Patient Guide to Ductal Carcinoma in situ (DCIS) Surgery and Treatment

Jen D.
A busy mother of two and active community volunteer.

An educational guide prepared by Genomic Health®
INTRODUCTION

Take Charge of Your Care

With your recent diagnosis of ductal carcinoma in situ (DCIS), and throughout your preparation for surgery and treatment planning, it is normal for you to feel frightened, overwhelmed, and full of uncertainty. But you are not alone. Millions of women have been successfully treated for DCIS.

While discussing the information in this booklet with your breast surgeon, don’t be afraid to share any questions or concerns you may have. More importantly, allow yourself to rely on your family and closest friends for the strong support that only they can provide.

Remember:

DCIS IS TREATABLE: It is a non-invasive form of breast cancer and in most cases is highly curable.

YOU HAVE TIME: It is important to understand your disease and your treatment options. In most cases, treatment does not need to begin immediately—there is time to make informed decisions.

TAKE CHARGE: Make informed decisions and work with your healthcare team in planning your care and treatment.
Your Healthcare Team

Your DCIS care team consists of healthcare professionals whose job is to make sure that you are informed and that your surgery and overall treatment are a success. You can help them help you by asking questions and becoming an active member of the team. Here are the medical experts who might be involved on your care team:

**BREAST SURGEON:** Plans the surgery and removes the breast tumor

**PATHOLOGIST:** Analyzes the tumor cells to characterize your DCIS

**RADIATION ONCOLOGIST:** Treats DCIS using localized radiation therapy

**MEDICAL ONCOLOGIST:** Treats DCIS using hormone therapy

**ONCOPLASTIC SURGEON:** Performs reconstructive surgery if needed

**ONCOLOGY NURSE:** Manages your care and comfort before, during, and after treatment

**SOCIAL WORKER:** Helps with your psychological, family, and financial concerns as you return to your normal daily life

**PRIMARY CARE DOCTOR:** Attends to your general healthcare needs before, during, and after your DCIS surgery and treatment

**NURSE NAVIGATOR:** Educator and patient advocate who coordinates treatment and follows you from diagnosis to after treatment

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The Breast and DCIS

Learning the basic female breast anatomy and DCIS can help you understand your surgery options

Carol F.
Medical nurse and grandmother
Diagnosed with DCIS in 2012
ANATOMY OF THE BREAST

Use these illustrations for your notes and drawings

The female breast is a highly complex organ that gives women the ability to produce milk. It is composed primarily of fat and connective tissue, as well as the structures described below.

Milk-producing glands (lobules) are linked by small tubes called ducts. These glands are responsive to female hormones, including estrogen and progesterone.

Blood vessels deliver oxygen and nutrients to tissues in the breast.

Lymph nodes are part of the body’s lymphatic system. The lymphatic system drains and filters fluid from cells and is an important part of the immune system.

The lymphatic system drains breast fluid into bean-shaped lymph nodes, located in your blood stream. The sentinel node is the first lymph node to receive this drainage and, therefore, the first lymph node that the tumor would spread to if disease spread to the axilla (armpit).

There are no muscles in the breast. However, the breast lies over muscle that is involved in breathing and arm movement.
Types of Breast Cancer

Most cancers begin in your breast’s milk ducts (ductal cancer) or milk-producing glands (lobular cancer).

NON-INVASIVE BREAST CANCER

Non-invasive breast cancer is also called in situ breast cancer. The term in situ refers to the fact that the cancer cells are confined to one place—they have not spread to tissue surrounding the lobule or duct.

Ductal carcinoma in situ (DCIS) is confined to the lining of the milk ducts.
Breast Surgery

Choosing a breast surgery option is a difficult decision: you may have the option between lumpectomy (breast-conserving surgery) and mastectomy. Both can be effective. Your doctor will provide you with advice and facts about these options.

THE BIOPSY

When an abnormality is detected in your breast on a mammogram or by feeling a lump, a biopsy is performed to determine whether or not cancer cells are present. A biopsy can also determine the type of breast cancer, as well as other characteristics of the tumor that will help guide the treatment plan.

To perform the biopsy, tissue is taken from your tumor and examined under a microscope. Two of the most common types of biopsy are:

CORE BIOPSY: A hollow needle is used to remove tissue samples from your breast. Several small samples are sent to the pathologist for further analysis.

SURGICAL BIOPSY: All or part of the DCIS in your breast is removed through an incision in the breast, then the sample is sent to the pathologist for further examination.

LUMPECTOMY (BREAST-CONSERVING SURGERY)

Lumpectomy can be an effective treatment that conserves as much of your breast as possible. With a lumpectomy, the surgeon removes the tumor and some healthy tissue surrounding the tumor to help obtain a cancer-free surgical margin (area surrounding the tumor). As little as possible of the healthy breast tissue is taken and the breast usually retains its shape.

Lumpectomy is performed under local, regional, or general anesthesia. Recovery time is usually a matter of days.

AFTER YOUR LUMPECTOMY

After a lumpectomy, you may not experience excessive pain, but part of your breast and areas under your arm may feel tight or numb due to the effect of the surgery on nerve cells. The loss of sensation in your breast should be temporary, but it could remain to some extent for the rest of your life.
MASTECTOMY

Mastectomy involves the removal of all the glandular tissue in your breast. It is performed under general anesthesia, in most cases through an incision made across your breast.

During the mastectomy, the surgeon may place one or more small plastic tubes in the area of your breast to remove any fluids that may accumulate. This drain usually will remain in place for a short time after surgery (1-3 weeks). Recovery time is usually a few weeks.

AFTER YOUR MASTECTOMY

Your surgeon will provide you with detailed instructions, including how to care for your incision and drains, and when to resume normal activities. Don’t hesitate to discuss your concerns with your doctor.

Expect some discomfort. Depending on the extent of your surgery, you may experience pain, swelling, and bruising in your chest area.

TAKE CARE OF YOURSELF

Surgery can leave you feeling physically and emotionally exhausted. Follow your doctor’s instructions. Ask your friends and family members for help. Rest, don’t lift heavy objects, and maintain a healthy diet.
Characterizing Your DCIS

One of the most commonly diagnosed breast conditions, DCIS is an early, non-invasive form of breast cancer. Unlike invasive breast cancer, the cancer cells have stayed within the milk ducts. Although it may be overwhelming to get the diagnosis, the good news is DCIS is rarely life-threatening.

However, after therapy, women with DCIS are still at an increased risk for the cancer coming back in the same breast (called local recurrence) as either DCIS or invasive breast cancer.

To plan your treatment, the first step is usually surgery to remove the DCIS lesion. The next step is to characterize your lesion to understand how likely your disease is to return, and how beneficial certain treatments may be.

BIOLOGY OF YOUR DCIS

A unique diagnostic test, the Oncotype DX® Breast DCIS Score™ reveals the underlying biology of your DCIS by measuring the activity of certain genes.

Along with the pathology report and other factors, these results can help identify the risk that your disease will return in the same breast, either as DCIS or as invasive breast cancer.

DEFINITIVE DIAGNOSIS—THE PATHOLOGY REPORT

The pathology report provides detailed information about your disease. This information is obtained from tests performed on a biopsy or surgical sample taken from your tumor. Doctors use this information—along with other factors, including your age, medical history, and general health—to tailor your treatment and estimate the potential benefits of hormonal therapy and radiation. Information on your pathology report may include the following:

- **Tumor grade:** classifies how closely cells in the tumor sample resemble cells in normal (healthy) breast tissue

- **Tumor size:** usually reported in millimeters or centimeters

- **Surgical margins:** the edge of the tumor tissue removed during surgery
  - **Negative margins:** cancer was entirely removed during surgery (surgical margin is cancer-free)
  - **Positive margins:** residual cancer cells remain following surgery

- **Hormone receptor (ER/PR) status:** whether your tumor has receptors on the cell surface for estrogen or progesterone, which can be a driver of tumor growth
Grading and Staging

Results obtained from your biopsy enable your doctors to make treatment decisions and to determine the likelihood that your cancer may come back in the future. Grading and staging are methods that doctors use to organize this information.

**GRADING**
Grading is based on differentiation, or how closely the DCIS cells resemble normal breast cells. DCIS cells may be classified as:
- Grade 1: well differentiated
- Grade 2: moderately differentiated
- Grade 3: poorly differentiated

The higher the grade, the more different the cells are from normal.

**STAGING**
Staging is a classification method that determines the extent of your cancer. Staging is based on the results of your biopsy as well as other information. Because DCIS has not spread outside of the milk ducts, it is considered stage 0.

Treatment Options for DCIS

For women diagnosed with DCIS, standard treatment options include:

1. **LUMPECTOMY ALONE**

2. **LUMPECTOMY FOLLOWED BY RADIATION THERAPY**
Radiation therapy may be recommended for women who have had a lumpectomy to reduce their chances of the disease returning. However, radiation therapy has not been shown to prolong survival in women with DCIS.

Some of the most common side effects from radiation therapy are:
- Tiredness
- Lowered white blood cell counts
- Swelling and inflammation
- Skin sensitivity and discoloration

3. **MASTECTOMY**
Removal of the breast may be recommended for some women with DCIS.
4. HORMONAL THERAPY

Hormonal therapy blocks or limits the growth effects of hormones, including estrogen and progesterone, on cancer cells. Hormonal therapy is often used to lower the risk of hormone receptor-positive (HR+) DCIS from returning.

Tamoxifen is a common hormonal therapy for DCIS. It is a drug that blocks the estrogen receptors on cancer cells and limits the growth of these cells. Tamoxifen is given orally (by mouth) in pill form.

Hormonal treatments can lead to side effects similar to menopause, including:
- Hot flashes or flushes
- Aches and pains in the muscles and joints
- Nausea
- Blood clots
- Fertility issues

Duration of hormonal therapy is determined by your healthcare team.

The Oncotype DX® Test

The Oncotype DX test for DCIS is based on genomic science. Unlike genetics, which can help tell you your risk for getting cancer, genomics can help you choose your treatment plan once you have been diagnosed with DCIS. The test identifies which women with DCIS are more likely to have the breast disease come back, either as DCIS or as invasive breast cancer. This information may be useful in helping you and your doctor take a personalized treatment approach.

WHAT THE TEST MEASURES

The Oncotype DX test for DCIS uses genomic science to look at the activity of 12 genes in your tumor tissue, providing personalized information about your DCIS.

Your doctor is the best source of information about the Oncotype DX test and can answer additional questions that you may have.

BENEFITS OF THE TEST

The Oncotype DX test can tell you and your doctor the chances of your DCIS returning and provides personalized information that is not available from any other test or measure. This may help you and your doctor tailor your treatment plan specifically for you.
HOW THE TEST IS PERFORMED
The Oncotype DX® test is performed on a small amount of tissue that was removed during your surgery (lumpectomy or core biopsy).

When your doctor orders the Oncotype DX test, the hospital will send a sample of your tissue to the Genomic Health® laboratory that performs the Oncotype DX test.

You will NOT have to go through any additional surgery or procedure to get the Oncotype DX test.

HOW THE TEST CAN HELP YOU
Your doctor will receive a report with the results of your Oncotype DX test. The report contains your unique DCIS Score™ result, which is a number between 0 and 100.

- Women with a lower DCIS Score result may have a lower risk that their disease will return as DCIS or as an invasive tumor. It is important to note that a lower DCIS Score result does not mean that there is no chance that a woman’s DCIS may return.
- Women with a higher DCIS Score result may have a higher risk that their breast disease may return. A higher DCIS Score result does not mean that a woman’s DCIS will definitely return.

The Oncotype DX test results also provide additional information, such as the activity levels of the estrogen receptor genes in your tumor, to help guide your treatment.

IS THE ONCOTYPE DX® TEST RIGHT FOR YOU?
You may be a candidate for the Oncotype DX test if you meet both of these criteria:  
• You have been recently diagnosed with DCIS and are making treatment decisions with your doctor  
• You have had a lumpectomy or biopsy

INSURANCE COVERAGE FOR THE ONCOTYPE DX TEST
Coverage varies by insurance plan for all medical services and benefits.

In addition, Genomic Health® offers the Genomic Access Program (GAP), a comprehensive program designed to help you with the coverage process and provide financial assistance when necessary, based on eligibility. Please call (866) ONCOTYPE (866-662-6897) for more information on insurance and for financial-aid questions.
Help is close at hand through your healthcare team, support groups, and online resources.
Taking Care of Yourself

Among the many options you may choose for your DCIS treatment, perhaps the most important of all is your own involvement. Become an active participant in your treatment.

Work with your healthcare team. Learn, ask questions, maintain a positive outlook, and join a support group. Joining a support group is a great way to find answers, receive encouragement, and meet others who can assist you in getting the help you need.

RESOURCES

American Cancer Society
cancer.org
The American Cancer Society (ACS) is a nationwide, community-based voluntary organization that provides information on breast cancer prevention, detection, treatment, and community activities.

Breastcancer.org
breastcancer.org
Breastcancer.org is a non-profit organization that offers information about breast cancer diagnosis and treatment, community resources, and living day to day with breast cancer.

NCCN® Guidelines for Patients
nccn.org/patients/guidelines
The National Comprehensive Cancer Network® (NCCN) provides people with cancer and the general public with cancer treatment information in easy-to-understand language.

National Cancer Institute
cancer.gov
The National Cancer Institute (NCI) is part of the US National Institutes of Health (NIH). The NCI website provides comprehensive information on breast cancer, clinical trials, ongoing research, patient support, and resources.

Susan G. Komen for the Cure
komen.org
Susan G. Komen for the Cure is the world’s largest grassroots network of breast cancer survivors and activists. The website provides information and support for patients and caregivers, including a phone help line.

Mybreastcancertreatment.org
mybreastcancertreatment.org
For newly diagnosed patients with invasive or pre-invasive breast cancer, this is a resource to hear how others have used the Oncotype DX® test in making decisions about their treatment with their doctors.
Glossary

Useful terms and definitions for breast cancer patients and caregivers

Carol F.
Medical nurse and grandmother.
Diagnosed with DCIS in 2012.
Glossary of Terms

**Adjuvant Therapy**: Treatment performed in addition to surgery.

**Assay**: A laboratory test.

**Axilla**: A term that refers to the area near or in the armpit. Most of the lymph fluid that leaves the breast drains into the lymph nodes in the armpit.

**Cancer**: A term for diseases in which abnormal cells divide without control or order. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymph nodes to other parts of the body.

**Cell**: The smallest unit of a tissue that makes up any living thing. Cells have a very specialized structure and function.

**Ductal Carcinoma in situ (DCIS)**: An early or non-invasive form of breast cancer that is confined to the milk ducts within the breast, and is considered Stage 0 disease.

**Early-Stage Breast Cancer**: Breast cancer is categorized by stage based on the size of the tumor and whether the cancer has spread. Stage I, II, IIIA, IIB, and IIA are considered “early-stage” and refer to cancers that may have spread to nearby lymph nodes but not to distant parts of the body.

**Estrogen Receptor (ER)**: A protein that may be present on certain cells to which estrogen molecules can attach. The term “ER-positive (ER+)” means a woman’s cancer cells may be sensitive to (respond to) hormonal therapy.

**Hormone Receptor**: A hormone receptor is a protein on the surface of a cell that binds to specific hormones such as the female hormones estrogen and progesterone.

**Hormonal Therapy**: The use of specific drugs, such as tamoxifen or aromatase inhibitors, to reduce or regulate the production or effects of hormones in the body.

**Lumpectomy**: A surgical procedure that removes a localized mass of tissue, including the breast cancer tumor and a small amount of tissue surrounding the tumor.

**Lymph Nodes**: Small bean-shaped organs (sometimes called lymph glands); part of the lymphatic system. Lymph nodes under the arm drain fluid from the chest and arm. During surgery, some underarm lymph nodes are removed to help determine the stage of breast cancer.

**Mastectomy**: A surgical procedure to remove the breast.

**Oncotype DX® Tests**: The Oncotype DX tests are unique diagnostic tests that look at the genomic profile of a tumor.

**Progesterone Receptor (PR)**: A protein that may be present on certain cells to which progesterone molecules can attach. The term “PR-positive (PR+)” refers to tumor cells that contain the PR protein. These cells are generally sensitive to (respond to) hormone therapy.

**Radiation**: The use of radiation to destroy cancer cells. Radiation therapy may be used before or after surgery. Radiation is used for local control of the cancer at the site of the tumor.

**Staging**: A classification system for breast cancers based on the size of the tumor, whether the cancer has spread to the lymph nodes, and whether the cancer has spread to other sites in the body (metastasis).

**Surgical Margin**: The edge of the tumor tissue that was removed during surgery. “Negative” or “clear” margin means the cancer was entirely removed; “positive” margin means some cancer cells still remain after surgery.

**Tumor**: Tissue growth in which the cells that make up the tissue have multiplied uncontrollably. A tumor can be benign (non-cancerous) or malignant (cancerous).

**Tumor Grade**: Characterization of a tumor based on how similar the cancer cells are to normal cells.

**Tumor Size**: How big the tumor is, usually reported in metric units (millimeters [mm] or centimeters [cm]).
YOUR TREATMENT PROFILE

Tumor type: 
Tumor size: 
ER status: _____ positive _____ negative  
PR status: _____ positive _____ negative  
DCIS grade: 
Your Oncotype DX test result: 
Type of surgery: _____ lumpectomy _____ mastectomy  
Additional therapy: _____ hormonal _____ radiation

NOTES

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## IMPORTANT DATES AND SCHEDULE

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## HEALTHCARE TEAM CONTACT INFORMATION

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## NOTES

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This educational piece is not designed to provide individual advice in connection with your diagnosis or treatment plan. Such matters should be discussed with your healthcare provider.