“I’ve gone through life believing in the strength and competence of others; never in my own. Now dazzled, I discover that my capacities are real. It’s like finding a fortune in the lining of an old coat.”

— Joan Mills
Held annually at the Kanata Golf and Country Club
Supporting those affected by Breast Cancer
www.ladiesgolfclassic.ca

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Personal Breast Cancer

Information guide
Prepared for you by

Women’s Breast Health Centre
The Ottawa Hospital Civic Campus
Grimes Lodge, 5th Floor, 200 Melrose Ave.
Ottawa, Ontario K1Y 4K7

Made possible by
Donations to
Women’s Breast Health Centre from
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Work _________________________________________________________________

Other ________________________________________________________________

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Personal Contacts

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Relationship __________________________________________________________

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NAME ________________________________________________________________

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What is the Personal Breast Cancer Information Guide?

This information guide will:

➢ Provide me with some basic information about breast cancer, its treatment and the possible effects of breast cancer on me and those close to me;
➢ Help me to organize the information I collect about my breast cancer and make sense of this information;
➢ Help me to understand the cancer care system;
➢ Allow me to share the information I have gathered with my health-care team.

How to use the Information Guide

Many women may find the information they receive overwhelming and confusing. My guide contains some basic information that many other women diagnosed with breast cancer have found helpful. This information is organized into sections that address different needs. My guide can also direct me to additional sources of information that I might find useful. I can add personal information about my breast cancer to this guide so that it can help me find answers about my specific questions. My family and friends may also use the information in my guide.

Each guide section includes:

➢ A story from a breast cancer survivor;
➢ A list of common questions;
➢ Answers to commonly asked questions.

Women with breast cancer want various types of information, in different amounts and at different times. As I collect information that is helpful to me, it can easily be added to my guide.
I can take my guide to medical appointments so that:

- I can use it as a reference;
- My health-care professionals can see the information that I have collected so that they can help me understand the information.

Other considerations:

- It is important to remember that I am carrying confidential information about myself and I should keep it secure at all times;
- I can also photocopy any part or section of the guide (for example, if you need additional pages to record appointments you can photocopy a blank sheet).

The CD guide:

Included with the guide is a CD titled “Healing Imagery for Women with Breast Cancer”. The CD may be an aid to your healing. It is meant to be another method that can provide support, and focus “worry time” into relaxation and healing.

- The first part of the CD is intended for women who are awaiting breast surgery for breast cancer. If you have already met your surgeon and you have a surgical date, you can start using this CD.
- The second part of the CD is a healing place imagery exercise that will use relaxation and your senses to foster health and well being. This CD can be used as often as you would like.

It is important to remember that I do not need to complete or keep up-to-date every section in my guide. I can use my guide in whatever way it best helps me.
My personal journey

- My appointments
- Questions for my health-care provider(s)
- My medication record
- Summary of my breast cancer pathology results
- My test results
- Decision making tool and worksheet
- Personal notes and diary
  (You may want to photocopy additional sheets within this section as needed.)
- My schedule (separate booklet)
My appointments

Date _____________________  Reason for visit _________________________________________
Health-care provider _____________________  Name of clinic ____________________________
Location ___________________________________________________________________________
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- **Reason for visit**: 
- **Health-care Provider**: 
- **Name of clinic**: 
- **Location**: 
- **Transportation arrangement (i.e., relative, friend, volunteer driver)**: 
- **Questions, answers or comments**: 

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- **Next appointment**: 

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<th>NAME OF MEDICATION and dosage instructions</th>
<th>Time of day taken</th>
<th>Reason for taking</th>
<th>Doctor</th>
<th>Side effects</th>
<th>Advice for side effect relief</th>
<th>Date started</th>
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<th>SIDE EFFECTS</th>
<th>ADVICE FOR SIDE EFFECT RELIEF</th>
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<th>DATE STOPPED AND REASON FOR STOPPING</th>
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MY MEDICATION RECORD
Summary of my breast cancer pathology

(You may need your doctor or nurse to help you fill out this part. Section 4 contains the information describing breast cancer which may be helpful to refer to when you fill out this part.)

Many people on your health-care team will ask you similar questions about your breast cancer. You may find it helpful to complete this section so that you will have a record that you can share when these questions are asked.

1. What kind of breast cancer do you have (i.e., ductal carcinoma in situ, invasive ductal breast cancer, invasive lobular breast cancer, inflammatory breast cancer)?

2. What was the size of the tumour? _____ cm or _____ mm

3. Did the edges (margins) of the breast tissue removed have cancer cells?
   - Yes  
   - No

4. Were any lymph nodes removed from your armpit(s) (axillary node dissection)?
   - Yes  
   - No

5. Did you have a Sentinel Lymph Node Biopsy?
   - Yes  
   - No

6. How many lymph nodes were removed? __________________________

7. How many lymph nodes had cancer cells? __________________________

8. What were the hormone receptor test results?
   - Estrogen receptor:  
     - Positive  
     - Negative  
     - Not done
   - Progesterone receptor:  
     - Positive  
     - Negative  
     - Not done
   - HER2/neu over expression:  
     - Positive  
     - Negative

9. What stage was your breast cancer when you were first diagnosed?
   - Stage 0  
   - Stage I  
   - Stage IIA  
   - Stage IIB
   - Stage IIIA  
   - Stage IIIB  
   - Stage IV  
   - Not done

10. Other (including other medical history):
    __________________________________________
    __________________________________________
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<th>Yes</th>
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You will be guided through four steps:

1. Clarify the decision.
2. Identify your decision making needs.
3. Explore your needs.
4. Plan the next steps.

**Clarify the decision.**

What is the decision you face?

What is your reason for making this decision?

When does this decision have to be made?

How far along are you with your decision?

Are you leaning toward a specific option?

If yes, which one?

**Identify your decision making needs.**

A. Support

Do you have enough support and advice from others to make a choice?

Are you choosing without pressure from others?

B. Knowledge

Do you know which options are available to you?

Do you know both the benefits and risks of each option?

C. Values

Are you clear about which benefits and risks matter most to you?

D. Certainty

Do you feel sure about the best choice for you?

People who answer “No” to one or several questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes. Therefore, it is important to work through steps three and four that focus on your needs.

**Explore your needs.**

A. Support

Who else is involved?

Name:

Name:

Name:

Which option does this person prefer?

Is this person pressuring you?

Yes

No

Is this person pressuring you?

Yes

No

How can this person support you?

What role do you prefer in making your choice?

I prefer to share the decision with __________________________________________

I prefer to decide myself after hearing the views of __________________________________________

I prefer that someone else decides. Who? __________________________________________

Decisional Conflict Scale © 2006 O’Connor
B. Knowledge
In the balance scale below, list the options and main benefits and risks that you already know. Underline the benefits and risks that you think are most likely to happen.

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<td>Reasons to choose this option</td>
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C. Values
Use stars (★) to show how much each benefit and risk matters to you. 5 stars means that it matters “a lot”. No star means “not at all”.

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D. Certainty
Circle the option with the benefits that matter most to you and are most likely to happen. Avoid the option with the risks that are most important to avoid.

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Plan the next steps based on your needs.

✓ Things making the decision difficult
✓ Things you are willing to try

A. Support
☑ You feel you do NOT have enough support
☐ You feel PRESSURE from others to make a specific choice

☐ Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends)
☐ Find out what help is on hand to support your choice (e.g. funds, transport, child care)

B. Knowledge
☑ You feel you do NOT have enough facts

☐ Find out about the chances of benefits and risks.
☐ List your questions and note where to find the answers (e.g. library, health professionals, counsellors):

C. Values
☑ You are NOT sure which benefits and risks matter most to you

☐ Review the stars in the balance scale to see what matters most to you.
☐ Find people who know what it is like to experience the benefits and risks.
☐ Talk to others who have made the decision.
☐ Read stories of what mattered most to others.
☐ Discuss with others what mattered most to you.

☐ Other factors making the decision DIFFICULT

List anything else you need:

Ottawa Personal Decision Guide © 2006 O’Connor, Jacobsen, Stacey, University of Ottawa, Ottawa Health Research Institute, Canada
“When someone tells you that you can’t go any farther, just tell them to look behind you and see how far you’ve come.”

— Linda Pitre
Personal notes and diary

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“If I have the belief that I can do it, I shall surely acquire the capacity to do it even if I may not have it at the beginning.”

— Mahatma Gandhi
Personal notes and diary
“Grant me the serenity to accept the things I cannot change; the courage to change the things I can; the wisdom to know the difference.”

— Reinhold Niebuhr
“You need time for crying, time for healing, and time for laughing. Laughter is reassuring and can provide a spark of hope.”

— Catherine Ripplinger Fenwick
“Start by doing what’s necessary, then do what’s possible and suddenly you are doing the impossible.”

— Saint Francis of Assisi
I have been diagnosed with breast cancer

A woman’s story: Colleen MacDonald

Frequently asked questions:
- What is breast cancer?
- How do I make sense of all of the information?
- What is a common reaction to a diagnosis of breast cancer?
- How should I share my diagnosis?
- “Stepping stones” in coping with breast cancer
- My support team
**Colleen MacDonald**

**Diagnosed:** Age 34  
**Diagnosis:** Infiltrating Ductal Carcinoma with metastases of the lymph nodes  
**Treatment:** Chemotherapy, modified radical right breast mastectomy, radiation  
**Occupation:** Restaurant Manager, for McDonalds Restaurants of Canada Limited

I can still remember that morning I discovered the lump in my right breast. I thought it was nothing, I waited two days to see if it would go away, but it did not. I called my doctor and went for an appointment to get it checked out. My doctor sent me for a mammogram and ultrasound. The results from those two tests sent me to get a biopsy. Within a week, I received the results from my biopsy, staying positive about what he was going to say was hard but I hoped for the best when I went to his office. He came in and sat down and began to say, “I am sorry but you have breast cancer.” My first reaction was I have a 5 year old daughter and was I going to die? He assured me that I was not going to die and that things would be alright. I walked out of his office and all I kept asking myself was how could this happen? I need to see my daughter grow up, I need to be there for my family.

I continued to work for about two weeks after I was diagnosed just to keep my mind occupied on something other than my having cancer. Then came all the tests and appointments that I had to attend and that is when I had to go on leave from work. I was angry about leaving work because I was doing well and I enjoy my job.

Being at home gave me time to spend with my daughter and try to explain to her what was going to happen to Mom. At 5 years old she does not know what the word CANCER means, yes mom is going to lose her hair and she won’t feel well for a while. But to her it was playtime as usual. It was hard to say to her that I am just too tired and don’t feel well enough to play.

Half way through my chemotherapy, I joined a support group (Stepping Stones) and it was one of the best things that I could have done. I realized that there were other women out there going through the same thing as I was and they had the same feelings as I did. Even though the support group ended some of the ladies still meet every week. I have made some really great friends.

As my journey continues with breast cancer, I live every day to the fullest and take things one day at a time. Staying positive and having my family and friends supporting me has helped me to get through this journey.

“Never, never, never give up.”
Questions you may want to ask your doctor....

- What is breast cancer?
- What type is my breast cancer?
- How do I make sense of all of the information?
- What are the common reactions to being diagnosed with breast cancer?
- How can I tell my family and friends about my breast cancer diagnosis?
- Where else can I go to get breast cancer information and treatment?

What is breast cancer?

Breast cancer cells, unlike normal cells, cannot control their growth and division. Malignant or breast cancer cells can take over and harm tissues and organs near them because they grow rapidly and without any order. As well, breast cancer cells can break away from the tumour and enter the blood system or lymphatic system (the system that fights infections). This may result in the breast cancer cells spreading to other parts of the body (metastases). Although most breast cancers occur in women, approximately one per cent of all breast cancer occurs in men; treatment is similar in both settings.

Breast cancer may be described as either non-invasive or invasive:

- **Non-invasive or in situ breast cancer** has not grown into surrounding tissue. Ductal carcinoma insitu (DCIS) is when there are cancerous changes in the cells lining the milk ducts (the channels in the breast that carry milk to the nipple). However, the breast cancer cells are completely contained within the ducts and do not have the ability to spread to the surrounding breast tissue. DCIS is a non-invasive breast cancer. DCIS is considered by many to be an early stage breast cancer and is often detected by mammography. Because the cancer cells are contained in the duct, there is no chance for spread through the blood or lymph system to other parts of the body, including lymph nodes under the arm.

- **Invasive breast cancer** is also known as infiltrating cancer. This type of cancer has spread outside of the ducts or lobules where it began. Cancer that is invasive has the potential to spread to the lymph nodes in the axilla/arm pit and elsewhere in the body. Spread to lymph nodes will not be known until after they are removed by the surgeon.
and examined by the pathologist. About 70 per cent of all breast cancers are *infiltrating ductal carcinomas*, the most common type of breast cancer. The cancer begins in the milk duct and spreads outside the wall of the duct. *Invasive lobular cancer* begins in the milk producing glands called lobules and has spread outside of the lobules into the nearby breast tissue.

*Inflammatory breast cancer* is a less common form of invasive breast cancer (less than five per cent). This type of cancer can cause the breast to become swollen, reddened, tender and warm because cancer cells block the tiny channels (lymph vessels) in the skin of the breast and as a result the breast looks inflamed.

**Breast anatomy**

![Diagram of breast anatomy with labels for Lobule, Duct, DCIS (non-invasive), Ductal Carcinoma In situ, Invasive ductal carcinoma, and Invasive lobular carcinoma.]

**Where to start...breast cancer**

Suggestions for resources when you begin to look for information about breast cancer.

* Prepared by Learning Services
  The Ottawa Hospital Cancer Centre
  [www.ottawahospital.on.ca/patient/visit/chlib/index-e.asp](http://www.ottawahospital.on.ca/patient/visit/chlib/index-e.asp)
How do I make sense of all the information?

When you are diagnosed with breast cancer, you will receive a lot of information from many sources. It is important to keep the following points in mind:

★ Consider how much information you want to get about the diagnosis and its treatment and ask for the information. Some people want as much information as they can possibly get and others may want very little;

★ Write down questions as you think of them. You may want to take your notes with you to each appointment;

★ Record your conversations (i.e., take notes; use tape recorder) with your health-care Providers or bring along a friend or family member to listen and take notes. It’s sometimes hard to listen, understand and remember everything that you are being told;

★ Write down instructions or ask for them in writing;

★ Ask your health-care provider to explain if you do not understand;

★ If you are feeling overwhelmed with the amount of information you have received, make an appointment to discuss it with one of your health-care providers (i.e., doctor, nurse, social worker) or contact a breast cancer support group(s). They may have some ideas about what is the most important information to focus on given your situation;

★ Sometimes friends and family members try to help by giving you information that you really don’t feel you can take in. Thank them for their help and tell them that you will read the information when you are feeling up to it;

★ If you have questions about information that you have read, do not hesitate to ask your health-care providers. It is often difficult to judge if information is coming from reliable sources or how it might be useful to you;

★ It is important to remember when reading information there may be differences between American and Canadian standards of care, insurance and health-care systems.

Remember: Not everything you read will apply to you. Read so that you can know the types of questions to ask about your situation. Also, information needs change as people progress through their cancer treatment. Sometimes patients don’t want to read anything at the start, but later will feel the need to know more. Some patients rely on family members and friends to gather information for them.
What is a common reaction to a diagnosis of breast cancer?

By the time most women are diagnosed with breast cancer they have been through a series of tests and many have thought about breast cancer. However, finding out for sure that you have breast cancer may come as a shock. For most, the shock of knowing you have breast cancer may make thinking clearly and problem solving hard. It may be difficult to take in and remember all of the information; this can be frustrating and frightening.

🌟 Often, the first thought is, “Am I going to die?” This is a common reaction. A sense of panic and overwhelming anxiety can take over, especially when you do not have the information.

🌟 Sadness is another feeling that women describe. At times, these feelings bubble to the surface and women feel grief. It is okay to cry.

🌟 Other women may be angry. “Why me?” “Why now?” Do not blame yourself—you should not feel guilty. This is not your fault.

🌟 You may feel very tired. Many women have trouble sleeping and notice changes in their appetite.

🌟 Some women have difficulty believing they have breast cancer. A certain amount of “putting it aside” may need to happen for women to continue with their other responsibilities such as looking after their family, work, etc.

Each person deals with this situation differently. It may be helpful to talk about how you are feeling and learn how you might deal with these feelings.
How should I share my diagnosis?

The most important reason for sharing with others is that it allows family and friends to be supportive and women who have support seem to do better. You may also find it helpful to talk about your breast cancer.

As you tell others, it may help you to understand the information you have been given;

It avoids secrets, people who find out from someone else do not know if they have permission to talk to you;

Some people such as close family may need to know as it would cause them greater distress to be left out;

It may lift the burden of keeping it to yourself.

How to tell family and friends:

There is no easy way to say it. Here are a few tips to think about when sharing this news:

First give the headline: e.g., “I have gone through a series of tests and my doctor has told me I have breast cancer.”

Give them any other information you have: e.g., “I have the most common type of breast cancer and I expect to have surgery soon.”

Allow them to ask questions: e.g., “Do you have any questions?” You may not have the answers; tell them this.

Tell them how you’re feeling: e.g., “I’m frightened and need your support.”

Tell them what they can do: e.g., “I need you to tell Aunt Susan about my diagnosis.”

Often family and friends feel helpless as to what they can do to help. It will be up to you to let them know that you need them as an important part of your support team. You may not be certain what you need specifically but only that their support will be important.

The way in which you tell certain family and friends will be different.
Stepping stones in coping with breast cancer

As you begin to deal with your breast cancer diagnosis, these are some steps that may be helpful...

**STEP 1**

**Become self-caring:** Change the perception of putting your own needs first as being selfish. Caring for yourself is priority #1.

**STEP 2**

**Build your team:** Choose the people you want as a part of your support team and allow them to help. This serves a double purpose of supporting you and giving those around you permission to be involved. Be selective! Avoid the people who get in the way of your healing. (See the next page to build and list your own support team.) Remember that you are a valuable member of your team.

**STEP 3**

**Take on one issue at a time:** Leave the things that can be left, try not to jump ahead.

**STEP 4**

**Develop a good working relationship with your health-care team:** Ask questions and share your feelings, develop a sense of trust, include your family doctor.

**STEP 5**

**Take time:** Some things do not have immediate solutions and do not require action. Try relaxation techniques, listen to music, take time out, spend time doing the things that are important to you.

**STEP 6**

**Trust yourself:** Learn the facts but also listen to your internal voice. If you think something is wrong, check it out.

**STEP 7**

**Make changes slowly:** Only do the things that make sense to you. Any change is difficult, do not add stress by expecting too much of yourself.
The Ottawa Hospital Civic Campus Women’s Breast Health Centre
‘Stepping Stones’
a support group for women newly diagnosed with breast cancer

- Become a partner in your health care
- Learn how to be active in making your decisions
- Develop new coping skills
- Find out about community resources

For more information and to register, contact the social worker at the Women’s Breast Health Centre 613-798-5555, ext. 16563.

- Six week program

The Ottawa Hospital Civic Campus,
Maurice Grimes Lodge
200 Melrose Avenue
Solarium, 1st floor

Remember you are truly unique, and your path to healing belongs to you!
My support team

Family

_______________________________________________

_______________________________________________

_______________________________________________

_______________________________________________

_______________________________________________

_______________________________________________

_______________________________________________

_______________________________________________

Friends

_______________________________________________

_______________________________________________

_______________________________________________

_______________________________________________

_______________________________________________

_______________________________________________

_______________________________________________

_______________________________________________

Doctors involved in my care

Family Doctor continues to play a role in your care

_______________________________________________

_______________________________________________

_______________________________________________

Surgeon**

_______________________________________________

Medical Oncologist

This physician will discuss with you whether chemotherapy (drug) treatment is indicated.

Radiation Oncologist

This physician will discuss and arrange radiation treatment to the breast for you if indicated.

The Ottawa Hospital is a teaching hospital so there may be residents (physicians) and medical students as part of the care team. Please let us know if you do not wish to have a learner present.
Others involved in my care

Nurses(s)*

_______________________________________________

Community Nurse

_______________________________________________

Social Worker***

_______________________________________________

*** If you need help with the following:
Contact the Social Worker, 613-798-5555, ext. 16563
• Emotional support for yourself and/or family
• Resources and support for breast cancer
• Navigation through the health-care system
• Help with transportation for medical appointments, medications, finances
• Decision-making
• “Stepping Stones Support Group” for women recently diagnosed with breast cancer

Pharmacist/Drug Store

_______________________________________________

Dietitian

Dentist

Who to call when:

* If you have questions about your surgical procedure, wound care post-operatively, decision making, what happens next, or any other concerns, please call your nurse at the WBHC.

** If you have questions about your pre admission date or your surgery date, please call your surgeon’s office.
If you would like a copy of any of your medical reports, they are available through the Medical Records Department of your hospital.

Emergency Rooms
If you need to present to an emergency room, go to the closest hospital. If you are able to, it is preferable to go to the hospital where you had your surgery.
Other support
(e.g., spiritual providers, neighbours, volunteer driver)

Complimentary care providers
(such as massage therapists, chiropractors, exercise specialist, physiotherapist, occupational therapist or herbalist)
How will my breast cancer be treated?

A woman’s story: Pam Carvish

Frequently asked questions:
- What are the common treatments?
- Possible problems and discomfort after surgery
- What are clinical trials?
- What is new on the horizon?
Pam Carvish

**Diagnosed:** Age 37
**Diagnosis:** Invasive Ductal Carcinoma with metastatic lymph nodes
**Treatment:** Modified radical mastectomy on right side with complete lymph node removal and prophylactic removal of left breast, chemotherapy, radiation, Tamoxifen, Herceptin

**Occupation:** Construction Coordinator, Federal Government

Being a wife and a mother of two young children (5 and 2) with a full time job, this diagnosis came as a complete surprise. Finding the lump myself, I quickly went to see my doctor, who said it didn’t feel like a cancer lump but ordered up a mammogram and ultrasound to be safe. The images prompted a core biopsy which confirmed Invasive Ductal Carcinoma. After meeting with the surgeon, she wanted an MRI which showed lymph node involvement and a biopsy confirmed positive for cancer.

After long talks with my husband about mastectomies, it became my decision to have both breasts removed, as I was heavy chested and worried about recurrences. Since my children are so young that they would not understand the word ‘cancer’ so it took many small conversations to tell them that “mommy’s breasts need to be removed to make mommy better.” I was horrified at how this was going to affect the kids but they are resilient little things and in the end with no breasts and after losing my hair to chemotherapy, I was still mommy to them.

My coping strategy was to be very open about my situation with my family and friends, who became a huge support system and kept my spirits up when I could not. I even set up a Website that chronicled my appointments and my feeling so that everyone was updated as it happened. To me, hiding behind a screen to get my support was the way I liked it but after being resistant to join a support group, I finally went and was very surprised first by the number of women in the same situation but also by the love and compassion that each woman gave to the other. I made lasting friends through the Stepping Stones support group and we all went through it together no matter what stage of treatment each of us was in.

Unfortunately, I lost my grandmother before my cancer treatments started, but a poem was read one night during the mourning period and it stays true to me with every friend I made during this process.

> A butterfly lights besides us, like a sunbeam…
> And for a brief moment it’s glory
> And beauty belong to our world….
> But then it flies on again, and although
> We wish it could have stayed,
> We are so thankful to have seen it at all.
Questions you may want to ask your doctor...

What treatment are you recommending for me?
- Do you have a preference for the type of surgery I should consider?
- When and why are lymph nodes removed?
- Do I need a breast MRI?
- What are the risks of breast cancer surgery?
- Should I consider breast reconstruction?
- What are my other options?
- Do I have to prepare for surgery?
- How do I look after my incision?
- Are there physical limitations after surgery?
- How long will I be in hospital?
- How quickly will I recover physically?
- Will I need help at home during my recovery from surgery?
- Are there specialty stores that cater to women’s needs after surgery?

Radiation
- What is radiation therapy?
- Will I require radiation therapy?
- Are there side effects to radiation therapy?

Chemotherapy
- What is chemotherapy and who gets it?
- Will I require chemotherapy?
- Why do some people have chemotherapy before surgery, and others afterwards?

Hormonal Therapy
- What is hormonal therapy for breast cancer?

Research
- Are there research studies looking at better ways to treat breast cancer?
What are the common treatments?

Surgery
In most cases, surgery is the first step in the treatment of breast cancer. Some women have a choice between lumpectomy and mastectomy; others may not. For those who have a choice, studies have shown that survival is the same whether you have a lumpectomy with radiation or a mastectomy. It is a personal decision.

In some cases, women will need another kind of treatment for their first step. The surgeon may make a referral to an oncologist who may offer women chemotherapy prior to surgery.

Type of surgery

Lumpectomy
(by also be called segmental or partial mastectomy, or wide excision)
This kind of breast surgery involves removing the breast cancer with a good margin of normal breast tissue around it. It is important that the tissue around the tumour (also known as the margin) is free of breast cancer cells. For invasive breast cancer, sampling of the lymph nodes serves several important roles. The information gained from the assessment of the lymph nodes helps determine the stage of the cancer and directs further treatment; as well it may help to locally control any disease in the armpit. The pathologist checks the lymph nodes to see if there are any cancer cells. In DCIS (non invasive cancer), generally, lymph nodes are not removed because the tumour cells do not have the ability to spread to the axillary lymph glands.

Lymph node staging
Knowing whether you have cancer cells in your lymph nodes or not will help your doctors decide what kind of treatment you may need after your operation for breast cancer. If the sentinel lymph node is cancer free, the rest of the lymph nodes will most likely be cancer free as well. Lymph node staging may be performed by sentinel lymph node biopsy or standard axillary dissection.

In sentinel lymph node biopsy or dissection the surgeon removes the node that is the first one to receive lymph drainage from the breast. We expect that it will be the one most likely to contain cancer if cancer cells have spread. There may be more than one sentinel node. If a sentinel node is removed, examined by a pathologist and found to be healthy,
the chance of finding cancer in the remaining nodes is small. This procedure spares many women from having an axillary lymph node dissection where more nodes are removed and provides comparable information for staging the cancer.

**What are the benefits of a Sentinel Lymph Node Biopsy?**

The sentinel lymph node biopsy decreases the risk of problems such as arm numbness, difficulty with moving your shoulder or swelling in the arm (lymphedema) when compared to the standard axillary dissection. Your doctor can further discuss these potential adverse effects and benefits with you.

**When is it appropriate to have a sentinel lymph node biopsy?**

A sentinel lymph node biopsy is an alternative way of staging the axilla for women with operable breast cancers and whose lymph nodes are not abnormal by physical examination or investigation before surgery. You may not be a good candidate if you have had any prior surgery or treatment that could have changed the normal flow of lymph from the breast.

**How is it done?**

To identify the sentinel lymph node or nodes two “tracers” are used. These tracers are injected into the breast and then flow through the lymph channels into the axilla (armpit). The first tracer contains a small amount of radioactive material that is injected the day before or the day of surgery. The amount of radiation is much less than a regular x-ray. The surgeon then uses a hand-held Geiger counter to locate the sentinel lymph node(s) during the operation. The second tracer sometimes used is a blue dye, which is injected during the operation. The surgeon observes where the dye travels and identifies the blue stained lymph nodes.

**How do I prepare for my operation?**

The day before or the morning of your surgery you will need to go to the Nuclear Medicine Department located at your hospital. You will be brought into an imaging room and will lie on an examination table. The technologist will clean an area of the affected breast. The technologist or nuclear medicine specialist will use a small needle to put the radioactive material in your breast. It usually takes a short time for the injection to be done and you may feel some burning/pain at the injection site. This feeling will pass after a few minutes. Fifteen to thirty minutes later the technologist will take several images of your breast and underarm area. He or she will place a small black mark on your skin with a marker. This indicates the location of the lymph node. After the procedure, you are free to return home if your surgery is the next day.
MASTECTOMY

Mastectomy is performed in cases where the surgeon feels he or she must do so to remove all of the breast cancer. In other cases, it is a woman’s preference to have the entire breast removed. With this kind of breast surgery, all of the breast is removed including the nipple.

Total (Simple Mastectomy)

❖ The entire breast is removed.
❖ Lymph nodes under the arm are not removed.

Modified Radical Mastectomy (simple mastectomy with axillary dissection)

❖ The complete breast is removed including the lymph nodes under the arm.
❖ The chest wall muscles are not removed.

For more information or pictures of what these procedures can look like, refer to www.breastcancer.org.

MRI

In some cases it will be necessary to have a breast MRI. Your surgeon will make this decision based on his assessment of the need for it.

Localization

Sometimes the surgeon may need help to accurately identify where the cancer is in the breast.

1. Radioactive seed localization
   A few days before your surgery, the radiologist will place a tiny radioactive seed (the size of a grain of rice) at the site of the cancer. During your surgical procedure your surgeon will be able to locate the site of the cancer and then remove both seed and cancer.

2. Wire localization
   In this case, the radiologist will mark the area with the help of mammography or ultrasound. Freezing is often used and a small thin wire(s) is placed at the site of the cancer.
Reconstruction

Women who are having a mastectomy may be offered the choice of reconstructive surgery to rebuild the contour of the breast. Reconstructive surgery is done by a plastic surgeon. This may be done at the same time as the breast cancer surgery (immediate) or at a later date (delayed). If you are interested in breast reconstruction, mention this to your surgeon. There are some settings where immediate reconstruction is not appropriate. Your surgeon will discuss this with you.

Reconstruction can be done in different ways:

1. With implants:
   a. There are two ways in which implants can be used to reconstruct a breast after mastectomy.
      i. A tissue expander (a fancy “water balloon”) that is placed under the muscle and involves a number of trips to the plastic surgeon to inject fluid into the implant. Once the expander is the appropriate size, it is replaced by a permanent implant.
      ii. Directly to an implant at the time of the mastectomy. This requires the use of donor human tissue to provide support and coverage of the implant and is only possible if your general surgeon feels it is safe to spare the skin of the breast at the time of mastectomy.

2. With your own tissue:
   a. There are several ways to use your own tissue to reconstruct a breast after mastectomy. These surgeries are longer than implant surgeries and require a longer stay in hospital and a longer recovery.
      i. A TRAM (transverse rectus abdominis muscle) flap involves taking skin, fat, and muscle from your abdomen to create a breast shape.
      ii. A DIEP (deep inferior epigastric perforator) flap involves taking only skin and fat from your abdomen to create a breast shape.
      iii. A latissimus dorsi flap involves taking skin, fat and muscle from your back and creating a breast shape using an implant to increase the breast volume.
      iv. Other sites are possible if your abdomen and/or back are not options.

There may also be other reconstructive procedures available to you—ask your surgeon. For more information about reconstruction options, there is an informative article in the New England Journal of Medicine, Vol. 359, 1590-1601, October 9, 2008, No. 15 available by googling www.nejm, vol 359; 1590-1601.
Pre-operative teaching sessions
A two hour presentation by a nurse, social worker and a volunteer where the patient and family are given information about what to expect with surgery and with post-operative recovery. Call 613-761-4400, option #3 to register.

Pre-operative care

Pre-admission appointment
A pre-admission appointment before the date of your surgery is part of the standard preparation. A nurse will explain what to expect during your hospital stay and review your past medical history. Usually you will have blood work done and sometimes a chest x-ray and/or electrocardiogram (ECG) if necessary. Sometimes there will be a meeting with the anesthetist (the doctor who puts you to sleep during the surgery). You will be given instructions at this time in how to prepare for your surgery and post-op care.

Post-operative care
Women who are being discharged the same day as their surgery may have a nurse from the home care program visit them at home the night of their surgery. There may be a visit the next day as well as the 5th day after surgery. This visit at day five will be in the patient’s home or at an outside clinic. At this visit the patient’s dressing will be changed.

Some people find it helpful to have a pillow in the car for the drive home from hospital. It can provide support for the operative site during the drive.

Hospital stay
Most breast surgery is done as an outpatient or at the most, a one night stay. Most women who have had a standard axillary dissection or a mastectomy are discharged with a soft plastic tube in place that drains fluid from the surgical site. This tube usually stays in place for five to seven days. The nurse will teach you how to empty this container. It is quite straight forward. The drain will be removed by a visiting nurse or by your surgeon. More information about the drain is available in the pathway booklet or you can check with your nurse. Your surgeon, nurse or physiotherapist will provide you with information on arm exercises. As well, you will be taught how to care for your bandage/dressing. If you have had a lumpectomy it is important to wear a bra after your dressing is removed to support your breast as it heals.
For women who wish to arrange for a prosthesis, there is a form you can download from the Ministry of Health Website. A portion of the cost for the prosthesis is covered by the Assistive Devices Branch of the Ministry of Health. If you have your own health insurance plan, they may cover the difference between what the government will pay and the total cost for the prosthesis. It is a good idea to wait two months before purchasing a permanent prosthesis. A temporary prosthesis may be obtained from Reach to Recovery Program of the Canadian Cancer Society by calling 613-723-1744. Prosthesis can be fitted and purchased in Ottawa from:

- Marianne’s, 1309 Carling Avenue, 613-722-6614
- Ontario Medical Supply, 1100 Algoma Rd., 613-244-8820
- Kelly’s Mastectomy Boutique, 1747 St. Laurent Blvd., 613-248-8989
- Shoppers Drug Mart, 1309 Carling Avenue, 613-722-4277

If you wish, after your surgery you can receive a call from a volunteer from the Peer Support of the Canadian Cancer Society. As a breast cancer survivor, she will share both her personal experience and helpful tips with you. You may also choose to speak to women who have had breast cancer through other community agencies listed in this guide. For people having a mastectomy, there is a program available from Kelly’s Mastectomy Boutique which will supply you with a free post-op mastectomy camisole—ask your nurse.

**Exercises after breast surgery**

Exercises are important to do after surgery and will help you with your recovery. Start with three to five sets for each exercise, twice daily.

To help you prepare try practicing these exercises in the days before surgery.

The exercises can be found in the booklet put out by the Canadian Cancer Society called *Exercises after breast surgery*. Many of you will have received this booklet at your first visit with your surgeon. It can be accessed as well online at www.cancer.ca or by calling the Cancer Society at 1-888-939-3333.

**Guidelines**

- Do not cause undue strain to your incision: exercise within your pain limit.
- Use your arm to assist with daily activities such as dressing, handling objects, etc. Work.
- Avoid heavy lifting.
- Balance activity with rest periods: pace yourself.
Walking is an excellent general activity to be done during your recovery period.

Exercise within your pain limit — use of a mild analgesic may make it easier to do your exercises.

If you experience severe pain or decreasing range of motion consult your primary nurse or surgeon.

Weight lifting restrictions:
- 5 lb. for first two weeks following surgery
- Nothing heavier than 10 lb. until four weeks after surgery

Driving: do not drive until you have complete range of motion on the affected side and are able to respond quickly if need be.

At home
You may experience fatigue and discomfort. You will be given a prescription for pain medication when you are discharged from the hospital. There will be a large bandage/dressing over the incision which may be changed by a visiting nurse or at your first post-operative visit with your surgeon. Give yourself lots of time to rest. If you have concerns about caring for yourself at home, discuss them with your surgeon or nurse.

Possible problems and discomforts after surgery

Pain/discomfort
You will probably feel some discomfort or pain after your surgery. This is expected. Your physician will prescribe pain medication for you. It is important to take pain medication (analgesic) as needed. You will be better able to mobilize and do your exercises if your pain is controlled. Many people fear the side effects of pain medication or they fear that they will become addicted to the pain medication. Addiction almost never occurs in cancer patients. Many side effects wear off in time or are easily managed with other medications.

Pain is not just a physical thing. The ability to cope with pain is worse if you are tired, sad, angry, afraid, or stressed. Family and friends may be able to provide emotional support, but sometimes counselling or support groups are helpful as well.

Seromas
This swelling is caused by a build up of fluid (serum) near the incision (at the breast or armpit). There is a “pocket” or a space left after surgery that may fill up with fluid. This is not abnormal. In many cases, the fluid will absorb over time. However, if there is a large amount of fluid, the surgeon may drain it if necessary.
**Infection**  
The risk of infection with breast surgery is low. However, if there is a foul-smelling drainage, red and tender skin around the incision, or fever, there may be an infection.

**Lymphedema**  
This is swelling in the chest, arm or hand caused by lymph fluid that has built up. It can be a result of lymph node removal or radiation under the arm (axilla). It can happen any time after surgery—sometimes years later. Should you notice swelling of your arm, notify your physician.

Listed below are some simple tips to help care for the skin and reduce the risk of infection:

- Remember the importance of gentle daily moisturizing of the skin with non-perfumed cream or oil. This enables the skin to remain in good condition;
- Treat even small grazes and cuts with antiseptic and keep them clean until they heal;
- Try to avoid being scratched, especially when playing with cats or other animals—wear gloves and long-sleeved clothing when handling animals or gardening;
- Use insect repellents to prevent insect bites;
- Use a thimble when sewing;
- Avoid getting a sunburn;
- Use an electric razor to avoid nicks if you shave your underarms;
- Use a nail clipper instead of scissors to cut your nails and use hand cream regularly—take care if you push back or cut the cuticles;
- Avoid having acupuncture, blood pressure readings or blood taken from the arm on the same side as your surgery if at all possible.
- Following axillary dissection, for long distance flights you may want to wear a compression sleeve. Discuss this with your physician or physiotherapist.

If you have been diagnosed with lymphedema, the Ministry of Health and Long-Term Care has coverage for lymphedema sleeves. Visit their website to download the Assistive Devices Program application form to apply for funding of a sleeve.
Surgical pathology

Surgical pathology report

Following breast cancer surgery, the tumour is sent to the hospital lab where it will be assessed by the pathologist. He/she will examine the tissue samples and report the findings back to the surgeon usually within two weeks. Your surgeon will discuss the pathology results when available with you at your two week follow-up visit. You may request a copy of your pathology report as it contains an invaluable blueprint of your cancer and is used to plan further treatment.

A pathology report may contain the following information:

Gross description

Describes the appearance of the tumour and lymph nodes including weight, colour, texture, size, margin measurements, tissue samples and contents of each microscopic slide.

Microscopic description

Describes what was seen under the microscope. This description includes:

- Type of breast cancer cell (i.e., infiltrating ductal);
- Histologic grade (Grade 1, 2, 3)—a description of how closely the cancer cells resemble normal breast cells. A tumour may be described as well or poorly differentiated. Well differentiated cells look more like normal breast cells and generally are less aggressive. Grade 1 is well differentiated. Poorly differentiated cells have little resemblance to normal breast cell cells—usually Grade 3.
- Resection margins—the pathologist looks to see if there are breast cancer cells along the edges (margins) of the tissue that has been removed.
- Vascular/lymphatic invasion—describes whether the cancer cells are present in blood (vascular) or lymphatic vessels. This may mean the cells are more likely to spread outside of the breast.
- Number of lymph nodes removed and, of those, the number with tumour cells.
Hormone receptor status—Some breast cancers exhibit receptors for hormones such as estrogen and progesterone that make them sensitive to hormonal manipulation. A test that is positive indicates that the tumor is sensitive to hormones. This will guide further treatment you may be offered by your medical oncologist. Tamoxifen is a drug which blocks this receptor. Hormone receptor status may not be available at the same time as your pathology report after surgery.

HER2/neu stands for human epidermal growth factor 2. It is a protein normally found in the body. Approximately 15 to 20 per cent of breast cancers over produce this protein product. Identifying whether a breast cancer is positive or negative for HER2/neu overexpression will help to guide your treatment.

Staging

How tumours are staged:

The stage of your breast cancer is determined by its size and whether it has spread. The stage of the tumour is important in deciding which treatment is best for you. Staging tests may be ordered by your surgeon or oncologist. This may include chest x-ray, bone scan and abdominal ultrasound.

T.N.M. staging system

<table>
<thead>
<tr>
<th>Stage</th>
<th>Size of Tumour (T)</th>
<th>Lymph Nodes Have Cancer (N)</th>
<th>Metastases (M)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>In Situ</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>1</td>
<td>&lt;2 cm</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>IIA</td>
<td>&lt;2 cm</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>2 – 5 cm</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>IIB</td>
<td>2-5 cm</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>&gt;5 cm</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>IIIA</td>
<td>&gt; 5 cm but hasn’t reached chest wall</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Stage</td>
<td>Size of Tumour (T)</td>
<td>Lymph Nodes Have Cancer (N)</td>
<td>Metastases (M)</td>
</tr>
<tr>
<td>-------</td>
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</tr>
<tr>
<td>IIIB</td>
<td>&gt;5 cm and may have reached the chest wall or skin</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>IV</td>
<td>Any size</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**After surgery**

**Follow-up short and long term**

Once the pathology report is available, it is faxed to The Ottawa Hospital Cancer Centre by the surgeon’s office. It is usually about two weeks until you hear about an appointment with medical oncology and radiation oncology. If chemotherapy is indicated, it happens before radiation. If it is just radiation treatment it may take a few weeks to get started. The Ottawa Hospital Cancer centre will follow you for approximately five years (initially every three months, then six months and then yearly). Standard follow-up involves clinical breast exam with the oncologist and screening mammogram (yearly). There are no other tests routinely done.

**Chemotherapy**

Chemotherapy for breast cancer is the use of drugs to fight cancer cells. Chemotherapy drugs travel throughout the body to slow the growth of cancer cells or kill them. They are usually given by injecting the drug into a vein (intravenous). Some chemotherapy drugs are given as pills. *Not everyone diagnosed with breast cancer will get chemotherapy.* Normally you can expect to receive chemotherapy as an outpatient at the Cancer Centre or a hospital clinic.

**Chemotherapy is used to:**

- Destroy tumour cells that may be present in the body and decrease the chances that cancer will come back after breast cancer surgery.
- Shrink breast cancer before surgery, when the tumour is large or if it is an inflammatory type of breast cancer.
Control the disease when breast cancer is found in the lungs, bones, liver, brain, or other parts of the body.

At your first visit to The Ottawa Hospital Cancer Centre (TOHCC), the medical oncologist will discuss a treatment plan according to your individual situation. Sometimes, additional tests may be required before a treatment plan can be recommended. The chemotherapy drugs recommended for you will depend on many factors such as the type and stage of your cancer; where it is located, how much or how fast it has grown, and how it is affecting you. Sometimes the chemotherapy recommended will require the insertion of a central venous device (known as a Port-A-Cath) to lower the risk of irritation to the veins. Specific information on chemotherapy drugs, including side effects, will be given to you at the Cancer Centre. A nurse at the Cancer Centre and/or at your home will be available for added support.

Throughout chemotherapy, your oncologist and nurse will monitor how you respond to the treatment. You will have frequent check-ups and blood tests.

Chemotherapy affects all quickly growing cells throughout the body. This is what may cause side effects such as hair loss including eye lashes and eye brows, mouth sores, fatigue and low blood count. Hair always grows back after chemotherapy in completed. Today, because of what has been learned in research studies, doctors and nurses are able to control, lessen, or avoid many side effects of chemotherapy. Your oncologist and nurse will explain which side effects are common with your treatment, but everyone is different.

**Radiation therapy**

Radiation therapy is almost always given after a lumpectomy and sometimes to the chest wall after mastectomy. During radiation therapy, a machine delivers high-energy (radiation) to the affected breast, chest area and in some cases, to the lymph nodes under the arm or at the collarbone (clavicle). Radiation therapy kills or slows growth of cancer cells.

You will meet with your radiation oncologist before your treatment begins where he/she will explain the recommended treatment plan and schedule, as well as the possible side effects and their management. At this first visit for radiation treatment planning, your chest area will be marked with coloured ink or you may have a plastic shell made to keep your breast and arm in the same position for each
treatment. The marks show the exact area where the radiation will be given. Possible side effects may include skin reactions and fatigue.

Brachy Therapy is one type of radiation therapy used to treat cancer. It involves placing a radioactive material directly inside or next to the area requiring treatment.

**Anti-hormonal therapy**

Anti-hormonal therapy refers to a number of different treatments designed to reduce the effect of female hormones on breast cancer cells in the body. Some breast cancers depend on hormones, like estrogen, to help them grow. When the hormone is blocked, the expectation is that the cancer will stop growing and shrink (changing the hormone levels affects the cancer cells and slows their growth).

Anti-hormonal therapy can block your body’s natural hormones from reaching any remaining cancer cells. It may be used together with chemotherapy or on its own.

**With anti-hormonal therapy:**

✔ You may be given an anti-hormonal drug. Some of the more common drugs used for anti-hormonal therapy for breast cancer are Tamoxifen and Arimidex.

The medical oncologist at the Cancer Centre will recommend a treatment plan according to your individual case. If lab tests describe your tumour as estrogen or progesterone positive, the oncologist may offer hormonal therapy as part of your treatment.

**What are clinical trials?**

Clinical trials, also called research studies, test new drugs, new ways of giving drugs or radiation, new approaches to surgery, and new methods such as gene therapy. Each clinical trial attempts to answer specific scientific questions that will ultimately lead to better treatment. All trials are strictly monitored to ensure that the participant receives the best available care. Standard treatments are those which have been well studied in clinical trials and which have been proven to be helpful for most patients. The best way to learn whether or not an appropriate trial is available in Ottawa is to discuss this option with your physician.
Participating in a clinical trial is voluntary. You must consider all your choices when deciding to join in a clinical trial and keep in mind that although the decision to participate is entirely yours, you may not be able to choose all of the treatment(s) you will receive. You should expect to receive treatment that is anticipated to be at least as good as current conventional (standard) therapies.

It is important to know that if you do not wish to participate in a clinical trial, you will continue to receive the best possible standard of care.

What is new on the horizon?

You may be hearing a lot about new treatments to fight breast cancer. Treatments such as a cancer vaccine, immunotherapy, gene therapy, monoclonal antibodies are being tested in clinical trials and are generally not part of standard treatment.

Chemotherapy

There are always new chemotherapy treatments being tested in clinical trials. To find out what is available speak with your oncologist.

Monoclonal antibodies

Herceptin, the first in a group of new gene-based drugs, has been shown to shrink tumours in women with a specific type of breast cancer that involves a gene call HER2. This gene produces a protein which acts like an antenna on the membrane of a cancer cell, sending and receiving the signals that tell the cell to reproduce. Herceptin stops the cancer by attaching to the protein that prevents the tumour from growing. It is important to know that only a small proportion of breast cancers involve the gene HER2, and that only those that do may benefit from treatment with Herceptin.
**Gene therapy**

More research will be done on treatments that directly target and correct these gene defects (gene therapy) linked to breast cancer. Gene manipulation is a controversial topic but may provide future treatment.

**Immunotherapy**

Immunotherapy involves boosting the body’s own natural defenses against cancer cells. Medical researchers are looking at many types of biological therapies that use and boost the substances produced naturally by the body’s own cells. They are also creating new substances that can imitate or help the body’s natural immune system to work against infection and disease. These are being used in clinical trials with chemotherapy and radiation therapy.

**Examples:**

*Interleukin-2*: Triggers the body’s own killer cells
*Interferon*: Kills the cancer cells and activates the body’s own disease-fighting white cells

**Anti-angiogenesis drugs**

As a cancer grows, new blood vessels are formed to bring the necessary oxygen and nutrients to the cells. This is called “angiogenesis”. Research is being done on “anti-angiogenesis drugs” which aim to block the growth of these new blood vessels and slow the growth of the cancer or shrink the cancer.
How do I cope during my treatment?

Frequently asked questions:

- How do I feel my best during my treatment?
- How do I manage fatigue?
- How do I cope with the emotional aspects of treatment?
- How do I deal with sexuality issues? (Self-esteem, body image, sexual relations)
- What are the complimentary therapies I might consider?
- Should I keep my regular schedule (i.e., routine at home, working)?
- How do I manage my financial and personal care issues/concerns?

A woman’s story: Giftell Jamieson
Giftell Jamieson

**Diagnosed:** Age 46

**Diagnosis:** Invasive Ductal Carcinoma of the left breast

**Treatment:** Chemotherapy first followed by Lumpectomy left breast in 2006 and lymph node removal, then chemotherapy again plus Radiation therapy. In 2007 left breast mastectomy with prophylactic removal of right breast. Lymphedema in left arm and hand followed by lymphatic drainage massage

**Occupation:** Personal Support Worker

Being a single black woman and out of work, I was shocked and surprised when I heard that I had breast cancer. Constant pain in my left breast, arm and shoulder prompted me to go my family doctor. After a careful examination, he sent me for a mammogram and ultrasound. The mammogram was fine but the ultrasound pointed to something different that led to a core biopsy which confirmed Invasive Ductal Carcinoma.

My surgeon recommended surgery but I refused because I did not want to lose my breast at such a young age. So we decided on a lumpectomy first after chemotherapy treatments. When I did have my breasts removed, I was more ready for this loss because I had been suffering continual pain and swelling. After talking to my doctor, we decided it was wiser to go ahead with the double mastectomy.

All along, I gathered strength and support from my family and my church community.

Prayer and talking with friends helped me cope. I also got help by attending community programs like Maycourt day hospice program where I felt cared for and met many wonderful people. Social workers at the Women’s Breast Health Centre and at The Ottawa Hospital Cancer Centre also helped me deal with my finances and housing problems. During my chemotherapy sessions, I landed in hospital on several occasions and there too, my church family visited me and the inpatient social worker also helped me to stay on track.

To my surprise, I found new strength in myself when faced with my breast cancer. I decided, “this is not the time to be weak” and I told myself, “cancer is not going to beat me, I’m going to beat my breast cancer”. I am very proud of achieving this especially because this all happened at a very low time in my life.

Because of my openness about my situation, I found that people were ready to help me. Having hope and a positive attitude also helped me to cope with my scared feelings.
I also attended a cancer centre support group, which taught me the importance of breathing exercises and how to stay focused. Talking to other women who have been through this helped me tremendously because it helped me to feel not so alone.

If you find yourself in this situation, don’t feel ashamed, it’s not your fault, and don’t shut people out. Just remember that others have been through it too.

Talk about it and get support. It helps.
Questions you may want to ask your doctor...

- Will I feel tired during my treatment? How do I manage my fatigue?
- Will I experience nausea and vomiting with my treatment?
- How do I manage nausea and vomiting?
- Will I notice a loss of sex drive? How will my partner respond to me after surgery?
- Will I lose my hair? How soon after treatment will I lose my hair?
- If I lose my hair, where do I go to get fitted for a wig or what else could I use besides a wig?
- How do I manage my anxiety?
- Will I be able to continue working?
- Should I consider other treatment(s) such as nutritional support, relaxation techniques, massage, aromatherapy, acupuncture or other related approaches?

How do I feel my best during my treatment?

Each individual is unique and may respond to treatment differently. The following are suggestions only and may help you to feel your best during treatment. These suggestions are from two breast cancer survivors.

- Taking an active role in your treatment may give you a sense of being in control.
- Join a support group and learn different coping techniques from others.
- Have a friend or family member accompany you to treatments.
- Sign up for the “Look Good…..Feel Better” session early.
- Listen to your body, take naps and don’t feel guilty as fatigue is a common side effect.
- Exercise
Pace yourself and learn to respect your limits.
Pamper yourself and let others pamper you.
There are times you may not wish to wear your wig. There are plenty of stylish alternatives including the beauty of your own skin and pretty scarves.
Avoid sun exposure and use a good sunscreen (minimum of SPF 15).
Keep a journal.
Nurture your spirit.
Have a treat to look forward to: dinner in a favourite restaurant, a drive in the countryside.
Talk to a friend or someone who’s “been there”. It might be a big help and also lessens the stress on your family.

How do I manage fatigue?

Fatigue is one of the most common side effect experienced by women with breast cancer undergoing cancer treatment.
The fatigue related to cancer and cancer treatment feels different from the fatigue of everyday life.
Cancer-related fatigue can appear suddenly. It is not always relieved by rest or sleep. It sometimes will continue on for many months after treatment ends.
Rest and sleep are important, but don’t overdo it. If you have trouble sleeping, talk to your health-care provider.
Regular exercise like walking several times each week may help.
You can do more by spreading your activities over the day. Take rest breaks between activities.
You may wish to let others help you with meals, housework or errands. Do activities that you enjoy and make you feel good, like spending time with family or light gardening.
Fatigue is often made worse by stress. It is important to anticipate fatigue and stress and plan ahead.

Individuals receiving chemotherapy may have specific concerns regarding nutrition, weight and hair loss. Suggestions to cope with these can be found in the Chemotherapy Patient Information booklet and Breast Radiation Information Sheet may provide suggestions to cope. These resources can be found in the Women’s Breast Health Centre and The Ottawa Hospital Cancer Centre.
How do I cope with the emotional aspects of treatment?

Some of the most difficult aspects of treatment are just before treatment begins. People often have preconceived ideas about treatment; some of them incorrect. As part of informed consent, each patient is given information on side effects that may happen. This does not mean that it will happen to you. The unknown and imagined is usually much worse than reality. Try not fall into the trap of always thinking about the worst case scenario. Imagination is a wonderful thing, but can get the better of you. Imagination should be harnessed to focus on the best case situation.

Try to prepare yourself for treatment

- Understand the benefits of your treatment;
- See your treatment as helpful in treating your disease (use imagery techniques);
- Use relaxation techniques before and during treatment;
- Take a friend/relative who has a calming influence with you to treatment, or someone who is upbeat. Choose the sort of person who will be most helpful to you.

Between treatments, listen to what your body and mind needs, be gentle and kind to yourself. Now is a good time to pamper yourself. Try to always keep in mind that treatment is temporary and will come to an end. Plan treats and rewards as you go through treatment, and keep a goal in mind of what you would like to do or achieve after treatment is over.

Most women find it helpful to seek out others who have experienced breast cancer and can offer support. Look for survivors groups. Breast Cancer Action offers individual peer counselling, exercise classes and information session. Reach to Recovery offers individual peer support and home or hospital visits post-operatively. It is also common for women to have friends or relatives who have had breast cancer. The Women’s Breast Health Centre and The Ottawa Hospital Cancer Centre also run support groups. For women who live in rural areas, there are usually survivor lead groups.

Groups can be very helpful. Research has shown that groups may increase the quality of a woman’s life. However, you may not feel that a support group is right for you, and perhaps individual support would be more helpful. The Women’s Breast Health Centre and The Ottawa Hospital Cancer Centre have social workers on staff who can offer individual and family counselling and also refer you to other health-care professionals such as psychiatrists and psychologists.
For many women thoughts about their own spirituality becomes important at this time. If you have a strong religious faith and a close spiritual community, they will become an essential part of your support system. Spirituality plays a central role in each person’s life; it is about feeling the connection to a larger order. For those who can develop a sense of this order, even disease can be seen as having a role and meaning in a person’s life. Different women find different meanings; the path is unique for each individual. Try to foster an openness to spiritual beliefs and practices. Rituals can be helpful; many people rely on the rituals learned as children while others learn new rituals.

**How do I deal with sexuality issues? (Self-esteem, body image, sexual relations)**

**Self esteem**

Good self-esteem can be a challenge for women at the best of times. Very often self-esteem can be affected by body image. Breast cancer can further impact a woman’s confidence in herself and her ability to cope. Try not to define yourself by the way your body looks or to blame yourself for getting breast cancer. You did not cause your breast cancer.

**Body image**

For many women, breasts signify all or a combination of the following: femininity; sexuality; comfort; fertility; beauty and normality. Breasts are more than a body part; many emotions are connected to breasts and for each woman it can be a little different.

Many women have not truly thought about what their breasts mean to them until they are facing surgery that will alter their appearance. Women may think about how they value themselves and how others value them.

For information on wigs, refer to the section on Quality of Life on page 130.

**Sexual relations**

**Intimacy**

Intimacy is the need or ability to experience emotional closeness with another human being and to have that emotional closeness reciprocated.
As women go through diagnosis and treatment, they usually feel vulnerable and go through a wide range of emotions. Feelings of grief for their change in appearance can impact intimacy. Women may need reassurance from partners and loved ones.

**Communication with your partner**

If communication with your partner has been good before your breast cancer diagnosis, it will probably continue to be through treatment and recovery. Women often worry that their partners will not find them as sexually attractive and this will impact the stability of their relationship. The crisis of breast cancer can add to previous difficulties in the marriage.

Breast cancer does not come with a rule book and partners are learning and dealing in their own way with your breast cancer diagnosis and treatment. Sometimes partners can seem silent and detached, or conversely always trying to be positive. This may mask the fear of falling apart and not being able to provide the type of support a woman may need. Partners of women with breast cancer may be experiencing anxiety and distress at levels similar to their partners.

**Sexuality**

If a woman has had a satisfying sexual relationship before breast cancer, with some adaptation this should continue. However, it is important to note that sexual desire can be impacted by emotion such as anxiety, sadness, fear, denial, depression and anger. Sexual desire can also be affected by treatment side effects such as skin changes, fatigue, weakness, radiation skin reactions, weight changes and menopausal symptoms. Chemotherapy often causes vaginal dryness that can lead to painful intercourse. A water-based lubricant such as KY jelly or a moisturizer such as Replens may be helpful. You may wish to discuss these issues with your health-care provider.

Refer to page Where to Start...Sexuality. Suggestions for resources when you begin to look for information about sexuality issues for cancer patients.

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*New ways of relating sexually can be developed over time. Try to listen to your body and your own needs. Be kind and patient with yourself and try to be open to new things.*
What are the complimentary therapies?

Complimentary therapies are more and more being accepted as part of the care of people with cancer. Complimentary therapies are used to decrease symptoms and to enhance the quality of a person’s life along with conventional medical care. One aim of complimentary health care is to help people take charge of their health care and lifestyle. They can help you live your daily life in a healthy way, even when faced with a life-changing illness. An experienced complimentary therapist will work with you to find treatments that will be most effective for you.

A selection of complimentary therapies frequently used in cancer care

The following list includes very brief description of some therapies. Services may also be listed in the Yellow Pages according to the name of the therapy.

How to choose a complimentary therapist

As most complimentary therapies are not regulated, the best way to find a therapist is through personal recommendation. Look for personal and professional experience—ask questions and look for someone who is working full-time in the business. An increasing number of complimentary therapies are covered by Extended Health-Care Insurance.

Traditional Chinese medicine and acupuncture

Traditional Chinese medicine uses acupuncture, herbs, diet and exercise for the prevention and treatment of diseases. Some of these are provided within the health-care systems. For example, some physiotherapists provide acupuncture. Acupuncture is an ancient Chinese medical procedure, based on the principle that health related energy flows through the body through energy lines called meridians. Any type of stress or illness can cause blocks in this flow of energy. The insertion of fine needles into various acupoints along these meridians may change or increase energy flow through the body. Symptoms may decrease; energy and sense of wellness may be improved.
Aromatherapy
Aromatherapy is the use of aromatic essences from plants called essential oils, to effect changes in well-being. Massage, inhalation and baths containing essential oils are used to transport the essences throughout the body to produce sedation, stimulation and improved digestion. The effect varies depending on the type of essence used.

Massage therapy
Massage therapy uses therapeutic stroking and kneading, usually using oil and working in a systematic pattern. The goal is to treat a specific problem, (i.e. lymphedema) and/or to create relaxation in the body. The techniques are designed to relax, or strengthen and stimulate; both may happen at the same time. Specific techniques are designed to stimulate the lymphatic system and treat lymphedema.

Music therapy
By surrounding ourselves with soothing, pleasing sounds and gentle vibrations, we can maintain or alter the vibrations of the body to a frequency which induces a sense of well-being and harmony.

Naturopathy/naturotherapy
Naturopathy/Naturotherapy is a combination of various natural therapies and healing techniques, using ancient traditions and modern sciences, based on “the healing power of nature.” Underlying causes of illnesses are considered, predominately lifestyle and dietary. Naturopaths and naturotherapists use varying therapies, including reflexology, herbalism, aromatherapy, etc.

Homeopathy
Many Naturopaths are also trained in Homeopathy. Homeopathy is a system of medicine based on the principles of “like cures like” and “less is more.” Homeopaths use remedies to promote the body’s ability to heal itself. Homeopathic therapy includes a detailed personal history, followed by remedy and dose selection. After taking the remedy for a specified length of time, the effect is evaluated and a decision is made about further treatment.

Nutrition therapies
There are many different nutrition therapies that may cover anything from allergies to emotional issues. Counselors can assist clients to examine their eating habits and make appropriate changes. Check your local library for many books describing different nutrition therapies.
Reflexology

A specific body work technique, where the therapist strokes, massages and applies pressure to the hands or feet to effect changes in another part of the body, relax muscles and stimulate the body’s natural ability to heal itself. Reflexology produces rest and relaxation, relieves stress and helps the nervous system to better function.

Reiki

Reiki is a non-invasive, gentle energy healing system based on ancient Tibetan knowledge. When receiving a Reiki treatment, the therapist gently places his/her hands on the body and face of the client in a set pattern. It very quickly induces deep relaxation. It is useful in stress management as well as the management of pain and other symptoms.

Therapeutic touch

Based on research into energy-based healing, the therapeutic touch method is laying-on of hands for energy redistribution in the act of healing. Therapeutic touch uses life energy transfer from practitioner to client to vibrate energy and balance body’s energy field. The practitioner’s hands are held just above the client’s body in order to sense energy and detect any blocked or problem areas.

Relaxation techniques

Relaxation techniques can help to decrease the anxiety and stress that result from day-to-day life. These methods help you relax, working with the mind and/or the body. They are techniques that can be easily learned, and something that people can do personally. You can buy or borrow tapes that can talk you through relaxation exercises. The basis for all relaxation is focusing on breathing. This could include learning deep abdominal breathing or simply learning to focus on the breath coming in and out of the body. Some specific relaxation techniques include:

Imagery

Imagery is a technique that uses relaxation to create a sense of health and well being through visualization, touch, smell, taste, movement and hearing. Many psycho-therapists utilize this method.
**Meditation techniques**

Meditation is a method of relaxation from ancient times. Meditation is stilling of the mind by focusing on one thing at a time, whether it is breathing, counting or repeating one word. Yoga classes may offer instruction.

**Should I keep my regular schedule?**
*(i.e., routine at home, working)*

**Routine at home**

For many women a clean house gives a sense of order and control. If you feel like washing floors, you do it. However many women find that this may be a time to ask for family help or invest in a house cleaning service if this is financially possible, or let it go a bit!

For those on chemotherapy, you may not feel like cooking at certain times of the chemotherapy cycle. Try to make sure you have some meals ready; again, when friends ask what they can do, an extra casserole for a hungry family can be helpful.

Hobbies can be very important at this time: painting; needlework; reading; gardening; watching movies and cycling—whatever gives you pleasure and fun.

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_The rule is: Do those things that you enjoy and are helpful to your physical and mental health; try to avoid or ask others to do those things that are a burden._
Work issues

When to stop work? Is it necessary? How long should I be off?

Many women decide as soon as they have their diagnosis to take sick leave immediately. The majority of people have busy stressful jobs and the thought of juggling doctor appointments and family commitments becomes overwhelming. However, if an important part of your support system is at your work place, and sitting at home would be more stressful, you may continue to work; but try to pace yourself or reduce your hours. These issues should be discussed on an ongoing basis with your physician and your employer.

Questions

1. How quickly can I return to work after surgery?
   Approximately three weeks after surgery for lumpectomy or mastectomy. More time would be required for immediate reconstruction surgery.

2. Can I work while I have chemotherapy?
   Some people maintain a presence at work; however, there are usually times when you feel particularly tired and nauseous. You must also guard against being around people with colds and flu as this may compromise your health status and delay your treatment. If your work can be done out of your home, you may wish to make arrangements with your employer to support this alternative while undergoing treatment.

3. Can I work while I have radiation therapy?
   Many people do manage to work through radiation treatment. The biggest complaint at this time can be fatigue; therefore, some people try to schedule their treatment at the end of the day.
How do I manage my financial and personal care issues/concerns?

You may have specific questions related to financial concerns such as “Can I get disability pay or unemployment insurance benefits while I am getting treatment?” In the Cancer Centre Booklet some of these issues are discussed. However, if you need more information and guidance, social workers are available at the Cancer Centre and the Women’s Breast Health Centre. They can provide assistance by informing you about community support for: finances, extra help at home, transportation assistance to treatment, power of attorney and will, etc.
Should I change my lifestyle practices?

A woman’s story: Linda MacDonald

Frequently asked questions:

- What can I do to promote a healthy lifestyle? (i.e., nutrition, exercise, weight, alcohol, smoking)
- What is the role of my family physician in my overall general health?
Linda MacDonald

Diagnosed: Age 51  
Diagnosis: Ductal Carcinoma in situ  
Treatment: Modified radical mastectomy  
Occupation: Project Manager

My reaction, when I was told I had breast cancer in September of 98, was shock and anger. My response was to read books and talk to people who had knowledge on the subject. As a result, I started to believe my past illnesses were trying to tell me to change. I have become more self-caring as a result of having breast cancer. Previously, I would anticipate what others needed and provide it without them even asking, using my personal time to do things for others before thinking of myself. Now, I think before I act. I now take time to decide on how I want to spend my time. It has not been easy to change my behaviour at 50 years of age but I believe previously I was pretending to be good to myself, but it was on the outside not inside.

I now take responsibility and participate in my healing. I have taken the time to reflect, meditate and chart a new course in my life. I use much less energy on things of the past and things I cannot do anything about. I try to stay in the present as much as possible and try not to judge others. Relaxation tapes have helped me heal my body by giving it the total relaxation it needs to gain energy and heal. After the relaxation exercises, I have renewed energy. Yoga gives me the stretching and peacefulness that I require to stay focused on the person I want to be and how I want the day to unfold. Meditation helps me to see my body and mind more clearly and where I want to be. I believe it reduces wear and tear on both body and mind creating a better and longer life. I had a lot of fear and resentment, now I try to stay in the present and try to take things as they come. Sometimes I can influence the outcome, sometimes I just have to let go. Massage therapy has played a major role in my healing as well. I have changed therapists a few times when I have felt my body needed something different, but I have also been lucky in finding the right person at the right time for me. My body responds to massage and it is a time to totally relax. Acupuncture played a role, when my body physically felt out of balance and lacked energy.

I am healthier, happier and more at peace as a result of these changes. I welcome the quiet time with myself each day along with doing other physical exercise such as swimming, walking, skiing, sailing and gardening.
Questions you may want to ask your doctor...
- When can I resume my normal life activities such as exercise again?
- Should I eat a special diet?
- Should I continue to see my family physician?

What can I do to promote a healthy lifestyle?

Because of your breast cancer experience, adopting healthy lifestyle choices may be something you can consider to help you stay well during your breast cancer treatment and to possibly help reduce the risk of the cancer recurring. There is much to learn about the link between breast cancer and lifestyle. There is usually not a need to radically change your lifestyle. If you are considering lifestyle changes, you may wish to discuss this with your health-care team. The following are suggestions to ensure an overall “well-being”. A healthy diet, exercise, limited alcohol use, non-smoking and the maintenance of a healthy body weight is encouraged.

Based on these results and guidelines of the Canadian Cancer Society and the Canadian Dietetic Association, the following are healthy lifestyle recommendations:
- Eat five or more fruits and vegetables a day;
- Limit alcoholic drinks to one drink a day;
- Maintain a healthy weight;
- Exercise regularly aiming for 20 to 30 minutes most days of the week.

It is believed, over the next 5 to 10 years, that prevention research will provide us with evidence to guide a more specific approach to lifestyle recommendations.
What is the role of my family physician in my overall general health?

The role of your family physician during the course of your treatment should remain much the same as before your cancer diagnosis. He/she will receive reports about your appointments, as well as results of any diagnostic or screening test. It may be helpful to specifically ask for copies of test results, appointments, etc. to be sent to your family physician. Your family physician is a member of your breast cancer health-care team and assists in coordinating your care as well as providing information and support for your entire family. Make sure that the cancer clinic and hospital have the name of your family physician. Although women can feel overwhelmed with numerous appointments, it is important to remember to attend to all areas of your health. Regular visits with your family physician continue to be just as important as they were before your cancer diagnosis. If you do not have a family physician, speak to your oncologist or nurse and they may be able to help you find one.

Breast health

Patients should continue with breast self exam and routine mammography. It is important to become familiar with how your breasts/chest wall feels after surgery and to be aware of any changes. Also follow up with your medical oncologist or family doctor.
What happens after my treatment is over?

A woman’s story: Colleen Kanna
A daughter’s story: Maddison de Beaupré

Frequently asked questions:
How will I be followed?
Colleen Kanna

Diagnosed: Age 49
Diagnosis: Infiltrating ductal carcinoma, micropapillary subtype, with metastatic lymph nodes
Treatment: Neo-adjuvant chemotherapy, followed by lumpectomy of right breast and lymph node removal, radiation, and hormone therapy
Occupation: Clothing Designer/Chartered Accountant/Entrepreneur

I was diagnosed with Stage III invasive breast cancer in October 2010. My initial reaction was shock and disbelief. I remember driving home from work and saying to myself “How did this happen to me?” I have no family history of cancer, I’ve never smoked, I’ve always eaten healthy, and I’ve always exercised.

After the shock came the fear. Not just fear for myself but more overwhelmingly so for my daughter, Maddison, who was 6 years old at the time. My husband, Adrien, and I adopted Maddi from China when she was 15 months old. It was unbearable for me to even think about how it would affect her…the possibility of her losing another mother.

Then there was also the burden of “Do we tell Maddison, what do we tell her, do we use the “C” word…cancer is such a scary word. But kids are so intuitive. She sensed something was wrong even though we thought we were doing a good job of hiding it. One night as we were having our nightly chat before bed, she said to me out of the blue “Mommy, I don’t want you to ever die”. And then she said “I wish you were 30” (meaning 30 years old). I asked her why and she said “So I could have a bigger life with you”.

From that moment on, I realized two things: 1. I was determined to get through all the treatments and not only get through them but get through them as well as I possibly could; and 2. To be candid with our daughter.

I kept as active as possible through treatments by running, and participating in exercise and yoga classes. I sought out complementary therapies such as acupuncture, meditation, naturopathy, physio and massage therapy, and herbal remedies. Although I had almost every side effect in the book, all in all, we got through the treatments quite well with lots of support from family and friends. After my final chemotherapy treatment, I wrote this poem.
Final treatment done and Bell of Hope rung,
Never thought this day would come.
Such helpful friends and family near and far,
You definitely know who you are.
Meals and baking, playdates and sleepovers,
Rides to hospital, just being there and supportive.
You have been there for us tried and true,
And we could not have completed this journey without you.
This is what sets you all apart,
And we thank you from the bottom of our hearts.

Maddison de Beaupré

Age at Mother’s diagnosis: 6 years old

When my Mom told me she had breast cancer, I felt really bad and was scared but I’m glad she told me.

She also told me her hair would fall out from chemo. We tried to cover up Mommy’s hair to see what she would look like bald and then we laughed about it. We went wig shopping and tried lots of wigs. I liked the long blonde haired wig the best. It was fun.
Questions you may want to ask your doctor...

- Do I need to be followed after my treatment is over, if so, why?
- Who will follow me? Where will I be followed?
- What can I expect during my follow-up appointments? How often will I need to see my doctor?
- How will I feel at the end of my treatments?
- Do I still need a mammogram; if yes, how often?

How will I be followed?

Any follow-up you have will depend on the type of treatment you had for your breast cancer and your surgeon’s and oncologist’s recommendations.

All patients with a diagnosis of breast cancer are referred to The Ottawa Hospital Cancer Centre. In most cases, the Cancer Centre will continue with your care and follow-up. Regular appointments will be scheduled for you with your oncologist, more frequently in the first few years after your diagnosis. These appointments usually involve a discussion with your oncologist and a physical examination.

Some women find routine follow-up appointments emotionally difficult. The uncertainty of knowing whether your cancer can has back can be very distressing. It might be helpful to talk to someone who has already been through this. Bring along someone you trust to these appointments if this will make you feel more comfortable and reassured.

Your family physician will continue to help you co-ordinate your total health care needs.

Questions that you wish to ask your physician at the end of treatments include:

- Who will see me for follow-ups? How often?
- What tests will be done to monitor my condition? How often?
- What will the tests tell us?
- Do I need any medications?
- What symptoms should I notify you of? How likely are they to occur?
What changes might I experience? Are there long-term effects of treatment?
Are there any limitations to doing exercises? Are there benefits?
Will I be able to return to work?
Who else can I talk to about specific problems, e.g., sexual concerns, rehabilitation?

How will I feel at the end of my treatment?

When women finish treatment, there is an expectation that they will feel relieved and able to get back to "normal". However, "normal" has become visiting the Cancer Centre for treatment. Treatment has taken total energy and commitment and as with any experience that ends, there can be a sense of loss. Feelings of loss can engender sadness and anger. This can be a confusing time—it is important to reach out to others who have been through this experience.

Do I still need a mammogram?

Screening:

All women who have had prior breast cancer and have had a lumpectomy:

- Require annual mammograms
- This should occur even if your cancer was difficult to see on your mammogram

With prior mastectomy:

- Require annual mammogram of contralateral breast
- May require chest wall mammogram if enough tissue is left to warrant mammography
- Require mammogram of reconstructed breast (TRAM or implant)

If possible, you should have your mammogram done at the same clinic or hospital each time or ask that your previous mammograms be compared.
Cancer Survivorship

By 2017, it is expected that 83,200 Ontarians will be diagnosed with cancer in a single year. At the same time, improvements in detection and treatment are resulting in a greater number of Ontarians living with cancer. By 2017, it is expected there will be 400,000 Ontarians living with cancer.

Although there are many definitions of cancer survivorship, many who work in cancer programs consider survivorship to be the recovery phase, or after the treatment is complete.

The Ottawa Hospital Cancer Program is committed to providing support and care to people from the time of diagnosis to end of treatment. This includes care and support for people at the end of their cancer treatment. To ensure people receive the best possible care at the end of their treatment, the “Wellness Beyond Cancer Program” (WBCP) was established.

What is the Wellness Beyond Cancer Program?

The WBCP is a multidisciplinary team of health care providers who ensure that people, at the end of their active cancer treatment, are aware of their individual needs and have access to appropriate follow-up care required to best meet these needs. Our team will help develop your Wellness Care Plan.
Your individualized wellness care plan

As time goes by, it may be difficult for you to remember all the details of your diagnosis and treatment. Also, this information will be valuable to the doctors who care for you throughout your lifetime. A “Wellness Care Plan” is a document that provides a summary of your diagnosis and the treatment you received. Also, follow up recommendations are provided in this document. These follow up recommendations describe how often you should have a check-up with your Primary Care Provider and what tests they can arrange for you in the future.

When and how are individuals referred to the program?

Your surgical, medical or radiation oncologist will refer you to the program once you have completed your treatment. Your oncologist, with you, will determine who the most appropriate health care provider is to lead your ongoing oncology medical care. The decision depends on several factors, including the type and stage of disease and treatment side effects you may have experienced. The WBCP offers three scenarios for follow up:

a) Discharge to the Primary Care Provider

b) Discharge to the WBCP Nurse Practitioner, including shared care with the Primary Care Provider

c) Continued care by a surgical, radiation or medical oncologist, including shared care with the Primary Care Provider

Regardless of who follows you for your ongoing medical care, the goal will be to return you to the care of your Primary Care Provider. If your ongoing oncology care remains at the Cancer Centre with a Nurse Practitioner or an Oncologist, it is important that you continue to be seen regularly by your Primary Care Provider to ensure you receive care necessary to keep the rest of you healthy.

When you are referred to the WBCP, you will be asked to complete a needs assessment to identify your individual personal needs. Identified needs of 3 out of 5 or greater will be entered into your Wellness Care Plan. The Wellness Care Plan includes your treatment summary, cancer team, recommended surveillance, and summarizes your self-identified needs. A discharge letter and the Wellness Care Plan will be sent to your Primary Care Provider. You will receive a copy as well for future reference. You will also be invited to attend a breast survivorship class.
Primary Care Providers have access to the WBCP phone number to call with any questions and to quickly refer you back into the Cancer Center if it is necessary. Please see TOH Website for links.

**Importance of follow-up care**

Participating in your follow-up care is very important to regain physical and emotional health. Cancer survivors feel in control when they participate in their care as they transition back to their everyday lives. The first goal of follow-up care is to watch for a recurrence of cancer. Your doctor can identify and address any health issues caused by cancer or by its treatment.

🌟 For more information on the Wellness Beyond Cancer Program, please call us at 613-737-7700, ext. 70256 between the hours of 7 a.m. to 3 p.m. Monday through Friday.
What about my family needs?

- A spouse’s story: Adrien de Beaupré

**Frequently asked questions:**
- What might my family be experiencing?
- The reactions of family and friends
- What can my family members do to lower their risk of developing breast cancer and/or detecting it early?
- Assessing your genetic risk
Adrien de Beaupré

Spouse of Colleen Kanna

Diagnosed: Age at wife’s diagnosis
42 years

Occupation: Information Technology
Security Consultant

One of the challenges we faced was to keep life normal for our daughter while managing the logistics of the treatments. The most useful skills I utilized were to ask lots of questions and take detailed notes at every appointment and treatment, and to research side effects and how to relieve them. The most important lesson I learned throughout this period was to ask for and be able to accept help from friends and family.

I helped in every way I could as my wife took control of her healing process. It is not possible for the husband to take control of the situation and fix the problem, as we often try to do when faced with an issue.

The roles of logistics manager, supportive partner, chauffeur, cook, researcher, child care provider, loving husband, and other sundry duties as they arise, can be overwhelming. You have to maintain and rely on your own support group as the caregiver and take care of yourself too.

“What a power is love!
It is the most wonderful, the greatest of all living powers.”

(Baha’i Writings)

Resources:

Breast Cancer Husband, Marc Silver, 2004

### Questions you may want to ask your doctor...

- How do families normally react when someone is diagnosed with breast cancer?
- Are my family members at a higher risk of developing breast cancer?
- How can I find out if I’m a carrier of the breast cancer gene (BRCA1 or BRCA2)?
- If I have the gene, how does this affect my family?
- What options do my family members at higher risk have to reduce their risk? Should my family members be followed because of their higher risk?

### What might my family be experiencing?

The diagnosis of breast cancer affects everyone in your family—husband, lover, parent, child. Many of the same feelings you experience, they also experience. Shock, disbelief, confusion, anger, anxiety, guilt, fear and a host of other tumultuous feelings are common. These emotions are normal! Often family members are on “emotional overload” just as you are. They want to help but feel helpless.

### The reactions of family and friends

A diagnosis of cancer not only affects you but also partners, family and friends. They too are feeling worried, anxious, and concerned. They may even feel angry and shocked that you have been affected by cancer. They will want to support you through this experience and often feel frustrated that they cannot do more for you. Remember that this is a stressful time for all and everyone may be feeling that they are on “emotional overload”. Sometimes tempers are short or you or your loved ones may be more impatient than normal as each of you comes to grips with the cancer and the upcoming treatments.

It may help to talk to someone who has dealt with this experience before, such as another woman with breast cancer or for your partner and family—other family members who
have supported their loved one through breast cancer. Frequently patients will consult with
the social workers at The Ottawa Hospital Cancer Centre for some guidance through this
challenging time. They may also want to contact a support group that could meet their
needs.

See Section 10 for information on support groups and other community agencies that
may be of benefit to you.

Suggestions for family members and caregivers to help you

Face the cancer together. It is reassuring and comforting for your loved one to know your
support will always be there. “We can bear more when we have someone to share with.”
(Rabbi Kushner)

Don’t assume you know what your loved one
is thinking or feeling. Talk to each other about your emotional reactions and concerns.

Communication can also be physical; holding hands or hugging.

Often everyone feels they have to maintain a positive attitude. Pretending that
everything will be all right denies the person with cancer the opportunity to discuss
fears and anxieties. Also avoiding discussions about cancer, out of concern to protect
each other, results in feelings of isolation.

It is important to have life go on as close to normal as possible. Don’t let the breast
cancer “move in” and take over your home.

Suggestions for family members and caregivers to help themselves

Take time for yourself and remember to be good to yourself. This is not selfishness; it’s
keeping yourself replenished and healthy in order for you to continue caring for your
loved one’s needs.

Take care of your own body. To avoid stress-related illness, pay attention to your own
physical needs by eating a healthy diet, exercising, getting sufficient sleep and finding
time to relax. Don’t put off your own medical and dental check-ups.
Delegate responsibility and accept help from outside the home. Often other family members and friends want to help but are not sure what they can do. This makes them feel useful and helps reduce stress.

Be assertive. Be realistic about what you can and cannot be responsible for right now.

Discuss your feelings and reach out for support.

Give yourself permission to ask questions from health-care professionals. Having answers to your questions can be a great stress reducer.

Set priorities. Don’t try to do everything.

Laugh. It is said that 20 minutes of belly laughter is equal to 5 hours of deep meditation.

Suggestions to help children

When someone they love is ill, children experience sadness, loneliness, confusion, anger and fear of separation and being left alone. They worry about the safety of the family. Depending on their age they will react differently. Sometimes they act out, withdraw, or overcompensate by taking on too many responsibilities. Children tend to express their emotions in actions rather than words.

When you (and your partner) feel ready, consider talking with your child/children about your diagnosis. Go at your own speed and explain terms they understand. It is important to know that their imagination may be worse than the reality. Social work at WBHC or in PSOP are happy to help you if you have questions.

Reassure the children that there is nothing wrong with feeling sad, angry or crying—it’s like a sneeze—you have to let it out. Drawing, reading story books, having special play times sometimes allows children to express their fears.

Tell them that cancer is not an illness such as the flu or colds that you catch from someone else.

Assure them nothing they have done, said or thought caused the cancer to occur.

Try to keep to the family routine as much as possible, including being consistent with discipline.

Notify teachers and all significant adults in the child’s life, such as sitters, coaches and neighbours, as soon as possible. They can offer extra attention and support.

Communicate with children on a regular basis. Try to reserve consistent time for them.

Encourage children to keep up outside activities.
What can my family members do to lower their risk of developing breast cancer and/or detecting it early?

A frequently asked question by women diagnosed with breast cancer is, “Does my daughter(s) have a higher risk of developing breast cancer? What about my sister, mother or other female relatives?”

Their risk may be higher than other women their age with no family history. However, this does not mean they will get breast cancer. Everyone’s personal and family breast cancer profile is different.

To evaluate your family members’ risks, several points such as those listed below need to be considered:

- How old were you when you developed breast cancer?
- Did the cancer affect one or both of your breasts?
- How many of your close relatives also have/had breast cancer?
- How old are the individual family members?
- Do they have any other risk factors?

It is also important to remember that only 5 to 10 per cent of breast cancers develop because of inherited genetic defects. Two genes have already been identified for breast cancer and are named BRCA1 and BRCA2. If there is a very strong family history of breast cancer, an unaffected member of the family may be interested in genetic counselling to assess more accurately her individual risk of developing breast cancer. If there are concerns regarding whether family members are at higher risk for developing breast cancer, they should discuss these with their family doctors. An assessment of individual risk factors can be reviewed and screening methods considered. A referral to the Breast Cancer Risk Assessment Clinic at the Women’s Breast Health Centre, or for genetic counselling, may be appropriate.

There are specific criteria that must be met before a referral for genetic counselling can be initiated.
Are there things such as diet and exercise that may help reduce my family’s risk?

Lifestyle practices such as a healthy diet, regular exercise, reduction in alcohol use and having a healthy body weight may help lower a person’s risk for not only breast cancer, but improve overall good health as well. Starting good health habits when children are younger helps to form a life-long practice of a healthy lifestyle. (See Section 6 for more information.)

How often should screening be done if my family members are considered at high risk?

Women at high risk for developing breast cancer should have yearly mammograms beginning five to ten years prior to the age of the youngest relative diagnosed with breast cancer, with a lower age limit of 30 years. Monthly breast self-exam and a careful breast examination by a physician or nurse every six to twelve months are also important in the early detection of a new breast abnormality. Although still controversial, women at high risk for developing breast cancer, whose screening mammogram shows very dense breasts, may also have bilateral breast ultrasound.

Assessing your cancer risk

Cancer Care Ontario is promoting a new initiative that allows individuals to find out what their risk is for developing a breast, colorectal, lung or cervical cancer. It is an online tool to assess risk as well as providing personalized recommendations to help reduce your cancer risk.

Assessing your genetic risk

There is a specific criteria that must be met before a patient is referred for genetic testing. If a referral is made for you, a genetic counsellor or other health-care professional trained in breast cancer genetics will help you prepare a family tree. This chart, also known as a pedigree, lists members of each generation of your biological family, with all available health and disease information. Ideally, this family tree should go back at least three generations and should include the type of cancer each relative has had, as well as the person’s age at diagnosis. But in reality, most people don’t have much information before their grandparents’ generation.
After the family tree has been constructed, the genetic counselor analyzes the pattern of breast cancer in the family. Your family’s pedigree can be categorized in one of three ways:

- **Sporadic.** This means your personal or family history of breast cancer doesn’t follow any regular pattern of inheritance. Instead, breast cancer appears in a scattered, isolated way. About 70 per cent of all women with breast cancer have a sporadic family pedigree.

- **Familial.** This means there may be a strong family history of breast cancer, but there is no well defined pattern suggesting that the breast cancer was passed genetically from one generation to another. About 20 to 25 per cent of all women with breast cancer have a familial breast cancer pedigree.

- **Hereditary.** This means there is compelling family history, including multiple blood relatives with breast and/or ovarian cancer. That pattern strongly suggests an inherited form of the disease. Heredity accounts for about 5 to 10 per cent of all breast cancers, and abnormal BRCA 1 and BRCA 2 genes explain a large number of these cancers. But other genes that have not been discovered yet are probably also involved.

### Judging the need for genetic testing

Experts generally agree that women in the first category of family history—sporadic—will not benefit from the gene test. Those in the second category—familial—are at moderate risk and probably would not be encouraged to get the test.

If you fall into the third—hereditary—category, you may decide to go ahead with the breast cancer gene test.

For more information on genetic testing, counselling and support visit the FORCE (Facing Our Risk of Cancer Empowered) Website.

### Can men get breast cancer?

Men also have breast tissue that can undergo cancerous changes. It is rare but about one per cent of all breast cancers occur in men. Treatment usually involves a mastectomy and axillary dissection. The prognosis for male breast cancer is about the same as for breast cancer in women.

Some of the difficulties men may face with this diagnosis are isolation, shock, the stigma, the change in body image, a lack of resources, and difficulty accessing information and
emotional support.

Websites:
- Breastcancer.org: www.breastcancer.org/symptoms/types/male_bc/index.jsp
- Canadian Breast Cancer Network: www.cbcn.ca/en/?section=3&category=76
- Medline@Plus: www.nlm.nih.gov/medlineplus/malebreastcancer.html

Book:
- Saving Jack, A Man’s Struggle with Breast Cancer, Willis, 2006
What are the issues for women with recurrent disease?

Frequently asked questions:

- What if the cancer comes back in the same breast?
- What if the breast cancer comes back in the lymph nodes?
- What if breast cancer spreads to other parts of the body?
- How are symptoms managed?
Questions you may want to ask your doctor...

- What is metastatic disease?
- If breast cancer returns, where is it likely to spread?
- Why did the cancer recur? How will the recurrence be treated?
- What support and resources are available if breast cancer recurs or goes to other organs?
- How does one cope with physical symptoms?
- How does one get access to palliative care services?

What if the cancer comes back...

... in the same breast?

This is referred to as a local recurrence. The usual treatment for this kind of local recurrence is mastectomy and possibly hormone therapy or chemotherapy.

A local recurrence can also happen after a mastectomy. This most commonly happens in the scar or skin and fat at the mastectomy site. Further surgery, radiation and/or chemotherapy may be used to treat this recurrence.

A new cancer may occur years after in a different area of the breast. This is treated as a completely new cancer, similar to the situation where cancer occurs in the opposite breast. Most often, if the breast has already been treated with radiation, a mastectomy will be necessary. Again chemotherapy and hormone therapy may be considered.

... in the lymph nodes?

This may occur in the lymph nodes under the arm, above the collar bone and in the neck. This is referred to as a regional recurrence. Regional recurrence is usually more serious than local recurrence and requires aggressive treatment, often with radiation, chemotherapy and/or hormone therapy and sometimes surgery.
What if breast cancer spreads to other parts of the body?

Metastatic breast cancer is breast cancer that has made its way through the blood stream or the lymphatic system and has spread to other areas of the body. The most common areas for the breast cancer to spread are the bones, lungs, liver and brain.

The goals of treatment for metastatic breast cancer are to relieve symptoms, maintain quality of life and prolong survival. Curing the cancer will no longer be possible. The most common treatments used are hormone therapy and chemotherapy. Radiation and surgery may be used to treat more “local” problems such as pain or fracture at an area where the cancer has spread to the bone.

A diagnosis of metastatic breast cancer can be devastating. People believe that there is no hope and nothing more can be done to treat their disease. Many women can live for years with metastatic disease that is under control.

How are symptoms managed?

Pain and other symptoms can be managed through a variety of methods. There are specialists in pain management who can assist you in developing a pain management plan. A number of complimentary therapies may also be used to help manage pain.

A few of these include: Acupuncture, Transcutaneous Nerve Stimulation (TENS), Therapeutic Touch, Reiki.

It is important to remember that pain is not just a physical thing. The ability to cope with pain is made worse if one is tired, sad, angry, afraid and stressed. Family and friends may be able to provide emotional support, but some women really find counselling or support groups helpful in dealing with some of the feelings that they have if their breast cancer recurs or spreads.

Palliative care professionals may be called in to help manage symptoms — this does not mean your disease is not treatable. The word “palliative” can be confusing. Many people, when they hear the term “palliative care” believe that there is no hope and that nothing more can be done to treat their illness. However, palliative care focuses on the management of pain and other symptoms, and helping (patients and their families) to be their best emotionally, socially and spiritually. As such, palliative care may take place both
during and after active treatments like chemotherapy. Palliative care is available at home, in the Cancer Centre, in local hospitals, at the Regional Palliative Care Centre, and at local hospices.

The key word in fighting illness is recovery — from illness. The key word following illness is discovery — of meaningful, profound spiritual and human fulfillment. May you recover and discover.

(from Prayer and Hope, by Rabbi Reuven. P. Bulka, 1996)
Support and information resources at The Ottawa Hospital, the Cancer Centre and in the community

- Information and support services
- Support groups
- Medical, counselling and home care resources
- Programs
- Lodging and transportation
- Financial
- Legal issues
Ottawa hospitals and treatment centres

1. The Ottawa Hospital Cancer Centre, Civic Campus
   190 Melrose Avenue

2. The Ottawa Hospital
   Civic Campus
   1053 Carling Avenue

3. The Ottawa Hospital Cancer Centre, General Campus
   503 Smyth Road

4. The Ottawa Hospital
   General Campus
   501 Smyth Road

5. The Ottawa Hospital Riverside Campus
   1967 Riverside Drive

6. Montfort Hospital
   713 Montreal Road

7. Queenway-Carleton Hospital
   3045 Baseline Road

Satellite sites

- Cornwall General Hospital
  510 2nd Street East
  Cornwall

- Hawkesbury and District General Hospital
  1111 Ghislain Street
  Hawkesbury

- Perth and Smiths Falls District Hospital
  33 Drummond Street West
  Perth

- Winchester District Memorial Hospital
  566 Louise
  Winchester
Centre Hospitalier des Vallées de l’Outaouais (C.H.V.O.)

1. **C.H.V.O. Pavillon de Hull**  
   116 boul. Lionel-Émond  
   Gatineau, Québec

2. **C.H.V.O. Pavillon de Gatineau**  
   909 boul. de la Vérendrye  
   Gatineau, Québec
Information and support services

The Ottawa Hospital Cancer Centre (TOHCC)

Tel: 613-737-7700

- Web: www.ottawahospital/sc/cancer/index-c.asp
- Operates two sites; at the General campus of The Ottawa Hospital and the Irving Greenberg Family Cancer Centre at the Queensway Carleton Hospital as well as outreach clinics at a number of regional hospitals
- Provides comprehensive cancer care and treatment which includes chemotherapy treatment, radiation therapy treatment, clinical trials, follow-ups and consults
- Provides a full range of supportive care program including counselling and support groups
- The Ottawa Hospital Psychosocial Oncology Program
  613-737-7700
  Unit Coordinator . . . . . . . . . . . . . . . . . . . . ext. 70516
  Intake Coordinator . . . . . . . . . . . . . . . . . . . . ext. 70148
  Irving Greenberg Family Cancer Centre . ext. 25200

TOHCC is the cancer treatment centre for Eastern Ontario. TOHCC has two campuses: the General Campus is at The Ottawa Hospital, 501 Smyth Road; and the Irving Greenberg Family Cancer Centre is at the Queensway Carleton Hospital, 3045 Baseline Road. The Centre is open Monday to Friday from 9 a.m. to 4 p.m. The main number is 613-737-7700.

For problems or emergencies during Cancer Centre hours, phone the main number and ask for your nurse’s extension. For emergencies that are related to your cancer treatment, after hours or on weekends and holidays, call 613-737-7700 and wait for TOH switchboard. You will be asked to leave a message including your name and phone number, the name of your oncologist, and if you would like to speak to the Oncologist “on call”. If your concerns are not related to your cancer or treatment, please call your family physician first. In an emergency situation, please go to your nearest Emergency Department or call 911 for assistance.
In addition to the medical care given at the Cancer Centre, many other health-care professionals and services are available at no cost, including the following:

🌟 The Ottawa Hospital Cancer Centre Psychosocial Oncology Program (PSOP)

Provides support and rehabilitation to patients and families for concerns related to their cancer diagnosis and treatment such as:

- Social Work Counselling services that cover such issues as patient and family adjustment to illness and group counselling as well as practical assistance.
- Physiotherapy provides physical assessments and education. In addition, they can assist with increasing movement (mobility) and pain management. Services are limited to issues directly related to the cancer diagnosis and treatment.
- Lymphedema education classes available.
- Nutrition focuses on counselling in order to restore or improve nutritional status, help minimize side effects, improve strength and overall quality of life.
- Speech Language Pathology focuses on those patients who may have problems with swallowing.
- Psychiatry focuses on the concerns of patients with significant levels of anxiety and depression and may need medication.
- Psychology provides assessment and treatment for such issues as significant anxiety and chronic pain as well as insomnia.
- The Ottawa Hospital Learning Services provides reliable information on cancer and how to live with it. Email Learning Services at learningservices@toh.on.ca.

🌟 Palliative Medicine Clinic — the goal of palliative care is to improve the quality of life for cancer patients and their families. Palliative care physicians and nurses provide help with pain and symptom management. Referral is required.

🌟 Aboriginal Patient Co-ordinator for First Nations, Inuit or Metis patients, call 613-447-6790.

**The Ottawa Hospital Website — www.ottawahospital.on.ca**

The Website provides information about the programs and services offered at The Ottawa Hospital. The Patient Services section tells you what you need to know if you are admitted to the hospital or coming for an appointment and includes maps, parking information and bus schedules. The Cancer Centre section contains information specifically for people receiving treatments for cancer.
Online are a number of booklets produced by The Ottawa Hospital Cancer Centre:
1. The Ottawa Hospital Cancer Patient Information Booklet
2. Chemotherapy Patient Information Booklet
3. Radiation Therapy Patient Information Booklet
4. Coping…with loss of income and other financial issues
5. Patient Education Calendar

**Canadian Cancer Society**

The Canadian Cancer Society offers a wide range of services to cancer patients. These services include transportation, emotional support, information, cloth hats, wigs, smoking cessation, etc. In some areas, the Canadian Cancer Society runs support groups. The Canadian Cancer Society has the following offices in Ottawa and surrounding areas:

<table>
<thead>
<tr>
<th>Canadian Cancer Society Unit Office</th>
<th>Phone Number</th>
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<tbody>
<tr>
<td>Ottawa Unit</td>
<td>613-723-1744</td>
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<tr>
<td>Lanark, Leeds and Grenville Unit (Brockville, Carleton Place, Gananoque,</td>
<td>1-800-367-2913</td>
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<tr>
<td>Perth and Smiths Falls)</td>
<td>or</td>
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<tr>
<td></td>
<td>613-267-1058</td>
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<tr>
<td>Renfrew County Unit (Amprrior, Deep River, Eganville, Pembroke, Petawawa</td>
<td>1-800-255-8873</td>
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<td>and Renfrew)</td>
<td>or</td>
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<td></td>
<td>613-735-2571</td>
</tr>
<tr>
<td>Stormont, Dundas, Glengarry and Prescott Russell Unit (Cornwall, Hawkesbury</td>
<td>1-800-669-4181</td>
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<tr>
<td>and Russell)</td>
<td>or</td>
</tr>
<tr>
<td></td>
<td>613-932-1283</td>
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<tr>
<td>Québec Division (Gatineau)</td>
<td>819-777-4428</td>
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You can also find out about resources in your community on the Ontario Division section of the Canadian Cancer Society’s Website at www.ontario.cancer.ca.
Web: www.cancer.ca

Speakers available to provide community presentations on cancer risk reduction including breast health

Breast cancer/breast health information available

Canadian Cancer Society (CCS) Peer Support Program
- Practical and emotional needs of breast cancer patient met post-operatively
- Transportation available through local offices for cancer related appointments

The Canadian Cancer Society also provides the following national programs:

**Canadian Cancer Society Peer Support Program**
The Peer Support Program will connect you by phone with someone who has experienced the same or similar cancer. For more information, phone 1-800-263-6750.
- Confidential toll-free telephone cancer support service offered by the Canadian Cancer Society (CCS) for people diagnosed with cancer and their caregivers
- People living with cancer and their caregivers are matched with trained volunteers who have had a similar experience

**Cancer Information Service**
This is a free telephone information service, offered in both English and French to answer questions about cancer and its treatment, prevention and early detection, drugs and clinical trials, complimentary therapies, etc. For more information, phone 1-888-939-3333.

**Women’s Breast Health Centre**
Tel: 613-761-4400

- Provides a comprehensive service to women with breast abnormalities and their families and women at higher risk for breast cancer.
- Assists health professionals to ensure a coordinated diagnostic work-up of breast problems.
Diagnostic Imaging Services; Tel.: 613-761-4831, option 5

- Mammography—ultrasound of the breast
- Core needle biopsy (x-ray or ultrasound guided)

Coordination of diagnostic services and presentation of necessary treatment options.
Consultation service with surgical staff skilled in diagnosis and treatment of breast disease.
Supportive Care Services, such as Stepping Stones Support Group for women recently diagnosed with breast cancer.
Individual family and group counselling for those who have received a diagnosis of breast cancer. Ask to see the social worker.
Pre-operative breast surgery teaching sessions. These are held twice monthly at these community locations: Breast Cancer Action and at the Canadian Cancer Society. Ask your nurse for more information.

**Breast Cancer Action**

Tel: 613-736-5921       Fax: 613-736-8422       Email: info@bcaott.ca

Web: www.bcaott.ca
A volunteer survivor-led non-profit organization providing support and education for patients, survivors, families and the community:
- Support and Resource Centre at the Riverside Mall, 739A Ridgewood Ave., Ottawa (across from side of St. Elias Church near Mooney’s Bay Beach entrance)
- Open Monday to Friday, 8:30 a.m. to 4 p.m.

Monthly meetings on topics of interest to survivors (open to public, no charge)
Peer support
Workshops on a variety of topics
Lymphedema workshops
Exercise programs
Quarterly newsletter
Advocacy
Dragon Boat team
The Maplesoft Centre for Cancer Survivorship

Tel: 613-247-3527

A place of quiet refuge, reflection, support and empowerment for cancer patients and their families throughout their journey. There are a wide range of programs available to patients.

Willow: Breast Cancer Support and Resource Services

Tel: 1-888-778-3100 or 416-778-5000        Fax: 416-778-8070        Email: info@willow.org

Web: www.willow.org
Information and support line staffed by breast cancer survivors
Free information packages in response to breast cancer questions
Drop-in library and resource centre in Toronto

Information re surgery and reconstruction – breastcancer.org

Prostheses and Mastectomy Clothing

Kelly’s Mastectomy Boutique
1747 St. Laurent Blvd. Ottawa, 613-248-8989

Lorraine’s—your breast care studio and more
6 Lake Avenue West, Carleton Place, 613-854-7112
lorrainesyourbreastcarestudio@gmail.com

Marianne’s Mastectomy and Lingerie Boutique
Westgate, 1309 Carling Avenue, 613-722-6614, marianneweidemann@sympatico.com

Sears 1-800-267-3277

La Vie en Rose Post Mastectomy Collection
Rideau Centre, 613-563-2959

Janac Mastectomy Wear
On-line store, 1-866-290-0821
www.janacsportswear.ca

This list may not be inclusive.

Ask your nurse at WBHC for a complete list.
Support groups

Arnprior and District Breast Cancer Support Group

Provides support and encouragement to breast cancer patient in the Arnprior and surrounding area. Contact Elta Watt, 613-623-7455.

Kanata and District Breast Cancer Support Group

Support group for breast cancer patients, where information and sharing is provided
Meets on the last Thursday of the month at 7 p.m. at the Mlacak Centre, Hall D, Kanata
Contact: Pauline Cramphorn, 613-592-0305 or pauline.cramphorn@sympatico.ca
www.ourbcsg.goldengraphics.ca

Support Groups at The Ottawa Hospital Cancer Centre

Call the Psychosocial Oncology Program for current listing of support groups and Counselling Services. Call Unit Coordinator at 613-737-7700, ext. 70516 to register or to get more information.

Stepping Stones Support Group

Stepping Stones Support Group for women newly diagnosed with breast cancer. Contact the Women’s Breast Health Centre (refer to page 43 for more information).

Caring Voices

www.caringvoices.ca
An online community for breast cancer survivors where you can meet other breast cancer survivors and share experiences. You can access current information and resources about breast cancer and view topic specific forums. Registered users can take part in online chats, professionally moderated discussions and contribute to forum topics.
Hospices

Hospices provide support and care for people diagnosed with a life-threatening illness, and for their families. Both Ottawa Hospice programs at Maycourt and Bruyère offer an inpatient unit. Maycourt also offers home support and a day hospice. There are no costs associated with the services offered by Maycourt. Costs for the Elizabeth Bruyère services are only associated with private and semi-private room coverage.

- Hospice at Maycourt, 114 Cameron Ave., tel. 613-260-2906
  www.hospicemaycourt.com
- Bruyère Continuing Care (Palliative care unit) at 43 Bruyère Street, tel. 613-562-6262, ext. 4063; www.bruyere.org
- Friends of the Hospice Ottawa, tel. 613-838-5744
  www.friendsofhospiceottawa.ca
- A palliative outreach program for francophones “Une fleur a la main” provides volunteers for home support/respite. For information, phone 613-241-1266.
- Canadian Virtual Hospice; www.virtualhospice.ca

Medical, counselling and home care resources

Medical

How to find a family doctor
- Health Care Connect (Government of Ontario)
- College of Physicians and Surgeons of Ontario
  1-800-268-7096, ext. 626

Fertility resources in Ottawa
- The Ottawa Fertility Centre – Phone 613-686-3378
  – Sperm Cryopreservation Storage
  – IVF Fertilization Treatment Cycle
  – Embryo Cryopreservation Storage
  – Fertile Futures: www.fertilefuture.ca
  A national Canadian charitable organization that provides fertility preservation information and support services to cancer patients and oncology professionals.
Clinical trials

If you are interested in participating in a local clinical trial, or would like more information on what clinical trials are offered at The Ottawa Hospital Cancer Centre, please speak to your oncologist or call the Clinical Trial office at 613-737-7700, ext. 70310.

To learn more about promising new cancer treatments and clinical trials in other locations, visit www.ontariocancertrials.ca or call the Canadian Cancer Society at: 1-888-939-3333.

Film library

If your imaging was done at The Ottawa Hospital, copies of your CTs, MRIs, x-rays and radiological records are kept at The Ottawa Hospital Film Library. Since 2002, CTs and MRIs are put on CDs. If you need a CD with a copy of your CT or MRI, ask your physician to make the request. If the receiving physician (even if they reside outside Canada) sends a request by fax, there is no charge to the patient. If the patient initiates the request, there is a charge.

If the record you require is (1) not a CT or MRI or (2) dates before 2002, you will need a copy of the actual radiological film. If the films are to be reviewed by another physician within Canada, the films can be loaned. If the films are being sent out of the country, copies will be made, for which there is a charge. Payment must be made in advance. The films can be ordered over the phone by giving a credit card number. Call the film library at the campus of the hospital where the films were taken.

The direct phone numbers for The Ottawa Hospital Film Library are:

<table>
<thead>
<tr>
<th>Campus</th>
<th>Telephone</th>
<th>Fax</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>613-737-8502</td>
<td>613-739-6593</td>
</tr>
<tr>
<td>Civic</td>
<td>613-761-4333</td>
<td>613-761-5321</td>
</tr>
</tbody>
</table>

Do you need a family doctor?

If you do not have a family physician, please call Health Care Connect at 1-800-445-1822 and they will try to help you with finding one.
# Counselling

## Professional counsellors

Sources for professional Counselling include:

<table>
<thead>
<tr>
<th>Source</th>
<th>Contact information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women’s Breast Health Centre Social Worker</td>
<td>613-798-5555, ext. 16563</td>
</tr>
</tbody>
</table>
| The Ottawa Hospital Psychosocial Oncology Program (If you are registered with The Ottawa Hospital Cancer Centre) | 613-737-7700
Unit Coordinator ext. 70516                                    |
| Employee Assistance Program                                 | Contact Human Resources at your place of employment      |
| Champlain Community Care Access Centre                      | Ask your Case Manager                                    |
| Private Counsellors                                         | See the yellow pages of your telephone book              |

## Champlain Community Care Access Centre (CCAC)

Champlain Community Care Access Centre is funded by the Ontario Ministry of Health and Long-Term Care. CCAC can arrange in-home services such as nursing, physiotherapy, occupational therapy, nutritionist, social worker, speech therapist, and, in some instances, a home support worker to assist with personal care. If you feel you need a referral to community care, ask your nurse or physician who will make that referral for you. You can also contact CCAC yourself. A CCAC case manager can meet with you at the Cancer Centre to talk about what you may need. Your case manager will see you if you are admitted to hospital and will reassess your needs before you are discharged.

<table>
<thead>
<tr>
<th>City or region</th>
<th>Telephone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ottawa</td>
<td>613-745-5525, 1-800-538-0520</td>
</tr>
<tr>
<td>Leeds, Grenville Counties (Brockville)</td>
<td>613-345-0060, 1-800-267-4403</td>
</tr>
<tr>
<td>Lanark County (Perth, Smiths Falls, Carleton Place)</td>
<td>613-283-8012, 1-800-267-6041</td>
</tr>
<tr>
<td>City or region</td>
<td>Telephone</td>
</tr>
<tr>
<td>----------------</td>
<td>-----------</td>
</tr>
</tbody>
</table>
| Renfrew County  
(Pembroke, Renfrew, Arnprior) | 613-732-7007, 1-888-421-2222 |
| Stormont, Dundas, Glengarry, Prescott, Russell Counties  
(Cornwall, Winchester, Hawkesbury) | 613-936-1171, 1-800-267-0852 |

**CCAC Offices and Phone Numbers**

Information about the Champlain Community Care Access Centre is also available on the Website at www.champlain.ccac-ont.ca or phone 613-745-5525 or 1-800-538-0520.

Your hospital or Cancer Centre social worker can provide information on other community resources that provide services in the home.

- **Personal emergency response systems**, which link individuals to 24-hour emergency assistance. There is a cost for this system.

- **Meals on Wheels**: a program that delivers hot meals (some programs also have a frozen food plan) to individuals unable to prepare meals at home. There is a cost.

- **Senior Home Support Programs**: These agencies provide a variety of services, including homemaking, transportation, escorts, sitters, and friendly visitors. Every agency may not be able to provide all services. They have reasonable rates for home help and transportation.

- **Telephone Assurance Program**: The program provides a daily telephone call to senior citizens and handicapped people who live alone to make sure all is well.

**Ontario Works/Ontario Disability Support Program**

Ontario Works/Ontario Disability Support Program may be able to provide financial assistance for home support help and child care for people on either of these programs. Discuss this with your worker if you are already receiving these benefits.

**Private homemaker services and nursing registries**

If you wish to hire privately, or have extended health insurance that covers private-duty nursing, look in the yellow pages of the Telephone Directory under “Nurses”. If you plan to claim on your insurance, make sure you receive prior approval.
Programs

Medical equipment

**Assistive Devices Program (ADP)**

The Ontario Ministry of Health and Long-Term Care runs a program to help people who have physical disabilities get needed medical equipment and supplies such as a prosthesis.

For more information, phone 1-800-268-6021, or visit the link off the Web page www.health.gov.on.ca.

Loan cupboards

Many communities have loan cupboards that offer medical equipment, at a nominal charge, for limited time periods. For further information, contact a hospital or a Cancer Centre social worker or a Champlain Community Care Access Centre.

Quality of life

**Information on wigs**

- Wig Salon (The Canadian Cancer Society facilitates this program to provide free wigs, wool caps and cotton bandanas free of charge to cancer patients.)

- To book an appointment to select a free wig supplied by the Canadian Cancer Society and to have a professional fitting of your wig, call the Canadian Cancer Society phone number at 613-723-1744 and ask for the Hair For You program. You will be shown how to wash and care for the wig/head dressing.

- To find a salon that sells wigs, look in the yellow pages of the Telephone Directory under Wigs or Health Hair Replacement and Wigs or speak to your nurse or social worker.

- A list can be provided from PSOP.

**Look Good … Feel Better Program**

The Look Good…Feel Better program offers free workshops about facial skin care, makeup and options for hair loss for women who are receiving cancer treatment. The workshop is offered twice a month, alternating between the Civic and General Campus. Pre-registration is required. If you wish to register or need more information, call 613-737-7700, ext. 10315.
**Victoria’s Quilts Canada**

Victoria’s Quilts offers handmade quilts to cancer patients. If you wish to request a quilt or would like further information, please call 613-843-9212 or visit the Website at www.victoriasquiltscanada.com.

**Smoking cessation programs**

Smoking is detrimental to your health. There are programs to help you quit.

- The University of Ottawa Heart Institute sponsors the Heart Check Smoking Cessation Program at The Ottawa Hospital, Civic Campus. This six-step program is for adults who require a combined medical and behavioral approach for quitting. For further information, phone 613-761-4753.

- Canadian Cancer Society’s Smoking Helpline provides information, advice, and support. There is no charge. For more information, phone 1-877-513-5333.

- For information on other programs, see the following table:

<table>
<thead>
<tr>
<th>City or region</th>
<th>Facility</th>
<th>Telephone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ottawa</td>
<td>Public Health Info Line (Smoking Cessation Program)</td>
<td>613-580-6744 ext. 24179</td>
</tr>
<tr>
<td>Renfrew County and District Health Unit</td>
<td>Health Info Line</td>
<td>613-735-8666 ext. 547 or 1-800-267-1097 ext. 547</td>
</tr>
<tr>
<td>Leeds, Grenville and Lanark District Health Unit</td>
<td>Health Action Line</td>
<td>613-345-5685 or 1-800-660-5853</td>
</tr>
<tr>
<td>Eastern Ontario Health Unit</td>
<td>Tobacco Use Coordinator</td>
<td>613-933-1375 or 1-800-267-7120</td>
</tr>
</tbody>
</table>
Lodging and transportation

Maurice Grimes Lodge

- The Maurice Grimes Lodge, Civic Campus of The Ottawa Hospital Cancer Centre, provides accommodation for out-of-town patients requiring assessment or treatment at the Cancer Centre. It is open Monday to Friday. For more information, phone 613-725-6328.

Criteria for admission to the lodge includes:
1. A registered Cancer Centre patient.
2. Live more than 40 km outside of Ottawa.
3. Be able to manage stairs.

- Rotel, 411 Smyth Road, provides inexpensive accommodation for out-patients, and for friends and relatives of in-patients at Ottawa area hospitals. For more information, phone 613-733-1412.

- The Ottawa Hospital Intern’s Residence, 751 Parkdale Avenue, rents apartments for short stays for out-of-town families of Ottawa Hospital patients. For more information, phone 613-761-5400.

Transportation to medical appointments

If family or friends are unable to assist you with transportation to medical appointments, the following are some options.

- Canadian Cancer Society volunteers may be able to provide transportation to the Cancer Centre. Call your local Cancer Society Unit Office. For phone numbers, please refer to the table in the previous section on the Canadian Cancer Society.

- Senior Home Support Programs may be able to provide transportation. There is a fee for this service. Check with the Senior Support Program in your local community.

- If you are on the Ontario Works or Ontario Disability Support Program, contact your worker to determine if you are eligible for any financial assistance for transportation expenses.

For the Ottawa region only:

- Para Transpo provides special transportation for disabled persons who cannot board a conventional bus.
For information on the application process, phone 613-244-1289. For bookings after you are registered, phone 613-244-7272.

**Parking**

Passes are available on daily, weekly or monthly basis. You may purchase your pass at any campus. If you cannot pay for parking, please contact your social worker.

**Physically disabled parking permits**

The Ministry of Transportation of Ontario issues Disabled Parking Permits. The application can be picked up at any Private License Bureau or from a hospital or Cancer Centre social worker.

**Financial information**

A) Replacing lost income – Options for patients

B) Replacing lost income – Options for caregivers

C) Paying for prescription drug cost

**Loss of income**

Whether you are living with cancer, or acting as a caregiver to a person with cancer, your income can be affected through unexpected expenses or time away from work. This section discusses the options.

**A. Replacing lost income – options for patients**

Some people who have cancer may be unable to continue to work either temporarily or permanently. The resulting loss of income can cause additional stress to an already stressful situation. Options you can explore to replace lost income are discussed below.
1. **Taking leave from your place of employment**
   Talk to Human Resources personnel at your place of employment about your coverage for sick leave, vacation leave, and short or long-term disability.

2. **Employment Insurance Sickness Benefit**
   This is a federal program accessed through Service Canada. Sickness benefits are paid up to 15 weeks.
   - **Eligibility**: 600 hours of insurable employment in the last 52 weeks, or since the start of the last Employment Insurance (EI) claim. Some exceptions are allowed.
   - **How Much**: Most claimants receive the basic rate of 55 per cent of their earnings, to a weekly maximum.
   - **When Benefits Start**: There is a two-week waiting period. However, if you get paid sick leave from your employer or group insurance benefits, you may not have to wait the two weeks. The claim can take four to six weeks to process. Ontario Works (Social Services) may assist in the interim.
   - **To Apply**: Application can be done online at: http://www.servicecanada.gc.ca/ or at a Service Canada centre. A medical form is also necessary and can be completed by your family physician or by your oncologist. If you require assistance with this process, please communicate with your social worker or the Psychosocial Oncology Program at 613-737-7700, ext. 70516.

   For more information on the Employment Insurance Sickness Benefit, contact your local office. For phone numbers and addresses, look in the blue pages of the telephone directory, or see their Web page: www.servicecanada.gc.ca.

3. **Canada Pension Plan (CPP) or Quebec Pension Plan (QPP) Disability Benefit**

   **CPP Disability Benefit**
   The CPP Disability Benefit is a federal program run by Service Canada, Income Security Programs. Qualification for this program is based on medical need, not financial need.

   **Eligibility**: The applicant must be:
   - between the ages of 18 and 65
   - have enough CPP contributions
   - have a disability that is “severe and prolonged”
- **How Much:** Dependent on contributions to the plan. Call 1-800-277-9914 to determine the amount for which you might be eligible. CPP Disability Benefits are deducted from the Ontario Disability Support Program, or from your private insurer. Benefits are taxable.

- **Disabled Contributor’s Child Benefit:** Dependent children may be eligible for benefits if they are less than age 18, or are between 18 and 25 and attending school full time.

- **When Benefits Start:** Benefits start in the fourth month after you are deemed to have become disabled. You can receive up to twelve months of retroactive payments.

- **To Apply:** Application forms are available from a Social Worker at the Hospital or Cancer Centre, or from Service Canada.

For more information on the Canada Pension Plan, call 1-800-277-9914, or see their Web page: www.servicecanada.gc.ca.

**QPP Disability Benefit**

The QPP Disability Benefit is similar to CPP Disability Benefits. If you have contributed only to the QPP, or if you contributed to both plans but reside in Quebec, you should contact: La Régie des rentes du Quebec at 819-772-3049, or 1-800-463-5185.

4. **Ontario or Quebec Social Assistance**

   **Ontario Works**

   Ontario Works replaces General Welfare Assistance. This program is for people who need financial assistance to pay for day-to-day living expenses such as food, housing, and utility costs.

   - **Eligibility:** It is based on a financial needs test. You can have only a certain amount of assets. People applying for the Ontario Disability Support Program (ODSP) are allowed higher levels of assets.

   - **How Much:** Depends on various factors. An Ontario Drug Benefit Card is provided.

Extra financial help is available for special dietary needs, medical transportation, dental and vision care for children, and the balance for medical equipment or prostheses not covered by the Assistive Devices Program.
To Apply: Phone the local office of Ontario Works, as shown in Table 1.

<table>
<thead>
<tr>
<th>City or region</th>
<th>Telephone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ottawa</td>
<td>613-560-6000 (ask for intake)</td>
</tr>
<tr>
<td>Lanark County (Smiths Falls, Perth, Almonte, Carleton Place)</td>
<td>613-267-4200, 1-866-878-9588</td>
</tr>
<tr>
<td>United Counties of Leeds/Grenville (Brockville)</td>
<td>613-345-4101, 1-800-267-8146</td>
</tr>
<tr>
<td>Renfrew County (Renfrew, Pembroke, Arnprior)</td>
<td>613-433-9846, 1-888-281-7526</td>
</tr>
<tr>
<td>Stormont, Dundas, Glengarry County (Cornwall)</td>
<td>613-933-6282</td>
</tr>
<tr>
<td>Prescott, Russell County</td>
<td>613-675-4642, 1-800-667-9825</td>
</tr>
</tbody>
</table>

Table 1 Phone numbers for Ontario Works

Quebec Social Assistance

For information on financial resources, contact your local CLSC, at the phone numbers shown in Table 2.

<table>
<thead>
<tr>
<th>City or region</th>
<th>Telephone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hull Sector</td>
<td>819-770-6900</td>
</tr>
<tr>
<td>Gatineau Sector</td>
<td>819-561-2550</td>
</tr>
<tr>
<td>Aylmer Sector</td>
<td>819-684-2251</td>
</tr>
</tbody>
</table>

Table 2 CLSC phone numbers

5. Ontario Disability Support Program (ODSP)

ODSP is a provincially funded disability benefit. This program is based on medical needs as well as financial needs. An application for ODSP goes through a medical determination process by the Disability Adjudication Unit in Toronto (medical decisions are not made locally).

- **Eligibility:** The applicant must “have a substantial health condition expected to last more than 1 year”. ODSP allows you to have more assets than what is allowed by Ontario Works.
- **How Much**: Depends on various factors. Amount received is higher than what is received under Ontario Works. An Ontario Drug Card is provided.

- **When Benefits Start**: Application process can take three to four months or longer. If you do not have other income or assets, you should apply for Ontario Works in the interim.

- **To Apply**: Ontario Works and ODSP (for phone numbers, see Table 1).

If you don’t qualify for Ontario Works, call ODSP directly, using the numbers listed in Table 3.


<table>
<thead>
<tr>
<th>City or region</th>
<th>Telephone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ottawa</td>
<td>613-234-1188</td>
</tr>
<tr>
<td>Lanark County</td>
<td>613-283-1165, 1-800-267-7911</td>
</tr>
<tr>
<td>Leeds-Grenville County</td>
<td>613-345-1200, 1-800-267-0834</td>
</tr>
<tr>
<td>Stormont, Dundas, Glengarry County</td>
<td>613-932-3381, 1-800-565-5374</td>
</tr>
<tr>
<td>Prescott, Russell County</td>
<td>613-632-1171, 1-800-565-4431</td>
</tr>
<tr>
<td>Renfrew County</td>
<td>613-735-1073, 1-800-267-0112</td>
</tr>
</tbody>
</table>

*Table 3 Phone numbers for ODSP*

6. **Private retirement plans/CPP/QPP retirement plans**

Some people may choose to take early retirement. Talk to Human Resources personnel at your place of employment. Canada Pension Plan (CPP) and Quebec Pension Plan (QPP) benefits are accessible as early as age 60; but are reduced by 0.5 per cent for each month that the beneficiary falls short of age 65.
7. Other sources of financial assistance

1. **Specific disability insurance**
   Check to see if you have disability insurance on your mortgage, your line of credit, etc.

2. **Essential Health and Social Support (EHSS)**
   In Ottawa, for those of low income, financial assistance may be provided for:
   - Trillium Prescription Drug Plan Deductible
   - Dental and vision care for children and adults
   - Medical transportation
   - Mobility aids
   - Assistive Devices Program top-up

   If you live in Ottawa, for information, call Social Services at 613-560-6000. If you live outside Ottawa, call Social Services in your local municipality to determine whether they provide any financial assistance for these items.

3. **Gas mileage**
   Patients who live 40 km or more from a Regional Cancer Centre are eligible for income tax deductions for their mileage. Patients who live 80 km or more from a Regional Cancer Centre can also claim for meals and accommodations.

   You must keep track of the number of kilometers driven for the purpose of medical treatment. To get the rates allowed for each kilometer, plus any additional information, visit Canada Revenue Agency Website www.cra.gc.ca/travelcosts or see Bulletin IT-519.

4. **Disability Tax Credit (Revenue Canada–Taxation Office: Form T2201)**
   The Disability Tax Credit is a non refundable tax credit that reduces the amount of federal income tax you pay. Apply if you “have a severe and prolonged (at least 12 months) mental or physical impairment such that you are markedly restricted in your ability to perform one or more basic activities of daily living.”

B. **Replacing lost income – options for caregivers**

When a loved one is seriously ill, a caregiver may want to take time off work to help care for them. The following are some options to replace income lost due to caregiving responsibilities.
1. **Taking leave from your place of employment**
   Talk to Human Resources personnel at your place of employment to determine if you are eligible for sick leave, personal leave, vacation leave, and the like.

2. **Employment Insurance Compassionate Care Benefits**
   This program provides a maximum of six weeks of benefits to “eligible workers who have to be absent from work to provide care to a family member who has a serious medical condition with a significant risk of death within 26 weeks (6 months)”. To qualify, you will need a medical certificate from the physician treating the gravely ill family member. You will also need a Record of Employment (ROE) from your employer.

   You can share the six weeks of compassionate care benefits with other family members so long as they also (1) meet the eligibility criteria and (2) apply for the benefits.

   A two-week (14-day) unpaid waiting period applies.

   For further information, phone Automated Telephone Information Service, at 1-800-206-7218, or visit the Website at www.servicecanada.gc.ca.

3. **Tax savings**
   For details on the Medical Expense and Disability Tax Credits and Attendant Care Expense Deduction, refer to Canada Revenue Agency (CRA) Interpretation Bulletin IT-519R2. This document is available electronically on the CRA Website at: http://www.cra-arc.gc.ca/E/pub/tp/it519r2-consolid/README.html, or by calling 1-800-959-8281.

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**For more information on financial assistance, the Social Workers at The Ottawa Hospital Psychosocial Oncology Program will gladly assist you.**

Although the Canadian Cancer Society does not provide financial assistance, it does have information on the Website at www.ontario.cancer.ca. (Select “service directory” from the “get support” section and then “where will my money come from” from the menu on the left. (http://www.ontario.cancer.ca/ccs/internet/standard/0,3182,3543_316353_langId-en,00.html).
C. Paying for prescription drug costs

1. Drug insurance plan
   If you are covered by a drug insurance plan at work or privately, check any limitations that your plan might have, for example: partial or total coverage for drugs, maximum amounts each year, and exceptions to the coverage.

2. Ontario Drug Benefit (ODB) Program
   If you are an Ontario resident with a valid Ontario Health Insurance Number, you are eligible for coverage under the ODB program if you are:
   - 65 years or older (there may be a deductible and a higher dispensing fee for seniors with a higher income)
   - receiving professional services under the Champlain Community Care Access Centre program
   - receiving social assistance through the Ontario Works or Ontario Disability Support programs
   - resident in a long-term care facility
   There is a $2 co-payment charge for each prescription.

3. Trillium Drug Program
   The Trillium Drug Program is designed to help individuals and families who spend a large portion of their income on prescription drugs. There is a deductible, based on the number of people in your family, and your family’s net income. To help you calculate your deductible, a chart is included in the application form. Once you have spent your deductible on prescription drugs, (you will need to submit all prescription receipts) you will receive coverage for drugs listed on the Ontario Drug Benefit Formulary list.

   Clients pay the deductible in four installments over the Trillium program year, which begins August 1st of each year, and ends July 31st of the following year.

   Sometimes Ontario Works (Social Services) may help with the deductible expenses. To be eligible for this, you will be required to undergo a financial means test. To apply for financial assistance with the deductible from Ontario Works, in Ottawa call 613-560-6000.

   You can apply for the Trillium Drug Program if your private insurance plan does not cover all the costs of your prescription drugs. (You will still be required to pay the deductible.)

   Once you are eligible, there is a $2 co-payment charge for each prescription.
Application forms are available from your pharmacist, Hospital or Cancer Centre Social Worker, from the Ministry of Health and Long-Term Care – Trillium Drug Program at 1-800-575-5386, or online at www.gov.on.ca/health.

For more information, see the Ministry of Health and Long-Term Care’s Web page: www.gov.on.ca/health.

4. **Questions on reimbursement**
   For a guide to reimbursement for prescription medications in Canada, see the Website: www.drugcoverage.ca.

### Legal issues

Every adult, regardless of age or health, should complete a Power of Attorney and make a will.

**Power of Attorney**

A Power of Attorney is valid only when you are living. There are two types of Power of Attorney:

1. *Continuing Power of Attorney* for Property allows you to name a person(s) to manage your financial affairs on your behalf, under specified conditions.

2. *Power of Attorney for Personal Care* allows you to name a person(s) to make decisions about your personal care, should you become mentally incapable. Personal care includes decisions about health care, living arrangements, food, clothing, and safety. You can give verbal or written instructions, conditions, and restrictions to the person you have named. The most common type of instructions is to decline artificial life support in the event of a terminal disease. Your healthcare wishes, as expressed in this document, make it easier for both your family and your physician(s).

When you are planning to do a Power of Attorney, make sure you ask the person you want to manage your affairs or make decisions on your behalf, to make sure they are willing to take on this responsibility. When you have done the paperwork, let this person know, and tell them where it is kept.
To do a power of attorney

1. Contact a lawyer

OR

2. Go to the Ministry of the Attorney General Website at www.attorneygeneral.jus.gov.on.ca/html/PGT/powkit.htm, or contact a Hospital/Cancer Centre social worker, to obtain the “Ontario Ministry of the Attorney General” booklet which has information and the Power of Attorney forms. Using this booklet, you can do both the Power of Attorney for Property and Power of Attorney for Personal Care, at no expense.

Will

A Will takes effect only upon a person’s death. The purpose of a will is twofold. It states your wishes for the distribution of your assets, and it names the person (the executor) to carry out this distribution. There are two types of wills: “formal wills” and “holographic wills”.

1. A formal will is usually prepared by a lawyer, but a will form can be purchased from a stationary store. For this type of will, the client signs it in the presence of two witnesses (beneficiaries and their spouses should not be witnesses).

2. A holographic will is prepared without a lawyer’s help. To be binding, a holographic will must be entirely in the person’s handwriting, with no printing or typewriting anywhere on the document and must end with the signature of the testator (the person making the will). This type of will does not need to be witnessed, but having it witnessed is preferred.

When you are planning to write a will, make sure you ask the person you want to be your executor, to make sure they are willing to take on this responsibility. When you have done the paperwork, let this person know, and tell them where your will can be found.
SECTION 11

Glossary and terminology
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abscess</td>
<td>Infection that has formed a pocket of pus.</td>
</tr>
<tr>
<td>Adjuvant therapy</td>
<td>Additional treatment given after surgery to prevent recurrence or further spread or growth of cancer cells, using radiation, chemotherapy and/or hormone therapy.</td>
</tr>
<tr>
<td>Alopecia</td>
<td>Hair loss (this can include all body hair including scalp hair), a common side effect of chemotherapy.</td>
</tr>
<tr>
<td>Amenorrhea</td>
<td>Absence or stoppage of menstrual period, usually as a result of chemotherapy.</td>
</tr>
<tr>
<td>Analgesic</td>
<td>A drug that relieves pain. Aspirin and acetaminophen are examples of mild analgesics.</td>
</tr>
<tr>
<td>Anorexia</td>
<td>Loss of appetite.</td>
</tr>
<tr>
<td>Antiemetic</td>
<td>A drug that reduces or eliminates nausea and vomiting.</td>
</tr>
<tr>
<td>Atypical hyperplasia</td>
<td>Cells that are both abnormal (atypical) and increased in number.</td>
</tr>
<tr>
<td>Axillary dissection</td>
<td>Surgical removal of lymph nodes found in the armpit region.</td>
</tr>
<tr>
<td>Benign</td>
<td>Not cancerous.</td>
</tr>
<tr>
<td>Blood count</td>
<td>The number of red blood cells, white blood cells and platelets in a sample of blood.</td>
</tr>
<tr>
<td>Bone marrow</td>
<td>The soft inner part of large bones that produce blood cells.</td>
</tr>
<tr>
<td>Bone scan</td>
<td>A picture of the bones using a radioactive dye that shows any injury, disease or healing. This test helps to determine if cancer has spread to the bones.</td>
</tr>
</tbody>
</table>
**BRCA1/BRCA2**  
The principal genes that, when altered, indicate an inherited susceptibility to breast cancer. These gene alterations are present in 80 to 90 per cent of hereditary cases of breast cancer.

**Cancer**  
A general name for more than 100 diseases in which abnormal cells grow out of control. Cancer cells can invade and destroy healthy tissues and they can spread through the bloodstream and the lymphatic system to other parts of the body.

**Chemoprevention**  
The use of drugs or vitamins to prevent cancer in people who have precancerous conditions or a high risk of cancer, or to prevent the recurrence of cancer in people who have already been treated for it.

**Clear margins**  
An area of normal tissue that surrounds cancerous tissue, as seen during examination under a microscope.

**Clinical trial**  
A carefully designed scientific experiment for testing a new therapy or treatment approach.

**Complimentary therapy**  
Used to decrease symptoms and to enhance the quality of a person’s life, they are used together with mainstream (conventional) therapy.

**Contralateral**  
Situated on, affecting or relating to the opposite side of the body.

**Core biopsy**  
A procedure (with freezing) performed by a radiologist where small tissue samples are taken from a lump or an abnormal area in the breast.

**Differentiated**  
Clearly defined. Differentiated tumour cells are similar in appearance to normal cells.

**Ductal carcinoma in situ (DCIS)**  
Breast cancer that has not invaded through the walls of the milk ducts.
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ducts</strong></td>
<td>Tube like structures in the breast that carry milk from the lobes to the nipple.</td>
</tr>
<tr>
<td><strong>Estrogen</strong></td>
<td>Female sex hormones produced by the ovaries, adrenal glands, placenta and fat.</td>
</tr>
<tr>
<td><strong>Estrogen receptor</strong></td>
<td>Protein found on some cells to which estrogen molecules will attach. If a tumour is positive for estrogen receptors, it is sensitive to hormones.</td>
</tr>
<tr>
<td><strong>Excisional biopsy</strong></td>
<td>Surgeon removes tissue in an operative procedure usually to obtain a diagnosis.</td>
</tr>
<tr>
<td><strong>Frozen section</strong></td>
<td>A sliver of frozen biopsy tissue. A frozen section provides a quick preliminary diagnosis but is not 100 per cent reliable.</td>
</tr>
<tr>
<td><strong>Fine needle aspiration</strong></td>
<td>Radiologist or surgeon may use a small needle to aspirate cells from a lump in the breast.</td>
</tr>
<tr>
<td><strong>Hematoma</strong></td>
<td>Collection of blood in the tissues. Hematomas may occur in the breast after surgery or biopsy.</td>
</tr>
<tr>
<td><strong>Lesion</strong></td>
<td>A general term indicating a change in the structure of any body tissue.</td>
</tr>
<tr>
<td><strong>Lobular carcinoma in situ (LCIS)</strong></td>
<td>Abnormal cells in the lobules of the breast; a sign that a woman is at increased risk of developing breast cancer.</td>
</tr>
<tr>
<td><strong>Lobules</strong></td>
<td>The milk-producing or glandular parts of the breast.</td>
</tr>
<tr>
<td><strong>Lumpectomy</strong></td>
<td>A term usually used when referring to cancer surgery. It is the removal of the breast tumor and some of the normal tissue that surrounds it. Breast conservation surgery is another name for this procedure.</td>
</tr>
<tr>
<td><strong>Lymphatic system</strong></td>
<td>The system that removes waste from body tissues and filters the fluids that help the body fight infections.</td>
</tr>
<tr>
<td><strong>Lymphedema</strong></td>
<td>Lymphedema of the arm is an accumulation of lymph fluid in the soft tissue of the arm with accompanying swelling.</td>
</tr>
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<td>---------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Lymph nodes</strong></td>
<td>Small bean-shaped organs (sometimes called lymph glands); part of the lymphatic system. Lymph nodes under the arm drain fluid from the chest and arm. During surgery, some underarm lymph nodes may be removed to help determine the stage of breast cancer.</td>
</tr>
<tr>
<td><strong>MRI Magnetic resonance imaging</strong></td>
<td>Is a medical test that helps to diagnose and treat breast problems. MRI is not a replacement for mammography and ultrasound but a complimentary examination. MRI does not use radiation but powerful magnetic fields, radio waves and a computer to produce detailed images of your breast. It may be used whenever required to:</td>
</tr>
<tr>
<td></td>
<td>• Further evaluate abnormalities detected by mammogram and ultrasound</td>
</tr>
<tr>
<td></td>
<td>• Assess multiple tumor locations</td>
</tr>
<tr>
<td></td>
<td>• Search for multiple tumors prior to breast conservation surgery</td>
</tr>
<tr>
<td></td>
<td>• Determine whether cancer detected by mammogram and ultrasound has spread further in the breast or into the chest wall</td>
</tr>
<tr>
<td></td>
<td>• Determine how much cancer has spread beyond the surgical site after lumpectomy</td>
</tr>
<tr>
<td></td>
<td>• Assess the effect of chemotherapy</td>
</tr>
<tr>
<td><strong>Malignant</strong></td>
<td>Cancerous; capable of invading, spreading and destroying tissue.</td>
</tr>
<tr>
<td><strong>Mammogram</strong></td>
<td>A specific type of imaging that uses a low dose x-ray system to examine the breasts. It is used as a screening and diagnostic tool to detect abnormalities in the breast.</td>
</tr>
<tr>
<td><strong>Metastatic (metastases)</strong></td>
<td>Spread of cancer from the original part of the body to another. Cells that have metastasized are like those in the original (primary) tumour.</td>
</tr>
</tbody>
</table>
**Microcalcifications**  
Tiny deposits of calcium in the breast which can show up on a mammogram. Certain patterns of microcalcifications can be a sign of breast cancer.

**Modified radical mastectomy**  
A breast cancer operation that removes breast and underarm nodes but no muscle.

**Neoplasm**  
A new growth of tissue or cells; a tumour that is generally malignant.

**Oncologist**  
Doctor who specializes in the treatment of cancer.

**Oncology**  
The study and treatment of cancer.

**Palliation**  
Act of relieving a symptom without necessarily curing the cause.

**Post-biopsy “Clip”**  
A small stainless steel or titanium marker that may be placed at the site of the biopsy (ultrasound or stereotactic guided) so that the area can be located in the future if necessary.

**Pre-operative wire localization**  
It is a technique in which a small wire is placed into the breast to guide the surgeon to the tissue/area to be removed. The wire or needle localization can be done under mammographic or ultrasound guidance.

**Primary cancer**  
The cancer in the original location where it was first detected.

**Prognosis**  
The expected outcome of a disease; the life expectancy.

**Prosthesis**  
An artificial breast form or device worn in or under clothing to create a “normal-looking” breast after mastectomy.

**Protocol**  
An action plan for a clinical trial. The plan states what the study will do, how and why. It explains how many people will be in it, who’s eligible to participate, what study agents they’ll take, what test they’ll receive and how often and what information is gathered.
Recurrence: The reappearance of a disease after previous treatment had caused it to disappear.

Segmental mastectomy (lumpectomy): Removal of the lump and a small amount of surrounding breast tissue.

Sentinel lymph node biopsy: The first lymph nodes to which cancer cells spread after leaving the area of the primary tumour. Presence of cancer cells in these nodes alerts the doctor that the tumour has spread to the lymphatic system.

Seroma: A pocket of clear serous fluid that sometimes develops in the body after surgery.

Side effects: Reactions from drugs or radiation that are not intended or wanted.

Simple (total) mastectomy: Removal of the whole breast; the lymph nodes under the arm are not removed.

Staging: Classification of breast cancer according to its size and extent of spread.

Stereotactic imaging: At WBHC stereotactic imaging is done while the patient lies on her stomach and the breast is positioned through an opening in the table. The breast is compressed as it would be during a mammogram. An image of the abnormality will then appear on the computer screen. This guides the radiologist to the area where tissue samples of the abnormality will be taken.

Other centers may use the “upright” technique when the patient is seated in a chair.

The common use of stereotactic imaging includes:

- breast biopsy
- pre-operative wire localization

Stereotactic breast biopsy is most helpful when mammography shows microcalcifications.
<table>
<thead>
<tr>
<th><strong>Systemic</strong></th>
<th>Affecting the body in general rather than one specific part.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tamoxifen</strong></td>
<td>A drug used to treat breast cancer and help prevent the recurrence of breast cancer. It is an anti-estrogen drug since its main action is to block the growth-stimulating effects of estrogen on cancer cells. It is a common form of “hormone therapy”.</td>
</tr>
<tr>
<td><strong>Tumour</strong></td>
<td>An abnormal growth of tissue. Tumours may be either benign (not cancer) or malignant (cancer).</td>
</tr>
<tr>
<td><strong>Ultrasound</strong></td>
<td>Involves examining the breast using high frequency sound waves that can give the radiologist more information about the abnormality. It is not painful. The primary use of breast ultrasound today is to help diagnose or characterize breast abnormalities. <em>Ultrasound imaging can also be used to:</em> 1. Help drain a cyst or an abscess 2. Guide a needle for breast or lymph node biopsy 3. Guide a needle for pre-operative breast biopsy 4. Evaluate effectiveness of cancer treatment</td>
</tr>
<tr>
<td><strong>Undifferentiated</strong></td>
<td>Not clearly defined. Undifferentiated cells do not look like normal cells.</td>
</tr>
<tr>
<td><strong>Wide excision biopsy</strong></td>
<td>Surgery to remove a breast lump/lesion and wide rim of surrounding tissue.</td>
</tr>
<tr>
<td><strong>Wire localization</strong></td>
<td>A technique to direct a surgical biopsy to an area of the breast which is abnormal on a mammogram but which cannot be felt. A thin wire is placed into the breast using diagnostic imaging such as mammography or ultrasound. This wire will guide the surgeon to the area of the breast that is to be removed.</td>
</tr>
</tbody>
</table>
Other resources

Books, pamphlets and websites

Resources for young families with children and teenagers

Breast cancer genetics: prevention and screening

Index
Books, pamphlets and Websites

The references listed are just a few of the many books, pamphlets, Websites, etc. that are available at the Learning Services at The Ottawa Hospital Cancer Centre, the Women’s Breast Health Centre and The Ottawa Hospital Cancer Centre waiting rooms. Other regional sources such as support groups, libraries and other breast cancer agencies may have these and other additional informational resources.

These resources are provided for information purposes only and are not intended as a substitute for medical care. If you have any questions about your health care, please consult your health-care provider. Inclusion of a resource does not imply endorsement by The Ottawa Hospital. If you would like more information about this topic, please email Learning Services at learningservices@toh.on.ca.

Cancer information specialists

Tel: 1-888-939-3333 (Tom Sparling)

- Confidential toll-free information service of the Canadian Cancer Society (CCS)
- Questions answered on various aspects of cancer, i.e., prevention, treatment, alternative therapies, support
- Staffed by caring and qualified information specialists
- Free pamphlets available on request

Books


Breast Cancer Husband, Mark Silver, 2004
Breast Cancer: Real Questions, Real Answers, David Chan, 2006


Crazy Sexy Cancer Tips, Kris Carr, 2007


Examining Myself, One Woman’s Story of Breast Cancer Treatment and Recovery, Musa Mayer, Faber and Faber, 1993.


Women, Cancer, Sex, Katz, Anne, 2009. Hygeia Media


To search our catalogue, please visit: www.ottawahospital.on.ca/library/consumerhealthcatalogue-e.asp

Booklets

Breast Cancer: Understanding Your Diagnosis, Canadian Cancer Society Publications. A 15 page booklet providing information about breast cancer, its diagnosis and treatment, produced by the Canadian Cancer Society, revised 2007. It can be ordered from the Website or by calling 1-888-939-3333.
**Pamphlets**

Chemotherapy: Patient Information. May 2004; www.orcc.on.ca

Radiation Therapy: Patient Information. The Ottawa Hospital Cancer Centre, 2005

Sentinel Lymph Node Biopsy: An Information Guide for Patients, The Ottawa Hospital, August, 2007

**Websites — Canada**

Canadian Breast Cancer Foundation ........................................www.cbcf.org

Canadian Breast Cancer Network ........................................... www.cbcn.ca

Willow: Breast Cancer Support Canada ..................................... www.willow.org

Caring Voices .................................................................www.caringvoices.ca/en/

Rethink Breast Cancer ....................................................... www.rethinkbreastcancer.com

(A charity that helps young people affected by and concerned about breast cancer)

**Websites — U.S.**

Breast Cancer ...............................................................www.breastcancer.org

The National Cancer Institute .............................................www.cancer.gov

Dr. Susan Love’s Website .....................................................www.dslrf.org

Memorial Sloan-Kettering Cancer Centre ............................... www.mskcc.org

MedlinePlus ........................................................................www.nlm.nih.gov/medlineplus

**Audiotapes**

Helping Yourself — A Workbook For People Living With Cancer, Alastair J. Cunningham, C. Psych., Ph.D. Sponsored by the Canadian Cancer Society. 1989 (Contains a book and two audiotapes)

Medical books and journal articles

Available from the Learning Services at the The Ottawa Hospital Cancer Centre, General Campus:

🌟 “Where to Start?” Information Sheets on Breast cancer; Lymphedema, Fatigue, Nutrition, Exercise; also available on Website at www.ottawahospital.on.ca.

Zora K. Brown, Breast Cancer Resource Committee/Rise, Sister, Rise, Integris Health - Cancer Awareness Program Services/Breast Cancer Resource Committee/Rise, Sister, Rise, Harold P. Freeman, MD, Ralph Lauren Center for Cancer Care and Prevention, Elizabeth Platt, Jones and Bartlett Publishers, Sudbury, Massachusetts.

Resources for young families with children and teenagers

Resources have been divided into sections for adults, teenagers, children. However, this is just a guideline and books which appear in one section may be helpful for other age-groups too.

* Indicates resource in French

Resources for adults

A unique collection of shared stories from mothers around the world who have had breast cancer. Included are chapters for talking with children ages 0-12, talking to teenagers and another one for talking with adult children about breast cancer.

This book helps parents to speak to their children about cancer. It is written by a father of two children, ages 11 and 13, who was diagnosed with cancer at the age of 47. The book provides chapter by chapter series of questions and answers dealing with diagnosis, surgery, radiation and chemotherapy. The answers are written so that they are understandable to the children. Some of the questions he faces are: What is cancer? When I get older will I get cancer because you did? and Can I still kiss you?
Cancer in the family: helping children cope with a parent’s illness,
This book outlines valuable steps necessary to help children understand what happens when a parent has been diagnosed with cancer. The book offers suggestions for talking to children each step of the way, helping children cope when a parent is ill, recognizing signs that a child needs help and answering difficult questions about cancer.

* Ces enfants qui vivent le cancer d’un parent,
  Marie France Delaigue-Cosset, 2005.

* Comment vivre avec une personne atteinte d’un cancer,

* Et mes enfants dans tout ça : un guide pour les parents vivant avec un cancer du sein,
  Linda Corsini, 2006; www.cbcf.org/etmesenfantdanstoutca.

Hear how I feel, (video – 25 min)
Northeastern Ontario Regional Cancer Centre, 1996
This is a video produced to heighten awareness of the experience of cancer in the family. It is a combination of reflections and experiences of five young adults in a support group. It particularly addresses the impact on young adults whose parents are diagnosed with cancer. Intended for parents and guidance counselors.

Helping your children cope with your cancer: a guide for parents and families,
Peter Van Dernoot. 2nd ed., 2006.
Divided into three parts: Professionals: sharing their insight, Parents: helping their kids cope and Children: expressing themselves, this book provides advice on how to discuss the impact of this disease on the whole family. In part one a professional writes about communicating with your children, children’s support groups etc. Part two is a collection of personal stories from parents who have been diagnosed with cancer and part three contains a few contributions from children whose parent has been diagnosed.

How to help children through a parent’s serious illness: supportive, practical advice,
Kathleen McCue, 1996
A practical handbook that prepares parents to address children’s fears with honesty and empathy.

* Quand un parent est malade : comment expliquer une maladie grave aux enfants,
  Joan Hamilton, 2001
Raising an emotionally healthy child: when a parent is sick,
Paula K. Rauch, 2006
This book promises to become the gold standard for parents living with illness. As the authors state in the epilogue: “This is a book about good parenting. It happens to focus on taking care of children when a parent is sick, but it mostly talks about things that would help any child grow up emotionally secure and healthy.” (review from www.hurricanevoices.org)

We can cope: when a parent has cancer,
Set of three video tapes (parent/teen/child) and guidebook. 2002.
On the first tape, which is 40 minutes long, the parents from seven families talk about how they coped after a parent was diagnosed with cancer. The teen tape features a group of teenagers discussing their parents’ cancer and how they coped, learned and grew from facing the challenge of cancer. The third tape, 20 minutes long, features children discussing their feelings and reactions about having a parent with cancer. Dr. Wendy Harpham, a cancer survivor herself, hosts the program.

What about my kids?: a guide for parents living with breast cancer,
Linda Corsini, 2006
Written by a Social Worker from The Ottawa Hospital Cancer Centre, this book takes the reader from diagnosis to survivorship. Difficult subjects like recurrence, advancing illness and dying are also discussed. Although it was primarily intended for parents living with breast cancer much of the content could be applied to any parent diagnosed with cancer. The book is also available in CD format. English and French available. English available on line: www.cbcf.org/whataboutmykids.

When a parent has cancer: a guide to caring for your children (includes Becky and the worry cup for children),
Wendy S Harpham, 1997
Written to provide parents with practical and concrete suggestions on caring for your children when diagnosed with cancer, this book includes a chapter on family members with special needs, for example teenagers, single parents, unstable marriages etc. In addition the book includes an illustrated children’s book that tells the story of a seven year old girl whose mom has cancer, “Becky and the Worry Cup”.

When a parent is sick: helping parents explain serious illness to children,
Joan Hamilton, 2001
This book provides parents and other caregivers suggestions on how to approach children with the information that their parent is ill. Much of the book is written in a “bullet-style” format, enabling the reader to grasp particular content quickly.
When cancer hits home: straight talk with Derek McGinty
This 60 minute VHS videotape focuses on how families cope with life-threatening illness.
The video opens with a 15 minute clip of a wife (the patient), husband and four year old
son discussing the disease and how they survived it as a family. Featured in the studio
discussion are Dr. David Spiegel, professor of Psychiatry and Behavioral Sciences at
Stanford University School of Medicine and Dr. Wendy Schlessel Harpham, cancer
survivor and author of three books on this subject.

Resources for teenagers and older children

Mom’s cancer (for older teenagers),
Brian Fies, 2006
This book is a graphic/comic style publication describing one family’s experience dealing
with their mother’s metastatic lung cancer. The family characters are older and the writing
is very honest and revealing, which is why the book would be most appropriate for older,
mature teenagers and adults.

Moms don’t get sick, Pat Brack, 1990
This slim volume tells the story of a mother’s fight against breast cancer from both her
point of view and that of her (then) 10-year-old son. In alternating narratives, Pat and
son Ben discuss their feelings about her mortality, her struggle through surgery, and all
the times in between. Their ups and downs, their reaching out and withdrawal, and their
happiness and despair are all described. This is a valuable book because it can help
the reader see the real-life struggle to survive from a family perspective. (Book review
supplied by Library Journal).

Our family has cancer too,
Christine Clifford, 1997
Providing comfort through the knowledge that “you are not alone.” Our Family Has
Cancer, Too! is an ideal book for children ages 7 to12 whose families have been touched
with cancer. A special “Questions to Ask” section invites kids to write down their questions
for parents, doctors, teachers, and others. Additional worksheets inspire family members
to draw and record their feelings for later discussion. Powerful “Stop and Discuss”
suggestions throughout the book encourage dialogue between parents and children. The
book also contains a glossary of the most common words kids might hear when someone
in their family has cancer. Suggested reading level ages nine to twelve. (from www.
Amazon.com)
When your parent has cancer: a guide for teens, National Cancer Institute, 2005.
This booklet can help prepare a teenager for some of the things they may face when a parent or relative has cancer. A useful glossary is provided in the back of the booklet for any terms which were bolded throughout the text. Covering topics such as taking care of yourself, changes in the family, learning about cancer etc. this booklet may be a useful communication strategy between the teen and their parent.

When someone in your family has cancer, NIH Publication 96-2685, 1996.
This booklet was written for children who have a parent or sibling with cancer. It is intended to help readers understand more about cancer, how it is treated, and changes that may be happening in the family’s life because of cancer. In addition, it is intended to help readers understand and deal with their feelings about cancer and about the person in the family who has cancer. (Review from www.eric.ed.gov).

For children (5 – 10 years)

Becky and the worry cup (In When a parent has cancer: a guide to caring for your children), Wendy S Harpham, 1997
This little book is included with the book, When a parent has cancer. It helps to illustrate the concerns kids have and how parents can help them cope. The story is sympathetic, sensitive and suitable for children between the ages of eight to twelve.

A Day with Dr Waddel: an introduction to cancer written for children, 1988
A Day With Dr. Waddle was written and illustrated by staff members of the Cancer Center at Kansas State University to help children understand cancer. Your day with Dr. Waddle begins in a research laboratory where Dr. Waddle, a friendly duck, who just happens to be a scientist, explains that cancers are diseases of cells. Dr. Waddle describes a cell and tells how scientists do research, like detectives, to find clues to diseases like cancer. Intended for children ages seven to ten. (from www.amazon.com)

* Un dragon dans le coeur, Sophie LeBlanc, 1997.

Good luck, Mrs K!, Louise Borden, 1999.
Narrated by a nine year old girl named Ann, this book talks about a favorite teacher and what happens when she is no longer teaching their grade 3 class. Based on a true story the book does not place undue emphasis on the teacher’s illness but more gives the
reader a sense of continuation in the student’s life with a substitute teacher and a caring principal. Suitable for children ages six to ten.

The Hope tree: kids talk about breast cancer,
Wendy Harpham, 1999
A comforting picture book written to help children cope with a mother’s breast cancer. The authors have created 10 “testimonials” by animal characters in an imaginary support group, allowing each of them to talk about issues they are facing. The “narrators,” all between the ages of 5 and 12, describe how the family reacted to the diagnosis, meeting the doctors and nurses, trying to look for good things among the bad, and dealing with scary emotions, and they offer hints for helping Mom feel better. In the final spread, “Jessie, age 9½,” expresses her feelings and creates a hope tree, each leaf representing one wish for the future. (Book review from School Library Journal) Suitable for ages four to eight.

Kids tell kids what it’s like … when a family member has cancer (video – 30 min), Cancervive, 1998.
Children aged 6 to 10 talk openly about their reactions, emotions, fears, coping mechanisms and hopes related to their parent’s cancer. (from www.Hurricanevoices.org) It is recommended that parents preview the video before showing it to the family.

Mommy’s in the hospital again,
Suitable for children five to nine years old.

My daddy’s cancer: An interactive book for children,
This book provides a story for adults to read to children ages 3 and up. The story answers many questions that children have when a loved one is ill. There are several activities that help children and pointers for parents and caregivers. (excerpt from www.Amazon.ca).

This video features interviews with seven children and four mothers who have experienced breast cancer treatment firsthand. In the interviews, the children, who have successfully weathered this experience, describe their reactions and feelings, particularly the fear of the loss of their mother at the time of diagnosis. The children also describe their difficulties learning to cope with a significantly altered family life. In spite of the intense emotions displayed and the upsetting experiences described, the children and mothers maintain an optimistic view of life. This is illustrated by a variety of coping strategies, including humor. (from www.kidscope.org).
My mommy has cancer.
Told in Eric’s voice this story deals with the emotion surrounding his mom’s hospitalization. Realistic illustrations help to add an authentic flavor to this simple story. Suitable for children ages four to seven.

Once upon a hopeful night.
Once Upon a Hopeful Night is a unique story that helps parents with cancer talk to their young children about their disease and treatment. It touches on many of the issues facing young children who have a parent with cancer, such as anger, sadness, fear and hope, and encourages parents and children to talk about these issues. Once Upon a Hopeful Night helps prepare children for what to expect, and offers reassurance they will be loved and cared for despite the parent’s illness. The story is written in verse, a format that is familiar to children and comfortable for parents. Beautiful illustrations accompany the text and enhance the story. Once Upon a Hopeful Night is appropriate for reading to pre-school children, while older children may find comfort in reading it alone. (from www.amazon.com)

Our mom has cancer.
Abigail and Adrienne Ackerman, 2001.
Two sisters, ages eleven and thirteen, describe what it was like for them when their mother was diagnosed with breast cancer and underwent surgery and chemotherapy. Illustrated as well as written by these children, this book is a hopeful account of the year their mother was being treated. Suggested reading level is ages nine to twelve.

The paper chain.
Clare Blake, 1997.
… a story about Marcus and Ben, whose mother undergoes surgery, chemotherapy, and radiation. Simple explanations of these procedures are given in a matter-of-fact but gentle and positive tone. Mom loses her hair and must rest a lot during her treatments. Sometimes the boys feel sad and cross because she can’t enjoy the activities she once did, and their parents help them understand their emotions. In time, the woman regains her strength and her hair grows back, and the children are delighted, but the text clearly states that she will be closely monitored by her doctor to check for signs of the disease’s return. The book, which is factual but not frightening, would be very helpful for families dealing with other forms of cancer and serious illnesses in general. (from www.amazon.com).
Promises,
Told in the first person by a six-year-old girl whose mom has cancer, this book does an excellent job of integrating the typical events that occur after diagnosis with the child’s emotional reactions. Illustrated by Caldecott Honor book artist Betsy Lewin, it warmly shows the angry, sad, fearful, and happy narrator with her bald mom and loving dad. Perfect for very young children. (from www.Hurricanevoices.org).

Time for me: an activity book for kids when someone in the family has cancer,

When Eric’s mom fought cancer,
When Eric’s mother goes to the hospital for cancer surgery, Eric is frightened and lonely. When she returns, he is still frightened and often resentful because she is too tired to do the things they used to do together and therapy causes her hair to fall out. With Grandma’s help, he makes a snow figure that wears one of his mother’s turbans and has ski poles for arms, but when his mother returns from treatment, she is too sick to admire his work. Angrily, Eric smashes the sculpture and sobs his frustration. The next day, Eric’s father takes him to a nearby slope to ski and brings some needed normalcy and pleasure to his life. He purchases a knit cap with yarn pigtails for his mother, who tells him she hopes to wear it and ski with them next year. Vigna’s watercolors have a gentle quality that complements the text. The story says it’s all right to be angry about illness and offers hope without false promises. A reassuring tale for children with illness in their homes. Sheilamae O’Hara. Written for children ages four to eight. (From Booklist, www.amazon.com).

When mommy had a mastectomy,
When Mommy Had a Mastectomy is a children’s book that explains, in a simple and clear manner, why Mommy is sick and what she does after she feels better to return to normalcy. It tells the story of a mother and daughter discovering new ways to show they care despite the painful illness of breast cancer and subsequent breast reconstruction surgery. Written for children ages four to eight. (from www.amazon.com).

When Pete’s dad got very sick: a book about chronic illness,
Kathleen Long Bostrom, 2005.
This book describes the story of a boy named Pete who is learning to deal with the chronic illness of his father. Pete’s dad used to be able to run and play but now he can hardly walk. Written to help children cope with difficult life issues the booklets children know that God is with them always. The back cover lists this book for children ages four to eight.
When someone is very sick,
Elfo leads us through this playful yet realistic story of feelings children may experience when confronted with a serious illness in a family member. Elfo tells us about issues related to sickness: how the sick person may look, talk, and act differently and how he or she may now need medicines, tubes and machines. Children often have unexpressed worries, and Elfo encourages the readers to express their feelings and write and talk about their experiences. (Grades 3 to 4) (from www.amazon.com).

Where’s Mom’s hair? A family’s journey through cancer,
Debbie Watters, 2005.
Written from the child’s point of view this book shows how love and humour can triumph over the impact that cancer has on the whole family. Real photography is used to illustrate the story that honestly demonstrates how this family coped with their mother’s illness. Classified as juvenile literature it would be a good choice for pre-teens and young teenagers to read.

Why? Charlie Brown, Why? A story about what happens when a friend is very ill,
Charles Schulz, 1990.
In this timeless classic, the Peanuts gang faces the serious sickness of a good friend, Janice. When Janice is diagnosed with leukemia each member of the gang does some soul searching. With compassion the author describes the effect of Janice’s illness on her family, classmates and friends.

The Year my mother was bald,
This is a fictional story written from the child’s perspective. It describes the medical treatments, the family’s experiences and her own feelings and concerns while her mother undergoes treatment for breast cancer. Suitable for children four to eight.

For very young children

My mummy is sick: a story about breast cancer,
Fani Madill, 2001. (phone 1-800-387-9816 to order).
The story takes us through each stage of the mother’s illness, from diagnosis, surgery (showing her surgical scars to the child), having chemotherapy, side effects of treatment (losing her hair), and radiation therapy (child goes to the hospital with her, meets doctor and nurses). In the final two pages, the family is gathered together during the final phase
of treatment, and the story ends as we see the mother restored to health, her hair having grown back, hugging her child who is giving her a greeting card, entitled “Surprise”! (Description provided by www.cfpc.ca).

Sammy’s mommy has cancer: a story for children who have a loved one with cancer. Sherry Kohlenberg, 1994.
This book was written for the author’s young son to help him understand what was happening to her. Geared for baby to preschool level children it uses simple language with colourful pictures.

Breast cancer genetics: prevention, screening, testing, environmental factors, prophylactic mastectomy

Books and DVDs in the Family and Patient Library

Breast Cancer: A Patient’s Journey.
CancerQuest and Susan G. Komen for the Cure, Emory University. 2008 (DVD).
Topics presented include: Breast Cancer Pathology; Medical Testing: Sensitivity and Specificity; Medical Testing: False Positives and Negatives.

Discovery Health Channel Documentary, 2004 (DVD).

The Intelligent Patient Guide to Breast Cancer.
Chapter 41: Familial Breast cancer and Genetic Testing (p. 250)

Understanding Breast Cancer Genetics.
Clinical explanations for the genetic causes of the disease women most greatly fear.
Barbara T. Zimmerman. UP of Mississippi, 2003
Internet links

Prevention, screening and testing

Assessing your risk - Breast cancer.org
http://www.breastcancer.org/risk/genetic/testing/index.jsp

BRCA-1 and BRCA-2 Tests – American Association for Clinical Chemistry
http://www.labtestsonline.org/understanding/analytes/brca/test.html

Breast Cancer (PDQ): Prevention – National Cancer Institute

Environmental Factors and Breast Cancer Risk – National Institute of Environmental Health Sciences - Links to PDF

Estimating Breast Cancer Risk: Questions and Answers – National Cancer Institute

Genetic Testing for BRCA1 and BRCA2: It’s Your Choice – National Cancer Institute
http://www.cancer.gov/cancertopics/factsheet/risk/brc

Genetics Home reference – Your guide to understanding genetic conditions
http://ghr.nlm.nih.gov/condition=breastcancer

GeneReviews – BRCA1 and BRCA2 Hereditary Breast/Ovarian Cancer

Hereditary Breast and Ovarian Cancer: Are you at Risk? University Health Network
http://www.uhn.ca/include/retrieved/uhnflv027581_1_21_2009.pdf

Hereditary Breast and Ovarian Cancer: Patient Info Sheet. University Health Network
http://www.uhn.ca/include/retrieved/uhnflv027580_1_21_2009.pdf

Hereditary Cancer and Options – Hereditary Breast + Ovarian Cancer Foundation
http://www.hboc.ca/hereditary.html

Seeking your Genetic Information – Pros and Cons - Breast cancer.org
http://www.breastcancer.org/risk/genetic/test_pros_cons.jsp
Prophylactic mastectomy

Prophylactic mastectomy – Breast cancer.org
http://www.breastcancer.org/treatment/surgery/prophylactic_mast.jsp

Prophylactic mastectomy – MayoClinic.org
http://www.mayoclinic.com/health/prophylactic-mastectomy/WO00060

Preventive Mastectomy: Questions and Answers – National Cancer Institute
http://www.cancer.gov/cancertopics/factsheet/Therapy/preventive-mastectomy
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Guide feedback
Guide feedback

1. How helpful was the guide to you in understanding breast cancer and its treatment?
   - [ ] Extremely helpful
   - [ ] Very helpful
   - [ ] Helpful
   - [ ] Somewhat helpful
   - [ ] Not at all helpful

2. How helpful was the guide in helping you to “navigate” the system?
   - [ ] Extremely helpful
   - [ ] Very helpful
   - [ ] Helpful
   - [ ] Somewhat helpful
   - [ ] Not at all helpful

3. How helpful was the guide to you in sharing information with others; i.e., care providers, family?
   - [ ] Extremely helpful
   - [ ] Very helpful
   - [ ] Helpful
   - [ ] Somewhat helpful
   - [ ] Not at all helpful

4. What did you find was the most helpful about the guide?
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

5. What did you find was the least helpful about the guide?
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

6. Was the guide too lengthy?  [ ] Yes  [ ] No

7. Was the guide easy to read?  [ ] Yes  [ ] No

8. Please feel free to share any additional comments or suggestions:
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

Thank you for taking time to complete this survey about the guide. This survey may be returned to the Women’s Breast Health Centre.

Your feedback is important!