

CHAPTER







# 5

## Resources for Information and Referral

Support Groups and Health Care Information Services.....	48
Additional National and State Resources .....	53
Professional Education .....	55
Electronic Resource Directory .....	56
Patient Education Pages .....	57

# Support Groups and Health Care Information Services for Women with Breast Cancer

## The American Cancer Society (ACS)

-  Toll-free number: 1-800-ACS-2345
-  Website: [www.cancer.org](http://www.cancer.org)
-  Tel: (505) 260-2105
-  Addr: 5800 Lomas Blvd. NE, Albuquerque, NM 87110
-  Tel: (505) 988-5548
-  Addr: 839 Paseo de Peralta, Suite H, Santa Fe, NM 87501

The American Cancer Society is the nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer, through research, education, advocacy, and service.

The American Cancer Society offers a variety of services to cancer patients and their families. ACS also helps women with breast cancer through various patient services, which offer emotional support.

### Patient Services

**Road to Recovery:** Volunteer drivers provide transportation to doctor's appointments and cancer treatments, providing access to medical care for elderly and disabled patients.

**Look Good Feel Better:** Women with cancer learn make-up and skincare techniques to offset the effects of chemotherapy and radiation, resulting in increased self-confidence and knowledge of self-care.

**I Can Cope:** Quality-of-life classes, including care-giving, medication and treatment options and resource availability, help to strengthen the emotional status of cancer patients and their families.


**Reach to Recovery:** Breast cancer survivors provide one-on-one support to women facing breast cancer and to those who have had breast surgery to increase their ability to cope, manage illness, and to maintain work and family roles.


**Gift/Loan Items:** Items, such as wigs, hats, turbans, and ostomy supplies are available to cancer patients to help enhance their quality of life.

**Cancer Information & Referral:** Brochures, general and site-specific cancer information, and employment and insurance issues often faced by cancer patients and their families, are available to individuals, services organizations and medical facilities. Your local American Cancer Society office also can provide local referrals to other services.

Call the Albuquerque or Santa Fe office for information about services and support groups in your city or county.


## ENCORE <sup>Plus</sup>


 Tel: (505) 254-9922


 Addr: YWCA, 303 San Mateo NE, Albuquerque, NM 87108


ENCORE <sup>Plus</sup> (Encouragement, Normalcy, Counseling, Opportunity, Reaching Out, Energies Revived) is a program sponsored by the YWCA (Young Women's Christian Organization) and Avon Breast Cancer Crusade and United Way of Central New Mexico to provide information about breast and cervical cancer screening services in New Mexico. The program includes one-on-one counseling, referral and support for screening mammography or diagnostic screening. For further information, call the Albuquerque number above, or consult the local YWCA listed in your phone book.


## People Living Through Cancer (PLTC)

 Tel: (505) 242-3263

 Toll-free number: 1-888-441-4439

 Fax: (505) 242-6756

 Website: [www.pltc.org](http://www.pltc.org)

 Addr: 323 Eighth Street SW, Albuquerque, NM 87102

PLTC was founded by and for those coping with a cancer diagnosis or the cancer of a friend or loved one. PLTC's breast cancer resources include:

- *Peer support groups* for survivors and family members
- *One-to-one matching* with others who have had breast cancer or have similar concerns
- *Living Through Cancer Journal*, a quarterly publication
- *Training* for those wishing to improve their skills at giving support
- *The largest cancer-related library for health care consumers in New Mexico*

- *Telephone “Lifeline”* offering immediate support, information and referrals
- *Annual statewide survivorship conference*
- *The New Mexico Breast Cancer Coalition*

PLTC includes Hispanic, American Indian, and African American breast cancer survivors serving their communities.

## **The Cancer Research and Treatment Center (CRTC) UNIVERSITY OF NEW MEXICO HEALTH SCIENCES CENTER**





- ☎ Tel: (505) 272-4946
- ☎ Statewide toll-free number: 1-800-432-6806
- 📍 Address: 900 Camino de Salud NE, Albuquerque, NM 87131-5306

The CRTC is New Mexico’s only cancer center formally recognized by the NCI. The CRTC serves the entire state and the Navajo Nation. Breast and cervical cancer are the focus of much ongoing research and clinical activity at the CRTC:

- The New Mexico Tumor Registry, a department of the CRTC, monitors cancer incidence rates statewide and serves as one of the NCI’s resources for data on cancer incidence in American Indian and Hispanic populations.
- The CRTC conducts 138 ongoing clinical trials, serves more than 30,000 patient visits per year for the statewide population and provides indigent care at a cost of more than \$3.4 million annually, for which the CRTC receives no reimbursement from any source.
- The CRTC offers the state’s most comprehensive cancer diagnosis and treatment services, including specialty clinics for breast, prostate, skin, orthopedic, gynecologic, neurologic, pulmonary and thoracic cancers.
- The CRTC offers familial cancer genetics information.

For more information on the clinical trials, call (505) 272-3839 or 1-800-432-6806.

## The New Mexico Breast & Cervical Cancer Detection and Control Program (B&CC Program)

-  Tel: (505) 841-5860
-  Statewide toll-free number: 1-877-852-2585 (Spanish & English)
-  Fax: (505) 841-5865
-  Addr: 625 Silver SW, Suite 203, Albuquerque, NM 87102

The New Mexico Department of Health Breast and Cervical Cancer Detection and Control Program endeavors to increase screening, early detection and follow-up care among low income, high risk women, particularly minority and older women. The B&CC Program provides evaluation, follow-up, and promotes increased public knowledge and awareness about breast and cervical cancer. Professional education is also an important component of the B&CC Program.

All counties in New Mexico and the Indian Health Service (IHS) provide free breast cancer screening for income and age eligible women. The B&CC Program has provided over 71,000 mammograms as of December, 1999.


For information about eligibility requirements and referral to a local B&CC Program provider, call toll-free 1-877-852-2585. Information about the B&CC Program is available on the Internet at the New Mexico Department of Health website: [www.health.state.nm.us](http://www.health.state.nm.us) or [www.cancernewmexico.org](http://www.cancernewmexico.org).


## National Alliance of Breast Cancer Organizations (NABCO)


-  Tel: (212) 719-0154
-  E-mail: [NABCOinfo@aol.com](mailto:NABCOinfo@aol.com)
-  Website: [www.nabco.org/](http://www.nabco.org/)
-  Addr: 9 E 37th Street, 10th floor, New York, NY 10016


NABCO is a non-profit central resource for information about breast cancer and is a network of more than 370 organizations which provide women with cancer detection, treatment, and care. NABCO can provide information about local support groups.

## National Lymphedema Network (NLN)

 Tel: (510) 208-3200

 Fax: (510) 208-3110


 E-mail: [nln@lymphnet.org](mailto:nln@lymphnet.org)


 Addr: 1611 Telegraph Ave, Suite 1111, Oakland, CA 94612-2138


The NLN is a non-profit resource center established to provide information and guidance to women and their health care providers about primary and secondary lymphedema and other venous disorders. Services the NLN provides include:

- A toll-free hotline (1-800-541-3259) to give emotional support, education, and referrals to health care professionals, treatment centers, support groups, and exercise programs throughout the United States
- A quarterly newsletter: [www.lymphnet.org](http://www.lymphnet.org)

## The National Coalition for Cancer Survivorship (NCCS)

 Tel: 1-888-650-9127

 Fax: (301) 565-9670

 Addr: 1010 Wayne Ave., Suite 770, Silver Spring, MD  
20910-5600

The NCCS is a network of cancer survivors and their organizations across the United States. The NCCS helps cancer survivors and their families start local support groups or contact existing ones, sponsors a clearinghouse of national resources for support and information on life after a cancer diagnosis, provides advice to reduce cancer-based discrimination, and serves as a unified voice of cancer survivors. To find a local NCCS group, contact the national office at the above number.

# Additional National and State Resources

Health care providers may want more general information for themselves, their patients, and their patients' families. The services listed below will help them obtain what they need. Additional information is available from local libraries, bookstores, and support groups.

The National Cancer Institute (NCI), one of the National Institutes of Health, supports the following services: the Cancer Information Service, CancerFax, Physician Data Query, and CancerNet. These and other resources are highlighted below.

## Cancer Information Service (CIS)


 Tel: 1-800-4-CANCER (1-800-422-6237)

The CIS provides a nationwide telephone service for cancer patients and their families, the public, and health care professionals. CIS can provide specific information in understandable language about particular types of cancer as well as information on state-of-the-art care and the availability of clinical trials.

Callers' questions are answered by Certified Information Specialists trained by the NCI. Bilingual information specialists are available. CIS offices can be reached anywhere in the country by dialing 1-800-422-6237, Monday through Friday, 9 a.m. to 4:30 p.m. local time. Persons with TTY equipment can call 1-800-332-8615 for cancer information.

The CIS also coordinates state and regional outreach and cancer education efforts of the NCI.

## CancerFax

 Tel: (301) 402-5874

The NCI's CancerFax service provides up-to-date cancer treatment information including treatment and supportive care information summaries from the Physician Data Query database (see below). CancerFax is available in English and Spanish and operates 24 hours a day, seven days a week. Call the phone number above to have information sent directly to a fax machine.

## Physician Data Query (PDQ)

The PDQ is a computer database which contains cancer information statements, listings of research studies (clinical trials), and directories of physicians and organizations involved in cancer care. PDQ was developed by the NCI and contains information statements on state-of-the-art cancer treatment, screening, and prevention, supportive care for cancer patients, and investigational and newly approved chemotherapy.

There are a number of ways people can obtain information from PDQ. Cancer patients, their families, and the public can call the Cancer Information Service (CIS) at 1-800-422-6237. CIS Information Specialists use PDQ information to answer callers' questions.

Physicians and other health professionals can obtain customized PDQ information through the PDQ Search Service (Tel: 1-800-345-3300, Fax: 1-800-380-1575). The e-mail address is: [pdqsearch@icic.nci.nih.gov](mailto:pdqsearch@icic.nci.nih.gov). In addition, the Health Sciences Library at the University of New Mexico has PDQ access. Selected PDQ materials are also available on the NCI's World Wide Web site: [www.cancer.gov](http://www.cancer.gov).

### CancerNet

 E-mail: [Cancernet@icic.nci.nih.gov](mailto:Cancernet@icic.nci.nih.gov)

CancerNet is a way to obtain PDQ information summaries and other NCI information via Internet and selected electronic information services. To use CancerNet, send an e-mail message to the address above. Enter the word "HELP" as the text of the message to receive materials in English; enter "SPANISH" to receive the information in Spanish.

# Professional Education

The following organizations are available to health care providers in search of professional education materials, practice guidelines and recommendations, and educational resources for patients with special needs.

<b>Organization</b>	<b>Phone Number</b>
American Academy of Family Physicians .....	(913) 906-6000
American Association of Retired Persons .....	(703) 550-9703
American Cancer Society .....	(800) ACS-2345
American College of Obstetricians and Gynecologists .....	(202) 638-5577
American College of Physicians/American Society of Internal Medicine .....	(215) 351-2400
American College of Radiology .....	(703) 648-8900
American College of Surgeons .....	(312) 202-5000
American Medical Association .....	(312) 464-5000
American Medical Women's Association .....	(703) 838-0500
American Nurses Association .....	(202) 554-4444
American Society of Radiologic Technologists .....	(800) 444-2778
Cancer Information Service .....	(800) 422-6237
The National Alliance for Hispanic Health .....	(202) 387-5000
Food and Drug Administration .....	(800) 838-7715
Indian Health Service Cancer Prevention and Control Program .....	(505) 248-4132
National Black Women's Health Project .....	(202) 543-9311
National Health Information Center .....	(800) 336-4797
Native American Women's Health Education Resource Center .....	(605) 487-7072
Office of Minority Health Resource Center .....	(800) 444-6472

# Electronic Resource Directory

Resource	Website
American Cancer Society (ACS) .....	<a href="http://www.cancer.org">www.cancer.org</a>
Centers for Disease Control & Prevention .....	<a href="http://www.cdc.gov/nccdphp/dcp/">www.cdc.gov/nccdphp/dcp/</a>
CDC Spanish language website .....	<a href="http://www.cdc.gov/spanish/">www.cdc.gov/spanish/</a>
Cochrane Database of Systemic Review Online .....	<a href="http://www.cochrane.org">www.cochrane.org</a>
Edu-Care, Inc: Breast Health and Breast Cancer Network .....	<a href="http://www.CancerHelp.com/">www.CancerHelp.com/</a>
Jacobs Institute of Women's Health .....	<a href="http://www.jiwh.org">www.jiwh.org</a>
National Alliance of Breast Cancer Organizations (NABCO) .....	<a href="http://www.nabco.org">www.nabco.org</a>
National Cancer Institute (NCI), includes cancer clinical trials .....	<a href="http://www.cancer.gov">www.cancer.gov</a>
National Guidelines Clearinghouse .....	<a href="http://www.guideline.gov">www.guideline.gov</a>
Native Health Research Database .....	<a href="http://www.hsc.unm.edu/nhrd/">www.hsc.unm.edu/nhrd/</a>
New Mexico Department of Health, New Mexico Breast and Cervical Cancer Program .....	<a href="http://www.health.state.nm.us">www.health.state.nm.us</a> <i>or</i> <a href="http://cancernewmexico.org">cancernewmexico.org</a>
Office of Minority Health Resource Center .....	<a href="http://www.omhc.gov">www.omhc.gov</a>
National Women's Health Information Center .....	<a href="http://www.4woman.gov">www.4woman.gov</a>
National Women's Health Resource Center .....	<a href="http://www.healthywomen.org">www.healthywomen.org</a>
US Department of Health and Human Services resources on consumer health .....	<a href="http://www.healthfinder.org">www.healthfinder.org</a>

# Patient Education Pages

The following three pages may be photocopied and distributed as patient education materials.

**The first two pages** describe the breast self-examination procedure and the signs and changes which should prompt a woman to seek a professional examination. It is appropriate for all adult patients. Photocopy these two pages onto a single page, front and back.

**The third page** defines and describes the mammogram procedure and answers some basic questions about mammograms. It may be appropriate for patients who are considering or have been referred for a mammogram.

Space is provided for health care providers to include contact information for themselves and their practices.

## What is the breast self-exam?

It is a simple exam which any woman can do herself to detect changes in her breasts which might indicate breast cancer. By doing the exam regularly, a woman can notice changes earlier. The sooner breast cancer is found, the easier it is to treat.

## Who needs to do breast self-exams?

All women age 20 or older should do breast self-exams each month. Women age 40 or older should also have a clinical breast exam performed by a health care provider each year. Women under 40 can discuss how often they need a clinical breast exam with their health care provider.

## How do I do the breast self-exam?

The exam is simple and takes only a few minutes each month. **The back of this sheet contains step-by-step instructions.** Your health care provider can also demonstrate it for you.

## What if I find something?

If you notice any **changes** in your breast which do not go away, such as a **lump, swelling, dimpling, nipple tenderness, nipple discharge, or lasting pain**, you should contact a health care provider immediately. You can call the Cancer Information Service to find someone who can help. Their number is:

1-800-4-CANCER (800-422-6237).

## Did You Know?

All women age 20 or older should perform a breast self-exam each month.



1 in 8 women who lives to age 85 will develop breast cancer in her lifetime.



By performing regular breast self-exams, you will be better able to notice any changes which may point to breast cancer.



# The Breast Self-Exam Step-by-Step

Check your breasts at the same time of each month.

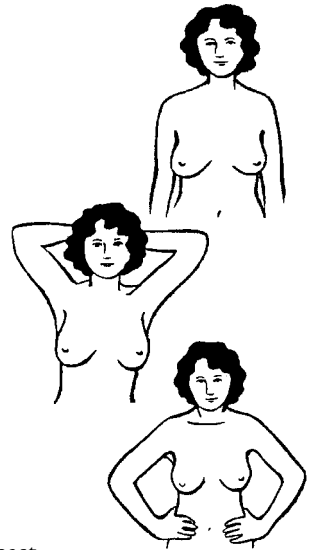
The best time is 2–3 days after your period ends. If you are not having periods, pick a day in the month, like the first day of the month, to examine your breasts.

## 1 Looking in the mirror for changes

Take off your shirt and bra and stand in front of a mirror with your arms at your side. Look for wetness from your nipples and for skin on your breasts which looks wrinkled or flaky.

Hold your hands behind your head and press your hands forward. Look for any change in the shape of your breasts.

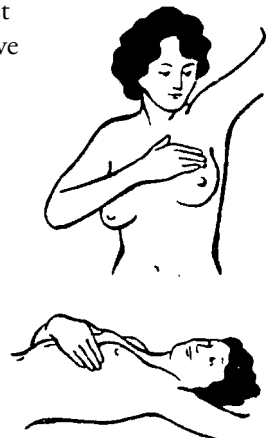
Press your hands firmly on your hips. Bend a little forward and pull your shoulders and elbows forward. Look for any changes in the shape of your breasts.



## 2 Feeling for lumps

Raise your left arm. Use three or four fingers to feel your breast firmly. Begin at the outer part of the breast. Press on your breast with the flat part of your fingers and move in small circles. Move around the entire breast, working toward the nipple. Be sure to feel the whole breast. Feel the area between the breast and underarm and also under your arm. Raise your right arm and do the same with the right breast and underarm.

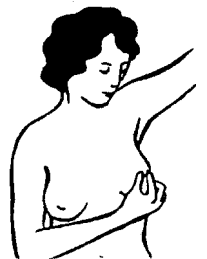
Lie down flat on your back with your left arm over your head. Put a pillow or folded towel under your left shoulder. Feel your breast and underarm the same way you did when you were standing. Do the same with your right breast and underarm.



## 3 Checking for nipple discharge

Gently squeeze each nipple to see if anything comes out.

**If you notice a lump, swelling, dimpling, nipple tenderness, nipple discharge, or lasting pain, contact a health care provider immediately.**



## What is a mammogram?

It is an x-ray picture of the breast. Mammograms are safe and easy to perform. A woman stands in front of a special machine which takes several x-ray pictures of the breast. The x-rays are then examined by a specialist who looks for early signs of breast cancer.

## Who needs a mammogram?

All women age 50 or older should have a mammogram performed every 1–2 years. Some women between the age of 40 and 49 may also need to have a mammogram. If you are unsure, discuss with your health care provider how often you should have a mammogram.

## How do I get a mammogram?

You can contact your health care provider to schedule a mammogram. Or you can call the Cancer Information Service for help. Their number is 1-800-4-CANCER (800-422-6237).

On the day of your mammogram:

- ✓ Wear a blouse and skirt or slacks instead of a dress or jumper. You will need to undress to the waist.
- ✓ Don't use deodorant, perfume, powders, or ointment on your breasts or underarms. They could cloud the x-ray.

## Did You Know?

1 in 8 women who lives to age 85 will develop breast cancer in her lifetime.



All women 50 years old or older should get a mammogram every 1–2 years.



A mammogram can find a lump up to 2 years before you can feel it. If it is found early, breast cancer is easier to cure.

