



ACCESS

Access means being able to get the care you need when you need it. Most importantly, that means having a way to pay for health care. It can be health insurance, a health plan, or some other way to pay, such as free care programs.

Access means a lot of other things, too. For example, it means having doctors and nurses in your area who speak your language. And it means getting help caring for your family while you get care. There are roadblocks to getting health care. But there is also a lot of help out there, if you know where to look.

Quality Breast Cancer Care Means:

Finding Affordable Care

Getting Comprehensive Care

Finding Affordable Care

You may have **health insurance** or a **health plan** that pays for all the care you need. Or it may pay for some of what you need, but not all. Or you may have no health insurance or plan.

Sadly, we are not guaranteed a right to health care in the United States. Someone has to buy it. It could be your employer, the government, or you. It is important to understand your health plan so you can be sure your plan is paying for everything it should.

What if you have no insurance? There are ways to get free and low-cost services.

What You Can Do:

If you have health insurance, learn how it works.

Many of us feel that our health plan should pay all the costs of our health problems. But health care is like car insurance or home insurance. There are different packages and types of **coverage**. Your plan may not pay for all the health care you need or want. You need to learn about *your* health plan package.

Find out who pays for your health plan.

Most American adults under age 65 get their health insurance through their jobs. Employers may pay for all, some, or no health insurance costs. There is *no* law that says employers must provide health insurance to their employees.

Other adults buy health insurance for themselves. For example, self-employed people usually buy their own insurance.

Most Americans age 65 or over can get health insurance through the federal **Medicare** program. The federal-state **Medicaid** program covers mostly lower-income families and people with disabilities. The rules for getting Medicaid vary by state.

Your health insurance “carrier” is the company that carries out your health plan’s rules. It is also the company that pays for your care. Blue Cross and Blue Shield is an example of a health insurance carrier. When your insurance carrier pays for something, it is called a “**benefit**.”

Find out what is covered.

Health insurance plans vary a lot in what they cover and cost. You need to learn what your health plan covers:

- Do you get your insurance through your job? Ask your benefits manager for a copy of your plan’s benefits.
- Do you buy your own insurance? You should have a booklet that explains what is covered by your plan.
- Are you age 65 or older? You can probably get Medicare. The government office that manages the Medicare program is called the Centers for Medicare and Medicaid Services (CMS). Contact CMS (page 101) for information on the Medicare program.

There are ways to get free and low-cost services.

- Are you disabled? Will your disability last six months or more? If so, you may be able to get disability benefits from the federal government through the Social Security Disability Insurance (SSDI) program.

The government usually agrees that you are “disabled” if you have **metastatic breast cancer** (breast cancer that has spread to another organ in your body).

Are you under age 65? And have you gotten SSDI benefits for at least 24 months? Then you can also enroll in Medicare. Contact the Social Security Administration (page 106) and Medicare (page 103) program for more information.

- Do you earn very little money? You may be able to get Medicaid. Contact your state’s health department. The phone number should be in the government pages of your phone book. Someone there can tell you if you can get Medicaid. He or she can also tell you which benefits your state offers.

If you don’t have health insurance, look for free or low-cost services.

Contact breast cancer activists in your state. NBCCF’s field coordinators work closely with NBCCF’s national office. They know about the services you can get in their areas. And they can connect you with others who have been down the same road. Contact NBCCF (page 99) to see if there’s a field coordinator near you.

Find out if you can get screened at a CDC site. The U.S. Centers for Disease Control and Prevention (CDC) runs the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). The program has a long name, but a simple and important task. It gives breast and **cervical cancer** screenings and treatment to low-income women. All 50 states offer screening and **diagnostic services** through the NBCCEDP. And most states provide free treatment through the program, too.

NBCCF worked hard to pass the Breast and Cervical Cancer Treatment Act in 2000. The Act expands the NBCCEDP. It allows states to give treatment through the Medicaid program. Now, if a woman gets a **mammogram** through this program, and it turns out she has breast cancer, the NBCCEDP can pay for her treatment, too.

To get breast cancer care through the program, you must:

1. get your mammogram through the CDC NBCCEDP and need treatment for breast cancer (You qualify if your mammogram shows a **precancerous condition**, too),
2. not have health insurance that covers breast cancer care,
3. not qualify for the Medicaid program in any other way,
4. be under age 65 (so that you can’t get Medicare), and
5. be a U.S. citizen or a “**qualified alien**.”

What is Medicare?

The Centers for Medicare and Medicaid Services (CMS) run the Medicare program. Medicare is a health insurance program for:

- people age 65 and older,
- some people with disabilities under age 65, and
- people with End-Stage Renal Disease (permanent kidney failure).

Medicare has Two Parts:

- Part A (Hospital Insurance)—Most people do not have to pay for Part A.
- Part B (Medical Insurance)—Most people pay something every month for Part B.

PART A (Hospital Insurance)

Helps Pay For:

Care in hospitals, nursing homes, **hospice care**, and some home health care.

Cost:

Most people get offered Part A when they turn age 65, without even asking for it. If you paid Medicare taxes while you worked, then Part A is free. That means you don't have to pay a monthly payment called a "**premium**" for Part A.

What if you have never paid Medicare taxes? You can also get Part A free if your *spouse* (husband or wife) paid Medicare taxes while working.

What if *neither* you *nor* your spouse paid Medicare taxes while working? You still may be able to *buy* Part A if you are 65 or older.

If you are not sure you have Part A, look on your red, white, and blue Medicare card. Does it show "Hospital Part A" on the lower left corner of the card? If so, then you already have Part A. If not, you can find out about buying Part A by calling the Social Security Administration (page 106). Or call your local Social Security office. They can also tell you how to get a Medicare card if you don't have one.

PART B (Medical Insurance)

Helps Pay For:

Doctors' services, **outpatient** hospital care, and some other medical services that Part A does not cover. These can include **physical** and **occupational therapy** and some home health care.

Cost:

You pay the Medicare Part B premium of about \$50 per month. This amount may be higher if you did not choose Part B when you first turned 65.

Enrolling in part B is your choice. You can sign up for Part B anytime during a seven-month period that begins three months before you turn 65. Call the Social Security Administration (page 106) for more information. Or visit your local Social Security office to sign up

For More Information:

Contact the Centers for Medicare and Medicaid Services (page 101) and the Social Security Administration (page 106). They can help you find out if you qualify for Medicare and how it works.

What is Medicaid?

The Medicaid program serves mostly low-income families with children and some people with disabilities. The federal government and the states share the cost of the program. States manage and run most of the program. Each state decides its own rules about who can get health care through the program. These rules are complex and vary a lot from state to state.

For More Information:

Contact your state's health department. The phone number should be in the government pages of your phone book. Someone there can help you find out if you qualify for Medicaid.

Contact the CDC (page 101) to find out:

- if you can get a mammogram through this program,
- where you can get a mammogram, and
- if your state gives treatment through this program.

Check if your state offers its own cancer screening and treatment program. A few states have health care programs for people without insurance. Contact your state health department to see what services your state offers. The phone number should be in the government pages of your phone book.

Learn about the Hill-Burton free care program. In 1946, Congress passed a law called the "Hill-Burton Act." It gave hospitals and other care centers money for building and updating. In return, the centers that received these funds agreed to:

1. provide a reasonable volume of services to people who can't pay and
2. make their services available to all people living in the center's area.

This means that many care centers must give health care to some people who can't afford to pay. To qualify for free care, your income must be below a certain level. And, you must not be covered by Medicare or Medicaid, or some other health insurance program. You can apply to the program at any time. You can apply before or after you receive care. You can even apply if a bill has been sent to a collection agency. If you qualify, Hill-Burton funds will cover the care center's charges. It doesn't cover your private doctor's bills. Still, this can be a huge help.

Hill-Burton care centers must post a sign that says, "NOTICE—Medical Care for Those Who Cannot Afford to Pay." This sign must be posted in the care center's Admissions Office, Business Office, and Emergency Room.

Here's how to find out if you can get free care through the Hill-Burton program:

1. Contact the Hill-Burton program (page 102). Ask for a list of Hill-Burton care centers in your area.
2. After you find a Hill-Burton care center, go there and ask for a copy of its "Individual

Ask everyone for help.

Notice.” This notice will tell you which types of free or low-cost services the care center provides through the Hill-Burton program. It will also tell you where in the care center to apply to the program.

3. Apply to the program. Usually, you must go to the Admissions Office or Business Office to apply. The care center may ask you to fill out an application.
4. If you are asked for proof of your income, give this information to the care center. A pay stub may be requested.
5. If you are asked to apply for Medicaid, Medicare, or some other financial assistance program, you must do so.
6. When you return the completed application, ask for a “Determination of Eligibility.” This will tell you whether you can get free care through the program.

Contact a local or state health services group. Many local and state groups give free or low-cost mammograms and other health services. For example, the Avon Breast Care Fund gives money to many community groups. These groups give free or low-cost mammograms to women without health insurance. Contact the Avon Breast Care Fund (page 100) to find out what is in your area.

Find other ways to get help paying for care. Look for groups that can help pay for care. A nonprofit group called Cancer Care (page 100) has a booklet called, “Helping Hand Resource Guide.” It lists cancer-related assis-

tance programs available across the country. Ask the group to send you a copy.

Ask for free medicine. Ask your doctor or nurse about “drug assistance programs.” Some drug companies give free medicine to patients who can’t pay for it. Every drug company has different rules. These programs don’t include all drugs. But they’re worth looking into. Your doctor or clinic may have access to these programs. The drug companies have a group called Pharmaceutical Researchers and Manufacturers of America (PhRMA) (page 106). PhRMA has information on all the drug assistance programs their members offer. Contact PhRMA to see if a drug company can help you.

Ask for help getting to and from your treatment center.

- Your NBCCF field coordinator may know about ride services in your area. Contact NBCCF (page 99) to see if there is a field coordinator near you.
- You can ask doctors, nurses, and social workers about services that can help you.
- Local groups may also have information. Try cancer organizations, community centers, churches, temples, and women’s groups. Sometimes they can give you free or low-cost rides to your doctors’ offices or to hospitals.
- The Patient Travel (page 106) organization has free information and referrals. The group helps people who must move far away

for care after an illness or accident. Contact Patient Travel for more information.

Ask everyone for help.

- Ask people to hold fund-raisers for you. Or talk with leaders of your religious group. See if they can help you cover the costs of your care.
- Contact your local, state, and national elected public officials. (Some examples are mayors, state representatives and senators, and U.S. representatives and senators.) They may be able to help you.
- Go to your local hospital. Explain your problem to a doctor, nurse, or social worker. They know the system. They may be able to direct you to the right place for help.

Get time off work.

The Family and Medical Leave Act (FMLA) lets people take time off from work. People use the time to care for their families or themselves

without losing their jobs. Do you work for a company with more than 50 workers? If so, you can take up to 12 weeks of unpaid leave a year. The leave can be used to:

- care for a newborn or newly adopted child,
- care for very ill family members, or
- recover from your own health problems.

Some states have even better laws. The National Partnership for Women and Families (page 105) is a nonprofit group. They work on health, work, and family issues. Call and ask them for their guide to the FMLA.

There are also programs that may help women with metastatic breast cancer if they want to retire from work. Women with metastatic breast cancer may be able to get Social Security Disability Insurance (SSDI). SSDI gives money to women who qualify. Contact the Social Security Administration (page 106) for more information.

Getting Comprehensive Care

Breast cancer patients need a wide range of services. Sometimes it's hard to know if you've gotten all the care you need.

Everyone needs:

- an accurate **diagnosis**,
- timely follow-up care,
- **second opinions** about both diagnosis and treatment options,
- a complete and honest talk about the **evidence** behind treatment choices,
- help judging the value of joining **clinical trials**.

- help judging **complementary** and **alternative therapies**, and
- social and support services.

You may also need:

- surgery and **reconstructive surgery**,
- medicines,
- **radiation** treatments,
- **palliative care** (such as **pain control**),
- mental health services,
- **physical therapy**,

- translators if your doctors and nurses do not speak your language,
- help paying for your care,
- wigs, bras, and **breast prostheses**,
- help getting the care you need if you are disabled, and
- help coordinating care with your other doctors if you have other health problems.

Women with **end-stage breast cancer** may also need:

- help with symptoms caused by their disease or treatments,
- household help and child care,
- emotional and practical support for the caregiver and other family members, including children,
- **hospice care**,
- family counseling, and
- help with **advance directives**.

All of this care needs to be coordinated. That means that all of your doctors and nurses talk to each other. It also means that one person:

- manages all parts of your care and recovery,
- keeps track of your overall health, and
- keeps track of the care you get from different doctors and nurses.

What's more, your care should be timely. That means you should get the care you

need when you need it. Waiting two weeks to get a lump checked may not affect the course of your disease. But you shouldn't have to wait so long and live with the worry.

You should get the same care whether you live in a big city, a small town, or a remote village. But studies have shown that where you live *does* affect the quality of your care. For example, people living in cities often get different care than those in rural areas.⁴

What You Can Do:

Learn about the standard of care for breast cancer.

There are breast cancer treatment guidelines based on medical evidence. These guidelines say what treatments are most likely to help breast cancer patients. Most doctors agree about most of the guidelines. The guidelines make up a **standard of care** for breast cancer. You should read these so you'll know what to expect and what kind of care you deserve. See page 39 for more information on guidelines.

Think about joining a clinical trial. If your doctor did not tell you about clinical trials, you are not alone. A recent study found that only about 38% of patients are offered a clinical trial by their doctors.⁵

4 Howe HL, et al. Patterns of breast cancer treatment: a comparison of a rural population with an urban population and a community clinical oncology program sample. *Cancer Control* 1995;2(2):113-20.

Ayanian JZ, Guadagnoli E. Variations in breast cancer treatment by patient and provider characteristics. *Breast Cancer Research and Treatment* 1996;40(1):65-74.

5 Siminoff L, et al. Factors that predict the referral of breast cancer patients onto clinical trials by their surgeons and medical oncologists. *Journal of Clinical Oncology* 2000;18(6):1203-11.

Studies show that breast cancer patients who take part in clinical trials tend to do better than patients who do not.⁶

Studies show that breast cancer patients who take part in clinical trials tend to do better than patients who do not.⁶ This may be because most patients are given good care and follow-up in a clinical trial. They get good care no matter which treatment they get. Ask your doctor about clinical trials. And see pages 23-25 for more information about clinical trials.

Think about traveling to a bigger care center.

Try to get care somewhere that treats a lot of women each year for breast cancer. Studies have shown the following:

- Breast cancer patients tend to get better care at larger hospitals.⁷
- Breast cancer patients do better with surgeons who see more than 30-50 new cases each year.⁸ (Ask your doctor's office how many breast cancer patients they treat each year.)
- Patients treated by breast cancer **specialists** tend to do better than patients whose surgeons are not breast cancer specialists.⁹

It's important to see an experienced doctor who has done what you need many times. For reconstructive surgery, your **plastic surgeon** should offer you "before-and-after" photos.

That way you can see what to expect from the surgery.

Ask about tele-medicine. With access to the Internet, both doctors and patients can get up-to-date information on how to treat breast cancer. And now doctors across the country can consult each other over the phone and Internet. Ask your doctors if they consult with cancer specialists. If your doctor doesn't want to, maybe you should find one who will.

Know your rights as a breast cancer patient.

Congress passed a law that makes most **health plans** and **health insurance** companies cover certain parts of breast cancer care. The law is called "The Women's Health and Cancer Rights Act of 1998." For example, one treatment for breast cancer is to remove the breast. This is called a "**mastectomy**." Reconstructive surgery is a kind of plastic surgery that rebuilds the breast. Federal law says that health plans and insurance companies must cover reconstructive surgery if they cover a mastectomy. And they must cover surgery on the healthy breast to make both breasts the same size and shape. The law also says that they must pay for breast prostheses and treatment of **lymphedema**,

6 Gnant M, et al. Impact of participation in randomized clinical trials on survival of women with early-stage breast cancer: an analysis of 7985 patients. *Proceedings ASCO* 2000; 19 (abstract 287).

7 Roohan PJ, et al. Hospital volume differences and five year survival from breast cancer. *American Journal of Public Health* 1998;88(3):454-57. Ayanian JZ, Guadagnoli E. Variations in breast cancer treatment by patient and provider characteristics. *Breast Cancer Research and Treatment* 1996; 40(1):65-74.

8 Sainsbury R, et al. Influence of clinical workload and patterns of treatment on survival from breast cancer. *Lancet* 1995;345(8960):1265-70.

9 Gillis CR, Hole DJ. Survival outcome of care by specialist surgeons in breast cancer: a study of 3786 patients in the west of Scotland. *British Medical Journal* 1996;312(7024):145-48.

It is important that *one* person keep track of all your medical issues.

which is the swelling of the arm that sometimes happens after lymph node removal.

Sometimes states have better laws than the federal government about breast cancer care. To find out if your state has passed breast cancer laws, contact the National Conference of State Legislatures (NCSL) (page 104). Or contact your state health department. The phone number should be in the government pages of your phone book.

If you think you were turned down for care unfairly, you can appeal. This means that you ask your health plan to review your care request again. Appealing works best when you can back your appeal with proof that you need the care. Care that you need is called “medically necessary” care. Contact your health plan to find out how to appeal a decision the plan made. For more information on how to file an appeal, see pages 71-73.

Ask about coordination of care.

It is important that *one* person keep track of all your medical issues. This is called “**coordination of care**.” Ask about this when you choose a team of doctors and a place to get your care. Ask:

- Who is in charge of my care?
- How does he or she share information with my other doctors and nurses?
- How is my case reviewed and by whom?
- Whom do I call when I have questions?
- Can I get a care plan in writing? Will it have information such as test results, care instructions, appointments, and medicine instructions?

Some doctors and nurses really *do* coordinate care. So look for this service if you have any choice about where you get your care.

Patient Navigators

Some care centers have breast care coordinators, or “patient navigators.” They may be nurses, health educators, social workers, or **behavioral medicine** specialists. No matter what their background, their job is to help you through the care process. For example:

- They may gather your medical records, films, and **slides** for your second opinion.

- They may arrange a meeting with several specialists at one time. That way you can hear a range of opinions. You can hear where your doctors agree and disagree about your care.
- They can also help you find support groups.

Patient navigators often serve as a resource for all parts of your care. There usually is no extra fee for this service.

What are clinical trials?

A clinical trial is a research study. Clinical trials are used to find out if new treatments work better, the same, or worse than the standard treatment for the same disease. Carefully run clinical trials are the fastest and safest way to find treatments that work.

How Are Clinical Trials Designed?

Clinical trials of **investigational treatments** go through three phases:

- In Phase I trials, researchers test a new treatment in a small group of people. The goals of Phase I trials are to:
 - judge if the treatment is safe,
 - find safe dosage levels, and
 - find out about any side effects.
- In Phase II trials, the new treatment is given to a larger group of people. The goals of Phase II trials are to:
 - see if the new treatment helps and
 - further judge its safety.
- In Phase III trials, the new treatment is given to an even larger group of people. The goals of Phase III trials are to:
 - compare the new treatment to the standard treatment,
 - get more information about whether the new treatment helps,
 - keep track of side effects, and
 - collect information for using the new treatment safely.

In most Phase III trials and some Phase II trials, patients are divided into at least two groups or “arms.” One group of patients

gets the new treatment. This group is called the “**investigational group**.” The treatment they get is called the “investigational treatment.” Another group of patients gets the standard treatment. This group is called the “**control group**.” The standard treatment is the treatment you would get if you did not take part in the clinical trial. Groups are compared to see which treatment works better.

In well-designed clinical trials, patients are assigned to different “arms” of the trial using a system similar to flipping a coin. In other words, patients do not choose whether they will get the new treatment (investigational group) or the standard treatment (control group). Grouping patients by chance is called “**randomization**.”

In some trials, patients know which arm they are in. In other trials, patients do not know which arm they are in. This is called a “**blind study**.” In some trials, neither doctors nor patients know which arm the patients are in. These trials are called “**double-blind studies**.”

Should I Join a Clinical Trial?

There are three main reasons why you should think about taking part in a clinical trial:

1. Clinical trials may be the best way to be sure that you get good treatment. Many studies have found that just being in a clinical trial raised patients’ chances of surviving. This was true no matter which arm the patients were in.¹⁰

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¹⁰ See for example: Ghant M, et al. Impact of participation in randomized clinical trials on survival of women with early-stage breast cancer: an analysis of 7985 patients. *Proceedings ASCO 2000*; 19 (abstract 287).

What are clinical trials?

2. Clinical trials are the only way we will ever find new ways to detect, treat, and finally cure breast cancer. Right now, only 3% of adult cancer patients take part in clinical trials. The more patients that join clinical trials, the more quickly research moves forward.
3. Being in a clinical trial means that you might get a promising new treatment earlier. Of course, you can't be sure that the investigational treatment will help you.

How Can I Find Trials?

There are many ways to find clinical trials. You can ask your doctors or call the National Cancer Institute (page 103). You can also search the **Internet**. No one can give you a list of *all* the clinical trials you might join. For that reason, you should use all the tools you can.

- First, ask your doctor. Your doctor may not know of any trials for you. But talking about it will let her or him know that you are interested in clinical trials.
- The National Cancer Institute (page 103) maintains a database of cancer clinical trials.
- The Internet is the fastest-growing source of clinical trials information. No one **web site** is complete. But you can get a lot of information from a few sources. One of the best web sites is sponsored by the Library of Medicine (page 105). It lists all National Cancer Institute trials as well as other trials.

How Do I Know If It is a Quality Clinical Trial?

NBCCF has standards for judging clinical trials. A good trial needs *at least* these three things:

- Approval by an **Institutional Review Board**—This means that a committee has checked that the study meets ethical standards, does not put patients at great risk, and includes safeguards for patients.
- Meaningful **Informed Consent**—This means that you understand what you are doing and what can happen to you in the trial.
- A Good Design—This means that the trial is well-designed to answer an important question about breast cancer. Questions may concern how best to prevent, detect, diagnose, or treat breast cancer.

Remember that for many clinical trials, doctors and informed consent forms can't tell you what might happen to you. The purpose of the clinical trial is to see if a new treatment works better than the standard treatment. Sometimes new treatments don't work as well as the standard treatment. Or the new treatment may have serious side effects. This is why it is important that clinical trials are watched closely.

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What are clinical trials?

For more information, contact NBCCF (page 99) and ask for a copy of our “Criteria to Evaluate Quality Clinical Trials.” Do you need help judging the quality of a clinical trial? An NBCCF-trained **advocate** may be able to help you. NBCCF’s trained advocates are not medical professionals. They cannot give you medical advice. But they may be able to help you sort out the details and make an informed choice. Contact NBCCF for more information.

What Will It Cost to Take Part in a Clinical Trial?

The trial sponsor usually pays for the cost of the investigational drug or other treatment that is being studied. The trial sponsor may be a drug company or the National Cancer Institute. But there may be other costs involved in taking part in a clinical trial (for example, doctor visits, blood work, and other tests). And sometimes patients must pay for some or all of these costs. This is often because their health insurance or health plan won’t pay for them. And sometimes health plans only agree to pay these costs under certain conditions. For example, your health plan may cover the costs for your blood work and other tests. But it may only cover them if

you have the tests done at a certain care center. This may be a problem if the care center where you must have your tests done is far away from the place where you go for the clinical trial. Sometimes patients can work out a deal with the trial sponsor so that they will cover the costs of the blood work and other tests at a more convenient location.

NBCCF thinks all health insurance companies and health plans should pay for the costs involved for patients to take part in clinical trials. Whether you will have to pay for some of the care you get in a clinical trial depends on a lot of things. It depends on:

- who is sponsoring the trial,
- what your health insurance or health plan covers,
- how your doctor gets paid for your care, and
- many other things.

So it is important that you find out what costs related to the clinical trial your health insurance or plan will cover. Ask your doctor or nurse to explain exactly what the trial sponsor will cover.

