drains, identified below, during your surgery to remove fluid from the incision site. A small plastic tube is inserted through the skin near your incision to allow fluid and blood to drain from the wound to speed up healing. The surgeon attaches this tube to a container that is later emptied by the nurse in the hospital and then you at home. You will need to empty the container at least twice a day, or as needed, measure the drainage and keep track of the amount of drainage for every 24 hour period. If there is any leakage around the drain simply apply a gauze dressing. Your drain is kept in place with a stitch and will not fall out easily. Use a safety pin to secure your drain to your clothing at waist level. You should have received instructions about emptying the drain before leaving the hospital but the Home Care nurse will be able to remind you about how this is done or assist you, if needed. You should also be taught how to milk the drain to prevent clot formation.

## Hemo-vac Drain



## Jackson-Pratt Drain



### To Empty The Drain:

- Wash your hands with soap and water.
- Try not to touch the tip of the drain plug or spout. Avoid tugging on the tubing that goes into the site.
- Open the 'post' or remove the plug and empty the fluid into a measuring container. Record the amount of fluid and the time. Discard the fluid into the toilet.
- To re-establish suction, squeeze the drain on both sides until it appears flat. While maintaining this pressure, close the post or replace the plug and slowly release your grip. The drain should remain somewhat flat, not fully inflated.
- Wash your hands with soap and water.

### **Weeks 1 to 6**

Normally, over time, the drainage from your incision will change in colour from clear red, to clear pink and then to clear yellow. There should be minimal odour. Your doctor or the Home Care nurse will remove the drain when there is minimal drainage (less than 25 to 30 mL, about 2 tablespoons) in 24 hours. When the drain is removed you may feel a pulling sensation with a little pain for a few seconds. A bandage will be placed over the drain site. You may notice some discharge from the site of the drain after it is removed. The drain site should close within three or four days.

After the Home Care nurse removes your dressing, you can keep a small gauze dressing over your incision and change it as necessary. Keep the dressing dry and clean. Some drainage of fluid from the incision may occur for up to ten days after the surgery (or longer). This fluid may be somewhat red in colour. This is normal.

You may shower normally or take a bath once the original dressing and drain are removed. Use a mild soap and water to gently wash gently over your incision; do not use any other cleanser or ointment on your incision unless advised by your surgeon. If there are adhesive strips on your incision these can be removed at about day ten if the incision is healing well. Please note that you may have a blue-green tinge to your skin where dye was injected during the sentinel node biopsy, if you had one. This can last for several months.

Continue to control your pain and nausea in order to accelerate your recovery. Every one experiences different levels of pain after surgery. Use the prescriptions your surgeon gave you, as instructed. If you feel your pain is not being well-controlled, contact your doctor. If the pain is easing or you find the prescription pain reliever too strong, you can switch to extra strength Tylenol and Gravol as needed. Some pain medications cause constipation. Use a stool softener like Colase, if needed, or a mild laxative such as Senokot. Be sure to drink plenty of fluids and eat high fiber foods.

**Notify Your Doctor Immediately If:**

- The drain falls out. If this happens, cover the site with a clean gauze dressing or a large Band-Aid.
- Redness or swelling develops beyond the incision or drain sites.
- There is a significant change in the drainage or it develops a strong odour.
- The pain or discomfort over your incision or drain sites increases (this should be easing with time).
- You notice fluid build-up around the incision.

## **Complications**

In addition to the above issues, here are a couple possible complications you should be watching for.

- **Seroma**

A seroma is a collection of fluid under the skin after surgery. It is common and very treatable, and does not indicate that you will have worse cosmetic results. It can occur whether you have had a drain in place or not. Applying a tensor bandage can provide some comfort. Your body will eventually re-absorb this fluid, but if there is a large amount of fluid, it may need to be drained. If necessary, the seroma can be drained at your surgeon's office, so you do not have to go to the Emergency Department unless you have signs of infection. Signs of infection include a fever (over 38 C or 100.4 F) and chills, increased redness, swelling, tenderness at your incision site, a change in the colour of the drainage and/or a foul smelling discharge.

- **Lymphedema**

This topic will be covered in detail below but if you notice swelling in your chest or arm that is not decreasing over time, you may be experiencing the early signs of lymphedema. It is difficult to distinguish normal post-surgical swelling in the breast, armpit and arm areas from early lymphedema. Generally, post-surgical swelling decreases over time, whereas lymphedema swelling does not, or gets worse. You should have had pre-surgery arm measurements taken. Repeating these and comparing them over time may give you a sense of whether or not the swelling is increasing.

Lymphedema is swelling caused by a buildup of lymph fluid in part of the body. The swelling may happen because lymph nodes, which normally act as filters, aren't able to do their job because they were removed by surgery or damaged by radiation or the cancer itself. Lymphedema can happen soon after treatment, months or even years later. It can be temporary if caught early, however may become a long-term condition. Following the activity and exercise recommendations is a very important part of lymphedema prevention. In particular, avoid raising your arm over 90 degrees while you still have your drain in, avoiding lifting for the first six weeks post surgery, and do not lift anything over your head.

The most important thing to do if you suspect you are developing lymphedema is to get a referral to physical therapy or to a therapist with special training in the assessment and treatment of lymphedema. If there is a wait to get into these services in your health region, a private physical



therapist or massage therapist with knowledge or training in manual lymphatic drainage could be helpful to you while you wait. You can learn self-massage techniques and other ways to reduce swelling and keep lymphedema from progressing.

## Returning to Activity – Weeks 1 to 6

Your ability to carry out activities of daily living and the recommended exercises depends on how extensive your surgery was, how quickly your body heals, how well you have been able to control your pain and whether or not you had neck or shoulder issues prior to surgery. Exercise is an important part of your treatment and can help you to become more independent with your daily activities such as bathing and dressing. Exercise will help to maintain movement in your arm and shoulder, improve muscle tone, decrease joint stiffness and reduce pain in the neck and back areas. It can also improve your overall feeling of well-being.

Everyone is different – you will heal at your own pace. The timelines, exercises and activities suggested are only guidelines. Simple exercises are started right after surgery; while exercises that involve moving your shoulders and arms can be started after your drain is removed. Strengthening and general conditioning exercises are added much later when you have healed more.

### ***General Guidelines***

- Wear comfortable, loose clothing that is easy to take on and off (tops with buttons in the front). Women who have had a lumpectomy can wear a supportive sports type bra (no underwire) with light gauze over the incision, once the original dressing is removed. Women who have had a mastectomy may find a light cotton camisole comfortable after the larger dressing is removed.
- Use your affected arm for light activities around the house like grooming and dressing. Begin the first day after surgery. Do not get out of bed using the arm that was operated on or on the side of the surgery.
- Do not raise your arm over 90 degrees (straight out from your shoulder) until AFTER your drains have been removed. Do not lift anything over your head for the first six weeks after surgery.
- Do not drive if you are taking medications that contain narcotics or any other medication that make you feel drowsy. Do not drive while you still have your drain in.

- Do not use your affected arm for moderate or heavy activities such as carrying groceries, vacuuming, lifting or doing workouts in the gym for the first four to six weeks after surgery. Do not lift more than 1 kg (about 2.5 pounds) during weeks one and two after surgery. Do not lift more than 4 kg (about 10 pounds) during weeks three to six after surgery.
- Do not carry a purse or back pack on the affected side.
- Slowly increase activities of daily living as you can tolerate them.
- Go for frequent short walks and gradually increase your distance, speed and length. Aim for 20 to 30 minutes of brisk walking up to five times per week or three 10-minute walks daily. It could take several months to achieve this level of activity depending on your recovery and how fit you were prior to surgery.
- Resuming sexual activity will vary from person to person. You need to be careful to protect your affected side until incisions have completely healed and movement is comfortable.
- Exercise after a warm shower when your muscles are warm and relaxed.
- Take your pain medication 30 minutes prior to exercising, if needed.
- Breathe deeply and often as you do each exercise.
- Exercise for short periods, three times per day, rather than one long session.
- Do the exercises until you feel a gentle stretch; not pain. Movements should initially be slow and controlled. Avoid bouncing or jerky movements.
- Do not over-exercise. Exercises and daily activities should not be painful. Increased pain and swelling may be signs that you are doing too much. If pain after activity or exercise does not go away after about two hours, delay doing any further exercise until the pain completely goes away. Build up your exercises gradually. After experiencing pain, you may need to back off the intensity of your exercises and then gradually rebuild.
- Contact your doctor if you have any unexplained swelling or pain.

### ***Exercises for When the Drain Is Still In***

Because of the post-surgical tightness across your chest and shoulders, you may find it difficult to sit or stand upright. Practice correct posture several times a day, either sitting or standing. Doing this in front of a mirror is sometimes helpful. Have your friends or family remind you if they see you slouching or tilting your head to the affected side. Several times throughout the day, do a series of five



deep, belly breaths. Breathe in through your nose and feel your stomach move outwards. Exhale slowly through your mouth.

The video that accompanies this binder demonstrates each of the following exercises for when the drain is still in.

1. Chin to Chest
2. Chin Tuck
3. Ear to Shoulder
4. Neck Rotation
5. Shoulder Blade Squeeze
6. Elbow Curls
7. Hand and Finger Movements

***Exercises Following Drain Removal And Up To Six Weeks After Surgery.***

The video that accompanies this binder demonstrates each of the following exercises.

1. Open Arms
2. Behind the Back Exercise
3. Overhead Exercise
4. Elbow Press
5. Snow Angel
6. Table Slides
7. Corner Stretch/Doorway Climb
8. Skin Stretch

***Exercises After six Weeks***

The video that accompanies this binder demonstrates each of the following exercises

1. Rowing
  - a. Elbows Low
  - b. Elbows High
2. Open Arms
3. Hitchhiker
4. Elbow Curls
5. Wall Push-ups

## Other Post-Surgery Issues

### **Nutrition**

Good nutrition is vital at every stage of your cancer treatment and recovery. Eating well gives you energy, helps you feel better and keeps your body strong so that you can cope with side effects from treatment. It will also help you heal and recover after treatment.

People's responses to food during their cancer experience vary widely. Some continue to enjoy eating and their appetite stays strong. Others find that when they need to eat well, they feel unable to do so. Side effects or emotions like fear and anxiety can make eating more challenging. To help you eat well during difficult times you might:

- Try to present your food in an attractive way on the plate to make it more appealing.
- Make mealtimes relaxed and pleasant. Try music or soft lighting, if this helps.
- Experiment with different foods. Some food that didn't taste good before might taste good now.
- Remind yourself that eating difficulties are temporary. Try to be patient and know that you will be able to eat with pleasure again – perhaps as soon as tomorrow.

Try to make your food choices as balanced and varied as possible so that your body gets all the nutrients it needs. Weight loss is common in cancer patients however, weight gain is also possible. Many people with cancer, especially those who are losing weight or who have side effects that affect their ability to eat well, need to make changes to what they eat – perhaps by “building up” their diet with extra protein and calories.

**The above information was taken from:** *Eating Well When You Have Cancer: A guide to good nutrition*, Canadian Cancer Society, 2008. This is a very detailed and comprehensive examination of the topic of nutrition for cancer patients and is highly recommended reading.

### **Cookbooks That Are Highly Recommended:**

- The World's Healthiest Foods: Essential Guild for the healthiest way of eating by George Mateljan, founder of Healthy Valley Foods.
- Crazy Sexy Diet: Eat Your Veggies, Ignite Your Spark and Life Like You Mean It by Kris Carr
- Crazy Sexy Kitchen: 150 Plant-Empowered Recipes to Ignite a Mouthwatering Revolution by Kris Carr

Some women find that adding nutritious home-made smoothies to their diets helpful. There are an endless number of web sites and recipes but here are a few that were recommended:

- **Juice Baby Juice** - [www.youtube.com/watch?v=RLp2kx27VU](http://www.youtube.com/watch?v=RLp2kx27VU)
- **Blend It and Mend It** - [www.blenditandmendit.com](http://www.blenditandmendit.com)
- **Montel Williams** - <http://montelwilliams.com>
- **The Mayo Clinic** - [www.mayoclinic.com/health/juicing/AN02107](http://www.mayoclinic.com/health/juicing/AN02107)
- **The Green Smoothie Revelation (Victoria Boutenko)**  
[www.livingintherealworld.net/healthy/2011/05/health-benefits-of-green-smoothies](http://www.livingintherealworld.net/healthy/2011/05/health-benefits-of-green-smoothies)

### ***Prosthetics***

What to do after surgery to recreate your natural breast shape – if anything – is a very personal decision. Some women use a breast form or prosthesis inside their bra that matches the size and shape of their breast. Other women have surgery to reconstruct a breast. Some do neither. Other women may use a form for a while and then have reconstructive surgery. Depending on the type of surgery you have had and how much breast tissue was removed, you might not feel that you need any of these options.

- ***Temporary Prosthesis***

A temporary prosthesis is a soft, light form that can be pinned inside your clothes or worn on the inside a loose-fitting bra. It is very soft and light so that it won't hurt while you're still feeling sore. Your health care team will let you know when you are healed enough to begin wearing one.

- ***Partial Prosthesis***

Most women who have breast-conserving surgery do not need prosthesis to fill in the missing breast tissue. If you have had a lot of breast tissue removed you may wish to wear a partial prosthesis, also called a shaper or a shell. This is worn over the breast to create a fuller and smoother appearance. They come in a number of shapes, sizes and colours and can be worn with a regular bra or a mastectomy bra. A mastectomy bra has a pocket sewn in it.

- ***Permanent Prosthesis***

A permanent prosthesis is designed to look and weigh the same as a normal breast. When it is properly fitted, it provides balance for good posture, prevents the bra from sliding up and gives a natural shape to clothing. Some attach directly to the skin on your chest, using a special kind of glue. Others are inserted into a regular bra or a mastectomy bra. Public health benefits or your own health insurance plan may cover the cost of a permanent prosthesis.

When shopping for a permanent prosthesis:

- Get fitted by someone who is trained and experienced in fitting breast prosthesis.
- Try the prosthesis on in a comfortable, supportive bra. Wear or take along a form-fitting top or sweater.
- Match the form as closely as possible to the shape of your other breast from all angles as well as from the front.
- Focus on good fit, comfort and an attractive natural appearance in the bra and under clothing. The form should look good and feel comfortable. Different types of incisions and body shapes will affect what feels and looks good.
- Ask if the prosthesis can be worn with swimwear. Some breast forms are made especially for swimming. Check whether you can wear your regular swimsuit or whether you would need a specially designed swimsuit with the breast form you are considering.
- Compare styles and prices – many options are available. Don't feel that you need to buy the first one you try on.

Once you have bought a form and have started to wear it, you may find that it feels heavy. Wearing it for a few hours each day will allow your body to adjust.

**Content credit:** *Understanding Treatment for Breast Cancer: A guide for women.* Canadian Breast Cancer Society, 2006

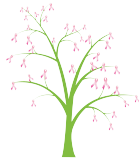
## Questions to Ask About Post-Surgery

What tests can be done to find out if the cancer has spread? When will I have them?	
How big was the tumor? What does that mean?	
How many lymph nodes were removed? Did any of them show cancer?	
Did I have an axillary lymph node resection or a sentinel node biopsy?	
What is the grade of the cancer? How fast is it growing?	
At what stage is my cancer?	
What does estrogen-receptor mean? Why could this be important to me?	
What chance is there that the cancer will show up in my other breast? In other parts of my body?	
When, if ever, is it a good idea to have my second breast removed as a precaution?	
What pain or discomfort might I have? How long will it last?	
What about exercises for my affected arm? Could I have a physical therapy referral?	
Could I have a referral for wound care and scar management?	
How long will it take for the incision to heal? What is the best way to take care of my incision?	
If I have a drain or drains from the breast or underarm area, how long will they need to be in place? How should I care for them? Who will remove them?	
How long after surgery until my follow-up appointment? How often will I see a	

doctor after surgery?	
What types of activities (if any) should I avoid?	
What symptoms – swelling, fever, nausea and so on? Who do I call if I have a concern?	
Will I need help at home? Who should I talk to about getting help for activities such as bathing, cooking and housekeeping?	
What is lymphedema? Am I at risk of developing it? What can I do to try to avoid it?	
What should I do if I get lymphedema?	
Will my arm be numb? If so, how long will it last?	
When can I have reconstructive surgery? What are the options for me?	
What is breast prosthesis? Kinds?	
Where can I get one? Is it covered by health insurance?	
When should I buy one? How often will it have to be replaced?	
Do I need a special bra to hold my prosthesis in place?	
Where can I find special mastectomy bras and swimwear?	

**Taken in part from:** *Questions to Ask about Breast Cancer: A workbook for women.* Canadian Cancer Society, 2006

**More questions available at:** The American Cancer Society, [www.cancer.org](http://www.cancer.org) (Find Support & Treatment section, Questions to Ask My Doctor About Breast Cancer)



# Lymphedema

*You will have to create the path by walking yourself;  
The path is not ready-made, laying there and waiting for you.*

Osho

## What is Lymphedema?

**Lymph** is a thin, clear fluid that circulates throughout the body to remove wastes, bacteria, and other substances from tissues. **Edema** is the buildup of excess fluid. **Lymphedema** occurs when too much lymph collects in any area of the body, causing swelling. Surgery and radiation, and sometimes the cancer itself, can cut off or damage some of the nodes and vessels through which lymph moves. Over time, the flow of lymph can overwhelm the remaining pathways, resulting in a backup of fluid into the body's tissues. Lymphedema can happen soon after treatment, months following or even years later. If lymphedema develops in people who have been treated for breast cancer, it usually occurs in the arm and hand but sometimes it affects the breast, underarm, chest, trunk and/or back.

### ***Differentiating Between Lymphedema and Post-Surgical Swelling***

Lymphedema is different from the swelling in the breast, chest, armpit and upper arm areas that can happen just after surgery. Post-operative swelling following breast cancer surgery is to be expected and generally lasts up to about three months; it appears almost immediately following surgery and places additional stress on the lymphatic system by contributing to the lymphatic workload. The difference between “normal” post-operative edema and lymphedema is that with lymphedema, the swelling lingers following the completion of treatment and there are changes in tissue texture.

### ***Stages of Lymphedema***

Several staging systems for lymphedema have been developed. The following is a generally accepted one that health professionals use:

- Stage 0: A sub-clinical state where swelling is not evident despite impaired lymph transport. This stage may exist for months or years before swelling becomes evident.

- Stage I: This represents early onset of the condition where there is accumulation of tissue fluid that subsides with limb elevation. The swelling may be pitting at this stage (does not bounce back when pressed). Stage I can be managed with early treatment and often improves greatly.
- Early Stage II: Limb elevation alone rarely reduces swelling and pitting is present. Early Stage II lymphedema can be improved with intense treatment.
- Late Stage II: There may or may not be pitting as tissue fibrosis (hardening) is present.
- Stage III: The tissue is hard (fibrotic) and pitting is absent. Skin changes such as thickening, hyperpigmentation (colour changes), increased skin folds, fat deposits and warty overgrowths develop. Stage III lymphedema can be improved with intense treatment and it can be prevented from getting worse but it is rarely reversed to an earlier stage.

## Prevention

As has previously been mentioned, one key action that you can take to prevent lymphedema is to not raise your affected arm above 90 degrees (straight out from your shoulder) until your surgical drains have been removed. Also key is to avoid lifting, especially lifting over your head for the first six weeks after surgery. You should not lift over 1 kg (about 2.5 pounds) for the first two weeks after surgery or over 4 kg (about 10 pounds) until after week six.

Doing the exercises identified in this binder and demonstrated on the video are key preventive measures. Be sure to do the correct exercises for your stage of healing.

Use a pink wristband to signify that an arm is either affected by or at risk for developing lymphedema.

If you have or are at risk for lymphedema you should either wear or carry a pink wristband with you at all times.

If you have had lymph nodes removed in your surgery or if you have had radiation that could have damaged the lymph nodes, you are considered at risk for lymphedema. There are a number of other preventive measures you can take including:



- Have a medical checkup or screening for lymphedema regularly
- Report changes to the at-risk body part to your health care provider (increase in size, change in sensation, colour, temperature or skin condition).
- Maintain normal body weight as obesity is a major risk factor for lymphedema.
- Follow exercise recommendations.
- Consider wearing a compression garment for air travel; wearing a compression garment during exercise is not necessary unless you notice swelling occurs during exercise.
- Consider the treatment of any infectious skin condition, such as cellulitis, as an urgent medical situation.
- Maintain good skin condition with proper hygiene and moisturizing to prevent skin cracking.
- Avoid any trauma to the at-risk area including falls, fractures, burns, venipuncture (getting your blood taken from that arm), scratches, punctures or other breaks in the skin. Wear non-constrictive protective gear (like gloves for gardening) and keep your nails well manicured (ideally by a professional).
- Avoid any excessive or prolonged constriction of the at-risk body part (tight sleeves, bra with an underwire).
- Avoid exposure to extreme heat or cold.
- Avoid surgery on the at-risk body part – make sure your surgeon is aware of your risk.
- Avoid sitting or standing for long periods of time without moving.
- Wear sun screen to avoid sun burn.
- Wear insect repellent to avoid bug bites.
- Be careful when shaving under your arms.

- Wear rubber gloves if you are going to be doing chores that require your hands to be in water for extended periods of time.
- Use a thimble when sewing.
- Avoid using the at-risk arm for lifting or carrying heavy objects like suitcases.
- Check with your doctor before using any hormones, especially hormone creams.
- Avoid tight jewelry, rings and watches.
- Use sauna, steam baths and hot tubs with care.
- Take extra care when traveling to a hot climate.

## Early Detection

### Signs of Early Lymphedema

Before you can actually see the swelling of lymphedema more subtle signs may be evident that come and go over a period of time. Some of these are:

- A feeling of pressure, fullness, heaviness or swelling in the arm. About 50% of people diagnosed with arm lymphedema report that the first symptom was feeling heaviness or fullness in the arm, even before they saw any swelling.
- Puffiness, swelling or any increase in the size of the arm or other area that has undergone surgery or radiation (arm, armpit, breast, another part of the chest or around the surgical scar).
- Pins-and-needles sensation in the arm.
- A feeling of heat in the arm or in the affected side of the body.
- Redness and inflammation (this could indicate infections so see your doctor right away).
- Pitting: if you press the skin and hold it in for a moment it does not bounce back when released.

- A “bursting” or shooting pain sensation in the arm.
- Aching in the arm, shoulder or shoulder blade area.
- The inability to pinch a fold of skin on the top of one of your fingers (between the finger joints) or between the forefinger and the thumb.
- Tingling or numbness in the arm that comes and goes.
- Rings that are too tight, watches that don’t fit, a bra that feels tight or leaves a mark on the shoulders, or sleeves that are tighter on one arm than the other.
- One side of your back looking different than the other (asymmetry).
- Decreased flexibility of the wrist joint.
- Veins and tendons in the hands or arms are more difficult to see. Knuckles that are less pronounced. Previously wrinkled hands look smoother.
- Changes in the texture or appearance of skin, tightness, redness or hardening.
- Rash, itching, pain, warmth or redness of the skin.
- Fever or flu-like symptoms.

### ***Sudden Swelling***

Lymphedema usually happens gradually. However, some women have reported that their swelling came on suddenly. If you ever experience sudden severe swelling -- meaning that your hand, arm, or other body part seems to “blow up” to a larger size within a day or two -- see your doctor right away. It could mean that you have an infection, a blood clot (also known as deep vein thrombosis) or a recurrence of the cancer that is affecting the lymphatic system.

## **Pre-Treatment Arm Measurements**

You should have base-line, pre-treatment (before surgery or radiation, which ever comes first) measurements taken of both of your arms so repeating these and comparing them over time may give you a sense of whether or not the swelling is increasing. A change of just 2 cm (about  $\frac{3}{4}$  of an inch) in the

circumference of the arm can be an indication that lymphedema is developing but you may not even notice this difference. These measurements should be taken at every follow-up appointment with your doctor.

The publication, *Best Practice for the Management of Lymphedema* International Consensus, 2006, includes tracking sheets that your health care professional can use to record frequent arm measurements and other early signs of lymphedema. It also includes guidelines on how to do the measurements (six places on each arm). The video that accompanies this binder demonstrates these measurements so that you, with some help from a friend or family member, can be taking your own measurements regularly.

You may work with a health care provider who isn't experienced with lymphedema. You know your own body best. If you experience any of the above early signs of lymphedema, make sure you inform your health care provider(s) and seek the services of a Certified Lymphedema Therapist. Your physician and/or health care team can assist you in accessing these services. Your health region's Therapies Department should be able to connect you with a therapist in your health region or one close by.

A current list of private and public Complex Decongestive Therapy Therapist in Saskatchewan is available at: [www.sasklymph.ca](http://www.sasklymph.ca)

## Treatments for Lymphedema

### ***Complex Decongestive Therapy (CDT)***

CDT is the treatment of choice for lymphedema regardless of stage. It consists of manual lymph drainage (MLD), multi-layer, short-stretch compression bandaging, lymphatic exercises, skin care and education on lymphedema self-management and elastic compression garments. CDT is considered to be safe and effective and usually consists of an initial reduction phase, followed by a maintenance phase. The goals of CDT are to decrease swelling, increase lymph drainage from the congested areas, reduce skin fibrosis (hardening) and improve the skin conditioning, enhance the ability to function, relieve discomfort and improve quality of life and reduce the risk of cellulitis.

### ***Manual Lymph Drainage (MLD)***

This is a hands-on, massage-like technique that improves fluid removal from congested areas where the lymph system is not working into lymph vessels and lymph nodes that are functioning properly.

### ***Compression Bandaging***

This is a specific technique that uses multiple layers of materials to create a safe and effective gradient compression (from the hands up to the armpit). Different wrapping materials used exert different levels of pressure and are combined to create a pump-like action to move fluid out of the arm and into the functioning lymph nodes. Muscle contractions underneath the bandaging also move fluid out of congested areas.

### ***Exercise***

Specific remedial exercises are taught to patients with lymphedema. Usually compression garments are worn during these exercises to counterbalance the buildup of fluid in the tissues.

### ***Skin Care***

Meticulous hygiene is recommended to keep the skin free of fungus and bacteria. Moisturizer is also used to keep the skin from cracking and producing entry points for infection. Cellulitis is a serious infection of the skin that requires antibiotic treatment.

### ***Patient Education***

Since lymphedema is a life-long condition, patient education in self-management is very important. Risk-reduction practices, self-lymph drainage, skin care, signs and symptoms of infection, proper fit and care of garments and the importance of good nutrition, exercise and weight control are taught.

### ***Compression Garments***

Compression garments are commonly used in the treatment of lymphedema. They may provide the only form of compression needed or be a part of a CDT regimen. The prescription of compression garments should only be undertaken after a full assessment of the patient has been completed. This assessment takes a number of factors into consideration including the stage and severity of the lymphedema and your comfort, preferences, lifestyle, psychosocial status, concurrent disease and ability to apply and remove the garment.

The most common use of compression garments is in the long-term management of lymphedema. They are also however, used for prevention purposes or as a part of initial lymphedema treatment. After MLD and other therapies have minimized swelling and stabilized the area, measurements for compression garments can be taken. People wear garments for varying reasons and needs. Some wear a garment during waking hours only, for exercise only, or

24 hours per day. Night garments are sometimes needed to maintain the benefits derived from daytime compression garments. For night wear, inelastic adjustable compression garments provide more consistent pressure and are superior in terms of ease of use compared to nightly bandaging. These compression devices are adjusted by altering how tightly the straps used to fix the garment in place are pulled and are considered a useful self-management tool.

It is recommended that you use two garments at a time for each affected body part: one to wear, while one is washed and dried. Two garments ensures you do not wear a dirty or wet garment that promotes bacterial or fungal infection. Garments should be washed daily following the care instructions so the garment lasts as long as possible and does not lose its compression strength.

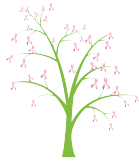
### **Compression Pumps**

The use of intermittent pneumatic compression therapy (IPC) is one of several components available for the treatment of lymphedema, regardless of the cause. IPC consists of a pump that supplies air to garments worn over the areas of the body to be treated. Air cells within the garments are filled in a specific sequence, alternating waves of compression with brief periods of pause and refill. This produces a massaging effect from the far end of a limb toward the trunk. A typical session lasts from 30 to 120 minutes. It should be noted, however, that not all lymphedema clients require IPC or are suitable for its use. IPC is less effective for stage III lymphedema and patients with cellulitis or excessive scarring.

## Questions to Ask About Lymphedema

What is lymphedema?	
Am I at risk for developing lymphedema? Why or why not?	
What symptoms should I watch for?	
What should I do if I notice swelling or any other symptoms?	
What can I do to reduce my risk of lymphedema?	
What kinds of exercises should I be doing?	
Will you be doing my arm measurements at each appointment? If not, why not?	
Could I see a physical therapist right now for some preventative therapy?	
Who does lymphedema treatment in this health region? Is there a wait time?	

**More questions available at:** The American Cancer Society, [www.cancer.org](http://www.cancer.org) (Find Support & Treatment section, Questions to Ask My Doctor About Breast Cancer)



# Other Challenges

***Our wounds are often the openings into the best  
and most beautiful parts of us.***

**David Richo**

## Your Feelings and Self-Image

Coping with breast cancer is about more than getting through the surgery and managing side effects from treatment. Cancer is a disease that may affect your emotions, your relationships and your feelings about yourself and your place in the world.

### ***Your Feelings***

The diagnosis and treatment of breast cancer can change how you think and feel about many things. These changes and feelings will not be the same for everyone. You may feel afraid, angry, frustrated, depressed, lonely or isolated. Feeling a wide range of emotions is a normal part of a cancer experience. Feeling hopeless at the same time as hoping for the best is also normal. You may think that you have lost control of your life or that your body has betrayed you. You may also feel grief for the loss of your breast or part of it.

You may be feeling many different emotions and these emotions can vary greatly over time throughout your treatment and recovery. One day you may feel as though you have gained some control over your life, while the next day you feel scared, angry or that life has been very unfair to you.

Recovering emotionally from breast surgery can take some time. Fatigue related to your treatment can make coping with your emotions even tougher. Everyone copes differently so try to be easy on yourself.

### ***Talking About Your Feelings***

You may not be used to talking about personal and private feelings. Even though it can be hard, talking about how you feel instead of keeping it inside has many benefits. Talking can make you feel better and more in control, make you feel less alone and strengthen bonds between you and other people.



There are many good reasons for talking about your emotions but if you feel that the best way for you to cope is to just get on with things, you can ask others to respect your wishes and not talk. Let them know that if you want to discuss anything, you will bring it up.

### **Self-image**

The changes that breast cancer often brings can have a big impact on your self-image and affect how you see your place in the world. You may experience some of the following changes from cancer or its treatment:

- Changes in energy levels may mean you need to give up a favourite sport for some time or cut back on working hours. If being active or working hard is part of your self-image, it can be difficult to adjust to these changes.
- Mental changes may be a side effect of treatment or a result of stress, fatigue, anxiety or depression. If you find that you can rarely remember where you put something, or can't concentrate enough to follow a simple recipe, frustration can build and affect how you feel about yourself.
- Changes to independence means that you may have to learn to balance accepting help with doing things for yourself. While it can be difficult to give up some of your independence, having cancer may make it harder for you to do things you once did on our own.
- Changes to appearance may make you feel unattractive and negative about your body at times. For some women, their breasts are a very important part of their self-image as a woman, a mother or a partner. Changing or removing a breast through surgery can have a very serious impact on how they feel about their appearance and their sexuality. Other treatments may lead to hair loss, skin changes or weight gain or loss.

All of these changes can affect self-image. You may worry about rejecting or not wanting to be intimate with your partner. Coping with these feelings can be difficult. It can help to remember that some of the changes are only temporary and you will probably begin to feel more like yourself when treatment is over. You also have options such as prosthesis or possibly breast reconstruction.

## Getting Help From Others

Throughout your cancer journey you might need help getting to treatment, doing housework or yard work, cooking meals, taking care of children, walking the dog and so on. Some people – often family and friends – are very good at this sort of practical help.

Another important kind of help is the kind that comes with listening, offering support or counseling. Some of your family and friends may support you by doing this or you may find it helpful to turn to health care professionals or other people living with cancer.

Although you may find it hard to ask for and accept help, having help often makes it easier to cope with cancer. Many people with cancer and their caregivers are often surprised – and deeply touched – by just how much people want to help.

### ***Asking For or Accepting Help***

Many people find it hard to ask for help. They may be used to being independent and arranging everything on their own. They see needing help as a sign of weakness. Some people are uncomfortable talking about their needs or asking people to do things for them. They may feel like they are being selfish or burdening other people.

If you are finding it hard to ask for or accept help, remember that many people really want to help. People often don't know what to do when someone is ill. Helping out is one way for them to feel useful. Many people see the opportunity to help as a gift; something that is good for them and you.

### ***Building Your Support System***

When you or someone you love has cancer, help comes in many different forms and from many different people and places. You might find help through support groups, family and close friends, co-workers, your community, through volunteer agencies or counseling.

It can be comforting to know many people want to help and there are many resources available. It can also be overwhelming when people ask what they can do. Sometimes it can be helpful to have a “point person” ask for and organize help on your behalf. This person can create charts or lists and give

people specific tasks on specific dates. They can update people on your condition, and let them know good times to call or visit.

There may also be times when people with cancer and their caregivers feel they don't have the support they need or want. People with cancer who are far away from family and friends may feel isolated and overwhelmed. If that's the case, talk to someone on your health care team in order to learn more about support services and support groups in your community.

### ***Support Groups***

Support groups help by giving people a chance to talk to others going through similar circumstances. Although your friends and family might be very supportive, it can also be comforting to spend time with people who have gone through the same things as you. You can often talk to these people about things you can't discuss with anyone else. Someone who has had cancer can:

- Understand how you feel
- Talk to you about what to expect
- Tell you how they coped
- Help you learn ways to enjoy each day
- Give you hope for the future

You may already know someone you can talk to, or you may meet them through friends, family or co-workers. You may also benefit from talking to a professional counselor or a spiritual care worker.

## **Family Issues**

Although you are the one being treated, other people in your life such as your partner, family members and close friends, will also be affected by the fact that you have breast cancer. Like you, they are coping with their emotions and adjusting to cancer being part of their lives. Like you, they will cope with things in their own way, the best way that they can.

Sharing your feelings can give you both the chance to talk about how you feel and lead to a better understanding of each other's thoughts and needs.

### ***Younger Children***

Younger children can be a source of great joy and comfort for you throughout your cancer experience. They may, however, have a hard time adjusting to cancer in the family. You will be the best judge of how much your younger children need to be told, but in general, try to answer their questions as honestly as you can, in words they can understand. Even very young children are able to sense that something is wrong. What they imagine to be happening is possibly more upsetting for them than the reality.

As much as you can, talk to your children about how their lives might change. Younger children thrive on routines. You can help them cope by letting them know how their daily life might change and preparing them for what to expect.

The effect of your diagnosis on your children may be reflected in their behaviour. Your children may act out in different ways to get your attention. They may misbehave, act younger than they are, become clingy or insecure and refuse to leave your side. If you're concerned about how your children will act at school, you might choose to tell their teachers or other staff at the school about the situation at home. It may help them support your children.

### ***Teenagers***

Teenagers are at a stage in their lives when they are trying to break away and be independent from their family. When someone in the family has cancer, this can be hard to do. They may react in very different ways: getting angry; acting out; getting into trouble; withdrawing from you; taking on, but possibly resenting more responsibility, or offering to help; and seeking assurances of love.

To help your teen maintain some independence, it's important to encourage them to keep doing the things they like to do. Talking about their feelings with someone they trust is also important for teens. Try to be patient if you can't understand or predict your teen's behaviour or emotions. Teens may not have the words or the ability to express emotions like anger, guilt or grief – and may resort to moodiness or outbursts instead.

If you have a teenage daughter, she may need special attention. She may wonder whether she, too, will develop breast cancer. Try to talk openly about how you're both feeling and any fears that you both have. As your daughter gets older, she will need to know about the importance of mammography and clinical breast examinations. She will also need to learn what is normal for her breasts so that she will be able to notice any changes that could lead to problems.

### ***Partners or Spouses***

Even the best relationships will be challenged by cancer. Cancer is a very stressful event that can strengthen a relationship or strain it – or both. You and your partner may cope very differently with cancer. If you and your partner can recognize your strengths and weaknesses, then your differences can be an advantage. For example, the person who likes to do research can take on that responsibility and feel useful, while the person who is better at talking about feelings can make sure you both talk about what you need and feel.

A breast cancer diagnosis in a same-sex relationship may raise some particular concerns. The fact that your partner can understand what it might be like to lose a breast may put her in a position to be very supportive. On the other hand, as a woman, she may focus on her own risk and worries about the disease which may lead to a distance in your relationship.

Here are some other things to keep in mind as you and your partner face the disease together:

- As you cope with cancer, think about how you and your partner have coped through difficult times in the past. What strategies worked for you then? What would you do differently? It can help to write down a list of things that you both do to make the relationship strong.
- If you are feeling stressed, it may help to give yourselves short breaks from each other. The partner with cancer may need time to be alone and not feel like “the patient” while caregivers need to rest and find ways to care for themselves.
- Try to keep communication open and honest. Avoid assuming, attempting to mind-read or expecting your partners to know just what you need.
- Think about what you most need from the other person when things are tough. Then, ask for it.
- Give yourselves some “cancer-free” space – space where cancer is not the topic of conversation. Talk about and do other things together.

### ***New Romantic Partners***

If you are single, you may find that you feel differently about dating or starting a new relationship. For some people, their outlook on dating changes for the better.

For example, you may feel that having breast cancer has allowed you to know yourself better, and that you now have more to offer in a relationship.

For others, dating becomes harder. There may be many reasons for this such as being unhappy with your appearance; being uncertain about the future and how a relationship will fit; or worrying that the cancer will return and how your new partner will support you through another cancer experience.

If you'd like to date but are finding it difficult, it can help to:

- Keep in mind that dating and new relationships often make people insecure – whether or not they've had cancer.
- Try to meet new people and make new friends, without worrying too much about dating at first.
- Consider talking about your difficulties with a counselor or look for a support program where you can talk about dating with other cancer survivors.
- Remember that not every date has to be a success. If someone doesn't want to see you again, which can happen with or without cancer, you have not failed. After all, not all dates worked out before you had cancer.

### ***When to Tell Someone New About Your Cancer Experience***

Deciding when and how to tell someone new about your cancer experience can be very stressful. Some people are most comfortable talking about it right away while others prefer to wait while they get to know a person. Others take each situation as it comes and do whatever feels right at the time.

You will be the best judge of when to tell someone new about your cancer experience. If you feel that it doesn't affect your new relationship, you may decide not to talk about it. In making this decision, though, remember that many people find honesty to be a very important part of a relationship, especially a relationship that becomes long-term.

If there is physical evidence of your treatment, it may be better to tell someone you're dating about your cancer experience before the relationship becomes intimate or sexual. Waiting to tell until the moment of sexual intimacy may add a lot of tension to what could already be an intense or emotional situation.

## Sexuality and Intimacy

Breast cancer and its treatment can have an impact on your sex life:

- You may be worried or self-conscious about changes in your appearance such as scars or the loss of your breast or part of your breast, the loss of your hair, weight gain or weight loss.
- You may be worried that your partner won't be attracted to you anymore.
- Being tired may result in you not wanting to have sex. Stress or worry can reduce sexual desire.
- Surgery can leave the area of your breast very tender or with less sensation and chemotherapy or radiation may leave you feeling ill or tired and not in the mood for sex. Some cancer treatments and antidepressants can reduce your desire for sex or affect your sexual function including the ability to become aroused.

A physical relationship is very important for some people and they are sad when it stops or changes. If cancer and treatment are affecting your sex life, talking about things with your partner may help ease your fears. Or, if you're not interested in sex at the moment, you can explain that it's because of fatigue or stress, not because you don't love or respect your partner. Knowing how each other feels may help you both feel more secure.

If talking to each other about sex is difficult, a counselor may be able to help you talk more openly. You can also let a member of your health care team know if you are having problems. There may be medicines that can help or other ways you and your partner can give each other pleasure. Some people also find it helpful to talk with others about how to stay close while dealing with cancer.

You and your partner may find that sex and intimacy change during treatment. Hugging, holding and cuddling may become more important than sexual intercourse and other forms of sexual activity. There are many ways to express sexuality and to satisfy your need for physical closeness. Together, you and your partner can decide what gives you both pleasure and comfort.



## Work and Finances

Many people continue going to work while being treated for breast cancer but it's quite possible that your way of working will change, especially if you have additional treatment such as chemotherapy or radiation. You may have to take some time off or adjust your work schedule to allow for treatment and to rest and recover.

If you need to take time off work, talk to your employer, human resources manager, personnel officer, union or employee association about what you are entitled to. Even if you don't need to use sick days or take a leave of absence, you may find it helpful to simply know what your options are.

Time away from work often means less money coming in and being treated for cancer can mean that you have new expenses. You may have to spend more on things like childcare, help around the house or drugs or therapies that are not covered by your provincial or private health insurance plans.

A good first step is to find out what your insurance will pay for and what you will need to pay for. If you have private disability insurance or insurance through your employer, get familiar with the terms and conditions of your coverage. Social workers can help you find out more about financial assistance programs in our province and government benefits that you are entitled to. If your health care team doesn't include a social worker, you can ask to speak to one.

Account managers at your bank, personal financial planners or advisors can help you budget your money.

**Content credit for this section:** *Understanding Treatment for Breast Cancer: A guide for women.* Canadian Cancer Society, 2006 and *Living With Cancer: A guide for people with cancer and their caregivers.* Canadian Cancer Society, 2012



## Questions to Ask About Emotional Recovery

What kinds of feelings (such as grief, anger, vulnerability, loss of control) might I have after the surgery and other treatments?	
Where can I find help for coping with my feelings if I need it?	
How might my family and friends feel? What behaviour might I expect from them?	
What support is available for my family members?	
How do I talk to my children about breast cancer and my treatments?	
How does a partner or spouse usually react? What can we do to help each other?	
How can I talk about the changes in my body with my partner?	
How can I rekindle my sexuality?	
Treatment has made me feel less desirable and incomplete. How can I begin to feel whole again?	
Would using complementary therapies help me cope? Where can I find these?	
What is the best way to get back to work gradually? Is there someone who can help me negotiate a plan to return to work?	

**Taken in part from:** *Questions to Ask about Breast Cancer: A workbook for women.* Canadian Cancer Society, 2006

**More questions available at:** The American Cancer Society, [www.cancer.org](http://www.cancer.org) (Find Support & Treatment section, Questions to Ask My Doctor About Breast Cancer)



# When Treatment is Finished

*As my sufferings mounted I soon realized that there were two ways in which I could respond to my situation - either to react with bitterness or seek to transform the suffering into a creative force. I decided to follow the latter course.*

Martin Luther King Jr.

## Follow-up Care

Follow-up care helps you and your health care team monitor your progress and how well you are recovering from any side effects. At first, your follow-up care may be managed by one of the specialists from your health care team and later your family doctor may manage it.

The schedule of follow-up visits is different for each person. You might be seen more frequently in the first year after treatment and less often after that. Once a year, your visit will include a mammogram. You won't need one for a reconstructed breast if you have had a total modified radical or radical mastectomy. Your doctor may order other tests as well or suggest ways that you can monitor your health.

At follow-up visits, your medical history will be updated and you will have a clinical breast examination.

### **Medical History**

Your doctor will want to know about any side effects of treatment such as swelling or tenderness in your breast, stiffness in your shoulder or swelling in your arm since your last visit.

### **Clinical Breast Exam**

Your doctor will examine both breasts, including the affected breast or mastectomy site, the lymph nodes in your armpit and collarbone areas, the chest wall and the abdomen. Your arm will also be checked for lymphedema.

If you notice any of the following symptoms, report them to your doctor right away:

- Pain
- Cough
- A lump in either breast
- Unusual changes at the site of the surgery or in the scar itself
- Feeling tired
- Loss of appetite
- Nausea
- Tingling or numbness in the arm or hand
- Swelling of the arm
- Swollen lymph nodes in the neck, under arms, or groin
- Any other unusual or severe symptoms

## Genetic Testing

The benefit of having genetic testing is to gain a better understanding of your risk for a certain disease. Testing is not perfect, but it can help you make decisions about your health. A negative result on a genetic test in families at risk for a specific cancer may relieve uncertainty. In the same way, a positive result can help you make important decisions about your future. A positive result may lead to finding disease earlier and preventing deaths. Testing can help learn the prognosis (outlook) for a person diagnosed with cancer, and can even help with deciding which treatments are most likely to work. As scientists learn more about the genes that contribute to cancer, genetic testing will probably become more helpful in learning about a person's risk for a disease.

There are also drawbacks to genetic testing including:

- Answers are limited - genetic tests do not give precise answers about inherited diseases, especially colon and breast cancer. Test results may be flawed or read incorrectly.
- Psychological or emotional impact: It can be very frightening to know that you might have or develop a serious disease. A positive genetic test can also impact other family members. Having a gene or passing a gene on to children might bring feelings of guilt and anger.
- Privacy issues: Most people are afraid that insurance companies or employers might get and use their genetic information.

For more information on the benefits and drawbacks of genetic testing go to:  
[www.cancer.org/cancer/cancercauses/geneticsandcancer/genetic\\_testing/genetic-testing-benefits-and-drawbacks](http://www.cancer.org/cancer/cancercauses/geneticsandcancer/genetic_testing/genetic-testing-benefits-and-drawbacks)

[www.saskatoonhealthregion.ca/your\\_health/ps\\_medical\\_genetics\\_services\\_cancer\\_genetic\\_services.htm](http://www.saskatoonhealthregion.ca/your_health/ps_medical_genetics_services_cancer_genetic_services.htm)

## What If Cancer Comes Back?

The end of cancer treatment may bring mixed emotions. You're probably glad it's over and looking forward to going back to your normal activities. You may feel anxious as well. You may feel that as long as your health care team was treating you, you were safe. If you feel anxious about treatment ending, talk to your health care team. They are there to help you through this transition period.

As time goes by, many people find that their fear of cancer coming back becomes less and they find themselves thinking about cancer less often. Certain events, however, may bring the worries back. These include:

- Follow-up visits
- Critical dates, such as the date of the diagnosis or surgery
- Illness of a family member
- Symptoms similar to the ones that led to a cancer diagnosis
- The death of someone who had cancer

If you find that you are worried and anxious all the time, or if your anxiety is interfering with your daily activities, you may want to talk about your feelings with a counselor or another member of your health care team. It's important to get your worries under control so that you can focus on living, take good care of your health and making the most of each day.

## The New Normal

What is “normal” after cancer treatment? Just as everyone’s cancer experience is unique, adjusting to life after treatment will be unique as well.

For some people, normal may mean going back to exactly how their life used to be. The best thing about treatment ending will be getting back to their previous routines and ways of doing things. For others, life has definitely changed. There may be new physical or practical issues that are a permanent part of life – perhaps there is a new health regimen or new financial realities to deal with on an ongoing basis. Values and priorities may have changed. Material things may be less important than spending time with loved ones, doing volunteer work, or enjoying hobbies or sports. If you feel that your cancer experience has changed you, it's not so much a matter of getting back to what used to be normal as it is figuring out what will now be “normal” for you and your family.

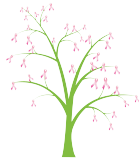
You may find that you're somewhere in between. In some areas of life your new “normal” is very different from your old, and in other areas, things go back to exactly as they used to be. One way isn't better than the other. The most important thing is figuring out what works for you.

## Questions to Ask About Getting On With Life

Are there changes I can make to my lifestyle that will reduce my risk of cancer coming back?	
When will I get back to my normal energy level?	
What can I do to deal with my fear of recurrence?	
Is it safe to take birth control pills after breast cancer?	
Does my daughter have a greater risk of getting breast cancer? What should I tell my daughter about breast cancer?	
What about my sisters and nieces? Are they more likely to develop this disease?	
What can they do to help reduce their risk and ensure that breast cancer is detected early?	
What follow-up care will I need? How often will I be getting mammograms from now on and who will arrange these?	
Should I be getting genetic testing done? What is that process? What are the benefits and drawbacks for me and for my children?	
Are there any resources that will help me regain my sense of self, or define who I am now, post-cancer?	

**Taken in part from:** *Questions to Ask about Breast Cancer: A workbook for women.* Canadian Cancer Society, 2006

**More questions available at:** The American Cancer Society, [www.cancer.org](http://www.cancer.org) (Find Support & Treatment section, Questions to Ask My Doctor About Breast Cancer).



# Resource List

The following list includes resources that the working group thought may be useful for the reader. Please note that this list may not include all resources available.

## **American Cancer Society**

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

American Cancer Society (2006). Lymphedema: understanding and managing lymphedema after cancer treatment. American Cancer Society: Atlanta, GA.

The American Cancer Society has a number of comprehensive tracking sheets for various aspects of your progress that you can download, print and add to your binder including:

- Questions to Ask My Doctor About Breast Cancer
- Medicine List
- Daily Pain Diary
- Chemotherapy side Effects Worksheet
- External Radiation Side Effects Worksheet (general symptoms & radiation to chest sections)

To find these go to: [www.cancer.org](http://www.cancer.org)

Click on “Find Support & Treatment”

There you will see 2 sections:

- Find Support & Treatment Topics
- Treatment Tools

Under Treatment Tools, you will find all of the above tracking sheets.

## **BOOKS**

Burt, B., & White, G. (2005). Lymphedema: a breast cancer patient’s guide to prevention and healing. Publishers Group West: Alameda, CA.

Magee, S. & Skalzo, K. (2006). Picking up the Pieces: moving forward after surviving cancer. RainCoast Books: Vancouver.

Olivotto, I., Gelmon, K., McCready, D., Prichard, K., Kuusk, U., (2006). The Intelligent Patient Guide to Breast Cancer, 4<sup>th</sup> Edition. Intelligent Patient Guide: USA ISBN 0-9696125-8-3.

Silver, M. (2004). Breast Cancer Husband: How to help your wife (and yourself) during diagnosis, treatment and beyond. Rodale Books: USA.

Swirsky, J. & Sackett Nannery, D. (1998). Coping with Lymphedema: sound, helpful information for those who must deal with the problems associated with lymphedema. Avery Publishing Group: New York.

### **Breastcancer.org**

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

Comprehensive compilation of information on breast cancer

Breast Cancer Diagnosis Guide iPhone App:

[www.breastcancer.org/symptoms/iphone-app-breast-cancer-diagnosis-guide](http://www.breastcancer.org/symptoms/iphone-app-breast-cancer-diagnosis-guide)

My Breast Cancer Coach

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

Pathology Report Checklist

[www.breastcancer.org/symptoms/diagnosis/path\\_checklist](http://www.breastcancer.org/symptoms/diagnosis/path_checklist)

### **Canadian Association of Psychological Oncology**

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

The Emotional Facts of Life with Cancer – a guide to counseling and support for patients, families and friends

### **Canadian Breast Cancer Foundation, Prairies-NWT**

[www.cbcbf.org/prairiesnwt](http://www.cbcbf.org/prairiesnwt)

Breast Cancer: Early Detection: A Life Plan

Breast Cancer: Know Your Risk

Breast Cancer: Your Path to Diagnosis

Breast Cancer: Knowing Your Cancer

Breast Cancer: Reduce Your Risk

Breast Cancer: Then, Now & the Future



Breast Cancer: Your Treatment Begins  
YWCA encore after breast cancer exercise program  
Saskatoon: 510 – 25<sup>th</sup> St. East 306-244-0944, Ext 100

### **Canadian Breast Cancer Network**

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

- Never Too Young: Psychosocial Information and Support for Young Women with Breast Cancer
- Breast Cancer – Economic Impact and Labour Force Re-Entry

### **Canadian Cancer Society**

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

Breast Cancer: Understanding your diagnosis  
Cancer information and support: from a source you can trust  
Clinical Trials: A guide for people with cancer  
Complementary Therapies: A guide for people with cancer  
Eating Well When You Have Cancer: A guide to good nutrition  
Exercises after Breast Surgery: A guide for women  
Getting to know your breasts (breast examination guide)  
Living with Cancer: A guide for people with cancer and their caregivers  
Questions to Ask about Breast Cancer  
Reduce Your Risk of Breast Cancer  
Sexuality and Cancer  
Understanding Treatment for Breast Cancer: A guide for women  
When Someone You Know Has Cancer: How you can help  
You are not alone: Support for people living with cancer

### **CLINICAL TRIALS**

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

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

[www.breastcancer.org/treatment/clinical\\_trials](http://www.breastcancer.org/treatment/clinical_trials)

[www.nih.gov/health/clinicaltrials](http://www.nih.gov/health/clinicaltrials)

Ehrlich, A., Vinje-Harrewijn, A. & McMahon, E. (2005). Living Well with Lymphedema. LymphNotes: San Francisco.

### **Crazy Sexy Series by Kris Carr:**

Crazy Sexy Cancer Survivor: More Rebellion and Fire For Your Healing Journey  
Crazy Sexy Cancer Tips

Crazy Sexy Diet: Eat Your Veggies, Ignite Your Spark and Live Like You Mean It

Crazy Sexy Kitchen: 150 Plant-Empowered Recipes to Ignite a Mouthwatering Revolution

#### Dragon Boat Teams

- Busting with Energy (Saskatoon, SK)
- Canadians Abreast (National)
- Papetista (Regina, SK)

#### Financial Assistance

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

#### Health Canada

Information on Mammography for Women Aged 40 and Older:  
A Decision Aid for Breast Cancer Screening in Canada

#### INTEGRATIVE HEALTH CARE

Inspire Health Life Program

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

#### LymphFx Physiotherapy

Julie Jensen, BScPT, MLD/CDT and Alt Trained (Saskatoon, SK)

#### LYMPHEDEMA RESOURCES

Finding Out About Lymphedema

Saskatchewan Breast Cancer Network (2010)

331 Cooper Street, Suite 602

Ottawa, ON K2P 0G5

Tel: 613-230-3044

Toll-free: 1-800-685-8820

Fax: 613-230-4424

Email: [cbcn@cbcn.ca](mailto:cbcn@cbcn.ca)

Website: <http://www.cbcn.ca>

Lymphedema Association of Saskatchewan Inc. (LAS)  
[www.sasklymph.ca](http://www.sasklymph.ca)

Can You See the Difference?

Lymphedema: Information and Useful Tips  
Medi - [www.valco.com](http://www.valco.com)

Lymphedema – management today  
JOBST - [www.jobst-usa.com](http://www.jobst-usa.com)

Swollen Legs – what now?  
Medi - [www.valco.com](http://www.valco.com)

National Lymphedema Network Position Papers  
[www.lymphnet.org](http://www.lymphnet.org)  
1-800-541-3259  
[nln@lymphnet.org](mailto:nln@lymphnet.org)

### **Mastectomy Bras, Prostheses and Other Products**

- Blue Sky Lingerie (Swift Current, SK)
- Bodacious Bust Lines (Warman, SK)
- D and D Quality Care (Moose Jaw, SK)
- Hats for Comfort (Regina, SK)
- Lisa B. Originals Inc. (Regina)
- Lots of Looks Boutique Inc (Regina & Saskatoon SK)
- Pink Tree Specialty Merchants (Regina, SK)
- Pink Tree, The Fitting Shop (Saskatoon and Moose Jaw, SK) On-line Ordering
- Prima Deanna (Regina, SK)
- Serendipity Bra Boutique (Prince Albert, SK)
- Thee Lingerie Shoppe (Regina, SK)

**Regina Qu'Appelle Health Region**  
[www.rqhealth.ca](http://www.rqhealth.ca)

Breast Cancer Education Class  
Pasqua Hospital Therapies 306-766-8600

### **Rethink Breast Cancer**

Breast Cancer in Young Women: a needs assessment  
[www.rethinkbreastcancer.com](http://www.rethinkbreastcancer.com)

**Saskatoon Cancer Centre & the Allan Blair Cancer Centre, Regina**

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

**Saskatoon Health Region**

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

After Breast Conserving Surgery  
After Mastectomy  
After Mastectomy with Immediate Reconstruction  
Breast MRI and MRI-guided Biopsy  
Core Needle Biopsy  
Galactography  
High Risk Breast Cancer Clinic  
Wire Localization

**Support Groups**

- Breast Cancer Action Saskatchewan (Regina, SK)
  - [www.breastcancersurvivors-ethnodrama.ca](http://www.breastcancersurvivors-ethnodrama.ca)
  - Canadian Cancer Society (Swift Current, SK)
  - HOPE Cancer Help Centre Inc. 129D Pinehouse Drive, Saskatoon, SK (306-955-HOPE (4673)).
  - Kamsack Self-Help Group (306-542-3931)
  - Lymphedema Association of Saskatchewan Inc. [www.sasklymph.sk.ca](http://www.sasklymph.sk.ca)
  - Ovarian Cancer Awareness & Treatment in Saskatchewan (Regina)
  - Pink Earth Angels- [www.pinkearthangels.ca@pinkearthanges@yahoo.ca](mailto:www.pinkearthangels.ca@pinkearthanges@yahoo.ca)
  - Saskatchewan Breast Cancer Connect - [www.saskbreastcancerconnect.org](http://www.saskbreastcancerconnect.org)
  - Saskatoon Cancer Centre (Saskatoon, SK)
  - Sharing the Journey (Weyburn, SK) - [www.sharingthejourney@sasktel.net](mailto:www.sharingthejourney@sasktel.net)
  - Spirit of Women Healthing Support Group (Regina, 306-549-0493)
  - Triple Negative Support Group (306-781-0181)
  - Women's Metastatic Cancer Support Group (Saskatoon, 306-655-2713)
- 
- Bonnie Chapman: registered and Master Therapeutic Counselor. [www.bonniechapman.com](http://www.bonniechapman.com) or [Bonniechapman@sasktel.net](mailto:Bonniechapman@sasktel.net)
  - Cancer Chat Canada: on line 10 week support program. [www.cancerchatcanada.ca](http://www.cancerchatcanada.ca)

- Cancer Transitions 6 week program for patients who have completed cancer treatments. Offered at Saskatoon Cancer Centre and Allan Blair Cancer Centre, Regina
- Look Good Feel Better. Free 2 hour workshop. Pre-registration required. Saskatoon Cancer Centre 306-655-2688; Allan Blair Cancer Clinic, Regina 306-766-2213.

### **Talking with Friends and Relatives About Your Cancer**

[www.cancer.org/treatment/understandingyourdiagnosis/talkingaboutcancer/talking-with-friends-and-relatives-about-your-cancer](http://www.cancer.org/treatment/understandingyourdiagnosis/talkingaboutcancer/talking-with-friends-and-relatives-about-your-cancer)

**Victoria's Quilts Canada** (Climax and Moosomin, SK)

[www.victoriasquiltscancada.com](http://www.victoriasquiltscancada.com)

### **Wigs and Head Coverings**

- Lots of Looks Boutique Inc (Regina and Saskatoon, SK)
- Pink Tree, The Fitting Shop (Saskatoon and Moose Jaw, SK)

### **Willow Breast Cancer Support Canada**

30 St. Patrick Street, 4th Floor

Toronto ON M5T 3A3

1-888-778-3100

E-mail: [info@willow.org](mailto:info@willow.org)

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

Breast Cancer? At Risk? Need to Talk?

Coping With Your Financial Concerns When You Have Breast Cancer

### **Yoga**

Renew Yoga for cancer survivors

[www.bodhitreeyoga.com](http://www.bodhitreeyoga.com) (306-721-1871 in Regina)

Renew Yoga for Breast Cancer, Bodhi Tree (Regina, SK)

[www.bodhitreeyoga.com](http://www.bodhitreeyoga.com) or 306-721-1871.

Restorative Yoga (Allan Blair Cancer Clinic, Regina)

306-766-2042

Yoga in Moose Jaw, [yogainmoosejaw@sasktel.net](mailto:yogainmoosejaw@sasktel.net) or

[www.yogainmoosejaw.com](http://www.yogainmoosejaw.com)

YWCA Saskatoon

Renew, [www.fitnesson25th.com](http://www.fitnesson25th.com) or 306-244-0944 ext. 123