

*Self-Help Manual for Managing Uncertainty
After Breast Cancer*



*Managing Uncertainty
Day-to-Day*



Introduction

This manual is designed to help you, as a breast cancer survivor, manage the uncertainties and concerns you may have about six different problems that are long-term side-effects of breast cancer treatment. It also contains a section on maintaining a healthy lifestyle. It was developed with the assistance of a number of breast cancer survivors who were kind enough to participate in group discussions and to review the material. We gratefully acknowledge their help.

Each section of the manual focuses on a particular long-term side-effect of breast cancer treatment. Each one contains a description of the problem, how and why it occurs, strategies for prevention, tips for managing the problem if you have it, when to call the doctor, and a list of additional resources for information like books, tapes, pamphlets, web sites and organizations. If there is controversy about some aspect of problem management, we have also included information about some professional journal articles that we used to support our suggestions.

❧ How to Use This Manual ❧

This manual can be used in several ways. Certainly everyone can benefit from learning more about healthy lifestyles. If you have any of the long-term problems included in the manual, you will want to read the sections on those problems in some detail and use them to help manage your own long-term side-effects. You may be interested in reading every section because many of them contain important information on prevention of long-term breast cancer treatment-related

problems and because you may have heard of or discussed some of these problems with other women.

Another way to use the manual is to look at the resource lists at the end of each section and in the separate section in the manual. The resource lists contain many interesting and informative places that you can get additional information or help.

We hope this manual will be useful for you to learn and gain confidence in managing your life as a breast cancer survivor.


 *Best wishes from the Managing Uncertainty in Breast Cancer Survivors research team and the many survivors who helped develop this manual.*

Table of Contents

<u>Chapter 1</u> - Fatigue	1-10
Causes of fatigue in cancer	1
Effects of fatigue	3
Talking with your doctor about fatigue	4
Managing fatigue in everyday life	4
Resources	9
<u>Chapter 2</u> - Hormonal Changes and Sexuality	11-20
What do estrogen and testosterone do?	11
Hormones and sexual function	12
Managing problems related to hormonal changes ...	13
Resources	18
<u>Chapter 3</u> - Joint Stiffness	21-30
Causes	21
Prevention	23
Managing joint stiffness	23
Exercises	24
Resources	28

<u>Chapter 4 - Lymphedema</u>	31-50
Definition	31
Managing lymphedema	35
Treatment	41
Lymphedema treatment centers	43
Financial issues	45
Resources	47
<u>Chapter 5 - Pain Management</u>	51-64
Cause/links to breast cancer treatment	51
Factors that may make pain worse	52
Pain relief methods	53
Management strategies	61
Resources	64
<u>Chapter 6 - Skin Changes</u>	65-72
Cancer treatment and effects on skin.....	66
Prevention of skin changes	69
Managing skin changes.....	69
<u>Chapter 7 - Maintaining a Healthy Lifestyle</u>	73-94
Emotional support and health	74
Clothes and hairstyle.....	76
Diet.....	77
Exercise	78
Starting an exercise program	79


Advocacy	81
Communicating with health care providers	82
Resources	88
<u>Appendix</u>	95-108
Breast self-examination	95
Post-mastectomy breast self-examination	99
Stretching exercises	102
Regional support organizations	106
Evaluating websites	107
Glossary	109
<u>General Resources</u>	117-122
<u>Index</u>	123-125


Acknowledgments

We wish to acknowledge the contributions of the following individuals in the production of this manual:

 Merle H. Mishel, PhD, RN - Principal Investigator
Barbara Germino, PhD, RN - Co-Principal Investigator

Karen M. Gil, PhD - Co-Investigator
Iris Carlton-LaNey, PhD - Co-Investigator
Michael Belyea, PhD - Co-Investigator

 Jill Hamilton
Kristina Killgrove
Lynne Lewallen
Mary Lynn Piven
Laura Porter
Daniel Shelverton
Janet Stewart

 All of the breast cancer survivors who have participated in our focus groups.

Fatigue



∞ General Information ∞


∞ Description/Definition

If you are feeling tired, weak, drowsy, lacking energy, bushed, beat, or washed out, you may be having fatigue. Other signs of fatigue can be harder to recognize. For example, pain in your legs, problems climbing stairs, and walking short distances are all signs of fatigue. Fatigue can mean being short of breath after only light activity, like cooking a meal or taking a shower.

∞ Why Does Fatigue Occur With Cancer Treatment? ∞

For most people, fatigue is a short-term, temporary condition relieved by rest or sleep. For breast cancer survivors, fatigue may be caused by many different things.

∞ Fatigue commonly begins **during or after radiation or chemotherapy** treatment and can be a result of tumor cells being broken down. It can also be related to anemia (too few red blood cells) caused by treatment.

 Fatigue **after surgery** is not unusual as the body recovers from the effects of anesthesia and the surgery itself. It takes a lot of **emotional energy** to deal with a diagnosis of cancer and to go through the treatment.

We do not know the reason that fatigue continues for years after treatment for some breast cancer survivors, but there are many of possibilities:

- ✿ Research shows that it can take longer for energy to come back if you are **older** and have had **combined therapy** (chemotherapy and radiation) for your breast cancer.
- ✿ Fatigue after cancer treatment may be caused **by lack of physical activity**. Sometimes, patients who have been treated for cancer may be less physically active than before their treatment, so loss of fitness may contribute to fatigue.
- ✿ Fatigue may be a symptom of **depression**. If you are not only tired but also have trouble enjoying things that are usually enjoyable, have trouble concentrating, have persistent negative thoughts about your life, have sleep disturbances or appetite changes, you need to tell your doctor about all these symptoms. Depression is an illness that can be managed effectively with medication and/or talk therapy.

- ✿ Most experts agree that **worry and stress** are two common causes of fatigue. Worry takes a lot of energy, and many times we do not know when we are actually having worrying thoughts.
- ✿ Some fatigue may have other **medical causes** like low thyroid (hypothyroidism), so it is important to talk to your doctor so he/she can check for those other causes.

✿ Effects of Fatigue ✿

Fatigue can affect your ability to function in your everyday life and make life less enjoyable. Fatigue can also affect the way you think and the way you feel. Many people with fatigue have trouble concentrating when reading, watching television, and even talking with their family. Fatigue can be a problem in getting work done and in enjoying those things you do for pleasure.

✿ Talking with Your Doctor about Fatigue ✿

It is important to let your doctor know about your fatigue if it continues and is a problem for you. Unfortunately, many breast cancer survivors do not talk to their doctors about fatigue because they do not understand exactly what it is or because they think that feeling tired long after cancer treatment is “normal.” Here are some **ideas that will help** you discuss your concerns with your doctor:


- ✿ **Write down your questions** before you go to the doctor so you are ready.
- ✿ **Tell your doctor which things you can't do.** Be very specific. Your doctor should know if you are working or staying home, if you are able to take walks or climb stairs, if you are too tired to shower or cook, and if the fatigue is worse in the morning or at night.
- ✿ **Talk about your feelings and report any changes** in your sleep, appetite, and personal relationships resulting from fatigue.
- ✿ **Tell your doctor if you have lost interest** in certain activities you used to enjoy, **or if you are having trouble concentrating or having many negative thoughts** about your life.
- ✿ **Ask the doctor what could be causing this fatigue.**
- ✿ **Ask the doctor if there is a treatment** that can help.







🌀 **Managing Fatigue in Everyday Life** 🌀


There are two keys to managing fatigue:





- ❶ Using energy wisely and using rest effectively.
- ❷ Getting help when you need it.


Using energy wisely and using rest effectively

 Keep track of the pattern of your fatigue over several days in a notebook:

-  When are you the most fatigued? Least fatigued?
-  What are you doing when you begin to feel fatigued?
-  Do different types of activities make you feel more or less fatigued?
-  What helps you recover your energy?
-  Is your fatigue mental as well as physical?
-  Do you get tired when you try to pay attention or to concentrate?

 Once you understand the pattern of your fatigue, plan to use your energy for the things that are most important to you and when you need it most:

-  **Set priorities.** Schedule important daily activities during times of least fatigue.
-  **Protect your low-energy times** from stressful events and people. However, don't isolate yourself too much. This can lead to depression and increase your fatigue.
-  **Minimize stress-producing activities.**
-  **Manage worries and fears** that keep you from relaxing.

 Eat as well as you can and drink plenty of fluids, especially water. Avoid sleeping for long periods during the day. Take several short naps or breaks. Stay with your normal sleep patterns at night.

❁ Simplify your work:

- ❁ A slow, steady work rate with short rest periods helps you get work done without getting exhausted.
- ❁ When the weather is hot and humid, plan activities for the cooler parts of the day and evening, or do your work in a cool place.
- ❁ Spend some time on exercise—research shows it will pay off in better physical condition, a more positive outlook on life, more energy, and better control of your weight, allowing your heart and lungs to work more easily.
- ❁ Do things that take the most energy when you have the most energy. For example, if you plan to see friends in the evening, rest in the afternoon so you won't be too tired to enjoy yourself.
- ❁ Take into account your age and health, and pace yourself.
- ❁ The same work can get done at a slower pace with additional time and rest periods.

❁ Find interests that can be less strenuous but still enjoyable.

❁ Stay as healthy as possible. See the **Health Maintenance** section of this manual on pages 73-94 for information on maintaining a healthy lifestyle.

More ways to use energy wisely

- ✿ Move fairly slowly, controlling your breathing and using smooth movements. Think about what you are going to do next.
- ✿ Remember to take frequent rests.
- ✿ Organize your activities and equipment needed for them; do them in a routine way-this makes you more efficient.
- ✿ Use shortcuts whenever possible.
- ✿ Slide, wheel, push, or roll things rather than lifting and carrying.

Ask for help when you need it

- ✿ This is hard for many people to do, but it is an essential part of managing fatigue.
- ✿ Remember that there are people who want to help but don't know how to until you tell them.
- ✿ Remind yourself of the times you have helped others; plan to continue to help when you are able.
- ✿ When writing down the pattern of your fatigue, ask yourself what kinds of activities you really need help with and what kinds of help would allow you to better use your energy.

- ✿ Ask for help from those who are willing and able to help you.
- ✿ Divide up the help you ask for among several people, matching people to jobs you know they are good at or would like to do.
- ✿ Join a support group, or try to get help from an oncology social worker or counselor. Sharing your feelings with others can ease the burden of fatigue, and you can often get hints about how to manage your own fatigue by talking with others.

🎗 These suggestions should help you:

- ✿ Be more aware of the pattern of your fatigue.
- ✿ Plan ahead to take advantage of those times when you feel least fatigued.
- ✿ Set priorities for your activities, and be selective about activities.
- ✿ Find support for yourself.

Resources for Fatigue

Websites

Focus on Fatigue from Oncolink

<http://www.oncolink.upenn.edu/sunnot/fatigue>

CancerFatigue.org

<http://www.cancerfatigue.org>

Available in Spanish

Campaign on Fatigue from Cancer Care, Inc.

<http://www.cancercare.org/campaigns/fatigue.htm>

Living Beyond Breast Cancer

<http://www.lbbc.org>

e-mail: lbbc@earthlink.net

Phone: 1-888-753-LBBC; contact Marilyn Arnot

10 East Athens Avenue, Suite 204

Ardmore, Pennsylvania 19003

Sisters Network

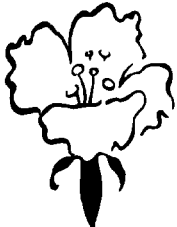
<http://www.sistersnetworkinc.org>

e-mail: sistersnet4@aol.com

Contact: Karne Jackson (713) 781-0255

End of Fatigue Section

Hormonal Changes and Sexuality



❧ General Information ❧

Some women have physical and emotional changes after breast cancer treatment that may affect the way they feel about themselves. These changes come from dealing with the cancer itself and also from the actual cancer treatment that can change our hormones. Although it is not clear why, chemotherapy can damage the ovaries, causing the ovaries to produce less estrogen and testosterone, hormones that are important to sexual functioning in women. Further, chemotherapy can cause menopause to start earlier than it would have without chemotherapy.

❧ How do hormones help us? ❧

- ❁ *Estrogen* is made by the ovaries and helps in lubrication of the vagina during intercourse. The right amount of estrogen in your body prevents you from going into menopause.
- ❁ *Testosterone* is made by the ovaries and stimulates sexual desire. It also affects how much pleasure a woman feels during intercourse.

✿ *Menopause* can result in hot flashes, vaginal dryness and thinning of the walls of the vagina.

✿ Although it is unclear why, chemotherapy can damage the ovaries and stop the ovaries from making enough estrogen and testosterone. Not enough estrogen can cause the vagina to get smaller and can dry the mucous membranes inside the vagina. These changes can cause intercourse to be painful. Not enough testosterone can make intercourse less enjoyable and make you less interested in intercourse.

✿ **What treatment factors affect sexual function?** ✿

- ✿ Type and amount of chemotherapy you received.
- ✿ Your age when you received chemotherapy.
- ✿ Use of *tamoxifen* for breast cancer prevention.

✿ **How do these factors affect sexual function?** ✿

- ✿ Premature menopause
- ✿ Hot flashes
- ✿ Vaginal dryness
- ✿ Vaginal thinning
- ✿ Decreased interest in sex and decreased pleasure when having sex
- ✿ *Tamoxifen* may cause some of the same symptoms as menopause

☞ What can I do to manage these problems? ☞

☞ Hot Flashes



Keep a log of hot flashes for one week to try to figure out a pattern of when and how they happen. Record when and where the hot flashes occur, what happens (the effects)--for example, face very red, blouse soaked with sweat. Rate how severe each hot flash is on a scale of 1-10, how long it lasts, and anything you ate, drank, or did in the 30 minutes before the hot flash.



Check your diet for foods that can cause hot flashes and avoid them. Common foods that cause hot flashes are caffeine, cayenne pepper, citrus fruits, coffee and tea, aged cheese, red wine, and tomatoes.



Keep a pitcher of ice water handy. Frequent drinks—or sucking on ice cubes—can make hot flashes less severe. Remember that alcohol can cause hot flashes.



Keep your home cool, especially the bedroom. A cool bath or shower may help ease flushing.



Wear comfortable, loose-fitting clothing made of natural fibers like cotton and sleep on all-cotton sheets to help cut down on flushing and night sweats.



Stress reduction techniques may help reduce flushing and other menopause symptoms. **(See the audiotapes included with this manual for instructions on relaxation techniques.)**



Vitamin E 400 IU once or twice a day may reduce hot flashes. B-complex vitamins, up to 200mg/day, may also help relieve symptoms. Eating soy foods like tofu or soy cheese or taking soy pills may also help.



If hot flashes continue even when you follow these suggestions, speak to your gynecologist about prescription medications that may help. Some of these are: *clonidone*, *methyldopa*, *megestrol acetate*.



Increased vaginal dryness, itching and burning



Avoid antihistamines and decongestants (cold tablets) since any drug that causes drying of the mucus membranes may worsen the problem.



Daily perineal wash. Sit far back on the toilet seat and rinse well between your legs with a quart of plain

water. Opening the labia with one hand, spray the water from a squirt bottle or pour it slowly from one corner of a square or rectangular container.

- ✿ Apply Vitamin E oil to lubricate the vaginal membranes. Creams or ointments from calendula (*calendula officinalis*), comfrey (*symphytum officinale*), or St. John's Wort (*hypericum perforatum*) may decrease the vulvar or vaginal burning, itching, and other symptoms of dryness that result over time from thinning of the skin. These products can be applied externally once or twice a week or as needed.

- ✿ Olive oil, wheat germ oil, and sesame oil may be used as vaginal lubricants. Soak a square, quilted cotton makeup pad in any of these oils, squeeze out, and insert into the vagina overnight once per week or as needed. Be sure to remove the pad the next day. K-Y Jelly can be purchased over the counter, and another product, Replens Vaginal Moisturizer, moistens the vagina for 2-3 days after a single application.

- ✿ Vaginal itching may be eased with an oatmeal bath. Cooked oatmeal can be placed in a strainer and held under the tap as the tub fills. An over-the-counter product, natural colloidal oatmeal, is also available at the drugstore and may be more convenient.

Decreased sex drive

- ✿ Decreased sexual desire can result from many things such as stress, fatigue, poor body image, and relationship problems. Some drugs, such as antidepressants, can decrease sex drive. Breast cancer survivors who lose desire for all types of sexual activity, including masturbation, may be suffering from a deficiency of testosterone. Loss of feeling or decreased feeling in the nipples and clitoris, as well as fleeting, barely pleasant orgasms, are other symptoms of testosterone deficiency. Testosterone in the body can be measured by a blood test. Speak to your doctor about having a testosterone level drawn. If testosterone is low, your doctor or nurse practitioner can prescribe a testosterone supplement. Testosterone can be dispensed in a cream, but must be made by a compounding pharmacist. (See **Resources** on pages 18-20 of this section.) The cream is rubbed on the vulva, inner thigh, wrist, or abdomen and costs approximately \$45 per month. Testosterone cream has not been tested in breast cancer survivors.
- ✿ Listen to your body and mind. Share your thoughts and feelings with your partner. You and your partner can still enjoy closeness in sexual ways or just by being together through touching, holding, and kissing. Let your partner know where you want to be touched and where you don't want to be touched.

What about hormone replacement therapy (HRT)?

- ✿ Many women use estrogen therapy to control hot flashes, vaginal dryness, and osteoporosis (thinning of the bones) that may occur during menopause. Some breast cancers are known to be stimulated by the presence of estrogen. Estrogen has been shown to increase the risk of uterine cancer. When progesterone is added to estrogen, the risk of uterine cancer is thought to be less, but some scientists are concerned that adding progesterone to estrogen may increase the risk of breast cancer. This is still controversial. A woman considering hormone replacement therapy should discuss these issues with her doctor. (See **Resources** on pages 18-20 of this section for more information about this topic.)

❧ Resources for Hormone Changes and Sexuality ❧

Lubricants, dilators, sex toys, videos

Good Vibrations.

May request catalog by calling 1-800-289-8423, or web site <http://www.goodvibes.com>.

🎀 Books

The Hormone of Desire by Susan Rako, MD (Harmony Books, 1996)

I'm Not in the Mood by Judith Richman, MD (William Morrow, 1998)

Sexuality & Fertility After Cancer by Leslie R. Schover, Ph.D. (John Wiley, 1997).

Dr. Susan Love's Hormone Book: *Making Informed Choices About Menopause*, by Susan M. Love with Karen Lindsey (Random House, New York, 1997). *Offers information on menopause and coping with symptoms and addresses concerns about breast cancer.*

Menopause by Richard J. Santen, MD, Margaret Borwhat, and Sarah Gleason (The Hormone Foundation, Bethesda, MD, 1998). Summary of a meeting that discussed various ways to identify and treat symptoms of post-menopausal hormone deficiency in patients surviving breast cancer. Provides information for women on estrogen treatment, heart disease, and breast cancer. For a free copy, call The Hormone Foundation at 1-800-Hormone or see the website <http://www.hormone.org>.

Compounding Pharmacists

International Academy of Compounding Pharmacists
P.O. Box 1365, Sugar Land, TX 77487
1-800-927-4227 -- Call to find the nearest compounding
pharmacist in your area.

Websites

Breast Cancer and Sexuality: *Surviving and Thriving*
<http://www.cancercare.org/campaigns/breast1.htm>

Oncolink: *Cancer and Sexuality*
<http://www.oncolink.unenn.edu/psychosocial/sexuality>

Pamphlets

Sexuality and Cancer: For the Woman Who Has Cancer and Her Partner. American Cancer Society pamphlet #4657; 1991. Contact ACS or view on-line at their website: <http://www2.cancer.org/DatientGuides/index.cfm>

When the Woman You Love Has Breast Cancer. Y-ME publication. Contact Y-ME at <http://www.y-me.org>

References

Gapstur, SM., Morrow, M., & Sellars, T.A. (1999). Hormone replacement therapy and risk of breast cancer with a favorable histology: Results of the Iowa women's

health study. Journal of the American Medical Association, 281, 2091-2097.

Grodstein, F. Stampfer, M.J., Manson, J.E., Colditz, G.A., Willett, W. C., Rosner, B., Speizer, F.E. & Hennekens, C.H. (1996). Postmenopausal estrogen and progestin use and the risk of cardiovascular disease. The New England Journal of Medicine, 335, 453-461.

Schairer, C., Lubin, J., Troisi, R., Sturgeon, S., Brinton, L., & Hoover, R. (2000). Menopausal estrogen and estrogen-progestin replacement therapy and breast cancer risk. Journal of the American Medical Association, 283, 485-491.

Jacoby, S. (2000). Where do I go from here? AARP Bulletin, vol. 41, no. 5, pp. 3, 22, 24-46.

Joint Stiffness



General Information

Some survivors of breast cancer have muscle weakness and joint stiffness on the side they were operated on. Muscle weakness and joint stiffness of the shoulder, arm, and/or hand can develop any time after treatments have stopped. As time passes, the stiffness and weakness can cause changes in posture. You may notice changes like rounding of the shoulders, a forward tilt to the head, or a lowering or lifting of the operated shoulder.


Causes of Stiffness


Causes that cannot be prevented (often a side-effect of surgery):


- 🎗️ Weakness and stiffness in your shoulders, arms, and/or hand can happen from:
 - 🌸 Nerve or tissue injuries from removal of cancer tissue, breast tissue, or lymph nodes, or from radiation.
 - 🌸 Tiny blood vessels (capillaries) in the breast damaged by surgery.
 - 🌸 Nerve damage from breast reconstruction.


Damage that results from breast cancer treatment is not necessarily preventable.


Preventable Causes


 There are other causes of muscle weakness and joint stiffness that **can be prevented**. These causes are:

 Trying to protect the joints of the affected hand, arm, and shoulder during and after treatment by not using them as much as normal.

 “Bracing” your joints to protect them by tightening your arm and shoulder muscles.

 How do muscle weakness and joint stiffness develop from these preventable causes?

 **Lack of use** of joints and muscles in any situation for any prolonged period of time will cause joints to stiffen and muscles to shrink (atrophy) and lose strength. If you had joint stiffness to begin with from arthritis, limited exercise, or other causes, further lack of use will make it worse. If your muscles were not strong because of lack of exercise or other causes, further lack of use will make it worse and can cause changes in posture.

 **Bracing your joints** may cause stiffness and lack of flexibility because the muscles are tightened and kept more in a “flexed” position than normal. It is like making a fist and keeping your hand in a fist position—the muscles will become tight, and it will eventually become very difficult to straighten out

your hand. The finger and wrist joints will also be difficult to move after some time.

❧ Prevention of Stiffness ❧

- ❧ **Stretching and resistive exercise** can help maintain joint mobility and strengthen muscles. If you have not done so yet, start exercising. See the **Maintaining a Healthy Lifestyle** section on pages 73-94 for information on establishing an exercise program and stretching exercises.

- ❧ If you are not in a habit of stretching, go slowly and gently at first. You may find it harder to stretch in the morning and easier in the afternoon or evening. A warm bath or shower can decrease early morning stiffness and make it easier to do the exercises. **Increasing your flexibility** is one of the best ways to regain function and reduce the chance of serious injury if you fall or are in an accident. Stretching helps increase flexibility.

❧ Management ❧

Management of shoulder stiffness is focused on **restoring mobility** and **reducing discomfort** from stiffness. The best way to do this is with exercise for the whole body and special exercises for the shoulders and arms.

- ❧ The three exercises listed below will decrease shoulder/arm stiffness and increase shoulder range of motion.

- ❧ Daily exercise can decrease general body stiffness by improving muscle tone and strength. A daily, brisk,

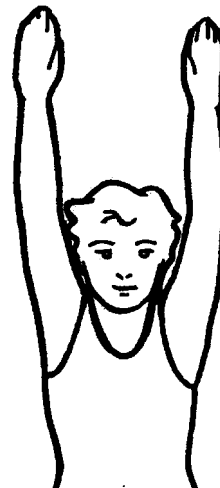
30-minute walk is a form of exercise that carries a low risk of injury, and you can continue it through the years. See the **Maintaining a Healthy Lifestyle** section on pages 73-94 for information about how to establish a regular exercise program.

❧ Exercises ❧

Overhead Raise—To regain full range of motion in shoulders.

This exercise can be done either sitting or standing. If you are standing, be sure feet are hip-width apart, knees are slightly bent, and abdominal muscles are tight. Relax your arms and allow them to hang straight in front of your hips or down at your sides if sitting.

Slowly (count to two slowly) raise arms in front of your body until they are stretched overhead as far as possible. Slowly (count to two) lower arms down to their original position in front of the hips. Repeat this 8 to 10 times and do this three times a day. Don't forget to breathe in and breathe out when doing this exercise. This will allow you to reach higher each day. The goal is to fully flex each arm.

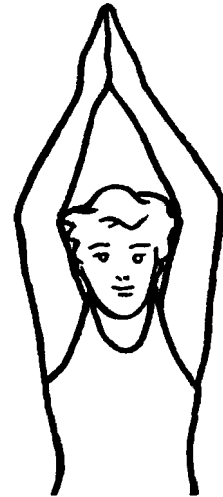


Clapping Hands Overhead—To stretch shoulders, chest and back.

This exercise can be done standing or sitting. Stand with your legs hip-width apart, arms relaxed at your sides. Tighten your abdominal

muscles (hold in your stomach). Slowly raise both arms until they are parallel with your shoulders (straight out to the sides).

Then, raise both arms above your head, palms up. Try to clap your hands overhead. Slowly lower arms to shoulder-height position. It should take four counts to reach overhead and four counts to lower to shoulder position., Do this 8 to 10 times and repeat the whole exercise three times a day.



Walking Up The Wall—To stretch and regain full range of motion.

For this exercise you will need wall space. Stand with one side of your body facing a wall. Place your feet about 6 inches away from the wall.

Using the arm nearest the wall, slowly walk your fingers up the wall as far as you can reach. Hold for 4 seconds. Inhale (breathe in) and exhale (breathe out) as you hold the stretch. Slowly walk your fingers down to the original position. Turn your body and repeat the exercise using the other arm.



Each day, stand a little closer to the wall. This will help you reach higher each time. It is important to do this exercise on both sides even if you have only had surgery on one side. Do this 8 to 10 times and repeat the whole exercise two or three times a day.

☞ What else can I do to help with shoulder and arm stiffness? ☞

- ☞ Plan everyday activities to use arm and shoulder motion whenever possible. For instance:
 - ☞ Use a lightweight duster and reach up to sweep cobwebs out of comers.
 - ☞ Work in the garden.
 - ☞ Do some light sweeping or raking.
 - ☞ Alternate exercise and activity with rest.
 - ☞ Pull on shirts and sweaters over your head so you have to raise your arms.
 - ☞ Use non-prescription medication such as aspirin or ibuprofen to help with minor discomfort. (See the **Pain** section of the manual on pages 51-64.)
 - ☞ Use heat if you are not at risk for lymphedema. (See the **Lymphedema** section of the manual on pages 31-50.)

☞ When to Seek Help and From Whom ☞

See a doctor if:

- ☞ You have stiffness and increasing pain as you move your shoulder; OR
- ☞ You have shoulder or neck pain that gets worse or does not ever go away; OR
- ☞ You have been able to sleep on your stiff shoulder but cannot sleep on it any more because of the pain.

☞ Resources for Joint Stiffness ☞

☞ Websites

Thriveonline -- Sponsored by the University of Texas with pages devoted to specific problems such as shoulder pain and frozen shoulder.

<http://thriveonline.com>

Intellihealth web site -- Guidelines for starting a fitness program, working out at home, maintaining motivation

<http://www.intellihealth.com>

☞ Programs

YWCA of the USA ENCOREplus Program offers women recovering from breast cancer support and exercise groups focusing on physical strength, health and psychological well-being. Call your local YWCA for more information, or call the YWCA Office of Women's Health Initiatives, 624 9th Street, NW, Washington, DC, 20001, (202) 628-3636. In your own community, ask at, your physician's office, women's health clinic or at local hospitals for referrals to qualified personal trainers or fitness centers.

Books

Exercise: A guide from the National Institute on Aging (exercises, motivation, safety, self-tests, benefits and nutrition). Publication No. NIH 99-4258. Public Information Office, National Institute of Aging, National Institutes of Health. Toll Free Information Line: 800-222-2225

<http://www.nih.gov/nia>

❧ Acknowledgments ❧

Images in the **Exercise** section were drawn by Daniel Shelverton.

End of Stiffness Section

Lymphedema



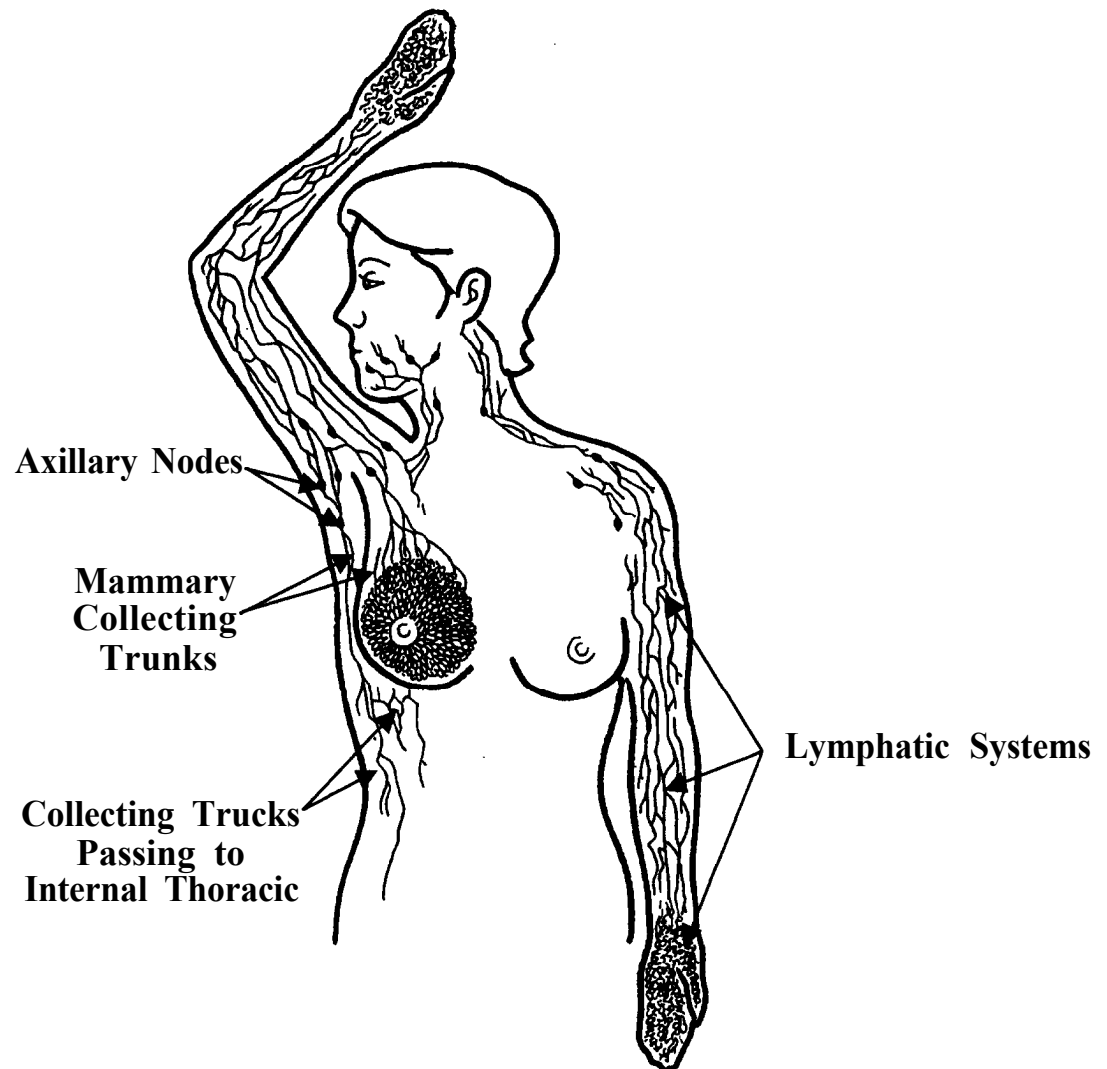
❧ What is lymphedema? ❧

Lymphedema is a collection of lymph fluid in the flesh that causes swelling. The word lymphedema comes from *edema* (normal body fluid that helps fight infection) and *edema* (swelling due to a collection of the fluid). Women who have had surgery or radiation for breast cancer may develop lymphedema in the arm on the same side or on both sides if both breasts were treated. The lymphedema may happen soon after breast cancer treatment, or it may happen many years later.

- ❧ *Lymph fluid* is an almost clear fluid that carries cells that help fight infection. It normally travels through *lymph vessels*, similar to the network of vessels that carry blood through the body. On the following page is a picture of a portion of the lymph system so you can see what it looks like.

- ❧ When the amount of lymph fluid becomes more than the amount that the vessels can carry, the fluid leaks into the flesh, causing swelling or *edema*.

Diagram of the Lymphatic System



⚔ There are several things that can result in more fluid than the lymph system can handle. Understanding these things will help you understand what you can do to try and prevent lymphedema from occurring, or from worsening if you already have it.

- ❶ The *first thing* is **obstruction or blockage** of the vessels. Women who have had surgery to remove lymph nodes under the arm or who have

had radiation treatment for breast cancer will have some blockage of the lymph vessels. This puts them at risk for lymphedema, meaning that they may develop lymphedema in the arm on the same side or on both sides if both breasts were treated. The lymphedema may happen soon after breast cancer treatment, or it may happen many years later. Anything that makes the blockage of the vessels worse will increase the risk of developing lymphedema. This could be pressure from tight sleeves or watchbands. It could also be tissue swelling from other causes. For example, muscle injury from heavy lifting may cause swelling. An infection or bad sunburn may cause swelling. These types of swelling might apply just enough pressure on the lymph vessels to begin a cycle of lymphedema.

- ② The *second thing* is **increased amount of lymph fluid**. Exercise is important to help maintain strength and motion of your arm. However, strenuous exercise may increase lymph production. An infection may also cause the body to increase lymph fluid production.
- ③ The *third thing* is a **tendency for lymph to leak from the vessels**. This can be affected by differences or imbalances of pressure. Outside the body, reduced atmospheric pressure, such as when you are flying in an airplane or when you are at high altitudes, can affect lymphedema. Inside the body, hydrostatic pressure changes, as when protein levels are very low, can also affect lymphedema.

❧ When does lymphedema occur? ❧

Sometimes lymphedema occurs years after breast cancer treatment for no apparent reason. Often, however, something happens (triggering event) that starts the cycle. Too often, women ignore early lymphedema and delay getting treatment until it gets worse. This is unfortunate because treatment will be most effective if it is started at the first sign of lymphedema. When lymphedema first starts, there is simply some extra fluid in the tissues. At that point, it is fairly easy to move the fluid out, to start precautions about avoiding activities that would allow it to return, and to use bandages or compression sleeves when those activities cannot be avoided. When lymphedema has persisted over time, the swelling, damages the tissues, making it much more difficult to move the fluid out.

⚔ Risk of developing lymphedema

In breast cancer, both surgery on the lymph nodes and radiation treatment can cause damage, such as scarring, that destroys part of the lymph system and interferes with the vessels' ability to carry fluid. If you have had lymph nodes under your arm removed or have had radiation to your breast and armpit area, you will always be at **risk of developing lymphedema** and should take measures to prevent it.

If you have had both surgery and radiation, your risk of lymphedema is even greater.

⌘ **What are some of the early signs of lymphedema?**

- Feeling of tightness or heaviness in arm
- Even slight swelling of hand and/or arm
- Noticeable difference in size of arms--one sleeve may be tighter than the other
- Watch or rings feel tight

⌘ **What should I do if I notice any of these signs in my fingers, hand, or arm?**

Because there is no cure for lymphedema, recognizing the signs and symptoms of lymphedema can be important in order to obtain **early treatment**. See your doctor immediately! If lymphedema is diagnosed, it is **VERY IMPORTANT** to seek immediate treatment. When lymphedema first appears, it is simply extra fluid in the tissues. When lymphedema continues, the swelling damages the tissues, making it much more difficult to move the fluid out. **A swollen arm from lymphedema will get worse if not treated and may interfere with movement and strength.**

⌘ **How can I prevent lymphedema?** ⌘

Lymphedema is best prevented by avoiding those activities that cause the body to make more lymph fluid than the damaged lymph system can handle. This means avoiding more blockage of vessels, increased production of lymph fluid, or leaking of fluid from the vessels. The following suggestions will help you avoid some or all of these factors.

🎗️ Take very good care of skin and nails



Keep the at-risk hand, arm, shoulder, chest, and back spotlessly clean, and make sure you regularly wash all fabric that is worn next to your skin. Using mild soap like Dove for washing your skin is recommended.



Use a top-quality moisturizing lotion to help keep your skin soft and well-moisturized. Some of the best lotions to use are Eucerin, Lubriderm, Keri, and Curel. You may also use bag balm or udder cream--these are available at most drug and department stores. Apply lotion after bathing and before bed or in the morning.



Avoid extreme temperature changes when bathing, showering, swimming, washing anything, or receiving therapeutic treatments. Do not use a sauna, whirlpool, or hot tub where the temperature will be higher than usual bath temperature.





Be careful cutting nails. Do not nick skin or cut cuticles. If someone does your nails for you, inform them of your risk. If you must push back your cuticles, use a cuticle stick covered with cotton.





If you live in a damp or humid climate and your skin is frequently moist from sweat, try dusting the skin with cornstarch.

Avoid any injury to the arm, shoulder, or breast areas


 Avoid chemical hair removers for underarm hair. If possible, use a well-maintained electric razor, replacing heads regularly. Because of the danger of cuts and nicks, do not use a regular razor. If you use one, wash the blades in hot soapy water and change them often.

 If you get a cut, scrape, or other break in the skin, wash it carefully with soap and water, use an antibiotic ointment, and notify your physician at once.

 Avoid all tight clothing, jewelry, watches and elastic bands on the affected arm because these may block the flow of lymph fluid and lead to swelling.

 If you have had an axillary (armpit) lymph node dissection (surgery), you may want to wear soft pads under your bra straps, as this protects the lymph nodes and vessels around the collar bone. Avoid wearing a heavy breast prosthesis or underwire bra. You may wear a sports bra instead of normal bras, as sports bras have a wide strap. Some models come with front zippers.

Protect the arm, shoulder, and breast area from injury

 Stay in air conditioning in hot weather and heated areas in cold weather. In sunny weather, protect the


arm with sunscreen and/or covering. Sunbathing, even with sunscreen, is too much of a risk.


- 🕶️ Avoid all types of trauma: cuts, scrapes, bruises, bums. Use a thimble if you sew. Wear rubber gloves when washing dishes or gardening. When outdoors, wear insect repellent, sunscreen, and clothing to cover your arms.


🎗️ Medical Care

- ❶ Be sure to inform your doctor that you are at risk for developing lymphedema. Have your doctor measure both arms and check the at-risk arm every year for swelling.
- ❷ Swelling from lymphedema is not the same as swelling from heart or kidney problems. Diuretics. (water pills) may help swelling from heart or kidney problems but do not work for treating lymphedema.
- ❸ Medical care, such as injections, blood pressure, drawing blood, blood sugar testing, allergy tests, etc., should not be performed on the affected arm. (Note: A leg can often be used if both arms are at risk.) Any procedure that punctures the skin of the finger, hand, arm, shoulder, back, or chest is to be avoided, including acupuncture.

❧ What else can I do? ❧

 Thoroughly examine the affected arm, chest wall, and back every two weeks. Look for areas that are puffy or larger than usual. Comparing your opposite hand, arm, or other area helps determine whether there is swelling in one. How rings, sleeves, and other things fit can be a clue to swelling. Report any swelling immediately. If any of the following are present, see your oncologist or regular doctor immediately: redness, hot areas, blistering, rash, fever, change in the texture (feel) of the skin, or leakage of clear fluid (lymph) through the skin.

 **1** Check all areas of the arms every day for signs of problems. You can learn to measure around the arm at the same places periodically or if the arm seems swollen. Measure both arms to compare. Starting at the tip of the middle finger, measure up the finger 4 centimeters and mark with a pen. Then measure around the finger (the circumference). From the pen mark, measure toward the arm another 4 centimeters, and then measure around the hand or arm. Continue to measure circumferences every 4 centimeters until you reach the armpit. Be sure to record all measurements. You may have to have someone help you.

 If you notice any slight increase in the size of your fingers, hand, arm, chest wall, or back, see your doctor for a proper diagnosis. If you are diagnosed with lymphedema, seek treatment. Lymphedema is easier to control at the beginning, and further deterioration can be prevented.

❧ Will diet and exercise help prevent lymphedema? ❧



Maintain your ideal weight and drink plenty of pure water. The recommended amount of water is one ounce for every two pounds of body weight. For example: If you weigh 128 pounds, drink 64 ounces, or two quarts of water daily. The recommended amount of water keeps the body well hydrated and helps the kidneys rid the body of liquid wastes.



Eat a diet in which easily digestible proteins like beans, lentils, and soy make up between 10 and 30 percent of your total caloric intake.



Exercise is important. However, if the at-risk arm begins to ache or feels tired, rest it immediately and prop it up if possible. Propping the arm up will help keep the swelling from getting worse. Consult a lymphedema specialist before proceeding with an exercise routine. Safe recommendations are walking, swimming, and other water exercises. Other good exercise choices for people with lymphedema include low-impact aerobics, yoga, and tai chi.



Avoid pushing, pulling, or lifting with the affected arm. Do not use over-the-shoulder straps (like a shoulder bag purse) on an affected arm. Do not lift anything over 15 pounds--less than that if you are out of shape or if the weather is hot and humid. This includes lifting of babies, children, and pets. Carry packages, purses, or briefcases

only on your unaffected side, and ask baggers at the store to pack bags lightly or to place your bags in the car for you.



Avoid any repeated movements, especially with weights or weight machines.



Never do anything so hard or so long that you are exhausted. Your at-risk arm and shoulder will get tired more quickly than the rest of your body and will ‘take longer to recover from physical exertion. If your arm begins to ache, rest and prop it up. If propping it up does not help the symptoms, see your physician.

Following these guidelines may help protect you from developing lymphedema or perhaps postpone its onset.

❧ If I develop lymphedema, how will it be treated? ❧

❧ Since there is no cure for lymphedema, the goal of therapy is to reduce the swelling and maintain the normal size and function of the arm. Comprehensive Lymphedema Management (CLM) is a widely accepted method for treatment of lymphedema. CLM is recognized as a treatment for and as prevention against lymphedema.

❧ CLM consists of four basic steps:

- ❶ **Skin and nail care** to keep skin and nails in good condition.

② **Manual lymph drainage**, a special form of massage each day to remove the excess fluid and protein and increase the flow of lymph to unaffected parts of the body.

③ **Compression therapy** is the use of special bandages and sleeves to stop the swelling from returning. Compression , bandages and sleeves act like a second skin to help the arm muscles keep the lymph fluid moving along. Wearing a compression bandage or sleeve regularly is very important to decrease swelling and keep it down. Like needing eyeglasses, dentures or a hearing aid, one of the compression therapies should become a part of your life.

- Bandages are long pieces of low-stretch material that are wrapped around the arm so that there is more pressure at the hand and less pressure as the bandage is wrapped up the arm. Getting the right amount of pressure can be hard, especially when learning to use the bandages. Winding, unwinding, and starting over can be frustrating and take a lot of time.
- Sleeves do the same thing as bandages but are more convenient and faster to put on. They are tightly knit, stretchy, one-piece cotton garments that are like the type of stockings used for varicose veins. Sleeves can be made especially for your arm size or already made up. Sleeves already made up can be a problem for heavy women because the sleeve may cut into the arm, making the sleeve uncomfortable to wear.

Though sleeves are faster to put on than bandages, they can still be hard to put on because they fit tightly. They should be fitted properly by a trained fitter who can teach you how to use them. Some newer sleeves are easier to use than bandages and the one-piece sleeves. These newer sleeves use adjustable compression bands to fasten the sleeve and to more easily and quickly adjust the amount of pressure on the arm (Reid; CircAid Measure-Up). (See the **Resources** on pages 47-50 for suppliers of bandages and sleeves.)

- ④ **Decongestive exercises** to reduce swelling are performed when the compression bandages or garment is in place. These exercises help the arm and hand muscles push the lymph fluid along to decrease swelling and keep good movement in the joints. However, these special exercises should be prescribed by a lymphedema therapist because if they are not done right, they can do more harm than good. Typical exercises prescribed by the lymphedema therapist include: relaxation, bending the fingers, elbows; turning the shoulders and neck; massage; sit-ups and breathing exercises.

❧ If I am diagnosed with lymphedema, where should I go for comprehensive treatment? ❧

In North Carolina there are several options:

Charlotte Institute of Rehabilitation
Comprehensive Lymphedema Management Program
1100 Blythe Boulevard
Charlotte, NC 28203
Phone: (704) 355-4465
Fax: (704) 355-7873

Adult Physical Therapy Department
Lenox Baker Children's Hospital
3000 Erwin RD
Durham, NC 27705
ATTN: Lisa Massa, RPT
Phone: (919) 684-0874

East Carolina University Dept. of Physical Therapy
James Tracy, PT
Belk Building
Greenville, NC 27858-4353
Phone: (252) 328-4449

Lym-flo Therapies
1320 Broad Street
Durham, NC 27705
Contact: Joanna Burgess
Phone: (919) 479-0767
E-mail: lymflo@aol.com

Lymphedema Acknowledgment and Action Program
Rex Cancer Resource Center
4420 Lake Boone Trail
Raleigh, NC 27607
Contact: Regina K. Heroux
Phone: (919) 784-7200
Fax: (919) 784-7046
E-mail: regina.heroux@rexhealth.com

Moses Cone Outpatient Rehabilitation Center
1904 North Church Street
Greensboro, NC 27405
Phone: (336) 271-4840
Fax: (336) 271-4921

Ultimate Health Center, Inc.
372 Montford Avenue
Asheville, NC 28801
Phone: 1-800-268-6905
Fax: (828) 669-1047
E-mail: uhc@primeline.com
Website: <http://members.xoom.com/uhc/>

There are other resources on pages 47-50 concerning prevention, treatment, and management.

❧ **What about costs and insurance?** ❧

- ❧ It depends. Treatment varies in cost, depending on its intensity and where it is provided. Some insurance companies will pay for Comprehensive Lymphedema Management, but many will not unless the patient is determined and pushes for payment.
- ❧ Compression bandages are difficult to get reimbursed, so Duke provides bandages for people being treated there regardless of ability to pay.
- ❧ Compression sleeves may be reimbursable. Check with your insurance company. If a sleeve will help you get back to work, vocational rehabilitation might pay for it.

- 🎗 Churches may be able to provide assistance for payment.
- 🎗 For women without insurance and with financial difficulty, Alexander Health Services in Wake Forest, North Carolina, may be able to help with sliding scale pricing and payment plans. Contact them at (919) 556-8934.

🌀 If I have lymphedema, are the prevention guidelines listed earlier important to me? 🌀

Yes! If you already have lymphedema, following the guidelines above for **prevention** may help prevent your lymphedema from getting worse.

🌀 Are there other management-strategies for lymphedema that I should follow? 🌀

Here are some management strategies for lymphedema:

💧 Put on a good quality recommended lotion before applying and after removing bandages or compression garments and after bathing.

🩹 It is important to wear compression bandages during exercise to keep lymph fluid in the vessels and help it circulate.

✈ If you travel by plane, wear compression bandages instead of a compression garment because they offer greater protection against further swelling.

Resources for Lymphedema

Organizations

National Lymphedema Network

A nonprofit organization providing information about the prevention and treatment of lymphedema to patients and health care professionals, as well as support groups.

Latham Square

1611 Telegraph Avenue, Suite 1111

Oakland, CA 94612

Phone 1-800-541-3259

Fax (415) 921-4284

<http://www.lymphnet.org>

nln@lymphnet.org

NABCO Fact Sheet on Lymphedema

<http://www.nabco.org/resources>

Bosom Buddies: Breast Cancer and Lymphedema Support Group

<http://www.go-icons.com/bosombuddies.htm>

American Lymphedema Institute

Stickney, Illinois

Phone: (708) 795-5951

Voice Mail: (708) 802-0737

National Cancer Institute's Cancer Information Service

1-800-4-CANCER (1-800-422-6237). See below for address.

National Cancer Institute
Building 31, Room 10A24
9000 Rockville Pike
Bethesda, Maryland 20892

 Compression Bandages/Garments

Bandages Plus -- <http://www.bandagesplus.com>
4748 SW. 74th Avenue
Miami, FL 33155
Phone: (800) 770-1032
Fax: (305) 273-8099

Beiersdorf-Jobst, Inc. -- <http://www.jobst-usa.com>
5825 Carnegie Boulevard
Charlotte, NC 28209
Phone: (704) 554-9933 or (704) 551-7189

CircAid Medical Products, Inc. -- <http://www.circaid.com>
9323 Chesapeake Drive, Suite B-1
San Diego, CA 92123
(800) CIRCAID or (858) 576-3550
Fax: (858) 576-3555
email: info@circaid.com

Guilford Ostomy & Medical Supply, Inc.
2216 Golden Gate Drive
Greensboro, NC 27405
Phone: 1-800-458-3164
Contact Person: Catherine Propst, RN, MSN

Juzo (Julius Zom Inc.)
PO Box 1088
80 Chart Road
Cuyahoga Falls, OH 44223
(800) 222-4999; Fax: (800) 645-2519
E-mail: support@juzousa.com (for general information)

Peninsula Medical -- <http://www.reidsleeve.com>
PO Box 7317
Stanford, CA 94309-7317
(800) 29-EDEMA

Chiropractic

Comfort Chiropractic
3672 Capital Blvd.
Raleigh, NC
Contact: Linda Orlasky
Phone: (919) 872-1050
Fax: (919) 872 5025

Programs

Look Good...Feel Better -- A public service program sponsored by the Cosmetic, Toiletry and Fragrance Association Foundation in partnership with ACS and the National Cosmetology Association, that helps women recovering from cancer handle changes in their appearance resulting from cancer treatment. Spanish-language print and videotape materials are available both to patients and to health professionals.

(800) 395-LOOK or (800) ACS-2345

Lymphedema Acknowledgment and Action Program (LEAP) A multi-tiered program designed to educate, support, assess and rehabilitate women diagnosed with breast cancer who are at risk for or have developed lymphedema. Call the Rex Cancer Resource Center at (919) 784-1641

Books

Lymphedema: A breast cancer patient's guide to prevention and healing. Jeannie Burt and Gwen White. Hunter House, Berkeley, California, 1999.

Coping With Lymphedema: A practical guide to understanding, treating, and living with lymphedema. Swirsky, J. & Nannery, D.S. New York, Avery Park Publishing Group, 1998.

Acknowledgments

The diagram of the lymphatic system was drawn by Daniel Shelverton.

Pain Management



❧ General Information ❧

Years after treatment, some women continue to report different feelings at the site of their surgery, in the arm, or in the shoulder. These feelings are sometimes described as burning, pricking, pressing, tightness, tingling, numbness, and/or increased skin sensitivity. Women who have had breast removal can sometimes experience *phantom breast pain*, a sensation of pain in the area where the breast is missing. *Post-mastectomy pain syndrome* can also occur in some women. This is a chronic pain that occurs in the front of the chest and/or upper arm and first begins immediately after surgery.

❧ Cause/Links to Breast Cancer Treatment ❧

Pain or changed feeling (sensation) can be especially common in women who have had either a lumpectomy or a mastectomy with axillary (armpit) lymph node dissection (removal). During these procedures, the nerve that runs to the axilla (armpit) and upper arm may be cut and, as a result, can cause unusual sensations or pain for many years. Rarely, a nerve in the chest may be damaged or cut during surgery and can cause loss of arm strength.

- ✿ *Fibrosis* (scarring or scar tissue formation) is one of the most common long-term radiation side-effects and can also be a late effect of surgery.
- ✿ Scarring of the skin and/or soft tissue can cause pressure on the nerves, causing them not to work properly. A “catch” or twist of an area of scarring can cause flashes of pain. Radiation of the chest can cause toughening and tightening of the chest muscle and may lead to difficulty moving the arm.

✿ Factors That May Make Pain Worse ✿

- ✿ Pain has different effects on different people. It can be a minor annoyance that does not require any specific action or it can interfere with daily activities. For some women, pain or tingling at the mastectomy site may be a “trigger” for unwanted thoughts about cancer recurrence.
- ✿ Feelings of nervousness or depression can make the pain seem worse. Fatigue can also make it harder to deal with pain. For example, when you are tired, you may not be able to deal with the pain as well as when you are rested. Some people notice that pain seems to get worse as they get tired.

❧ Pain Relief Methods and Helpful Information ❧



Nonprescription Pain Relievers

Nonprescription pain relievers are analgesics that can be bought without a doctor's order (prescription). Sometimes they are called "over-the-counter" pain remedies. They include:

- *Aspirin* (Bufferin, Ascriptin, Ecotrin)
- *Acetaminophen* (Anacin-3, Tylenol, Datril)
- *Ibuprofen* (Advil, Motrin, Nuprin)
- *Naproxen sodium* (Aleve, Naprosyn, Anaprox).

Many nonprescription pain relievers have different names, but if you check the labels, nearly all contain one of these four medicines. They are often effective for relief of mild and moderate pain and, in some cases, may relieve severe pain.

In many cases, the nonprescription medicines are all you will need to relieve your pain, especially if you control your pain by taking them on a regular, preventive basis. These medicines are stronger analgesics than most people realize. If you get pain relief from nonprescription medicines, you do not need to take prescription pain relievers. For most people, nonprescription pain relievers have side effects that are different from those they get with prescription pain relievers.

It is very important to take no more of these medicines than is directed on the label, unless told to do so by your doctor.

Caution: If you had chemotherapy for your breast cancer, the effects of the chemotherapy on your liver may limit the amount of some of these medications you should take. Consult your doctor about this.

The following are the usual **maximum** daily doses:

- *Acetaminophen* (Tylenol) – 600 mg, up to four times daily. Do not exceed 4000 mg/day.
- *Acetylsalicylic acid* (aspirin) – 600 mg, up to four times daily. Do not exceed 5200 mg/day.
- *Ibuprofen* (Motrin, Advil) – 200 to 400 mg, up to six times daily (every 4 hours). Do not exceed 3200 mg/day.
- *Naproxen sodium* (Aleve) – 220 to 440 mg daily. Do not exceed the recommended dose or take more often than recommended.

Aspirin, acetaminophen, ibuprofen and naproxen have similar pain-relieving effects, but they have some important differences:

- *Aspirin, ibuprofen, and naproxen* reduce inflammation; *acetaminophen* does not.
- *Aspirin, ibuprofen and naproxen* are often used to reduce the pain of swollen joints and other inflamed areas; *acetaminophen* does not work on inflammation, but may help relieve the pain of swollen joints.
- *Aspirin, ibuprofen, and naproxen* can irritate the stomach. Sometimes they even cause stomach

bleeding. *Acetaminophen* does not have this effect, but can, in larger doses, affect the liver and kidneys.

- *Asprin, ibuprofen* and *naproxen* can affect blood clotting and, in large doses, may cause bleeding. *Acetaminophen* has no effect on blood clotting.
- *Ibuprofen* can make existing kidney problems worse. In normal doses, *aspirin* and *acetaminophen* usually do not injure the kidneys.

Avoid aspirin or take with caution if you:

- Are on anticancer drugs that may cause bleeding
- Are on steroid medicines (such as *prednisone*)
- Will have surgery within one week
- Are allergic to aspirin
- Are taking blood-thinning medicine (such as *coumadin*)
- Have stomach ulcers or a history of ulcers, gout, or bleeding disorders
- Are taking a prescription drug for arthritis
- Are taking oral medicines for diabetes or gout

Prescription medications for pain relief are available for severe pain. If you are not able to manage your pain with the strategies explained in this manual and the help of nonprescription medications, share this information with your doctor so she or he can evaluate your pain.

☞ Behavioral Techniques to Help You With Your Response to Pain ☞

The following techniques are designed to change your response to pain by causing a deep relaxation and thereby turning your

attention to something other than the pain. There are several tapes in your packet that teach some of these techniques and can provide further instruction and information.



Relaxation

Relaxation relieves pain or keeps it from getting worse by reducing tension in the muscles. **For instructions on relaxation techniques, see the tape in your packet labeled “Relaxation.”** It can help you fall asleep, give you more energy, make you feel less tired, reduce your anxiety, and make other pain relief methods work better. For instance, some people find that taking a pain medication or using a cold or hot pack works faster and better when they relax at the same time.



Imagery

Imagery is using your imagination to create mental pictures or situations. The way imagery relieves pain is not completely understood. Imagery can be thought of as a deliberate daydream that uses all of your senses—sight, touch, hearing, smell, and taste. Some people believe that imagery is a form of self-hypnosis. Certain images may reduce your pain both during imagery and for hours afterward. If you must stay in bed or can't go out of the house, you may find that imagery helps reduce the closed-in feeling; you can imagine and revisit favorite spots in your mind. Imagery can help you relax, relieve boredom, decrease anxiety, and help you sleep by diverting your attention from the pain to a more pleasant image. **See the tape in your packet labeled “Imagery” for more specific directions on using this technique.**



Distraction

Distraction means turning your attention to something other than the pain. Many people use this method without realizing it when they watch television or listen to the radio to “take their minds off” the pain. Distraction is useful when you are waiting for pain medicine to start working. **To learn this skill, find the tape in your packet labeled “Distraction” for more specific directions.**



Calming Self-Talk

Calming self-talk is a skill that can help you control unwanted negative thoughts by talking to yourself using calming, comforting words or sentences. **The tape in your packet labeled “Calming Self-Talk” will help you learn this skill.**



Skin stimulation:

CAUTION!! All of the strategies described in this section. Skin Stimulation, should NOT BE DONE on the shoulder, chest, arm, or hand IF YOU ARE AT RISK FOR LYMPHEDEMA OR IF YOU HAVE LYMPHEDEMA!

See manual section on LYMPHEDEMA on pages 31-50 to determine if you are at risk.

Skin stimulation is done either on or near the area of pain. You also can use skin stimulation on the side of

the body opposite the pain. For example, you might stimulate the left arm to decrease the pain in the right arm. Stimulating the skin in areas away from the pain can be used to increase relaxation and may relieve pain.

✿ **Massage** is most effective when using slow, steady, circular motions. You can massage over or near the area of pain with just your bare hand or with any substance that feels good, such as talcum powder, warm oil, or hand lotion (**Note: Test the substance on a small area of skin first to determine if you are allergic**). Depending on where your pain is located, you may do it yourself or ask a family member or friend to give you a massage. Some people find brushing or stroking lightly more comforting than deep massage. Long strokes are relaxing; short strokes are stimulating. Use whatever works best for you.

✿ **Pressure** is usually most effective if it is applied as firmly as possible without causing pain. Apply pressure:

- ✿ with the entire hand
- ✿ with the heel of the hand
- ✿ with the fingertip or the knuckle
- ✿ with the ball of the thumb, or
- ✿ by using one or both hands to encircle your arm or leg.

✿ **Trigger Points**

You can also feel around your pain to see if you can find “trigger points,” small areas under the skin that

are especially sensitive or that trigger pain. Putting pressure on trigger points can help your pain.

You can use pressure for up to about one minute. This often will relieve the pain for several minutes to several hours.

- ✿ **Vibration** over or near the area of pain may bring temporary relief. For example, the scalp attachment of a hand-held vibrator often relieves a headache. You may use a vibrating device, such as a small battery-operated vibrator, a hand-held electric vibrator, a large heat-massage electric pad, or a bed vibrator.

- ✿ **Menthol preparations** are available for pain relief. These are creams, lotions, liniments, or gels that contain menthol. Brands include Ben-Gay, Icy Hot, Mineral Ice, and Heet. **(Note: Test the substance on a small area of skin first to determine if you are allergic.)** When they are rubbed into the skin, they increase blood circulation to the affected area and produce a warm (sometimes cool) soothing feeling that lasts for several hours.

- ✿ **Heat** often relieves sore muscles; **cold** lessens pain by numbing the affected area. For cold, try gel packs that are sealed in plastic and remain soft and flexible even at freezing temperatures. Gel packs are available at drugstores and medical supply stores. They are reusable and can be kept in the freezer when not in use. Wrap the pack with a layer of towels so that it is comfortable for you. An ice pack

or ice cubes wrapped in a towel can be just as effective.

To use heat for pain relief, a heating pad, that generates its own moisture is convenient. Gel packs heated in hot water, hot water bottles, a hot, moist towel, a regular heating pad, or a hot bath or shower can also be used to apply heat. Using heat therapy involves intermittent applications of heat for short periods of time (5 minutes on and 5 minutes off for acute pain and 20 minutes on and 20 minutes off for chronic pain).

Caution: Any time heat is used, it is important to be careful about temperature so that you are not burned. Do not apply any source of heat over areas of numbness.

✿ **TENS** (transcutaneous electric nerve stimulation) is a technique in which mild electric currents are applied to selected areas of skin by a small power pack connected to two electrodes. The sensation is described as a buzzing, tingling, or tapping feeling. The small electric impulses seem to interfere with pain sensations. The current can be adjusted so that the sensation is pleasant and relieves the pain. Pain relief lasts beyond the time the current is applied.

Caution: With burning pain, the TENS unit may make pain worse if the pain is due to nerve damage. Your doctor or physical therapist can tell you where to get a TENS unit and evaluate how useful it would be for your particular pain.

❧ Management Strategies For Your Pain ❧

- ❶ Try to prevent the pain before it starts or gets worse by using some pain-relief method on a regular schedule. If pain begins, don't wait for it to get worse before doing something about it.
- ❷ Know yourself and what you can do. Often when people are rested and alert, they can use a method that demands attention and energy. When tired, they may need to use a method that requires less effort. For example, try distraction when you are rested and alert; use hot or cold packs when you are tired because they require little thought. Take precautions if you are tired so that heat and cold applications are not left on longer than recommended. If there is someone with you, have him or her remind you when the time has elapsed in case you fall asleep. If you are alone, set an alarm clock for the time period in case you fall asleep.
- ❸ Learn which methods of pain relief work best for you. Vary and combine pain relief methods. Combining two pain relief methods may be more effective than either one alone. For instance, you might use a relaxation method at the same time you take medicine for the pain. The relaxation method can help the pain medication work.
- ❹ Try each method more than once. If it doesn't work the first time, try it a few more times before you give up. Keep in mind that what doesn't work one day may work the next day.
- ❺ Keep a "pain diary." Tracking important characteristics of the pain can help you "get to know" the pain. A pain diary

helps you recognize any significant changes in the pain, manage your pain more effectively, and discuss the characteristics of the pain with your doctor. To keep a pain diary, write down the following every day:

- **Rate** your pain as a number between 0 and 10. The numbers between 0 and 10 represent the amount of pain a person could have. Zero means no pain and 10 means pain as bad as it could be. Think of 0-10 as a ladder, with 0 being at the bottom of the ladder representing no pain or discomfort. Each rung of the ladder represents a gradual increase in pain or discomfort. The top of the ladder means the pain is as bad as it can be.
- **When** the pain starts, and **how long** it lasts. **The place or places** on your body where you feel the pain. **How much** pain you feel, and **how** the pain feels to you. **Examples** of how the pain feels: is it aching, burning, gnawing, heavy, sharp, dull, shooting, nagging, or tight?
- Any **activity** that makes the pain worse or makes the pain better.
- Any **pain relief method** that you use, including rest, relaxation techniques, distraction, or imagery. (See tapes included with this package.) After 1 to 1½ hours, write down the number that indicates how much pain you have. This number will help you know how well the pain relief method worked.
- If **you** take **medication**, write down the name of the medicine, how much you take, and at what time you take it. After 1 to 1½ hours, write down the number

that indicates how much pain you have then. This number will help you know how well the medication worked.

❧ When to Seek Help and From Whom ❧

If the pain cannot be controlled with the above suggestions, contact your nurse, oncologist, or surgeon for further suggestions.

Resources for Pain

Websites

Pain from Cancer Care, Inc. Information about cancer pain, side effects, information for caregivers, links and resources.

<http://www.cancercareinc.org/campaigns/pain1.htm>

Pamphlets

Questions and Answers About Pain Control: A Guide For People With Cancer and Their Families (95-3264, 1995). Discusses pain control using both medical and non-medical methods. The emphasis is on explanation, self-help and patient participation. Contact the American Cancer Society at (800)-ACS-2345 or National Cancer Institute (800) 4 CANCER

<http://cancernet.nci.nih.gov/peb/pain-control/>

Talking With Your Doctor (4638-CC, 1997 edition). Suggestions for effective doctor/patient communication. American Cancer Society, (800) ACS-2345

<http://www.cancer.org/patinform/talking.html>

Organizations

Cancer Information Service (CIS)
1-800-4-CANCER

Skin Changes



∞ Some Facts about the Skin ∞

There are two primary purposes of the skin:

- ① to serve as a protective covering for the body against infections and the loss of body fluids;
- ② to regulate body temperature.

The skin has two layers, the *epidermis*, or the top layer, and the *dermis*, which lies underneath the epidermis. These layers of skin vary in thickness, but the top layer is thinner than the layer underneath. Underneath both these layers of skin is a layer of fatty tissue.

The *epidermis* contains cells that are responsible for skin pigmentation or color. The *dermis* is made up of collagen fibers, which are important in wound healing. Within the *dermis* are also blood vessels, lymph vessels, and nerves. Both layers of skin contain oil-producing glands, sweat glands, and hair follicles. Oil-producing glands secrete an oily substance that keeps skin and hair from drying out. Sweat glands are responsible for regulating body temperature by producing water.

❧ What causes skin changes? ❧

If you have experienced changes to your skin since having breast cancer, this may be the result of radiation or the combined effects of radiation and chemotherapy treatments. When radiation is given before or during chemotherapy treatments, there is an increased risk for skin reactions. One reaction is called *radiation recall*. Chemotherapy agents associated with radiation recall effects are *cyclophosphamide*, *dactinomycin*, *doxorubicin*, *5-fluorouracil*, *methotrexate*, *ifosfamide*, and *hydroxyurea*.

After the usual skin effects of radiation have healed, if certain chemotherapy agents like the ones mentioned above are taken, a *radiation recall reaction* may occur. The skin that was radiated in the past looks like it did during the radiation treatments, even though you are not getting radiation. There is no research to support that there are any late skin changes from chemotherapy treatments alone.

Radiation treatments may also damage blood vessels in the *dermis*, which results in less oxygen and nutrients being carried to the parts of the skin that need them. When skin and underlying tissues do not receive adequate amounts of oxygen and nutrients, there is an increased chance that infections may develop.

Although skin cells are especially sensitive to radiation treatments for breast cancer, not all women who have radiation treatment for breast cancer will have skin changes. This is because newer radiation equipment can deliver radiation doses below the level of the skin and closer to the tumor site. When skin changes do occur, they are seen on the top layer of the skin and on tissues underneath the skin such as the blood vessels, lymph vessels, and nerves.

❧ What causes some women to be more susceptible to skin changes? ❧

Amounts of radiation exposure—Higher doses of radiation make underlying skin tissues more likely to show skin changes.

Length of time between treatments—Shorter time periods between radiation treatments make skin tissues more susceptible to skin changes.

Extent of skin exposure—When larger areas of skin are treated with radiation, skin changes are more likely to occur. Also, when treated skin areas include skin folds such as the armpit and areas under the breast, there is an increased risk for skin changes. This increased risk of skin reactions occurs because there is an uneven distribution of the radiation dose being delivered.

Poor nutrition—Damage from radiation begins to heal within the first 4 to 6 hours after a treatment. Healing occurs best when patients are eating well-balanced meals that include proteins and vitamins. Eating a diet with adequate amounts of protein and vitamins (especially Vitamin C) is helpful for healing skin reactions and maintaining healthy skin and tissues underneath the skin.

Age—The process of aging increases the likelihood of dry skin. However, dry skin may be worsened by radiation treatments.

- ☯ Combination treatments—Patients receiving radiation treatments before, during, or after chemotherapy treatments are at a higher risk for developing skin problems.

☯ **When do skin changes develop?** ☯

Some women don't experience any skin changes at the end of radiation treatments. Other women may experience changes that can occur within 24 hours of their treatment or up to 5 years after radiation treatments.

☯ **What skin changes are associated with radiation treatment, and when do they occur?** ☯

Late changes to the skin after radiation treatment can be in the form of:

- ☼ Problems with dry skin. These can occur any time after breast cancer treatment and may also happen as you get older.
- ☼ Loss of skin color or an increase in skin color may occur 1 to 5 years after breast cancer treatment.
- ☼ Decreased functioning of sweat glands usually occurs immediately after breast cancer treatment and may or may not improve with time.
- ☼ Increased possibility of skin irritation such as itching can occur any time after breast cancer treatment.

- ☀ Increased possibility of infection at affected skin areas and underlying tissues can occur any time after treatment for breast cancer.

☞ Is there anything I can do to prevent skin changes? ☞

There are several things that can cause skin changes to occur. Unfortunately, many of these things, such as the dose and frequency of previous radiation treatments, cannot be controlled. Also, some women are more susceptible to skin changes than others. If you have experienced skin changes, there are some things that may help minimize problems you may be having or help prevent problems from occurring.

☞ What are some things that I can do to manage skin changes? ☞



Avoid irritants such as sun exposure, harsh soaps, and perfumes.



Avoid friction to the affected area with such things as tight fitting clothing, scratching, vigorous rubbing or massaging, or use of adhesive tape.



Avoid the use of ice packs or heating pads to the affected area.



Do use mild soaps and shampoos such as Dove and baby shampoos.



Do wash the affected area with hands, not with a washcloth; pat the area dry with a soft clean towel, or blow dry the area with a hair dryer on cool setting.



Do wear loose-fitting, cotton clothing. Wear bras and other undergarments that are not tightly fitting. Consider wearing sports bras. If bras with under-wires are used, check the area frequently for skin irritation.



Do keep skin folds dry, especially in the armpits and under the breast folds.



Do use an electric razor instead of a blade razor if you must shave the affected area.



Do use paper tape if needed for any bandages to the area.



Minimize sun exposure by:

- Staying indoors, avoiding hot times of the day, staying in shaded areas.
- Using hats, umbrellas, long sleeves to block out the sun.
- Using sunscreen (there is no evidence that SPF sunscreens higher than 15 are of any added benefit).



Eat a well-balanced diet with adequate amounts of protein and vitamins to help maintain healthy skin.



Check your skin often for swelling, redness, and pain that may be signs of infections to the skin. Also check the skin for any open, draining areas that may be from an infection in underlying tissues and muscle.

Medical Treatment

Consult a doctor for management of:



Chronic ulcerated (open) areas.



Signs of infection in affected skin areas such as redness, swelling, pain, or draining of fluids.

End of Skin Changes Section

Maintaining a Healthy Lifestyle



❧ What does lifestyle have to do with being a breast cancer survivor? ❧

Although there may be multiple causes of breast cancer, we still do not know specifically how to prevent cancer from coming back. We do know that maintaining a healthy lifestyle is important to staying healthy as long as possible. *Lifestyle* means more than what we eat and whether we exercise. It means how well we take care of ourselves overall. Lifestyle includes the quality of our relationships with others and how we manage our negative feelings and thoughts.

Treatment for breast cancer can bring with it a number of changes in your body and emotions. Besides possible changes in physical appearance, there can be important hormonal changes. Many changes can affect the way we see ourselves. Though many women may feel uncomfortable talking about it, having treatment for breast cancer can change sexual function and cause some uncomfortable symptoms one can learn 'to live with. See the **Hormonal Changes and Sexuality** section of the manual on pages 11-20 for further information.

Besides continuing to check your breasts for any important changes, there are other things that you can do to stay healthy:



We know that eating a better diet can improve immune functioning and overall health.



Maintaining a healthy weight can help you keep your cholesterol and blood pressure down.



Regular physical activity can help you have more energy, a clearer mind, and better sleep.



Taking care of ourselves emotionally is also important.

☞ How does emotional support help me maintain health? ☞

Research tells us that being able to talk freely about feelings can help your body fight disease and be healthier. Talking to your spouse or a close friend about your feelings can improve your state of mind by reducing feelings of isolation and worry. Even when family and friends are available and supportive, you may be reluctant to share your painful feelings for fear of putting a burden on those you love. Many women who have experienced cancer report that even when communication with family and friends is open, there is a special sense of release and relief when talking over their problems and situations with women who have “been there.” Support groups of other women who have shared experiences can also offer encouragement, ways to cope, information, and the opportunity to form friendships with other women who understand the physical, emotional, and other problems you are facing.



Make room in your life to spend time with those you know care about you. Try to talk openly and honestly with them about what makes you happy and what makes you sad. This can be hard, especially if you are a very private person who usually keeps sadness to yourself.



Consider joining a support group. See the **Resources** on page 93 of this section and page 106 in the **Appendix** for support groups in your area. If a support group is too far away, consider creating your own.



If you prefer not to be in a group, consider talking on the phone, or writing letters to women that you feel comfortable with.



If you have a computer available, there are support groups available on the internet. See the **Resources** in this section on page 93 for online support groups.

It is important to keep in mind that appearance is only part of who you are. Even if you are not happy with a part of your body, remember it is only part of you, not the whole of you. How we see ourselves in our head is as important, maybe more important, than how we see ourselves in the mirror. The following are self-management suggestions if you need help managing day to day.

☞ Clothes and Hairstyle ☞

- ➊ Go through your wardrobe. You may do this alone or with a good friend whose opinion you trust and value. Remove clothes from the closet that do not fit. Try on the rest of your clothing; decide which clothing items feel comfortable and that you will wear regularly.
- ➋ If you use a prosthesis, try it on with each outfit to check for fit and comfort. Though expensive, you may consider buying a better fitting prosthesis. Feeling comfortable and good about the way you look is worth the cost.
- ➌ Though some mail-order services are listed in the resource section below, having a trained fitter discuss your needs is the best way to assure well-fitting clothing. Lingerie departments in some large stores, employ professional fitters who will help you find a comfortable and suitable prosthesis, and a bra to wear with it. Women who cannot afford a prosthesis may contact the Y-ME Prosthesis Bank or the Breast Cancer Resource Center of the Princeton YWCA. See contact information in the **Resources** on page 91.
- ➍ Check out your hairstyle. Many of us stay with a particular style because it is comfortable and fits our lifestyle. Are you spending too much time or not enough time on your hair? Sometimes we just need a change, so a good hairstylist that you trust can help you find a flattering style that can give a needed lift.

∞ Diet ∞

How can I improve my diet?



Avoid being overweight and gaining weight during adulthood.



Be moderately to vigorously active for at least 30 minutes on most days.



Eat five servings of fruits and vegetables daily.



Replace red meat with chicken, fish, nuts, and legumes, and consume dairy products in moderation.



Limit alcohol consumption to one drink a day for women and two for men.



Consider taking a multivitamin containing folic acid, especially if you drink alcohol every day.



Eat cereal products in a minimally refined, whole grain Form

What about taking vitamins?



As mentioned above, the latest recommendations by the American Cancer Society include taking a multivitamin containing folic acid, especially if you drink alcohol every day. There has been a lot in the newspapers and magazines about taking anti-oxidants. Taking extra tablets of anti-oxidants is still controversial. See the **Resources** on pages 88-93, of this section for more information. Talk to your doctor about what he/she recommends.

❧ Exercise ❧

What are the types of exercises?



Endurance — Increases your breathing and heart rate to help your heart, lungs, and blood circulation system. This exercise refers to aerobic exercise, such as walking, running, cycling or swimming, doing many muscle contractions with little or no resistance.



Strength — Builds your muscles to make you stronger, increases your metabolism, and prevents osteoporosis. This exercise refers to anaerobic exercise or progressive resistance exercise, such as using hand weights.



Flexibility — Keeps your body limber, increases your range of motion, and reduces stiffness and pain. This exercise refers to stretching exercises.



Balance — Strengthens ligaments and prevents falls.

How do I start an exercise program?



Consult your physician or nurse if you have not exercised regularly and wish to begin exercising.



Contact your local health department, hospital, YMCA, or university to find out what exercise groups are available in your area.



Before you exercise, it is important to gradually stretch and warm up the muscles used in exercise. (See the **Appendix** on pages 102-105 for examples of stretching exercises.)



The type of exercise you choose depends on your lifestyle, weather conditions, and any physical limitations you may have. Fast walking, jogging, and swimming or water aerobics are good options. There are many exercise machines that can be used at home, like a stationary bicycle, that are easy on the joints and allow you to watch TV or read at the same time.



Resistance training should be directed at the large muscle groups that are important in everyday activities, including the shoulders, arms, spine, hips, and leg.



Always include a warm-up and stretching before your strength training. As we grow older, muscles become less flexible, increasing the risk of injuring them.



Don't rush the exercises. Performing the exercises more quickly will not enhance strength gains and may increase your risk of an injury.

What if I have lymphedema?



See the **Lymphedema** section of this manual on pages 31-50.

Self-Image



Sometimes it is hard to notice when we are having negative thoughts and feelings about ourselves, we get so used to them and they happen automatically. Consider keeping a journal and writing in it daily at about the same time of day. Writing helps us “talk out loud” to ourselves. Once you know what some of this negative thinking is, you can begin to come up with different ways to think or things to do that will change your thoughts and feelings. **Use the audiotapes included in this program for different strategies to help with these thoughts and feelings.**



Relaxation is a wonderful way to “hear yourself” think. Consider doing relaxation exercises regularly.



Assess your priorities. Are you leading a balanced life?
Are you spending enough time with friends and family?

❧ Advocacy ❧



How can I make a difference in the lives of other survivors?

If you want to work in a way that helps other women who will learn they have breast cancer, there are a number of ways that you can make a difference. You can make a difference on many levels from a personal to a political level. For instance, you can provide personal support as someone who has “been there” for a woman who is newly diagnosed with breast cancer by working as a Reach to Recovery volunteer. Women who enjoy working with other women in a group may consider getting involved in becoming a support group leader, or training other women in breast self-examination. There are opportunities to become involved on a political level by contacting legislators to lobby for increased funding for breast cancer research. See the **General Resources** section on page 117 for the *Breast Cancer Coalition of North Carolina* web site on ways to become an advocate.

❧ . **Advocating for Self** ❧

Communicating with Health Care Providers

Ten Easy Steps

to an

Improved Relationship with Your Doctors, Your Nurses, and Other Healthcare Providers

1. Always bring a written list of questions and concerns about your cancer and your treatment.

- This should include questions you want to ask and information you want to give.
- Start the list the day you make an appointment and keep it tacked up in an obvious place so you can easily add items. Encourage family members to add questions.
- Remember that your time is limited, so use it wisely.

2. Communication is a two-way street.

Giving information is as important as getting information. Healthcare professionals want to know about you. Consider discussing some or all of the following:

- your occupation
- close relatives who have cancer
- how much you already know about cancer
- family problems
- work stress
- hobbies and other interests, and
- your goals for quality of life during and after treatment.

3. Two heads are better than one.

Ask a family member or friend to accompany you to doctors' appointments. Choose someone who can give emotional support, who listens and remembers well, and who can think objectively. Ideally, the same person will be with you every time.

4. Permanently record your visit on tape.

Eliminate the need to say, “I forgot.” One study found that patients had to listen to taped explanations at least three times before understanding the whole message. If you don’t tape record your visit, do take careful notes or ask your family member or friend to.

5. Don’t say you’re “just fine” unless you really are.

- When healthcare professionals ask how you are, they really want to know. If you don’t report a problem, they can’t help you solve it.
- Try to express as clearly as you can changes in bodily functions--from sleep and bowel habits to changes in sensation anywhere. Never withhold information out of fear.

6. Be cooperative.

It’s easy to vent your anger at those treating you, but working as a team takes cooperation. Your healthcare professionals want to see you succeed. Remember that smiles are contagious. Cooperation yields a more productive appointment.

7. Make sure you understand the words.

Insist on hearing explanations in familiar terms. If you’re unclear, repeat back what you heard and what it means to you. Keep after it until you understand. Doctors sometimes don’t realize that their language often sounds foreign to the lay person. Be familiar with the **Glossary** we provide in this manual on pages 109-116.

8. Keep to the point.

The focus of your appointment should be the cancer and its treatment. Your list will help you stay focused.

9. Ask for the information you want.

But first, ask yourself, “How much do I want to know?” Some people want to know everything about their cancer and feel much better when they know all the facts about what is happening to them. They need to ask for specific details and background information.

Other people may want only an overview; an overload of information might confuse or perhaps depress them. State clearly how involved you wish to be in the treatment process and what you really need to know.

10. Leave yourself an out.

If any part of your healthcare team doesn’t suit your standards, be prepared to find a replacement. Good relationships with your healthcare providers won’t change the cancer, but it could improve your outlook and your understanding of the disease. Be choosy. Don’t settle for second best.



When you are talking to your doctor, keep in mind these behaviors:

1. Use clear, concise statements.
2. Stick to the issue/problem at hand.
3. Express your thoughts and opinions openly.
4. Share your feelings directly.
5. Initiate and maintain conversation.
6. Use “I” statements or “we” collaborative messages.
7. Speak in a loud, firm, fluent voice.
8. Maintain eye contact.

9. Use appropriate facial expressions.
10. Use gestures that enhance spoken words.
11. Use body posture to convey openness and interest.
12. Stand or sit an appropriate distance from the other.
13. If the doctor stands over you, you also stand up.



If you have not been satisfied with how your doctor responds to your concerns, consider using the following:

- Step 1. *Describe* the doctor's behavior in objective terms. Look, observe, examine exactly what he or she has been saying or doing.
- Step 2. *Express* your feelings or thoughts about this behavior or problem. Ex: "I feel that you are not listening to me."
- Step 3. *Specify* one behavior you want the doctor to make. Ask for agreement. Ex: "I would like you to ask me questions about the concerns I present to you."
- Step 4. Stipulate *the consequences* you will deliver (or what will happen) if the doctor keeps the agreement to change. Ex: "I will be pleased with my care and will convey that to other patients who see you."

If necessary, tell the doctor what negative consequences you will provide if there is no change. Write them here, but understand that you do not say them unless it becomes necessary. Ex: "I will not be pleased with my care, and I will convey my displeasure to other patients who see you."

Talking to the Doctor about Medical Problems

Communicating with your doctor is a two-way street. It's important for you to explain your medical problems clearly. And you should expect the doctor to ask you questions and tell you what is known about your condition. When you communicate well, you can accomplish a lot. Here are some ways to make communication easier.

- ◆ Collect your thoughts before you visit the doctor. Think about the symptoms that are bothering you. Sometimes it helps to make a list.
- ◆ Be on time for the appointment. You and your doctor will feel less rushed, and you will have more time to go over your concerns.
- ◆ Let the doctor know which medicines you're taking--including those you buy without a prescription. Take all of your medicines with you to show the doctor.
- ◆ Tell the doctor if you're upset or afraid because of your illness. Feel free to discuss confidential things. Your doctor will guard the confidential information carefully.
- ◆ Describe the worst symptoms first. There may not be time to cover everything in one visit.
- ◆ Express your concerns over, and over again until the doctor recognizes and responds to them.
- ◆ Be specific: What are the symptoms located? What do they feel like? How have they troubled you? Did you ever have these symptoms before? Do any members of your family have problems like yours? Did you ever go to a hospital or have surgery because of the symptoms?
- ◆ Try to answer questions as carefully as you can. If you don't understand a question, ask the doctor to repeat it or ask it in a different way.

- ◆ Ask questions if you can't follow the doctor's explanations. You have a right to know what's happening to you.
- ◆ Continue to repeat your question until you get a response that is acceptable to you.
- ◆ Discuss any diagnosis or treatment that you don't agree on. The doctor may be able to arrange a different way of dealing with the problem.
- ◆ Make an effort to remember and follow the doctor's instructions. Write them down if it will help you remember.
- ◆ Bring a tape recorder to your visit.
- ◆ Think of yourself and your doctor as partners. That way you'll get the most out of your visits.



**QUESTIONS FOR
YOUR DOCTOR**



I am most concerned about...

Symptoms _____

Pain _____

Medications _____

Other _____

☞ Resources for Maintaining a Healthy Lifestyle ☞

- Diet

☞ Organizations

American Institute for Cancer Research (AICR) -- Established to provide information on cancer and nutrition. Publishes a newsletter, cookbooks and a series of diet/nutrition brochures. To order written materials or a publication list, write to AICR, 1759 R Street, NW, Washington, DC 20009. AICR offers a hotline for nutrition-related cancer inquiries; callers will be connected to a registered dietitian.

Call (800) 843-8114 Website: <http://www.aicr.org>

☞ Books

Exercise: A guide from the National Institute on Aging (exercises, motivation, safety, self-tests, benefits and nutrition). Publication No. NIH 99-4258. Public Information Office, National Institute of Aging, National Institutes of Health.

Toll Free Information Line: 800-222-2225

Website: <http://www.nih.gov/nia>

☞ References

Goals for nutrition in the year 2000. Willet, W.C. (1999). CA, A Cancer Journal for Clinicians. 49, 6, 331-352.

What can randomized controlled trials tell us about nutrition and cancer prevention? CA. A Cancer Journal for Clinicians. Byers, T. (1999). 49, 6, 353-361.

- **Exercise**

-  **Websites**

Intellihealth web site

<http://www.intellihealth.com>

Guidelines for starting a fitness program, working out at home, maintaining motivation.

Thriveonline

<http://thriveonline.aol.com>

-  **Programs**

YWCA of the USA ENCOREplus Program offers women recovering from breast cancer support and exercise groups focusing on physical strength, health, and psychological well-being. Call your local YWCA for more information, or call the YWCA Office of Women's Health Initiatives, 624 9th Street, NW, Washington, DC, 20001, (202) 628-3636. Or call (202) 835-2351 and speak with Christine Gold. In your own community, inquire at your physician's office, women's health clinic or at local hospitals for referrals to qualified personal trainers or fitness centers.

Life Choices Wellness Center

9 Sandlewood Lane

PO Box 1084

Saluda, NC 28773

Phone: (828)749-1600 or 1-800-439-0083

“A Renewal Retreat for Women with Breast Cancer”, Non-profit organization dedicated to the emotional, physical and spiritual healing of women with breast cancer and women recovering from breast or other cancers. Seven day structured program utilizing meditation, stress reduction, group discussion, journaling, yoga and massage therapy. Fees are determined on a sliding scale and need-based system.

- **Alternative Medicine**

-  **Books**

Choices in Healing: Integrating The Best of Conventional and Complementary Approaches To Cancer. Michael Learner, MIT Press, Cambridge, MA, 1994. For those interested in considering alternative therapies together with standard medical. treatment.

National Center for Complementary and Alternative Medicine (NCCAM) Part of the National Institutes of Health and investigates alternative medical treatments, helps integrate effective treatment into mainstream medical practice and offers information packages.

NCCAM Clearinghouse, PO Box 8218, Silver Spring MD 200907-8218, (888) 644 6226; FAX (301) 495-4957 Website: <http://nccam.nih.gov>

Natural Health, Natural Medicine. Andrew Weil, MD, Houghton Mifflin, NY, 1998. Guide to preventive health maintenance and suggestions for treating common ailments.

Professional Articles

Complementary and Alternative Medicine Information for Breast Cancer on the World Wide Web: A Guide for Professional and Patients. Jacqueline C. Wootton, MEd. Innovations in Breast Care, vol. 4, no. 4, 1999 129-136.

- **Clothing, Protheses and Wigs**

Becoming, INC. A catalog filled with lingerie, workout wear, swimsuits, wigs, breast forms and accessories. Two percent of profits go to breast cancer awareness and research programs. For a catalog of products, call (800) 980-9085.

Lands' End offers five different styles of specially designed mastectomy swimwear. Order a catalog from (800) 963-4816.

Guilford Ostomy & Medical Supply, Inc. Offers various external prostheses, bras, and swimsuits. Fitter available. 2216 Golden Gate Drive, Greensboro, NC 27405. Phone: 1-800-458-3164. Contact person: Catherine Propst, RN, MSN.

Breast Cancer Resource Center of the Princeton YWCA Offers free wigs and prostheses to women in financial need nationwide. Shipping of \$15 must be prepaid. Paul Robeson Place, Princeton, NJ 08540, (609) 252-2003.

Y-ME Prosthesis and Wig Bank

Maintains a prosthesis and wig bank for women in financial need. If the appropriate size is available, Y-ME will mail a wig and/or breast prosthesis anywhere in the country. Hotline is staffed with breast cancer survivors and is a 24-hour service. A nominal handling fee is requested. Call (800) 221-2141.

The Breast Cancer Accessory Fund

Allows women with limited resources to obtain new wigs, prostheses, bras and other related accessories from selected area retailers. Rex Cancer Center Outreach Call: (919) 784-7200.

Zeus' Folly

Specializes in breast prostheses and bras for post-mastectomy patients. Located in New Jersey, it offers certified fitters and stocks bathing suits year-round. Medicare-approved. For phone orders, call (800) 719-7192.

Living in the Post-Mastectomy Body: Learning to Live in and Love Your Body Again. Becky Zuckweiler, MS,RN,CS, Hartley & Marks, Point Roberts, WA, 1998. The author is a nurse and psychotherapist who has had a double mastectomy and who guides women through all aspects of recovery, focusing on regaining confidence in your body and developing a comfortable self-image and intimate relationships.

- **Pamphlets**

Talking With Your Doctor (4638-CC, 1997 edition). Suggestions for effective doctor/patient communication. American Cancer Society, (800)-ACS-2345.
<http://www.cancer.org/Datinform/talking.html>

- **Books**

Love and Survival: the Scientific Basis for the Healing Power of Intimacy. Dean Omish, MD, Harper Collins Publishers, New York, 1997.

- **Online Support**

Association of Cancer Online Resources - *Access to almost 100 electronic mailing lists on cancer.*

<http://www.acor.org>

Cancer Care: Online Support - *Group discussions facilitated by trained oncology social workers.*

<http://www.cancercareinc.org/services/online3.htm>

OncoLink: Support Groups - *University of Pennsylvania Cancer Center's extensive support group list.*

oncolink.upenn.edu./psychosocial/support

OncoChat - *Chat with other cancer survivors.*

<http://www.oncochat.org>

❧ Acknowledgments ❧

Ten Easy Steps was adapted from *Coping*, May/June 1995, and *Taking with Your Doctor*, American Cancer Society, 1987; page 2.

Talking to the Doctor about Medical Problems was adapted from *Patient Care*, July 15, 1996, p. 87.

Appendix



1. Breast Self-Examination
2. Post-Mastectomy BSE
3. Stretching Exercises
4. NC Regional Support Organizations
5. Evaluating Websites
6. Glossary

1. Breast Self-Examination

After a mastectomy, breast self-examination (BSE) should be part of your routine. Examine your unaffected breast and the surgical site once a month to note any changes in the way they look or feel. Even if you performed self-exams before surgery, you will have to relearn what is normal for you now. About half the women who have mastectomies report that the remaining breast becomes larger.

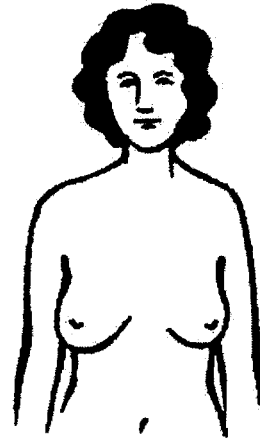
If you menstruate, the best time to do BSE is 2-3 days after your period ends, when your breast is least likely to be tender and swollen. If you no longer menstruate, pick a day, such as the first day of the month, to do BSE.

All women over 20 should perform a breast examination each month to get to know how their breasts feel, so they can notice any changes as early as possible. Try to pick the same day each month, like the first day of each month, to remind yourself it is time to do your exam. Women between 20 and 39 years of age are advised by the American Cancer Society to get a breast exam in the

doctor's office every 3 years. Women over 40 should get an exam every year.

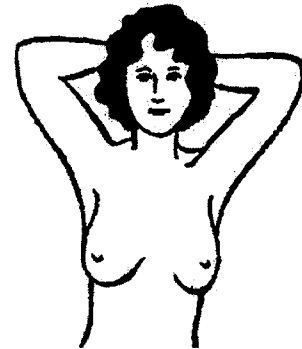
Breast Self-Examination

1. Stand in front of a mirror that is large enough to let you see your breasts clearly. It is important that you have good lighting in the room.

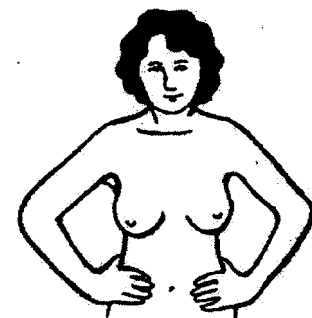


The next two steps will help you to find any change in the shape of your breasts. You should be able to feel your chest muscles tighten as you go through these steps.

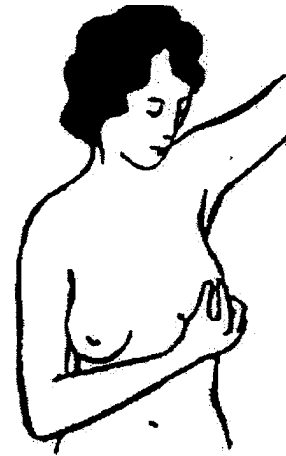
2. Look in the mirror. Put your hands behind your head with your fingers laced together. Pull forward, against the back of your head. Check for anything different.



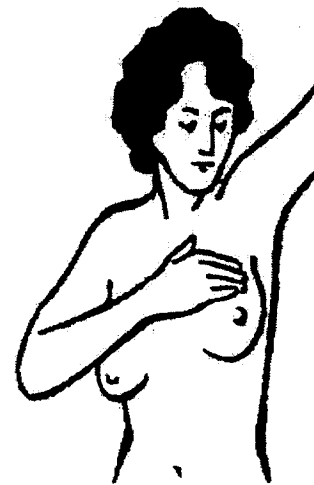
3. Look in the mirror. Put your hands on your hips and bend over, a little, toward the mirror. Try to point your elbows at the mirror. Check for any unusual changes in shape or any lumps.



4. Gently pinch each nipple. Look for any fluid or oozing.



5. Raise one arm above your head. With firm pressure, use the flat pads of your fingertips to check your breast for lumps or knots. Also check the area between your breast and arm and under your arm for any lumps or knots.



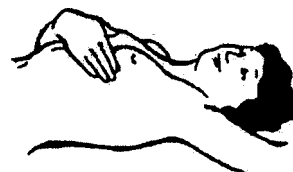
6. To make sure you do not miss anything, move your fingers, slowly, in circles. Start at the outside edge of your breast and go around and around making smaller and smaller circles. Take your time. Go slowly and touch all areas.



You can use lotion or powder to help your fingers slide smoothly over the skin. Some women repeat

Step 5 in the shower. Soapy fingers glide over your skin making it easier to feel things underneath it.

7. Lie flat on your back with a folded towel or pillow under one shoulder. Raise the opposite arm above your head. Lying in this position makes your breast easier to check. Repeat Step 5. Take your time. Go slowly.



If you see or feel anything unusual, call your doctor.

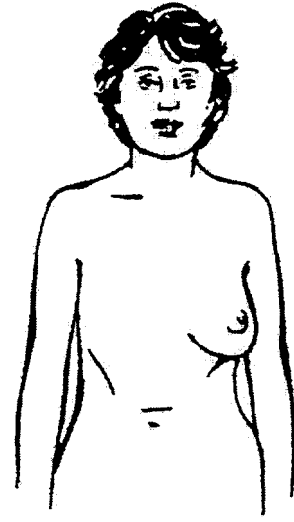
2. Breast Self-Examination Post-Mastectomy

After a mastectomy, breast self-examination (BSE) should be part of your routine. You will want to examine your natural breast and the surgical site once a month to note any changes in the way they look or feel. Even if you performed self-exams before your surgery, you will have to relearn what is considered “normal” for you now. About half the women who have mastectomies report their remaining breast becomes larger.

If you menstruate, the best time to do BSE is 2 or 3 days after your period ends, when your breast is least likely to be tender and swollen. If you no longer menstruate, pick a day, such as the first day of the month, to do BSE. Here is how to do BSE:

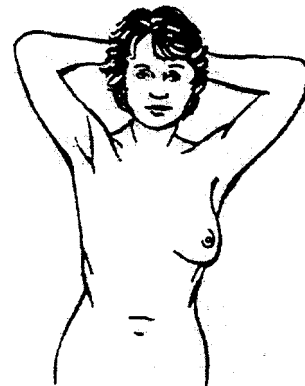
Breast Self-Examination Post-Mastectomy

1. Stand before a mirror. Inspect your breast for anything unusual, such as a discharge from the nipple, or puckering, dimpling, or sealing of the skin. Inspect the scar for new swelling, lumps, or even a little pimple on the scar line that was not there before. Look for redness or color change. Although redness can be due to irritation from your bra or prosthesis, report it to your physician.

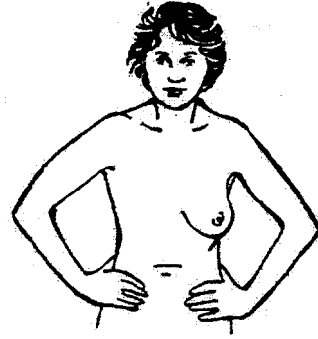


The next step is designed to emphasize any change in the shape or contour of your breast. As you do it, you should be able to feel your chest muscles tighten.

2. Watching closely in the mirror, clasp your hands behind your head and press your hands forward.



3. Press your hands firmly on your hips and bow slightly toward the mirror as you pull your shoulders and elbows forward.



Some women do the next part of the exam in the shower. Fingers slide over soapy skin, making it easy to concentrate on the texture underneath.

4. Raise your arm on the unoperated side. Using three or four fingers of your other hand, explore your breast firmly, carefully, and thoroughly. Beginning at the outer edge, press the flat part of your fingers in small circles, moving around the breast. Gradually work toward the nipple. Be sure to cover the entire breast including the collarbone area and all the way to the center of your breast bone.



5. Pay special attention to the area between the breast and the underarm, including the underarm itself. Feel for any unusual lump or mass under the skin. Gently squeeze the nipple and look for a discharge.



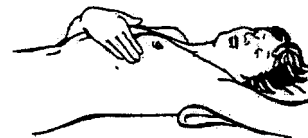
6. Raise your arm on the operated side, and begin examining your entire breast area on this side the same way you did the breast on the other side. Use three or four fingers of your opposite hand and begin to examine the scar. Press gently, using small circular motions, and feel the entire length of the scar.



Then spread your fingers slightly apart and “milk” the area between your ribs to feel for any lumps, thickening, hard places, or small pimples. Be sure to explore the collarbone area and all the way to the center of the breast bone.

As with your breast, familiarity with your scar makes it easier to notice any changes. Lumps, thickening, or inflammation are among changes you should bring to the attention of your doctor.

7. Steps 4-6 should be repeated lying down. Lie flat on your back, raise your arm on the unoperated side over your head, and place a pillow or folded towel under your shoulder. This position flattens the breast and makes it easier to examine. Use the same circular motion described earlier.

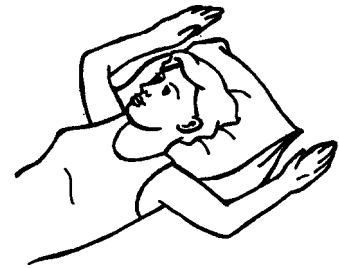


3 . Stretching Exercises

Before exercising it is important to gradually stretch and warm up the muscles used in exercise. The following are some basic stretches for the muscle groups before undertaking an exercise program.

Shoulder

1. Lie flat on the floor, pillow under head.
2. Stretch arms out to side.
3. Bend elbows to crook lower arms downward, at right angle.
4. Hold position for 10-30 seconds. Repeat 3-5 times.
5. Bend elbows to crook lower arms upright, at right angle.
6. Hold position for 10-30 seconds. Repeat 3-5 times.
7. Keep shoulders flat on floor throughout.



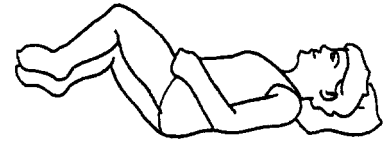
Neck

1. Lie on back.
2. Turn head from side to side, holding position each time 10-30 seconds. Repeat 3-5 times.



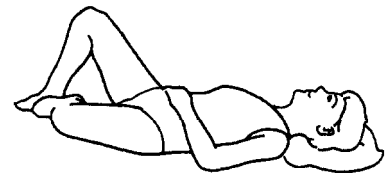
Hips (Double Rotation)

1. **Don't do this exercise if you have had a hip replacement, unless your surgeon approves.**
2. Lie on floor, knees bent.
3. Keep shoulders on floor at all times.
4. Keeping knees together, lower legs to one side.
5. Hold position for 10 seconds. Repeat 3-5 times.



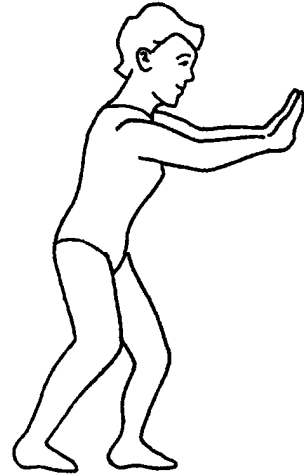
Hips (Single Rotation)

1. Lie on floor.
2. Bend knees.
3. Let one knee slowly lower to side.
4. Hold position 10-30 seconds. Repeat 3-5 times.
5. Bring knee back up.
6. Keep shoulders on floor throughout exercise.
7. Repeat with the other knee.



Calves

1. Stand with hands against wall, arms straight.
2. Step back 1-2 feet with one leg, heel and foot flat on floor.
3. Hold position.
4. Bend knee, of stepped-back leg, keeping heel and foot flat on floor.
5. Hold position for 10-30 seconds. Repeat 3-5 times.
6. Repeat with other leg.



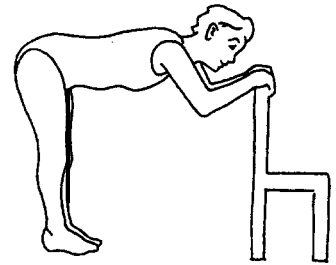
Front of Thighs

1. Lie on side.
2. Rest head on pillow or hand.
3. Bend knee that is on top.
4. Grab heel of that leg. (If you can't reach your heel with your hand, loop a belt over your foot.)
5. Gently pull that leg until front of the thigh stretches.
6. Hold position for 10-30 seconds. Repeat 3-5 times.
7. Reverse position and repeat with the other side.



Back of Thighs

1. Stand behind chair, holding the back of it with both hands.
2. Bend forward from the hips, keeping back and shoulders straight at all times.
3. When the upper body is parallel to the floor, hold position for 10-30 seconds.



4. North Carolina Regional Support Organizations

If you cannot find a convenient support group from this list, contact the Breast Cancer Coalition of North Carolina at their website: <http://cbcs.med.unc.edu/bccnc.htm>. Please note that some of these phone numbers reach the leader's home.

Asheville	Life After Cancer/Pathways, Inc.	(828) 252-4106
Chapel Hill	Chapel Hill Support Group	(919) 942-3249
Charlotte	Presbyterian Hospital	(704) 384-5223
Charlotte	Women Living with Cancer	(704) 355-7283
Durham	Duke Comprehensive Cancer Center	(919) 684-4497
Gastonia	Sisters Network, Piedmont Chapter	(704) 834-7200
New Bern	Peer Support Group	(252) 637-6594
Raleigh	Breast Cancer Support Group	(919) 787-2637 ext. 147
Rocky Mount	Rocky Mount Area Breast Cancer Alliance	(252) 443-8607
Wilson	Kathy Fanrris Memorial Mastectomy Group	(252) 237-0439
Winston-Salem	Pink Broomstick Breast Cancer Support Group	(336) 725-7421

5. Evaluating Websites

Source Selection Tip:

Try to select sources that offer as much of the following information as possible:

- Author's name
- Author's organizational affiliation
- Author's title or position
- Date of page creation
- Author's contact information
- Some of the indicators of information quality (listed below)

Checklist for Information Quality:

1. Credibility

There are several tests you can apply to a source to help you judge how credible and useful it will be:

- Author's credentials: education, training, experience in the field relevant to the information, biographical information about the author
- Author provides contact information (e-mail, address, phone number)
- Organizational affiliation (known and respected authority)

Indicators of lack of credibility:

- Anonymity - No author listed
- Negative information
- Bad grammar or misspelled words

2. Accuracy

The goal of the accuracy test is to assure that the information is actually correct:

- Up-to-date
- Detailed
- Exact
- Comprehensive
- Focused at a particular audience and clearly stated purpose
- Links are up-to-date and useful

Indicators of lack of accuracy:

- No date on the document
- Vague or broad generalizations
- Old date on information known to change rapidly
- Very one-sided view that does not acknowledge opposing views or respond to them

3. Reasonableness

The test of reasonableness involves examining the information regarding:

- Fairness of argument - offering a balanced, reasoned argument
- Objectivity - control of biases
- Moderateness - is the claim extraordinary or difficult to believe?
- Consistency - does the information contradict itself?

Indicators of lack of reasonableness:

- Inappropriate tone or language
- Extreme claims of information (example: one offering cures)
- Broad statements of excessive significance
- Conflicts of interest

4. Support

Support is concerned with the source of the information and the ability to confirm the information to other sources.

- Find other information that supports and reconfirms (or challenges) information you have found
- Find additional sources when the claim is dramatic
- Does the source discuss information already known? If so, does this information agree or conflict with what is known?

Indicators of lack of support:

- Numbers or statistics presented without an identified source
- Absence of source documentation when the discussion needs documentation
- No other sources can be found that provide the same information or acknowledges the information exists

6. Glossary

adenocarcinoma: cancer that starts in the glandular tissue, such as in ducts or lobules of the breast.

antiestrogen: a substance (for example, the drug *tamoxifen*) that blocks the effects of estrogen on tumors. Antiestrogens are used to treat breast cancers that depend on estrogen for growth.

axilla: the armpit.

axillary dissection: removal of the lymph nodes in the armpit (axillary nodes). They are examined for the presence of cancer.

bilateral: on both sides of the body; for example, bilateral breast cancer is cancer in both breasts.

breast implant: a sac used to increase breast size or restore the contour of a breast after mastectomy. The sac is filled with silicone gel (a synthetic material) or sterile saltwater (saline). Because of concern about possible, but as yet unproven, side effects of silicone, these implants are now available only to women who agree to participate in a study in which side effects are carefully followed.

breast reconstruction: surgery that rebuilds the breast contour after mastectomy. A breast implant or the woman's own tissue is used. If desired, the nipple and areola may also be re-created. Reconstruction can be done at the time of mastectomy or any time later.

breast self-exam (BSE): a method of checking one's own breasts for lumps or suspicious changes. BSE is recommended for all women over age 20, to be done once a month, usually at

a time other than the days before, during, or immediately after her menstrual period.

capsule formation: scar tissue that may form around a breast implant (or other type of implant) as the body reacts to the foreign object. Sometimes called a *contracture*.

clinical breast examination: an examination of the breasts done by a health professional such as a doctor or nurse.

dissection: surgery to divide, separate, or remove tissues. See also *axillary dissection*.

edema: build-up of fluid in the tissues, causing swelling. Edema of the arm can occur after radical mastectomy, axillary dissection of lymph nodes, or radiation therapy. See also *lymphedema*.

estrogen replacement therapy: the use of estrogen from sources other than the body. Estrogen may be given after a woman's body no longer makes its own supply. This type of hormone therapy is often used to relieve symptoms of menopause. It has also been shown to provide protective effects against heart disease and bone thinning (osteoporosis) in women after menopause. See *hormone replacement therapy*.

fibrosis: formation of fibrous (scar-like) tissue. This can occur anywhere in the body.

hormone: a chemical substance released into the body by the endocrine glands, such as the thyroid, adrenal, or ovaries. Hormones travel through the bloodstream and sets in motion various body functions. For example, prolactin, which is produced in the pituitary gland, begins and sustains the production of milk in the breast after childbirth.

hormone replacement therapy (HRT): the use of estrogen and progesterone from an outside source after the body has stopped making its own supply because of natural or induced menopause. This type of hormone therapy is often given to relieve symptoms of menopause and has been shown to offer protection against heart disease and thinning of the bones (osteoporosis) in women after menopause. Since estrogen nourishes some types of breast cancer, scientists are working on the question of whether estrogen replacement therapy increases breast cancer risk. See *estrogen replacement therapy*.

hormone therapy: treatment with hormones, with drugs that interfere with hormone production or hormone action, or the surgical removal of hormone-producing glands to kill cancer cells or slow their growth. The most common hormonal therapy for breast cancer is the drug *tamoxifen*. Other hormonal therapies include *megestrol*, *aminoglutethimide*, *androgens* and surgical removal of the ovaries (oophorectomy). See also *tamoxifen*.

imaging studies: methods used to produce a picture of internal body structures. Some imaging methods used to help diagnose cancer are x-rays (a breast x-ray is called a *mammogram*), CT scans, magnetic resonance imaging (MEU), and ultrasound.

implant: an artificial form used to restore the shape of an organ after surgery; for example, a breast implant.

latissimus dorsi flap procedure: a method of breast reconstruction that uses the long, flat muscle of the back by rotating it to the chest area.

lymphatic system: the tissues and organs (including lymph nodes, spleen, thymus, and bone marrow) that produce and store

lymphocytes (cells that fight infection) and the channels that carry the lymph fluid. The entire lymphatic system is an important part of the body's immune system. Invasive cancers sometimes penetrate the lymphatic vessels (channels) and spread (metastasize) to lymph nodes.

- *lymph* (limf): clear fluid that flows through the lymphatic vessels and contains cells known as lymphocytes. These cells are important in fighting infections and may also have a role in fighting cancer.
- *lymph nodes*: small, bean-shaped collections of immune system tissue, such as lymphocytes, found along lymphatic vessels. They remove cell waste and fluids from lymph. They help fight infections and also have a role in fighting cancer. Also called *lymph glands*.
- *lymphocytes*: a type of white blood cell that helps the body fight infection.

lymphedema: a complication that sometimes happens after breast cancer treatments. Swelling in the arm is caused by excess fluid that collects after lymph nodes and vessels are removed by surgery or treated by radiation. This condition can be persistent but not painful.

mammogram, mammography: an x-ray of the breast; the method of detecting breast cancers which cannot be felt. Mammograms are done with a special type of x-ray machine that is used only for this purpose. A mammogram can show a developing breast tumor before it is large enough to be felt by a woman or even by a highly skilled health care professional. *Screening mammography* is used to help find breast cancer early in women without any symptoms. *Diagnostic mammography* helps the doctor learn more about breast masses or the cause of other breast symptoms.

mastectomy: surgery to remove all or part of the breast and sometimes other tissue.

- *Extended radical mastectomy* removes the breast, skin, nipple, areola, chest muscles (pectoral major and minor), and all axillary and internal mammary lymph nodes on the same side.
- *Halsted radical mastectomy* removes the breast, skin, nipple, areola, both pectoral muscles, and all axillary lymph nodes on the same side.
- *Modified radical mastectomy* removes the breast, skin, nipple, areola, and most of the axillary lymph nodes on the same side, leaving the chest muscles intact.
- *Partial mastectomy* removes less than the whole breast, taking only part of the breast in which the cancer occurs and a margin of healthy breast tissue surrounding the tumor.
- *Subcutaneous mastectomy* is surgery to remove internal breast tissue. The nipple and skin are left intact.
- *Prophylactic mastectomy* is a mastectomy done before any evidence of cancer can be found, for the purpose of preventing cancer. This procedure is sometimes recommended for women at very high risk of breast cancer.
- *Quadrantectomy* is a partial mastectomy in which the quarter of the breast that contains a tumor is removed.
- *Segmental mastectomy* is a partial mastectomy.
- *Simple mastectomy* or *total mastectomy* removes only the breast and areola.

menopause: the time in a woman's life when monthly cycles of menstruation cease forever and the level of hormones produced by the ovaries decreases. Menopause usually occurs in the late 40s or early 50s, but it can also be caused by surgical removal of both ovaries (oophorectomy), or by some chemotherapies that destroy ovarian function.

metastasis: the spread of cancer cells to distant areas of the body by way of the lymph system or bloodstream.

Nolvadex: trade name for *tamoxifen*, an antiestrogen drug commonly used in breast cancer therapy. See also *antiestrogen*, *tamoxifen*, and *hormonal therapy*.

osteoporosis: thinning of bone tissue, resulting in less bone mass and weaker bones. Osteoporosis can cause pain, deformity (especially of the spine), and broken bones. This condition is common among postmenopausal women. See also *estrogen replacement therapy*.

prosthesis: an artificial form, such as a breast prosthesis, that can be worn under the clothing after a mastectomy.

recurrence: cancer that has come back after treatment. *Local recurrence* means that the cancer has come back at the same place as the original cancer. *Regional recurrence* means that the cancer has come back in the lymph nodes near the first site. *Distant recurrence* is when cancer metastasizes after treatment to organs or tissues (such as the lungs, liver, bone marrow, or brain) further from the original site than the regional lymph nodes.

regional involvement: the spread of cancer from its original site to nearby areas (such as the axillary lymph nodes) but not to distant sites such as other organs.

sentinel node biopsy: a new procedure that might replace standard axillary lymph node dissection. Blue dye or a radioactive tracer is injected into the tumor site at the time of surgery and the first (sentinel) node that picks up the dye is

removed and biopsied. If the node is cancer-free, no more nodes are removed.

side-effects: unwanted effects of treatment, such as hair loss caused by chemotherapy and fatigue caused by radiation therapy.

survival rate: the percentage of people who live a certain period of time. The 5-year survival rate refers to the percent of patients who live at least 5 years after diagnosis, and 5-year rates are used to produce a standard way of discussing prognosis. For example, the 5-year survival rate for women with localized breast cancer (including all women living five years after diagnosis, whether the patient was in remission, disease-free, or under treatment) was 78% in the 1940s, but in the 1990s, it was over 97%.

Five-year *relative* survival rates exclude from the calculations patients dying of other diseases, and are considered to be a more accurate way to describe the prognosis for patients with a particular type and stage of cancer. Of course, 5-year survival rates are based on patients diagnosed and initially treated more than 5 years ago. Improvements in treatment often result in a more favorable outlook for recently diagnosed patients.

tamoxifen (brand name: Nolvadex): this drug blocks the effects of estrogen on many organs, such as the breast. Estrogen promotes the growth of some breast cancers. Recent research suggests that tamoxifen may lower the risk of developing breast cancer in women with certain risk factors.

transverse rectus abdominus muscle flap procedure: a method of breast reconstruction in which tissue from the lower abdominal wall, which receives its blood supply from the rectus abdominus muscle, is used. The tissue from this area is moved

up to the chest to create a breast mound and usually does not require an implant. Moving muscle and tissue from the lower abdomen to the chest results in flattening of the lower abdomen (a “tummy tuck”). Also called a TRAM flap or *rectus abdominus flap procedure*.

❧ Acknowledgments ❧

Post-Mastectomy Breast Self-Exam was adapted from *Mastectomy: A Treatment for Breast Cancer* published by National Institutes of Health and the American Cancer Society.

The glossary was adapted from The American Cancer Society’s *Breast Cancer Dictionary*, 2000.

Drawings of the **Stretching Exercises** were done by Daniel Shelverton.

General Resources



Websites

CANSearch: A Guide to Cancer Resources on the Internet (NCCS) -- A guide to cancer resources on the Internet compiled by the National Coalition for Cancer Survivorship (NCCS). Spanish page available.

<http://www.canceradvocacy.org>

Living Beyond Breast Cancer (National hotline/website)

Website: <http://www.lbbc.org>

E-mail: mail@lbbc.org

Phone: (610) 645-4567, (888) 753-LBBC (5222)

Sisters Network (A national organization geared to African-American women with many local chapters)

Website: <http://www.sistersnetworkinc.org>

E-mail: infonet@sistersnetwork.org

Phone: 866-781-1808

Susan B. Komen Breast Cancer Foundation—“I’m Aware” -- 800-IM-AWARE (800-462-9273)

<http://www.komen.org> or <http://www.breastcancerinfo.com>

Information and Referral

National Cancer Institute

Cancer Information Service of the National Cancer Institute (NCI) -- Toll-free number: 1-800-4-CANCER

Provides the most up-to-date information on all aspects of cancer through its regional network. makes referrals to oncologists, medical centers, clinical trial programs and provides information brochures. Spanish-speaking staff members.

<http://www.cancer.gov/newscenter>

Live Help

National Cancer Institute of National Institute of Health hosts an on-line live chat Monday through Friday from 9:00 AM to 11:00 PM Eastern Time. Experts in cancer topics will answer questions on a confidential network connection.

<https://cissecure.nci.nih.gov/livehelp/welcome.asp>

Oncology Nursing Society

This site provides information about the cause and effects of side effects of chemotherapy as well as symptom management strategies. Site also includes a glossary of terms.

“Ask an Oncology Nurse”

Users can send and receive confidential emails to an oncology nurse to obtain answers to questions.

<http://cancersymptoms.org>

Organizations

Care-Line Information and Referral, North Carolina Department of Health and Human Services -- Statewide toll-free human service information and referral program. Links clients in need of assistance with appropriate agencies and community resources designed to help them solve their problems. Available 8 am - 5 pm except

holidays. There are no fees for information but there is a nominal fee for print-outs. Spanish resources also available. Call (800)-662-7030

NC Department of Human Resources
325 N. Salisbury Street
Raleigh, NC 27611

Electronic database of 10,000 agencies across North Carolina available at

<http://www.dhhs.state.nc.us/ocs/careline.htm>

The American Cancer Society

Toll-free number: 800-ACS-2345

A nationwide, community-based, voluntary health organization which provides: support groups for women and their families; the “Reach to Recovery” program, which links women undergoing mastectomies with those who have already had this surgery; numerous publications.

Links to North Carolina Chapter

<http://www.cancer.org>

National Coalition for Cancer Survivorship

National Alliance of Breast Cancer Organizations (NABCO)

Nonprofit national resource center. Publishes “Breast Cancer Resource List,” one of the best all-around guides to finding resources including: organizations and groups that can provide information, support, education, and services; help in making treatment choices; lists of publications and videos, including resources available in Spanish; how to get in touch with a support group in your area; personal resources, such as places to find wigs, prostheses, and other items. Publications related to the care and support of cancer patients and treatments can be downloaded for free

or ordered from

<http://www.canceradvocacy.org/resources/nabco>

Email: info@canceradvocacy.org

Address: NCCS, 1010 Wayne Avenue, Suite 770, Silver Spring, MD 20910

Call: 877-622-7937

National Black Leadership Initiative on Cancer

<http://www.uic.edu/UI-Service/programs/UIC168.html>

311 SPHW m/c 922

2121 W. Taylor Street Chicago, IL 60612

312-996-8046

The Office of Cancer Survivorship (OCS) -- An office of the National Cancer Institute (NCI); links to survivorship research; direct access to funding opportunities, the OCS portfolio and resources for survivors, family members and health professionals.

<http://www.cancer.gov/prevention/index.html>

Y-ME National Breast Cancer Organization -

A nonprofit, consumer-oriented organization that provides information, hotlines, referrals, self-help groups and emotional support to individuals concerned about breast cancer. Trained counselors and volunteers staff their hotline and can link women and men to similar breast cancer survivors. Also sponsors a wig and prosthesis bank.

<http://www.y-me.org>

24 hour Hotline: 1-800-221-2141 (English and 150 other languages available)

24 hour Hotline: 1-800-986-9505 (Spanish)

Programs

The Cancer Survivor's Toolbox -- A self-learning audio program developed by leading national experts that focuses on six key skills to help survivors, family members and caregivers. Materials are available as audio cassette tapes or CD's, Free to survivors and professionals. Call (877)-TOOLS-4-U. (1-877-866-5748)
<http://www.cansearch.org:/programs/toolbox.htm>

Pamphlets

National Cancer Institute Publication Locator

A library of publications developed by National Cancer Institute. Includes information about breast cancer in men. Publications are available in multiple languages.

Download for free from

<https://cissecure.nci.nih.gov/ncipubs>.

Taking Time: Support for People with Cancer. National Cancer Institute. National Institutes of Health (NIH) Publication no. P126 (2003). (Call NCI)

What You Need to Know about Breast Cancer. National Cancer Institute. NCI pamphlet no P017 (2005). Call NCI at 1-800-4-CANCER or see website at:

<http://cancer.gov/cancertopics/wyntk>

Facing Forward Series. Life After Cancer (P119, 2002) addresses the special needs of cancer survivors and their families, focusing on four major areas of need: maintaining physical health, addressing emotional concerns, managing insurance issues and handling employment problems. National Cancer Institute, (800)-4-CANCER. Also available in Spanish.

<http://cancer.gov/cancertopics/life-after-treatment>

National Coalition for Cancer Survivorship

Offers several publications that can be downloaded from the inter-net for free or purchased for a small fee.

<http://www.canceradvocacy.org/resources/nabco>

 **Books**

Living Beyond Breast Cancer

Organization was founded by radiation oncologist Marissa Weiss, MD in response to women's need for breast cancer related information, connection and support. Site features access to free culturally specific guide books for breast cancer survivors on adjusting to life after treatment. Topics include long-term side effects of treatment, employment and insurance issues and sexuality.

Getting Connected: African-Americans Living Beyond Breast Cancer.

Living Beyond Breast Cancer's Guide for the Newly Diagnosed.

We Celebrate Tomorrow: Latinas Living Beyond Breast Cancer.

<http://www.lbbc.org>

Helpline: 888-753-5222

The Unofficial Guide to Surviving Breast Cancer, Stacie Zoe Berg with Richard Theriault, MD, IDG Books Worldwide Inc, Foster City, California, 1999. Guide with top cancer experts and leaders in breast cancer research, treatment and understanding of breast cancer.

The Breast Cancer Survival Manual. A step-by-step guide for the woman with newly diagnosed breast cancer. Link, J., Henry Holt & Co., 2003.

Dr. Susan Love's Breast Book. Love, S., Lindsey, K., Reading, Massachusetts, Addison Wesley, 2005.

For Women Only! Your Guide to Health Empowerment. Gary Null and Barbara Seaman, Seven Stories Press, NY, 2001.

Magazine

MAMM

<http://www.mamm.com>

349 West 12th St.

New York, NY 10014

1-888-901-MAMM to subscribe or see web address and subscribe electronically

A monthly magazine devoted to meeting the needs of women diagnosed with breast and reproductive cancer who have just been diagnosed or those who are longtime survivors. Provides the latest treatment updates, including emerging findings about alternative and complementary therapies, as well as profiles of survivors. \$17.68/year

Electronic Newsletter

NCI Cancer Bulletin

National Cancer Institute will email their monthly newsletter with the latest in cancer research.

<http://www.cancer.gov/newscenter>

Index

- advocacy** - 81
for others - 81
for yourself - 81-87
- alternative**
medicine - 90-91
pain relief - 55-63
- axillary lymph node dissection** - 32;
51
definition - 109
diagram of nodes - 32
- bandages** - 42; 70
compression - 42-43; 46; 48-49
- BSE**
See breast self exam
- breast self-exam** - 95-98; 109-110
clinical breast exam - 110
post-mastectomy - 98-101
- chemotherapy** - 11; 12
effects - 66
- chiropractic** - 49
- CLM** - 41
See also compression therapy
- clothing** - 14; 37; 69-70; 76; 91-92;
119
- communication**
with your doctor - 3-4; 82-87
with family and friends - 7-8; 74-
75; 120
- compression therapy** - 42
compression bandages - 42-43; 46;
48-49
compression sleeves - 42-43; 45-
46; 48-49
- depression** - 2
- diary**
fatigue - 5-7
hot flashes - 13
pain - 61-63
self-image - 80
- diet** - 5; 13-14; 40; 67; 71; 74; 77-78;
88-89
resources - 88-89
- dryness**
vaginal - 14-15; 17
skin - 67-68
itching - 14-15; 68
- estrogen** - 11-12; 17-18; 20; 109-110;
114-115
replacement therapy - 110
- exercise** - 6; 22-26; 28; 33; 40-41; 43;
46; 73; 74; 77; 78-80; 88-90
clapping hands overhead - 24-25
overhead raise - 24
resources - 89-90
stretching - 102-105
walking up the wall - 25
weight machines - 41
- fatigue** 1-10; 16; 52
causes of - 1-3

- fibrosis** - 52
definition - 110
- hot flashes** - 13-14
- hormone replacement therapy** - 17
definition - 111
estrogen replacement - 17; 110
- HRT**
See hormone replacement therapy
- journal**
See diary
- lifestyle** - 73-94
- lymphedema** - 31-50
definition - 112
early signs of - 35
lymphatic system
diagram - 32
definition - 111-112
lymph fluid - 31
lymph vessels - 31-32
prevention of - 35-41
risk of developing - 34
treatment of - 41-46
cost of - 45-46
insurance - 45-46
- mammogram**
definition - 112
- mastectomy** - 51-52; 91; 92; 95; 105; 109; 113
BSE - *See breast self exam*
definition - 109-110
- medication** - 2; 54-55; 61-63; 86
over-the-counter - 26; 53
prescription - 14; 55
See also pain, relievers
- menopause** - 11-12; 14; 17-18; 110
definition - 113
- osteoporosis** - 17; 110
definition - 114
prevention of - 17; 78
- pain** - 51-64
diary - 61-63
management strategies - 61-63
phantom breast - 51
post-mastectomy - 51
relievers - 53-55
alternative - 55-60
dosage - 54
non-prescription - 26; 53-54; 62-63
precautions - 55
- phantom breast pain** - 51
- physical activity**
See exercise
- post-mastectomy**
BSE - *See breast self exam*
pain syndrome - 51
- prostheses** - 37; 76; 91-92; 99; 119
- radiation**
treatment effects - 1; 2; 21; 31-34; 52; 66-69
recall - 66

relaxation - 56; 80

scarring - 52

sex drive

decreased - 16

skin changes - 65-72

causes - 66-69

color change - 68

itching - 68

sweat - 36,68

swelling - 31-35; 37-39; 41-43; 46;
71; 99; 110; 112

stiffness - 21-30

causes of - 21

prevention of - 22-23

treatment for - 23-26

stress - 3; 5; 16; 82

reduction - 14; 90

sunscreen - 70

support - 28; 47; 49; 89; 107

emotional - 74-75; 81-82

groups - 8; 75

in North Carolina - 105

online - 93

tamoxifen - 12; 109; 111; 114

definition - 115

TENS - 60

testosterone - 11-12; 16

vitamins - 14-15; 67; 71; 77-78

weakness - 21-30

causes of - 21-23

treatment for - 23-27

websites

evaluation of - 106-107

See also resources at end of each
section.

weight - 6; 40; 74; 77

wigs - 91-92



Y 3 0 3