

7 HELPFUL INFORMATION

This brochure is one starting point to help you understand your diagnosis and treatment options. To get up-to-the-minute information on the changes taking place in breast cancer treatment and research and for insights into treatments or studies that are now in progress, call the toll-free telephone number:

1-800-4-CANCER.

This number puts you in contact with the Cancer Information Service, operated by the National Cancer Institute. Trained cancer specialists, who speak English and Spanish, can:

- Mail you free literature on a range of topics including surgery, radiation therapy, chemotherapy, eating hints, and pain control.
- Provide names and addresses of doctors or cancer centers that provide second opinions .
- Provide fact sheets on current issues and controversies that show up in the daily news media.
- Give you access to Physician Data Query (PDQ), a computer information center that provides the most up-to-date information on treatments for most types of cancer.
- Give you information on **clinical trials**.

Clinical Trials

People who join clinical trials have a chance to benefit from new research and to make a contribution to medical science. Each study is designed to answer a scientific question on how to prevent, detect, or treat cancer. Studies place a portion of the patients in a “control group.” These study participants receive the standard treatment so that their results can be compared with those of participants who receive the new treatment. During the trial, you may not know in which group you have been placed. Clinical trials take time. Until a trial is over, the true value of the new treatment will not be known. There may also be unknown side effects. If you are thinking about joining a clinical trial, you will receive written material that will help you decide whether to join. You can quit the trial at any time.

WORDS TO KNOW

Anesthesia: drugs given before and during surgery so you won't feel the surgery. You may be awake or asleep.

Axillary node dissection: removal of some of the lymph nodes in the armpit.

Benign: a growth that is not cancer.

Biopsy: removal of a sample of tissue to see if cancer is present.

Chemotherapy: treatment with drugs to kill or slow the growth of cancer.

Clinical trial: controlled scientific studies set up to answer questions about how to prevent, detect, or treat cancer.

Core biopsy: a biopsy that uses a small cutting needle to remove a sample of tissue from a breast lump.

Estrogen or progesterone receptor test: laboratory tests done to determine if cancer is sensitive to estrogen and progesterone hormones in the body.

Excisional biopsy: surgical removal of the whole lump and some surrounding tissue.

Fine needle aspiration: a biopsy that uses a fine needle to remove fluid from a cyst or a cluster of cells from a solid lump.

Hormones: substances produced by various glands in the body that affect the function of body organs and tissues.

Implant: a silicone or saline-filled sac inserted under the chest muscle to restore breast shape.

Incisional biopsy: surgical removal of a portion of an abnormal area of tissue or lump.

Intravenous (IV): injection into the vein.

Invasive cancer: cancer that has spread to nearby tissue, lymph nodes in the armpit, or other parts of the body.

In situ "cancer": very early or noninvasive growths that are confined to the ducts or lobules in the breast.

Localization biopsy: using mammography or ultrasound to locate an area of concern that cannot be felt by hand.

Lumpectomy: surgical removal of breast cancer and a small amount of normal tissue surrounding the cancer.

Lymph nodes: part of the lymph system that removes wastes from body tissues and filters the fluids that help the body fight infection. Lymph nodes in the armpit are usually removed to determine the stage of breast cancer.

Lymphedema: swelling in the arm caused by fluid that can build up when the lymph nodes are removed during surgery or damaged by radiation.

Malignant: cancer.

Mammogram: an x ray of the breast.

Mastectomy: removing the breast by surgery.

Metastasis: spread of cancer from one part of the body to another.

Needle localization biopsy: use of mammography or ultrasound to guide a needle to a suspicious area that cannot be felt but shows up on a mammogram.

Prosthesis: an external breast form that may be worn in a bra after a mastectomy. Also, the technical name of a breast form that is placed under the skin in breast reconstruction.

Radiation: energy carried by waves or by streams of particles. Various forms of radiation can be used in low doses to diagnose cancer and in high doses to treat breast cancer.

Recurrence: reappearance of cancer at the same site (local recurrence), near the original site (regional recurrence), or in other areas of the body (distant recurrence).

Risk factors: conditions that increase a person's chance of getting cancer. Risk factors do not cause cancer; rather, they are indicators, linked with an increase in risk.

Silicone: a synthetic liquid gel that is used as an outer coating on implants and to make up the inside filling of some breast implants.

Staging: classifying breast cancer according to its size and spread.

Stereotactic needle biopsy: a technique that uses double-view mammography to pinpoint a specific target area; most often used with needle biopsy when a lump cannot be felt.

Tamoxifen: a hormone blocker used to treat breast cancer.

Tumor: an abnormal growth of tissue. Tumors may be either benign (not cancer) or malignant (cancer).

Two-step procedure: biopsy and treatment done in two stages, usually a week or more apart.

Ultrasound-guided biopsy: fine needle aspiration or core biopsy with guidance from ultrasound.

X rays: a high-energy form of radiation used for detecting or treating cancer.

WHERE TO GET HELP

Your local hospital, breast cancer organization, or cancer center will usually have **patient education materials** that they will send you if you call them for information.

Your doctor or the organizations listed below can help you get lists of local organizations or support groups. Also ask if your area has a local **resource guide** that lists providers, support groups, wig and prosthesis shops, etc.

Your local library or bookstore has numerous **books and publications** about breast cancer that have been written by women survivors and by medical professionals. **Breast cancer organizations** can also give you up-to-date lists of suggested books for further reading.

Breast Cancer Organizations and Services

These statewide or national organizations can provide you with information, materials, and services related to breast cancer. They also can refer you to breast cancer organizations and support groups in your area if available.

American Cancer Society, Information Line, 1-800-ACS-2345. Local chapters are listed in the white pages of your telephone book. Provides free information and emotional support from trained volunteers anytime before, during, or after treatment. Programs include Reach to Recovery, Partners, Early Support, and Look Good Feel Better. Supplies free brochures on treatment, reconstruction, sexuality, what to do about job discrimination, and other topics.

Breast Cancer Consultation Service, 450 Stanyan St., San Francisco, CA 94117, (415) 750-5848, Fax (415) 750-8123. Self-referral service specializing in second opinions and diagnosis of **in situ “cancers.”** Cost depends on extent of review. Fees may be covered by insurance. Sliding scale exists.

California Breast Cancer Organizations (CABCO), 555 W. Beech St. #452, San Diego, CA 92101, (619) 239-9283. A statewide coalition of breast cancer advocacy groups; members support legislation on breast cancer issues, increase awareness of breast cancer, and provide support and education. Contact group for local organizations.

Mary-Helen Mautner Project for Lesbians with Cancer, 1707 L St., NW, Ste. 1060, Washington, DC 20036, (202) 332-5536, Fax (202) 265-6854.

National Alliance of Breast Cancer Organizations (NABCO), 9 E. 37th St., 10th Floor, New York, NY 10016, (212) 889-0606, Fax (212) 689-1213. National coalition of breast cancer organizations; supplies fact sheets, articles, and a newsletter on topics of breast cancer.

National Breast Cancer Coalition, 1707 L Street NW, Suite 1060, Washington, DC 20036, (202) 296-7477. A national advocacy group that lobbies for increased research funding, access to medical services, and education.

National Cancer Institute's Cancer Information Hotline, 1-800-4-CANCER.

Offers free state-of-the-art information in English or Spanish on treatment, clinical trials, eating hints, advanced cancer, and services in your area.

National Coalition for Cancer Survivorship, 1010 Wayne Avenue, 5th Floor, Silver Spring, MD 20910, (301) 650-8868. Promotes the awareness of cancer survivorship by peer support and information.

National Women's Health Network, 514 10th St. NW, Suite 400, Washington, DC 20005, (202) 347-1140. Provides newsletters and position papers on women's health topics.

Susan G. Komen Breast Cancer Foundation, Komen Help Line, 1-800-462-9273. Dedicated to advancing research, education, screening, and treatment of breast cancer.

Women's Information Network (WIN) Against Breast Cancer, 19325 E. Navilla Place, Covina, CA 91723-3244, (626) 332-2255, Fax (626) 332-2585, email: winabc@flash.net. Provides educational information on breast cancer treatment, support, and resources to physicians and survivors.

YWCA of the USA/Encore Plus, 624 9th Street NW, 3rd floor, Washington, D.C., 20001, (202) 628-3636. Contact the national headquarters for the location of a group near you. Provides support and rehabilitative exercises for women with breast cancer.

Y-ME National Breast Cancer Hotline, 1-800-221-2141. Cancer survivor volunteers share personal experiences on everything from treatment information to emotional recovery. Local branches also provide wig and prosthesis bank. Contact group for local chapters.

Complementary Treatment Information

National Cancer Institute's Office of Alternative Medicine, 6120 Executive Blvd., Suite 450, Bethesda, MD 20892, (301) 402-2466.

National Council Against Health Fraud, Consumer Health Information Research Institute, 3521 Broadway, Kansas City, MO 64111, 1-800-821-6671.

Breast Reconstruction

Breast Implant Hotline of the Food and Drug Administration, 1-800-532-4400.

American Society of Plastic and Reconstructive Surgeons, 444 E. Algonquin Rd., Arlington Heights, IL 60005, 1-800-635-0635. A list of 5 certified plastic and reconstructive surgeons in your area will be mailed upon request.

California Society of Plastic and Reconstructive Surgeons: Maintains a consumer information and referral service at 1-800-722-2777.

Lymphedema

National Lymphedema Network, 2211 Post St., Ste. 404, San Francisco, CA 94115, 1-800-541-3259. Provides complete information on prevention and treatment of lymphedema.