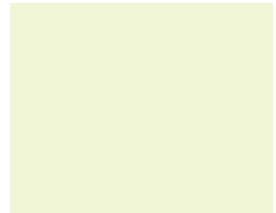
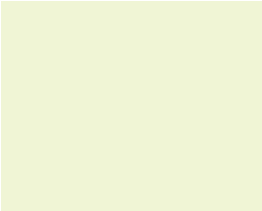


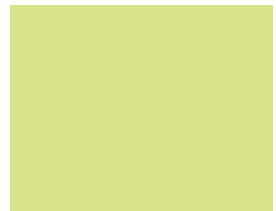
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BREAST CANCER SUPPORT CANADA



MANAGING YOUR CANCER CARE
A SELF-ADVOCACY GUIDE FOR
BREAST CANCER PATIENTS

2nd EDITION



Sponsored by





BREAST CANCER SUPPORT CANADA

Willow Breast Cancer Support Canada provides confidential support and information to anyone affected by breast cancer - free of charge. From the individual diagnosed, to their family and caregivers, Willow makes sure no one needs to face breast cancer alone.

For more information visit www.willow.org or call 1-888-778-3100

This booklet is also available online at www.willow.org

Managing Your Cancer Care was generously sponsored by GlaxoSmithKline.



GlaxoSmithKline, one of the world's leading research-based pharmaceutical and healthcare companies, is committed to improving the quality of human life by enabling people to do more, feel better and live longer.



Willow's Programs and Services

All of Willow's programs and services are provided free of charge

WILLOW'S PEER SUPPORT PROGRAM

When you call Willow you speak with someone who has had a diagnosis of breast cancer. Willow's peer support team is here to listen to you and provide compassionate support. We are experienced in answering a wide range of questions about breast cancer. Call Willow toll-free at 1-888-778-3100.

WILLOW'S INFORMATION SERVICES

Willow can provide you with current, credible and clear information on all aspects of breast cancer – diagnosis, treatments, coping with side effects, breast reconstruction, nutrition, complementary therapies and more. Willow's health librarian works with the peer support team to research your specific question(s) and send you a free personalized information package. Please call Willow at 1-888-778-3100 with your request.

WILLOW'S SUPPORT GROUP PROGRAM

Willow provides ongoing training and support for women to create and sustain peer-led breast cancer support groups. To inquire about starting a group in your community or upcoming facilitator training workshops, please call Willow at 1-888-778-3100.

For more information about Willow and our programs please call or visit us online.

Willow Breast Cancer Support Canada

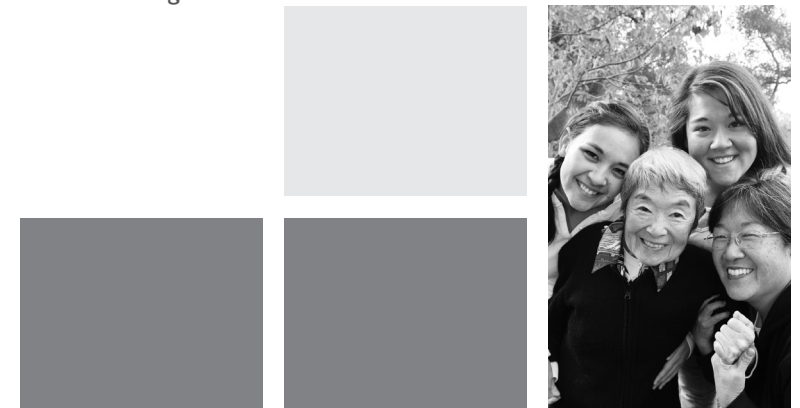
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Introduction

Being diagnosed with breast cancer can be an emotional roller coaster. You may feel frightened, angry, vulnerable, sad and overwhelmed. You may be worried about yourself and wondering how this will affect your family. You may wonder how you will cope during the days to come. You may have appointments with a variety of cancer specialists such as surgeons, medical oncologists, radiation oncologists and plastic surgeons. Finding your way through the maze of tests, appointments, doctors, nurses and medical jargon will be easier if you know what to expect and what you can do to manage your care.

This booklet was written to help you better understand:

- How you can participate in your own care
- What you can do to get the care you want
- Where you can find the information you need
- Where you can find help and support



“My friends and family didn’t understand how devastated I felt – how angry and terrified I felt at the same time. I was afraid to tell them. I needed someone to talk to – someone who understood how I was feeling – someone who had been through it and dealt with it, who would listen to me through my tears and inspire me to live a joyful life again.”



What is Self-Advocacy?

During your cancer experience you will meet with many health professionals and support people. The Canadian cancer care system is increasingly complex. Often, there is no single “case manager” or “patient advocate” to help you to manage your care from diagnosis through treatment and beyond.



As a result, you may find that you must advocate for yourself and take an active role in the coordination of your care. This is what is referred to as *self-advocacy*. You may also want to ask a trusted family member or friend to work with you or act on your behalf.

Self-advocacy means taking an active role in your treatment to make sure you get the support and care you need. It’s about asking questions and getting answers. Understanding more about your breast cancer will help you better communicate with your doctors and make informed decisions.



Understand Your Cancer and Your Treatment Options

Being well informed about your cancer diagnosis and treatment options is key to managing your health care. At every stage of the diagnostic process, treatment and follow-up, be sure you understand the next steps. Being prepared for what happens next can help alleviate any concerns or anxiety you might experience.

UNDERSTANDING THE DIAGNOSTIC PROCESS

It is important for your doctors to get a complete picture of your cancer and gather all the information they need to recommend the best treatment options for you.

Once your breast cancer diagnosis has been confirmed through a biopsy, it is still necessary to find out more about your cancer. Further tests may be needed to obtain more details, such as the size of your tumour and whether the cancer has spread to other parts of your body. You may have one or more of the following tests:

- **Diagnostic mammogram** – more x-ray pictures of the area of the breast that looked abnormal on the screening mammogram
- **Ultrasound** – detailed picture made by sound waves
- **Breast MRI (magnetic resonance imaging)** – diagnostic tool that uses magnetic fields to create images of the body
- **Bone scan** – image of the bones
- **Liver scan** – image of the liver
- **Chest x-ray** – image of the chest

UNDERSTANDING YOUR PATHOLOGY REPORT

Whenever breast tissue is removed, a pathology report will be written about the sample after it has been examined by a pathologist. A preliminary pathology report is prepared after a breast biopsy. A final, more detailed report is done after your breast surgery (lumpectomy or mastectomy).

Pathology reports summarize important information about your breast cancer, including the type it is. Common types of breast cancer are:

- **DCIS (ductal carcinoma in situ)** – an uncontrolled growth of cells within a milk duct. It is sometimes referred to as *pre-cancerous* because it has not spread outside the duct into surrounding breast tissue
- **LCIS (lobular carcinoma in situ)** – an uncontrolled growth of cells within the lobules, also referred to as *pre-cancerous* because it has not spread outside the lobule into surrounding breast tissue
- **Invasive** – cancer that began in either the milk ducts or lobules but that has spread to surrounding breast tissue (may have also spread to lymph nodes or other organs)

The report also describes the *characteristics of your tumour*, such as:

- **Stage** (size, location, whether it has spread beyond the breast)
- **Grade** (tells how fast the cancer cells are growing)
- **Hormone receptor status** (whether the cancer is sensitive to the influence of hormones)
- **HER2 status** (whether the body's cells “overexpress” or have too much of a protein called HER2)

Other important considerations include:

- **Vascular or lymphatic invasion** (whether cancer cells are found in the blood vessels or fluid channels of the breast)
- **Lymph node status** (whether cancer cells have spread to the lymph nodes)

The details in your pathology report help the doctor determine which treatment options will work best for you. Your doctor will also consider your personal characteristics, such as:

- Your age
- Your general health
- Whether you've been through menopause

Only after gathering all of the details in your pathology report can your doctor recommend the best treatment for you.

You are not a statistic!

Cancer statistics summarize information collected from large groups of people. They can make general statements about the group of people from which the information was collected. But no two people are alike. Statistics can't tell you what will happen to you. You and your situation are unique.

GATHERING THE INFORMATION YOU NEED

Gathering information, learning more about your cancer and understanding the treatments that are offered to you will empower you to be actively involved in the discussions and decisions about your care.

Knowledge is power.

Understanding your diagnosis and the language related to treatment may help you regain a sense of control. However, know your limits. You need only learn enough to give you a basic understanding of your cancer and treatment options. Your medical team will answer any questions that arise throughout the process. It is important to remember that you can, and should, ask questions at any time.

After dealing with the shock of your diagnosis, it may be difficult to determine what information you need. It is sometimes difficult to recognize how much will be enough for you to make the decisions you might be facing.

It will be helpful for you to get a copy of your pathology report and other test results from your doctor.

Let your doctor and the other healthcare professionals involved in your care know what your information needs are and how involved you want to be in your care.

Call Willow – You can often find the support you need by talking with someone who has been there and understands what you are going through. The Peer Support Team at Willow (1-888-778-3100) are breast cancer survivors – women who know first-hand what it is like to be diagnosed with breast cancer. They have been through an extensive training program and can help you through your cancer journey – from diagnosis to survivorship.

Willow has the latest information on all aspects of breast cancer – diagnosis, treatments, coping with side effects, breast reconstruction, nutrition, complementary therapies, and more.

Willow's health librarian works with the Peer Support Team to research your specific question(s) and send you a customized information package free-of-charge.

Find the right information for you.

- *Make sure the treatment information you are reading is current and relevant to you and the type of breast cancer you have.*
- *Evaluate the credibility of any book or website you find.*
- *Find a writing style that is easy for you to understand.*
- *Willow's health librarian that can help you find the information you need.*

RECOGNIZING THE FULL IMPACT OF YOUR DIAGNOSIS


The diagnostic phase is one of the most difficult times of the breast cancer experience. While still dealing with the shock of the diagnosis, you will be confronted with many new medical terms and the need to make difficult decisions during a time when you are feeling very vulnerable.

Take time to learn about your options and what you can expect with each choice. Do your research and don't be afraid to ask questions.

There is stress and anxiety associated with waiting. You will wait for the confirmation of your diagnosis; you will wait for doctor's appointments; you will wait for test results; and you will wait for referrals from one doctor to another. Waiting is difficult but unavoidable.

"I was in shock when I was first diagnosed... I needed the information to be simple at the beginning. Over time my need for information changed."






“I think getting the information gave me a sense of control that I was on top of things.”

In addition to the physical challenges that may accompany the treatment of breast cancer, there is an emotional impact as well. Family and friends want to support you but may not understand the emotional challenges of what you are going through. Many people feel more validated when sharing their feelings and concerns with another breast cancer survivor. This is commonly referred to as *peer support* and can be offered one-on-one or through support groups.

People develop different coping strategies following a breast cancer diagnosis. You may want to keep a journal or do something that reduces stress and anxiety, such as walking, yoga, meditation or visualization. Look after yourself – eating well, exercising and getting plenty of rest will help give you the energy to face every day. Joining programs or support groups that may be offered by hospitals or cancer centres in your community can help you cope. You may find you need the assistance of a professional counselor.

A cancer diagnosis often brings with it a heightened sense of mortality and a sense of uncertainty about the future. You may be dealing with challenges from treatment, reconstruction or infertility and you may be strained financially. Along with these issues of survivorship, you may find yourself with a new perspective in life. You may feel that you have changed emotionally, physically and spiritually. You and your family and friends may have a difficult time making adjustments to the new you.



“Talking to a survivor made me feel that I wasn't alone.”

Recognizing that there is a time of transition once treatment has ended and that these changes can't be managed all at once may make it easier for you and the people who care for you.



Working with Cancer Care Professionals

WHAT YOU CAN EXPECT

The doctors and other healthcare professionals involved in your cancer care should:


- Know about the latest advances in medicine and be able to answer your questions about them
- Communicate and give you information in a way that you can easily understand
- Take the time to listen to your concerns and answer your questions thoroughly
- Give you clear and understandable information about your treatment options, including what is involved and the risks and benefits of each treatment
- Keep you informed of what will happen next
- Encourage you to participate in decisions about your care

WHAT YOU SHOULD LET THEM KNOW

Let your healthcare team know how involved you want to be in your care and what your information needs are.

You may want them to know that you:

- Need help to understand your diagnosis and in making decisions about treatments
- Want recognition that being diagnosed with breast cancer has an emotional and spiritual impact as well as a physical one
- May choose complementary treatments as part of your healing



“I've always been the caregiver. It's been difficult for me to open up and let others help but I realize how much it meant to others to let them help me.”




Practical Tips for Managing Your Care

Here are some practical tips to manage your care and advocate for yourself.

ASSEMBLING AND MANAGING YOUR HEALTH RECORDS

Personal health records may be kept electronically on a computer or more often in paper format and sometimes in several locations. Keeping copies of your health records in a binder can be useful when coordinating your care.

- Ask for copies of all your medical and pathology reports.
- Keep a record of all the tests and appointments you have. This may prevent duplication.
- Include your hospitalization records and details of any surgery.
- Include a list of all prescription medications, as well as any side effects you may have had.
- Don't forget health insurance documents if you have additional coverage.
- Gather all the names and contact information of the people involved in your care.
- Include information about how to reach medical staff after hours in case of an emergency.



"I'm a nurse and I found my first oncology appointment to be completely overwhelming."

COMMUNICATING WITH YOUR DOCTOR

Fear and uncertainty may have taken away the confidence you normally have and may affect how you communicate with your doctor. Here are some practical suggestions to assist you as you communicate with your doctor.

For your visit

- Prepare a list of questions and concerns to bring to your appointment.

- Call your doctor's office for test results if they haven't called you. Waiting can make you feel very anxious. If the wait time is longer than you've been told it would be, call the doctor's office.
- Bring your health card and any doctor requisition (doctor's orders) you may have.

During your visit

- Take a notebook to all your appointments. You may also consider using a recording device to tape your consultations with your doctor.
- Bring a friend, family member or your chosen advocate to help you remember what is said, to take notes or to help speak up for you.
- Make sure that your doctor knows about any new issues or problems that have come up since your last visit.
- Your doctor and nurse need to know about new symptoms and changes in how you feel. They won't know unless you tell them.
- Ask questions. Make sure you get the answers you need. Don't be afraid to ask for clarification if you don't understand something.
- Ask for diagrams or other visual aids. Sometimes it is helpful when your doctor draws or shows you pictures while giving you information.
- Find out who you can contact when you have questions that come up between appointments.

Prioritize your questions.

You may not have enough time when you meet with your health care team to get all your questions answered. You may benefit more from your appointments if you prepare your questions in advance and prioritize which ones are most important.

After your visit

- Review your notes to help you remember what was said.
- Organize any new reports and information in your binder.
- Make a list of any questions that did not get answered or any new questions you may have.
- Get more information if you need it.
- Hold a family conference. Informing those close to you at the same time means you won't have to repeat the information.
- If you feel you need a second opinion, you can ask for a referral or your family doctor can also help you find another cancer specialist.

Why get a second opinion?

It is important for you to feel fully confident with the diagnosis you have received and recommended treatment plan. If not, you may wish to consult with another physician for a second opinion. It is your right to do so.

The second opinion may confirm what you have already been told about your diagnosis and treatment options. If not, it will open discussion so that you can make a more informed choice about your care.

During treatment

- Be sure you understand how your prescribed treatment will help you.
- Be aware of side effects you can expect with each treatment.
- Keep track of any symptoms or side effects you may be experiencing during treatment and tell your doctor or nurse about them.
- Understand which side effects you should report right away and which ones can wait until the next appointment.
- Know who to contact and what you should do in case of an emergency.
- Ask questions if you are unsure about something.

Remember, those involved in your cancer care are there to work with you and help you. Keep asking questions until you have all the information you need to feel comfortable with the care you are getting.

To find out more about what kind of questions you could ask, please contact Willow at 1-888-778-3100.

After treatment

- Schedule appointments with your specialists so that you are seen throughout the year. For example, your yearly check-up with your



Pamela Catton, MD
MEDICAL DIRECTOR, BREAST CANCER
SURVIVORSHIP PROGRAM,
PRINCESS MARGARET HOSPITAL
TORONTO, ONTARIO

“The issues of living with and beyond breast cancer begin at diagnosis and continue for the duration of a person’s life.”

“It’s normal to experience difficult emotions like anger, depression and anxiety during the breast cancer journey. By sharing feelings with a loving and wise family member or friend, joining a support group or other community program, most women feel less alone and can learn to draw on their own inner strength.”

Rob Rutledge, MD
RADIATION ONCOLOGIST, ASSOCIATE
PROFESSOR OF MEDICINE, DALHOUSIE
UNIVERSITY, HALIFAX, NOVA SCOTIA
LEAD FACILITATOR FOR THE
“SKILLS FOR HEALING”,
CANCER WEEKEND RETREATS

family doctor, mammogram and follow-up with your oncologist should be scheduled at different times throughout the year.

- Consider joining a support group (if you haven’t already).

KNOWING YOUR RIGHTS

You have the right to the best possible standard of care. As a breast cancer patient, you have the right to:

- Be given information and educational materials in simple, clear and understandable language
- Be fully informed about all treatment options and services (even if they are not available where you are being treated)
- Get a second opinion. If you have any doubts about your diagnosis or your care, you may want to seek a second opinion
- Make your own informed treatment decisions
- Review your medical records

The Canadian Breast Cancer Patient Charter


The Canadian Breast Cancer Patient Charter encourages patients to seek the high quality of care they deserve through a better understanding of their individual rights. To get a copy of the Charter, please contact Willow.



Accessing Support and Information

In addition to your healthcare team, there are other good sources of information and support available.

- Tell family and friends how they can help. Those close to you want to help, but often don't know how. You may want to consider keeping a list of tasks you are comfortable sharing so that you can make specific suggestions if someone asks "how can I help?"
- Online communities, such as discussion forums, chat rooms and blogs, can be a source of support. We encourage you to join Willow's online breast cancer community at www.willow.org.
- Talk to a breast cancer survivor. It can help to speak with someone who has been there and understands what you are going through.



"I needed to talk with someone who'd been through the breast cancer experience but wasn't emotionally connected to me. Someone who could offer information and objective comments, not just what they thought I wanted to hear."

JoAnne
BREAST CANCER SURVIVOR
WILLOW PEER SUPPORT
VOLUNTEER

Willow Breast Cancer Support Canada is a national breast cancer support organization. Our support staff and volunteers are breast cancer survivors – women who know first-hand what it is like to be diagnosed with breast cancer.

We believe that all people facing breast cancer should have timely access to unbiased information and compassionate support to help them live with this disease.


Willow provides free information and emotional support for people diagnosed with breast cancer, their families and their friends. We can research the answers to your questions and provide critical information specific to each unique question. We can connect you to someone who had a similar diagnosis or who had to make similar decisions. Willow's Peer Support Service is 100% confidential.

Willow offers:

- Empathetic and supportive listening by a breast cancer survivor
- Information that will help you understand your diagnosis, such as understanding medical terms and your pathology report
- Support and information to help you with decision-making
- Support as you advocate for yourself and navigate the healthcare system
- Practical information, such as where to get a wig or prosthesis, resources to help manage financial concerns, your reconstruction options, and how to tell your children and loved ones about your diagnosis

Need to talk? Call us at 1-888-778-3100.

To find out more about Willow, the services we offer and other breast cancer resources, visit our website at www.willow.org.



Please remember...you are not alone. No matter what point you are in your breast cancer experience, I encourage you to call Willow and speak with a member of our Peer Support Team. They are skilled at answering questions about breast cancer and treatment options and they truly understand how you feel. They are all breast cancer survivors themselves.


Virginia Yule
EXECUTIVE DIRECTOR, WILLOW



OTHER RESOURCES

The following resources are available on Willow's website at www.willow.org:

- *Coping with your financial concerns when you have breast cancer* – customized for each province to help people navigate the financial difficulties associated with breast cancer (also available in print)
- *Living with metastatic breast cancer* (also available in print)
- Resource lists covering topics such as nutrition, breast reconstruction, sexuality, talking with your children, complementary therapy, and more



“Cancer changed me, but it didn’t devastate me like I thought it would. I’m stronger than I ever thought I could be. During my darkest days, my spirit was lifted by the love and care offered to me.”

To obtain breast cancer support and information, contact:

Willow Breast Cancer Support Canada
30 St. Patrick Street, 4th Floor
Toronto, ON M5T 3A3
Toll free: 1-888-778-3100
E-mail: info@willow.org
Web: www.willow.org

Thanks to the generosity of our sponsors and donors, all of Willow's programs and services are delivered free of charge. Help ensure that no one needs to face breast cancer alone by donating to Willow Breast Cancer Support Canada.

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Breast cancer?
Need to talk?
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1.888.778.3100

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