surgery choices

For Women with Early-Stage Breast Cancer

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health
National Cancer Institute

PATIENT & FAMILY EDUCATION

NATIONAL RESEARCH CENTER FOR WOMEN & FAMILIES
The National Cancer Institute is grateful to the National Research Center for Women & Families for working in partnership with us to adapt their document, “Making an Informed Choice: Is Lumpectomy a Safe Option for Me?,” for dissemination nationally. We also wish to thank the expert development team, writers, reviewers, and pilot test and focus group participants.

Thanks also to the Susan G. Komen Foundation for their generous support for printing and disseminating this booklet.
As a woman with early-stage breast cancer (DCIS or Stage I, IIA, IIB, or IIIA breast cancer) you may be able to choose which type of breast surgery to have. Often, your choice is between breast-sparing surgery (surgery that takes out the cancer and leaves most of the breast) and a mastectomy (surgery that removes the whole breast). Research shows that women with early-stage breast cancer who have breast-sparing surgery along with radiation therapy live as long as those who have a mastectomy. Most women with breast cancer will lead long, healthy lives after treatment.

Treatment for breast cancer usually begins a few weeks after diagnosis. In these weeks, you should meet with a surgeon, learn the facts about your surgery choices, and think about what is important to you. Then choose which kind of surgery to have.

Most women want to make this choice. After all, the kind of surgery you have will affect how you look and feel. But it is often hard to decide what to do. This booklet has information that can help you make a choice you feel good about.

This booklet is for women who have early-stage breast cancer (DCIS or Stage I, IIA, IIB, or IIIA). If your cancer is Stage IIIB, IIIC, or IV this booklet does not have the information you need. To find information for you, see “Resources to Learn More” on page 17.

Of note, important words are in bold and defined through this booklet. They are also listed in "Words to Know" starting on page 20.
Step 1.
Talk with your surgeon

Talk to a surgeon about your breast cancer surgery choices. Find out what happens during surgery, types of problems that sometimes occur, and other kinds of treatment (if any) you will need after surgery. Be sure to ask a lot of questions and learn as much as you can. You may also wish to talk with family members, friends, or others who have had breast cancer surgery.

After talking with a surgeon, you may want a second opinion. This means talking with another doctor who might tell you about other treatment options or simply give you information that can help you feel better about the choice you are making. Don’t worry about hurting your surgeon’s feelings. It is common practice to get a second opinion and some insurance companies require it. Plus, it is better to get a second opinion than worry that you made the wrong choice.

Step 2.
Learn the facts

Stages of Breast Cancer

Doctors talk about stages of cancer. This is a way of saying how big the tumor is and how far it has spread. If you are unsure of the stage of your cancer, ask your doctor or nurse. Here are the stages of breast cancer discussed in this book:

- **Stage 0:** This means that you either have DCIS or LCIS.
  - DCIS (Ductal Carcinoma In Situ) is very early breast cancer that is often too small to form a lump. Your doctor may refer to DCIS as noninvasive cancer.
LCIS (Lobular Carcinoma In Situ) is not cancer but may increase the chance that you will get breast cancer. Talk with your doctor about treatment options if you are diagnosed with LCIS.

- **Stage I:** Your cancer is less than 1 inch across (2 centimeters) or about the size of a quarter. The cancer is only in the breast and has not spread to lymph nodes or other parts of your body.

- **Stage IIA:**
  - No cancer is found in your breast, but cancer is found in the lymph nodes under your arm; or
  - Your cancer is 1 inch (2 centimeters) or smaller and has spread to the lymph nodes under your arm; or
  - Your cancer is about 1 to 2 inches (2 to 5 centimeters) but has not spread to the lymph nodes under your arm.

- **Stage IIB:**
  - Your cancer is about 1 to 2 inches (2 to 5 centimeters) and has spread to the lymph nodes under your arm; or
  - Your cancer is larger than 2 inches (5 centimeters) and has not spread to the lymph nodes under your arm.

- **Stage IIIA:**
  - No cancer is found in the breast, but is found in lymph nodes under your arm, and the lymph nodes are attached to each other; or
  - Your cancer is 2 inches (5 centimeters) or smaller and has spread to lymph nodes under your arm, and the lymph nodes are attached to each other; or
  - Your cancer is larger than 2 inches (5 centimeters) and has spread to lymph nodes under your arm.
About Lymph Nodes

Lymph nodes are part of your body’s immune system which helps fight infection and disease. Lymph nodes are small, round, and clustered (like a bunch of grapes) throughout your body.

Axillary lymph nodes are in the area under your arm. Breast cancer may spread to these lymph nodes even when the tumor in the breast is small. This is why most surgeons take out some of these lymph nodes.

Lymphedema is a swelling caused by a buildup of lymph fluid. You may have this type of swelling in your arm if your lymph nodes are taken out with surgery or damaged by radiation therapy. Here are some facts to know:

- Lymphedema can show up soon after surgery. The symptoms are often mild and last for a short time.
- Lymphedema can show up months or even years after cancer treatment is over. Often, lymphedema develops after an insect bite, minor injury, or burn on the arm where your lymph nodes were removed. Sometimes, this can be painful. One way to reduce the swelling is to work with a doctor who specializes in rehabilitation or a physical therapist.

Sentinel lymph node biopsy is surgery to remove as few lymph nodes as possible from under the arm. The surgeon first injects a dye in the breast to see which lymph nodes the breast tumor drains into. Then, he or she removes these nodes to see...
if they have any cancer. If there is no cancer, the surgeon may leave the other lymph nodes in place. This surgery is new and is under study in clinical trials (research studies with people who have cancer). Talk with your surgeon if you want to learn more.

For ways to find out more about lymphedema, look in “Resources to Learn More” on page 17.

**Step 3. Find out about your breast cancer surgery choices**

Most women who have DCIS or Stage I, IIA, IIB, or IIIA breast cancer have three basic surgery choices. They are 1) breast-sparing surgery followed by radiation therapy, 2) mastectomy, or 3) mastectomy with breast reconstruction surgery.

**Breast-Sparing Surgery**

Breast-sparing surgery means that the surgeon removes only your cancer and some normal tissue around it. This kind of surgery keeps your breast intact—looking a lot like it did before surgery. Other words for breast-sparing surgery include “lumpectomy,” “partial mastectomy,” “breast-conserving surgery,” or “segmental mastectomy.”

After breast-sparing surgery, most women also get radiation therapy. This type of treatment is very important because it could keep cancer from coming back in the same breast. Some women also need chemotherapy and hormone therapy.
Mastectomy

In a mastectomy, the surgeon removes all of your breast and nipple. Sometimes, you will also need to have radiation therapy, chemotherapy, hormone therapy, or all three types of therapy. Here are some types of mastectomy:

- **Total (simple) mastectomy.** The surgeon removes all of your breast. Sometimes, the surgeon also takes out some of the lymph nodes under your arm.

- **Modified radical mastectomy.** The surgeon removes all of your breast, many of the lymph nodes under your arm, the lining over your chest muscles, and maybe a small chest muscle.

- **Double Mastectomy.** The surgeon removes both your breasts at the same time, even if your cancer is in only one breast. This surgery is rare and mostly used when the surgeon feels you have a high risk for getting cancer in the breast that does not have cancer.

Breast Reconstruction Surgery

If you have a mastectomy, you can also choose to have breast reconstruction surgery. This surgery is done by a **reconstructive plastic surgeon** and gives you a new breast-like shape and nipple. Your surgeon can also add a tattoo that looks like the **areola** (the dark area around your nipple). Or you may not want any more surgery and prefer to wear a **prosthesis** (breast-like form) in your bra. There are two types of breast reconstruction surgery:
**Breast implants.** In this kind of surgery, a reconstructive plastic surgeon puts an implant (filled with salt water or silicone gel) under your skin or chest muscle to build a new breast-like shape. While this shape looks like a breast, you will have little feeling in it because the nerves have been cut.

Breast implants do not last a lifetime. If you choose to have an implant, chances are you will need more surgery later on to remove or replace it. Implants can cause problems such as breast hardness, breast pain, and infection. The implant may also break, move, or shift. These problems can happen soon after surgery or years later.

**Tissue flaps.** In tissue flap surgery, a surgeon builds a new breast-like shape from muscle, fat, and skin taken from other parts of your body. This new breast-like shape should last the rest of your life. Women who are very thin or obese, smoke, or have other serious health problems often cannot have tissue flap surgery.

Tissue flap is major surgery. Healing often takes longer after this surgery than if you have breast implants. You may have other problems, as well. For example, you might lose strength in the part of your body where muscle was taken to build a new breast. Or you may get an infection or have trouble healing. Tissue flap surgery is best done by a reconstructive plastic surgeon who has done it many times before.

To learn more about breast reconstruction, see “Resources to Learn More” on page 17.
## Step 4

### Compare your choices

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Is this surgery right for me?</strong></td>
<td>Breast-sparing surgery with radiation is a safe choice for most women who have early-stage breast cancer. This means that your cancer is DCIS or at Stage I, IIA, IIB, or IIIA.</td>
</tr>
</tbody>
</table>
| **What are the names of the different kinds of surgery?**                | - Lumpectomy  
- Partial mastectomy  
- Breast-sparing surgery  
- Segmental mastectomy                                                                                                                                 |
| **What doctors am I likely to see?**                                     | - Oncologist  
- Surgeon  
- Radiation oncologist                                                                                                                                 |
| **What will my breast look like after surgery?**                        | Your breast should look a lot like it did before surgery.  
But if your tumor is large, your breast may look different or smaller after breast-sparing surgery. |
Mastectomy Surgery

Mastectomy is a safe choice for women who have early-stage breast cancer (DCIS, Stage I, IIA, IIB, or IIIA). You may need a mastectomy if:
- You have small breasts and a large tumor
- You have cancer in more than one part of your breast
- The tumor is under the nipple
- You do not have access to radiation therapy.

- Total mastectomy
- Modified radical mastectomy
- Double mastectomy

- Oncologist
- Surgeon
- Radiation oncologist

Your breast and nipple will be removed. You will have a flat chest on the side of your body where the breast was removed.

Mastectomy and Breast Reconstruction Surgery

If you have a mastectomy, you might also want breast reconstruction surgery. You can choose to have reconstruction surgery at the same time as your mastectomy or wait and have it at a later date.

- Breast implant
- Tissue flap surgery

- Oncologist
- Surgeon
- Radiation oncologist
- Reconstructive plastic surgeon

Although you will have a breast-like shape, your breast will not look the same as it did before surgery.

continued on next page
### Breast-Sparing Surgery

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will I have feeling in the area around my breast?</td>
<td>Yes. You should still have feeling in your breast, nipple, and areola (the dark area around your nipple).</td>
</tr>
<tr>
<td>Will I have pain after the surgery?</td>
<td>You may have pain after surgery. Talk with your surgeon or nurse about ways to control this pain. To find out ways to learn more about pain control, see “Resources to Learn More” on page 17.</td>
</tr>
<tr>
<td>What other problems can I expect?</td>
<td>• You may feel very tired after radiation therapy. • You may get lymphedema—a problem in which your arm swells. To find out more about lymphedema, see the “About Lymph Nodes” box on page 4 and “Resources to Learn More” on page 17.</td>
</tr>
</tbody>
</table>
### Mastectomy Surgery

Maybe. After surgery, you will feel **numb** (have no feeling) in your chest wall and maybe also under your arm. This numb feeling should go away in 1 to 2 years, but it will never feel like it used to. Also, the skin where your breast was may feel tight.

You may have pain after surgery. Talk with your surgeon or nurse about ways to control this pain.

To find out ways to learn more about pain control, see “Resources to Learn More” on page 17.

- You may have pain in your neck or back.
- You may feel out of balance if you had large breasts and do not have reconstruction surgery.
- You may get lymphedema—a problem in which your arm swells. To find out more about lymphedema, see the “About Lymph Nodes” box on page 4 and “Resources to Learn More” on page 17.

### Mastectomy and Breast Reconstruction Surgery

No. The area around your breast will always be numb (have no feeling).

You are likely to have pain after major surgery such as mastectomy and reconstruction surgery.

There are many ways to deal with pain. Let your surgeon or nurse know if you need relief from pain. To find out ways to learn more about pain control, see “Resources to Learn More” on page 17.

- It may take you many weeks or even months to recover from breast reconstruction surgery.
- If you have an implant, you may get infections, pain, or hardness. Also, you may not like how your breast-like shape looks. You may need more surgery if your implant breaks or leaks.
- If you have tissue flap surgery, you may lose strength in the part of your body where the flap came from.
- You may get lymphedema—a problem in which your arm swells. To find out more about lymphedema, see the “About Lymph Nodes” box on page 4 and “Resources to Learn More” on page 17.

*continued on next page*
**Breast-Sparing Surgery**

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will I need more surgery?</td>
<td>Maybe. You may need more surgery to remove lymph nodes from under your arm. Also, if the surgeon does not remove all your cancer the first time, you may need more surgery.</td>
</tr>
<tr>
<td>What other types of treatment will I need?</td>
<td>You will need radiation therapy, given almost every day for 5 to 8 weeks. You also may need chemotherapy, hormone therapy, or both.</td>
</tr>
<tr>
<td>Will insurance pay for my surgery?</td>
<td>Check with your insurance company to find out how much it pays for breast cancer surgery and other needed treatments.</td>
</tr>
<tr>
<td>Will the type of surgery I have affect how long I live?</td>
<td>Women with early-stage breast cancer who have breast-sparing surgery followed by radiation live just as long as women who have a mastectomy. Most women with breast cancer will lead long, healthy lives after treatment.</td>
</tr>
<tr>
<td>What are the chances that my cancer will come back after surgery?</td>
<td>About 10% (1 out of every 10) of women who have breast-sparing surgery along with radiation therapy get cancer in the same breast within 12 years. If this happens, you will need a mastectomy, but it will not affect how long you live.</td>
</tr>
<tr>
<td>Where can I learn more about coping with life after cancer?</td>
<td><strong>Step 4. Compare your choices continued</strong></td>
</tr>
<tr>
<td>Mastectomy Surgery</td>
<td>Mastectomy and Breast Reconstruction Surgery</td>
</tr>
<tr>
<td>---------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Maybe. You may need surgery to remove lymph nodes from under your arm. Also, if you have problems after your mastectomy, you may need to see your surgeon for treatment.</td>
<td>Yes. You will need surgery at least 2 more times to build a new breast-like shape. With implants, you may need more surgery months or years later. You may also need surgery to remove lymph nodes from under your arm.</td>
</tr>
<tr>
<td>You also may need chemotherapy, hormone therapy, or radiation therapy. Some women get all three types of therapy.</td>
<td>You may need chemotherapy, hormone therapy, or radiation therapy. Some women get all three types of therapy.</td>
</tr>
<tr>
<td>Check with your insurance company to find out how much it pays for breast cancer surgery and other needed treatments.</td>
<td>Check with your insurance company to find out if it pays for breast reconstruction surgery. You should also ask if your insurance will pay for problems that may result from breast reconstruction surgery.</td>
</tr>
<tr>
<td>Women with early-stage breast cancer who have a mastectomy live the same amount of time as women who have breast-sparing surgery followed by radiation therapy. Most women with breast cancer will lead long, healthy lives after treatment.</td>
<td>Women with early-stage breast cancer who have a mastectomy live the same amount of time as women who have breast-sparing surgery followed by radiation therapy. Most women with breast cancer will lead long, healthy lives after treatment.</td>
</tr>
<tr>
<td>About 5% (1 out of every 20) of women who have a mastectomy will get cancer on the same side of their chest within 12 years.</td>
<td>About 5% (1 out of every 20) of women who have a mastectomy will get cancer on the same side of their chest within 12 years. Breast reconstruction surgery does not affect the chances of your cancer coming back.</td>
</tr>
</tbody>
</table>

To learn more about life after cancer, you might want to read *Facing Forward: Life After Cancer Treatment*. You can get this booklet at [www.cancer.gov/publications](http://www.cancer.gov/publications) or 1-800-4-CANCER.
Step 5. Think about what is important to you

After you have talked with your surgeon and learned the facts, you may also want to talk with your spouse or partner, family, friends, or other women who have had breast cancer surgery. Then, think about what is important to you. Here are some questions to think about:

- Do I want to get a second opinion?

- How important is it to me how my breast looks after cancer surgery?

- How important is it to me how my breast feels after cancer surgery?

- If I have breast-sparing surgery, am I willing and able to also get radiation therapy?
If I have a mastectomy, do I also want breast reconstruction surgery?

If I have breast reconstruction surgery, do I want it at the same time as my mastectomy?

What treatment does my insurance cover, and what do I have to pay for?

Who would I like to talk with about my surgery choices?

What else do I want to know, do, or learn before I make my choice about breast cancer surgery?

“After I learned all I could and talked with my surgeon, I made a choice that felt right for me.”
Step 6. Make your choice

Now that you have talked with your surgeon, learned the facts, and thought about what is important to you—it’s time to make your breast cancer surgery choice.

“Now that my surgery is over, I don’t look back. I enjoy each day and take time for the simple pleasures.”
Learn More About Breast Cancer

National Cancer Institute

- **Cancer Information Service**
  Gives up-to-date information on cancer 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
  **Chat online:** www.cancer.gov
  click on “Need Help?” then “LiveHelp”

- **www.cancer.gov**
  The National Cancer Institute’s Web site contains information about cancer causes and prevention, screening and diagnosis, treatment, symptom management, and survivorship; clinical trials; statistics, funding, and training; and the NCI’s programs and research activities.

National Research Center for Women & Families

Provides information, such as questions to ask your doctor and treatment options; geographic, financial, and personal issues influencing breast cancer surgery; and advantages and risks of breast reconstruction surgery.

**Web site:** www.center4research.org
Office on Women’s Health
National Women’s Health Information Center
Provides information about breast cancer, including questions to ask your doctor.

Web site: www.4women.gov

Agency for Healthcare Research and Quality (AHRQ)
Provides information on breast cancer screening and prevention.

Web site: www.ahrq.gov/clinic

Learn More About Lymphedema

National Lymphedema Network
Provides education and guidance to lymphedema patients, health care professionals, and the general public by disseminating information on the prevention and management of primary and secondary lymphedema.

Phone: 510-208-3200
Toll-free: 1-800-541-3259
E-mail: nln@lymphnet.org
Web site: www.lymphnet.org

Learn More About Breast Reconstruction Surgery and Implants

American Cancer Society
Phone: 404-320-3333
Toll-free: 1-800-227-2345 (I-800-ACS-2345)
Web site: www.cancer.org
National Library of Medicine
Resources about breast reconstruction.

U.S. Food and Drug Administration
Center for Devices and Radiological Health
Information about breast implants.
www.fda.gov/cdrh/breastimplants

Learn More About Pain Control

National Cancer Institute

- Cancer Information Service
  Gives up-to-date information on cancer 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
  Chat online: www.cancer.gov click on “Need Help?” then “LiveHelp”

- www.cancer.gov
  The National Cancer Institute’s Web site contains information about cancer causes and prevention, screening and diagnosis, treatment, symptom management, and survivorship; clinical trials; statistics, funding, and training; and the NCI’s programs and research activities.
**Words to know**

**Areola:** the dark area around the nipple

**Axillary lymph nodes:** lymph nodes that are under the arm

**Breast-sparing surgery:** surgery that takes out the cancer and leaves most of the breast. Also called “lumpectomy,” “partial mastectomy,” or “segmental mastectomy”

**Breast reconstruction surgery:** surgery in which a surgeon builds a new breast-like shape

**Chemotherapy:** treatment with drugs that kill cancer cells

**Clinical trials:** research studies with people who have cancer

**DCIS (Ductal Carcinoma In Situ):** very early breast cancer that is often too small to form a lump. Doctors may refer to it as noninvasive cancer

**Double Mastectomy:** surgery to remove both breasts at the same time

**Early-stage breast cancer:** DCIS or Stage I, IIA, IIB, or IIIA breast cancer

**Hormone therapy:** treatment that blocks or remove hormones

**Implant:** a breast-like shape that is filled with salt water or silicone gel

**LCIS (Lobular Carcinoma In Situ):** this is not cancer but may increase the chance of getting breast cancer in the future
**Lumpectomy:** surgery to remove the tumor and a small amount of normal tissue around it. Also known as breast-sparing surgery

**Lymph:** a fluid that drains from breast tissue to lymph nodes under the arm

**Lymph nodes:** part of the body’s immune system which helps fight infection and disease

**Lymphedema:** swelling caused by a buildup of lymph fluid

**Mastectomy:** surgery to remove the whole breast and nipple

**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 muscles

**Noninvasive cancer:** has not spread beyond the layer of tissue in which it developed

**Numb:** have no feeling

**Prosthesis:** a breast-like form to wear in the bra

**Radiation therapy:** use of high-energy radiation from x-rays, gamma rays, neutrons, and other sources to kill cancer cells and shrink tumors

**Reconstructive plastic surgeon:** a surgeon who can build a breast-like shape after a mastectomy

**Second opinion:** talking with another doctor who might suggest other treatment options

**Sentinel lymph 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
Stages: a way of saying how big the tumor is and how far it has spread

Tissue flap surgery: surgery to build a new breast-like shape from muscle, fat, or skin taken from other parts of the body

Total (simple) mastectomy: surgery to remove all of the breast, nipple, and sometimes also the underarm lymph nodes