



ACCOUNTABILITY

Accountability means making sure that everyone involved in health care does what they're supposed to do. This includes patients, doctors, nurses, hospitals, health plans, and researchers.

NBCCF believes our health care system needs a whole new way of finding and fixing problems. We are fighting for a better health care system. Meanwhile, as patients, we can do our part to make the system more accountable.

Quality Breast Cancer Care Means:

Getting the Right Treatment at the Right Time

Being a Responsible Patient

Having a Way to Fix Problems

Getting the Right Treatment at the Right Time

We need a health care system that provides the right treatment, at the right time, every time. There are still many questions about breast cancer treatment. But there is overwhelming scientific **evidence** that many treatments work well for many breast cancer patients. Breast cancer treatment can, and often does, save lives.

There is only one reason why a breast cancer patient should not have the most effective treatments available: because the patient herself, informed and educated, decided against it.

Sometimes it takes years for better treatments and care practices to make their way into the health care system. This is unacceptable. Our health care system must deliver **evidence-based care** to every patient. That means everyone, regardless of where they live, gets the most effective treatment known, based on the most recent scientific evidence.

There are many people and groups involved in your health care:

- doctors
- nurses
- your **health plan** or insurance company
- hospitals, and
- cancer centers

Who is responsible for making sure you get the right treatment at the right time? The answer is all of these people and groups. Patients should not have to wonder if they are getting the most effective treatment available. They should be able to assume that they are.

Sadly, right now, our health care system doesn't have to report on the care it delivers or explain why some of its patients don't receive standard care. And until we pressure the health care system to do this, patients sometimes have to work hard to be sure they are getting the right care at the right time.

What You Can Do:

Read this guide cover to cover. This guide contains our best advice about getting quality breast cancer care. You may hear some of our advice elsewhere. But you probably won't hear much of it anywhere else. For specific treatment decisions, start by reviewing some national guidelines (see page 39). If your doctor hasn't recommended the **standard of care**, ask why.

Be a good advocate for yourself. Remember that many kind and helpful doctors and nurses may not be providing the most up-to-date care. It may not be one person's fault. And while you're choosing your treatment, it probably isn't helpful to focus on who is to blame. The point is that you should be getting the most effective treatment at the most effective time, unless you specifically refuse it. NBCCF thinks that the more informed you are, the more likely it is you'll get the best treatment for you.

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Being a Responsible Patient

Accountability is a two-way street. As a breast cancer patient, you are responsible for:

- giving your doctors correct information,
- being respectful to doctors and other health care workers,
- saying when you don't understand something, and
- doing what you say you'll do.

But please remember: your breast cancer is *not* your fault. We don't know what causes breast cancer. But we know that it isn't caused by one thing that women do or don't do. Nothing we know says, "Do X and get breast cancer," or "Do Y and don't get breast cancer." Many known risk factors are out of your control. These include:

- being a woman,
- age,
- family history,
- genetics,
- getting your first period earlier, and
- reaching menopause later.

What You Can Do:

Be honest with your doctors.

It's hard to tell your doctor when you're doing something unhealthy. (Smoking and not exercising are examples.) But they need that information to understand your health care needs. It might also be hard to tell a doctor that you're trying an herb or a special diet. They might not approve. But something you are taking could affect other parts of your treatment. You have to give doctors the whole picture to get the right care.

Be responsible for your choices.

You have to live with your health care decisions. This is true no matter how many doctors work with you. So you need to understand your choices. That way you can feel comfortable and confident about what you decide.

Be prepared to take some matters into your own hands. In the end, you are your own best watchdog for getting what you need.

Evidence-Based Coverage

One important issue is how health care plans decide what they pay for. NBCCF believes they should decide this based on **evidence** from medical research studies. They should judge their decisions against set standards that are kept up-to-date.

But deciding what evidence means is hard. Different health plans and doctors

often disagree. Plus there is *no* evidence for many areas of breast cancer care.

An evidence-based system still makes sense and can be fair. Everyone should be able to easily find out how decisions are made from start to finish. And patients should be able to challenge decisions about what is covered.

Having a Way to Fix Problems

The rules of our health care system are not always clear. And sometimes they are unfair. For example, it isn't always clear what care is covered by a **health plan** or why. And the rules about **coverage** and other health care decisions vary a lot from health plan to health plan.

NBCCF believes the health care industry needs much better rules about breast cancer care. These rules must be given to everyone in an easy-to-understand way. And when the rules are broken, patients need a quick and easy way to get the problem fixed.

For now, patients who want to challenge their health plans' decisions usually must begin with an appeal. The health plan itself designs its own appeals process. So it may be a long and frustrating process. But sometimes the fight is well worth it.

What You Can Do:

Identify the source of the problem.

You may face a number of problems with our health care system. Your health plan may limit your choice of doctors or care centers. Or maybe your health plan won't pay for care that you need. Or maybe one of your caregivers has given you the wrong care.

Sometimes it's hard to get to the root of the problem. For example, let's say your doctor recommends a treatment that your health plan won't cover. Is the problem that your

health plan won't pay for a treatment that you need? Or is the problem that your doctor is recommending a treatment that isn't effective? Either is possible in our health care system. That's why it is important to understand the **evidence** behind your doctor's treatment recommendations.

You need to know the source of the problem. That way you can decide whether you want to appeal your health plan's decision.

What is the goal of an appeal? The goal is to get your health plan to change their decision and pay for care that will help you.

Read your health insurance policy carefully.

Every health plan is different. So be sure you understand what services your plan does and does not cover. Health plans can limit your choice of doctors and care centers. They can also limit the type of care they cover.

Keep in mind that employers buy most private **health insurance**. Employers can decide how much coverage to offer their employees. They can base this on how much they want to spend. That means that sometimes even a proven treatment isn't covered by your health plan. For example, employers can decide not to cover mental health services even though they can be "needed and effective."

Also, **Medicare** does not cover prescription drugs used outside the hospital. So they don't cover the drug **tamoxifen** even though it helps

Remember— more care does not always mean better care.

some women with breast cancer.¹⁹

Health plans have to be honest about what they do and don't cover—and why. They have to cover the same things for everyone on the same plan. But they don't have to cover everything.

Find out about the appeals process under your health plan. Read your policy and your denial letter to find out about the appeals process. Find out who to talk to about the denial. (This information may

be in your denial letter. Or you may have to call your health plan.) Then you should:

- Ask your health plan for a written copy of the steps you need to take to make an appeal, including any deadlines.
- If you do not have a copy of your denial letter, request one from your health plan. It should tell you why your treatment is not being paid for.
- Make sure that you meet all the deadlines for appeals set by your health plan.

¹⁹ Early Breast Cancer Trialists' Collaborative Group. Tamoxifen for early breast cancer: an overview of the randomized trials. *Lancet* 1998; 351(9114):1451-67.).

Remember — more care does not always mean better care.

Sometimes patients fight their health insurance companies to get a treatment paid for even when no research has shown that the treatment works. Getting more care isn't always good for you. Sometimes "less is more." Let's say your doctor advises a treatment, and your health plan covers it. That doesn't mean it is the best treatment for you. For example, some doctors still give high-dose **chemotherapy** with bone marrow transplants to treat breast cancer. And some health plans still cover them. But recent studies show that this treatment works no better than

standard chemotherapy for breast cancer patients. And it can hurt your body more.²⁰ For more information on this issue, contact NBCCF (page 99). Ask for a copy of our position statement on High-Dose Chemotherapy with Bone Marrow Transplant or Stem Cell Support.

It's tempting to think that the more you do, the healthier you'll become. But that's often wrong. Don't focus on how much you do. Focus on doing what medical evidence suggests will be most helpful.

²⁰ Stadtmauer EA, et al. Conventional-dose chemotherapy compared with high-dose chemotherapy plus autologous hematopoietic stem-cell transplantation for metastatic breast cancer. *New England Journal of Medicine* 2000;342(15):1069-76.

Peters WP, et al. A prospective, randomized comparison of two doses of combination alkylating agents (AA) as consolidation after CAF in high-risk primary breast cancer involving ten or more axillary lymph nodes (LN): preliminary results of CALGB 9082/SWOG 9114/NCIC MA-13. *Proceedings ASCO* 1999; 18 (abstract 2).

Try to get copies of your medical records.

- When possible, contact your health plan in writing. Send letters to them by certified mail, and ask for a return receipt. If you speak to anyone at your health plan about your case, make sure you take notes. Write down the name of the person you spoke to, the person's and phone number, what was said, and the date of your conversation. This gives you a record of your appeal, and it may be helpful down the road.
- If you have health insurance through your employer, tell the **benefits** manager about your problem. She or he may be able to pressure the health plan to change its decision.

Get copies of your medical records.

Try to get copies of your medical records and any correspondence between your doctor and your health insurance carrier. This includes your doctor's "request for payment authorization." In most states you should be able to get copies of your records, but your doctor may charge a fee for copying them.

Learn about your illness.

Learn all you can about your illness, what your doctor advises for your treatment, and why. Ask your doctor if there is evidence from medical studies that this treatment will help you. This information will help you make the best appeal you can.

Write an appeal letter.

Your appeal letter should tell your health plan why you think the plan should pay for your care. The letter should be clear, firm, and polite. You should tell them:

- **Who You Are**—Give your name and your health plan group and member numbers. Also include the claim number and any other information used to identify your case.
- **What Has Happened So Far**—Tell them about your illness, the treatment you need, and why it was denied.
- **Your Best Case**—Correct anything in the record that is wrong. Give any medical or scientific evidence that supports your case.
- **What You Want Your Health Plan to Do**—Tell them why you believe their denial was wrong. Say that you want them to review your case and approve payment for your treatment as soon as possible.
- **Next Steps** – Tell them when you will follow up.

Ask your doctor to help with your appeal.

Get a signed statement from your doctor that specifically describes your illness and what is needed to treat it. (Were there any **specialists** called in to consult or treat you? Get them to sign statements, too.) This statement should also include a short medical history and your **prognosis** with and without treatment. Your

doctor(s) should include copies of **peer-reviewed** research articles relevant to your illness and proposed treatment. If possible, send all of this information to your insurance carrier with your first written appeal.

You may want to get help from a lawyer.

The information in this guide *can't* take the place of legal advice. A lawyer can file your case in court if that is the only option you have left. He or she can also tell you if what your health plan or caregiver did was against the law. Would you like help from a lawyer, but you

can't afford to pay for one? There are lawyers who may be able to give you free advice. Contact the American Bar Association's Commission on Women in the Profession (page 99) to find free legal help in your area.

Be prepared to fight for your health!

You may have to be stubborn and demanding when you make your appeal. Your health may make it hard for you to fight for your own treatment. A friend or family member may be able to help you make your appeal.

