

Every Woman's Guide to Breast Cancer



Y-ME National
Breast Cancer
Organization™

Acknowledgments

Every Woman's Guide to Breast Cancer is a revision of our 1995 publication, *For Single Women With Breast Cancer*. The idea of transforming the "Singles" booklet into Every Woman's Guide was well received, since for many years staff, volunteers and callers have told us they read the "Singles" book even though they have partners.

Breast cancer support group leaders from hospitals and organizations throughout the Chicagoland area enabled us to reach many women who completed a questionnaire, responded to early drafts and answered additional questions. Y-ME Hotline staff and volunteers provided assistance and insight. Our medical advisors and other physicians reviewed the booklet for clarity as well as accuracy. We thank them for their valuable contributions.

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Introduction

After being diagnosed with breast cancer, many women describe feeling vulnerable and alone. The love and support of family members and friends can be comforting and encouraging at this time of crisis, but cannot alter the fact that the cancer is in your breast.

The sense of isolation may be especially acute for women whose partner is unable to provide the support she seeks, women without partners or women who live alone. Feeling helpless and defenseless is a perfectly normal reaction when facing a life-threatening disease. Women must identify sources of strength and support to cope and move forward.

This booklet was created to offer practical guidance and emotional support in coping with breast cancer. We hope the experience and testimonies of other women will help alleviate your fear and assure you that you are not alone.

We have tried to represent diverse experiences of women with breast cancer. Naturally, what is true or useful for some women will not be so for everyone. As you read about breast cancer and talk with other women facing this disease, you may find yourself reaching across differences to a common ground of support.

This booklet does not address all problems facing women with breast cancer. We have not included a great deal of technical medical information, as this is available from other sources, including Y-ME. More importantly, as progress is made in research, you will want to get the most current information available.

We encourage you to reach out for the assistance and support you need and deserve: for information, to express feelings, to share strategies for coping or to overcome barriers.

Many women contributed to the writing of this booklet. We would like to honor their struggles, celebrate their victories, and thank them for sharing their challenges and triumphs with us.

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I. BETWEEN DIAGNOSIS AND TREATMENT

Many women say their most difficult time was between diagnosis and treatment. During this time, you must continue to handle daily responsibilities while coping with the shock of diagnosis and uncertainties about your illness.

Taking action is the best way to cope with this anxiety. Learn as much as you can about the disease and treatment options available to you. Go to the library or a bookstore; call cancer hotlines and resource centers; read; take notes; talk to breast cancer survivors. Despite the emotional chaos you may be experiencing, this is the time you have to make some of the most important decisions about your treatment.

Initially, you may be overwhelmed by feelings you cannot control. You may be easily distracted and have difficulty concentrating. Many women experience confusion and mood swings. It is important not to compound your distress by questioning your feelings, or telling yourself you shouldn't feel this way. Respect your feelings, and listen to your inner voice — whether you hear yourself questioning the wisdom of a doctor, or simply protesting your fate. If you are angry, allow yourself to be angry. Let your feelings come, express them as best you can, then let them go. Your gut feelings may give you important information for making decisions along the way to recovery.

This is a good time to reach out to people you trust: family and friends, a neighbor or co-worker, a hotline counselor or members of a support group. As a woman, you may be well practiced at caring for others but reluctant to ask for help for yourself. But asking for help when you need it is healthy, and will not compromise your strength. Getting assistance can help you make informed decisions, cope better and heal faster.

By educating yourself to select the doctors and treatment plan that are right for you, you can take charge of a situation that seems beyond your control. Looking back at this turbulent time, your assessment that you did your best, with the options available to you, will be a source of pride and will strengthen your self-esteem.



Choosing your doctors

Choosing a team of physicians you trust is the first step in your treatment plan. The best way to find a good physician is through referrals. While your choice may be limited by your health care plan, you can still try to find the best doctors available to you. You can obtain referrals from former patients, or from doctors you know. Y-ME maintains a list of cancer centers supported by the National Cancer Institute, and a list of hospitals with cancer programs accredited by the American College of Surgeons. A cancer center or hospital cancer program can provide you with referrals.

When you meet with doctors, interview them as you would interview anyone providing a service to you. Check for competency and experience. While you won't want to make your selection based solely on personality, you should feel comfortable with the physicians you choose.

Be sure to get a second or third opinion regarding diagnosis and treatment. A diagnosis of breast cancer is rarely a mistake, but doctors' opinions regarding the type or extent of the malignancy, as well as treatment options, may vary. Even if you are satisfied with your physicians, getting a second opinion is a good idea. It may validate an earlier opinion or simply provide another perspective to consider when making decisions about treatment. Make sure all of your records, test results, and pathology slides are made available to anyone giving another opinion.

If you live in a rural area, it may be necessary for you to travel to get a second opinion. Try to do so. Teaching hospitals at universities usually have up-to-date diagnostic equipment that general practitioners cannot afford. At a teaching hospital, you will also have the benefit of seeing a breast specialist. A breast specialist will be able to give you the most accurate assessment of your treatment options. You may be able to arrange for specialists at a teaching hospital to prescribe your treatment plan, and have a local physician administer the treatment. Talk with your physician about arranging this kind of cooperative relationship. If you are not able to travel to a teaching hospital, you may want to arrange a telephone consultation with a breast specialist.

“Let me tell you about my best friend, Nancy. When I was diagnosed, I was in such a fog. I had stacks of information from the American Cancer Society and my surgeon. I would read the materials and not absorb a thing. Nancy took all the materials home and read them and made me lists of questions for my surgeons and oncologist. She acted as my advocate in those early days and forced me to evaluate my choices and ask the important and uncomfortable questions. I will never be able to repay her. In a way, I feel she saved my life as surely as my doctors did.”

Cancer is not a punishment. You don't deserve to be treated like a victim! It is important that you communicate your questions and concerns as clearly and directly as possible. In return, you deserve to be respected, to get a response to all your questions, and most of all, to be taken seriously. If a doctor is not respectful and responsive, find another.

The following guidelines may be helpful when choosing a physician:

- *Is the doctor a breast specialist?* How much experience does s/he have with new techniques? Is s/he aware of current clinical trials and research in the field of breast cancer treatment?
- *Does the doctor invite discussion, encourage your participation and give you time to ask questions?* Or does s/he interrupt you, try to tell you what to do or rush you out of the office?
- *Does the doctor describe in some detail what is likely to happen to you and how you may feel?* Does the doctor openly discuss possible side effects or consequences of treatment? Or does s/he tend to minimize or discount your fears?
- *Does the doctor explain things well, in language you can understand?* A doctor should be willing to talk both in lay and medical terms to ensure you understand and become familiar with medical terminology.
- *Finally, does the doctor respect your right to make your own decisions, and to take the time to do so?*

Choosing your treatment

Although it is important not to delay lifesaving treatment — especially if you have been diagnosed with an aggressive tumor — it is also important not to rush into making decisions that will affect the quality of the rest of your life. It is very important that you are informed in advance of possible side effects of treatments, including how treatments may affect you — temporarily or permanently.

The tumor inside you took years to grow. Waiting an extra two or three weeks to feel comfortable with your decisions will probably not hurt, and may help you. If you feel pressured — by yourself, a family member, friend or physician — into making decisions before you are ready, you give up the opportunity to decide what feels right for you, decisions you will have to live with. Educate yourself so that you can be an active participant in choosing your treatment.

During consultations, you may be too upset to remember everything the doctor says or to ask what you want to know. Bringing someone you trust along with you as an advocate, or recording consultations with a tape recorder, can be helpful.

Bring a list of prepared questions to ask your doctor. Include everything you want to know about your diagnosis, prognosis and after-care. Do not hesitate to ask about all aspects of the procedures and consequences of your treatment - even those that may seem minor or unlikely. Many women complain that doctors did not inform them sufficiently of treatment options, especially about possible side effects of treatment.

Find out about tests that will be done on your biopsy specimen regarding hormone receptor status, Her-2 status and aggressiveness of the tumor. (See Y-ME's brochure, *Understanding Your Pathology Report: A Guide for Breast Cancer Patients*.) The results of these tests will be the basis for choosing your treatment. Get copies of reports and test results, including your pathology slides (actual specimens of the tumor), the pathology report, mammograms and radiologists' reports on your mammograms. Take these along with you when you go for second opinions.

Don't attach a lot of importance to statistics. While you can get general information from statistics, they cannot adequately predict what will happen to you.

Talk with other women whose diagnosis was similar to yours, and who had treatments you are considering, before you make your final decisions. Be careful not to rely on the experience of only one or two women, as their circumstances or reactions to treatment may differ greatly from yours. And while you shouldn't discount information from a woman who has had difficulties with treatment, a woman who is overwhelmed by her own distress will not be able to give you encouragement and support. Attending a support group may give you access to several women who have already had treatment. Let group members know you were recently diagnosed, and have come for information and encouragement.

If you feel confused or overwhelmed, you may want to consult with a therapist who can give you guidance in making decisions.

Decisions about treatment

When making your decisions, it is important to consider how a treatment will affect the quality of your life, as well as what is medically effective. In order to do so, discuss all your treatment options with each doctor you see, as concerns or preferences regarding one type of treatment may affect other treatment options. For example, if giving birth to a child is important to you, an oncologist may suggest a modified course of chemotherapy, as chemotherapy sometimes causes premature menopause.

Whether to have a lumpectomy or mastectomy is another important decision many women have to make. Some women opt for lumpectomies in order to save their breast. Some women feel having their breast removed gives them greater peace of mind. However, having a mastectomy does not guarantee that cancer will not develop in the other breast or the chest wall. Lumpectomies are increasingly recommended for women with early-stage tumors, and studies to date indicate that survival rates for women after mastectomy and lumpectomy are the same.

Currently there is no guaranteed cure for breast cancer. Keeping this in mind will relieve you of feeling responsible for making the "absolutely right" decision. Knowing yourself, and the options available, you can only do what seems best for you at the time.

What you want to do may be clear to you, or you may feel that you don't have many viable options. If you have trouble clarifying your options, try putting your thoughts on paper or making a list of pros and cons. Save what you have written and look at it again later. What you care about most may become clear. Decision making is a process. Be patient with yourself.

Preparing for treatment

Insurance Check with your insurance company to arrange all relevant insurance matters before surgery. While second opinions are always recommended, some companies may actually require a second surgical opinion. Most insurance companies require that you get pre-authorization for surgery.

live & love

When it came right down to deciding... I felt inside myself for what I really felt and wanted and that was to live and to love and to do my work, as hard as I could and for as long as I could. So I simply chose the course that I felt most likely to achieve my desire, knowing that I would have paid more than even my beloved breast of my body to preserve that self that was not merely physically defined, and count it well spent.

— Audre Lorde from *The Cancer Journals*

Employment Make sure you understand your employer's policy regarding leave of absence for illness and disability. Delegate responsibility or make other necessary arrangements for the time you will be away from work. As you plan, try to give yourself a cushion of time for your emotional, as well as physical recovery before you return to work.

Self-care plan Create a plan for getting assistance and comfort. Arrange for help with shopping, laundry or housekeeping. Make sure the other important people and things in your life — your children, pets or apartment — are being well cared for, so as not to cause you additional worry.

Decide in advance what you can do to soothe yourself if you should begin to panic, or feel lost or lonely at home or in the hospital. Keep a favorite shawl or sweater to wrap around your shoulders to feel comforted and protected. Keep a list of people you can talk to about your feelings.

If you don't have family or friends you can look to for assistance, you may have to be creative. Contact hospital social service programs, community-based organizations, your local YWCA, women's groups, churches, mosques or synagogues. They may have volunteer programs or may be willing to improvise to respond to your needs. Nearly everyone knows someone who has had breast cancer, and people may be very willing to help. If the first or second place you contact cannot assist you, ask them to suggest someone who can. Keep trying until you get what you need.

buoyed my spirits

I could have asked for more help. I would recommend that a newly diagnosed patient, however self-sufficient, independent and strong, should ask for help — not only because it is too burdensome and lonely to go through cancer therapy alone — but because it makes other people feel better as well. The latter took a while for me to learn, but eventually I realized how honored people felt to be included and relied upon in something as precious as fighting for a life. It brought us all closer, tighter and buoyed my spirits tremendously — and undoubtedly theirs, too.

II. COPING WITH TREATMENT

Continue to be involved and assertive throughout your course of treatment. Doctors, nurses or technicians may assume you are fine if you do not express your concerns. Ask them to explain what they will be doing, and why, during each step of your treatment. Be sure to tell them about difficulties you may have with side effects.

It is normal to feel disturbed by the procedures and effects of treatment — even though the procedures are for your benefit, and even if the effects are temporary.

You may find meditation or guided visualization useful during this time. These techniques have helped many cancer patients transform what seems like an alien or invasive experience into one they feel confident promotes their well-being. Relaxation techniques require practice. If the first time you try you become anxious or distracted, let it go and try again later.

Surgery

Before surgery you may find yourself reviewing and coming to terms with the decisions you have made. You may want to create a small ritual to give yourself a sense of protection during surgery, to say goodbye to your breast or breasts, or prepare for other changes in your body.

For some women, a hospital feels like a comfortable, safe place to be cared for, but for others the sterile environment of a hospital feels alien. Bringing a favorite poem, photograph, music tape or your journal to the hospital can help you feel safe. Finding out in advance about hospital routine will help you prepare for your stay.

Many women do not experience a lot of physical pain as a result of breast surgery. However, some women do experience pain, lasting from a couple of days, to weeks, or even months. All these experiences are normal. If you experience severe or prolonged physical pain, be sure to discuss this with your surgeon.

While individual reactions to surgery vary, some procedures are common:

- When you wake up there may be a tube leading from the area near the surgical site to a small plastic container, to drain fluids that collect as a result of surgery. This may be bothersome, but not usually painful.
- Anesthetics are very powerful drugs, and you will feel their effects for at least 24 hours after surgery. You may be groggy, or unable to think or remember clearly, during this time.
- Most women have numbness of the upper arm and a stiff shoulder on the side of the body where surgery was performed. This is usually temporary, though for some women a degree of numbness persists.

Initially, you may not be able to move your shoulder or arm. Or you may experience some difficulty with movement. Your doctor, or a nurse, can show you how to do gentle stretching and reaching exercises to regain the use of your arm.

Unless your doctor indicates otherwise, it is important to work at using and strengthening your arm and shoulder as soon as possible, and to continue your stretching exercises for at least several weeks. This will minimize your chances for ongoing discomfort or limited use of your arm and shoulder in the future. If you experience severe pain when exercising your arm, inform your doctor. You may have tendonitis or "frozen shoulder" and may need physical therapy.

Most breast cancer surgery requires the removal of lymph nodes to determine if the cancer has spread beyond the breast. Lymph nodes process lymphatic fluids and contain white blood cells used to fight infection. There are now two methods of sampling lymph nodes — Axillary Lymph Node Dissection (ALND) and Sentinel Node Mapping (SNM). ALND is the removal or sampling of several layers or levels of lymph nodes. SNM is a procedure that looks at only one or two nodes. Not all women are candidates for SNM, and if the sentinel node is positive (cancer cells are present), ALND will likely be done. Ask your doctor if SNM is available to you.

The importance of SNM is the possible reduction in the incidence of lymphedema. Removal of the lymph nodes disrupts the network of lymphatic vessels. This can cause a build-up of lymphatic fluid, which may result in swelling, or lymphedema, in your arm. Trauma to the arm or shoulder from physical exertion, injury or infection can also cause lymphedema. Lymphedema can be temporary, or it can persist. If you have an ALND, your doctor can give you information about reducing the risk or treating lymphedema.

Preparing for radiation or chemotherapy

Your doctor will probably have you wait three weeks or so after surgery before you begin your course of supplemental or adjuvant chemotherapy and/or radiation treatment. Your body will need this time to recuperate from surgery. You will probably need to replenish yourself emotionally as well. You can also use this time to complete preparations for the weeks ahead that you didn't have time to do before surgery.

Ask your doctor to schedule treatments to cause as little disruption as possible to your work routine. You may want to schedule radiation treatments early in the morning or late in the afternoon. If you schedule chemotherapy treatments for Fridays, or the end of your work week, you may not have to miss work if you feel ill afterwards. Knowing you will have time to recover can alleviate anxiety, even if you do not have severe reactions to treatment.

Since many women experience fatigue or depression during radiation and chemotherapy, give special attention to this possibility. Respect your body's need for extra rest, and allow yourself time just for that. After treatment is completed, your former level of energy and endurance will gradually return over a period of months.

Some women have trouble sleeping during chemotherapy. This can intensify feelings of exhaustion, frustration or depression. If this happens, ask your doctor to prescribe sleep medication, or use an herbal tea or compound to help you sleep. Setting aside a few minutes each day just to sit quietly, or to meditate, can also be beneficial.

Depression associated with the loss of energy should be distinguished from depression caused by drugs used in chemotherapy. Women describe this kind of depression as unusually intense and oppressive. It may help just to know that these feelings are caused by drugs and are not related to your emotional health. If you find yourself becoming overpowered by depression, contact your doctor immediately.

It is possible you will not suffer severe, adverse reactions to treatment. This doesn't mean that something is wrong with the treatment or that it's not working.

Radiation

Some women find radiation treatment frightening, especially the first time. The treatment involves lying on a table under a large machine, which directs high doses of radiation to the area where the tumor was removed. You may be apprehensive about having radiation directed to your body, or the machine may intimidate you. Washable marks will be drawn on your chest by the radiation technician to indicate radiation points. You may find this annoying or disconcerting.

Some women arrange to see the room and equipment before treatments begin, so they will know what to expect. Having a thorough discussion with your doctor about radiation can also ease your fears about its effects. It is very important that technicians who administer treatment are respectful and courteous. If they are not, feel free to challenge their behavior, or tell your doctor. Having someone accompany you the first couple of times can also alleviate fears associated with the treatment.

Your skin may suddenly become sensitive after radiation, with symptoms similar to sunburn or a rash. A gel prescribed or recommended by your doctor, can soothe your skin. Your irradiated breast may also become swollen and the texture of your skin may change. It may take two to three years for the swelling to subside. The change in the skin texture of your breast may be permanent. Cotton bras, without tailored cups, or an undershirt, can minimize irritation to your skin. Be prepared to have your undergarments stained by the markings drawn on your chest.

I bought myself a music tape of Louis Armstrong singing "It's a Wonderful World" and played that in the car on my way to each radiation treatment. While I lay on the table I sang that song over and over to myself...

There will probably be restrictions on when and how you can wash your upper body during radiation treatment. Chemicals used in some soaps and deodorants interact and interfere with radiation. Find out if you can wash with mild soap. Cornstarch or non-talc baby powder can be used in place of deodorant. Health food stores have non-talc baby powder, soaps and other personal care products without detergent base or chemicals.

Radiation treatment lasts only about five minutes, but must be given five days a week for five to six weeks. You may feel your life is being disrupted or consumed by this treatment, especially if you must travel some distance. Make sure you have a reliable source of transportation for getting to and from treatments. You may also find it unnerving to sit in a room surrounded by other cancer patients — some of whom may appear to be far more ill or weak than you are. One woman eased the tension and gloom of a silent waiting room by engaging other patients in a lively discussion. Reward yourself for your patience and give yourself something to look forward to by planning or giving yourself something special at the end of each week.

Chemotherapy

Everyone has heard horror stories about chemotherapy. But not everyone's experience of chemotherapy is horrible. Chemotherapy is a combination of different drugs, each with its own side effects. Strong drugs used in chemotherapy cause many women to experience nausea and vomiting, dizziness, changes in appetite, and weight gain; or to feel confused, light-headed or distracted. Your doctor can prescribe anti-nausea medication. You may also find some relief from nausea by eating whole grains, or whole grain products, such as bread or crackers.

Unpleasant or distressing effects of chemotherapy should not be minimized, however not all women suffer severe reactions. Some women say the fear of chemotherapy was worse than the treatment. The effects of chemotherapy are unpredictable. Consider having someone accompany you to chemotherapy, and staying with you afterwards. Uncertainty about how you may react, and whether you will be able to care for yourself, can be alleviated by the presence of someone you trust.

my friend
"My friend got me through chemotherapy.
We would meet for breakfast my first good
day after every cycle."

Most women, though not all, lose some or all of their hair as a result of chemotherapy. Many women say losing their hair was the most traumatic part of treatment. Hair loss usually begins within two to three weeks after the first treatment. When hair begins falling out, some women opt to cut their hair very short, or have their heads shaved, to take charge of the process.

In most urban areas, and in some smaller towns, there are stores that cater to the needs of women with cancer and carry wigs, scarves and turbans. If you plan to wear a wig, you may want to shop for one before you begin treatment, so that you can choose one that closely matches the color and texture of your hair. Wigs made of synthetic fibers are often more attractive and easier to maintain than human-hair wigs. Experiment with scarves, turbans or hats. They can be quite attractive, and provide relief from a wig — especially in hot weather. Be cautioned against buying nylon or polyester scarves. They will not allow your skin to breathe, and can easily slip off.

Some women choose not to cover their heads at all. If you feel more comfortable not wearing a wig or other head covering, allowing yourself and others to see you as you are, can be an expression of acceptance of what has happened to you.

Completing treatment

Once it is underway, treatment may seem endless. You may long to return to your normal routine. It is important to keep in mind that your discomfort and the disruption of your daily life are temporary. Some women recommend maintaining as many of your usual activities as possible. If you have the energy and interest, don't let treatment keep you away from people and projects you enjoy.

If you do not feel well, or are self-conscious about your appearance, you may be tempted to isolate yourself. Maintaining regular telephone contact with family or friends, inviting them to visit or going to their homes will remind you that you are not just a cancer patient.

When treatment is finished, you may discover you miss the regular contact and care that come with treatment. Sometimes women express concern that without ongoing treatment, the cancer can start to grow again. Some women feel they must maintain an emotional vigilance, concerned that cancer may surprise them again if they begin to move forward and enjoy life. Discussing and planning your follow-up care with your physicians can help alleviate these concerns.

Explore ways to care for and nurture yourself. Join a support group. Take an exercise, dance or swimming class that will feel healing and loving to your body. Go for a massage. Cook a special meal. Buy yourself flowers. Or keep a journal. Writing or tape-recording a journal can help you express yourself when you are overburdened with feelings. Your journal will also document your experience as you reclaim your health and strength.

III. RECOVERY

Coping with loss, change, mortality

Since you were first diagnosed with breast cancer, you may have felt that what was happening to you was unreal. It is difficult to accept that your body can harbor a life-threatening illness while you experience no pain and appear to be just as you always were. But surgery, sudden changes in your body, and perhaps the loss of a breast or breasts, will make visible and real the fact you had cancer.

Denial, anger, anxiety and grief are perfectly normal responses to this trauma. After surgery, whether you have a lumpectomy or mastectomy, you may feel that your body has been damaged. You may feel assaulted, first by the cancer, then by treatment, and may experience the same feelings that accompany any kind of assault: fear, loss of control, self-doubt or shame.

You may feel many things at once: relieved to have the cancer removed, angry that this has happened to you, proud that you survived, and fearful of recurrence; strong one moment and devastated the next. All your feelings and fears are valid. Acknowledging and expressing your feelings will help you accept the way you feel, and will allow your feelings to change.

A second chance

“Once you have had cancer, your life will never be the same. It was the best and worst thing that ever happened to me. I really learned a lot about myself and my survival instincts. I never realized what a fighter I was until it happened to me... I learned to appreciate life, and somehow the little things that used to bother me were no longer so important. I became aware of my own mortality — and the things I had not done with my life, that I always felt could wait, suddenly became more important. Now I am not afraid of taking risks... I have been given a second chance. I look at life differently now. My cup is always half full, and not half empty.”

A change in your breast, or the removal of a breast, is a loss. You have the right to mourn this loss as you would any other. You may also feel a loss of your former self, who you were before you were diagnosed with breast cancer. While breast cancer has changed your life, you may find that time and healing give you a larger perspective, one that encompasses all of who you are and all of your experiences.

You may also experience grief that seems to be caused by the cancer, but is actually related to a prior loss, which is suddenly reawakened. To resolve this grief, you will have to examine the earlier pain or conflict.

It is possible to understand and accept all your feelings in time. Psychologists say that recovering from the trauma of diagnosis and treatment can take up to two years.

Being diagnosed with a life-threatening disease forces you to confront your fears about death. We are all mortal, we are all going to die someday. The best way to come to terms with your fears about death is to face them and accept them so that you can go on living. Many women find it helpful to examine specific fears. What at first seems like a large, pervasive fear may be smaller, separate fears, which can be more easily managed. Many women find comfort and peace of mind by strengthening a spiritual connection, or developing a new one.

Self-esteem

Having breast cancer challenges a woman's self-esteem: her sense of who she is, her self-worth and self-image. You may need time to adjust to changes in your body, and to recognize that you still retain the essential qualities that make you unique. Changes in your body may cause you sorrow or regret, but they do not diminish your value or beauty as a human being.

If you need to strengthen your self-esteem, a competent, compassionate therapist can help you do so.

I spent a year feeling that death was just around the corner. I was terrified and anxious, and I didn't want to upset my friend by talking about it. I found a therapist who shared my fear of dying. He never lost patience with my fears, and I never felt that I was depressing him. It was an enormous job.

Choosing to tell

Telling people who are mature and sensitive enough to handle a disclosure of cancer will relieve you of the burden of inventing explanations, or being on guard against discovery of your illness. This may be especially helpful when you are struggling to cope with many pressures. You may also find unexpected sources of support and understanding from others, including people who have struggled with a life-threatening illness.

Telling people you do not know well or trust may prove more of a burden than a relief, and undermine your strength and sense of safety. Many people are still ignorant about cancer. The fears or phobias of others may cause you discomfort, and you could find yourself reassuring them. This is not to your benefit.

Use your own judgment. If you do tell someone who reacts badly, you may regret your decision and want to exercise more caution next time, but let it go. You are not responsible for the feelings or behavior of others.

Family and friends

Being honest and direct with family and friends will give them clear guidelines about what they can do to help, and will ensure that you get what you really need. If someone offers to visit you in the hospital, but you don't feel like having company, say that you appreciate their concern but would much rather have them visit you at home. If what you really want is for someone just to be with you, or to listen, tell them so. Explain that you don't expect them to have solutions, you simply need someone to be there, or listen if you want to talk or cry.

Don't assume that people know what you need, or what is the "right" thing to do. Some people are better at coping with crises than others. Most people will truly care and want to help, but not know what best to say and do. Some people feel awkward because of their own fears about illness and death, sense of helplessness or sadness at what has happened to you. While it is not your responsibility to take care of others' feelings, understand that they are also trying to cope.

Breast cancer is sometimes blamed for causing problems in relationships. Weaknesses or conflicts in relationships often become acute and unavoidable during a crisis, such as cancer. Coping with breast cancer may reveal long-standing problems like poor communication or lack of trust - problems clearly not caused by cancer.

Often, it is a woman's assertiveness and stronger sense of self and purpose that create conflict. Many breast cancer survivors say they are more focused on their own needs, and less willing to accommodate the needs of others. You may want to make clear to other people your desire and willingness to work through this period of adjustment. Individuals who value personal growth will respect the changes in you. Give yourself permission to explore ways of enhancing your health and self-esteem; to let go of old behaviors and patterns, including relationships that hold you back.

Others may be impatient for you to "get over" your experience. This is not a realistic or fair expectation. You have survived an ordeal — one that does not end on the last day of treatment. Even respectful, understanding family members and friends may find it difficult to understand how you feel. Accept their limitations.

If you become so preoccupied with the cancer that you can't seem to get on with your life, or if certain feelings linger for long periods of time, you may be stuck in the process of emotional healing. Assistance from a support group or therapist can help you move forward.

Hotlines and support groups

Talking with a hotline counselor can also meet important needs: obtaining specific information, a sympathetic listener or reassurance from a woman who has been there. A hotline counselor can be a strong ally along the way to recovery. The 24-hour Y-ME National Breast Cancer Hotlines (English 1-800-221-2141; Spanish 1-800-986-9505) offer peer counseling, information and support to women throughout the United States.

hard to convey
I've been less successful in sharing with friends the emotional experience of recovery than with sharing the shock and pain of initial diagnosis and early stages of physical recovery. I find it hard to convey to them how changed I am now, how normal challenges and disappointments feel different now. And I sense some impatience on their part at my seeming unwillingness to let go of the cancer or to put it behind me... As a result, I sometimes feel a bit estranged from my friends. I guess reclaiming the connection is the next step.

Attending a support group can give you the opportunity to meet other women who have a special understanding of your experience, and may be a source of inspiration. It may be a way to connect with someone who has had a procedure or treatment that you are contemplating. You can share experiences, grieve and celebrate, while maintaining your privacy and choices about bringing new people into your life. Others who have lived through breast cancer can provide insight and validation missing from even the most loving relationships with family and friends. As one woman said, "Nothing can take the place of immediate response from other people who went through what you went through."

For most women, putting together a patchwork of support is the most practical and satisfying way to meet many needs. An African-American woman who is single and lives in the suburbs says, "I attend three different meetings: one, because it's in the suburbs, another to talk with other African-Americans and the third because it's a meeting for singles."

You may find your experience is different from other women in the group because you are single, lesbian, African-American, Latina, Asian, older or younger. You deserve to have your experiences heard and respected. Tell others what it feels like to be the only single, married, lesbian or African-American woman in the group.

Some women become impatient with support groups, or find them depressing. They prefer groups that offer education as well as support, because speakers and discussion topics give focus to the group. You may become frustrated or dissatisfied with meetings that do not address your specific concerns. One solution may be to start your own group for women who share similar circumstances to yours.

Transformation

Many people who have had cancer say the experience provoked a complete reassessment of their lives, their sense of purpose, values, relationships and goals. Healing can be an opportunity as well as a challenge, an opportunity to take risks to live the life you really want to live.

Facing and triumphing over a life-threatening illness leads many women to discover new sources of inner strength, and the value of asserting that self-determination in all areas of their lives. As you emerge from a period of uncertainty, fear, pain or confusion, you may be surprised by the changes you find in yourself and the world around you. Getting to know the woman you have become as a result of having cancer can be a source of new insights, excitement and hope for the future.

IV. DECISIONS ABOUT RECONSTRUCTION AND PROSTHESIS

Reconstruction

Breast reconstruction offers many women hope that they will be able to live with the loss of a breast or breasts. A reconstructed breast can spare a woman the constant reminder of the cancer, and give her a sense of freedom that helps her get on with her life. A woman can go without a bra, and wear bathrobes, nightgowns and swimsuits without worrying about exposing the loss of a breast. For many women, the imperfections of a reconstructed breast are worth having — it makes one feel complete.

There are many aspects of breast reconstruction that should be carefully considered before making a decision. If you are ambivalent about having reconstruction, consider giving yourself time to recover from treatment before making your decision. You may first want to know how you feel without your breast or breasts. This is one area where your health will not be compromised if you take as much time as you need to consider your options.

If you are certain you want reconstruction, discuss this with your surgeon and plastic surgeon before your mastectomy. The surgeon will probably adapt your surgery to accommodate the reconstruction.

I had abdominal flap surgery six months after my mastectomy. My surgeon was great, and I've had no problems.

I had an immediate reconstruction and then a couple of years later had a revision done by a different plastic surgeon. I did more research and interviewing for the revision than I even thought to do for the initial surgery.

I'm happy with the results of my reconstruction. It makes me feel more self-confident in my new single status.

Make sure the plastic surgeon presents all your options, and discusses potential side effects and drawbacks, as well as benefits, of each procedure. Ask him or her to show you photographs of reconstructed breasts. Looking at varying results of reconstructive surgery will give you realistic expectations about a reconstructed breast, as well as information about a physician's expertise. Consultations with two or three plastic surgeons will help you achieve the results that are best for you.

The most common procedures for reconstruction involve the use of an implant or a tissue flap, using a woman's own body tissue. Reconstruction of a nipple using a woman's own tissue is also possible.

An implant is a sac filled with liquid that is placed under the chest muscle. Inserting an implant is the easiest and least costly procedure. Some women have no problems with implants. Some women experience ongoing discomfort, difficulty sleeping in certain positions, and the need to massage the breast daily to avoid encapsulation (hardening of the tissue around the implant). An implant may leak or rupture.

The Food and Drug Administration (FDA) continues to restrict the use of silicone breast implants (SBIs). However, the Institute of Medicine's Information for Women About the Safety of Silicone Breast Implants reported that SBIs do not cause auto-immune disease or any cancers. If you are interested in implants, ask your plastic and reconstructive surgeon about participating in an ongoing study of SBIs.

A tissue flap, taken from the abdomen, back or buttocks, has the advantage of being a woman's body tissue and gives the reconstructed breast a natural feel. But the procedure is complex, and involves surgeries and scarring in two areas of the body. Some women do not have enough body fat to take tissue from the abdomen. An abdominal flap also requires the removal of a stomach muscle, which compromises the elasticity and strength of the stomach area. This can affect a woman's ability to carry a pregnancy to term.

My sister said early on that she felt that if I didn't get reconstruction I'd spend the rest of my life thinking about it and considering it. Well, after fifteen months I've pretty much decided that if I did get implants I'd spend the rest of my life thinking about them also.

disappointed

I wanted reconstruction. I wanted to believe promises of things I knew were possible: "We'll make you a new breast that will be so much like the real one that most people won't know the difference." Given this, it is no surprise that I am disappointed in the appearance. After three years, my reconstruction is still uncomfortable. I would not do it again.

While reconstruction may be the best alternative for you, be aware that a reconstructed breast may not assume or retain its desired shape, and will have little or no sensation. Some women report problems with reconstructive surgery. Most women say they are satisfied with the results. For them, the psychological benefits of having a breast outweigh any physical inconveniences or discomfort.

There are no rules about who should have reconstruction or when they should have it. Some women live for years without a breast and then decide to have reconstruction. You may be pressured by doctors, family or friends to have reconstruction because they will feel more comfortable if you have a breast in place. Or people may assume that you don't, or shouldn't, care about having a breast — especially if you are older. The most important feelings about your breasts and your body are yours. The decision whether or not to have reconstruction should be your decision, not someone else's. If you are thirty and don't want reconstruction, that's fine. If you are seventy and want reconstruction, go for it.

Prostheses

After your diagnosis, you may find people available to talk about reconstruction, but no one to talk with about breast prostheses, or breast forms. Prostheses are usually made of silicone, a flexible material, which gives them a feel and weight resembling a breast. A prosthesis can be worn with a regular bra, or a prosthesis bra with a pocket to keep it from slipping. A prosthesis can also be affixed directly to the body with special tape, and now, some without tape, and worn without a bra.

You need to wait a few weeks after surgery for your chest to heal before you can wear a prosthesis. Many women find being fitted for a prosthesis an event that brings them both pain and comfort; pain at confronting their loss, comfort in adjusting to the loss. You may want to have someone accompany you when you go for a fitting. Stores that specialize in prostheses will have private areas for fitting and changing, so you can feel comfortable coming with a male or female friend or family member. Phone in advance to make an appointment. Expect the same sensitive, respectful attention from sales staff that you would expect from any other professional caregiver.

I have decided that reconstruction is not for me. I wear a prosthesis, which is comfortable, and I am satisfied. I was told that I might consider a breast reduction instead, since I was large-breasted to begin with. This is a definite possibility later on.

Most women who do not have reconstruction opt for wearing a prosthesis. When worn with clothes, a prosthesis has the appearance of a natural breast. Prostheses sometimes cause women inconvenience, irritation or embarrassment. You can't wear a prosthesis with a low-cut dress; sometimes a prosthesis will irritate a woman's skin; and a prosthesis can slip out of place. But many women are comfortable and satisfied wearing prostheses, and prefer dealing with these problems to risking further surgery and complications or discomfort that may come with reconstruction. Many women like having the option of taking off an artificial breast when they don't want to wear it.

Doing without

You may choose not to cover the loss of a breast with a prosthesis or reconstruction. Some women feel that wearing a prosthesis denies their experience of breast cancer and the loss it has caused them. Some women do not want to hide the fact that they are missing a breast because they want to be visible to other women who have lost a breast to cancer. Some women feel the need to create the appearance of a breast to make other people feel comfortable. If this is your only reason, you may decide to opt for your own comfort instead.

Others may not always accept your choices about whether and when to wear a prosthesis. They may feel uncomfortable seeing you without a breast or breasts, and try to pressure you to wear a prosthesis. You have the right to challenge others who want you to conform to their expectations. You may not have this freedom, however, when it comes to your professional appearance. Doing what is right for you may be different at different times.

One woman who had a double mastectomy always wears her prostheses when she's in public, professionally or socially. She never wears them when she's in her backyard gardening. She says her neighbors see her and know she is a woman who has had breast cancer.

V. INTIMACY

Sexuality

For many women, knowing that they will be sexually attractive, and able to express and enjoy their sexuality after breast cancer, is important encouragement during the process of healing. At the same time, women almost always believe that the loss of a breast makes them less attractive and less sexually exciting. In fact, most men and women say they are not repulsed or greatly disturbed by the absence of a partner's breast or breasts. They are more likely to be distressed by their partner's grief over the loss.

Cancer is not contagious! Nor can the effects of treatments, such as radiation or chemotherapy, be transmitted to your partner in any way. However, it is very important to have safe, protected sex while you are in treatment. Avoid becoming pregnant while having chemotherapy. Birth control pills should not be taken at any time during treatment for breast cancer. Most doctors recommend that women who have had breast cancer find an alternative to using birth control pills.

Lack of interest in sexual activity during treatment is generally due to exhaustion and stress. During or after treatment, if you do not feel strong enough for vigorous sexual activity, you may want to enjoy intimacy with your partner in other ways, such as massage, touching, stroking or kissing, or with words and other gestures. If you do not feel ready for physical intimacy, consider reading a book on sexuality together. If you are too tired to read, have your partner read aloud to you.

You may have difficulty reorienting your body to feel pleasure, or to feel sexy after enduring physical discomfort or emotional distress. Getting in touch with your sensuality can help you reclaim your sexuality. Focus on your ability to enjoy your sense of touch, sound, smell, sight and taste. A massage, a bath with scented oils, a good meal or new outfit can give you physical pleasure, and enhance your sense of well-being.

I had to seek help from a psychologist when it came to having sex after surgery. I am a full-figured woman, and the surgery left me quite disfigured. She told me to buy black slips — full slips or camisoles — and leave them on until I felt comfortable. I had dated the same man on and off for a long time. He told me as long as I was alive he didn't care about my scars, or not having hair anywhere. At first I was apprehensive, but now it makes no difference. I strip totally for sex.

If you have had a breast or breasts removed, you need to adjust to their absence and to the loss of the role the breast(s) or nipple(s) had in your sexual arousal or response. This is true for women who have had reconstruction after mastectomy, as a reconstructed breast will not have sensation. Most women who have had a single mastectomy do not experience considerable physical changes in their capacity for sexual arousal or response. Naturally, it may be more difficult to adjust after a double mastectomy, especially if you were aroused by stimulation of your nipples. One of Dr. Susan Love's patients describes an interesting change in her sexual response. Sensations she had previously experienced in her breasts "moved southward." As a result, they were twice as pleasurable.

Having a lumpectomy and radiation may also cause temporary or permanent changes to your breast or chest area. A breast that has been irradiated may become sensitive or sore. Physical discomfort is usually temporary. There may be some loss of nipple sensation.

You may find it useful to distinguish what is primarily a physical change in sexual response — such as loss of nipple sensation, or discomfort from an irradiated breast — from what is primarily emotional, such as self-consciousness or anger about changes in your body. Coping with your emotional response may be the most complex and challenging adjustment to sexuality you will have to make. But unlike physical differences that are unalterable, your emotional and sexual response to changes in your body can be transformed. For most women, time and love, including self-love, bring self-acceptance.

If you find that the loss of a breast or breasts diminishes your sexual arousal, you may want to explore new techniques to enhance sexual pleasure. A technique developed by sex therapists William Masters and Virginia Johnson, called "sensate focus," encourages mutual exploration without the touching of genitals or breasts. The idea is to direct focus to other areas of the body that give sensual pleasure to reprogram sexual responses.

Some women experience a change or disruption in their sexual desire, arousal or ability to achieve orgasm during or after chemotherapy. Some drugs used in chemotherapy suppress the production of estrogen and can interrupt the body's normal reproductive and sexual functions, temporarily or permanently.

comfortable
If having only one breast makes me undesirable to someone else, that is their problem, not mine. I am comfortable with only one and there is someone out there who will be comfortable with it, too.

Premature menopause caused by chemotherapy brings the same changes that come with natural menopause — abruptly, rather than gradually. This can be very disconcerting. Reduction in estrogen production usually diminishes sexual desire, and reduces the lubrication, elasticity and even the size of the vagina. Because the walls of the vagina tend to thin with the reduction of estrogen, intercourse can become painful and in some instances, cause bleeding.

To alleviate this condition you can apply ointments and lubricants two to three times each week and just prior to intercourse. Ointments made with vitamin A and D can thicken and moisten the vaginal lining and reduce discomfort and bleeding. They are available in drugstores and health food stores without prescription. Vaginal lubricants that do not contain estrogen can be purchased without prescription in a drugstore, and safely used to lubricate the vaginal area. Petroleum-based creams are not recommended, as they can cause bacterial infection.

Women who experience vaginal dryness and discomfort after menopause sometimes find relief with estrogen-based creams or an Estring. An Estring is a ring that is inserted into the vagina and left there for 3 months. The ring releases small amount of estrogen into the vagina. But women who have had breast cancer are cautioned against taking estrogen-replacement drugs or using creams that contain estrogen, because of the role estrogen may play in contributing to the disease. Studies about estrogen supplements and breast cancer are still inconclusive, and controversial. You may want to do some research about current thinking and treatment, and discuss options with your doctor.

Tamoxifen also suppresses the body's production of estrogen. Taking tamoxifen as ongoing, adjuvant therapy after your primary treatment may result in a lessening of sexual drive and sexual response.

Many women who experience loss of sexual interest and desire have very low levels of the hormone testosterone. The presence of testosterone is critical for maintaining sex drive. If you are experiencing chronic sexual impairment, ask your doctor to check your estrogen and testosterone levels. Women with low levels of testosterone can safely take testosterone supplements, and expect some improvement in sexual desire.

Problems here seem to be in my mind. I feel less free with men, and I act less sexy. But my limited experience suggests that men who are interested in something more than a one-night stand are not as disturbed about my lack of a breast as I am.

Becoming sexually active

Give yourself the time and attention you need to enjoy sex with comfort and confidence. If you don't feel ready, wait!

A gentle way to adjust to changes in your chest is to expose your body gradually. If you want to have sex, but don't feel comfortable undressing completely, treat yourself to a negligee or camisole that will let you feel intimate while keeping a certain measure of privacy.

If you don't have a spouse, a steady partner, or do not date often, explore other ways to feel comfortable with your body. One woman who had a double mastectomy began weekly massage therapy. "Greatest thing that ever happened to me. I now have weekly massages and recommend them very highly to all single women — especially if you don't have a regular lover. The massage reduces the stress, but more importantly, the touch, the body contact is what will bring you around to accepting your chest the way it is. The masseuse has seen it before. You have a human being looking at you and not being repulsed — not being affected at all. It makes you realize it's not the end of the world to have a flat chest."

Your spouse or partner may try to initiate sex as a way to prove that you are desirable, or they may hang back out of fear of causing you discomfort or pain. You may have difficulty relaxing and feeling sexy if you feel self-conscious about your chest. It is important to discuss your mutual feelings or fears about sex. Establishing good communication in advance will help you avoid misunderstandings, and enable you to address questions and concerns - especially during sex - as soon as they arise.

Continue to communicate during sex. Let your partner know what feels good, or what causes you pain or discomfort. Guide him or her toward helping you accept changes in your body. You may find it comforting to have your partner kiss or caress the scarred or altered parts of your chest. Showing tenderness for an area — emotional or physical — where you have felt pain, or feel vulnerable, can create a bond of trust that deepens and intensifies sexual intimacy.

I bought a stretchy cotton-knit top with lace shoulder straps. It was very comfortable — a great way to introduce my changed body. After a few tears (grief for my lost breasts) I was able to remove the camisole and feel okay.

amazed & delighted

At first I wondered if I would still feel like the same person without my breast. Now I am amazed and delighted to see how little difference the loss has made — I feel as feminine as I did before the surgery; in some ways I am less afraid of losing my femininity because I have come to see that femininity and sexiness are much more in the mind than the body.

For some couples, adapting to changes in the intimate areas of their relationship can be a strain. Sometimes, problems that were not addressed in the earlier stage of the marriage or partnership will increase with the stress of dealing with breast cancer. If you experience problems resuming sexual activity, seek help from a physician or therapist, or encourage discussion about sexuality in your support group. If your doctor isn't willing to address these problems seriously or to help you seek solutions, find a doctor who will. People who suggest that you should be glad to be alive and not worry about orgasms are not going to be of any help to you. You have had to face the possibility of your life being shortened by cancer. Your desire for love and intimacy may be heightened by your experience. Go after what you want!

VI. PREGNANCY

Being diagnosed with a life-threatening disease interrupts the normal cycle of life, especially for young women. You may suddenly feel transported in time, faced with concerns that usually come with aging before you have fully lived and enjoyed your middle years. If you want to become a mother, or have more children, you may be concerned that cancer, or cancer treatment, could disrupt your dreams and plans.

In the past, physicians routinely advised women with a history of breast cancer against becoming pregnant. Since the body produces more estrogen during pregnancy, and estrogen promotes the growth of some tumors, many doctors believed pregnancy increased the risk of recurrence.

In fact, it is not clear that pregnancy during or following a breast cancer diagnosis and treatment increases risks of recurrence. No studies to date indicate with certainty that pregnancy increases the likelihood of a recurrence of this disease.

Since the chances of reoccurrence are greatest within two years of an initial diagnosis of breast cancer, some doctors advise women to wait from two to five years after diagnosis before becoming pregnant. Physicians may be concerned about a woman's ability to care for a young child if she has a recurrence, or about the future of a child whose mother may die of cancer. While these concerns are valid, they are more the concerns of a woman and her family.

For me there was no greater expression that I was healed and was whole. Becoming pregnant is an affirmation of life — that something is growing inside you that is not killing, but is healthy and strong. Cells divide, mutate, become cancer. Or cells divide and grow into an embryo.

— Nora Frenkiel from *"Question of Life"* *The New York Times Magazine*, May 3, 1992

Prior treatment for breast cancer, including surgery, radiation, chemotherapy and hormonal therapy, does not affect the health of a child. Children born to women with breast cancer grow and develop normally. Cancer cannot be passed from mother to child during pregnancy or breast-feeding. However, most physicians recommend that women do not take tamoxifen if they plan to become pregnant, since tamoxifen may affect a woman's ability to conceive or may adversely affect a pregnancy.

Daughters of women who have had breast cancer do have a higher risk for developing the disease than other women, but heredity is only a contributing factor — most instances of breast cancer are not due to heredity. Daughters of women with breast cancer, like all young women, must learn good breast health care, including how to do regular breast self-examination for early detection of the disease.

All expectant mothers face fears that they may not always be there for their children, fears that are heightened for a woman who has had a life-threatening disease. Having a good network of support in place before you conceive a child will ensure the ongoing support you will need as a mother. Making sure other responsible, caring adults are involved in raising your child, and committed to his or her future, will address fears you may have of leaving your child without a mother. Talk with other mothers who have had breast cancer. Their experience can give you guidance and confidence as you make decisions and plan for the future.

Increasingly, women are making decisions about pregnancy based on their own judgments of the risks and rewards. When you are ready, research current medical literature and consult with a physician, making sure she or he respects your right to make your own choice.

Forgoing pregnancy and motherhood may appear to be a safer choice for women who have had breast cancer. But if giving up this experience will cause you deep, ongoing disappointment, it may not truly be the healthier choice. Many women with breast cancer become pregnant, give birth and remain cancer free for many years. For breast cancer survivors, conceiving and bearing a child can be a celebration of life and a commitment to the future.

VII. DIET, EXERCISE AND HOLISTIC HEALING

Diet

The role of diet in the development of cancer has not been clearly established. Most studies now show that a diet high in fats does not increase one's risk of getting cancer. However, a diet low in fats and high in fiber, reducing the amount of meat and dairy products, sugar, processed foods, alcohol and caffeine in your diet, and increasing the amount of whole grains, fresh vegetables and fruits is recommended for your general good health.

A nutritious diet is important to maintaining a strong immune system and general good health. Eating foods that nourish your body will strengthen your ability to cope with illness, infection and stress, and enhance your self-esteem. Cooking and eating well is a way of taking responsibility for your health and reminding yourself that you are committed to caring for your body.

Books are available at bookstores and health food stores, which discuss the relationship between diet and health. Increasingly, cookbooks and restaurant menus are available for people who want to eat low-fat meals, live a vegetarian lifestyle or follow a diet of natural, whole foods.

If you decide to make sweeping changes in your diet, you will probably want to do some careful research before doing so, and consult a qualified nutritionist or other certified health practitioner.

Making changes in eating, and other life-style habits, takes time and may require exploration and experimentation until you find what feels right for you. It's a process. Be patient with yourself. Set reasonable goals that you are likely to meet. Trying to follow a regime that you find too time-consuming, costly or rigid may not advance your goal of feeling better.

Exercise

Exercise is another area of your life where you can act to promote your health. Regular exercise will help you feel better, and help you reclaim your body, during or after treatment.

*Working out feels great, but I had to teach myself not to overdo it...
to create good, as opposed to bad, stress on my body.*

*Exercising has been an important part of making friends with my
changed body. It has helped me to feel assured that I can still do
all the things I did before my illness.*

Choose a workout or exercise program that is compatible with your interests and lifestyle. Stretching for a few minutes in the morning is free and takes little time. It can help you feel more flexible and invigorated and can make a difference in the way you start your day. Riding a bicycle, swimming, dancing, yoga, aerobics or studying a martial art can tap inner resources of strength and energy, calm the spirit as well as the body, and generate excitement for life.

Exercises or activities that put weight or pressure on your arms, while they are in a downward position, can cause lymphedema. You may want to refrain from doing push-ups or lifting weights or other heavy objects. Doing pull-ups or working with weights with your arms in an upright position is safer.

If you develop lymphedema, there are many options for you to explore. Exercise, manual lymph drainage (gentle massage that stimulates the flow of lymphatic fluid), compression bandaging, customized compression sleeves, and pneumatic compression sleeves are some of the options. You should consult a healthcare professional who knows all of the different methods of treatment in order to find out what will work best for you.

Exercise is meant to feel good and be enjoyed! If your workout bores you, or feels more like punishment than pleasure, find a new routine. If you have a hard time going it alone, a class or a walking buddy may be what you need. It helps to work out with people you enjoy.

If you want to work out at a health club, find one where the atmosphere is friendly and less competitive. Health clubs, like anyplace else, will differ, and there may be one that feels right for you. Some women feel very self-conscious at health clubs — whether or not they have had breast cancer. You may want to dress in a private area at first. In time you may find that, as you are able to feel more comfortable with your body, others will too.

aided my recovery
I was always bugging the doctor to let me get back to my health club workouts as soon as possible. At the very least, I would walk every day. I think my level of fitness and my quick return to exercise really aided my recovery, both physically and emotionally.

Holistic healing practices

Many people benefit from holistic healing practices, such as homeopathy, acupuncture, naprapathy or macrobiotics. If you decide to pursue alternative health care after or during your primary course of treatment, you should inform your doctor. It would be wise to view alternative methods as complements to, but not substitutions for, traditional care. Doctors who respect the value of holistic healing practices will welcome your efforts to improve your health.

VIII. FEARS ABOUT RECURRENCE

It is common for women to be preoccupied with the fear of recurrence for two to three years after diagnosis. Every time you have an ache or pain, or sustain a bruise, you may worry that your cancer has returned. A visit to the doctor for a blood test or mammogram may reawaken anxiety. After all, your body was ill before without your knowledge — why not again?

Living with this uncertainty is a challenge. As time passes, women do accept and live with the uncertainty. It's a reality everyone must face, no one knows how long we will be here.

A recurrence does not mean your cancer is fatal. With regular check-ups, if you do have a recurrence, it is likely to be detected at an early stage. You may feel that you couldn't bear to go through a second diagnosis of breast cancer, or fear that you've exhausted the support of family and friends. But you, as well as friends and family, may be better prepared to cope with a recurrence than with the first diagnosis.

Dr. Susan Love explains the possibility of recurrence this way: "With breast cancer, unlike some other cancers, five years without recurrence doesn't mean you're cured. Because it's usually a slow-growing cancer, it can spread to another part of your body and go undetected for 10 or even 20 years. The longer you go without a recurrence, however, the less likely a recurrence is, and the more treatable it will be if it does happen.... Therefore, you're wise to think of breast cancer as a chronic disease, like high blood pressure or diabetes or asthma that you'll always have in your life. You're also wise to remember that it's very likely that, as with other chronic diseases, it's something you can live with."

Redirecting anxiety about recurrence into energy for taking action will help you cope. Follow the plan developed by your doctor including regular office visits, mammography screenings and blood tests. Doing regular breast self-examination is very important. If you find you are too anxious to do breast self-examination, talk over your fears with your doctor. You may decide to visit your doctor more frequently, and have him or her do your exam, at least for a while.

If you discover a lump, or feel there is something wrong with a breast, do not hesitate to have an examination. If a doctor tells you to "wait and watch" a suspicious lump until your next mammogram, but you continue to feel uneasy, get a second or third opinion.

Sometimes women feel impatient, or distressed, at being preoccupied with their bodies. You may find yourself wondering if you will bring on a recurrence because you are under stress or eating rich foods. It is important to take a balanced approach in accepting your role in the responsibility of the wellness or illness of your body. You did not cause yourself to develop cancer, and you cannot cause yourself to have a recurrence.

You can take an active role in promoting your health. Since a healthy immune system can destroy a certain number of cancerous cells, maintaining good general health is important for people who have had cancer.

Some preliminary studies indicate that women with advanced breast cancer who belong to support groups live longer than women who do not. You may not want to join a support group, but you may want to develop some clear guidelines for getting ongoing support that promotes your well-being. This can be a network of family, friends or colleagues that validate your feelings and sense of self-worth. Living each day to its fullest, while it may not guarantee longevity, will enhance the quality of your life.

I told myself that if I ever had a recurrence, it would be over. But when I had the recurrence I just dealt with it. Now when I think about recurrence, I just tell myself that if it happens again, I'll deal with it again. I'm not going to worry about it because I need to use my energy in other ways. I will always have the fear, but I have learned to live with it and put it in perspective. Even if I didn't have cancer I could still have a fear of dying. It's comforting to me that I'm adjusting to and accepting the fear.

IX. INSURANCE AND EMPLOYMENT

Insurance

Coping with medical bills and insurance procedures may be a serious and ongoing source of stress during and after treatment. Having a good understanding of your policy, and asserting your right to get the coverage promised, will help you cope effectively.

You should know both the extent of your coverage, and what is required of you, to receive full coverage. Find out, for example, if your policy covers the cost of getting a second opinion and if your policy requires that you get a second opinion.

Check to make sure you are not being improperly billed — for procedures, or for the length of time taken for procedures. Check for any discrepancies between what your policy is supposed to cover and what the insurance company offers to cover — sometimes referred to as "policy interpretation." If you challenge the company's decision, you will probably be referred to the claims department. If you are not satisfied with the information you are given, ask to speak with a supervisor or manager. You may also want to speak with a medical director. An insurance company is a business committed to its own interests. You must be just as prepared to represent and protect your interests.

Most insurance policies will cover costs within certain limits; charges by physicians or hospitals that they consider "reasonable and customary" or "usual and customary." If your physician's charges are higher, you may want to tell your doctor. Some doctors will discount their fees or "forgive" the additional amount that you would otherwise have to pay. If your physician agrees to do this, but you receive a bill for the standard fee, don't be alarmed. Billing services may not be aware of the arrangement that was made, and you will need to make a follow-up call.

If you need assistance with processing a claim, contact your state Department of Insurance. In the event of a disagreement or dispute between you and the insurance company, the Department of Insurance can tell you if there are state laws that apply to your case.

I had one poignant conversation with a hospital billing office, which had billed for a mastectomy rather than a lumpectomy. "Are you sure you didn't have a mastectomy," the woman asked. "Could you be mistaken?"

I asked her whether she wanted me to look again and check if my breast was still there.

Some hospitals employ patient representatives who act as patient advocates in case of a dispute with an insurance company. If the hospital where you were treated has a patient representative, s/he can contact your insurance company to challenge or negotiate a determination.

Employment

You may find that insurance considerations play an important role in your employment options. Many women who have had breast cancer express frustration about their inability to seek new jobs because many insurance companies refuse to insure individuals with a "pre-existing condition." This can be particularly frustrating at a time when you may want to explore new directions in your life. However, a bill passed in 1997 attempts to address this issue. The Health Insurance Portability and Accountability Act (HIPPA or the Kennedy/Kassebaum law) allows people who have been enrolled in a group health plan for 12 months to be covered by a new group health plan with no exclusions for pre-existing conditions.

Though discrimination against people with cancer is illegal, you may understandably feel uneasy about disclosing your medical history to a prospective or new employer. The rights of people with cancer, summarized below, are protected under the Americans with Disabilities Act:

- An employer may not require any pre-employment medical examinations or ask for any medical history, either in a job interview or on an application form.
- After a job has been offered, an employer can make medical inquiries or require a medical examination, if this is a standard procedure for all employees. A job offer cannot be withdrawn as a result of the medical inquiry, unless the problem will interfere with the employee's ability to perform her job.
- An employer must also provide "reasonable accommodations" to the physical limitations or needs of the employee, such as modifying a work schedule or permitting unpaid leaves for necessary treatment. These obligations, however, must be balanced with the employer's needs for conducting business.

To find out more about your rights and the responsibilities of employers, or to report any problems or discrimination you experience, contact your local Equal Employment Opportunity Commission (EEOC) office.

X. SPEAKING OUT AS A BREAST CANCER SURVIVOR

There are over two million women in the United States who are breast cancer survivors. As you regain your strength and reassert yourself in the world, you may find your experience of breast cancer prompts a desire to take action. For many women, participation in the efforts to increase awareness and provide support as the fight against breast cancer continues, is a way to feel empowered.

There are many ways to contribute to the cause — become a support group leader or public speaker, train other women in breast self-examination, perform community outreach, financially support organizations, attend events, lobby public officials. Participation gives many women the strength of community with other women who are living with breast cancer and working to end this disease. Efforts must continue to increase the support and assistance to all who have breast cancer and those whose lives are touched by it.

Remember — you are not alone.

Helping other women cope with breast cancer has given me my only sense that I am fighting back against cancer. Being able to reassure other women that they can cope has helped me cope.

*I refuse to be in the closet on this issue. I had breast cancer. It wasn't my fault. I hope that by being open about it I can help other women.
"See me — I'm doing fine!"*

Mission

The mission of Y-ME National Breast Cancer Organization is to ensure, through information, empowerment and peer support, that no one faces breast cancer alone.



212 W. Van Buren Street, Suite 500
Chicago, IL 60607

24-hour Y-ME National Breast Cancer Hotline
1-800-221-2141*
1-800-986-9505 (Español)

*Peer support available in nearly 150 languages.