

The mission of WomenStories is to produce videos about breast cancer and distribute them nationally and internationally, so information and support about the disease will be readily available to all newly diagnosed women.



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Resource Guide

RESOURCE GUIDE

WomenStories videos, created and produced by breast cancer survivors and medical professionals, are intended for women newly diagnosed with breast cancer. Each video is a collage of survivors' stories describing their various responses to breast cancer: their diagnoses, decisions they made for treatments, their families, and their intimate relationships. Every woman on the videos offers a different perspective about her experience. As you meet the women on these tapes, we hope you will recognize yourself in parts of their stories, and that you will feel less fearful and alone as you travel on your own road to recovery.

VIDEOS IN THE WOMENSTORIES SERIES;

Initial Discovery and Diagnosis of Breast Cancer
Family Support
Surgical Choices
Chemotherapy
Intimacy
Recurrence/Metastasis
Young Women and Breast Cancer
Hormone Treatment
Radiation
Life After Breast Cancer

ANNOTATED BIBLIOGRAPHY

We have made a selection of books we believe will be helpful, but we encourage you to go to your bookstore or library and investigate others. Please note, books may go out of print.

Breast Cancer, the Complete Guide
by Yashar Hirshaut, M.D., and Peter I. Pressman, M.D.
Winner of the Rose Kushner Award of the American Medical Writers Association, this book deals with emotional and treatment issues for breast-cancer patients.

Breast Cancer Husband: How to Help your Wife (and Yourself) Through Diagnosis, Treatment and Beyond
by Mark Silver

A practical, and often humorous guide to how a man can help when his partner has been diagnosed with breast cancer.

The Breast Cancer Survival Manual
by John Link, M.D.

A step-by-step guide for the woman newly diagnosed with breast cancer. This "crisis manual" is designed to help women understand their life-changing diagnosis and to develop a course of action.

Cancer Patients' Workbook
by Joanie Willis.

This book features a host of organizational aids: charts for tracking physician and hospital visits, places to record medical history, insurance information, questions to ask doctors and note their answers.

Confíe en el Mañana: Guía para el tratamiento del cáncer de seno

By Vladimir Lange, M.D.

A comprehensive guide to breast cancer treatment, in Spanish, that includes testimonials from Hispanic breast cancer survivors and their partners.

Coping With Lymphedema

by Joan Swirsky and Diane Sackett Nannery.

Provides comprehensive, current information on lymphedema, a possible side effect of cancer surgery, radiation treatments or trauma that manifests itself in swelling in the arm of breast cancer patients.

Dr. Susan Love's Breast Book

by Susan M. Love, M.D.

The breast cancer "Bible" is a standard reference for women diagnosed with breast cancer. It contains detailed explanations and diagrams of all aspects of this disease, and is best sampled for specific information, not read from cover to cover.

Entre mujeres: su recuperacion fisica y emocional despues de la mastectomia

by Rosalind Dolores Benedet, N.P., MSN

In Spanish, this book advises the newly diagnosed patient from the time before her surgery, through her hospital stay, follow up treatments and to her return to normal activities. Illustrated with line drawings, it also gives information about: diet, brassieres, prostheses, exercise, lymphedema, sexuality, and emotions.

Fighting for Our Future: How Young Women Find Strength, Hope and Courage While Taking Control of Breast Cancer

by Beth Murphy, Ann Curry, George Sledge

This book presents information about breast cancer as it relates to the unique medical and emotional issues and challenges that young women face. It integrates scientific facts about the disease with histories obtained from personal interviews with survivors.

Living Beyond Breast Cancer: A Survivor's Guide For When Treatment Ends and The Rest of Your Life Begins

by Maris C. Weiss M.D. and Ellen Weiss

A comprehensive and practical book that helps the breast cancer patient through initial treatment and gives encouragement for the future.

Show • Me

Fran Hulzapple, Editor and Project Coordinator.

www.pennstatewomenshealth.com/showme.

A Photo collection of breast cancer survivors' Lumpectomies, Mastectomies, Breast Reconstruction and thoughts on Body Image. This 108 page book presents women who have had breast surgery. On one side of the open page is the patient's story in her own words (with an occasional section by the woman's partner) and opposite are several color photographs of her breast(s) after surgery.

When a Parent has Cancer

by Wendy S. Harpham, M.D.

A guide for parents on how to help children understand and come to terms with a parent's cancer diagnosis. Included with the book is a children's book Becky and the Worry Cup, the story of a young girl whose mother had cancer.

A Woman's Decision: Breast Care, Treatment and Reconstruction

by Karen Berger and John Bostwick III, M.D.

Details the newest treatments, reconstructive procedures and rehabilitation for the patient and her family. Includes interviews, line drawings and photographs.

www.submarino.com.mx

Book Store in Spanish similar to Amazon.com

CANCER ORGANIZATIONS

You will find additional organizations and websites devoted to particular aspects and treatments of breast cancer. We suggest you use the Internet to look up information for your specific needs.

American Cancer Society (ACS)

800-227-2345

<http://www.cancer.org>

ACS is a nationwide organization that provides services and support to cancer patients and their families. One of these is Reach to Recovery that assists women during hospitalization and immediately following by offering personal visits from survivors. Access to services and programs are available in English and Spanish.

CancerCare, Inc.

800-813-4673

<http://www.cancer.org>

Services include support groups, educational programs, workshops and teleconferences. Oncology social workers are available in person, over the telephone, and through the web site. Access to services and programs are available in English and Spanish.

Cancer Information Service (CIS)

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

For hearing impaired: 800-332-8615

<http://cis.nci.nih.gov>

Access to comprehensive, accurate information from the National Cancer Institute on a range of topics, including the most recent advances in cancer treatment. Staff provides materials at no cost, refers people to clinical trials, treatment centers, mammography facilities and other cancer organizations. Access to services and programs are available in English and Spanish.

Susan G. Komen Breast Cancer Foundation

800-462-9273

<http://www.komen.org>

Dedicated to funding breast cancer research and education. The site celebrates survivors, has a calendar of breast cancer events, and hosts "talk back" a question and answer forum. It operates a 'helpline' for breast cancer patients and their families, in *Spanish and English* staffed by volunteers and staff.

Y-ME National Breast Cancer Organization

800-221-2141 English Hotline

800-986-9505 Spanish Hotline

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

Provides information, educational programs, support groups, and 24 hour telephone counseling for breast-cancer patients and their families. Y-ME has 27 affiliates.

CANADIAN CANCER ORGANIZATIONS

Abreast in the West

Fax: 604-879-9267

<http://www.abreastinthewest.ca>

Abreast in the West is a quarterly newsletter produced by the Alliance for Breast Cancer Information & Support, British Columbia and Yukon (ABCIS) to provide current and accurate information. Abreast in the West works collectively with partners to ensure resources and services are accessible to those living with breast cancer, their families and supporters.

Canadian Cancer Society

1-888-939-3333

<http://www.cancer.ca>

The Canadian Cancer society is a national, community-based organization whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer. Access to services and programs is available in English and French.

Hope & Cope

1-514-340-8255

<http://www.hopecope.jgh.mcgill.ca>

Hope & Cope provides resources, advocacy and support groups to patients and their families. Their web site contains an extensive list of resources available from books and videos, as well as for companionship and advocacy. Access to services and programs is available in English and French.

GLOSSARY

Adjuvant Therapy: Additional treatment given at the same time, or after the primary therapy.

Aromatase Inhibitors: Many breast tumors are “estrogen hungry,” meaning that the hormone estrogen makes them grow. Aromatase inhibitors (AIs) help to prevent the growth of these tumors by lowering the amount of estrogen in the body.

Benign: Not malignant.

Biopsy: Removal of tissue to make a diagnosis. May remove cells by needle aspiration, part of lesion by incision, or all of lesion by excisional biopsy.

Brachytherapy: Radioactive sources (seeds or wires) are placed in or near the tumor itself, giving a high radiation dose to the tumor while reducing the radiation exposure to the surrounding healthy tissues. Brachytherapy is localized and precise.

BRCA1 & BRCA2: Human genes which, when present in a mutated form, increase a woman’s risk of developing breast and ovarian cancer.

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

Carcinoma: Cancer of glandular tissue within an organ.

Chemotherapy: Chemical treatment of cancer.

Clear Margins: No evidence of cancer in the tissue surrounding the tumor.

Clinical Trials: Clinical trials, also called cancer treatment or research studies, test new treatments in people with cancer, treatments such as new drugs, new approaches to surgery or radiation therapy, or new combinations of treatments. Participation in clinical trials is voluntary.

DCIS (Ductal Carcinoma in Situ): Cancer cells lining the ducts but not invading the tissues of the breast.

Edema: Swelling due to fluid collection within the tissues, usually of the hand and/or arm in breast cancer cases.

Estrogen Receptor: Special markers on the tumor cells identifying the tumor as “estrogen hungry.”

Genome Testing: Testing available for women who have stage I or stage II, estrogen receptor-positive, and node-negative breast cancer. The goal of such testing, done on tumor tissue, is to try and determine both prognosis (likelihood of recurrence), and magnitude of benefit from receiving chemotherapy and/or hormone therapy.

Hormone Therapy: Treatment of cancer with drugs that block the tumor’s ability to use estrogen.

Lesion: A tumor, mass or other abnormality. An area of tissue that is diseased.

Lumpectomy: Removal of a portion of the breast, including the cancer, but sparing the majority of breast tissue. Also called breast conservation.

Lymph Node Dissection: Removal of tissue that drains the breast in the axilla or armpit where nodes are contained.

Malignant: Cancerous.

Mammogram: An X-ray photograph of the breast that can often detect tumors too small to be felt.

Mastectomy: Surgical removal of all breast tissue and axillary lymph nodes.

Metastasis: Spread of tumor cells to other tissues or organs.

Microcalcifications: Very tiny calcium deposits only visible by X-ray techniques such as mammography. Certain patterns of microcalcifications are sometimes a sign of breast cancer.

Oncologist: A specialist in cancer care. A Surgical Oncologist treats the cancer surgically and coordinates the care of the cancer with the Medical Oncologist and Radiation Oncologist. A Medical Oncologist treats the cancer with either chemotherapy or hormonal therapy. A Radiation Oncologist treats the cancer using radiation.

Pathology: The study of tissue under a microscope to determine if abnormal disease is present.

P.E.T.: Positron Emission Tomography is a non-invasive diagnostic technique. A glucose formula with a tracer is injected into the patient. After the injection, the patient waits 45 minutes to an hour and then receives a full body scan. Areas using more glucose show up as “hot spots” on the scan and may be areas where cancer is detected.

Radiation Therapy: Treatment of cancer using radiation.

Recurrence: Cancer that has returned at the same site as the original tumor.

Second Opinion: Consultation with a different physician after the first diagnosis and recommendation for treatment. This consultation may help with decisions by confirming original diagnosis or suggesting alternatives.

Sentinel Lymph Node Biopsy: A procedure that involves removing only the sentinel node, the first lymph node in the lymphatic chaining, to determine whether breast cancer has spread to the lymph nodes. Sentinel node biopsy can significantly reduce lymphedema (arm swelling), the most common side effect of axillary node dissection.

Stages of Cancer: Determined by size and extent of the primary tumor.

Stage I: Cancer is early and localized to the breast. A primary tumor is less than 2 Centimeters (3/4 inch) and lymph nodes are not involved.

Stage II: The tumor is 2 to 5 centimeters (3/4 inch to 2 inches) in the breast, or there is evidence of lymph node involvement.

Stage III: Cancer is locally advanced. The tumor is over 5 centimeters, and /or it has spread to the lymph nodes or it is inflammatory, but there is no evidence of distant metastasis.

Stage IV: Metastatic disease.

Ultrasound: The use of high frequency sound waves to locate a tumor inside the body. Helps determine if a breast lump is solid tissue or filled with fluids.