Breast Cancer
Carcinoma in Situ

STAGE 0

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Breast Cancer
Carcinoma in Situ
STAGE 0

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As the nation’s leading organization serving the hereditary breast and ovarian cancer community, FORCE is pleased to endorse the NCCN Guidelines for Patients with breast cancer. This guide provides valuable, evidence-based, expert-reviewed information on the standard of care, empowering patients to make informed decisions about their treatment. www.facingourrisk.org

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Sharsheret is proud to endorse this important resource, the NCCN Guidelines for Patients: Breast Cancer. With this critical tool in hand, women nationwide have the knowledge they need to partner with their healthcare team to navigate the often complicated world of breast cancer care and make informed treatment decisions. www.sharsheret.org

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Young Survival Coalition (YSC) is pleased to endorse the NCCN Guidelines for Patients: Breast Cancer as an invaluable resource for young women diagnosed with breast cancer and their co-survivors. This in-depth, illustrated series clearly explains what breast cancer is, how it is treated and what patients can expect on the journey ahead. www.youngsurvival.org

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NCCN Foundation would like to thank Rockin’ for the Cure for providing much needed support for the NCCN Guidelines for Patients! Rockin’ For The Cure 2016 was a giant success and we are incredibly grateful to the Rockin’ For The Cure team for their hard work and passion to promote cancer awareness. We look forward to 2017. www.rockinforthecure.net
NCCN aims to improve the care given to patients with cancer. NCCN staff work with experts to create helpful programs and resources for many stakeholders. Stakeholders include health providers, patients, businesses, and others. One resource is the series of books for patients called the NCCN Guidelines for Patients®. Each book presents the best practice for a type of cancer. The patient books are based on clinical practice guidelines written for cancer doctors. These guidelines are called the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). Clinical practice guidelines list the best health care options for groups of patients. Many doctors use them to help plan cancer treatment for their patients.

Panels of experts create the NCCN Guidelines®. Most of the experts are from NCCN Member Institutions. Panelists may include surgeons, radiation oncologists, medical oncologists, and patient advocates. Recommendations in the NCCN Guidelines are based on clinical trials and the experience of the panelists. The NCCN Guidelines are updated at least once a year. When funded, the patient books are updated to reflect the most recent version of the NCCN Guidelines for doctors. For more information about the NCCN Guidelines, visit NCCN.org/clinical.asp.

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Breast cancer is the most common type of cancer in women. Learning that you are at risk for or have breast cancer can feel overwhelming. The goal of this book is to help you get the best care. It presents which tests and treatments are recommended for carcinoma in situ by experts in breast cancer. Carcinoma in situ is stage 0 breast cancer.

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 27 of the world’s leading cancer centers. Experts from NCCN have written treatment guidelines for doctors who treat breast cancer. These treatment guidelines suggest what the best practice is for cancer care. The information in this patient book is based on the guidelines written for doctors.

This book focuses on the treatment of carcinoma in situ (stage 0) of the breast. Key points of this book are summarized in the related NCCN Quick Guide™. NCCN also offers patient resources on stages I–IV breast cancer, ovarian cancer, sarcoma, lymphomas, and other cancer types. Visit NCCN.org/patients for the full library of patient books, summaries, and other patient and caregiver resources.
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Carcinoma in Situ

STAGE 0

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Who should read this book?

This book is about care of women with carcinoma in situ. Patients and those who support them—caregivers, family, and friends—may find this book helpful. It may help you talk with your treatment team, understand what doctors say, and prepare for treatment.

The recommendations in this book are based on science and the experience of NCCN experts. However, these recommendations may not be right for you. Your doctors may suggest other tests and treatments based on your health and other factors. If other recommendations are given, feel free to ask your treatment team questions.

Where should I start reading?

Starting with Part 1 may be helpful. It explains what carcinoma in situ—stage 0 breast cancer—is. Understanding the disease will help you understand its treatment. Read Part 2 to learn what health care is advised for LCIS. Treatment for DCIS is covered in Part 3. Tips for making treatment decisions are presented in Part 4.

Making sense of medical terms

In this book, many medical words are included. These are words that you will likely hear from your treatment team. Most of these words may be new to you, and it may be a lot to learn.

Don't be discouraged as you read. Keep reading and review the information. Don't be shy to ask your treatment team to explain a word or phrase that you do not understand.

Words that you may not know are defined in the text or in the Dictionary. Words in the Dictionary are underlined when first used on a page.

Acronyms are also defined when first used and in the Glossary. Acronyms are short words formed from the first letters of several words. One example is LCIS for lobular carcinoma in situ.
Carcinoma in situ
You’ve learned that you are at risk for or have breast cancer. It’s common to feel shocked and confused. Part 1 reviews some basics about carcinoma in situ.

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**Women’s breasts**

Before learning about carcinoma in situ, it is helpful to know about breasts. The ring of darker skin seen on the outside of the breast is called the **areola**. The raised tip in the middle of the areola is called the **nipple**. In young girls, there are small **ducts** under the nipple that branch into fatty tissue like early growth from a seedling. These immature ducts are supported by **connective tissue** called **stroma**.

Increases in female **hormones** among girls during **puberty** cause their breasts to change. The stroma increases, the ducts grow and branch out like tree limbs, and **lobules** form at the end of the ducts like leaves at the end of twigs. Lobules are small sacs that make breast milk after a baby is born. Breast milk drains from the millions of leaf-like lobules into the ducts that connect to the nipple. See Figure 1.1 for a look inside women’s breasts.
The 3 types

Carcinoma in situ is a confusing term. “Carcinoma” is a type of cancer that starts in cells that make up the skin or tissue that lines or covers organs. “In situ” means that no abnormal cells have grown into the stroma. However, not all carcinoma in situ is cancer.

Lobular carcinoma in situ
Although called a carcinoma, LCIS (lobular carcinoma in situ) isn’t cancer. It is an abnormal cell growth within the lobules. However, having had LCIS increases your chances for breast cancer.

Ductal carcinoma in situ
DCIS (ductal carcinoma in situ) is breast cancer. It is a carcinoma that started in ductal cells and hasn’t grown outside the breast ducts. If left untreated, DCIS could grow outside of the ducts and spread beyond the breast.

Paget's disease of the breast
Paget's disease of the breast is breast cancer. It is a carcinoma involving the nipple. It is a very rare form of breast cancer and isn't addressed in this book.

Figure 1.1 Inside women’s breasts

Inside of women's breasts are millions of lobules that form breast milk after a baby is born. Breast milk drains from the lobules into ducts that carry the milk to the nipple. Around the lobules and ducts is soft tissue called stroma.
Understanding cancer

Cancer is a disease of cells. Inside of cells are coded instructions for building new cells and controlling how cells behave. These instructions are called genes. Genes are a part of DNA (deoxyribonucleic acid), which is grouped together into bundles called chromosomes. See Figure 1.2. Abnormal changes (mutations) in genes cause normal cells to become cancer cells. Researchers are still trying to learn what causes genes to mutate and cause cancer.

Cancer cells don’t behave like normal cells in three key ways. First, mutations in genes cause normal cells to grow more quickly and live longer. Normal cells grow and then divide to form new cells when needed. They also die when old or damaged as shown in Figure 1.3.

In contrast, cancer cells make new cells that aren’t needed and don’t die quickly when old or damaged. Over time, cancer cells form a mass called the primary tumor.

The second way cancer cells differ from normal cells is that they can grow into surrounding tissues. If not treated, the primary tumor can extend beyond the walls of lobules or ducts into the stroma. Breast cancers that haven’t grown into the stroma are called “noninvasive” and breast cancers that have grown into the stroma are called “invasive.” DCIS is a noninvasive breast cancer.

Third, unlike normal cells, invasive cancer cells can leave the breast and form tumors in other parts of the body. This process is called metastasis. In this process, cancer cells break away from the tumor and

Figure 1.2 Genetic material in cells

Most human cells contain the “blueprint of life”—the plan by which our bodies are made and work. The plan is found inside of chromosomes, which are long strands of DNA that are tightly wrapped around proteins. Genes are small pieces of DNA that contain instructions for building new cells and controlling how cells behave. Humans have about 24,000 genes.
merge with blood or a clear fluid called lymph. Then, the cancer cells travel in blood or lymph through vessels to other sites. Once in other sites, secondary tumors can grow and sometimes cause major health problems. This is why it is important to find and treat breast cancer before it becomes invasive and can metastasize.

Figure 1.3 Normal cell growth vs. cancer cell growth

Normal cells increase in number when they are needed and die when old or damaged. In contrast, cancer cells quickly make new cells and live longer because of abnormal changes in genes.
Review

• Inside of women’s breasts are lobules, ducts, and stroma. Lobules are structures that make breast milk. Ducts carry breast milk from the lobules to the nipple. Stroma is a soft tissue that surrounds the lobules and ducts.

• Not all carcinoma in situ is cancer. LCIS is abnormal cell growth within breast lobules. DCIS is cancer that hasn’t spread outside the breast ducts.

• If not treated, breast cancer can spread beyond the breast through lymph or blood and cause major health problems.
Treatment guide: LCIS
LCIS isn’t cancer but a group of abnormal cells within breast lobules. However, having had LCIS increases your chances for getting breast cancer. Part 2 presents the health care that is advised for women with LCIS.

The health care that is addressed in Part 2 should follow a diagnosis of LCIS. LCIS can only be diagnosed by a pathologist who has examined tissue from your breast. A pathologist is a doctor who’s an expert in testing cells to find disease. Following a LCIS diagnosis, other tests are needed to further assess the health of your breasts. Read the section Health tests to learn more.

A risk factor is anything that increases your chances of an event. LCIS is one of many risk factors for breast cancer. In the section Risk-reduction treatment, the decision process of and the ways to reduce the risk of breast cancer are briefly described.

Breast cancer screening is advised for women who’ve had LCIS. The aim of screening is to find any cancer early when treatment will work best. There is more than one method to screen for breast cancer. Read the section Breast cancer screening to learn more.
Health tests

Medical history
Your medical history includes any health events and medicines you’ve taken in your life. Your doctor will want to know about illnesses, breast biopsies, prior treatment with radiation, and if you are pregnant. It may help to make a list of old and new medications while at home to bring to your doctor’s office.

Breast cancer and other health conditions can run in families. Thus, your doctor will ask about the medical history of your relatives. About 10 out of 100 breast cancers are due to abnormal genes that are passed down from a parent to a child. Such cancers are called hereditary breast cancers.

Physical exam
Doctors often perform a physical exam along with taking a medical history. A physical exam is a study of your body for signs of disease. During this exam, your doctor will listen to your lungs, heart, and gut.

Your doctor will also look at and feel parts of your body. This is done to see if organs are of normal size, are soft or hard, or cause pain when touched. A clinical breast exam involves your doctor touching your breasts and nearby lymph nodes. Your breasts may be felt while you sit or stand up as well as when you lie back. Some women feel uneasy having their breasts touched by their doctor. Keep in mind that this test provides important information and is quick.
Bilateral diagnostic mammogram

A **mammogram** is a picture of the insides of your breast. The pictures are made using x-rays. Mammograms that are used for breast cancer screening are often made from two x-rays of each breast. A computer combines the x-rays to make detailed pictures. **See Figure 2.1** for more information.

Many women with LCIS have had a **bilateral diagnostic mammogram**. If you haven't had this test, it is advised. A bilateral mammogram is a picture of each breast. Diagnostic mammograms are made with more x-rays from different angles than screening mammograms. By using more x-rays, the picture is clearer and can better show if there is more than one mass.

---

**Figure 2.1 Mammogram**

Mammograms are pictures of the insides of your breasts. They are often easy to get. Before the test, don’t use deodorants, perfumes, powders, or lotions on your breasts and armpits or wash them off. These products can make the pictures unclear. You will also need to remove your top and bra.

In the exam room, a technician will tell you how to place your body next to the machine. Your breast will be placed onto a flat surface, called a plate. A second plate will be lowered onto your breast to flatten it. This may be painful but it gets the least fuzzy picture of your breast. Pictures will be taken from a camera that is attached to the two plates. Mammograms of both breasts take about 20 minutes to complete.

The pictures are either printed on film or saved on a computer. An expert in mammograms, called a radiologist, will view the pictures. He or she will report the test findings to your doctor.
Excisional biopsy

A biopsy is a procedure that removes tissue samples for testing. There is more than one type of biopsy used to remove breast tissue. Fine-needle aspiration and a core needle biopsy use a needle to remove tissue samples. Some core biopsy needles use vacuum suction to remove tissue.

Besides needles, there are biopsies that remove tissue during a minor surgery. See Figure 2.2. An incisional biopsy is a surgery that removes part of a tissue mass. An excisional biopsy is a surgery that removes the whole tumor with some normal-looking tissue around its edge. The normal-looking tissue is called the surgical margin.

Your doctor may advise you to get an excisional biopsy if one has not been done. It can be used to rule out DCIS and invasive breast cancer. You may have a second excision if pleomorphic LCIS is found and abnormal cells are found in the surgical margin. Pleomorphic LCIS consists of larger cells that are more likely to become an invasive cancer than classic LCIS.

Figure 2.2 Excisional biopsy

An excisional biopsy removes the whole tumor along with normal-looking tissue around its edge. The normal-looking tissue is called the surgical margin. Before the biopsy, your doctor may want you to stop eating so that your stomach is empty for the procedure. You may also need to stop taking some medicines. Local or general anesthesia may be used.

The tumor will be removed with a surgical knife called a scalpel. If your surgeon can’t feel a lump, an ultrasound probe may be used to find the right spot. Another method to find the tumor is wire localization. Using mammograms or ultrasound, a small wire will be inserted through the breast and into the tumor. Then your surgeon will remove the tissue at the end of the wire.

An excisional biopsy will leave a small scar. It may also cause some pain and swelling for a few days. Ask your treatment team for a complete list of rare and common side effects.
Risk-reduction treatment

Although LCIS increases your risk for breast cancer, you may not need risk-reduction treatment. There are many other risk factors to consider. One very important risk factor is if any of your blood relatives have had breast or ovarian cancer, especially at a young age.

Using your medical and family history, your doctor will tell you, in general, how likely you are to get breast cancer. If there’s a history of cancer in your family, you should be referred for genetic counseling. A genetic counselor is an expert in gene mutations related to cancer. The counselor can better determine your risk for breast cancer.

The counselor may suggest testing for mutations in genes that are related to breast cancer and passed down in families. Such mutations can occur in BRCA1 and BRCA2 genes. Normal BRCA genes help to prevent tumor growth. Women with BRCA1 and BRCA2 gene mutations are more likely to have breast and ovarian cancer than other women.

Based on all risk factors, your genetic counselor will advise if risk-reduction treatment would be helpful. However, it’s your choice whether to start treatment. Risk-reduction treatment is briefly described next.

Lifestyle changes
Changes in your lifestyle may reduce your chances of developing breast cancer. Examples are eating more healthfully, limiting alcohol use, exercising more, and achieving a healthy body weight. Your doctor can suggest lifestyle changes that are specific to you.

Endocrine therapy
Female hormones help some breast cancers grow. Endocrine therapy includes treatments that stop cancer growth caused by hormones. Endocrine therapy is sometimes called hormone therapy and

Pathology review
All biopsy samples must be viewed by a pathologist. The type and extent of the disease will be confirmed. Among women with LCIS, over half have LCIS in more than one lobule. Sometimes, both LCIS and breast cancer are found. The breast cancer may be confined to or have spread beyond the breast ducts. If an invasive breast cancer is found, read the NCCN patient book related to the cancer stage.

The pathology results will be recorded in a report. It’s a good idea to get a copy of your pathology report. It’s used to plan treatment.
is not the same as hormone replacement therapy. Not all women at risk for breast cancer should take endocrine therapy. Your doctor can let you know if endocrine therapy is right for you.

Which medicine is used sometimes differs between women who have menstrual periods and those who don’t. Tamoxifen is advised for women who have menstrual periods (pre-menopausal). Tamoxifen blocks hormones so the growth of cancer cells isn’t triggered. Tamoxifen and similar medicines may also be given to women without menstrual periods (post-menopausal). In addition, post-menopausal women may be given medicines called aromatase inhibitors. These medicines lower the amount of female hormones in your body.

Although endocrine therapy lowers breast cancer risk, it can cause side effects. Side effects are unplanned physical or emotional responses to treatment. Side effects vary between medicines. Some side effects of endocrine therapy are hot flashes, cataracts, leg cramps, joint pain, blood clots, and other cancers. Ask your treatment team for a complete list of side effects. Your doctor may also know about research of endocrine therapy or other medicines that you can join.

If you start endocrine therapy, you will have follow-up visits with your doctor. Tell your doctor about any side effects from endocrine therapy. There may be ways to get relief. Depending on which medicine you’re taking, you may need to get GYN (gynecologic) exams, vision tests, and bone density tests.

**Surgery**
A third risk-reduction treatment is surgery. Surgery is mostly done among women at high risk for breast cancer. If you choose surgery, a bilateral total mastectomy is advised. This surgery completely removes both breasts but no lymph nodes and chest muscles.

Following the mastectomy, or in some cases at the same time as the mastectomy, you may want to have breast reconstruction. Breast reconstruction is a surgery that inserts breast implants or uses your body tissue to make a more normal-looking breast mound. Breast reconstruction is described in more detail in Part 3.

Your doctor may suggest that you have a bilateral salpingo-oophorectomy. This surgery removes both ovaries and both fallopian tubes. It is only advised if you have or very likely have mutations in the BRCA1 and BRCA2 genes.
Breast cancer screening

Since you’ve had LCIS, your doctor will want to watch you closely. Breast cancer screening is an ongoing testing that can help to find cancer before it spreads. Cancer that is only in the breast is more likely to be cured.

Breast cancer in women who’ve had LCIS can start anywhere in the breast. It doesn’t always start where LCIS was found. Breast cancer may start in the ducts rather than the lobules. It can also start in the breast that didn’t have LCIS. Although rare, breast cancer can still occur if you’ve had a total mastectomy of both breasts.

Your doctor will create a screening plan that is right for you. Your plan will depend on how likely you are to get breast cancer. The tests used to screen for breast cancer are discussed next.

Breast awareness
A self-exam is advised for all women at increased risk for breast cancer. Examining your own breasts is important. You should know the feel and look of your breasts so that you can tell if major changes have occurred. If you get menstrual periods, an exam at the end of your period is best.

See your doctor if you find changes that last for more than a month. He or she can decide if you need more tests. Changes in breasts are often not cancer. However, if there’s a problem, you will get treated faster the sooner you see your doctor.

Complete breast exam
A complete breast exam is advised every 6 to 12 months after a diagnosis of LCIS. This exam involves your doctor touching your breasts and nearby lymph nodes. If you had a total mastectomy of both breasts, your doctor will examine your chest or reconstructed breasts.

Screening mammogram
Screening mammograms are advised after a diagnosis of LCIS for women 30 years of age and older. Screening of both breasts every year is needed. A mammogram isn’t done if you’ve had both breasts removed even if you had breast reconstruction.

Breast MRI
Your doctor may want you to get a breast MRI (magnetic resonance imaging) every year. It is advised if your family has a strong history of breast cancer. Breast MRI is also advised if you’ve had radiation therapy near your breasts.

Breast MRI uses a magnetic field and radio waves to make pictures of the insides of your breasts. Before the test, a contrast dye may be injected into your vein to make the pictures clearer. The dye may cause you to feel flushed or get hives. Rarely, serious allergic reactions occur. Tell your doctor if you have had bad reactions before.

For breast MRI, you must remove your top and bra and lie face down on a table. The table has padded openings for your breasts. In the openings, there are coils that help to make pictures. During breast MRI, the table moves slowly through the tunnel of the MRI machine.
My notes
Review

- Following LCIS diagnosis, a medical history, physical exam, and bilateral diagnostic mammogram is needed if not done before.

- The breast tumor should be fully removed by an excisional biopsy. The removed tissue will be studied by a pathologist, who will look for other breast diseases.

- Lifestyle changes, endocrine therapy, and surgery may help to prevent breast cancer.

- Breast cancer screening includes breast exams by your doctor and yourself as well as mammograms. You may get a breast MRI as well.
Treatment guide: DCIS
Part 3 describes the care for DCIS. DCIS is cancer that starts in the cells that line the milk ducts of the breasts. The cancer has not grown outside of the ducts.

The health care presented in Part 3 follows a diagnosis of DCIS. DCIS can only be diagnosed by a pathologist using tissue that was removed from the breast tumor with a biopsy. A pathologist is a doctor who’s an expert in testing cells to find disease.

There is more than one type of biopsy that removes breast tissue. You may have had a biopsy that removed tissue samples with a needle. Such biopsies include a fine-needle aspiration and a core needle biopsy. An excisional biopsy is a minor surgery that removes the whole tumor but not much else.

Following a DCIS diagnosis, other tests are needed to plan the best treatment. Read the section Treatment planning to learn more. When your test results are back, talk with your doctor about which options described in Breast cancer treatment, Risk-reduction treatment, and Breast reconstruction are best for you. Health care following cancer treatment is explained in the section Follow-up care.
Treatment planning

Medical history
Your medical history includes any health events and medicines you’ve taken in your life. Your doctor will want to know about illnesses, breast biopsies, prior treatment with radiation, and if you are pregnant. It may help to make a list of old and new medications while at home to bring to your doctor’s office.

Breast cancer and other health conditions can run in families. Thus, your doctor will ask about the medical history of your relatives. About 10 out of 100 breast cancers are due to abnormal genes that are passed down from a parent to a child. Such cancers are called hereditary breast cancers.

Physical exam
Doctors often perform a physical exam along with taking a medical history. A physical exam is a study of your body for signs of disease. During this exam, your doctor will listen to your lungs, heart, and gut.

Your doctor will also look at and feel parts of your body. This is done to see if organs are of normal size, are soft or hard, or cause pain when touched. A clinical breast exam involves your doctor touching your breasts and nearby lymph nodes. Your breasts may be felt while you sit or stand up as well as when you lie back. Some women feel uneasy having their breasts touched by their doctor. Keep in mind that this test provides important information and is quick.

Bilateral diagnostic mammogram
A mammogram is a picture of the insides of your breast. The pictures are made using x-rays. Mammograms that are used for breast cancer screening are often made from two x-rays of each breast. A computer combines the x-rays to make detailed pictures. Read page 14 for more information.

Many women with DCIS have had a bilateral diagnostic mammogram. If you haven’t had this test, it is advised. A bilateral mammogram is a picture of each breast. Diagnostic mammograms are made with more x-rays from different angles than screening mammograms. By using more x-rays, the picture is clearer and can better show if there is more than one mass.

Breast MRI
Breast MRI (magnetic resonance imaging) also makes pictures of the insides of the breasts. The pictures are made using a magnetic field and radio waves. Breast MRI is not usually done for treatment planning of DCIS, but it is an option. It may help show the extent of the cancer.

Before the test, a contrast dye may be injected into your vein to make the pictures clearer. The dye may cause you to feel flushed or get hives. Rarely, serious allergic reactions occur. Tell your doctor if you have had bad reactions before.

For breast MRI, you must remove your top and bra and lie face down on a table. The table has padded openings for your breasts. In the openings, there are coils that help to make pictures. During breast MRI, the table moves slowly through the tunnel of the MRI machine.

Pathology review
All tissue removed from your body must be viewed by a pathologist. He or she will confirm if you have DCIS, invasive breast cancer, or another condition. If an invasive cancer is found, read the NCCN patient book related to the cancer stage.

If DCIS is confirmed, the type and grade will be assessed. There are 3 grades of DCIS. Grade I looks the most like normal cells and is the least likely to spread. Grade II also grows slowly. Grade III looks the least like normal cells and is the most likely to spread.
Grade III is often associated with comedo necrosis. Comedo necrosis refers to the buildup of dead cells within the duct.

All lab results are included in a pathology report that gets sent to your doctors. It’s a good idea to ask for a copy of your pathology reports. These reports are used to plan treatment. Ask your treatment team any questions about the lab results.

**Estrogen receptor test**

Estrogen is a hormone present in all women. Among some women with DCIS, the cancer cells have receptors to which estrogen attaches and causes the cells to grow in number. See Figure 3.1. However, the growth of cancer cells with estrogen receptors is usually slower than cancer cells without these receptors.

Testing for estrogen receptors is important. There are drugs that can be used to stop estrogen from causing cancer growth. IHC (immunohistochemistry) is the lab test used by pathologists for estrogen receptors.

IHC involves applying a stain to cells then looking at them with a microscope. The stain shows how many cells have estrogen receptors and the amount of estrogen receptors in the cells. If at least 1 out of every 100 cancer cells stain positive, the cancer is called estrogen receptor–positive DCIS. If fewer cancer cells stain positive for estrogen receptors, the cancer is called estrogen receptor–negative DCIS.

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**Figure 3.1 Estrogen receptors**

Some breast cancers have a high number of cells that have estrogen receptors. When estrogen binds to these receptors, it causes the cells to increase in number. It is important to test for estrogen receptors so that you can get the best cancer treatment.
Genetic counseling
If you likely have hereditary breast cancer, your doctor will refer you for genetic counseling. A genetic counselor is an expert in gene mutations that are related to disease. The counselor can tell you more about how likely you are to have hereditary breast cancer. He or she may suggest that you undergo genetic testing to look for gene mutations that increase your chances of developing breast cancer.

Hereditary breast cancer is most often caused by mutations in the BRCA1 and BRCA2 genes. Normal BRCA genes help to prevent tumor growth by fixing damaged cells and helping cells grow normally. Genetic testing can tell if you have a BRCA or another mutation. Your test results may be used to guide treatment planning.

Some abnormal changes in genes, called VUS (variants of unknown significance), are not fully understood by doctors. Your doctors may know of research that aims to learn more. If interested, ask your doctors about taking part in such research.
Breast cancer treatment

Chart 3.1 What are my options?

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<thead>
<tr>
<th>Treatment options</th>
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</thead>
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| **Lumpectomy only** may be an option if *all* these factors describe you | • Are older than 50 years of age,  
• Have a small tumor,  
• Have a low-grade cancer (grade I),  
• Your doctor can’t feel the tumor, and  
• Your surgeon removed large and cancer-free surgical margins |
| **Lumpectomy + radiation therapy** (AKA breast-conserving therapy) is an option if *all* of these factors describe you | • Haven’t had radiation close to where the cancer is,  
• Can have all cancer removed through one cut,  
• Have no health conditions that might cause problems,  
• Don’t have a genetic risk for breast cancer  
• Your breast won’t be too disfigured afterward, and  
• Your surgeon removed cancer-free surgical margins |
| **Total mastectomy ± sentinel lymph node biopsy** is an option if *all* of these factors describe you | • Are unable or refuse to have a lumpectomy, and  
• Are healthy enough for surgery |

Chart 3.1 lists the treatment options for DCIS. The goal of treatment is for you to be free of cancer. Because DCIS is confined within the breast ducts, surgery that removes the tumor is the central part of treatment. As shown in Figure 3.2, there are two types of breast surgery—lumpectomy and total mastectomy. Other treatments may be used with breast surgery to rid your body of cancer.

**Lumpectomy only**  
A lumpectomy is a surgery that removes the tumor along with normal-looking tissue around its edge. The normal-looking tissue is called a surgical margin. Lumpectomy is a breast-conserving surgery because most of the normal breast tissue won’t be removed. It’s like an excisional biopsy except more tissue is removed.
Surgery that removes the tumor is the central part of treatment for DCIS. Lumpectomy with radiation therapy (breast-conserving therapy) is an option for many women. Very few women can have lumpectomy alone. Total mastectomy is another option. Often, a sentinel lymph node biopsy is done with mastectomy.
Only a small group of women with DCIS are able to have a lumpectomy without any other cancer treatment. These women are very unlikely to have the breast cancer return after surgery because the extent of DCIS is so small. Your doctor will assess if the cancer is likely to return. Breast cancer is less likely to return if you are older than 50 years of age, the tumor is small and low grade (grade I), and the surgical margins are large and cancer-free. Talk with your doctor about how likely it is the cancer will return so that you can decide together if a lumpectomy alone is the best treatment.

**Lumpectomy overview**

Before the lumpectomy, you will be asked to stop eating, drinking, and taking some medicines for a short period of time. If you smoke, it is important to stop. Pain is prevented with either local or general anesthesia. Often, breast tissue is removed through a C-shaped cut. A lumpectomy is finished within 15 to 40 minutes. Afterward, a tube may be placed in your breast to drain fluid.

A lumpectomy will leave a small scar and may cause some pain and swelling for about a week. It may also cause a dent in your breast that can be fixed with breast reconstruction. Breast reconstruction is described later in this chapter. Ask your treatment team for a complete list of side effects of lumpectomy.

The tissue from the lumpectomy will be tested by a pathologist for cancer cells at or near the margin. You also may be given another mammogram to look for any cancer that wasn’t removed. If it appears that cancer remains in your breast, more surgery is needed. The second surgery is often another lumpectomy but sometimes a mastectomy is needed.

A lumpectomy followed by radiation therapy is called breast-conserving therapy. It is an option for many but not all women with DCIS. Radiation therapy uses high-energy rays to treat cancer. The rays damage the genes in cells. This either kills the cancer cells or stops new cancer cells from being made. Adding radiation therapy has been shown to help stop the return of cancer within the breast. It is given only after cancer-free surgical margins have been removed.

**Radiation therapy overview**

Most of your breast will be treated with radiation. This is called whole breast radiation. Recently, some doctors have given radiation only to the lumpectomy site instead of giving whole breast radiation. Radiation only to the lumpectomy site is called partial breast irradiation. If you’re interested in this treatment, NCCN experts advise that you receive it only within a clinical trial. A clinical trial is a type of research that studies a test or treatment.

The most common type of radiation therapy used for breast cancer is EBRT (external beam radiation therapy). This type of therapy uses a machine outside the body to deliver radiation. 3-D machines deliver beams matched to the shape of the tumor. IMRT (intensity-modulated radiation therapy) uses small radiation beams of different strengths based on the thickness of the tissue.

A planning (simulation) session is needed before treatment. During simulation, pictures of the tumor site should be made with CT (computed tomography). A CT scan takes many x-rays of the breast from different angles. Your doctors will use the pictures to decide the radiation dose and to shape the radiation beams. Beams are shaped with computer software and hardware added to the radiation machine. The beams are shaped so that normal tissue is spared. Radiation beams will be aimed at the tumor site with help from ink marks or tiny tattoos on your skin.
There are other methods that can be used to spare normal tissue. Moreover, there are ways to protect your heart if radiation will be given in that area. Ask your doctor what methods will be used for your treatment. Some methods are:

- Directing the beam not toward the heart,
- Lying face down during treatment,
- Holding your breath at times during treatment,
- Use of devices that keep you from moving during treatment,
- Radiation machines that give treatment only when the tumor is in the right spot, and
- Radiation machines that deliver very precise radiation beams.

During treatment, you will be alone while a technician operates the machine from a nearby room. He or she will be able to see, hear, and speak with you. As treatment is given, you may hear noises. A session can take between 15 to 30 minutes. Radiation therapy is given 5 days a week for 5 to 7 weeks.

Toward the end of treatment, you may receive extra radiation called a boost. A boost is advised if you are 50 years of age or younger. Also, a boost may be given if your doctor thinks the cancer is likely to return in your breast. The boost may be given with EBRT or by internal radiation. Internal radiation is also called brachytherapy. It involves placing radioactive seeds in the area where the tumor was. The seeds are placed using multiple small tubes (catheters) or one small catheter with a balloon at its end.

For multiple-catheter boost radiation, the seeds may remain in your body for a short time. If the seeds release a small dose of radiation, the catheters and seeds are left in your body for a few days. During this time, you must stay in the hospital. If the seeds release high doses of radiation, the seeds will remain in your body for 10 minutes twice a day for 5 days. You may get side effects from radiation although not everyone does. Often, the skin around the radiation site will look and feel as if it has been sunburned. Another common problem is extreme tiredness despite sleep (fatigue). Women sometimes have pain in their armpit or chest after radiation and, rarely, heart and lung problems. Ask your treatment team for a complete list of rare and common side effects.

**Total mastectomy with or without sentinel lymph node biopsy**

Some women with DCIS can’t have or don’t want a lumpectomy. A lumpectomy may not be an option because of your health, the tumor size, cancer in the surgical margins, and your chances of having another breast tumor. You may refuse to have a lumpectomy. Some women refuse because of how they want their breast to look after treatment. Others refuse because they will worry less about the cancer returning in that breast.

If a lumpectomy isn’t an option, a total mastectomy is advised. This surgery is also called a simple mastectomy. Your whole breast will be removed but not any chest muscle. Following the mastectomy, or in some cases at the same time as the mastectomy, you may want to have breast reconstruction. Breast reconstruction is described in more detail later in this chapter.

If not treated, breast cancer most often spreads outside the breast through lymph. Lymph is a clear fluid that gives cells water and food and helps to fight germs. Lymph drains from tissues into vessels. As lymph travels in vessels, it will pass through and be filtered by small structures called lymph nodes.
A sentinel lymph node biopsy is a surgery that finds and removes the first lymph nodes to which breast cancer spreads. It is also called a sentinel lymph node dissection. Your doctor may suggest having this biopsy during the mastectomy if it would be hard to remove your lymph nodes, if needed, afterward.

Total mastectomy overview
Before the mastectomy, you will be asked to stop eating, drinking, and taking some medicines for a short period of time. If you smoke, it is important to stop. Pain is prevented with general anesthesia.

Often, an oval-shaped cut is first made around the nipple. Next, the breast tissue will be detached from the skin and muscle and then removed. A total mastectomy is finished within 1 to 2 hours. Afterward, a tube may be placed in your chest to drain fluid. A total mastectomy will leave a large scar and cause pain and swelling. You may also have stiffness, severe tiredness despite sleeping (fatigue), and uncomfortable crawly sensations as your nerves heal. Ask your treatment team for a complete list of side effects.

Sentinel lymph node biopsy overview
Sentinel lymph nodes are the first few nodes to which breast cancer spreads. To find these nodes, a radioactive tracer, blue dye, or both will be injected into your breast. The tracer and dye will drain into lymph vessels within your breast and then travel to the breast’s lymph nodes. Most of these nodes are in the armpit (“axilla”). Often, there is more than one sentinel node to which the breast drains. After the dye marks your sentinel node(s), your surgeon will remove them and likely some other nearby nodes. The nodes are then sent to a pathologist for testing.

Risk-reduction treatment
After treatment for DCIS, some women take steps to lower their chances of having another breast tumor. This is called risk-reduction treatment. Risk reduction may help prevent a tumor from growing in either breast. Risk-reduction treatment is briefly described next.

Lifestyle changes
Changes in your lifestyle may reduce your chances of developing another breast tumor. Examples are eating more healthfully, exercising more, and achieving a healthy body weight. Your doctor can suggest lifestyle changes that are specific to you.

Endocrine therapy
Female hormones help some breast cancers grow. Endocrine therapy includes treatments that stop cancer growth caused by hormones. Endocrine therapy is sometimes called hormone therapy but is not the same as hormone replacement therapy. Research suggests that endocrine therapy lowers the likelihood of a second breast cancer among women with estrogen receptor–positive DCIS. Breast cancer is less likely whether the breast had or didn’t have cancer before.

NCCN experts advise that you think about taking endocrine therapy for 5 years following DCIS treatment. Research on taking endocrine therapy for more than 5 years is limited. How well endocrine therapy works for women who had estrogen receptor–negative DCIS is unclear. To help you decide, talk with your doctor about all the pros and cons of endocrine therapy.

Which endocrine therapy is given may differ between women who have menstrual periods and those who don’t. Tamoxifen is advised for women who have menstrual periods (pre-menopausal). As shown in Figure 3.3, tamoxifen blocks hormones so the growth
of cancer cells isn't triggered. Tamoxifen may also be given to women without menstrual periods (post-menopausal). Otherwise, post-menopausal women may be given medicines called aromatase inhibitors. These medicines lower the amount of female hormones in the body.

Although endocrine therapy lowers breast cancer risk, it can cause side effects. Side effects vary between medicines. Some side effects of endocrine therapy are hot flashes, cataracts, leg cramps, joint pain, blood clots, and other cancers. Ask your treatment team for a complete list of side effects. Your doctor may also know about research of endocrine therapy or other medicines that you can join.

If you start endocrine therapy, you will have follow-up visits with your doctor. Tell your doctor about any side effects from endocrine therapy. There may be ways to get relief. Depending on which medicine you’re taking, you may need to get GYN (gynecologic) exams, vision tests, and bone density tests.

**Surgery**

A third risk-reduction treatment is surgery. A total mastectomy is an option to reduce your risk in a breast that did not have cancer. This surgery completely removes your breast but no lymph nodes and chest muscles. Following the mastectomy, or in some cases at the same time as the mastectomy, you may want to have breast reconstruction. Breast reconstruction is discussed next in this chapter.

Your doctor may suggest that you have a bilateral salpingo-oophorectomy. This surgery removes both ovaries and both fallopian tubes. It is only advised if you have or very likely have mutations in the BRCA1 and BRCA2 genes.

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**Figure 3.3 Endocrine therapy**

Endocrine therapy stops cancer growth caused by hormones. Taking endocrine therapy for 5 years may prevent a second breast cancer among women who have been treated for DCIS. Tamoxifen is a commonly used endocrine therapy.
Breast reconstruction

Some women choose to have breast reconstruction after a lumpectomy or mastectomy. Breast reconstruction is a surgery that inserts breast implants or uses your body tissue to make a more normal-looking breast mound. Other women use external fake breasts or do nothing. Options for breast reconstruction are described next. Talk with your doctor about these options.

Reconstruction following lumpectomy
If you will have a lumpectomy, your breast can be re-shaped using volume displacement. Volume displacement is the shifting of the remaining breast tissue so as to fill the hole left by the lumpectomy. Shifting of the breast tissue is often done by the cancer surgeon right after the lumpectomy.

A larger piece of breast tissue is removed during lumpectomy for volume displacement. Despite a larger piece, the natural look of your breast will be kept. Besides, having a larger piece removed will likely reduce your chances of cancer returning in that breast.

You may not like the results of the volume displacement. In this case, breast revision surgery may help. Breast revision surgery is done by a plastic surgeon. Other options include a second volume displacement, or you may want to get breast implants or flaps, which are described below.

Reconstruction following mastectomy
You can have reconstruction at any time if you have a total mastectomy. Reconstruction at the same time as the cancer surgery is called immediate reconstruction. Delayed reconstruction can occur months or years after the cancer surgery. Breast reconstruction following a mastectomy is done by a plastic surgeon.

To enhance your breast reconstruction, you may be able to have a skin-sparing mastectomy. This surgery usually removes only the nipple, areola, and skin near the biopsy site. As a result, the size of the mastectomy scar will be smaller and your breast will have a more natural shape. Skin-sparing mastectomy that spares the nipple and areola may be an option for some women.

There is more than one way to reconstruct breasts and nipples after a mastectomy. All reconstruction is generally safe, but with any surgery, there are risks. Ask your treatment team for a complete list of side effects. The ways to reconstruct breasts and nipples are:

Implants
Breasts can be reconstructed using breast implants. Breast implants are small bags filled with salt water, silicone gel, or both that are placed under the breast skin and muscle. Implants have a small risk of breaking and leaking. A balloon-like device, called an expander, may first be placed under your skin or muscle and inflated to stretch out the tissue. Every few weeks for two to three months, the expander will be enlarged until the implant will fit in place. You may feel pain from the expander stretching your skin and muscle. Some women will also have pain from the implant, scar tissue, or tissue death (necrosis).

Flaps
Another type of breast reconstruction uses tissue from your body, known as “flaps.” Flaps are from the belly area, butt, or from under the shoulder blade. See Figure 3.4. Some flaps are completely removed from your body and then sewn in place. Other flaps stay attached and then are slid over to the breast area and are sewn into place. Women who have diabetes or who smoke are more likely to have problems with flaps than other women. Some risks of flaps are tissue death, lumps from death of fat, and muscle weakness that may cause a hernia.

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Breast implants and flaps are the two main methods used for breast reconstruction following mastectomy. Implants are small bags filled with salt water, silicone gel, or both that are placed under your breast skin and muscle. Flaps are tissue taken from your belly area, butt, or from under your shoulder blade to form breasts.

**Implants and flaps**

Some breasts are reconstructed with both implants and flaps. Using both types may give the reconstructed breast more volume and help match its shape to the other breast. However, for any reconstruction, you may need surgery on your real breast so that the two breasts match in size and shape.

**Nipple replacement**

Like your breast, you can have your nipple remade, use a fake nipple, or do nothing. The plastic surgeon can recreate a nipple mound with the surrounding tissues or, sometimes, tissue can be moved from other parts of your body, such as your thigh, other nipple, or female parts between your legs (vulva). You may lose feeling in your real nipple if tissue is removed. Tissue used from other areas of your body to make a nipple can be darkened in color with a tattoo.
Follow-up care

Follow-up care is important. It is done to assess your general health, find new breast tumors early, and check for side effects of treatment. The follow-up care for after DCIS treatment is discussed next.

**Medical history and physical exam**
After DCIS treatment, a medical history and physical exam should be done every 6 to 12 months for 5 years. If test results are normal for 5 years, you should then have these tests every year. During your visit with your doctor, tell him or her about any new or worse symptoms you have. There may be ways to get relief. As part of your physical exam, your doctor may look inside your vagina for bleeding or other signs of disease if you are taking endocrine therapy.

**Breast awareness**
A self-exam is advised for all women who’ve been treated for DCIS. Examining your own breasts is important. You should know the feel and look of your breasts so that you can tell if major changes have occurred. If you get menstrual periods, an exam at the end of your period is best.

See your doctor if you find changes that last for more than a month. He or she can decide if you need more tests. Changes in breasts are often not cancer. However, if there’s a problem, you will get treated faster the sooner you see your doctor.

**Mammogram**
Most new breast tumors after DCIS treatment occur within the breast tissue near to the DCIS site. Thus, the first mammogram should be done within 6 to 12 months after lumpectomy or breast-conserving therapy and every year after that. After mastectomy, a mammogram is recommended every year on the breast that didn’t have DCIS. If you had a mastectomy on both breasts, mammograms aren’t needed.

**Breast MRI**
Your doctor may want you to get a breast MRI every year. It is advised if your family has a strong history of breast cancer. Breast MRI may also be done if you’ve had radiation near your breast that didn’t have DCIS.
My notes
### Review

- DCIS should be tested to see if it is estrogen-receptor positive or negative.
- Genetic counseling can help assess if you have hereditary breast cancer.
- Most women with DCIS are treated with breast-conserving therapy or a total mastectomy.
- Lifestyle changes, endocrine therapy, and surgery help to prevent future breast cancer.
- Follow-up care includes breast exams by your doctor and yourself as well as mammograms.
Making treatment decisions
Having carcinoma in situ can be very stressful. While absorbing the fact that you are at risk for or have cancer, you have to learn about tests and treatments and accept a treatment plan. Parts 2 and 3 explained the health care options for LCIS and DCIS. These options are based on science and agreement among NCCN experts. Part 4 aims to help you make decisions that are in line with your beliefs, wishes, and values.
It’s your choice

The role patients want in choosing their treatment differs. You may feel uneasy about making treatment decisions. This may be due to a high level of stress. It may be hard to hear or know what others are saying. Stress, pain, and drugs can limit your ability to make good decisions. You may feel uneasy because you don’t know much about cancer. You've never heard the words used to describe cancer, tests, or treatments. Likewise, you may think that your judgment isn’t any better than your doctors’.

Letting others decide which option is best may make you feel more at ease. But, whom do you want to make the decisions? You may rely on your doctors alone to make the right decisions. However, your doctors may not tell you which to choose if you have multiple good options. You can also have loved ones help. They can gather information, speak on your behalf, and share in decision-making with your doctors. Even if others decide which treatment you will receive, you still have to agree by signing a consent form.

On the other hand, you may want to take the lead or share in decision-making. Most patients do. In shared decision-making, you and your doctors share information, weigh the options, and agree on a treatment plan. Your doctors know the science behind your plan but you know your concerns and goals. By working together, you are likely to get a higher quality of care and be more satisfied. You’ll likely get the treatment you want, at the place you want, and by the doctors you want.
Questions to ask your doctors

You may meet with experts from different fields of medicine. Strive to have helpful talks with each person. Prepare questions before your visit and ask questions if the person isn’t clear. You can also record your talks and get copies of your medical records. It may be helpful to have your spouse, partner, or a friend with you at these visits. A patient advocate or navigator might also be able to come. They can help to ask questions and remember what was said. Suggested questions to ask include:

What’s my diagnosis and prognosis?

It’s important to know that there are different types of cancer. Cancer can greatly differ even when people have a tumor in the same organ. Based on your test results, your doctors can tell you which type of cancer you have. He or she can also give a prognosis. A prognosis is a prediction of the pattern and outcome of a disease. Knowing the prognosis may affect what you decide about treatment.

1. Where did the cancer start? In what type of cell?
2. Is this cancer common?
3. What is the cancer stage? Does this stage mean the cancer has spread far?
4. Is this a fast- or slow-growing breast cancer?
5. What other test results are important to know?
6. How often are these tests wrong?
7. Would you give me a copy of the pathology report and other test results?
8. How likely is it that I’ll be cancer-free after treatment?
What are my options?

There is no single treatment practice that is best for all patients. There is often more than one treatment option along with clinical trial options. Your doctor will review your test results and recommend treatment options.

1. What will happen if I do nothing?
2. Can I just carefully monitor the cancer?
3. Do you consult NCCN recommendations when considering options?
4. Are you suggesting options other than what NCCN recommends? If yes, why?
5. Do your suggested options include clinical trials? Please explain why.
6. How do my age, health, and other factors affect my options?
7. What if I am pregnant?
8. Which option is proven to work best?
9. Which options lack scientific proof?
10. What are the benefits of each option? Does any option offer a cure? Are my chances any better for one option than another? Less time-consuming? Less expensive?
11. What are the risks of each option? What are possible complications? What are the rare and common side effects? Short-lived and long-lasting side effects? Serious or mild side effects? Other risks?
12. What can be done to prevent or relieve the side effects of treatment?
13. What are my chances that the cancer will return?
14. What are my options for breast reconstruction?
What does each option require of me?

Many patients consider how each option will practically affect their lives. This information may be important because you have family, jobs, and other duties to take care of. You also may be concerned about getting the help you need. If you have more than one option, choosing the option that is the least taxing may be important to you:

1. Will I have to go to the hospital or elsewhere? How often? How long is each visit?
2. Do I have a choice of when to begin treatment? Can I choose the days and times of treatment?
3. How do I prepare for treatment? Do I have to stop taking any of my medicines? Are there foods I will have to avoid?
4. Should I bring someone with me when I get treated?
5. Will the treatment hurt?
6. How much will the treatment cost me? What does my insurance cover?
7. Will I miss work or school? Will I be able to drive?
8. Is home care after treatment needed? If yes, what type?
9. How soon will I be able to manage my own health?
10. When will I be able to return to my normal activities?
What is your experience?

More and more research is finding that patients treated by more experienced doctors have better results. It is important to learn if a doctor is an expert in the cancer treatment he or she is offering.

1. Are you board certified? If yes, in what area?
2. How many patients like me have you treated?
3. How many procedures like the one you’re suggesting have you done?
4. Is this treatment a major part of your practice?
5. How many of your patients have had complications?
Weighing your options

Deciding which option is best can be hard. Doctors from different fields of medicine may have different opinions on which option is best for you. This can be very confusing. Your spouse or partner may disagree with which option you want. This can be stressful. In some cases, one option hasn’t been shown to work better than another, so science isn’t helpful. Some ways to decide on treatment are discussed next.

2nd opinion
The time around a cancer diagnosis is very stressful. People with cancer often want to get treated as soon as possible. They want to make their cancer go away before it spreads farther. While cancer can’t be ignored, there is time to think about and choose which option is best for you.

You may wish to have another doctor review your test results and suggest a treatment plan. This is called getting a 2nd opinion. You may completely trust your doctor, but a 2nd opinion on which option is best can help.

Copies of the pathology report, a DVD of the imaging tests, and other test results need to be sent to the doctor giving the 2nd opinion. Some people feel uneasy asking for copies from their doctors. However, a 2nd opinion is a normal part of cancer care.

When doctors have cancer, most will talk with more than one doctor before choosing their treatment. What’s more, some health plans require a 2nd opinion. If your health plan doesn’t cover the cost of a 2nd opinion, you have the choice of paying for it yourself.

If the two opinions are the same, you may feel more at peace about the treatment you accept to have. If the two opinions differ, think about getting a 3rd opinion. A 3rd opinion may help you decide between your options. Choosing your cancer treatment is a very important decision. It can affect your length and quality of life.

Decision aids
Decision aids are tools that help people make complex choices. For example, you may have to choose between two options that work equally as well. Sometimes making a decision is hard because there is a lack of science supporting a treatment.

Decision aids often focus on one decision point. In contrast, this book presents tests and treatment options at each point of care for women in general. Well-designed decision aids include information that research has identified as what people need
to make decisions. They also aim to help you think about what’s important based on your values and preferences.

A listing of decision aids can be found at decisionaid.ohri.ca/AZlist.html. Decision aids specific to carcinoma in situ of the breast are:

**Genetic testing:**
www.uofmhealth.org/health-library/zx3000

**Breast-conserving therapy vs. mastectomy:**
www.uofmhealth.org/health-library/tv6530#zx3718

**Breast reconstruction after mastectomy:**
www.uofmhealth.org/health-library/tb1934#zx3672

**Support groups**
Besides talking to health experts, it may help to talk to patients who have walked in your shoes. Support groups often consist of people at different stages of treatment. Some may be in the process of deciding while others may be finished with treatment. At support groups, you can ask questions and hear about the experiences of other women with breast cancer.

**Compare benefits and downsides**
Every option has benefits and downsides. Consider these when deciding which option is best for you. Talking to others can help identify benefits and downsides you haven’t thought of. Scoring each factor from 0 to 10 can also help since some factors may be more important to you than others.
Websites

American Cancer Society
www.cancer.org/cancer/breastcancer/index

National Coalition for Cancer Survivorship
www.canceradvocacy.org/toolbox

National Cancer Institute
www.cancer.gov/types/breast

NCCN
www.nccn.org/patients

Breast Cancer Alliance
www.breastcanceralliance.org

FORCE: Facing Our Risk of Cancer Empowered
www.facingourrisk.org

Living Beyond Breast Cancer
www.lbcc.org

Sharsharet
www.sharsheret.org

Young Survival Coalition (YSC)
youngsurvival.org

Rockin’ for the Cure®
www.rockinforthecure.net

Review

• Shared decision-making is a process in which you and your doctors plan treatment together.

• Asking your doctors questions is vital to getting the information you need to make informed decisions.

• Getting a 2nd opinion, using decision aids, attending support groups, and comparing benefits and downsides may help you decide which treatment is best for you.
Glossary

Dictionary

Acronyms
Dictionary

areola
A darker, circular area of skin on the breast surrounding the nipple.

aromatase inhibitor
A drug that lowers the level of estrogen in the body.

bilateral
Involving both sides of the body or both breasts.

bilateral diagnostic mammogram
Pictures of the insides of both breasts that are made from multiple x-rays.

bilateral salpingo-oophorectomy
Surgery that removes both ovaries and both fallopian tubes.

biopsy
Removal of small amounts of tissue or fluid to be tested for disease.

boost
An extra dose of radiation to a specific area of the body.

brachytherapy
Radiation received from a radioactive object placed near or in the tumor.

breast-conserving therapy
Cancer treatment that includes removing the breast lump and radiation therapy.

breast implant
A small bag filled with salt water, silicone gel, or both that is used to remake breasts.

breast reconstruction
Surgery to rebuild breasts.

cancer stage
Rating of the growth and spread of tumors.

carcinoma
Cancer that starts in cells that form the lining of organs and structures in the body.

carcinoma in situ
Abnormal or cancer cells have not grown into the next layer of tissue.

cataract
A health condition in which the lens of the eye becomes cloudy.

catheter
A flexible tube inserted in the body to give treatment or drain fluid from the body.

clinical breast exam
A physical exam of the breasts by a health professional to feel for disease.

clinical trial
Research on a test or treatment to assess its safety or how well it works.

computed tomography (CT)
A test that uses x-rays from many angles to make a picture of the inside of the body.

connective tissue
Supporting and binding tissue that surrounds other tissues and organs.

contrast
A dye put into your body to make clearer pictures during imaging tests.

core needle biopsy
Use of a needle to remove a large tissue sample to test for cancer cells.

diabetes
A disease that causes high levels of blood sugar.

duct
A tube in the breast that drains breast milk.

ductal carcinoma in situ (DCIS)
Cancer that started within and hasn’t grown beyond the breast ducts.

endocrine therapy
Treatment that stops the making or action of hormones in the body. Also called hormone therapy.

estrogen
A hormone that develops female body traits.
**estrogen receptor**
A protein inside of cells that binds with estrogen.

**estrogen receptor–negative**
Cancer cells that don’t use estrogen to grow.

**estrogen receptor–positive**
Cancer cells that use estrogen to grow.

**excisional biopsy**
Surgery that removes an entire tumor to test for cancer cells.

**external beam radiation therapy (EBRT)**
Treatment with radiation received from a machine outside the body.

**fine-needle aspiration**
Removal of a small tissue sample with a very thin needle.

**gene**
Coded instructions in cells for making new cells and controlling how cells behave.

**general anesthesia**
A controlled loss of wakefulness from drugs.

**genetic counseling**
Discussion with a health expert about the risk for a disease caused by changes in genes.

**hereditary breast cancer**
Breast cancer that was likely caused by abnormal genes passed down from parent to child.

**hernia**
A health condition in which muscles weaken or tear allowing organs or tissue to extend out.

**hormone**
Chemical in the body that activates cells or organs.

**hot flashes**
A health condition of intense body heat and sweat for short periods.

**immunohistochemistry (IHC)**
A lab test of cancer cells to find specific cell traits involved in abnormal cell growth.

**in situ**
In its original place – cancer cells have not spread from where they first formed.

**incisional biopsy**
A minor surgery that removes a tissue sample from a tumor.

**internal radiation**
Treatment with radiation received from an object placed near or in the tumor.

**invasive breast cancer**
Cancer cells have grown into the supporting tissue of the breast.

**lobular carcinoma in situ (LCIS)**
Abnormal cells within the breast lobules only.

**lobule**
A gland in the breast that makes breast milk.

**local anesthesia**
A controlled loss of feeling in a small area of the body from drugs.

**lumpectomy**
Surgery to remove a breast lump and some normal tissue around it.

**lymph**
A clear fluid containing white blood cells.

**lymph node**
Small groups of special disease-fighting cells located throughout the body.

**magnetic resonance imaging (MRI)**
A test that uses radio waves and powerful magnets to make pictures of the insides of the body.

**mammogram**
A picture of the insides of the breast that is made by an x-ray test.

**mastectomy**
Surgery to remove the whole breast.

**medical history**
All health events and medications taken to date.

**multiple-catheter boost radiation**
Use of multiple small tubes to place radioactive seeds in your body for treatment.

**mutation**
An abnormal change in the instructions in cells for making and controlling cells.
noninvasive breast cancer
Cancer cells have not grown into the supporting tissue of the breast.

partial breast irradiation
Treatment with radiation that is only directed at the surgery site.

pathologist
A doctor who’s an expert in testing cells and tissue to find disease.

physical exam
A review of the body by a health expert for signs of disease.

pleomorphic lobular carcinoma in situ (LCIS)
An abnormal growth of cells in breast lobules that is more likely to grow into the fatty tissue of the breast.

primary tumor
The first mass of cancer cells in the body.

puberty
The time when teens sexually develop.

radiation therapy
The use of high-energy rays to destroy cancer cells.

risk factor
Something that increases the chance of getting a disease.

risk-reduction treatment
Methods that aim to lessen the chance of getting a disease.

sentinel lymph node biopsy
Surgery to remove the first lymph node(s) to which cancer cells spread after leaving the breast tumor. Also called sentinel lymph node dissection.

sentinel lymph node
The first lymph node to which cancer cells spread after leaving the breast tumor.

side effect
An unhealthy physical or emotional response to treatment.

simulation
The steps needed to prepare for treatment with radiation.

skin-sparing mastectomy
A surgery that removes all breast tissue but saves as much breast skin as possible.

stroma
Fatty tissue of the breast.

surgical margin
The normal tissue around the edge of a tumor that is removed during surgery.

tamoxifen
A drug that lowers the amount of estrogen in the body.

total mastectomy
Surgery that removes the entire breast but no chest muscles. Also called simple mastectomy.

ultrasound
Use of sound waves to make pictures of the insides of the body.

vulva
The female organs between the legs.

whole breast radiation
Treatment of the entire breast with radiation from a machine outside the body.
Acronyms

CT
computed tomography

DCIS
ductal carcinoma in situ

DNA
deoxyribonucleic acid

EBRT
external beam radiation therapy

GYN
gynecologic

IHC
immunohistochemistry

IMRT
intensity-modulated radiation therapy

LCIS
lobular carcinoma in situ

MRI
magnetic resonance imaging

VUS
variants of unknown significance

NCCN Abbreviations and Acronyms

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National Comprehensive Cancer Network®

NCCN Patient Guidelines
NCCN Guidelines for Patients®

NCCN Guidelines®
NCCN Clinical Practice Guidelines in Oncology®
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The Ohio State University Comprehensive Cancer Center - James Cancer Hospital and Solove Research Institute
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901.683.0055 • westclinic.com

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UC San Diego Moores Cancer Center
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cancer.ucsd.edu

U.S. Army Institute of Surgical Research Cancer Center
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airforce.com

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mcancer.org

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Breast Cancer - Carcinoma in Situ (STAGE 0), Version 1.2016
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Breast Cancer
Carcinoma in Situ

STAGE 0


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