





## RESPECT

**Respect is an important part of health care. With breast cancer, respect is especially important because there is no sure cure. There are still many questions without answers. So doctors must offer what they know with respect. And they should admit what they don't know. Here are some ideas to help keep your sense of self as you work to get well.**

### **Quality Breast Cancer Care Means:**

**Being Valued**

**Keeping Your Records Private**

**Being Treated as a Whole Person**

## Being Valued

Doctors usually care deeply about their work and their patients. But our health care system does not train doctors well to talk and listen to their patients. And it does not reward them for respecting their patients.

You will probably be treated differently by different caregivers. Some will be as helpful as they can. Others may not care that you wait two hours in the doctor's office. Some doctors and nurses will do all they can to make sure you understand your treatment choices. They may even give you phone numbers where you can call them after hours. Others will expect you to do what they tell you without question.

You may have special needs that your doctors and nurses don't understand. And we all have our own set of values and preferences. Your doctors and nurses should respect your values and preferences.

There *are* things you can do to get the respect you deserve.

### What You Can Do:

To get respect, give respect.

You and your doctors need to work together. You *both* have information to share. That means you *both* have to give honest and complete information so you can get the best care. For example, if you are taking **alternative medicines** or other therapies but don't tell your doctors, they could advise the wrong care.

Ask a family member, friend, or breast cancer **advocate** to come with you to the

doctor. This tells your doctor that you want to learn about your breast cancer. With someone at your side, you'll ask better questions. You'll remember more. And you'll become a respectful partner with your doctors.

Meet as people rather than as a doctor and a patient.

No one should ever expect you to have an important talk about your health when you're not fully clothed. It will probably be more comfortable to first meet your doctor in his or her office with your clothes on. And if you do need to undress for something, ask for comfortable robes that cover you.

Take your time seriously.

Time can be a real problem for patients. Our health care system wastes patients' time and often doesn't give them enough time with their caregivers. Doctors and nurses need to hear loudly that valuing their time over yours is unfair and stressful. You can:

- Ask the doctor to call you later in the day to finish talking if you run out of time during the appointment.
- Ask your doctors and nurses how best to reach them. Can you call them during certain hours? Can you use e-mail? Should you call the doctor or nurse first? Also ask when they normally return calls. You can worry all day waiting for a call. But many doctors have a set time when they return calls. Talking about this helps both of you respect each other's time.

# If someone is really disrespectful, do us all a favor and let someone know.

- Let your **health plan** know when they are making things hard for you. For example, your doctor's office may send you to an outside lab to have blood drawn. They may do this to save time and see more patients. But it may waste *your* time.
- Ask your doctors if you can help solve the problem somehow. For example, some health plans pressure doctors to see 40 patients in one day *and* return phone calls. It may help to tell your health plan if this pressure affects you as a patient.

Complain when you need to. If someone is really disrespectful, do us all a favor and let someone know. You may complain to your health plan and/or change doctors. To complain, call the customer service department of your health plan. (The number should be in a booklet you got from your health plan.) Ask how to file a complaint. One complaint may not make a big difference. But if you complain, and other patients do too, things may change.

## Keeping Your Records Private

You have a right to keep your records private between you and your doctors. This is called "medical privacy." There are systems to protect your rights, but there are also gaps. At the same time, your doctors and nurses need to share information with each other. And records can be used for important research. The challenge is to protect your privacy and still make sure your caregivers have the information they need.

### What You Can Do:

Ask about confidentiality.  
Ask how your records will be kept private before you sign **informed consent** forms.  
At some point, a medical researcher may ask

to use your health care records. Sharing your health care information with researchers can be a great help to others. It helps answer important questions about breast cancer. But before agreeing to do this, ask:

- How will you protect my privacy?
- How will you share my information with other doctors or researchers?
- What research are you doing?
- How will you use that information?
- Who will get this information?
- When and how will I learn the results of the research?

The answers to these questions can help you make sure your information is used properly.

# Our health care system must treat the whole person, not just a person's disease.

## Know your rights.

There are state and federal laws to protect your medical privacy. The Health Privacy Project (page 102) at Georgetown University has a good summary of privacy laws around the

country. Contact the project to learn about privacy protections in your state. To learn more about medical privacy in general, contact NBCCF (page 99). Ask for a copy of our position statement on Medical Privacy.

## Should I get a genetic test?

**Genetic tests** look at your genes. They give information about you. That information can be anything from the color of your eyes to your chance of developing some diseases.

Women who have a strong family history of breast and/or ovarian cancer may be interested in genetic testing. Most breast cancer (at least 90%) is not linked to family genetics. But for those women with a strong family history of breast cancer, genetic tests may help them better understand their chances of developing breast cancer. Knowing this could help these women make more informed choices about their health care.

But sometimes employers and health and life insurance companies can use genetic tests against women. This is called

"genetic discrimination." For example, a company may not want to sell you life insurance if your test results show that you are at high risk for a disease. There are some legal protections but not enough. For more about this issue, contact NBCCF (page 99) and ask for a copy of our position statement on Genetic Testing.

If you are thinking about genetic testing, you should talk with a genetic counselor who is part of a "cancer risk assessment program." These programs can usually be found at teaching hospitals. The genetic counselor should not be employed by the company that performs the genetic testing. A good genetic counselor will help you sort out the possible benefits and risks of taking a genetic test.

## Being Treated as a Whole Person

You may need different doctors and nurses to help with different parts of your breast cancer care. They can help you take care of yourself, avoid other problems (**complications**), and keep up your **quality of life**. You may need **pain control**, **physical therapy**, mental health services, and care that treats other health problems. Our health care system must treat the whole person, not just a person's disease.

### What You Can Do:

Ask for a comprehensive treatment plan.

“Comprehensive” means covering all the bases. Your doctors and nurses should be able to create a plan with you that may include things like:

- surgery,
- **reconstructive surgery**,
- **chemotherapy**,
- **hormonal therapy**,
- **biological (targeted) therapy**,
- **radiation**,
- **clinical trials**,
- pain control,
- other therapies to help with side effects and symptoms,
- **complementary therapies**,
- physical therapy, and
- mental health services.

Remember that breast cancer treatment plans are not simple. They often need to be changed along the way. Ask your doctors to give you a list of all the treatments you will get. Ask for a timeline that tells when and for about how long you will get the treatments. What if you can't get the timeline in writing? Be sure to take notes about all the major parts of your care (for example, surgery, chemotherapy, and radiation, etc.). Ask your doctors if you can tape-record your meetings with them. That will help you remember what was said.

Be sure your plan reflects your values.

Some breast cancer choices are pretty easy ones. For example, most breast cancer patients would choose a treatment if they knew it would greatly increase their chances of living a long, cancer-free life.

Other choices are harder. For example, women with early breast cancer are often offered chemotherapy drugs. Chemotherapy drugs may cause several bad side effects such as upset stomach, hair loss, heart problems, and early menopause in young women.

**Anthracyclines** are chemotherapy drugs that work a small bit better than other chemotherapy drugs. They can raise a woman's chances of living longer by about 3% (absolute survival increase). But these drugs can also raise a woman's chances of getting some of the bad

# Remember that it is OK to disagree with your doctor.

side effects<sup>15</sup>. Many patients choose to take a different type of chemotherapy drug. They would rather have a better quality of life than the small increase in their chance of survival. And some patients choose not to get chemotherapy at all. These are tough personal choices.

Remember that it is OK to disagree with your doctor. Take a few weeks to get information and think about what is most important to you. Think about what care you want and from whom you want to get it. It will be time well spent.

Learn about follow-up care.

In the back of every breast cancer survivor's mind is the fear that the cancer will come back. Breast cancer survivors sometimes catch themselves worrying about every little ache or pain. These fears usually lessen the longer you have been out of treatment.

You should pay attention to any changes in your body if you are a breast cancer survivor. And you should tell your doctor about them. You should also stick to the follow-up care guidelines in the National Comprehensive Cancer Network's (page 104)

Breast Cancer Treatment Guidelines for Patients. Ask your doctor to order tests if you have any symptoms you can't explain or that don't go away. Breast cancer can come back:

- locally (near the original cancer),
- regionally (in the **lymph nodes** under the arm or above the collarbone), or
- as distant **metastases** (cancer that has spread to another organ).

When breast cancer spreads to another organ, it usually goes to the bones, lungs, or liver. Less often, it spreads to the brain, spinal cord, eye, or bone marrow.

You may find a local or regional **recurrence** yourself. Or your doctor may find it during a clinical breast exam or with a **mammogram** or other test.

Some patients want to have blood tests, bone scans, and chest X rays done every year. They want to be sure that the cancer hasn't come back. But this isn't recommended. Patients suspect or find most recurrences themselves without routine testing. And there is no evidence that treating a recurrence early improves survival.

15 Early Breast Cancer Trialists' Collaborative Group. Polychemotherapy for early breast cancer: an overview of the randomized trials. *Lancet* 1998; 352(9132):930-42.

Coombs RC, et al. Adjuvant cyclophosphamide, methotrexate, and fluorouracil versus fluorouracil, epirubicin, and cyclophosphamide chemotherapy in premenopausal women with axillary node-positive operable breast cancer: results of a randomized trial. The International Collaborative Cancer Group. *Journal of Clinical Oncology* 1996;14(1):35-45.

Levine MN, et al. Randomized trial of intensive cyclophosphamide, epirubicin, and fluorouracil chemotherapy compared with cyclophosphamide, methotrexate, and fluorouracil in premenopausal women with node-positive breast cancer. National Cancer Institute of Canada Clinical Trials Group. *Journal of Clinical Oncology* 1998;16(8):2651-8.

Learn about complementary and alternative medicine (CAM).

**Complementary treatments** are used *with* standard medical care. For example, taking vitamins *along with* your standard medical care is complementary care. **Alternative treatments** are used *in place of* standard medical care. For example, following a special diet

*instead of* getting standard medical care is alternative care. Both are names for any kind of care *outside* our country's mainstream medicine.

**Why do patients use CAM?** Breast cancer patients are interested in **CAM** for many good reasons. They want to do all they can to take care of themselves. They want to reduce their

## How Will I Know If The Cancer Has Come Back?

When should you worry about an ache or pain? When should you let it go? We can't tell you. But we can tell you:

- the symptoms (if any) of the most common areas where cancer comes back and
- which tests are used to learn whether the cancer has spread to those areas.

	Symptoms	Tests Commonly Used to Detect Spread
Bone Metastasis	<ul style="list-style-type: none"> <li>■ Steady bone pain or tenderness that won't go away</li> </ul>	<ul style="list-style-type: none"> <li>■ Blood tests</li> <li>■ Bone scan (If bone scan suggests cancer, an X ray can be done next.)</li> <li>■ CT scans (<b>Computed Tomography</b>)</li> <li>■ MRI scan (<b>Magnetic Resonance Imaging</b>)</li> </ul>
Lung Metastasis	<ul style="list-style-type: none"> <li>■ Chest pain and any shortness of breath</li> <li>■ Cough that won't go away</li> </ul>	<ul style="list-style-type: none"> <li>■ Chest X ray</li> <li>■ CT scans (Computed Tomography)</li> <li>■ MRI scan (Magnetic Resonance Imaging)</li> </ul>
Liver Metastasis	<ul style="list-style-type: none"> <li>■ Pain or discomfort under the right side of the rib cage that won't go away</li> <li>■ Loss of appetite</li> <li>■ Changes in weight, especially weight loss</li> </ul>	<ul style="list-style-type: none"> <li>■ Blood tests (complete blood count, platelet counts, and liver function tests)</li> <li>■ CT scans (Computed Tomography)</li> <li>■ MRI scan (Magnetic Resonance Imaging)</li> </ul>

# Don't ask if it's CAM or mainstream. Ask if it works.

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chances of the cancer coming back or getting worse. And they want to improve their overall physical and mental health. Some patients try CAM because mainstream treatments have not worked for them. Still others try alternative therapies because they simply do not trust mainstream medicine. Or they like the idea of using natural, holistic, long-standing healing traditions.

**CAM is not a fad.** It is an important part of healing for many patients. The truth is, standard medicine has promised too much. It has failed many breast cancer patients. Patients aware of standard medicine's limits continue to look for health care that works, wherever that may be. From a patient's point of view, it doesn't matter if care is standard or CAM. All that matters is what really helps.

**Can CAM help breast cancer patients?** Sadly, research on CAM cancer care has been limited. So we don't yet know if many CAM treatments are safe, or if they work for breast cancer patients.

Right now, there are standard treatments that extend lives and reduce the chances of the cancer coming back. At this point, there are no CAM treatments that have been shown to have the same effects.

Still, some CAM treatments may help strengthen your health in general, relieve the side effects of standard treatments, or ease pain and stress. For example, there is some evidence that **acupuncture** relieves the badly upset stomach many patients feel during chemotherapy.<sup>16</sup>

The National Center for Complementary and Alternative Medicine (NCCAM) (page 103) is a government research center in the National Institutes of Health. It's a good place to learn about complementary and alternative care. NCCAM can tell you what treatments exist and what is known about them. They can also tell you about open CAM clinical trials. The American Cancer Society (page 99) is a group that works on many cancer issues. They also have good information on what is known and unknown about many CAM treatments.

**Tell your doctors and nurses about any CAM treatments you are using.** Some CAM therapies can affect other medicines. For example, Saint John's Wort is a CAM treatment for depression. It gets in the way of a drug used to treat HIV infection.<sup>17</sup>

Not all doctors talk about CAM treatments. This may be because they don't know much about CAM. Or it may be because they aren't trained to combine complementary therapies

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16 NIH Consensus Conference: Acupuncture. *Journal of the American Medical Association (JAMA)* 1998;280(17):1518-24.

17 Piscitelli SC, et al. Indinavir concentrations and St. John's Wort. *Lancet* 2000;355(9203):547-8.

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with standard medical care. Some doctors simply think CAM is nonsense.

Are you interested in learning about or using CAM? If so, be sure to find a doctor who is willing to talk with you about CAM. You need a doctor who will help you sort through the pros and cons of CAM therapies.

**“Natural” does not always mean “safe.”**

We don't know all the risks of some CAM treatments. You should be very careful with these. This is especially true with starting a special diet, or taking herbs, vitamins, and other supplements. The U.S. Food and Drug Administration (FDA) does not control herbs, vitamins, or supplements. Many have not been studied for safety, how they act with other drugs, or if they work. This also means that no government agency checks the quality of the products on drugstore shelves. On top of that, companies often put misleading and unproven claims on their product labels. (For example, a product might claim that it “boosts metabolism and aids weight loss.”)

Just because something is “natural” or “organic” does not mean that it is safe. And it may not be good for breast cancer patients. One extreme example is the claim that something from the aloe vera plant can cure cancer.

There is no evidence behind this claim. In 1998, a doctor injected aloe into cancer patients. Several of the patients died because of the shots.<sup>18</sup> Aloe shots are dangerous and against the law.

**Don't ask if it's CAM or mainstream.**

**Ask if it works.** Doctors and patients should look at CAM with an open but critical mind. This is exactly the same way you should look at mainstream care.

Whether you're looking at a CAM therapy or a mainstream treatment, you need to ask the same questions:

- What are the benefits for breast cancer patients?
- What are the benefits for health in general?
- What are the risks of this therapy?
- How strong is the **evidence** that answers these questions?

It's important to understand the good and bad points of any treatment before you try it. For some CAM care, no one knows any specific benefits for breast cancer, but the risks are very low. Breathing to relax, meditating, and yoga are examples. Many breast cancer patients use these things in their lives. And many women are comforted by them.

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<sup>18</sup> Lipton E, Smith L. Was cancer cure a painful lie? For desperate patients, aloe vera clinic in Manassas became final, costly stop. *The Washington Post*. February 25, 1998, 1(A).

