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If you have questions about DCIS, call the  
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# DCIS



## *What You Need to Know*

Cancer Prevention and Treatment Fund  
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If you have been diagnosed with **DCIS** (ductal carcinoma in situ), this booklet is for you. You might want to share this booklet with close friends and family members, too. It has information to help you decide what kind of treatment is best for you.

This booklet is only about DCIS (sometimes called “**Stage 0**” breast cancer). If you have LCIS (lobular carcinoma in situ) or if you have **Stage 1, 2, 3, or 4** breast cancer (often written as Stage I, II, III, or IV), this booklet does not have the information you need.

Being diagnosed with DCIS is something to take seriously. But, it is not an emergency. You have many weeks from the time of diagnosis to talk with your doctors, learn about your treatment choices, perhaps get a second opinion, and think about what matters to you. Then you can decide what treatment to have.

This booklet can help. It includes:

- Information about DCIS, along with steps for making a treatment decision and staying healthy.
- Important medical words in **bold**. These are explained in the booklet and also in the section called “Words to Know,” starting on page 26.
- A chart that compares the advantages and disadvantages of DCIS treatment options, starting on page 12.
- A list of resources called “Ways to Learn More,” starting on page 31.



## Step 1. Learn the Facts

DCIS can not kill you. Some people think it should not be called cancer because it is so different from breast cancers that cause lumps or can spread to other parts of the body. DCIS is usually very small and seen on a **mammogram** as tiny white specks. Almost all women with DCIS who have surgery can expect to live long and healthy lives.

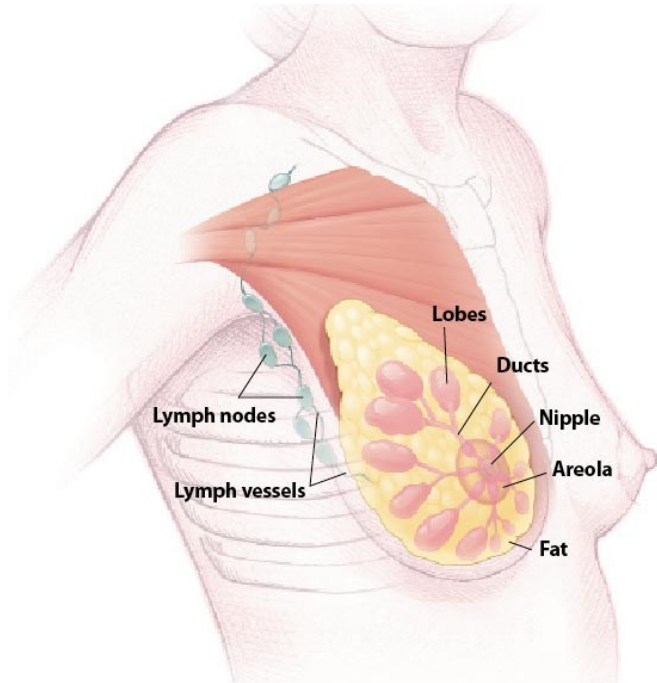
Some doctors call DCIS a very early cancer. Other doctors call it a “pre-cancer.” DCIS is in the milk ducts and can not spread to other parts of your breast or body.

Most breast cancers are called “**invasive**” because they can spread in the breast and to other parts of your body. That is what makes most breast cancer dangerous. Since DCIS is not invasive, it is much less dangerous.

Breast cancer that can spread outside the milk duct or to other parts of your body is called Stage 1, 2, 3 or 4. Stage 1 is early breast cancer and Stage 4 is very advanced breast cancer. DCIS is sometimes called “Stage 0” breast cancer because it is not invasive like Stage 1 breast cancer.

DCIS is like a warning sign. It tells you that your chance of getting invasive breast cancer is higher than for other women. Since no one knows for sure if your DCIS will turn into invasive cancer, you will want to get it treated.

The good news is that DCIS is usually easy to find and treat. Once you get treatment, your chances are excellent of staying healthy and not getting breast cancer in the future.



In this picture of a breast, you can see the milk ducts where DCIS can develop.

Treatment choices for DCIS are almost the same as for invasive breast cancer. But most women can choose fewer treatments with fewer side effects. You will need surgery. Your doctor may want you to also get **radiation therapy**. Your doctor might also suggest a **hormonal therapy** such as tamoxifen pills (to reduce the chance of someday getting invasive breast cancer). You will not need **chemotherapy**.



## Step 2. Talk with Your Doctors

For most women with DCIS, there will be many health professionals involved in your diagnosis and treatment. You will meet some of these professionals. Others you will only hear about. The health professionals often include a:

- Mammographer (breast radiologist) – looks at pictures of your breasts to see if there is anything abnormal.
- **Breast surgeon** – performs a **biopsy** to find out whether or not you have DCIS. He or she also does breast surgery to remove the DCIS.
- **Pathologist** – looks at breast tissue removed during surgery to determine if you have DCIS or another medical problem. The pathologist writes a **pathology report** that says whether you have DCIS or not.
- Medical **oncologist** – provides medical care that may include hormonal therapy. The medical oncologist may also work with all your other health professionals.
- Radiation oncologist – responsible for any radiation therapy after DCIS surgery.
- **Reconstructive plastic surgeon** – can create a new breast-like shape for women who have had a **mastectomy** (breast removed).

Some patients find it hard to talk with their doctor, or want a lot more information and advice. You may want to talk with a **patient navigator** or **nurse navigator**. Patient navigators often can spend more time with patients. They can also help you get a second opinion, if you want one.

A patient navigator is not a breast cancer expert, but can answer questions, help get needed services, and resolve any problems about care. The navigator can help find a local **support group** and may also help you get financial support or transportation services.

Most hospitals, clinics, and patient support organizations have patient navigators. If your health care facility does not have a patient navigator, ask if there is a nurse navigator (a navigator with a nursing degree), a social worker, or a case manager who can help.

## Understanding your diagnosis

Your doctor likely did a biopsy to find out if you have DCIS. During the biopsy a small amount of breast tissue is removed and placed on glass **slides**. The pathologist then looks at the slides under a microscope and writes a pathology report.

Your pathology report tells whether you have DCIS. If you do, the report describes your DCIS in detail. Your doctor uses this report to recommend what kind of treatments you need. DCIS is sometimes hard to diagnose and different pathologists may have different opinions.

## Getting answers to your questions

You and your doctors will talk about treatment choices. Choices include what kind of surgery to have, whether to get radiation therapy, and whether to get hormonal therapy. Be sure to ask a lot of questions and learn as much as you want to know.

It helps if you write a list of questions before going to the doctor. Then bring this list to the appointment. On page 25 of this booklet, there is a place to write your questions.

Think about bringing a family member or friend with you to your appointments. It often helps to have someone who can listen, take notes, and later talk with you about what the doctor said.

After talking with your doctor, you may want to talk with family members, friends, or other women who have had DCIS. Keep in mind that another woman's experience may not be the same as yours. People are different and treatments change. What was true for someone else with DCIS may not be best for you. While other patients can provide support, it is best not to rely on them for medical advice. You can learn about support groups in the back of this booklet.

You may also want a **second opinion**. This means asking another doctor to examine you, look at your mammogram, read your pathology report, look at the slides of your breast tissue, or talk with you about treatment choices. Be sure to provide copies of your mammogram, test results, or other medical reports to the doctor who provides a second opinion.

If you want a second opinion from a pathologist, you need to get all the slides of your breast tissue and send them to the new pathologist.

You will not hurt your doctor's feelings by asking for a second opinion. Doctors know that second opinions can help women feel better about their diagnosis and treatment plan. Medicare and Medicaid often pay for a second opinion. If you are not on Medicare, contact your insurance company to see if they will pay for a second opinion.



## Step 3. Learn about Your Surgery Choices

Women diagnosed with DCIS almost always need surgery. The three choices are:

1. surgery to remove your DCIS and keep your breast (also called breast-sparing surgery or **lumpectomy**), followed by radiation therapy,
2. breast removal (mastectomy), or
3. mastectomy with **breast reconstruction surgery**.

You have a few weeks to decide about surgery. This is because DCIS grows slowly. Most women with DCIS can choose lumpectomy. You can make a choice based on your specific DCIS diagnosis and what is best for you.

You can find a chart that compares treatment options, starting on page 12.

Surgery choices are discussed on the next few pages.

## Lumpectomy

Lumpectomy is a type of surgery in which the surgeon removes only the DCIS and some normal tissue around it. It is sometimes called “breast-sparing surgery,” “breast-conserving surgery,” or “partial mastectomy.” Lumpectomy keeps your breast looking a lot like it did before surgery. You usually do not need to stay overnight in the hospital after a lumpectomy.

Women with DCIS who have a lumpectomy usually do not need to have lymph nodes removed.

**Radiation Therapy:** Studies show that radiation therapy helps prevent DCIS and **invasive** cancer from growing in the same breast later on. That is why most women who have a lumpectomy also have radiation therapy treatments. These treatments start soon after surgery and usually take place almost every day for about 6 weeks.

Radiation treatment does not cause your hair to fall out and usually does not cause nausea. You may be more tired than usual while getting radiation therapy. The skin on your breast may become sensitive or irritated, but this will go away.

Women with DCIS who choose lumpectomy live just as long as they would with a mastectomy. Almost all women with DCIS who have lumpectomy with radiation will live long and healthy lives. Researchers are looking at which lumpectomy patients will not need radiation therapy, but they do not yet know the answer.

## Mastectomy

Having a mastectomy (surgery to remove the entire breast) is usually not necessary for women with DCIS. But, some women choose to have a mastectomy. Many women who have a mastectomy stay overnight in the hospital.

A doctor is more likely to recommend a mastectomy when:

- The DCIS area is large.
- A woman has two or more close relatives (mother, sister, or aunt) with breast cancer.
- A woman is at very high risk of breast cancer for other reasons (like having the BRCA1 or BRCA2 gene).
- A woman does not want radiation treatment.

Your doctor may mention a **grade** for your DCIS. A low-grade DCIS (**grade 1** or I) is better news than a moderate (**grade 2** or II) or a high-grade DCIS (**grade 3** or III). If you have a high-grade DCIS, your doctor may recommend a mastectomy.

Although a mastectomy will not help you live longer, it does lower the chances of getting breast cancer in the future. That is because you would have only one breast, instead of two. You could still get cancer in your chest wall or other breast.

Lumpectomy with radiation also reduces the chance of getting cancer again in the same breast. That is why most women choose a lumpectomy with radiation instead of a mastectomy.

Women with DCIS who need a mastectomy almost always have a total (“simple”) mastectomy. This is when the surgeon removes all of the breast and nipple. Sometimes one or more lymph nodes under the arm (**axillary lymph nodes**) are also removed and checked for cancer. This is a **sentinel lymph node biopsy**. Lymph nodes are part of your body’s immune system. They fight infection and disease, including cancer.

A mastectomy that removes most or all of the lymph nodes and sometimes part of the chest muscle is called a “**modified radical mastectomy**.” That is a more radical surgery than a total mastectomy and is almost never recommended for a woman with DCIS.

## Breast Reconstruction Surgery

If you have a mastectomy and do not want any more surgery, you can wear a **prosthesis** (breast-like form) in your bra.

Or, you can choose to have breast reconstruction surgery, where a plastic surgeon replaces your breast with a new breast-like shape. You may be able to keep your nipple or the surgeon will create a nipple and **areola** (the dark area around the nipple) to look like your old one.

There are two types of reconstruction surgery:

■ **Breast implants.** In this kind of surgery, an implant is placed under your skin or chest muscle to build a new breast-like shape. The implant is made from an “envelope” of silicone that is filled with salt water or silicone gel. Your breast with the implant will not have feeling because the nerves were cut during the mastectomy.

After a mastectomy, a temporary expander gradually stretches the skin to make room for the **breast implant**. The expander can be painful. After a few months, you would have surgery to replace the expander with an implant.

Women with breast implants may have problems very soon after surgery or years later. Problems with breast implants can include:

- The implant can harden, cause breast pain, infection, and other problems.
- The implant may break, leak, move or shift.
- You may need surgery to fix, remove, or replace the implant.

■ **Using your own tissue.** In tissue **flap** surgery, a surgeon builds a new breast-like shape using muscle, fat, and skin taken from your abdomen, your back, or your buttocks. Unlike an implant, this new breast-like shape feels more natural and should last for the rest of your life. Breasts made from your own tissue will get larger if you gain weight and get smaller if you lose weight. Women who are very thin or very overweight, smoke, or have other serious health problems often can not have tissue flap surgery.

Two of the most common tissue flap surgeries are TRAM flaps and DIEP flaps. The TRAM flap (transverse rectus abdominis muscle) takes tissue and muscle from the abdomen or tummy. This means you also get a “tummy tuck” while rebuilding your breast. The TRAM flap moves a muscle from your tummy to your breast, which is not good for physically active women.

If you are very active, you might consider a “free TRAM flap,” which removes less muscle. Or, you might want a DIEP flap (deep inferior epigastric artery perforation), which uses tissue from the tummy but does not remove muscle.

Some women have a “back flap” (latissimus dorsi flap), which uses muscle and skin from your upper back. The back flap is often done in combination with breast implants. Another choice is the gluteal free flap, which uses skin, fat, and muscle from your buttocks.

Flap reconstruction is major surgery. Healing often takes longer than breast implant surgery. Some women need to have physical therapy after their surgery. Any kind of flap may take months to heal. Tissue flap surgery is best done by a plastic surgeon who has done it many times before.


You can compare types of DCIS surgery on the chart that starts on the next page.



## Step 4: Compare Your Choices


	<p><b>Lumpectomy</b> (Surgery that Lets You Keep Your Breast)  <b>Followed by Radiation Therapy</b></p>
<p><b>Is this surgery right for me?</b></p>	<p>Lumpectomy followed by radiation therapy is recommended for most women with DCIS.</p>
<p><b>What will my breast look like after surgery?</b></p>	<p>Your breast should look a lot like it did before surgery. If your DCIS covers a large area, your breast may look “dimpled” or smaller.</p>
<p><b>What are the major advantages of this type of surgery?</b></p>	<p>This allows you to keep your natural breast. You may go home right after the surgery.</p> <p>Radiation therapy reduces the chances that you will develop invasive breast cancer in that same breast, compared with women who have lumpectomy without radiation.</p> <p>Women who get a lumpectomy with radiation live just as long as women who have a mastectomy.</p>

<p><b>Mastectomy</b> (Surgery that Removes all of Your Breast)</p>	<p><b>Mastectomy and Breast Reconstruction Surgery</b> (Making a New Breast Shape)</p>
<p>Your doctor may recommend a mastectomy if:</p> <ul style="list-style-type: none"> <li>• your DCIS covers a large area of your breast</li> <li>• you have DCIS in more than one part of your breast</li> <li>• you do not have access to radiation therapy</li> </ul>	<p>If you decide to have a mastectomy, you can choose to have your breast reconstructed with your own tissue (flap surgery) or with a breast implant.</p> <p>You can choose to start breast reconstruction surgery at the same time as your mastectomy or wait and have it at a later date.</p>
<p>Your breast and usually your nipple will be removed. You will have a flat chest and long scar where the breast was removed.</p>	<p>Although you will have a breast-like shape, your breast will not look the same as it did before surgery. Also, your two breasts may look different from each other.</p>
<p>You probably will not need radiation therapy.</p> <p>Your doctor may recommend a mastectomy if you are at a very high risk for invasive breast cancer.</p> <p>You will be less worried about DCIS or cancer in that breast in the future.</p>	<p>You will not need a prosthesis in your bra.</p> <p>Reconstruction using tissue from your tummy, back, or buttocks (flap surgery) builds a new breast-like shape that will last the rest of your life.</p> <p>Reconstruction with an implant creates a new breast-like shape that will likely last for years.</p>


	<p><b>Lumpectomy</b> (Surgery that Lets You Keep Your Breast)  <b>Followed by Radiation Therapy</b></p>
<p><b>Will I have feeling in the area around my breast?</b></p>	<p>Yes. You should still have feeling in your breast, nipple, and areola (the dark area around your nipple).</p>
<p><b>What are the major disadvantages of this type of surgery? Step 4.</b> Compare Your Choices (Continued)</p>	<p>Your DCIS may return in the future. A very small number of women with DCIS will develop invasive breast cancer sometime after lumpectomy with radiation therapy.</p> <p>Radiation therapy adds to the time and the cost of treatment.</p>
<p><b>Will I have pain after the surgery?</b></p>	<p>You may have pain after surgery. Talk with your surgeon or nurse about ways to control this pain.</p>

<p><b>Mastectomy</b> (Surgery that Removes all of Your Breast)</p>	<p><b>Mastectomy and Breast Reconstruction Surgery</b> (Making a New Breast Shape)</p>
<p>Maybe. After surgery, you will feel numb (have no feeling) in your chest wall. This numb feeling should go away in 1 to 2 years, but that part of your chest will never feel like it used to. Also, the skin where your breast used to be may feel tight.</p>	<p>No. The breast area will always be numb (have no feeling).</p>
<p>Mastectomy is a more drastic type of surgery with longer recovery time, compared to lumpectomy. You will probably stay in the hospital overnight.</p> <p>You will not have a breast, and your chest may feel numb.</p> <p>If you have lymph nodes removed, you may get <b>lymphedema</b>. To learn more about lymphedema, see page 32 in the section “Ways to Learn More.”</p>	<p>Reconstruction with a tissue <b>flap</b> is major surgery, with risks and a longer healing time. It should only be done by plastic surgeons with lots of experience doing this kind of surgery.</p> <p>You will not have feeling in your breasts.</p> <p>Complications from <b>breast implants</b> can include breast pain, hardness, or infection. Implants can break, leak, move or shift, or look unnatural. Surgery is often needed within 4 to 10 years to fix these problems. Implants may also cause a very rare cancer of the immune system called <b>ALCL</b>.</p>
<p>You may have pain after surgery. Talk with your surgeon or nurse about ways to control this pain.</p>	<p>You are likely to have pain after reconstruction surgery. Talk with your surgeon or nurse about ways to control this pain.</p>

### Step 4. Compare Your Choices (Continued)

	<p><b>Lumpectomy</b> (Surgery that Lets You Keep Your Breast) <b>Followed by Radiation Therapy</b></p>
<p><b>What other problems can I expect?</b></p>	<p>You may feel more tired than usual during the days you have radiation therapy.</p> <p>Radiation may cause your breast to feel tender or swollen, similar to a sunburn. In some cases, the skin can become raw and peel. If this happens, let your radiation oncologist or nurse know right away.</p>
<p><b>Will I need more surgery?</b></p>	<p>Possibly. If the surgeon is not able to remove all your DCIS the first time, you may need more surgery. The doctor might have to remove more tissue to get “clean <b>margins</b>” (healthy tissue surrounding the DCIS).</p> <p>In rare cases the doctor might recommend a mastectomy after not being able to find clean margins.</p>
<p><b>Will insurance pay for my surgery?</b></p>	<p>Check with your insurance company to find out how much it pays for DCIS breast surgery and other needed treatments.</p>

<p><b>Mastectomy</b> (Surgery that Removes all of Your Breast)</p>	<p><b>Mastectomy and Breast Reconstruction Surgery</b> (Making a New Breast Shape)</p>
<p>You may have pain in your neck or back.</p> <p>You may feel “out of balance” at first if you had large breasts and do not have reconstruction surgery.</p>	<p>It may take you many weeks or even months to recover from breast reconstruction surgery.</p> <p>You may not like how your breast-like shape looks or feels, compared to a natural breast.</p>
<p>Probably not. If you have problems after your mastectomy, you may need to see your surgeon for treatment.</p>	<p>Besides the surgery to remove your breast, you will need more surgery to make your new breast-like shape. If you choose implants for your breast reconstruction, you may need surgery again later on to fix problems or replace the implant when it breaks.</p>
<p>Check with your insurance company to find out how much it pays for DCIS breast surgery and other needed treatments.</p>	<p>Check with your insurance company to find out if it pays for reconstruction surgery if removal of the whole breast is not medically necessary.</p> <p>Also ask if your insurance will pay for problems that may result from reconstruction surgery, and ask if it will pay for <b>MRIs</b> (to check for leaking silicone gel implants) or to replace implants when needed.</p>

	<p><b>Lumpectomy</b> (Surgery that Lets You Keep Your Breast)  <b>Followed by Radiation Therapy</b></p>
<p><b>What other types of treatment will I need?</b></p>	<p>After you have healed from your surgery, you will need radiation therapy. This is usually given almost every day for 5 to 8 weeks. Sometimes it can be completed in a shorter amount of time.</p> <p>You may want to take hormonal therapy such as tamoxifen to reduce the chances of having DCIS again. It also reduces the chances of invasive breast cancer in both breasts.</p>
<p><b>How often will I have to see my doctor after I finish my treatment?</b></p>	<p>Your doctor will probably recommend a clinical exam every 6 months for the next 5 years, and then once a year after that.</p> <p>You will need a mammogram 6 months after finishing your treatment, and then every 6 to 12 months after that.</p>

<p><b>Mastectomy</b> (Surgery that Removes all of Your Breast)</p>	<p><b>Mastectomy and Breast Reconstruction Surgery</b> (Making a New Breast Shape)</p>
<p>You may want to take hormonal therapy such as tamoxifen to reduce the chances of having DCIS again. It also reduces the chances of invasive breast cancer, especially in the other breast.</p>	<p>You may want to take hormonal therapy such as tamoxifen to reduce the chances of having DCIS again. It also reduces the chances of invasive breast cancer, especially in the other breast.</p>
<p>Your doctor will probably recommend a clinical exam every 6 months for the next 5 years, and then once a year after that.</p> <p>You will likely need to get a mammogram of your remaining breast every 12 months.</p>	<p>Your doctor will probably recommend a clinical exam every 6 months for the next 5 years, and then once a year after that. You will likely need to get a mammogram of your remaining breast every year.</p> <p>If you have an implant in your healthy breast (to make the breasts look similar), you will need extra mammogram views and a specially trained mammography technician. The implant can make it more difficult to see DCIS or cancer.</p> <p>If you get a silicone gel implant, you will need regular MRIs to check for breakage.</p>

## Other Treatment Choices After Your Surgery: Hormonal Therapy

Female hormones cause some breast cancers to grow. Tumors that need estrogen to grow are called **estrogen-receptor positive** tumors. If you have estrogen-receptor positive DCIS, hormonal therapy may reduce your chance of invasive breast cancer in the future. If you do not have this kind of DCIS, you probably do not need hormonal therapy. Your doctor might also test your DCIS for other hormones. You can talk to your doctor about the kind of DCIS you have.

Hormonal therapy for breast cancer patients is different from the kind of hormonal therapy some women take for menopause. Hormonal therapy for DCIS prevents the hormones in your body from helping cancer to develop.

Tamoxifen is the most common type of hormonal therapy taken by DCIS patients. It is a pill you take once a day for up to five years.

Hormonal therapy is a type of “**adjuvant therapy**.” It is also sometimes called “**chemoprevention**.” Chemoprevention is not the same as chemotherapy. For example, you will not lose your hair if you take hormonal therapy.

Hormonal therapy has some serious side effects. It does not cause menopause but the most common side effects of tamoxifen are similar to symptoms of menopause. You might have hot flashes, vaginal dryness, joint pain, and leg cramps. It can also increase your chances of getting blood clots, strokes, cataracts, and endometrial or uterine cancer.

If you are taking tamoxifen or a similar hormonal therapy, you should not use oral contraceptives at the same time.

Talk to your medical oncologist about whether the risks or the benefits of hormonal treatment seem higher for you. Remember that hormonal therapy will not change how long you live. Almost all women with DCIS will still be alive many years later, whether or not they take hormonal treatment.



## Step 5. Think about What Matters to You

After you have learned the facts and talked with your doctors, you may also want to talk with your spouse or partner, family, friends, or other women who have had DCIS. Then, think about what matters to you. Here are some questions to think about:

- Who would I like to talk with about my treatment choices?
- Do I want to get a second opinion?
- What treatment does my insurance cover, and what do I have to pay for?
- What else do I want to know, do, or learn before I make my treatment choices?
- How important is it to me how my breast looks after surgery?
- How important is it to me how my breast feels after surgery?
- Am I willing and able to get radiation therapy after a lumpectomy?
- Do I want breast reconstruction surgery if I have a mastectomy? If so, am I willing to have more than one surgery? And am I willing to wait several months to complete the reconstruction?
- If my doctor suggests hormonal therapy, what are the risks and benefits for me?



## Step 6. Make Your Choice

Now that you have talked with your doctors, learned the facts, and thought about what matters to you – it is time to make your treatment choices. The important thing is to choose what is right for you. Here are some key points to keep in mind:

- Lumpectomy with radiation is usually recommended because women with DCIS will live just as long after a lumpectomy with radiation as they will with a mastectomy. If you choose to get a lumpectomy, radiation will reduce the chances of DCIS or cancer developing later in the same breast.
- Hormonal treatment slightly reduces the chances of having DCIS or invasive breast cancer in either breast in the future. However, it has side effects.
- Mastectomy is not usually recommended unless DCIS is widespread, or if the doctor can not get clean margins after two surgeries. Some women choose a mastectomy because they do not want radiation treatment or can not get it in their community.
- If mastectomy is needed, a “simple” mastectomy is recommended. “Modified radical” mastectomy is a more serious surgery and is not needed.
- Double (or bilateral) mastectomy is not recommended because it does not provide any benefit to your health. There is no medical reason to remove both breasts if DCIS was in one breast.
- Lymph node removal is not usually needed, because the risks outweigh the benefits for women with DCIS.
- Chemotherapy is almost never needed for DCIS.



## Step 7. Stay Healthy

### ■ Have regular breast exams.

Now that you have been diagnosed with DCIS, it is very important that you have regular breast exams. This includes a clinical breast exam (when the doctor or health provider examines your breast) and a mammogram every 6 to 12 months.

Any time you change doctors, make sure you mention that you have had DCIS. If you have silicone gel breast implants, the FDA has recommended that you get an MRI three years after getting your implants and every other year after that.

### ■ Eat a healthy diet.

Even women with good health habits can get DCIS. But, eating right and being active may lower your chance of getting breast cancer or DCIS again. Scientists are doing studies to learn whether certain foods can reduce your risk of breast cancer.

Studies show that women who are overweight are at a higher risk of breast cancer. Here are some things you can do to stay healthy:

- Limit the amount of alcohol (beer, wine, or spirits) you drink to no more than 1 to 2 glasses each day.
- Be active each day. This can be walking, taking the stairs instead of the elevator, going to the gym, or doing other activities for at least 20 minutes each day.
- Maintain a healthy weight, and try to lose weight if you are overweight.
- Eat at least 5 portions of fruits and vegetables each day.





## Words To Know

**Adjuvant therapy** (A-joo-vant THAYR-uh-pee): treatment given after surgery. Adjuvant therapy for DCIS likely includes radiation therapy or hormonal therapy.

**ALCL** (Anaplastic large cell lymphoma): a very rare cancer of the immune system. Women with breast implants may have a small but increased risk of ALCL.

**Areola** (a-REE-o-la): the dark area around the nipple.

**Axillary lymph nodes** (AK-suh-LAIR-ee limf nodes): lymph nodes that are under the arm.

**Biopsy** (BY-op-see): when the doctor removes a small amount of breast tissue to determine if there is DCIS or cancer.

**Breast implant**: a breast-like shape made of a silicone “envelope” that is filled with salt water or silicone gel.

**Breast surgeon**: this doctor is likely to do your biopsy and breast surgery to remove the DCIS.

**Breast reconstruction** (REE-kun-STRUCK-shun) **surgery**: surgery to build a new breast-like shape. Can include a breast implant or tissue flap reconstruction.

**Chemoprevention** (KEE-moh-pree-VEN-shun): the use of drugs or other substances to try to prevent cancer. Tamoxifen is one type of chemoprevention.

**Chemotherapy** (kee-moh-THAYR-uh-pee): treatment with drugs (usually intravenous) that kill cancer cells. Chemotherapy can cause nausea and cause hair to fall out.

**DCIS** (ductal carcinoma in situ): a very early breast cancer that is usually too small to form a lump. Some doctors call it a pre-cancer. Also called intraductal carcinoma or non-invasive cancer.

**Estrogen-receptor positive**: a type of DCIS or breast cancer that needs the female hormone estrogen to grow.

**Flap**: surgery to build a new breast-like shape from muscle, fat, and skin taken from other parts of the body. The TRAM flap moves fat and muscle from the abdomen to make a new breast-like shape after a mastectomy. The “free” TRAM flap and the DIEP flap move fat but not muscle.

**Grade**: how different the cancer cells are from normal cells. Grade is different from stage.

**Grade 1**: low grade cells. The cancer cells look a little different from normal cells and usually grow more slowly.

**Grade 2**: moderate grade cells. Grade 2 cancer cells do not look like normal cells and they grow a little faster than normal.

**Grade 3**: high grade cells. Grade 3 cancer cells look very different from normal cells and grow more quickly.

**Hormonal therapy** (hor-MOH-nul THAYR-uh-pee): usually a pill for patients with estrogen-receptor positive DCIS or cancer. Tamoxifen is the most common hormonal therapy for DCIS patients.

**Invasive** (in-VAY-siv) **cancer**: cancer that may spread to other parts of the breast or other parts of the body. Cancer that can not spread beyond the tissues where it developed is called non-invasive cancer.

**Lumpectomy** (lump-EK-toh-mee): surgery to remove the cancer and a small amount of normal tissue around it. Also known as “breast-sparing surgery,” “breast-conserving surgery,” or “partial mastectomy.”

**Lymphedema** (LIM-fuh-DEE-muh): swelling caused by build up of lymph fluid. Swelling can happen in the arm if lymph nodes are removed during mastectomy.

**Mammogram:** an x-ray of the breast. The person who takes the x-ray is called a mammographer.

**Margins:** the tissue surrounding DCIS. The surgeon tries to remove all of the DCIS and a little bit of healthy tissue surrounding it. “Clean margins” are when the margins have no DCIS or cancer. “Positive margins” mean that the DCIS is in the tissue and more surgery might be needed to remove it.

**Mastectomy** (ma-STEK-toh-mee): surgery to remove the whole breast and nipple. Also known as a “total” or “simple” mastectomy. Removal of both breasts is called double mastectomy or bilateral mastectomy. Removal of a breast that does not have cancer is called a prophylactic mastectomy.

**Modified radical mastectomy:** surgery to remove all of the breast, many of the underarm lymph nodes, the lining over the chest muscles, and maybe also some chest muscle. This is not recommended for DCIS.

**MRI (magnetic resonance imaging):** provides images of inside the body like x-rays but does not use radiation. Breast MRIs can be used to diagnose cancer or diagnose broken or leaking silicone gel breast implants.

**Nurse navigator:** a nurse who helps patients get the information and services they need. Similar to a patient navigator.

**Oncologist** (On-Kol-O-Jist): a doctor who treats cancer patients.

**Pathologist** (puh-THAH-loh-jist): a doctor who looks at breast tissue under a microscope to determine if there is DCIS or any other abnormal conditions.

**Pathology report:** report that describes breast tissue that was removed during biopsy or surgery. This report will tell the doctor if there is DCIS and describes the grade of DCIS.

**Patient navigator:** a person who helps patients get the information and services they need.

**Prophylactic** (PROH-fih-LAK-tik) **mastectomy:** removal of a breast that does not have cancer as a way of preventing breast cancer in the future.

**Prosthesis** (pros-THEE-sis): a breast-like form to wear in a bra.

**Radiation therapy:** use of radiation to kill DCIS and cancer cells and shrink tumors. Radiation can cause fatigue or a “sunburnt” feeling, but does not cause nausea or hair loss.

**Reconstructive** (REE-kun-STRUK-tiv) **plastic surgeon:** a surgeon who can build a breast-like shape after a mastectomy.

**Second hand smoke:** when you breathe smoke from someone else’s cigarette, pipe, or cigar. It may increase the risk of breast cancer and other diseases.

**Second opinion:** talking with a second doctor to ask for a diagnosis and recommendations for treatment.

**Sentinel lymph** (SEN-tih-nel limf) **node biopsy:** surgery to remove as few lymph nodes as possible from under the arm to see if cancer has spread to the lymph nodes. This is not usually done for DCIS patients who have a lumpectomy.

**Slides:** thin layers of breast tissue are removed during a biopsy or surgery and put between glass slides. A pathologist looks at the slides under a microscope to make a diagnosis.

**Stage 0 (zero):** breast conditions that are often considered “pre-cancer” and include DCIS and LCIS (lobular carcinoma in situ).

**Stage:** a way of saying how big the cancer is and how far it has spread. Stages of cancer are 1, 2, 3, and 4 (written I, II, III, and IV).

**Support group:** group that can put you in touch with other women who have been treated for DCIS and can share their experiences.



## Ways to Learn More

### National Cancer Institute (NCI) Cancer Information Service

Gives up-to-date information about DCIS to patients and their families, health professionals, and the general public. Information specialists explain scientific information in plain language and respond in English or Spanish.

**Toll-free:** 1-800-4-CANCER (1-800-422-6237)

**TTY:** 1-800-332-8615

**To chat online:** go to [www.cancer.gov](http://www.cancer.gov) and click "LiveHelp" LiveHelp is available Monday-Friday, 8:00 AM – 11:00 PM

### NCI Web page devoted to DCIS:

<http://appliedresearch.cancer.gov/dcis/>

The National Cancer Institute's Web site contains information about DCIS, cancer causes and prevention, screening and diagnosis, treatment, managing symptoms, and statistics. It also includes the NCI's programs and research activities, including clinical trials and training.

### National Institutes of Health (NIH)

NIH invited experts to meet and discuss DCIS in 2009 and come to an agreement about what is known and not known about DCIS. Video and research summaries can be seen at:

<http://consensus.nih.gov/2009/dcis.htm>. After the meeting, NIH published a report, called a consensus statement, which can be read online or downloaded as a PDF:

<http://consensus.nih.gov/2009/dcisstatement.htm>

### Office on Women's Health

National Women's Health Information Center

This U.S. government center provides information about DCIS and breast cancer, including questions to ask your doctor.

**Web page that explains DCIS:**

[www.womenshealth.gov/faq/early-stage-breast-cancer.cfm](http://www.womenshealth.gov/faq/early-stage-breast-cancer.cfm)

### National Lymphedema Network

Provides education and guidance to lymphedema patients, health care professionals, and the general public on the prevention and management of primary and secondary lymphedema.

**Web site:** [www.lymphnet.org](http://www.lymphnet.org)

**Phone number:** 1-800-541-3259

**E-mail:** [nln@lymphnet.org](mailto:nln@lymphnet.org)

### Resources in Washington, D.C.

#### Cancer Prevention and Treatment Fund

This national nonprofit charity provides free information about DCIS, such as questions to ask your doctor and treatment options, ways to prevent cancer, and advantages and risks of breast reconstruction surgery.

**Web site:** [www.stopcancerfund.org](http://www.stopcancerfund.org)

**If you have questions, you can write to:**

[info@stopcancerfund.org](mailto:info@stopcancerfund.org) or call our **DCIS hotline** at 202-223-4000.

#### D.C. Cancer Answers

Free hotline created by the D.C. Cancer Consortium for people with cancer and their caregivers.

**If you have questions, you can call:** 202-585-3210



### Support Group Information

Groups that can put you in touch with other women who have been treated for DCIS and can share their experiences:

#### Imerman Angels

**www.imermanangels.org**

**Telephone:** (toll-free) 1-877-274-5529

#### Living Beyond Breast Cancer

**www.lbbc.org** (See section called “Learning From Others”)

**Telephone:** (toll-free) 1-888-753-5222

#### Reach to Recovery

American Cancer Society

**http://www.cancer.org/Treatment/SupportProgramsServices/reach-to-recovery**

**Telephone:** (toll-free) 1-800-227-2345