

Canadian Breast Cancer Initiative

Questions and answers on breast cancer

A guide for women and their physicians

2nd edition

**Based on The Canadian Clinical Practice Guidelines
for the Care and Treatment of Breast Cancer**

As published in the Canadian Medical Association Journal



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**Based on The Canadian Clinical Practice Guidelines
for the Care and Treatment of Breast Cancer**

The Steering Committee on Clinical Practice Guidelines
for the Care and Treatment of Breast Cancer

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This booklet is about the decisions that must be made when breast cancer is suspected or diagnosed.

Breast cancer is the commonest cancer among women. In 1996, it caused 5300 deaths in Canada. In the same year, there were approximately 18 600 new cases.

There is considerable variation in the way in which breast cancer is diagnosed and treated across the country. Women and caregivers taking part in the National Forum on Breast Cancer held in Montreal in November 1993 identified a need for national guidelines for the care and treatment of this disease.

These guidelines, which appear here in an easy-to-read form for patients, have been prepared in response to this need. They are based on the more technical version entitled *Clinical Practice Guidelines for the Care and Treatment of Breast Cancer* that have been compiled for physicians.

This is the second edition of “Questions and answers on breast cancer.” It contains three new clinical practice guidelines, on lymphedema, chemoprevention and sentinel node biopsy, and four guidelines that have been updated and revised in 2001.

The guidelines are addressed primarily to women. However, men can also get breast cancer. Although much of the information presented is also applicable to

men, some is not. Your doctor can advise you on specific differences.

What is a clinical practice guideline?

A clinical practice guideline for breast cancer care is a set of recommendations to help women with breast cancer and their physicians deal with treatment issues about which there is some uncertainty. Guidelines try to resolve the uncertainty by a thorough review of all the medical evidence and extensive consultation with experts in the field.

The guidelines in this series were prepared by experts in breast cancer, representing Canadian national and provincial health agencies, and by women living with breast cancer. They reflect the best available scientific evidence and the consensus of experts across Canada.

A guideline is important for you, not just for your doctor

If you know what the experts are recommending for your condition and *why* they’re recommending it, then you’ll know what to expect and be able to make the best personal choices. As an active participant in your own care, you’ll know what’s going on and you’ll be able to ask the right questions. If you *don’t* get the treatment you expect, you’ll be in a position to find out why. If you feel uncertain at any stage, don’t be afraid to get a second opinion. ♦

Guideline 1. Investigation of a breast lump that can be felt

A lump can be felt in my breast. What should happen next?

First, be aware that finding a lump is common and that most lumps are not due to cancer. However, any new lump must be investigated to find out what it is.

The investigation should start with your doctor asking about your medical history, doing a complete physical examination and usually also ordering a diagnostic mammogram. An ultrasound examination can also be valuable, especially to distinguish between cysts (harmless fluid-filled sacs) and other kinds of abnormalities.

These steps may be all that is necessary to rule out cancer, especially if your doctor is experienced in breast examination.

What sort of questions will my doctor ask me?

You will be asked how long it has been since you first noticed a lump, whether it has changed at all (for example, whether it has grown bigger or changed in texture), and whether you've noticed any skin changes or irritation.

You will also be asked about possible risk factors. These are things that might increase your chance of having breast cancer at some time in your life. Your risk is higher if:

- you are older. Risk increases with age;
- you have had breast cancer before;
- you have had a breast biopsy in the past that showed some abnormality; or
- you had radiation treatment for Hodgkin's disease in childhood.

Your family's health history can also contribute to your risk of getting breast cancer. The risk is higher if there is a "strong" history of breast cancer in your family. You have a strong history if the person with cancer was your mother, sis-

ter or daughter. The risk rises if more than one person in your immediate family had breast cancer, and if their cancer was found before menopause or before they were 50 years of age.

Although these factors are associated with an increased risk, don't be too concerned if some of them apply to you. It may reassure you to know that *most women with the common risk factors don't get cancer.*

What will my doctor look for during the physical examination?

During the examination, the doctor is looking for signs that the lump is either "benign" (non-cancerous) or "malignant" (cancerous).

The armpit and the area above your collarbone will be examined to see if the lymph nodes are enlarged. These lymph nodes are sometimes called "glands." Swollen lymph nodes can be one of the first signals of a spreading cancer. The skin of the breast and the nipple will also be examined for any irritation, rash, dimpling or other abnormality that cancer can sometimes cause. Fluid leaking from the nipples unless it is blood-stained is usually not related to cancer, especially if it occurs in both breasts.

The lump itself will be felt to see if it can be moved within the tissue and whether its edges seem smooth or rough. Smooth, rounded lumps that move easily are much less likely to be cancerous. Lumps due to cancer are usually, though not always, painless.

What is a diagnostic mammogram? Do I need to have one?

A diagnostic mammogram is an x-ray of the breast and is recommended when there is reason to suspect cancer. Because

Guideline 1. Investigation of a breast lump that can be felt

younger women (generally less than 35 years old) have denser breast tissue, mammography is less helpful in this situation.

Diagnostic mammography is more thorough than regular “screening” mammography. It includes extra compression to “push” normal breast tissue out of the way and give a clearer image of the suspicious area. If tiny flecks of calcium (microcalcifications) are noticed, magnified views will be taken since these flecks are sometimes associated with cancer.

If there is any doubt about what the mammogram shows, it is recommended that two individuals experienced in reading mammograms should interpret the results. For an accurate diagnosis, a high-quality mammogram is important. To ensure high quality you should check that your centre is accredited by the Canadian Association of Radiologists.

However, even when all the best procedures are followed, cancer is not always visible on a mammogram, which means that *a normal result is not absolute proof that there is no cancer.*

I have gone through all these steps, but my doctor still cannot rule out cancer. What is the next step?

More tests may be necessary. Your doctor may suspect that the lump is actually a harmless cyst (a sac filled with fluid). This is a common condition. If a cyst is suspected, an ultrasound examination or a technique called “fine-needle aspiration” can help confirm the presence of a cyst.

In fine-needle aspiration, a very thin needle is inserted into the lump. If the lump is fluid-filled, the needle will draw out the fluid. If it is blood-stained it will be sent for testing. If not, you can be certain that it is only a cyst, and no further testing or treatment will be required.

What if the lump is solid and contains no fluid?

If fine-needle aspiration doesn’t draw out any fluid, the lump may still be a harmless, solid fibrous growth. The needle can retrieve cells from the lump for further examination under the microscope. Sometimes, this is enough to reach a clear diagnosis.

If the answer is still unclear, further investigation will be needed. Your doctor can use a larger needle to draw out some tissue from the lump. This is then examined under the microscope to see if there are any cancer cells. This procedure is called a “core biopsy.” Your doctor may be able to locate the lump by feel; if not, a mammographic or ultrasound “picture” of the lump is used as a guide to make sure the needle goes to the right place.

If cancer is still suspected, a “surgical biopsy” is done, in which the whole lump is removed for examination under the microscope. To make sure of getting it all, some of the surrounding normal tissue is also taken.

What about other diagnostic techniques such as thermography, light scanning and magnetic resonance imaging (MRI)?

Thermography, which detects the tumour’s heat, and light scanning, which shows the tumour by shining a light through the breast tissue, are inaccurate and not recommended for diagnosis.

The value of MRI is still being investigated. Right now, it is not a routine part of the diagnostic process.

I have a breast implant. Should I not have some of the tests?

You can and should have the same tests (and treatments, if necessary) as

everyone else. However, special techniques may be necessary to get a good mammographic image of a breast with an implant.

Will all these tests be done by my doctor?

Reliable results depend on the skill and experience of the people who do the tests and interpret the findings. Not all doctors have the required experience and skills and not all tests are available in every location.

Depending on these factors, you may be referred to different specialists for some or all of the tests you'll need. No matter who does the investigation, the goal is to reach a reliable diagnosis using the fewest possible procedures as quickly as possible. While this goes on, you should expect to be kept fully informed. Don't hesitate to ask any questions you may have.

Are any more follow-up tests needed if my lump is found to have no cancer?

It depends on the type of lump you have. For some lumps in which the diag-

nostic test results were difficult to interpret, your doctor may wish to schedule follow-up tests to be on the safe side. When the diagnosis is straightforward, however, no further tests are needed.

What if my lump turns out to be cancer?

In this case, you will have more decisions to make. Together, you and your doctors will decide which kind of surgery is best for you and whether you need other treatment such as radiotherapy, chemotherapy or hormonal therapy. Guidelines 3, 4, 6, 7 and 8 in this booklet will help you with these decisions.

Above all, don't feel rushed into taking action. This is a difficult time, and it is normal to feel anxious. A delay of 1 or 2 weeks will have no significant effect on the outcome and will give you time to gather information and talk things over frankly and openly with your doctor. Don't be afraid to ask questions or to ask for any additional support you need. Family and friends can be especially important at this time. ♦

Guideline 2. Investigation of an abnormality that is discovered by mammography

I had an “abnormal” result on a routine mammogram. Does this mean I have cancer?

Most abnormalities that show up on routine mammograms are not cancer. However, more tests will be needed to make a firm diagnosis.

What tests will I need to have?

Your doctor will take a clinical history, carry out a physical examination and order more thorough x-rays of the breast (a “diagnostic” mammogram). Ultrasound examination can also be valuable, especially to distinguish between cysts (harmless fluid-filled sacs) and other kinds of abnormalities.

What will the physical examination include?

The doctor will thoroughly examine the breasts and the areas under the armpit and above the collarbone for signs of cancer or other conditions that could cause the abnormal image on the mammogram.

What if a lump is found during the physical examination?

If a lump *can* be felt in the breast, go to guideline 1 for a description of the tests used to diagnose it, since breast lumps can be caused by several conditions. (This guideline describes the tests for abnormalities that can only be seen on the mammogram but not felt.)

Why do I need another mammogram?

You will need “diagnostic” mammog-

raphy, which is more thorough than the routine “screening” mammography you already had. Diagnostic mammography uses extra compression to “push” normal breast tissue out of the way and give a clearer image of the area where the abnormality is located. If tiny flecks of calcium (microcalcifications) are noticed, magnified views will be taken since these flecks are sometimes associated with cancer. If there is any doubt about what the image shows, it is recommended that two individuals experienced in reading mammograms should interpret the results. To ensure a high-quality mammogram, which is important for diagnosis, you should go to a mammography centre that has been certified by the Canadian Association of Radiologists.

What are the next steps?

The next steps depend on the likelihood that cancer is present, as judged by the mammograms you have had so far.

If the abnormality is *judged to be definitely benign* (no cancer), no further investigation is needed. (You should, of course, continue to have your usual check-ups.)

Even if the abnormality cannot be diagnosed with certainty as benign, it still may be *very unlikely to be cancer*. In this situation, usually nothing is recommended except regular follow-up mammography and physical examinations to detect any suspicious change quickly. These follow-up examinations usually take place after 6, 12 and 24 months, and annually for 2 to 3 years after that if no changes are seen. If the abnormality does turn out to be cancer, it will usually

Guideline 2. Investigation of an abnormality that is discovered by mammography

show a change within the first year. Rarely, it may take longer.

Although this sort of abnormality is very unlikely to be cancer, there is still a very small chance that it might be. If you feel a strong need to know with certainty at this point, a biopsy can be performed.

If the *risk of cancer is judged to be intermediate* (a probability of cancer between 2% and 10%), a “needle biopsy” (either fine-needle aspiration or core biopsy) is usually recommended to remove a small amount of tissue for microscopic examination. Fine-needle aspiration removes only a few cells. A core biopsy, using a larger needle, can give a more reliable result in some instances. Since the lump can only be seen on the mammogram but not felt, the doctor will use a mammogram or ultrasound “picture” to help locate the abnormality while doing the needle biopsy.

Sometimes the *risk of cancer is judged to be high* (a probability greater than 10%). In these instances, some centres may recommend core biopsy to remove some tissue for examination, and others may recommend surgical removal of the entire area of abnormal tissue for examination. This is called a “surgical biopsy.” Just before the operation, a mammogram or ultrasound image will be used to guide the placement of tiny wires in your breast. These are needed to “mark” the abnormal area for the surgeon (since no lump can be felt). After removal, the tissue is x-rayed to make sure it contains all the abnormalities seen on the mammogram. Often, if the abnormal tissue was removed during the biopsy, no further surgery is necessary.

I have now seen several different specialists for tests and consultations. Who can I talk to about what is happening overall?

Usually your family doctor will coordi-

nate the investigations and give you the results. If you have been referred to a centre for breast health, the specialists there may give you the results. Make sure you know who is *your* doctor responsible for keeping *you* informed. Overall, a reliable diagnosis should be reached as quickly as possible using the fewest possible procedures, and you should understand the reasons for each test and the meaning of the results. If you feel unsure, ask.

What if cancer is found?

This depends on the type of cancer that is found. One possible diagnosis is ductal carcinoma in situ (DCIS). This is a type of cancer that is located in the milk ducts. It is less likely to spread and has a better outlook than “invasive” cancers. For more information on DCIS and its treatment, see guideline 5.

If your tests show invasive cancer (cancer that has invaded the fatty tissue of the breast), you will have more decisions to make. Together, you and your doctors will decide on the kind of surgery that is best for you and whether you need to have other treatment such as radiotherapy, chemotherapy or hormonal therapy. Guidelines 6, 7 and 8 in this series will provide information to help you with these decisions.

Above all, don't feel rushed into taking action. This is a difficult time, and it's normal to feel anxious. A delay of 1 or 2 weeks will have no significant effect on your situation and will give you time to gather information and talk things over frankly and openly with your doctor. Don't be afraid to ask questions or to ask for any additional support you need. Family, friends and other women who have had breast cancer can be especially important at this time. ♦

Guideline 3. Mastectomy or lumpectomy? Choosing the most appropriate operation for women with early invasive breast cancer

What is mastectomy?

Mastectomy is the removal of the whole breast. Until the mid-1980s, this was the usual treatment for early breast cancer.

What is lumpectomy?

In a lumpectomy only the tumour is removed, along with a “shell” of healthy tissue to ensure that the whole tumour is taken. Because most of the breast remains in place, lumpectomy is often called “breast-conserving surgery” (BCS). You may also hear it called “partial mastectomy” or “segmental resection.”

Do I have a choice between mastectomy and lumpectomy?

Yes, in most circumstances. There is clear evidence that lumpectomy, *when followed by radiation therapy*, is just as effective as mastectomy, which means that they are both effective in removing the tumour and reducing the chances of the cancer returning. Since they are equally safe, the deciding factors are often your own personal preference and circumstances, as long as the cancer is in the early stages. For most women, lumpectomy is now the recommended procedure.

What are the advantages of lumpectomy?

Mastectomy removes the whole breast. With a lumpectomy, most of your breast stays the way it is. After mastectomy you can have your breast reconstructed by plastic surgery, but you may lose the natural “feel” and shape of the breast.

Are there disadvantages to lumpectomy?

Yes. After the surgery, you need to have radiation treatment (radiotherapy) daily for several weeks to reduce the risk of the cancer returning in the same breast. Depending on where you live, it may be inconvenient or difficult for you to get to a treatment centre. Radiotherapy may also cause problems like swelling and pain in your breast.

Another problem may arise if the cancer was not completely removed during the lumpectomy. If the tissue that was removed is still found to have cancerous cells on its edges (when examined later under a microscope) you will need another operation. This will be either a second lumpectomy (taking more tissue this time) or a mastectomy. Sometimes only a few abnormal cells are found on the edge of the removed tissue. In this situation, radiotherapy may be able to destroy these cells without requiring additional surgery (see guideline 6).

If I have a lumpectomy followed by radiation treatment, can the cancer still come back?

Yes, it can. But the chance of this is low and no greater than after a mastectomy. In about one out of every 10 women, cancer will come back in the same breast or in the underlying chest wall within 10 to 15 years after surgery, no matter which operation is chosen. In some cases, chemotherapy or hormonal treatment can lower this rate still further. For more information on these additional treatments, see guidelines 7 and 8.

Guideline 3. Mastectomy or lumpectomy? Choosing the most appropriate operation for women with early invasive breast cancer

If cancer does come back in the treated breast, another operation, either lumpectomy or mastectomy, will be necessary.

If lumpectomy is safe and preserves the breast, what are the advantages of a mastectomy?

Mastectomy is preferable for some women. There are several possible reasons:

- Some kinds of cancer are more likely to come back in the same breast, even after radiation treatment. This may make a mastectomy preferable.
- If a woman is unable to have radiotherapy after lumpectomy, the chances are higher that the cancer will return. Factors that would make radiotherapy inadvisable include pregnancy, previous radiation treatment to the breast, a disability such as arthritis that prevents you from lying flat or stretching out your arm, and certain diseases, such as systemic lupus erythematosus or scleroderma.
- In some instances the tumour may be very large in proportion to the breast. In this situation, removal of the tumour may mean loss of so much tissue that the cosmetic result would be poor. Mastectomy would then be the better option.

Is it possible to have a lumpectomy even if I can't have radiation treatment afterward?

Lumpectomy is still possible. However, you would have a high risk (about 40% within 8 years) of the cancer returning in the same breast.

If the cancer does come back, you will need more surgery and perhaps treatment with anticancer drugs. Nevertheless, your chances of prolonging your life would be the same as if you had had a mastectomy in the first place.

What if the tumour is right next to or involving the nipple?

You can still have a lumpectomy, but the operation will require special skill and experience. It may be necessary to remove some or all of the nipple and surrounding tissue. Some sensation may be lost, but with plastic surgery the shape and appearance of the breast can be almost normal.

My doctor says I should have the lymph nodes ("glands") in my armpit removed too.

This is often recommended. For detailed information, please see guideline 4 in this series.

What are the most important things to consider in making my choice?

There is no evidence that either lumpectomy or mastectomy leads to a better overall quality of life. This means that your own preference, lifestyle and priorities are important factors in the decision. For example, you may live so far from a treatment centre that travelling to and from radiation sessions could be difficult and time-consuming. In this situation, you may prefer mastectomy over lumpectomy.

You should weigh all the information carefully. Above all, don't feel rushed into making a decision. Take your time. A delay of 1 or 2 weeks will have no significant effect on your situation. Maintaining a healthy, positive self-image over the long term is important, and you should keep this in mind when making your choice. You are the best judge of your feelings about your body and the effects that each operation may have, and it has been found that women who take an active part in these decisions are less likely to feel depressed afterward. ♦

Guideline 4. Removal of lymph nodes during breast cancer surgery

What are lymph nodes?

Lymph nodes (sometimes called “glands”) are part of the system that conducts a fluid called “lymph” around the body, just as arteries and veins conduct blood. The lymph nodes that are connected to the breast area are located in the armpit and near the collarbone. When breast cancer spreads, cancer cells will usually collect in the nearby lymph nodes.

Lymph nodes are frequently removed during breast cancer surgery. Since the medical term for the armpit is “axilla,” this procedure is called “axillary dissection.”

Why are the lymph nodes removed?

Removal of the lymph nodes for microscopic examination can give important information about how far the cancer has progressed. The recommended therapy after your surgery is different depending on whether the nodes are “positive” (contain cancer cells) or “negative” (do not contain cancer cells). Removal of lymph nodes also reduces the risk that the cancer will come back in the armpit area.

How does the doctor know if cancer has spread to the lymph nodes?

Before your surgery, your doctor will examine your armpit and collarbone areas for any suspicious swelling. However, since cancer in the lymph nodes often cannot be felt, surgical removal and microscopic examination are needed to know for sure whether they contain cancer or not.

Is it always necessary to remove lymph nodes?

Removal of lymph nodes is recommended as the standard procedure for women with most forms of early breast cancer. However, some types of cancer, such as ductal carcinoma in situ (DCIS), have a very low risk of spreading to the lymph nodes. (DCIS is discussed in guideline 5.) Also, in certain cases the recommended treatment is the same whether or not cancer cells are found in the nodes. In such instances, it may sometimes be acceptable not to remove any nodes.

How many lymph nodes are removed?

The lymph nodes in the armpit region are found in 3 layers, or “levels”. When breast cancer spreads, it usually goes to the level 1 nodes first, then to levels 2 and 3. It is recommended that the surgeon remove all lymph nodes found at levels 1 and 2. In general, this will result in the removal of approximately 10 lymph nodes — enough to tell for sure whether the cancer has spread to the nodes or not. Removing 10 or more nodes also reduces the chance of the cancer returning to the nodes.

However, complications become more frequent and more severe as more nodes are removed. For this reason, removal of level 3 nodes is not usually recommended.

What kinds of complications can occur after the lymph nodes are removed?

Removal of nodes often affects nearby nerves, leading to the most common complication — numbness in the arm.

Guideline 4. Removal of lymph nodes during breast cancer surgery

In a few instances (less than 6%) there is also significant pain with this condition.

Another common problem is “lymphedema.” This is a pooling of lymph fluid in the arm, causing swelling, stiffness in the arm and shoulder, and sometimes infection and pain. The chance of lymphedema developing after surgery increases with the number of nodes removed. After a typical operation, between 2% and 7% of patients experience significant lymphedema. Mild lymphedema is more common and is experienced by about one out of every five patients.

Radiation treatment to the armpit area also increases the risk of lymphedema. For this reason, it should be avoided unless there is an especially high risk of the cancer coming back in this area.

What can I do if I have persistent pain after my surgery?

You do not have to live with pain, nor should you try. Guideline 10 in this series deals with chronic pain in detail, and describes recommended methods for dealing with it. ♦

Guideline 5. The management of ductal carcinoma in situ (DCIS) (2001)

What is DCIS?

DCIS stands for “ductal carcinoma in situ” — a kind of cancer that is found only inside the milk ducts of the breast. Because the cancer has not invaded tissues outside the milk ducts, it is also called “noninvasive” breast cancer. For women who have only DCIS, the outlook is much better than for those who have invasive cancer. However, untreated DCIS may become invasive in time. It may grow through the duct wall to surrounding tissue and possibly invade other parts of the body. If this happens, the cancer is no longer DCIS and must be treated as invasive cancer. The treatment described in this guide is for women who have only DCIS, not invasive breast cancer.

How common is DCIS?

Since more women in Canada are now having screening mammograms, DCIS is being diagnosed more frequently. DCIS now accounts for between 20% and 25% of all breast cancers detected in women who have regular mammograms.

What if DCIS and invasive breast cancer are found together?

Because almost all breast cancers start inside the milk ducts, almost every laboratory report for breast cancer will describe some DCIS. When DCIS and invasive cancer are found at the same time, treatment for invasive cancer will be needed.

How will I know if I have DCIS?

There are usually no warning signs, such as a lump in the breast, when a

woman has DCIS. Most often, evidence of DCIS shows up on a mammogram taken at a screening clinic. Your doctor may suspect that you have DCIS if “calcifications” (deposits of calcium) can be seen on your mammogram. However, you will only know for sure that you have DCIS if a piece of breast tissue is removed and examined in a procedure called a “biopsy.” A common kind of biopsy is a “needle” biopsy, where a small tissue sample is removed using a needle. The sample is then examined under a microscope by a pathologist (a doctor specializing in the examination of tissue). If the pathologist sees typical cancer cells inside the milk ducts, then a diagnosis of DCIS is made.

Why has my doctor recommended a surgical biopsy?

If your first biopsy was a needle biopsy that contained cancer cells, you will need a “surgical” biopsy to find out if the cancer has invaded any of the surrounding tissue. For this kind of biopsy, a larger amount of breast tissue is removed. (If DCIS seems very likely, a doctor will often recommend that a surgical biopsy rather than a needle biopsy be done first.) A surgical biopsy is crucial, since any cancer that spreads outside the milk ducts is invasive cancer rather than simply DCIS and will need a different kind of treatment.

When a surgical biopsy is done, the abnormal tissue is removed in one piece and x-rayed. Samples of the tissue are then examined under a microscope. If an x-ray of the removed tissue suggests that all of the cancer was not removed completely, you will need a second mammo-

gram after your breast tissue has had a chance to heal. You may also then need another operation to remove cancer cells left behind.

My surgical biopsy shows that I have DCIS. What should I do next?

When you have been fully informed of the findings from your surgical biopsy, you can begin to consider your treatment choices. DCIS is not a fast-growing cancer, so it is quite safe to take the time you need to consult with your doctors, family members, friends and other women who have had breast cancer.

What is the best treatment for me?

The first thing to consider is the possibility that the surgical biopsy did not remove all of the cancer. If there is a chance that some cancer cells were left behind, more treatment is required. This usually means more surgery. Your chief task will be to decide which type of surgery is best for you.

In the past, a diagnosis of DCIS always meant “mastectomy” (removal of the whole breast), and this may still be the best option for some women. The other option is “lumpectomy” (also known as “breast-conserving surgery”) followed by radiation treatment (“radiotherapy”). Lumpectomy followed by radiotherapy is now the generally recommended treatment for early invasive breast cancer, and is also used for DCIS.

Whether you choose mastectomy, or lumpectomy followed by radiotherapy, survival rates are very high: between 95% and 100% for women 10 years after surgery.

If the surgical biopsy removes all of the cancer and no other suspicious areas for cancer are found in the breast, then the surgical biopsy can be considered as a lumpectomy and no further surgery is required.

What factors should I consider when choosing between mastectomy and lumpectomy?

You will need to talk to your doctor about the type of DCIS that was found in your breast, and how much of the breast is involved. You will also want to consider the factors listed below, many of which are discussed in more detail in guideline 3.

- *Your concerns about appearance.* The first thing you must consider is whether you want to save the breast. This is a very personal and individual matter. Some women want to maintain the original appearance of their breasts if at all possible. For these women, a lumpectomy that removes the cancer and leaves enough tissue to make the breast look and feel natural is most desirable. Other women want to do whatever they can to lower the chance of recurrence. These women can choose a mastectomy. Women who choose mastectomy can consider breast reconstruction to make it easier to live with the body changes and still feel confident that the cancer will not return. Because the chances of controlling the cancer are excellent either with mastectomy or with lumpectomy and radiotherapy, many women today choose to save the breast. You will need to pick the surgical option that makes you feel best.
- *The presence of cancer cells at the cut edges of tissue removed during the surgical biopsy.* When examination of the tissue removed during the surgical biopsy shows that there are cancer cells at the cut edges, a woman choosing lumpectomy may need a second or even third operation to remove more tissue. If you want to avoid the possibility of several operations, you may want to consider mastectomy.
- *The likelihood that the cancer will come back in the same breast.* If your tumour is large or has other features that sug-

Guideline 5. The management of ductal carcinoma in situ (DCIS) (2001)

gest that recurrence of the cancer is likely (e.g., cancer cells are found close to the cut edges of the removed tissue or it is an aggressive type of cancer), you may want to consider mastectomy.

- *The amount of tissue to be removed.* When there is more than one tumour or when the tumour is large, a lumpectomy will require the removal of a great deal of tissue. If the lumpectomy will leave the breast disfigured, you may want to consider mastectomy, or mastectomy followed by reconstruction of the breast.
- *Your ability to undergo radiotherapy.* Radiotherapy is usually recommended after lumpectomy because it reduces the risk of the cancer coming back in the same breast. If you cannot have radiotherapy for any reason, or if it will be very difficult or inconvenient for you to do so because of your job or your distance from a treatment centre, you may want to consider mastectomy. (In a small number of cases, if the tumour is quite small and has no features indicating that it is especially likely to return, and if it is certain that all the diseased tissue was removed, lumpectomy without radiotherapy may be considered. You should, however, consider this option only after fully exploring the issues with your doctor.)
- *The possible complications related to each procedure.* All treatments carry the possibility of unwanted side effects. Persistent pain, swelling and delayed healing of the wound can occur with either lumpectomy or mastectomy, but they are more common with mastectomy. The radiotherapy that follows lumpectomy can also cause un-

wanted side effects, including fatigue, pain, tenderness and scarring of the breast. For more details about radiotherapy, see guideline 6.

Should the lymph nodes in the armpit also be removed?

Lymph nodes (sometimes called “glands”) are frequently removed for invasive breast cancer, but not for DCIS. This is because it is very rare for cancer to spread to the lymph nodes in DCIS, and any benefit of removal of the lymph nodes is outweighed by the possible complications of the operation.

If I have a mastectomy for DCIS, can the skin and nipple be kept intact for plastic surgery later?

This procedure (called “subcutaneous mastectomy”) has been done for patients with DCIS in the past because it gives a good cosmetic result. However, because it leaves 10% to 15% of the breast tissue behind, it only partly removes the risk of the cancer returning and is not as safe as mastectomy. If you are choosing mastectomy to minimize the risk that the cancer will recur, subcutaneous mastectomy is not recommended.

What about other treatments, such as tamoxifen?

There is some scientific evidence that treatment with tamoxifen, a drug that can prevent growth of cancer cells, may benefit women with DCIS who have had lumpectomy. You and your doctor will need to discuss whether the benefit of using tamoxifen outweighs any side effects (see guideline 12). ♦

Guideline 6. Radiation therapy after lumpectomy

What is a lumpectomy?

Until a few years ago, women with breast cancer almost always underwent a mastectomy (removal of the whole breast). Lumpectomy (also called “breast-conserving surgery” [BCS] or “partial mastectomy”) is a less radical operation that removes only the diseased part of the breast and leaves healthy breast tissue in place. Studies have now shown that women who have a lumpectomy followed by radiation treatment live just as long as women who choose to have a mastectomy. Four out of five women with breast cancer have tumours that are suitable for treatment with lumpectomy.

What is radiation therapy?

Radiation therapy (also called “radiotherapy”) is the use of high-energy x-rays to kill cancer cells.

Do I need radiotherapy if I have a lumpectomy?

Yes, radiotherapy is almost always recommended after lumpectomy. Cancer can return in the same breast after surgery (local recurrence), and it has been proved that radiation reduces this risk significantly.

Although there are no guarantees, the benefits of radiotherapy are so great that you should definitely consider it as part of your treatment.

But my doctor says I have a low risk of recurrence because I am over 50 years old and my tumour was very small.

It is true that your risk of recurrence is relatively low. Still, about one in five

women over 50 years old with small tumours will have a recurrence within 8 years if they have a lumpectomy without radiotherapy afterward. Radiotherapy can reduce that risk to about one in 50. It’s an extra margin of safety.

Does radiotherapy have unpleasant side effects?

Radiotherapy can have side effects that occur both during and after the treatment.

In the first weeks after beginning radiation therapy, you may notice reddening or swelling of the skin over the breast area and fatigue or tiredness. These problems usually disappear within 3 to 6 months.

In the first 5 years after treatment, you may experience discomfort, pain, swelling, discolouration or other skin changes in the breast area. However, over 90% of women are satisfied with the appearance of the breast after lumpectomy and radiation treatment. Some breast tissue may also shrink or become hard due to the death of fat cells, especially in areas where high-dose “boost” treatments were given. This hardening does not mean that the cancer has come back.

With current techniques, severe long-term side effects are rare. Even in older studies, which used different techniques and higher doses of radiation than would be recommended today, these problems occurred in under 2% of patients treated.

Isn’t it true that radiation can cause cancer?

Any danger from radiation depends on the type of radiation, how much is given and how it is applied. There is no convincing evidence that the kind of radiation therapy given after lumpectomy

Guideline 6. Radiation therapy after lumpectomy

can cause cancer, either in the breast or elsewhere in the body.

I had tissue removed from one small area, but my doctor wants to radiate the whole breast.

There is good evidence that radiation given to the whole breast is more effective than partial irradiation in preventing a recurrence.

What is a “boost”?

Sometimes, as part of radiotherapy, an extra dose (boost) of radiation is given to the small area where the cancer was removed. Most often it is used when not all of the cancer was taken out during lumpectomy. Normally, a second operation to remove any remaining cancer is the best choice when this happens. But if this is not possible for some reason, or if you decide not to have more surgery, a “boost” of radiation to the area can be the “second-best” option. However, there is no clear proof that a “boost” of radiation provides any benefit. Research is under way to investigate this question.

What is the best way to give radiation therapy? Is there a “right” dose of radiation?

Radiation treatment is not given all at once. It is divided into “fractions” — small doses scheduled 5 days a week that are given over 3 to 6 weeks. If “boosts” are given, they are also divided into fractions.

So far, no clinical trials have been completed to show exactly which treatment schedule or dose is best. Evidence from existing studies suggests that there are several different schedules that produce similar benefits. (These are described in the physicians’ version of this guideline.) Because all of these are acceptable, it may be possible to choose the treatment program that best fits your personal schedule. However, it is im-

portant to stay within a standard range. Unusually high doses can result in more severe side effects without giving extra benefit.

Should radiation treatment begin right after surgery? How long a delay is safe?

If you are not having chemotherapy, radiation treatment should begin as soon as possible after your incision heals, usually within 8 weeks after surgery. It is generally believed that radiation treatment should not be delayed longer than 12 weeks after surgery, although there is no proof to support this.

If you are having chemotherapy, most cancer centres recommend that radiation treatment be delayed until chemotherapy is finished. Sometimes both kinds of treatment are given together. However, there is no evidence that this improves the outcome, and it can increase the risk of unwanted side effects, especially if any of the anthracycline drugs (drugs like Adriamycin) are used as part of your chemotherapy.

Are there any situations where radiotherapy should not be given after surgery?

Yes. Pregnant women and those who have had previous high-dose radiotherapy to the chest (including radiation for Hodgkin’s disease) definitely should not receive radiation therapy.

Radiotherapy may pose an increased risk for some people with severe heart or lung disease. Also, people with scleroderma or systemic lupus erythematosus may be at increased risk for severe side effects from radiotherapy.

Some people with certain conditions such as arthritis may be unable to lie flat or to stretch out the arm on the same side as the breast being treated. In these instances it may be difficult or impossible to give radiation treatments properly. ♦

Guideline 7. Anticancer drug treatment for node-negative breast cancer (2001)

What is node-negative breast cancer?

Node-negative breast cancer means that no cancer cells from the breast have been found in the lymph nodes (sometimes called “glands”) in the armpit area. If your cancer is node negative, there is a lower risk of the cancer returning and spreading than if it is node positive.

I will be having surgery and radiation treatment for breast cancer. Do I need anticancer drug treatment too?

Although node-negative cancer indicates a smaller risk of the cancer returning than node-positive cancer, there is still a risk. Even when it seems certain that the whole tumour has been removed, cancer still returns elsewhere in the body (“metastasizes”) in up to 30% of all women with node-negative breast cancer.

However, this is simply an average. Some kinds of cancer are more likely to recur than others, and this will influence your treatment options. Your cancer will be examined and classified as having a high, medium or low risk of returning, depending on several factors outlined below.

- *Its size.* The larger the cancer, the higher the risk. Most cancers smaller than 1 cm in diameter are at a very low risk of recurring after surgery and radiation.
- *The type of cells it contains.* Some cell features are found more often in “aggressive” cancers, cancers that are more likely to recur and spread. Your pathologist will “grade” your cancer from I to III depending on its cell features. A grade I cancer is less likely to return than a grade III cancer.

- *Whether the cancerous cells have invaded nearby blood vessels and lymph channels.* When vessel invasion is found under the microscope, the cancer is more likely to return.
- *Whether your cancer was diagnosed as “ER positive” or “ER negative.”* “ER” stands for estrogen receptor. This is a receptor or “docking site” to which estrogen can bind. Women with cancers that have these receptors (ER-positive cancers) are at a slightly lower risk of the cancer returning. Also, such cancers react differently to treatment than ER-negative cancers.

All these factors must be considered when judging your overall risk of the cancer returning. This, in turn, will determine whether you should have additional treatment and, if so, which treatment is best for you.

What is the risk that the cancer will return if I have only surgery and radiotherapy, but no additional drug treatment?

If your cancer is classified as *low risk*, there is less than a 10% chance it will return in the next 10 years. In other words, it will come back in fewer than 10 women out of every 100 who have this type of cancer.

If cancer is classified as *intermediate risk*, the chance of the cancer returning is somewhere between 10% and 20%. Additional treatment will reduce this risk.

Women with *high-risk* cancers have a greater than 20% risk of the cancer returning and spreading. This risk is sometimes as high as node-positive breast cancer. For this group also, additional treatment will reduce this risk.

Guideline 7. Anticancer drug treatment for node-negative breast cancer (2001)

My cancer has been classified as *low risk*. Do I need additional treatment?

No. In your case, additional drug treatment is not recommended, since only one or two out of every 100 women would benefit from it. Your doctor may discuss the use of hormonal therapy with tamoxifen.

My cancer is classified as *high risk*. What additional treatment is recommended for me?

Chemotherapy is recommended for all premenopausal women and for postmenopausal women with ER-negative tumours.

Tamoxifen plus chemotherapy is recommended for postmenopausal women with ER-positive tumours. The increased toxicity of chemotherapy must be considered.

These treatments are discussed in more detail below.

What is recommended for women with *intermediate-risk* cancer?

If the cancer is ER positive, hormonal therapy with tamoxifen is recommended. This treatment is discussed in more detail below. (ER-negative cancers are usually classified as high risk.) Chemotherapy provides additional benefit to tamoxifen. However, the magnitude of the benefit is small, and the increased toxicity of chemotherapy must be considered.

Chemotherapy

What is chemotherapy?

Chemotherapy is treatment with drugs that kill cancer cells.

My doctor recommends chemotherapy.

What are the pros and cons?

Anticancer drugs also affect healthy

cells. This means they can have undesirable side effects, some of which are severe. For this reason, chemotherapy is recommended only when there is a good chance that you will benefit from it and are healthy enough to take it.

For premenopausal women and for women with ER-negative cancers, chemotherapy is the most effective means available for guarding against a return of the cancer. Since it can prolong your life, it would be unwise to refuse it without good reason. As described below, there is some room for choice between drug combinations in terms of specific side effects and length of treatment.

How is chemotherapy given?

There are two recommended combinations of drugs for treating women with node-negative breast cancer: CMF and AC. Both have proved effective.

The combination you choose is given in “cycles” as shown below.

- CMF (cyclophosphamide, methotrexate and 5-fluorouracil)

With this choice, you would take cyclophosphamide by mouth every day for 2 weeks. On the first day of each of these weeks you would also receive methotrexate and 5-fluorouracil by intravenous injection. Then there is a 2-week “rest period” when no drugs are given. This completes one full cycle. Six cycles are given altogether, for a total of 6 months of treatment.

- AC (Adriamycin [doxorubicin] and cyclophosphamide)

With this combination you do not have to take daily medication. Instead, you would receive the drugs by intravenous injection and then have a rest period of 21 days (3 weeks) when no drugs are given. On the 22nd day you would begin the second cycle. Four cycles are given altogether. The whole treatment lasts a little over 2 months.

What are the most common side effects of chemotherapy?

Side effects can include the following:

- Nausea and vomiting. If you are being treated with the CMF combination, nausea and vomiting will be mild to moderate and will last throughout treatment. However, it can be effectively relieved with medication. If you choose the AC combination, nausea and vomiting are likely to be more severe, but will be much briefer.
- Fatigue is common.
- Some weight gain may occur in about 14% of patients.
- Temporary hair loss. Hair loss is complete with AC. With CMF, 30% of patients have no hair loss at all, and only 40% have severe hair loss.
- Mild irritation of the eyes, the lining of the mouth and throat, and inflammation of the bladder.
- Temporary stoppage of monthly periods during treatment. In older women this may become permanent.
- Temporary suppression of the body's immune system during treatment. This increases the risk of infection. In a few individuals (2%), it may cause fever, requiring hospitalization.
- Severe side effects are rare, occurring in less than 1% of women receiving the usual doses of chemotherapy. However, they do happen, and chemotherapy can very rarely even be fatal. There is a very small risk of heart damage with AC. There is also a very small risk of leukemia developing in later life (perhaps 1 in every 1000 to 10 000 patients).

When should chemotherapy begin?

Chemotherapy should begin as soon as possible after your operation, usually within 8 weeks.

If I take chemotherapy, do I need any other treatment?

If you have a lumpectomy, radiotherapy will also be recommended. If you are having chemotherapy, the radiotherapy is usually delayed until the chemotherapy is finished. For more information on radiotherapy, see guideline 6 in this series.

Hormonal therapy

My doctor has recommended hormonal therapy. What does this mean?

The ovaries produce hormones such as estrogens, which can encourage the growth of breast cancers, especially those that are ER positive. Hormonal therapy with the drug “tamoxifen” interferes with this process without stopping the body's hormone production.

Tamoxifen has been found to prolong life in women with breast cancer, and it also reduces the chances of getting cancer in the opposite breast.

For how long should tamoxifen be taken?

It is recommended that you take the standard dose of tamoxifen (20 mg) by mouth every day for 5 years.

What are the side effects of tamoxifen?

Tamoxifen can cause temporary hot flashes in up to 20% of patients. Blood clots in the veins will develop in about one in every 100 patients taking tamoxifen. Rarely, these may pass into the lung, endangering life. Very rarely (about one woman in every 500 treated), tamoxifen can cause cancer in the lining of the uterus (endometrial cancer). For this reason, women taking tamoxifen should promptly report any vaginal bleeding — even slight spotting. Very rarely tamoxifen can cause cataracts.

Tamoxifen lowers the chance of cancer in the opposite breast and reduces the risk of osteoporosis — a common cause of “brittle bones” and fractures in postmenopausal women. ♦

Guideline 8. Anticancer drug treatment for node-positive breast cancer (2001)

What is node-positive breast cancer?

Node-positive breast cancer means that cancer cells from the tumour in the breast have been found in the lymph nodes (sometimes called “glands”) in the armpit area.

Although the breast cancer is removed during surgery, the presence of cancer cells in the lymph nodes means that there is a higher chance of the cancer returning and spreading.

I will be having surgery and radiation treatment for breast cancer. Do I need drug treatment too?

Almost all women with node-positive breast cancer require drug treatment in addition to surgery and radiation treatment (radiation is given following lumpectomy). Even when it seems certain that the whole tumour has been removed, many women die within 10 years from the cancer returning if they have had only surgery and radiation without drug treatment. There is now very powerful evidence that drug treatment in addition to surgery and radiation helps prolong life.

What does “drug treatment” mean?

Drug treatment can mean either chemotherapy or hormonal therapy. Chemotherapy uses special drugs to kill cancer cells.

Hormonal therapy uses a different approach. The ovaries produce natural hormones, such as estrogen, which encourages some cancers to grow. Hormonal therapy interferes with this process and can stop or slow the growth of cancer cells.

There are two kinds of hormonal therapy. The first, called “ovarian ablation,” stops hormone production by destroying the ovaries with radiation treatment or by removing them surgically. In the second type of hormonal therapy, estrogen is

still produced by the body, but its effect is blocked by a drug called “tamoxifen.”

The recommended treatment depends on individual circumstances.

What kind of therapy is best for me?

Several factors have to be considered. These include the following:

- *Your age, and whether you have gone through menopause (“change of life”).* Medication affects cancers differently before and after menopause.
- *Whether your cancer was diagnosed as “ER positive” or “ER negative.”* “ER” stands for estrogen receptor. This is a receptor or “docking site” to which estrogen can bind. If a tumour has these receptors (ER-positive cancer), it means that its growth may be influenced by your body’s natural hormones. This will affect the type of treatment recommended for you.
- *Your personal choice.* For example, one treatment may be slightly more effective than another but has more unpleasant side effects, which may affect your choice. You and your doctor will need to weigh the expected benefits against the possible problems that the treatments can cause.

Each of the treatments mentioned in the following columns are discussed in more detail later. The first choices to be made depend on your age and whether you have passed menopause. Menopause occurs over a period of time. You should consider yourself postmenopausal when you have not had your period for a year. Until then, for the purposes of cancer treatments, you are considered premenopausal. Women who can’t tell (they may have had their uterus removed) are considered to be postmenopausal after their 50th birthday.

Read this column if you are premenopausal

There is strong evidence that chemotherapy using a combination of drugs can prolong life and is the best choice for you.

Should I have hormonal therapy in addition to chemotherapy?

Right now, there is not enough evidence to recommend taking both.

Can I have hormonal therapy instead of chemotherapy?

A decision to refuse chemotherapy should not be made lightly. Hormonal therapy is less effective than chemotherapy for your situation.

However, if you are unable or definitely unwilling to have chemotherapy and your cancer was ER positive, hormonal treatment (ovarian ablation or tamoxifen) can have some benefit by itself.

If I have chemotherapy, what drugs will I be taking?

Three combinations have been widely tested and have proved effective. They are known as CMF, AC and CEF. Research studies are investigating adding a new class of drug called taxanes to AC chemotherapy, but the results are inconclusive. The best choice for you depends on your personal circumstances. Each combination is discussed in detail further on.

If I have hormonal therapy, what kind will it be?

If you can't have chemotherapy, ovarian ablation (surgical removal or radiation-induced destruction of the ovaries) may be the best choice for you. Although it is seldom used in Canada at present, ovarian ablation has proved effective in cases like yours. If you are unable or unwilling to have ovarian ablation and your cancer was ER positive, tamoxifen can be used.

For more information, read the sections on Chemotherapy and Hormonal Therapy (including ovarian ablation) that follow.

Read this column if you are postmenopausal

The best treatment for you depends on whether your cancer was ER negative or ER positive.

My cancer was ER negative. What is the best treatment for me?

If you are in good general health, chemotherapy is the best choice for you. Hormonal therapy is not recommended.

What is the best therapy if my cancer was ER positive?

If your cancer was ER positive, hormonal therapy is recommended. Chemotherapy can provide additional benefit to hormonal therapy.

If I take chemotherapy, what drugs will I be taking?

Two combinations have been widely tested and have proved effective in cases such as yours. They are known as CMF and AC. The best choice for you depends on your own personal circumstances. Each combination is discussed in detail further on.

If I have hormonal therapy, what kind will it be?

Treatment with tamoxifen is the recommended hormonal therapy for you.

If my doctor recommends tamoxifen, do I also need chemotherapy?

Chemotherapy can provide additional benefit to tamoxifen. If this possibility is important to you and you are willing to accept the unpleasant side effects of chemotherapy, this may be an option for you.

For more information, read the sections on Chemotherapy and Hormonal Therapy (tamoxifen) that follow.

Guideline 8. Anticancer drug treatment for node-positive breast cancer (2001)

Chemotherapy

My doctor recommends chemotherapy.

What are the pros and cons?

Anticancer drugs also affect healthy cells. This means they can have undesirable side effects, some of which are severe. For this reason, chemotherapy is recommended only when you are strong enough to take it.

For premenopausal women and for women with ER-negative cancers, chemotherapy is the most effective means available for guarding against a return of the cancer. Since chemotherapy can prolong your life, it would be unwise to refuse it without good reason. As described below, there is some room for choice between drug combinations in terms of specific side effects and length of treatment.

How is chemotherapy given?

There are three recommended combinations: CMF, AC and CEF. Premenopausal women can take any of them. Postmenopausal women can take either CMF or AC. All of them have proved effective against cancer. Research studies are investigating adding a new class of drug called taxanes (e.g., paclitaxel) to AC chemotherapy. The results are inconclusive. You can discuss this option with your doctor.

The combination you choose is given in “cycles” as shown below.

- CMF (cyclophosphamide, methotrexate and 5-fluorouracil)

With this choice, you would take cyclophosphamide by mouth every day for 2 weeks. On the first day of each of these weeks you would receive methotrexate and 5-fluorouracil by intravenous injection. Then there is a 2-week “rest period” when no drugs are given. This completes one full cycle. Six cycles are given altogether, for a total of 6 months of treatment.

- AC (Adriamycin [doxorubicin] and cyclophosphamide)

With this combination you do not have to take daily medication. Instead, you would receive the drugs by intravenous injection and then have a rest period of 21 days (3 weeks) when no drugs are given. On the 22nd day, you would begin the second cycle. Four cycles are given altogether. The whole treatment lasts a little over 2 months.

- CEF (cyclophosphamide, epirubicin and 5-fluorouracil)

This combination is given in the same way as CMF. The cyclophosphamide is taken by mouth every day for 2 weeks, and an intravenous injection of the other two drugs is given on the first day of each of those weeks. This is followed by a 2-week rest period, which completes the cycle. Six cycles are given altogether for a total of 6 months of treatment. Usually, when CEF is used, it is recommended that you take an antibiotic to guard against infection.

- AC followed by paclitaxel

AC is administered as described above. Three weeks after the last cycle of AC, paclitaxel is given by intravenous injection. Four doses of paclitaxel are given, one dose every 3 weeks.

What are the most common side effects of chemotherapy?

Side effects can include the following:

- If you are being treated with CMF chemotherapy, nausea and vomiting can be mild to moderate and can last throughout treatment. However, they can be effectively relieved with medication. If you choose AC chemotherapy, nausea and vomiting are likely to be more severe than with CMF, but they will be much briefer in duration. If you are being treated with CEF chemotherapy, nausea and vomiting can be moderate. However, they can be effectively relieved with medication.

Guideline 8. Anticancer drug treatment for node-positive breast cancer (2001)

- Fatigue is common.
- Some weight gain may occur in about 14% of patients.
- Hair loss is complete with AC and CEF, but your hair will grow back after completion of chemotherapy. With CMF, 30% of patients have no hair loss at all, and only 40% have severe hair loss.
- Mild irritation of the eyes and the lining of the mouth and throat, and inflammation of the bladder may occur.
- Temporary stoppage of monthly periods during treatment may occur. This side effect may become permanent in older women.
- Temporary suppression of the body's immune system may occur during treatment and can increase the risk of infection. In a few individuals (about 2% to 5%), it may cause fever, necessitating admission to hospital.
- Severe side effects are rare, occurring in less than 1% of women receiving the usual doses of chemotherapy. However, they can happen, and chemotherapy can very rarely even be fatal. There is a very small risk of heart damage with AC (less than 1%) and a small risk of heart damage with CEF (1%). There is also a very small risk of leukemia developing in later life with AC or CMF (perhaps one in every 1000 to 10 000 patients) and a small risk with CEF (1%).

When should chemotherapy begin?

Chemotherapy should begin as soon as possible after your operation, usually within 4 to 6 weeks.

If I take chemotherapy, do I need any other treatment?

If you have had a lumpectomy, you should also have radiotherapy. If you are having chemotherapy, the radiotherapy is usually delayed until the chemotherapy is finished. For more information on

radiotherapy, see guideline 6 in this series.

Hormonal therapy

My doctor has recommended hormonal therapy. What does this mean?

The ovaries produce hormones such as estrogen, which can encourage the growth of breast cancer. There are two kinds of hormonal therapy: ovarian ablation, which stops the body's hormone production, and the drug tamoxifen, which blocks the action of the body's hormones.

What is ovarian ablation?

Ovarian ablation stops the production of hormones in the ovaries, in effect causing menopause in premenopausal women. This is done by removing the ovaries through surgery or by destroying them with radiation treatment. The effects are permanent.

What are the side effects of ovarian ablation?

Ovarian ablation produces all of the usual symptoms of menopause, including hot flashes and mood swings. However, these symptoms are temporary. There is also a small increased risk of heart disease and osteoporosis (brittle bones), as happens in all women after menopause.

How does tamoxifen work?

Hormones such as estrogens that are produced in the ovaries can make cancers grow faster, especially those that have estrogen receptors (ER-positive cancers). Tamoxifen does not stop hormone production but blocks the hormones from reaching the cancer cells. The drug is taken daily by mouth.

Tamoxifen has proved to be effective in prolonging life in women who have been treated for breast cancer. It also reduces the chances of getting cancer in the opposite breast.

Guideline 8. Anticancer drug treatment for node-positive breast cancer (2001)

For how long should tamoxifen be taken?

It is recommended that tamoxifen treatment be continued for 5 years.

What are the side effects of tamoxifen?

Tamoxifen may cause temporary hot flashes in up to 20% of patients. In about one in every 100 patients, treatment with tamoxifen may cause blood

clots in the veins. Rarely, these can pass into the lung, endangering life. Very rarely (about one woman in every 1000 treated) tamoxifen can cause cancer in the lining of the uterus (endometrial cancer). For this reason, women taking tamoxifen should promptly report any vaginal bleeding — even slight spotting. Very rarely tamoxifen can cause cataracts. ♦

Guideline 9. Follow-up care after breast cancer treatment

My treatment for breast cancer is almost finished. Will I need further medical care?

Everyone who has had treatment for breast cancer should continue to visit the doctor regularly for the following reasons:

- *To receive ongoing support.* Your first visit after treatment will give you an opportunity to discuss problems, deal with any side effects of treatment and help you to find emotional or social support if you need it. You will also work out a schedule with your doctors for long-term care.
- *To establish your current health status.* About 4 to 6 months after treatment, when inflammation in your breast has settled down, you can expect to have mammography and a physical examination. This will show where you stand after treatment and serves as a “baseline” for comparison if changes occur at any time in the future. If you do not already practise breast self-examination, you may want to learn this technique now.
- *To detect problems early.* Cancer can return in the same breast, or a new one can start in the other breast. If this occurs, regular physical examination and mammography will help detect it at an early stage.

Who will be responsible for my follow-up care?

On your early visits, you will usually see the specialist(s) who have supervised your treatment: the surgeon, the medical oncologist or the radiation oncologist. At first, some or all of them may wish to see you.

Later, with your participation and agreement, responsibility may be transferred to one of them or to your family doctor.

The important thing is that the members of your medical team coordinate your care. They should keep you fully informed, and you should know exactly what follow-up arrangements have been made and *who is responsible* for carrying them out.

How often should I visit the doctor?

Canadian treatment centres often recommend visits every 6 months for 2 to 5 years after surgery. However, no one schedule has been proved best for everyone, and the timing should be adjusted to your own needs. You may wish to make additional visits if you need further advice or support, or if a new problem comes up.

It is recommended that yearly visits continue for life.

What will happen on my follow-up visits?

Every visit should include an updating of your medical history and a physical examination. Yearly visits should also include mammography.

- *Medical history.* Your doctor will want to know about any side effects of treatment such as swelling or tenderness in your breasts, stiffness in your shoulder or swelling in your arm since your last visit. If you’re taking tamoxifen as part of your treatment and haven’t had a hysterectomy, you should tell your doctor if any vaginal bleeding (even slight spotting) has occurred. This is because the risk of endometrial cancer (cancer

Guideline 9. Follow-up care after breast cancer treatment

in the lining of the uterus) is slightly higher for women taking tamoxifen.

- *Physical examination.* The main purpose of this examination is to look for recurrence of cancer and for new cancers in either breast. Your doctor will examine both breasts, the lymph nodes in the armpit and collarbone areas, the chest wall and the abdomen. Your arm will also be examined for “lymphedema” (swelling of the arm due to a build-up of lymphatic fluid, which can occur after removal of armpit lymph nodes) or any infection associated with it.

Shouldn't I have regular tests to make sure the cancer hasn't come back somewhere else?

No. The only regular test you need is mammography. Regular mammography is recommended to detect any return of cancer in the same breast or any new cancer in the opposite breast. The chance of a cure is better when these cancers are found early.

If cancer does spread to other parts of the body, life expectancy is the same whether it is detected early or not. So routine use of other tests — such as bone and liver scanning, chest x-rays, blood tests and tests for tumour markers — is unnecessary and not recommended.

What if I get new symptoms or feel something is wrong between visits?

After treatment for breast cancer,

many women will experience pain or other unpleasant symptoms. If these problems come and go, or disappear within a week or so, they are very unlikely to be related to cancer.

However, sometimes a problem does not go away. If you have any new, persistent symptoms, you should report them *immediately*, without waiting for your next regular appointment. Such symptoms may include the following:

- *new, persistent pain,*
- *persistent coughing,*
- *discovery of a lump in either breast,*
- *unusual changes at the site of your surgery or in the scar itself,*
- *a persistent tired feeling,*
- *loss of appetite,*
- *tingling or numbness in the arm or hand,*
- *swelling of the arm (even slight swelling can signal lymphedema, which can be painful and is often easier to treat if recognized early) or*
- *any new symptom that is unusual, severe or persistent.*

I would like to find someone to talk over these issues with, between visits to my doctor.

Support of this sort can be valuable in addition to any comfort it may give. It is briefly discussed in the section entitled “Support.” ♦

Guideline 10. The management of persistent pain after breast cancer treatment (2001)

I've had breast cancer treatment, and now I'm having pain. Does this mean the cancer has come back?

Pain after breast cancer surgery and treatment may occur for several reasons. In many cases, the pain may be caused by something that has nothing to do with breast cancer or its treatment. It may also be a result of the surgery, radiotherapy or chemotherapy you have experienced. Another possibility is that breast cancer has returned. If you have persistent pain at any time, you should consult your physician for assessment and advice. Additional investigations may be required. Regardless of the cause of pain, effective treatment is available.

What types of pain may come from surgery?

One cause of pain is the “postmastectomy syndrome.” This occurs because removal of a lump can damage nerves in the area. This problem is more common after a total mastectomy (removal of the whole breast) but can also follow a lumpectomy (removal of just the cancer), especially if you have also had lymph nodes removed in the armpit area. Usually, this type of pain is not severe and will gradually improve.

Swelling of the arm (lymphedema) is another condition that can cause discomfort and pain. Removal of lymph nodes from the armpit during surgery can damage the channels that drain lymph from the arm. This leads to swelling and can be painful for some patients (see guideline 11).

Could my pain be related to anticancer drugs?

Some drugs may cause painful conditions, including bladder inflammation (cystitis), numbness and tingling (peripheral neuropathy), mouth ulcers (mucositis) and aching joints. Taking drugs intravenously may also cause painful inflammation of the veins (phlebitis).

What about pain caused by cancer?

Cancer that grows in the bones may cause pain. If you have new or increasing pain in the bones, you should discuss this with your physician. These symptoms could occur because breast cancer has spread to the bones.

Although the bones are the most common site in which cancer returns, pain can also occur from cancer spreading to nerves and other organs.

One type of nerve pain is called “brachial plexopathy.” A burning or stabbing pain is felt in the arm, shoulder or hand when these areas are touched, or they may feel “different” — either numb or very sensitive. There may also be weakness in the arm, especially if the pain has been going on for a long time. Although this kind of pain may rarely be a side effect of radiotherapy or surgery, this pain may mean that cancer has come back in the lymph nodes behind the collarbone. Careful investigation may be necessary to rule out cancer.

Should medication get rid of all my pain?

Regardless of the cause of pain, anti-pain medication prescribed by your physician can usually provide good pain control.

Guideline 10. The management of persistent pain after breast cancer treatment (2001)

If the pain is caused by cancer, anti-cancer treatment such as radiotherapy or chemotherapy may treat the cause of the pain and reduce the need for pain medications.

It is important not to ignore pain or hope you will get used to it. People do not get used to pain. Putting up with pain can make it even harder to control later with medication. The goal of pain medication is to control pain as *rapidly* and *completely* as possible. This may require adjusting the type and amount of your pain medication. Remember, only you can report on your pain, and you need to let your doctors know if your pain is not controlled.

If the pain is persistent or chronic, you will need to take pain medication in regular doses around the clock. Additional doses may be necessary in case of “break-through” pain between regular doses. If you often have breakthrough pain, your regular dosage may need to be adjusted or another medication prescribed.

What kind of medication should I be taking to get rid of the pain?

If your pain is mild to moderate, painkillers you can buy without a prescription, such as acetylsalicylic acid (ASA), acetaminophen and ibuprofen (part of the family of drugs called nonsteroidal anti-inflammatory drugs), may be effective alone. You can choose the brand you are most familiar with, or ask your doctor or pharmacist to recommend one.

Ibuprofen and ASA are effective pain relievers, but they can have side effects. They may aggravate asthma and cause stomach ulcers or kidney damage. If you have stomach problems, there are new medications in the nonsteroidal anti-inflammatory group (for example, Cox 2 inhibitors) that may reduce your chances of having side effects.

If drugs like ASA, acetaminophen and ibuprofen alone do not control the pain, do not take more than the recommended dose. Higher doses will not help the pain but will increase your risk of having side effects. If these medications alone are not effective, your doctor can prescribe stronger medications. Opiates are a strong pain reliever. Several types are available. Your physician can work with you to select an opiate that is most effective for you (for example, codeine or oxycodone). Opiates are often most effective when they are prescribed with drugs such as ibuprofen, acetaminophen or ASA.

Many types of pain may require strong opiates such as morphine, hydromorphone or fentanyl. Any of these drugs may be effective depending on the patient and the situation. Usually a short-acting opiate is prescribed on a regular schedule (for example, every 4 hours). The dose taken will be increased every day or so until pain is controlled.

Some patients find that taking pain medications frequently is difficult. If your pain is well controlled, then you can consider switching to a long-acting opiate, which some patients find more convenient. Several long-acting preparations are available. Long-acting tablets are taken twice a day, and a long-acting patch, which allows pain medicine to be absorbed through the skin, works for 3 days. You should discuss with your physician whether one of these approaches is right for you.

Occasionally, some patients will need to take opiates by injection under the skin instead of by mouth. As well, suppositories can be used in some patients. Your physician can advise you which is the best option depending on your situation.

If I take opioids, what side effects should I watch out for?

All opioids can cause constipation. Laxatives should always be prescribed along with them. You will need to take the prescribed laxatives regularly to prevent constipation.

Nausea and vomiting may occur when you start taking an opioid, but these symptoms often disappear completely after a short time. In the meantime, there are many drugs that can control these side effects, such as dimenhydrinate (Gravol). You can buy these drugs without a prescription under several brand names. Additional options to prevent or treat nausea are available by prescription.

Sedation (feeling sleepy) or confusion can be a problem, especially for elderly patients. No one should drive or use potentially dangerous equipment for 3 to 5 days after starting opioid therapy or after any change in dosage. The drowsy feeling usually disappears with time.

Although these are the most common side effects, individuals vary a great deal in their reactions to opioids. This means that a particular side effect may disappear entirely if you switch from one opioid drug to another. For example, if you have an unpleasant reaction to morphine, your doctor can try other opioids such as hydromorphone, oxycodone or fentanyl.

The effectiveness of your medication should be re-evaluated after 24 hours every time you switch from one opioid to another, change your dosage or change the way you take the drug (for example, if you switch from tablets to injections).

It is important to report side effects to your doctor. You should not stop taking opiates because of side effects without first discussing it with your doctor.

Won't I get addicted to morphine or some of these other drugs?

True addiction (“psychological dependence”) is extremely rare when opioids are taken for cancer pain. Much more commonly, people who are not receiving enough medication may *seem* addicted simply because their continuing pain requires higher doses or switching to a stronger medication.

Rarely, you may develop “tolerance” to the pain medication. With tolerance, your body gradually becomes resistant to the medication and needs increasing amounts to get the same relief. Fear of developing tolerance is never a good reason to avoid taking enough pain medication to be pain free. Remember, there is no maximum dose for opioids, and the right amount to take is the amount that relieves your pain. If tolerance occurs, switching to another type of pain medication will relieve the pain.

Anyone who takes an opioid for longer than a few weeks may become “physically dependent.” This means that your body gets used to the drug, and withdrawal symptoms will appear if it is suddenly stopped. When the cause of the pain improves and an opioid drug is no longer needed for pain, it should be reduced gradually over a couple of weeks.

Are there other drugs that can be used?

Some drugs that are primarily used for other conditions have also proved useful in the relief of pain caused by cancer. These drugs are taken together with the pain medications already mentioned. Among these are corticosteroids, tricyclic antidepressants, anticonvulsants, some local anesthetics and bone-strengthening drugs called bisphosphonates.

In prescribing any of these drugs, your doctor should explain the possible side effects.

Guideline 10. The management of persistent pain after breast cancer treatment (2001)

Are there other ways to help me deal with pain?

There are various methods that may help, including exercise, electrical stimulation of nerves, acupuncture, massage, vibration and the application of heat or cold to the overlying skin. However, deep-heating methods such as diathermy and ultrasound should be used with caution, since they may help cancer cells to grow. Compression therapy may help control the swelling and discomfort caused by lymphedema.

There are also many alternative therapies such as meditation, biofeedback, prayer, visualization, yoga, Qi Gong, Tai Chi, therapeutic touch, Reiki, healing touch, homeopathy and herbal medicines. Although you should be aware

that there is a lack of scientific evidence supporting these methods, there is also no proof that they do not work. In fact, many patients report significant benefit from their use. Remember, too, that pain always has a psychological element, and pain can be worse if you are depressed, tired or anxious. For this reason, you may find real benefit in joining a support group or trying psychological techniques such as hypnosis.

What if I have tried everything, including medication, without satisfactory pain relief?

This kind of stubborn pain happens very rarely. If possible, you should see a pain specialist who can use a variety of surgical measures to block the nerves involved. ♦

Guideline 11. The management of lymphedema related to breast cancer

What is lymphedema?

Lymphedema is the swelling that occurs when a protein-rich fluid called “lymph” collects in part of the body. In lymphedema related to breast cancer, this pooling of fluid usually occurs in the upper arm, where it can lead to pain, tightness and heaviness, and recurrent skin infections.

What causes lymphedema?

Normally lymph flows through the lymphatic vessels and eventually enters the blood stream. Sometimes the flow of lymph is interrupted by damage to the vessels and the oval-shaped structures called “lymph nodes” that are located along the vessels.

In breast cancer patients, damage to the lymphatic pathways can be caused by the cancer itself, infection or certain breast cancer treatments. For instance, lymphedema can occur following removal of the lymph nodes in the armpit or “axilla” (called “axillary lymph node dissection”; see guideline 4 on the removal of lymph nodes during breast cancer surgery. Lymphedema can also occur when radiation therapy to the armpit causes scarring and blocks or slows the flow of lymph.

In many cases, lymphedema develops within the first year after surgery or radiation therapy, but it can develop at any time. It can be a temporary or a long-term problem.

How is lymphedema measured?

If you or your doctor suspect that you have developed lymphedema after surgery or radiation therapy, you will

need to be assessed. Your doctor may use a tape measure to compare the distance around each of your arms at different points and around your wrists and hands. A difference of 2 cm at any of these measurement points may require treatment. Your doctor will also check for tightness and feelings of heaviness in your arms. This assessment will allow your doctor to determine whether your lymphedema is mild, moderate or severe (severe lymphedema rarely occurs following breast cancer treatments). There are other methods of measuring lymphedema, such as water displacement, but they are used less often.

My doctor says I have lymphedema. What are my treatment choices?

Before you begin treatment for lymphedema, you will want to make sure that you do not have any other problems related to your original breast cancer. Your doctor will check for infection in your arm and tumours in your armpit. Your doctor will also check for blood clots in your armpit (called “axillary vein thrombosis”). Once your doctor has ruled out these problems, you can begin treatment for lymphedema.

Usually you will be offered treatment that involves wearing a compression garment. Other treatments, such as using a pneumatic compression pump or undergoing massage and physical therapies, are sometimes offered in addition to, or instead of, a compression garment. However, you should keep in mind that, at this time, the only treatment that can be recommended on the basis of scien-

Guideline 11. The management of lymphedema related to breast cancer

tific evidence — information from studies involving large numbers of women — is the use of a compression garment.

Compression garments

A compression garment (sometimes called a “compression sleeve”) is a tight-fitting piece of elastic clothing that covers all or part of the arm. It may also cover the wrist or part of the shoulder. Good compression garments are usually custom-made. They should be replaced every 4 to 6 months or when they begin to lose their elasticity. Ideally, trained personnel should fit the garment for you.

A compression garment works by putting pressure on your swollen arm and stopping the collection of lymph in any one area. Your doctor may recommend that you wear the garment 24 hours a day or that you wear it only during waking hours. Whatever your doctor recommends, you should keep in mind that research shows that the long-term and consistent use of compression garments for lymphedema will result in improvement.

Pneumatic compression pumps

A pneumatic compression pump is a device with a sleeve that can be inflated with compressed air in order to massage the arm. The device squeezes the lymph away from the hand and arm and toward the body. There are several commercially available pumps, ranging in complexity and cost. Most pumps used by therapists, clinics and patients are complex and cost several thousand dollars.

Unfortunately, no studies have been published regarding the most effective kind of pump, the most desirable pumping time or the best pressure levels. One thing that is known, though, is that you should not use pump therapy if you have an active infection or problems with blood clots (called “deep vein thrombosis”).

Massage and physical therapies

Massage and physical therapies are used to help the fluid drain from the affected area. Manual lymph drainage is a massage technique that involves the skin surface only. The therapist tries to improve drainage from the arm by clearing out the main lymphatic pathways of the body, starting in the neck and moving to the main part of the body. Complex physical therapy, also called complex decongestive physiotherapy, is a treatment routine that involves manual lymph drainage, skin care, bandaging, exercises and the use of compression garments.

In one study, the use of a compression garment combined with manual lymph drainage was compared with the use of a compression garment alone. Women in both groups had reduced arm volume and improvement in symptoms. However, manual lymph drainage did not provide additional benefit over the compression garment alone.

Other therapies

There are other therapies for lymphedema that you may hear about: laser treatment, electrical stimulation, transcutaneous electrical nerve stimulation (TENS), cryotherapy, microwave therapy, thermal therapy, surgery, and drug therapy with diuretics or benzopyrones. There is no research that indicates whether these therapies are useful. These therapies require further study and are not recommended at this time.

What should I do if I am having pain?

You must tell your doctor if you are having pain. Most often, the best way to control the pain is to control the lymphedema. You may need to change your treatment in some way. If changing your treatment does not help the pain, your doctor may prescribe a pain medication (see guideline 10 on pain management).

What can I do to help myself?

There are several things you can do to manage your lymphedema and prevent complications:

- *Look after your skin.* Avoid cuts, pin-pricks, hangnails, insect bites, pet scratches and burns to the affected arm. If your skin is injured, be sure to clean and protect the wound immediately. Stay away from substances that you are allergic to or that you find irritate your skin. Whenever possible, avoid blood pressure monitoring in the affected arm and avoid medical procedures that require pricking the skin in the affected arm (vaccination, blood drawing, insertion of an intravenous needle, acupuncture, and venography or lymphangiography [x-ray assessments that involve injections]).
- *Treat skin infections promptly.* Usually skin infections are streptococcal — that is, they are caused by bacteria called “streptococci.” On rare occasions an infection may be staphylococcal — caused by bacteria called “staphylococci.” In either case, the infection should be treated immediately with antibiotics such as penicillin. If you have recurrent infections, you may want to take regular preventive doses of antibiotics or receive monthly injections of penicillin. Your doctor may want you to have an emergency home supply of an antibiotic, to be taken at the first sign of infection. If you are visiting a remote area, be sure to take along a supply of antibiotics.
- *Use saunas, steam baths and hot tubs with care.* Heat can make your lymphedema worse. Be cautious about exposing yourself to hot environments.
- *Travel with care.* Some patients report that their lymphedema is worse when they travel to places with a hot climate. Some also report that their lymphedema is worse during flights. If you have a compression garment, you should wear it when travelling by air.
- *Exercise your arms.* Activities that exercise your arms may help control your lymphedema. Although some doctors say you should avoid activities such as rowing, tennis, golf, skiing, squash and racquetball, there is no research to suggest that these sports promote or worsen lymphedema. In fact, in one study, 20 women with breast cancer competed in the strenuous sport of dragon boat racing and found that the activity did not promote or worsen lymphedema. Some experts recommend that you wear a compression garment during exercise.
- *Maintain an ideal body weight.* Being overweight can contribute to the development of lymphedema and may make the use of compression garments or pneumatic compression pumps less effective. ♦

Guideline 12. Chemoprevention and breast cancer

Is this guide for me?

This guide is for women who have never had breast cancer and are thinking about taking a drug called tamoxifen to prevent breast cancer. If you are concerned about your risk of getting breast cancer, you may want to read on. Note that this guide is about taking tamoxifen to prevent breast cancer — it does not cover other ways to prevent breast cancer.

What is chemoprevention?

Chemoprevention refers to the use of medications to reduce a person's chance of developing cancer. You and your doctor may want to discuss chemoprevention if your risk of breast cancer is higher than the risk of other women your age.

Estrogen plays an important role in the development of breast cancer. Drugs that can block the action of estrogen have been studied to see if they can prevent breast cancer. Two of these drugs are tamoxifen and raloxifene.

What is tamoxifen?

Tamoxifen can affect the growth of cancer cells by blocking estrogen. The use of tamoxifen to prevent breast cancer has developed from its use to treat women with breast cancer. Research has shown that women with early breast cancer who take tamoxifen as part of their cancer treatment have a reduced risk of recurrent breast cancer. Studies have also shown that women with breast cancer treated with tamoxifen have a reduced risk of cancer in the opposite breast.

What have researchers learned about tamoxifen?

Three studies have examined tamoxifen for breast cancer prevention: the

National Surgical Adjuvant Breast and Bowel Project P-1 (NSABP P-1) Study, which took place in Canada and the United States, the Italian Tamoxifen Prevention Study and the Royal Marsden Hospital Trial, which took place in the United Kingdom. All of the studies compared women taking tamoxifen and women taking an inactive drug called a “placebo.”

Women with a higher risk of breast cancer who took tamoxifen in the largest trial (the NSABP P-1 study) had a significant reduction in breast cancer events (about 50%). However, women in the two smaller trials (Italian and Royal Marsden) did not. At this time we do not know if taking tamoxifen will increase a woman's chance of living longer.

Women taking tamoxifen were more likely than those taking a placebo to experience problems with stroke and blood clots in the lung or leg veins. In the NSABP P-1 study, there was an increase in cases of uterine cancer among women taking tamoxifen.

What are the benefits and risks of using tamoxifen for chemoprevention?

Tamoxifen can reduce the chance of breast cancer developing in women at higher risk of the disease. It can also cause harmful side effects. Side effects associated with the use of tamoxifen include stroke, blood clots in the lung or leg veins, cancer of the uterus, hot flashes and vaginal dryness. Obviously some of these effects are more serious than others.

In general, the likelihood of some of the side effects increases with a woman's age. The benefit of protection against

breast cancer is more likely to outweigh the risks in women aged 35 to 50. As age increases, the risk of side effects (especially stroke and blood clots in the lung) will increase, and at some point outweigh, the potential benefits of taking tamoxifen.

How do I find out about my risk of breast cancer?

“Risk” is the likelihood that a particular disease will develop in a particular person during a particular time. Determining risk is not easy. Your doctor will assess your risk of breast cancer by looking at a number of factors, including the following:

- Your age
- When you had your first menstrual period
- When you had your first child
- Whether you have had a biopsy for breast cancer
- Whether you have a close relative (mother, sister or daughter) with breast cancer
- Your ethnic origin

What is the Gail risk assessment index?

The Gail risk assessment index is a model used to estimate an individual woman’s risk of breast cancer. The index uses a series of risk factors (age, age at first period, age at first live birth, number of breast biopsies, family history and ethnic origin) to calculate a “baseline risk.” This is a woman’s chance of invasive breast cancer developing over the next 5 years and over her lifetime.

For example, if your baseline risk of breast cancer is estimated to be 2%, during a 5-year period you have a 2% chance of breast cancer developing (and

a 98% chance of the disease not developing). Another way to think about this is that, in the next 5 years, breast cancer would develop in two out of 100 women like yourself, and it would not develop in 98. Your individual risk is then compared with the risk of women the same age considered to be at average risk of breast cancer. For example, although your risk of breast cancer might be 2%, the risk of women in your age group with average risk factors might be 1%.

If you and your doctor are concerned that you may be at increased risk of breast cancer, the risk assessment index can help you begin thinking and talking about chemoprevention (see the Breast Cancer Risk Assessment Tool at <http://bcra.nci.nih.gov/brc>).

Should the Gail risk assessment index be used routinely to make treatment decisions?

No, a family physician should not use the Gail index on every woman. Although this index was used for enrolling women in the NSABP P-1 study (the one study that showed a potential benefit of tamoxifen use in preventing breast cancer), it has not yet been evaluated for routine use in your physician’s office. In addition, you should know that the Gail index was developed using information from a large number of white women and a very small number of non-white women; it is unknown whether this model can be used with the same degree of accuracy in women of all ethnic origins. However, when a woman or her physician are concerned about her increased risk of breast cancer, the index can be useful in deciding whether to further discuss the benefits and harms of taking tamoxifen.

Guideline 12. Chemoprevention and breast cancer

What information will I need to decide about using tamoxifen to prevent breast cancer?

First, you will need to know more about your risk of developing breast cancer during the next 5 years. You and your doctor or a specialist at a counselling centre might use the Gail index to estimate your risk. You will then need to consider evidence from the NSABP P-1 trial, in which women with a baseline risk of at least 1.66% at 5 years, according to the Gail index, participated. Results from the study suggest that taking tamoxifen will reduce your risk. Next you will have to learn more about the possible benefits of taking tamoxifen and the possible harms of side effects.

I am at low or normal risk of breast cancer (less than 1.66% at 5 years, according to the Gail index). Should I consider chemoprevention?

No. Researchers and physicians do not recommend chemoprevention for women at low or normal risk of breast cancer because the potential for harm outweighs the possible benefit of tamoxifen therapy.

I am at higher risk for breast cancer (1.66% or greater at 5 years, according to the Gail index). Should I consider chemoprevention with tamoxifen?

Yes, but you will need to discuss the possible effects of tamoxifen with your doctor and perhaps with a specialist at a counselling centre. You will want to consider how you might be affected by breast cancer versus how you might be affected by a stroke or blood clots in the

lung. You will also want to consider quality-of-life issues such as tamoxifen-associated hot flashes and vaginal dryness. You will need to weigh the potential benefits of chemoprevention against the potential harms of side effects. The value you place on the different possible outcomes will influence your choice. For example, you might feel that a tamoxifen-induced stroke would be far worse than breast cancer and decide against taking tamoxifen. Another woman might feel that breast cancer would be far worse than a stroke and decide to take tamoxifen. You will have to determine the value you place on the possible consequences of taking or not taking tamoxifen after a full discussion with your doctor. If you decide to take tamoxifen, it is recommended that you take it for 5 years.

Should I consider chemoprevention with the drug raloxifene?

Raloxifene, like tamoxifen, can block estrogen and affect the growth of cancer cells. It was originally studied in women with osteoporosis — a common cause of brittle bones and fractures in postmenopausal women. One study has suggested that raloxifene reduces the risk of the development of breast cancer. Although raloxifene research is promising, a study designed specifically to evaluate its use for the prevention of breast cancer has not been completed yet. A trial that will compare raloxifene and tamoxifen for breast cancer prevention (NSABP STAR trial) is underway. Researchers hope it will answer some of the many questions about the effects of raloxifene. Current evidence does not support the use of raloxifene for chemoprevention of breast cancer outside of a clinical trial. ♦

Guideline 13. Sentinel lymph node biopsy

I am about to begin treatment for breast cancer. What surgical procedures are used to find out if cancer has spread to my lymph nodes?

The most commonly used method for determining the extent or “stage” of a breast cancer is “axillary dissection” — a surgical procedure that involves removing and examining lymph nodes (sometimes called “glands”) from the armpit (see guideline 4 on the removal of lymph nodes during breast cancer surgery).

“Sentinel lymph node biopsy” is an alternative staging method. It is a newer surgical procedure that involves removal and examination of 1 or 2 lymph nodes identified as the most important in the area where the cancer was found.

Why are lymph nodes removed?

Lymph nodes are part of the system that carries a fluid called “lymph” around the body. When breast cancer spreads, cancer cells often collect in the lymph nodes in the armpit. By removing some of the lymph nodes in the armpit and examining them under a microscope, doctors can obtain important information about how far the cancer has progressed. Information on whether the nodes are “positive” (contain cancer cells) or “negative” (do not contain cancer cells) will help determine the right treatment for you after surgery (see guideline 7 and guideline 8). Removal of lymph nodes also reduces the risk that cancer will come back in the armpit area.

What is sentinel lymph node biopsy?

During a sentinel lymph node biopsy, radioactive material or a dye, or both, is

injected into the breast tissue surrounding the tumour or the place where the tumour was removed. As the lymph carries the material or dye through the lymphatic pathways, the surgeon uses a device to identify the first node the lymph reaches (the “sentinel lymph node”), which is then removed by the surgeon for examination in the laboratory by a pathologist.

If the sentinel lymph node is found to be positive (to contain cancer cells), this suggests that other nodes in the area may be positive. If the sentinel lymph node is found to be negative (not to contain cancer cells) this suggests that other nodes in the area are also negative. Thus, the sentinel lymph node is thought to accurately reflect the state of all the nodes in the armpit.

What are the benefits of sentinel lymph node biopsy?

If you have sentinel lymph node biopsy you may avoid some of the side effects related to axillary dissection. These side effects include restriction of shoulder movement, pain, numbness and lymphedema (arm swelling) (see guideline 4 and guideline 11).

What are the disadvantages of sentinel lymph node biopsy?

When a sentinel lymph node biopsy is performed, there is a small chance, usually less than 10%, that even though no cancer cells are found in the sentinel lymph node, cancer cells are present in other lymph nodes in the armpit. You should be aware that missing these cancer cells may affect the treatment you receive after surgery and the chance of breast cancer returning.

Guideline 13. Sentinel lymph node biopsy

What should be done if the sentinel lymph node is negative for cancer?

If the sentinel lymph node is found to be negative, further surgical procedures are not required for staging the cancer.

What should be done if the sentinel lymph node is positive for cancer?

If the sentinel lymph node is found to be positive, this suggests that other lymph nodes in the armpit may contain cancer cells and an axillary dissection should be done.

What are some of the questions you should ask your surgeon about sentinel lymph node biopsy?

Sentinel lymph node biopsy is a challenging procedure to perform and is only mastered with experience. This means that medical specialists who have not performed a large number of these biopsies may have a high failure rate; that is, they will not be able to accurately and consistently identify the sentinel lymph node and determine whether it does or does not contain cancer cells. You should ask your surgeon the following questions:

- *How often do you perform breast cancer surgery?* A surgeon who does not perform breast cancer surgery frequently should not do sentinel lymph node biopsy.
- *How many sentinel lymph node biopsies have you performed, and what is your success rate with the procedure?* Surgeons offering to perform this procedure should inform patients of the number of biopsies they have completed and the number of times they have correctly identified the sentinel lymph node. They should indicate the number of times they have found cancer cells in the lymph nodes in the

armpit when the sentinel lymph node was negative.

When surgeons first start performing sentinel lymph node biopsy, they should also perform back-up axillary dissection on all patients. It has been suggested that, before a surgeon performs sentinel lymph node biopsy alone (without axillary dissection), he or she should have performed at least 30 sentinel lymph node biopsies followed by axillary dissection. In these 30 cases, the surgeon should have identified the sentinel lymph node at least 85% of the time and found cancer cells in the nodes under the arm in no more than 5% of cases when the sentinel lymph node was negative.

When should sentinel lymph node biopsy not be performed?

If you have had breast surgery or radiation to the breast in the past, you should not have sentinel lymph node biopsy. You should also not have the biopsy procedure if you have “clinically palpable nodes” (lymph nodes that your doctor can feel), “locally advanced breast disease” (very extensive cancer in the breast) or tumours in more than one location in the breast, or if you have had breast reduction surgery in the past.

Should I have sentinel lymph node biopsy instead of axillary dissection?

You will need to discuss this question with your doctor and the other medical specialists involved in your care. Axillary dissection is still the most widely accepted treatment for the surgical staging of breast cancer. You and your doctor will need to discuss what is and is not known about sentinel lymph node biopsy before you make a decision about which procedure is best for you. You may choose to participate in a clinical research trial of sentinel lymph node biopsy. ♦

Where can I find support?

It has long been known that patients who have a good network of social and emotional support feel better. There is now some evidence that this kind of support can not only help control problems like pain, nausea and depression but may even prolong life in the long term after breast cancer has been diagnosed.

Good support is part of good cancer care. It can take many forms, including regular visits to a health professional, interaction with other women who have had breast cancer or simply talking things over

with a relative or a good friend. Any or all of these can make a great deal of difference.

Ask your doctor about breast cancer support groups and advocacy groups in your area. The people in these groups know what you're going through and know how to help in a way no one else can. You can also call your local branch of the Canadian Cancer Society or the Cancer Information Service, toll-free at 888 939-3333. The family counselling or social work department at your regional cancer centre will also be able to help you find support groups.

CLINICAL TRIALS

What is a clinical trial? My doctor has mentioned that I could participate in one.

A clinical trial is a carefully designed research study that usually involves comparing one cancer treatment with another. At some time you may be invited to take part in such a trial.

Whether you join the trial is entirely up to you. Just about everything that we already know about breast cancer treat-

ment comes from previous clinical trials. Yet, many questions about breast cancer treatment are still unanswered. Since there is still so much left to learn, new trials are urgently needed to plan the best care for the future. If you wish to add to knowledge in this way, ask your doctor about possible trials you could join.

Where can I find more information?

There are several places that can help you get the information and support you need. For example, you can call the nationwide the Cancer Information Service at 888 939-3333. There are no long-distance charges.

Many recent publications can help you learn more about your treatment and about coping with breast cancer. Some of the best include the following:

Breast Cancer and You by T.A. Al-Tweigeri, R. Clark, C. Harkness, R. Hasselback, J. Gorski, H. Hatton H and others. Published in *Current Oncology* 1996;S1-S32. Available without charge from the Cancer Information Service (tel 888 939-3333) or the National Breast Cancer Fund (tel 416 544-8487). A French version is available under the title *Vous et le cancer du sein*.

The Complete Breast Book by J. Engel. Published by Key Porter Books, Toronto. 1996 [ISBN 1-55013-643-7, 235 pages, paperbound].

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