DUCTAL CARCINOMA IN SITU
Choosing your treatment
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About Shared Decision-Making® Programs

In this chapter:
• What Is a Shared Decision-Making® Program?
• How Can This Program Help You?
• Are the Options Discussed in This Program Appropriate for You?
• Who Made This Program?
• How Can You Know If the Information in This Program Is Up-to-Date?
• Who Are the Women in This Program?

How Can This Program Help You?
The information in this program can help you prepare to talk with your doctor so you are ready to ask questions and discuss how you feel about your healthcare options. Then you and your doctor can talk about which option may be best for you and make a decision together—a shared decision.

You might be wondering, is this information right for me? Where did it come from? How can I use it? In this section you’ll find answers to these and other questions you may have.

What Is a Shared Decision-Making® Program?
You need good information to make good decisions about your health. Shared Decision-Making® programs include videos and booklets that give you up-to-date facts about health conditions and the pros and cons of different healthcare choices. Shared Decision-Making programs do not recommend treatment, give medical advice, or diagnose medical problems.

Are the Options Discussed in This Program Appropriate for You?
Some of the options in this booklet and video may not be appropriate for your individual medical situation. Talk with your doctor about how the information in this program relates to your specific condition.

Note that Health Dialog does not approve or authorize care, treatments, or tests. The care, treatments, or tests described in this program may not be covered by your health plan. If you have questions about whether your health plan covers a particular treatment or test, talk with your health plan or your doctor.
Who Made This Program?
The information in this program is based on the latest medical research. The Foundation for Informed Medical Decision Making carefully reviewed all the information in this program to make sure it is accurate and reliable.

Health Dialog produced this program booklet and video. Neither the Foundation nor Health Dialog profits from recommending any of the treatments in this program.

How Can You Know If the Information in This Program Is Up-to-Date?
All videos and booklets are reviewed regularly and updated as necessary. If you received this program some time ago, or if someone passed it along to you, don’t use it. The information may be out-of-date.

To make sure you have the most recent program, visit www.healthdialog.com, or call 800-966-8405.

Please use the product number located on the video label or booklet when you contact Health Dialog about a program.

Who Are the Women in This Program?
The women who appear in the video are real people, not actors. They are also quoted in this booklet. These women volunteered to share their stories about how they decided to deal with ductal carcinoma in situ. They received a small fee for their time. They do not profit from recommending any treatment or self-care strategy.

The women in this program were chosen because their stories show many of the reasons people have for making different treatment choices.

They were also chosen because they had both good and bad results after treatment. But the mix of women having good and bad results in this program is not the same as the mix of good and bad treatment results in the general population. The limits on the length of the video made it impossible to include enough women to represent the actual proportion of good to bad treatment results.
Introduction

About This Booklet

This booklet is for women with ductal carcinoma in situ (DCIS), which is sometimes called intraductal carcinoma; noninfiltrating, noninvasive, or preinvasive breast cancer; or Stage 0.

This booklet is to help you decide which treatment for DCIS is right for you. The treatment choices are:

• Mastectomy (surgery to remove the breast)
• Lumpectomy, also called breast-conserving surgery (surgery to remove only the DCIS and a margin of healthy tissue)
• Lumpectomy and radiation
• Hormone therapy, such as tamoxifen and aromatase inhibitors (generally combined with lumpectomy and radiation).

There is no one best treatment choice. There is only the best choice for you given your medical situation and how you feel about the possible benefits and harms of each treatment.

This Booklet Is Not for You If...

This booklet is not intended for women with any of the following conditions, which may limit or otherwise influence their treatment options:

• DCIS in several different areas of the breast so that a lumpectomy is not possible
• DCIS with any known areas of invasive cancer
• Lobular carcinoma in situ (LCIS)
• Pregnancy
• An overall health condition that makes mastectomy or radiation therapy life threatening.

Note: Italics are used in this booklet to emphasize key words or to identify medical terms. See the Definitions of Medical Terms section at the end of the booklet for full descriptions of medical terms that are italicized.
Almost All DCIS Cases Are Treated Successfully

Many women with DCIS feel frightened and confused. They hear the words carcinoma and cancer and are offered treatments such as surgery and radiation. But DCIS is not a threat to your life.

Most women with DCIS live long, healthy lives—almost all cases can be treated successfully. In fact, no matter which treatment they choose, most women do not go on to develop invasive breast cancer, nor do they ever have DCIS come back in either breast after treatment.

Even women who do have a recurrence of DCIS or develop invasive cancer can usually be treated successfully.

To understand why this condition can be treated with such success, it helps to know a bit about DCIS and where it develops in the breast.

Understanding DCIS

The breast sits on muscles that cover the ribs of the chest wall. It's made up of fatty tissue, lobules that make milk, and ducts that carry milk to the nipple.

Inside the Breast
Abnormal cells that grow in the duct lining are called ductal carcinoma. When these cells pile up inside the duct, the condition is called ductal carcinoma in situ (DCIS). In situ means “in place.” By definition, DCIS means that the cells are contained inside the ducts.

**Inside a Breast Duct with DCIS**

Abnormal cells in the breast duct lining are called DCIS.

DCIS can grow inside the ducts, which branch through the breast much like the branches of a tree. By growing within the branching ducts, DCIS can sometimes spread through a large area of the breast.

Even though the cells are still contained in the ducts, in some cases it may not be possible for a lumpectomy to remove all the DCIS, and a mastectomy may be needed.

**How Are DCIS and Invasive Cancer Different?**

DCIS cells grow within breast ducts, while invasive breast cancer cells grow outside the ducts. Invasive breast cancer can become life threatening if the cancer cells spread to other parts of the body. This is called a distant recurrence, or metastasis.

If doctors didn’t treat DCIS, over time, some cases of DCIS would break through the duct wall and become invasive breast cancer. Other cases of DCIS would stay contained in the ducts and never cause any problems.

Unfortunately, doctors cannot tell for sure which cases of DCIS are likely to stay within the ducts and which cases will turn into invasive breast cancer or come back and grow more DCIS cells after the initial treatment.
How DCIS Is Diagnosed

Routine mammograms often show the first signs of DCIS—white specks called microcalcifications. These are tiny deposits of calcium in the breast. If they look suspicious, a biopsy is done to find out if there is invasive cancer or DCIS in the breast tissue around the microcalcifications.

In a biopsy, some tissue is taken from the breast and examined under the microscope. When a biopsy confirms the diagnosis of DCIS or invasive cancer, the amount and location of the microcalcifications on the mammogram may indicate how much DCIS there is and where it is located in the breast.

Doctors look at a variety of information about the DCIS cells, including grade and type, to help guide treatment decisions. The grade, type, and other pieces of information are described in the next chapter, Pathology Reports.

Does DCIS Need to Be Treated?

How you feel about treating DCIS after a biopsy may depend on how you feel about the risks involved. The more treatment you have, the less chance you have of developing invasive breast cancer or of DCIS coming back. But more treatment also has some downsides. It can mean more surgery, more side effects, and possibly more of your time.

The goal of DCIS treatment is to prevent the occurrence of invasive breast cancer and reduce the recurrence of DCIS.

—Monica Morrow, MD

Because it’s possible that DCIS may never develop into invasive breast cancer, some women consider not having any further treatment, other than careful monitoring, after their biopsy. This is called watchful waiting.

It’s important to know that sometimes when more tissue is removed during the mastectomy or lumpectomy, some areas of invasive cancer may be found. This happens in about 15 to 25 out of 100 women who have DCIS diagnosed with a core needle biopsy. The biopsy only takes a sample of the suspicious area and can miss invasive cancer. This is why many...
doctors feel most comfortable removing the DCIS and checking to make sure the woman has only DCIS.

If you feel you’d like to consider carefully watching DCIS to avoid or postpone treatment, it may take some time to find a doctor who feels comfortable supporting your decision.
Pathology Reports

After your biopsy and after your final surgery, your doctor sends the breast tissue that was removed to a pathologist. The pathologist examines it under a microscope and creates a report.

Although each piece of information in the report can help provide a picture of your situation, none of them can predict 100% what will happen to you in the future.

This chapter lists some key pieces of information that you might find in your report.

**Key Parts of a Pathology Report**

**Gross Description:**
Gross description describes the color, texture, and size of the tissue that was removed during the biopsy or surgery.

**Tumor Size:**
If the surgeon removed all the DCIS, the pathologist will measure the size of the DCIS. If only part of the DCIS was removed (for example with a needle or core biopsy), the size estimate will come from your mammogram or the surgeon’s description of the DCIS, based on a physical exam.

**Margins:**
The surgical margin is a border of healthy tissue around the DCIS. The pathologist examines the tissue to see if there are any DCIS cells near the edges. If there are no DCIS cells near the edges, the margins are called clear or negative or uninvolved. If there are DCIS cells at the edges of the tissue, the margins are called positive or involved. This means that more breast surgery may be needed.

Your pathology report will not include information on surgical margins if the biopsy removed only a sample of the DCIS (for example, if you had a needle or core biopsy).

**Type:**
DCIS has traditionally been classified into five main cell types based on the cell structure. These five main subtypes include comedo, cribriform, papillary, solid, and micropapillary.

**Grade (or Histologic Grade):**
Grade is a description of how abnormal the cells look and how actively they are dividing. Pathologists generally report a Nuclear Grade of 1, 2, or 3. A lower number is better.

Any of the five types of DCIS can be any grade, although the comedo type is more often

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associated with high grade. Studies suggest that DCIS that is high grade and has necrosis (see below) has a higher short-term risk of recurrence and invasive disease, but over time the risk lessens. Low-grade DCIS has a lower short-term risk, but over time, the risk catches up to high grade.

**Necrosis:**
The presence of necrosis means that the pathologist can see dead cells in the DCIS. Having lots of dead cells suggests that the DCIS may be growing faster.

**Microinvasion:**
Sometimes the pathologist will find small areas of invasive cancer, of 1 millimeter or less. Larger areas of invasive cancer, of 1 to 10 millimeters, are called minimally invasive cancer.

**Hormone Receptor Status:**
Normal breast cells and some DCIS cells have receptors for the hormones estrogen and progesterone. Tests for hormone receptors measure how many of the DCIS cells contain these receptors.

If the DCIS cells have many estrogen or progesterone receptors, the pathology report will say that the tumor is estrogen-receptor-positive and/or progesterone-receptor-positive (or ER-positive and/or PR-positive).

If DCIS cells have only a few of these receptors, the pathology report will say that the tumor is ER-negative and PR-negative. DCIS that is ER-positive is more likely to respond well to hormone therapy, such as tamoxifen.
Understanding Treatment Goals

Treatment for DCIS has two goals:

• To help prevent invasive cancer from developing in the future

• To lower the chance of DCIS coming back.

It’s important to understand that neither of these problems is as serious as many women think.

If DCIS comes back in the breast some years after treatment, it is called a local recurrence. Having a recurrence of DCIS does not change the chance of dying of breast cancer—that is still very low—but it does require more treatment.

Sometimes invasive cancer develops in the breast after treatment for DCIS. Most of these cases are caught very early, when they are easy to treat and even cure. However, for some women, the invasive cancer is more serious.

Understanding Treatment Options

The next chapters describe the treatment options for DCIS. They also include numbers to show how much each treatment may reduce your chances of DCIS coming back and invasive cancer developing.

• Keep in mind that the numbers are averages to help you compare the treatments. The amount of benefit you may get will be higher or lower depending on your age and your situation.

• Most of these numbers come from two large U.S. studies of women who had a small amount of DCIS found by a mammogram.

• Since one of the treatments, tamoxifen, helps reduce the risk of DCIS and cancer in both breasts, this booklet also includes an estimate of the chance of having DCIS or invasive cancer develop in the other breast. This is called the contralateral breast (contralateral means the other breast). On average, about 5 out of 100 women develop DCIS or invasive cancer in the other breast in the 10 years after treatment.
The benefits for each treatment and the side effects for radiation and tamoxifen were estimated from several studies that are listed in the *Research Publications Used to Write This Booklet* section at the end of this booklet.
About Mastectomy

Women who have a mastectomy:

- Lose their breast
- Usually only need one surgery (although some women will have more procedures if they choose to have certain types of breast reconstruction)
- Are at the lowest risk of having DCIS come back or developing invasive cancer in the breast where DCIS was initially diagnosed.

Mastectomy is surgery to remove the entire breast and the nipple, leaving the chest muscle and the underarm lymph nodes.

Sometimes, mastectomy is recommended for medical reasons, such as:

- When DCIS is found throughout a large area of the breast, and it would not be possible to remove it all with a lumpectomy and still have a breast that looks acceptable to most women.
- When radiation would clearly be needed after surgery, but would not be safe to have. For example, women who are pregnant or who have already had radiation to the chest area may not be able to have radiation. Some older women with other health conditions may also want to avoid radiation near the chest wall.

With mastectomy, breast reconstruction is almost always an option, either at the same time as surgery or later. If you think you might want reconstruction, talk to a plastic surgeon before having your breast surgery so you can learn about your reconstruction options.
Benefits of Mastectomy

If a mastectomy has been recommended, or is something you’re considering, it’s important to understand how it affects the chance of developing invasive breast cancer or having DCIS come back.

The chart on the right shows what happens, on average, to 100 women 10 years after having a mastectomy:

- 5 women have invasive cancer
- 2 women have DCIS
- 93 women are free of DCIS and invasive cancer.

After mastectomy, invasive cancer can develop in the mastectomy scar, skin, or chest wall, or in the other breast. Mastectomy offers the lowest chance of developing invasive breast cancer or DCIS coming back.

---

I chose to have a mastectomy because I just didn’t want to face the issue of recurrence.

—Denyse

Lymph Nodes and Mastectomy

Women with invasive breast cancer generally have lymph nodes removed during mastectomy to see if any of the cancer cells have traveled beyond the breast area. The type of cells found in DCIS typically do not travel to other parts of the body, so it is usually not necessary to remove the lymph nodes.

In some cases, a sample of the underarm lymph nodes or one or two nodes called sentinel nodes may be removed and examined at the time of mastectomy. This is called sentinel node biopsy. This is more likely
when there is a large area of DCIS or the doctor thinks that there may be invasive cancer.

If you are considering a mastectomy, you might want to talk to your doctor to find out if he or she is considering removing any lymph nodes. If so, having the nodes removed at the time of mastectomy avoids the need to go back for a second operation if invasive cancer is found.

**Appearance After Mastectomy**

Almost all women who have a mastectomy are able to have breast reconstruction. Women who are thinking about a mastectomy should consider how they feel about:

- Living without a breast
- Using a prosthesis (a removable breast form that creates a natural-looking shape when worn under clothes)
- Having breast reconstruction.

Breast reconstruction involves surgery to re-create a breast shape. Having realistic expectations about breast reconstruction is important. Sometimes the shape and size of the other breast is changed during reconstruction, either with an implant or breast reduction, in order to match the treated breast.

I didn’t ever want to look back. The thought that a mastectomy would give me a clear mind from here on out was certainly of some comfort. —Catherine

---

**To learn more about breast reconstruction:**

- Talk with your cancer surgeon and make an appointment to talk with a plastic surgeon before your mastectomy
- See the For More Information section at the back of this booklet for organizations that provide information about breast reconstruction.
Lumpectomy Alone

In this chapter:
• About Lumpectomy Alone
• Benefits of Lumpectomy Alone

About Lumpectomy Alone
Women who have a lumpectomy without other treatment:

• Can keep their breast
• May need more than one surgery if margins are not clear or free of DCIS
• Avoid the possible side effects, time, and effort of having radiation and taking hormone therapy
• Are at higher risk of having DCIS come back or developing invasive cancer in the breast where DCIS was initially diagnosed.

Lumpectomy is surgery to remove the DCIS cells along with a border of healthy tissue (called the margin). Lumpectomy is also called wide excision or breast-conserving surgery.

Surgical Margins

When surgeons do a lumpectomy, they want to be sure that the tissue they remove has a border of healthy tissue around the DCIS cells. This healthy tissue, called clear or negative margins, is shown on the left.

I definitely wanted to preserve my breast if I could.
—Barbara, chose lumpectomy
The removed tissue is examined under a microscope.

- If no DCIS cells are in the margin, it is called a clear or negative margin. This may mean that all the DCIS was removed and no more surgery may be needed.

- If DCIS cells are found near the edges of the tissue, the margins are called positive. This means that more DCIS cells may remain in the breast, and more surgery may be needed to remove them.

About 40 to 50 out of 100 women will need a second surgery because they have positive margins after lumpectomy. That means that 50 to 60 out of 100 women will not need a second surgery.

**Benefits of Lumpectomy Alone**

The chart on the right shows what happens, on average, to 100 women 10 years after a lumpectomy alone:

- 18 women have invasive cancer
- 17 women have DCIS
- 65 women are free of DCIS and invasive cancer.

**Recurrence in Treated Breast or Other Breast 10 Years After Lumpectomy Alone**

![Chart showing recurrence rates](chart.png)

This chart shows the chance of DCIS coming back or invasive cancer developing in either breast within 10 years of lumpectomy alone.

Your chance of developing invasive cancer or having DCIS after lumpectomy alone may be higher or lower, depending on your situation.
About Lumpectomy and Radiation

Women who have lumpectomy and radiation:

• Can keep their breast
• Are at lower risk of having DCIS come back or developing invasive cancer, compared to lumpectomy alone
• May need to have more than one surgery, if margins are not clear
• Should plan for several weeks of radiation
• May experience side effects of radiation (temporary or permanent)
• Should be aware that radiation may affect reconstruction options if mastectomy is needed in the future.

Radiation Therapy

Scientific studies have shown that women with DCIS can reduce the risk of recurrence by having radiation therapy. It uses high-powered, focused x-rays to kill any DCIS cells that may remain in the breast after lumpectomy. Radiation therapy helps prevent invasive cancer and lowers the chance of DCIS coming back in the treated breast.

Before the first treatment, the radiation team will determine where to aim the radiation and how much to give. After that session, a typical radiation treatment takes about 15 minutes. Treatments are usually given five days a week for up to seven weeks. Some hospitals offer temporary housing for people who have to travel long distances to reach the treatment facility.

I did not consider mastectomy seriously ... because I could never feel the lump and because it was so small. If I'd had a mastectomy with it that small, it would be overkill.

— Beverly, chose lumpectomy and radiation
Some researchers are studying different approaches to radiation for certain women with smaller areas of DCIS who have lumpectomy. Instead of treating the entire breast with radiation, partial breast irradiation treats just the area around the DCIS. This method uses balloons, catheters, implanted seeds, or external beam radiation.

In some cases, this approach can take five days or less, rather than several weeks as with traditional radiation.

- Since partial breast irradiation is a newer approach, less is known about how well it may reduce the chance of DCIS or invasive cancer coming back, or what types of side effects may result over the long term.

- Women who might be interested in participating in clinical trials studying partial breast irradiation should talk to their doctors to find out if one of the newer approaches could be appropriate for them. To learn more about clinical trials, see the For More Information section at the end of this booklet.

## Benefits of Lumpectomy and Radiation

The following chart shows what happens, on average, to 100 women 10 years after lumpectomy and radiation:

- 10 women have invasive cancer
- 9 women have DCIS
- 81 women are free of DCIS and invasive cancer.

### Recurrence in Treated Breast or Other Breast 10 Years After Lumpectomy and Radiation
For some women, the benefit of radiation is relatively small because their risk of recurrence is low to begin with. For example, some doctors have found that women who have small areas of DCIS that can be removed with a wide margin of healthy tissue have a low risk of DCIS coming back or developing invasive cancer. These women may gain less from radiation.

Some women want to save the radiation option in case they have to deal with DCIS or invasive cancer later. But there are possible downsides to this approach because sometimes when the cancer comes back, it’s not always possible to do another lumpectomy.

—Marilyn Griffin, MD

However, not all doctors agree about how to identify which women are at low risk. One study found that among women with small amounts of low- or intermediate-grade DCIS that could be removed with a wide margin of healthy tissue, closer to 90 out of 100 women were free of DCIS and invasive cancer at eight years. Other studies using these same criteria have not been able to get the same results.

These studies found that 75 to 80 out of 100 women were cancer free at five years.

**Side Effects of Radiation**

Radiation therapy can produce temporary side effects such as fatigue, pain, and skin that feels like it’s sunburned. For some women, skin changes last for several months before gradually returning to normal.

Occasionally, there are permanent changes. Between 10 and 30 out of 100 women have some problems with permanent side effects, such as:

- A darkening in the skin color (which is like a permanent tan)
- An increased density or firmness that can make the breast feel hard
- A noticeable decrease in the size of the breast, which can make the breasts look lopsided.

Radiation may also affect reconstruction choices in the future if a woman needs to have a mastectomy.
Other side effects are more serious, but rare. Months after treatment, the lung tissue may become inflamed, but this is usually not permanent and can be treated.

Radiation can also increase the chance of heart problems or other cancers. These are reported by less than 1 out of 100 women and are generally considered rare.

To avoid increasing the chance of these serious side effects, doctors usually recommend that a woman not have radiation to the same breast more than once in her lifetime. This means that if a woman who’s had radiation develops DCIS or cancer in the same breast later, more radiation may not be an option, and a mastectomy is sometimes required.

**Appearance After Lumpectomy**

How the breast looks after lumpectomy (with or without radiation) depends in part on how much tissue is removed compared with the size of the breast. In many cases, the breast appears normal, except for a scar.

Sometimes the breast is a different size or shape because of the amount of tissue removed. Women who are bothered by this may choose to have reconstructive surgery on the treated breast, or surgery to make the other breast match more closely.

I’m a little indented, but it’s not noticeable. I’m not happy to have a scar on my body. But it’s okay. It beats the alternative for me.  
—Lynda

I was probably one or two breast sizes smaller. And that was awkward for me. I stuffed bras with shoulder pads, and all the other kinds of tricks that we use.  
—Joan
Hormone Therapy

In this chapter:
- About Lumpectomy, Radiation, and Hormone Therapy
- How Hormone Therapy Works
- Tamoxifen
- Benefits of Lumpectomy, Radiation, and Tamoxifen
- Mastectomy and Tamoxifen
- Tamoxifen Side Effects and Possible Harms
- Aromatase Inhibitors

About Lumpectomy, Radiation, and Hormone Therapy

Women who have a combination of lumpectomy, radiation, and hormone therapy:
- Can keep their breast
- Can lower the risk of recurrence of DCIS or developing invasive cancer in both breasts by adding hormone therapy
- May need more than one surgery if margins are not clear
- Plan for weeks of radiation treatment
- Plan for years of taking hormone therapy
- May experience side effects with both radiation and hormone therapy.

How Hormone Therapy Works

There are different types of hormone therapies used to treat DCIS. Tamoxifen and newer medications called aromatase inhibitors work in different ways, but they have the same goal. Most DCIS and breast cancer cells need the estrogen hormone to survive. Hormone therapies prevent these types of cells from using estrogen to grow.

Your pathology report includes information about whether your DCIS is hormone-receptor-positive, which means that hormone therapy may help prevent DCIS cells from growing. If the DCIS does not contain these receptors, then hormone therapy is usually not helpful.

Hormone therapies are usually pills that are taken daily for several years. The type of hormone therapy that a woman considers...
will depend on whether she has gone through menopause and how she feels about the possible side effects of each.

The information in this chapter focuses on tamoxifen because there is more long-term data on its benefits and side effects for women with DCIS compared to newer hormone therapies, which have not been well studied in women with DCIS. At this time, researchers do not know whether aromatase inhibitors are as effective as tamoxifen in preventing recurrences of DCIS, or how long women should take them.

**Tamoxifen**

Mastectomy, lumpectomy, and radiation lower the chance of DCIS coming back or cancer developing in the breast that is being treated. But women are also at risk of developing DCIS or invasive cancer in the other breast.

Tamoxifen can lower the chance of DCIS and breast cancer in both breasts. This medication is a pill that is taken daily, usually for five years. Researchers have found that tamoxifen seems to work best in women whose DCIS cells contain estrogen receptors (ERs).

Women with DCIS who do not have estrogen receptors do not seem to get as much benefit from taking tamoxifen.

Before you consider taking tamoxifen, you’ll want to check with your doctor to find out whether your DCIS was tested for hormone receptors. Your pathology report should say whether your DCIS is ER-positive (meaning it has estrogen receptors) or ER-negative (meaning it does not).

One of the reasons I feel more confident about not developing further breast cancer is that tamoxifen drops that risk down a lot.

—Joan

**Benefits of Lumpectomy, Radiation, and Tamoxifen**

The chart on the next page shows what happens, on average, to 100 women with ER-positive DCIS who have lumpectomy and radiation and take tamoxifen for five years.
In the 10 years after lumpectomy, radiation, and tamoxifen:

- 6 women have invasive cancer
- 5 women have DCIS
- 89 women are free of DCIS and invasive cancer.

Recent studies have shown that tamoxifen helps women who chose lumpectomy alone (those who do not have radiation), but it is not as good as radiation at reducing the risk of local recurrence.

**Mastectomy and Tamoxifen**

Women who have a mastectomy may also consider taking tamoxifen. For most women who have a mastectomy, their risk is already low, so the additional benefit of tamoxifen may be very small. However, a few women with a high risk of developing breast cancer in their other breast might consider it.

**Tamoxifen Side Effects and Possible Harms**

One large study compared women taking a sugar pill to women taking tamoxifen. The study found that out of 100 women taking tamoxifen or a sugar pill, many had problems with hot flashes and vaginal discharge (see the table on the next page).
Women who still have their menstrual periods may find that their periods become lighter or eventually stop when they take tamoxifen. Depending on how close a woman is to menopause, her periods may or may not start again when she stops taking the medication (in other words, she may enter into menopause).

Tamoxifen does not seem to cause depression or weight gain. Studies show that women who do not take tamoxifen are just as likely to report these problems as those who take tamoxifen.

Several studies have also reported more serious possible harms, but they are rare, between $\frac{1}{2}$ and 1 extra case for every 100 women who take tamoxifen.

These possible harms include:

- Endometrial cancer, or cancer in the lining of the uterus, which may be cured by surgery
- Blood clots in the lungs or leg veins (most of these are treatable, although some may cause death)
- Eye problems, called cataracts (some of these require surgery).

Almost all of these possible harms occur in postmenopausal women or women older than 50.

Each woman’s experience with tamoxifen is different, and many women do not have any problems. If women try tamoxifen and are very bothered by the side effects, they can always stop taking the medication. Also, it’s a good idea to ask your doctor about possible interactions of tamoxifen with other medications you may be taking.

You need to weigh the possible benefits against the side effects and possible harms to decide if adding tamoxifen may be right for you.
Aromatase Inhibitors

For women who are past menopause, medications called aromatase inhibitors are promising and may be an option for women who cannot take tamoxifen.

These medications include:

- Anastrozole (Arimidex®)
- Exemestane (Aromasin®)
- Letrozole (Femara®).

Research is ongoing to see which medications or combinations of medications might be most effective for women with DCIS.

In women who have invasive breast cancer, recent studies found that anastrozole seems to be slightly better than tamoxifen at lowering the chance that invasive breast cancer will come back. However, in women who have DCIS, researchers do not yet know whether these medications are as effective in preventing recurrences of DCIS or how long women should take them.

Aromatase inhibitors have some side effects that are similar to those of tamoxifen, and some that are different. Side effects of aromatase inhibitors can include:

- Cold sweats and vaginal discharge, which affect somewhat fewer women compared with tamoxifen
- Endometrial cancer and blood clots, also less common compared with tamoxifen
- Hot flashes (same as tamoxifen)
- Joint problems and broken bones, which are more common compared with tamoxifen
- Sexual problems, such as loss of sex drive and pain during intercourse, which are more common compared with tamoxifen.
Comparing Treatments

The information in this chapter highlights key differences between the treatments for DCIS. As you review the material, think about how you would feel living with the different results.

Comparing Benefits

Almost all DCIS cases can be treated successfully. The chances of women with DCIS dying from breast cancer are very low. Over 10 years, only 2 or 3 out of 100 women with DCIS will die from breast cancer. About 97 or 98 will be alive or will have died of something else.

Since the chance of dying from DCIS is very low, your age and health can be important factors in deciding how much treatment to have. An older woman with other health problems is more likely to have something else that will be more of a threat to her life than breast cancer.

The bar chart on the right shows the chance of having invasive cancer or DCIS, or being free of DCIS or invasive cancer in the 10 years after each treatment. This includes the chance in either breast. The numbers show how many women are in each situation.

<table>
<thead>
<tr>
<th>Treatment</th>
<th>invasive cancer</th>
<th>DCIS</th>
<th>free of DCIS and invasive cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mastectomy</td>
<td>5</td>
<td>2</td>
<td>93</td>
</tr>
<tr>
<td>Lumpectomy, radiation, and tamoxifen</td>
<td>6</td>
<td>5</td>
<td>89</td>
</tr>
<tr>
<td>Lumpectomy and radiation</td>
<td>10</td>
<td>9</td>
<td>81</td>
</tr>
<tr>
<td>Lumpectomy</td>
<td>18</td>
<td>17</td>
<td>65</td>
</tr>
</tbody>
</table>
The bar chart below shows where DCIS or invasive cancer may occur, either in the treated breast or in the other breast.

Mastectomy has the lowest chance of having DCIS come back or of invasive cancer developing, and lumpectomy alone has the highest.

The treatments have other differences, including:

- How much of the breast is removed
- Which possible harms or side effects you may have
- What's involved in the treatment (how much time it takes, the physical recovery, etc.).

To choose a treatment that's right for you, you need to feel comfortable about how much a treatment might lower your risk of DCIS coming back or of developing invasive cancer and how you feel about the possible downsides of each treatment.
Questions to Consider

In this chapter:

• Questions About Mastectomy or Lumpectomy
• Questions About Radiation
• Questions About Hormone Therapy

As you review the various treatment options, it may help to consider the following questions. These aren’t questions to ask your doctors, but questions to ask yourself.

There is no right or wrong choice of DCIS treatment. There is only the choice that best matches your values, preferences, and lifestyle.

Questions About Mastectomy or Lumpectomy

• How important is it to you to keep your breast? How do you feel about using a prosthesis or having breast reconstruction?

• How do you feel about the possibility of having more than one surgery to remove all the DCIS (to get clean margins)?

• How worried are you about DCIS coming back or invasive cancer developing?

• Is the lower risk of recurrence with mastectomy worth more extensive surgery?

Questions About Radiation

• How do you feel about having radiation treatments five days a week for up to seven weeks?

• How do you feel about the possibility of side effects, such as:
  – Fatigue
  – Skin changes that may affect future reconstruction options (if mastectomy is necessary)
  – Other possible longer-term harms?

• Have you talked with your doctor about whether your specific case is likely to benefit from radiation?
• Is the lower risk of recurrence with radiation worth the time and energy needed for treatment and the possible side effects?

Questions About Hormone Therapy
• How do you feel about taking a daily medication for at least five years? Is the lower risk of recurrence worth the inconvenience of taking pills every day for many years?

• How do you feel about coping with possible side effects, such as hot flashes or vaginal discharge?

• How do you feel about the possible harms, such as the increased risk of blood clots and endometrial cancer with tamoxifen, or bone pain or fractures with aromatase inhibitors?
Making Your Decision

DCIS is not a medical emergency. You have time to consider your options and get involved in deciding which approach is right for you.

Some women decide to do the least possible to treat their DCIS and have a lumpectomy, which is surgery to remove only the portion of the breast with DCIS.

Others decide to do the most possible to prevent more DCIS or the development of invasive cancer and have a mastectomy, which removes the entire breast.

Some women decide to do something in between, such as having radiation after a lumpectomy, and possibly taking hormone therapy, or choosing a combination of these treatments.

The more treatment you have, the less chance you have of developing invasive breast cancer or of DCIS coming back. But more treatment also has some downsides. It can mean more surgery, more side effects, and possibly more of your time.

How You Can Be Involved in This Decision

Making this decision is not easy, but it is important that you become involved. You can play an important role by:

- Learning about your choices
- Exploring how you feel about the different choices and the benefits and harms
- Talking to your doctor about what’s important to you
- Meeting with a plastic surgeon before surgery to learn if treatments you are considering now might limit or change your breast reconstruction options in the future.
Each woman reacts differently to the thought of losing a breast, and feels differently about the possibility of having to face DCIS or invasive cancer in the future. Shared decision-making can help you combine medical facts and your personal preferences.

Take your time to make your decision. Know the type of lifestyle you live and the values that you hold dear and make your decision based on those values.

—Charlotte

By thinking about the issues discussed in this booklet, you can begin to imagine your reactions and weigh your choices. Some women know quickly which treatment feels right for them. Most of the time, however, making a decision takes some time and energy, and includes having conversations with people close to you.

As you talk with others, gather more information, and discuss your preferences with your doctor, you can decide which benefits of the treatments are most important to you, and which harms of the treatments you most want to avoid.

Living with Uncertainty

No one wants to have DCIS come back, and some women worry that they will feel worse if they have a recurrence and they didn’t do everything possible to prevent it.

Part of making good decisions is realizing that there is only so much that we can control—that good and bad things may happen no matter what we do. Finding a way to get comfortable with some uncertainty about the future can help you with whatever treatment decisions you make.

Shared decision-making can help you feel good about your healthcare choices for a long time to come.

Understand what’s involved in the treatment and try and separate the normal, natural, emotional reactions … that come with a diagnosis.

—Monica Morrow, MD
Working with Your Healthcare Team

In this chapter:

- Working with Your Doctor
- Your Healthcare Team

Working with Your Doctor

In some medical situations there is a clear right answer, and your doctor can tell you exactly what’s best to do. In other situations—for example, DCIS—there are different choices that are reasonable.

What’s “best” depends on how you feel about the good and bad things that might happen with each choice. With DCIS, you have time to work with your doctor to find the treatment that is best for your health and that makes sense with the way you live.

Working with your healthcare providers to make decisions about your care that take your preferences into consideration is called shared decision-making.

When it comes to making a decision as personal as which type of DCIS treatment to have, shared decision-making is important for your physical health, your emotional well-being, and your quality of life during and after treatment.

Research shows that women who participate in medical treatment decisions are less likely to be anxious or depressed after treatment than women who do not participate in their care. What’s more, the way women feel after treatment is influenced by their participation in choosing their treatment, rather than the type of treatment they choose.

Shared decision-making can help you:

- Get more out of conversations with your doctors
- Feel more satisfied with your healthcare and treatments
- Get the type of treatments you want
- Avoid treatments or side effects you don’t want
- Gain a feeling of control over your life.

Shared decision-making starts with a shared goal. With DCIS, that goal is to get the treatment that’s right for your needs.
To get the right care, you and your doctor need to talk about your personal goals and preferences. Getting good care requires good communication between you and your doctor.

Shared decision-making also includes shared effort.

Part of your doctor’s job is to explain your condition and treatment choices, and listen carefully to your concerns. Your job is to prepare your questions, make sure you understand the answers, and help your doctor understand what is important to you.

- Learn about the medical conditions you have, as well as any health problems you may be at risk for in the future.
- Talk clearly and openly with your doctor about your health and habits.
- Ask questions until you understand the answers.
- Use your time with your doctor wisely.
- Work with your doctor to make your healthcare decisions.
- Follow through on the care plan you choose together.

If you have trouble following through, be sure to let your doctor know so that you and your doctor can figure out an approach that works for you.

Your Healthcare Team

Here’s a description of some healthcare professionals who might be involved in your care.

Medical Oncologist:
A doctor who specializes in diagnosing cancer and treating it with drugs such as chemotherapy and hormone therapy.

Medical Social Worker:
A mental health professional trained to talk with people about coping with a medical condition. A medical social worker can also help coordinate care and find support services for people and their families.

Nurse Breast Specialist:
A registered nurse or nurse practitioner with special training in breast health who provides information and support to women facing decisions about treating DCIS and breast cancer.
Oncology Nurse:
A registered nurse or certified nurse practitioner with special training in the care of cancer patients.

Pathologist:
A doctor who is trained to identify diseases by examining tissue samples and fluids using a microscope and laboratory tests. Pathologists’ findings help diagnose diseases, estimate how the disease may behave in the future, and predict how the disease may respond to different treatments.

Plastic Surgeon:
A doctor who does breast reconstruction surgery to re-create the breast after mastectomy. Also called reconstructive surgeon.

Radiation Oncologist:
A doctor who specializes in treating cancer with radiation therapy.

Radiologist:
A doctor who examines x-rays, mammograms, ultrasounds, and other imaging tests to look for cancer and other conditions.

Surgeon:
A doctor who does surgery to remove DCIS and cancer tumors, as well as lymph nodes; may be a general surgeon or specialized breast surgeon.

Surgical Oncologist:
A doctor who specializes in surgery to remove cancer, including lymph node surgery.
Definitions of Medical Terms

(Adapted from the dictionary of the National Cancer Institute, www.cancer.gov/dictionary)

aromatase inhibitor: A drug that prevents the formation of a female hormone by interfering with an aromatase enzyme. Aromatase inhibitors are used as a type of hormone therapy for postmenopausal women who have hormone-receptor-positive breast cancer. These medications include anastrozole (Arimidex®), exemestane (Aromasin®), and letrozole (Femara®). These medications have not been as well-studied as tamoxifen in women with DCIS.

biopsy: The removal of cells or tissues for examination under a microscope. When only a sample of tissue is removed, the procedure is called an incisional biopsy or core biopsy. When an entire lump or suspicious area is removed, the procedure is called an excisional biopsy. When a sample of tissue or fluid is removed with a needle, the procedure is called a needle biopsy or fine-needle aspiration.

carcinoma: Cancer that begins in the skin or in tissues that line or cover internal organs.

contralateral breast: The breast not initially diagnosed and treated for DCIS or breast cancer.

DCIS: Ductal carcinoma in situ. Abnormal cells that are contained in the lining of a breast duct. The cells have not spread outside the duct to other tissues in the breast. Also called intraductal carcinoma or Stage 0.

hormone receptor: A protein on the surface of a cell that binds to a specific hormone. Most DCIS and breast cancer cells have estrogen and/or progesterone receptors. These types of cells often respond to treatment with hormone therapies such as tamoxifen.

hormone therapy: Treatment that blocks or removes hormones. To slow or stop the growth of DCIS and breast cancer, hormone therapies may be given to block the body’s natural hormones. May also be called endocrine therapy.
**margin:** The edge or border of the tissue removed in DCIS or cancer surgery. The margin is described as *negative* or *clean* if no DCIS cells are found at the edge of the tissue, suggesting that all of the DCIS has been removed. The margin is described as *positive* or *involved* if DCIS cells are found at the edge of the tissue, suggesting that not all of the DCIS has been removed.

**microcalcifications:** Tiny deposits of calcium in the breast that can be seen on mammograms and are sometimes associated with DCIS.

**microinvasion:** Tiny areas of invasive breast cancer that have spread outside a breast duct that is affected by DCIS.

**needle biopsy:** A diagnostic test that takes a small sample of breast tissue from an area that looks suspicious on a mammogram, perhaps because microcalcifications are present.

**radiation therapy:** The use of high-energy x-rays to kill cancer cells. Radiation therapy is used to kill cancer cells that may remain after surgery.

**recurrence:** The return of DCIS or a new diagnosis of invasive breast cancer that develops after treatment.

**sentinel node biopsy:** Procedure in which a dye or radioactive substance is injected near the DCIS and flows into the sentinel lymph node(s), the first lymph node(s) that cancer is likely to spread to. A surgeon then looks for the sentinel lymph node(s) and removes it (or them) to check for the presence of cancer cells.

**tamoxifen:** Medication that prevents the female hormone estrogen from attaching to DCIS and cancer cells and stimulating them to grow.
For More Information

Administrators in Medicine DocFinder Service
www.docboard.org
This Web site can help you find out if your doctor is board-certified. However, the most reliable source of that information is your individual state’s Board of Medicine site.

American Cancer Society
www.cancer.org
Toll-free: (800) ACS-2345 [(800) 227-2345]
TTY: (866) 228-4327
The American Cancer Society (ACS) is a nationwide community-based voluntary health organization. The mission of ACS is to eliminate cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer through research, education, advocacy, and service.

American Society of Plastic Surgeons
www.plasticsurgery.org
Phone: (847) 228-9900
This professional organization can help you find surgeons in your area.

Breast Cancer Trials
www.breastcancertrials.org
Phone: (415) 476-5777
This Web site helps women with DCIS and breast cancer find clinical trials of treatments that might be appropriate for them. Women answer a series of questions, and the Web site uses that information to match women to trials that are specific to their personal health situation and geographic location.

Cancer.Net
American Society of Clinical Oncology
www.cancer.net
Toll-free: (888) 651-3038
Phone: (571) 483-1780
Cancer.Net, the patient information Web site of the American Society of Clinical Oncology, provides oncologist-approved information on more than 50 types of cancer and their treatments.
National Cancer Institute
www.cancer.gov
Toll-free: (800) 4-CANCER [(800) 422-6237]
TTY: (800) 332-8615
Cancer.gov is the Web site of the National
Cancer Institute (NCI), the government’s
principal agency for cancer research.
Physician Data Query (PDQ) is an NCI
database containing the latest information
about cancer treatment, screening, prevention,
genetics, supportive care, and clinical trials.

Susan G. Komen for the Cure® Breast Cancer
Foundation
www.komen.org
Toll-free: (877) GO KOMEN [(877) 465-6636]
The Susan G. Komen for the Cure® Breast
Cancer Foundation aims to eradicate breast
cancer as a life-threatening disease by
advancing research, education, screening,
and treatment. The Helpline is available to
help empower women and their families by
providing them with the knowledge they
need to make informed decisions about
breast health or breast cancer concerns.

University of Michigan Health System
“The Michigan Breast Reconstruction
Outcome Study Consumer's Guide”
http://surgery.med.umich.edu
This Web site contains information to
help you make choices related to breast
reconstruction following mastectomy.
From the main page, click “Plastic Surgery”
and then click “Breast Reconstruction.”
The “Michigan Breast Reconstruction
Outcome Study Consumer's Guide”
booklet contains photos and illustrations
and can be downloaded and printed from
this site.

U.S. Department of Labor
“Your Rights After A Mastectomy...Women’s
Health & Cancer Rights Act of 1998”
www.dol.gov
This publication explains the 1998 Women’s
Health and Cancer Rights Act. The act
guarantees coverage for breast reconstruction
or prostheses, surgery on the other breast to
match the reconstructed breast, and treatment
of any complications of mastectomy. Financial
barriers should not prevent women from
having reconstruction if they choose. However, women should not feel compelled to have reconstruction simply because the surgery will be covered by insurance.

Y-ME: National Breast Cancer Organization
www.y-me.org
24-hour YourShoes Breast Cancer Hotlines:
Toll-free: (800) 221-2141 English
Toll-free: (800) 986-9505 Español

The Y-ME: National Breast Cancer Organization works to decrease the impact of breast cancer, create and increase breast cancer awareness, and ensure—through information, empowerment, and peer support—that no one faces breast cancer alone.
This booklet was written using the most up-to-date medical and scientific research. The research is described in the articles listed below. Each listing includes the authors of the article, the article title, the journal in which it was published, and the publication year. If you are interested in reading any of these articles, your doctor or librarian may be able to help you get a copy.


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