



CHOICE

Patients should have choices about their doctors, their health insurance plans, and their treatments and care. Here are some tips to get all the choices you deserve.

Quality Breast Cancer Care Means:

Choosing Your Doctors and Care Centers

Making Decisions About Your Care

Choosing Your Doctors and Care Centers

You should have choices about who gives you breast cancer care and what your care will be. You should have a choice among a range of doctors who live near you. That way you can find one you respect and want to work with. You should have the choice to work with breast cancer **specialists** near you. But you should also be able to choose a cancer center much farther away if you want. Finding a doctor who makes you feel comfortable can take time and energy.

It's worth trying to find the doctor you want. Don't settle for the first doctors you see unless you're sure they are right for you. You have a right to your likes and dislikes. Your care may take months. And you may need years of follow-up care. So it's important to find a doctor you like and can work with.

What You Can Do:

Find the best doctor for you.

Who is the best doctor? That's the first question many people ask when they face breast cancer. We can't give you a list of good doctors. That's because a doctor that's "good" for one patient may not be "good" for another. Patients care about personal style, ways of communicating, and how easy it is to see their doctors. These things count along with what the doctors know about treating breast cancer.

You have a right to work with doctors you like. For example, do you want a doctor with a sense of

humor? Do you want straight talk and the facts? Other breast cancer patients in your area can tell you about the doctors they know. They can tell you if certain doctors listen, answer questions, and give clear information. But remember that one patient can adore a doctor that another patient dislikes.

Dr. Susan Love's Breast Book (page 106) has a good list of questions to think about when choosing a doctor. Here are a few questions you might not have thought of:

- Do they let you tape-record your time together?
- Do they offer other sources of education and support?
- Do they talk about **clinical trials**?

Remember—no single doctor has all the answers. But your doctor should tell you things in a supportive way. Your doctor should welcome your questions. Find another doctor if yours is not supportive or acts bothered by your questions. Most patients can safely take time to find the right doctor.

Know who is on your team before you start treatment.

Ask your doctors who they work with. Many doctors work as a team. So surgeons, **medical oncologists**, **radiation oncologists**, and others work together to treat one patient. Doctors who do this usually have certain doctors they like to work with. Also ask your doctors who will be the

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leader of your medical team. This person should make sure everyone knows what is happening. This is called “coordinating” your care. Your surgeon or medical oncologist may

play this role. Ask to be sure that someone is taking this role. If you can, be involved in choosing everyone on your care team.

Tips for Choosing Doctors and Care Centers

Try to compare health plans. If you have any choice about your **health plan**, make an informed choice. Most Americans under age 65 get their **health insurance** through their job. Often, employers only offer one or two health plans. People on **Medicare** and **Medicaid** have limited choices, too. Even if you have more than one choice, it’s hard to compare health plans. That’s because no one measures the quality of breast cancer care very well.

The National Committee for Quality Assurance (NCQA) (page 104) is a nonprofit group funded partly by the government. The NCQA rates the care of many managed care plans. You can contact them to see if your plan is rated. There are many other report cards on health plans out there. But be sure you understand *what* they’re measuring. There are many poorly designed quality surveys.

Look for a “Board-certified” doctor. Board certification means the doctor has passed tough national tests in his or her specialty. Common specialists are

surgeons (who remove tumors), medical oncologists (who treat cancer with medicines), and radiation oncologists (who use radiation for treatment).

Board certification doesn’t guarantee a good doctor. But we advise you to look for a doctor who has had this extra training.¹³ The American Society of Clinical Oncology (ASCO) (page 100) is an association for **oncologists**. They can tell you which oncologists are Board-certified in oncology and which are not.

Be sure that your hospital or care center is “accredited.” We think you’ll have a better chance of getting good care if your hospital is accredited. An accredited hospital has met standards set by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) (page 103). JCAHO is a nonprofit group. It measures the quality of hospitals and other health care centers. Contact them to see if your hospital is accredited. They may also have a report on your hospital. See how it compares with other hospitals.

¹³ The additional training is sometimes provided through a fellowship (for example, in medical oncology or therapeutic radiology/radiation oncology) after the doctor has completed a residency. Not everyone who completes a fellowship is Board-certified. Board certification means that doctors have taken and passed an examination on the specialty in which they’ve been trained. So, there’s an additional level of quality here. The best is Board certification. The second best is someone who has done a fellowship in the relevant specialty but is not Board-certified, followed by someone who has completed a residency but not a fellowship.

Making Decisions about Your Care

Patients used to answer questions, but not ask them. They accepted care and assumed the doctor knew best. And many doctors have been trained to treat diseases and health conditions instead of the whole person. These customs are slowly changing. But there are still many wrong ideas about what patients need and who should decide.

Some doctors make treatment recommendations based on what they think a patient wants without asking the patient. For example, some doctors may think that a 60-year-old woman will care less about losing her breast than a 40-year-old. But these are very personal decisions that often have nothing to do with age. Your doctor should always ask what is important to you. Even if your doctor doesn't ask, you should tell her or him.

Your breast cancer care should not be based on what other patients want. Nor should it be based on what your doctor wants for you. It should be based on what matters to you. The key is to be informed. And then be responsible for your choices.

What You Can Do:

Be involved in your care.
Or ask a friend or family member to do that for you.

Some patients want their doctors to make all the decisions. It is very tempting to hope your doctor is perfect and do as you are told. But NBCCF believes that is risky.

In breast cancer care, what you don't know *can* hurt you. Your choices can affect your chances of surviving, other parts of your health, and your **quality of life**. Asking a question doesn't mean you don't respect your doctor's or nurse's opinion. It means that you respect them—and yourself—enough to get all the information you need. For some good tips on how to talk with doctors and nurses, contact the National Coalition for Cancer Survivorship (NCCS) (page 104). They can send you their Cancer Survival Toolbox audiotapes. The tapes include sections on talking with doctors, making deals, solving problems, and standing up for your rights.

Most doctors and nurses want to hear your questions. Your questions help them know what you want and how they can help you be informed. Ask a friend or family member to ask the questions if you don't want to.

Learn about your treatment choices. Most breast cancer patients have more than one choice to make about their treatment. And often, one choice leads to another choice. For example, some women who choose to have a **mastectomy** also choose to have **reconstructive surgery**. But that choice leads to another choice—what kind of reconstructive surgery? There are different kinds of reconstructive surgery.

It takes time to really learn about your choices and to think about your own values and preferences. It takes time to make informed decisions.

Ask a friend or family member to ask the questions if you don't want to.

We can't tell you what all your choices will be, but we can tell you about the most common choices that breast cancer patients face.

There are many sources of information about breast cancer treatment options. One of the best sources is *Dr. Susan Love's Breast Book* (page 106). Her book talks about breast cancer treatment options in depth. Some of the information from her book is also available on her [web site](#).

Biopsies

If you or your doctor thinks you might have breast cancer, you may need to have a **biopsy** performed. A biopsy is done to remove, examine, and diagnose suspicious breast tissue. This is different from a **lumpectomy**. A lumpectomy is done to remove a cancerous tumor. A lumpectomy is a surgical treatment for breast cancer.

There are different types of biopsies. Some use a small needle to remove just a little bit of tissue. Others involve cutting the breast to remove a larger sample of tissue.

Be sure to ask your doctor what kind of biopsy procedure she or he recommends and why. Ask if it is the least invasive biopsy possible. If not, why not?

Local Treatments

Local treatments try to remove or destroy all the cancer cells in the breast. There are two main types of local treatment: surgery and **radiation** therapy.

Surgery – If you have been diagnosed with breast cancer, you will probably need some kind of surgery to remove the cancer from your breast. You may need a mastectomy. This surgery removes the whole breast. Or you may be able to have a lumpectomy. A lumpectomy removes the cancer tumor, but leaves the rest of your healthy breast tissue. Most women who have a lumpectomy also need to have radiation therapy.

A lot of breast cancer patients can choose between a lumpectomy and a mastectomy. In these cases, women who have a lumpectomy with radiation therapy have the same chances of survival as women who have mastectomy. But there are important pros and cons to each treatment.

The most obvious benefit of a lumpectomy is that it doesn't take away a woman's entire breast. But most patients who choose a lumpectomy must have radiation therapy. Each radiation treatment itself is quite short. But patients usually need to get radiation treatments five days per week for six to eight weeks.

This can be hard for some patients. They may have trouble getting to and from their care center. Or it may be hard for them to take that amount of time away from their work or their families. Some patients want to finish their treatment as quickly as possible and "get on with their lives." For them, a mastectomy may be the right choice.

The choice between a lumpectomy and a mastectomy is a very personal choice. If your doctor recommends one instead of the other, be sure to ask why.

During the breast surgery, most breast cancer patients have some of the **lymph nodes** under their arm removed. Doctors want to know whether the cancer has spread to your lymph nodes. They use this information to recommend further treatment for you.

Radiation Therapy—Radiation therapy is given to early-stage breast cancer patients to help kill any cancer cells that might be left in the breast after surgery. Radiation therapy is an important part of treatment for most breast cancer patients who choose a lumpectomy. But some patients with breast cancer that's at a very early stage may not need radiation therapy. Also, some evidence shows that breast cancer patients who have four or more positive lymph nodes or have a large tumor and who choose a mastectomy are likely to benefit from radiation therapy.¹⁴

Systemic Treatments

Systemic treatments treat the cancer that may be elsewhere in your body. Cancer cells may have left your breast through the blood or lymphatic systems. You want to try to kill these cancer cells with systemic treatments so that

they do not begin growing in a vital organ. There are two main types of systemic treatments: **chemotherapy** and **hormonal therapy**.

Chemotherapy—Chemotherapy drugs kill fast-growing cells such as cancer cells. But because chemotherapy kills fast-growing cells, it also affects your hair cells and the cells in the lining of your stomach. This is why some of the side effects of chemotherapy are hair loss and a badly upset stomach. Some chemotherapy drugs have more serious side effects such as cardiac toxicity (hurting the heart). Despite its bad side effects, chemotherapy can help a lot of breast cancer patients.

Hormonal Therapy—**Estrogen** and **progesterone** are normal hormones in every woman's body. Hormonal therapy blocks estrogen and progesterone from helping breast cancer cells grow and reproduce. This type of therapy has been shown to help breast cancer patients whose breast cancer is **estrogen** or **progesterone receptor-positive**. **Tamoxifen** is one type of hormonal therapy.

Other Treatments

Scientists are studying many new types of treatments in clinical trials. They are trying to find treatments that will target cancer cells without harming many healthy cells. These treatments,

¹⁴ National Institutes of Health Consensus Development Conference statement: adjuvant therapy for breast cancer, November 1-3, 2000. *J Natl Cancer Inst Monogr* 2001;(30):5-15.

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sometimes called “**targeted treatments**,” will hopefully be more effective and less toxic than current treatments. One type of targeted treatment that is already available to women with metastatic breast cancer is the drug called **Herceptin**. Herceptin has been shown to help women with **HER2/neu** positive, metastatic breast cancer. Research is underway to see if Herceptin helps women with HER2/neu positive, non-metastatic breast cancer.

Reconstructive Surgery

Reconstructive surgery is an important part of breast cancer care for many women. It rebuilds the breast tissue that was removed during a mastectomy. Breast tissue can be rebuilt a number of ways. It can be rebuilt using an **implant** or by using a tissue flap from another part of your body such as your back, belly, or buttocks. Some women do not want reconstructive surgery. Instead, they choose to use a **breast prosthesis** under their clothes or nothing at all.

If you are thinking about reconstructive surgery, you need to learn about the options available. There are important differences between the two major types of breast reconstruction: implants and tissue flaps. Here are some important things to think about:

- More plastic surgeons know how to do breast implant surgery better than **tissue flap surgery**. It is an easier and shorter surgery. So, if your plastic surgeon recommends one type of reconstructive surgery over another,

be sure to ask why. It may be that your breast surgeon is recommending an implant surgery because that is the only reconstructive surgery she or he knows how to do.

If you are interested in the tissue flap surgery, you can look for a plastic surgeon who has experience with this type of surgery. If you live in a small town, you may need to travel to a larger city to find a plastic surgeon who does a lot of tissue flap breast reconstructions.

- Tissue flap surgery is harder on patients because tissue and blood vessels from another part of their body must be used. The surgery and recovery take longer than when using implants.

But implants often involve more follow-up visits and additional surgeries in the long run. For example, some women need a temporary implant (an expander to stretch the skin and tissue). These women need an additional surgery to replace the temporary implant with a permanent implant. And sometimes the permanent implant needs to be replaced after a number of years.

Also, many patients who choose an implant also choose to have surgery on their other breast to make both breasts look similar. This happens because implant reconstructions tend to stick straight out from the chest rather than droop naturally. So, implants usually do not match the woman's other breast.

- Implants can get hard as scar tissue builds up. Tissue flap surgery results in softer breasts since your own tissue is used. But it can leave bigger scars.
- With tissue flap surgery, plastic surgeons can more easily shape the reconstructed breast to match the natural breast. This allows the reconstructed breast to have a more natural droop than is possible with implants.
- A nipple can be reconstructed or tattooed after you have healed from the surgery. This is done in the doctor's office. Some patients

Sometimes the cancer can't be cured.

No matter what your **diagnosis** is, you have treatment choices. For most women with breast cancer, the treatment will help. But, for some women, at some point, treatments stop working. This is sometimes called "end-stage" **metastatic breast cancer**.

At this point, the tumor becomes very resistant to treatment. The possible benefits of the treatment are so small, they may not be worth the side effects anymore. The patient may be very weak, and the treatments are making her feel even worse.

Often, nobody talks about what is happening. The doctors don't talk about it. Neither does the patient or family. This can be bad for everyone involved. People may say they "don't want to give up hope." But sometimes you need to redefine what you can hope for. Sometimes a peaceful death can become the goal. But, this often doesn't happen. Many patients get chemotherapy in the last week of their lives, when in fact their goal is comfort.

Hospice care is a special service for terminally ill patients and their families. It helps the sick person be comfortable. It also helps them lead a decent life through the phases of dying. Often hospice care is not called in until the last few *days* of a patient's life. This is too bad, because the final *weeks or months* could have been much easier with hospice care.

It is very hard to talk about dying. But an open, honest talk about where the patient is in her disease can make a big difference. Doctors, patients, family members, and other caregivers should all take part in the talk.

The Compassion in Dying Federation (page 101) works on issues that are important during the last stages of life. They have information about:

- **pain control,**
- **advance directives,**
- hospice care,
- stopping medical therapy, and
- how to plan a gentle death.

Contact them to get help with these difficult issues.

Different people will make different decisions about how much treatment they want, and for how long.

choose to have a nipple reconstructed, and others decide it's not that important to them.

- Reconstructed breasts and altered nipples will not have the same full sensation that a natural breast does.
- Implants do not get bigger when a woman gains weight, but tissue flaps do. This is especially important for women who have only one breast done.
- There are good results and bad results. It is very important to have your surgery done by a plastic surgeon who does a lot of the type of surgery you are going to have. For example, if you choose a tissue flap reconstruction, you want a plastic surgeon who has done this type of surgery many times. Ask your surgeon how many times she or he has done this surgery. And ask for before-and-after photos of some of her or his patients. That way you can see what to expect.

Ask yourself some hard questions.

Every breast cancer patient must ask herself some hard questions such as these:

- What will you go through for a small chance to live longer?
- What kinds of side effects are you willing to accept?

For example, think about the choice between a mastectomy and a lumpectomy with radiation. Both offer the same chances of survival for some women. But each choice has different results and consequences. Either choice is OK, depending on your preferences.

If your breast cancer has spread to other organs in your body (called “metastatic breast cancer”), it's even more important to ask these questions. That's because less is known about how to treat this type of breast cancer.

Different people will make different decisions about how much treatment they want, and for how long. Realize that treatment choices are in your hands.

It might help to talk with other patients. Many have faced the same choices. Contact NBCCF (page 99) to see if there's a field coordinator or breast cancer group near you.

