

Making treatment choices

Additional resources that give an overview of breast cancer biology and treatment are located under Breast cancer information, page 14. Handbooks and workbooks that can help you organize your doctors' appointments, medical records and other aspects of the treatment process are listed in the Handbook and workbook section on page 17.

Guide to Breast Cancer

(American Society of Clinical Oncology, 2006)

www.plwc.org or (888) 651-3038

Oncologist-approved cancer information from ASCO. This booklet covers the basics of breast cancer detection, diagnosis, staging and treatment options.

Guide to Quality Breast Cancer Care

(National Breast Cancer Coalition Fund, 2006)

www.stopbreastcancer.org or (866) 624-5307

The National Breast Cancer Coalition Fund (NBCCF) created this guide to help breast cancer patients based on the best advice about getting quality breast cancer care with a focus on making quality choices about cancer care. The guide includes sections on access, information, choice, respect, accountability and improvement.

NCCN Clinical Practice Guidelines in Oncology: Breast Cancer

(National Comprehensive Cancer Network, 2006)

www.nccn.org or (888) 909-NCCN

These guidelines include recommendations for the standard of care in treatment and follow-up and are available in booklet form or on the NCCN website.

You Are Not Alone

Directed and produced by Beth Murphy (Principle Pictures and Young Survival Coalition, 2003)

www.youngsurvival.org or (877) YSC-1011

This educational DVD is an intimate conversation with six young women diagnosed with breast cancer at a young age and is designed to help other young women facing a breast cancer diagnosis.

Working with your healthcare team

Talking with Your Doctor

(American Cancer Society, 2004)

www.cancer.org or (800) ACS-2345

This booklet aims to help the new patient to build a good working relationship with her doctors and discusses the importance of a good doctor-patient relationship.

Teamwork: The Cancer Patient's Guide To Talking With Your Doctor

Edited by Elizabeth J. Clark, PhD (National Coalition for Cancer Survivorship, 2006)

www.canceradvocacy.org or (877) NCCS-YES

Developed by cancer survivors and health care professionals, this comprehensive booklet addresses the need for good communication and provides a list of sound, practical questions that patients can use when talking with their doctor.

Diagnosis and treatment during pregnancy

Pregnant With Cancer
PO Box 1243
Buffalo, NY 14220
(800) 743-4471

www.pregnantwithcancer.org

National organization that offers support and hope to women who are diagnosed with cancer while pregnant through support groups, an online newsletter and other resources.

Inflammatory breast cancer

YSC Fact sheet: Frequently asked questions about inflammatory breast cancer

Breast cancer is not just one disease and not all breast cancer presents the same way. One type, inflammatory breast cancer or IBC, typically presents without a lump. We recommend that women become familiar with their breasts, learn what is normal for them and be aware of any changes that differ from the norm.

What is Inflammatory Breast Cancer (IBC)?

IBC is the most aggressive form of breast cancer and has a faster doubling time than other breast cancers. (Doubling time is the time it takes for cancer cells to divide and grow.) IBC usually grows in nests or sheets in the breast rather than a solid tumor.

Don't you have to have a lump in your breast to have breast cancer?

No—since IBC grows in the dermal lymphatic system there is often no breast lump. The cancer cells clog the lymph vessels just below the skin giving the classic symptoms of warmth and color changes to the skin.

What are the symptoms of IBC?

- Rapid, unusual increase in breast size
- Redness, rash, blotchiness or other skin color changes of the breast
- Persistent itching of breast or nipple
- Lump or thickening of breast tissue
- Stabbing pain and/or soreness of breast
- Feverish breast
- Swelling of lymph nodes under the arm or above the collar bone
- Dimpling or ridging of breast
- Flattening or retracting of nipple
- Nipple discharge or change in pigmented area around nipple

Although the above symptoms may indicate a benign breast disorder, any change to your breast(s) should be reported to your healthcare professional immediately. In addition, these symptoms may appear quickly and out-of-the blue.

How is IBC detected?

Unfortunately, mammograms and ultrasounds often miss IBC unless there is a defined tumor. If you notice any of the symptoms above, go to your doctor so he or she can begin diagnostic procedures.

How is IBC diagnosed?

A skin punch biopsy, a needle core biopsy, MRI, and/or PET scan may assist in diagnosis. Any biopsy must include the skin and tissue in the layers below the skin surface. The biopsy report may say “dermal lymphatic involvement,” rather than inflammatory breast cancer.

What if the doctor says I have mastitis and puts me on an antibiotic?

Since IBC symptoms are similar to those of mastitis, a benign breast infection, it is often misdiagnosed as such. After 7–10 days on antibiotics without significant improvement, insist on a biopsy.

My doctor says I'm too young to have IBC. Is that possible?

IBC can occur at any age, although the incidence of IBC is higher in younger women. Though rare, even teenagers have been diagnosed with IBC.

My doctor says that my rash is from detergent.

While skin rashes can be caused by allergic reactions or sensitivities to soaps and detergents, if a rash on your breast doesn't improve after you change detergents or persists, it is time to reassess the original diagnosis.

I've heard that breast cancer doesn't hurt. Is that true?

Breast pain can come from hormonal changes and other non-cancer causes. However, more often than not pain accompanies IBC, so breast pain should not be ignored.

If my doctor says "it's nothing" but I still have symptoms, what should I do?

Since IBC makes up only 1% to 6% of all breast cancers, many doctors are not familiar with the disease and may not recognize it or make the correct diagnosis. If you're not satisfied with the answer get a second opinion from a breast care specialist who is knowledgeable about IBC.

How is IBC treated?

Current treatment starts with chemotherapy which usually continues until there is sufficient clinical response to permit surgery. A modified radical mastectomy (MRM) and axillary lymph node dissection (ALND) are performed. Radiation and possibly more chemotherapy follow. In some cases hormonal treatment is used. Individual treatment can vary depending on specific circumstances. It is important to find a physician familiar with IBC to receive the best possible treatment.

Are there clinical trials for IBC patients?

Clinical trials are often available for patients with IBC. You can find information on these on the website of the Inflammatory Breast Cancer Research Foundation at www.ibcresearch.org. In addition, the YSC website has information on how to find breast cancer clinical trials at www.youngsurvival.org/research/current-studies.

Where can I find more information on IBC?

The Inflammatory Breast Cancer Research Foundation is the only organization dedicated solely to inflammatory breast cancer. Visit their website at www.ibcresearch.org or call the toll-free telephone line at (877) STOP-IBC for more information.

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Inflammatory Breast Cancer Research Foundation

321 High School Road NE #149

Bainbridge Island, WA 98110

(877) STOP-IBC

info@ibcresearch.org

www.ibcresearch.org

Dedicated to the advancement of research on inflammatory breast cancer, leading to finding its causes and increasing the effectiveness of its treatment.

www.ibcsupport.org

Website with information and resources on inflammatory breast cancer including an active listserv with an archive available on the site.

Diagnosis of recurrent or advanced breast cancer

If you have just been diagnosed with recurrent or advanced breast cancer, here are some of the very first things to think about, learn about, and know:

- Attend to your feelings first. Common feelings right after a diagnosis of recurrent breast cancer include rage, fear, disbelief and sadness. Learn about and seek out the many experts and approaches available to help you and your family with emotional and personal issues—and any other needs you may have. Volunteers may be available to help you in or near your community or on the phone. These women living with breast cancer can offer experience, suggestions and empathy. Contact the YSC to be connected to a YSC Point of Contact volunteer at (877) YSC-1011 or www.youngsurvival.org.
- Next, get all personal medical facts and details. As is always true when navigating complicated health care decisions, knowledge is power. Find out as much as you can about this diagnosis, and keep good notes and records from the start. Information to compile includes your precise diagnosis and extent of disease—is this a local, regional or distant recurrence? How was it discovered, and by whom? How many areas or sites are involved, and where are they, near the breast or chest area and elsewhere? What is already known, and what additional follow-up investigation is required? What symptoms have you experienced that relate to the diagnosis, if any? Which tests were used to confirm this? Make certain to obtain copies of all diagnostic test results and reports, including the availability and location of any film or other images, and biopsy or other tissue slides and samples. Revisit your files on your first breast cancer diagnosis. If these are not complete, available and in order, enlist help to contact those who can fill in this important background information.
- Evaluate your local medical and healthcare team and extent of available expert resources. If you have already had breast cancer at least once in the past, it is to some extent a “known quantity.” However, progress in treating breast cancer has evolved rapidly in recent years. Establishing an effective plan to treat recurrent breast cancer and maintain good quality of life both during and after treatment, requires assembling an expert multidisciplinary medical team.
- Begin learning about what’s new, and what’s changed, in breast cancer treatment and research. Start by asking your doctor for an information update. Other key information tools can include your local public library, or a medical library at a nearby university or academic medical institution. The Internet can be an extremely valuable source of up-to-date input, with its immense range of accessible medical information from around the world. Survivors and support groups are often very knowledgeable. Keep communicating, asking and learning.
- As you begin to think about and plan your treatment, consider a range of possibilities. There is no one right way to treat recurrent breast cancer, and there are many thousands of different therapeutic combinations and approaches. The best treatment for you will be one chosen in collaboration with an expert team, will be customized to the features and characteristics of your breast cancer diagnosis, and will take into account your history, general health status, preferences and requirements.
- Aim for a positive outlook, while balancing reality and hope. It has become increasingly possible for a larger number of women to live—and live well—for years with advanced breast cancer. Although so far, advanced breast cancer cannot be cured, that hope comes nearer each year, and may shortly be within reach for some patients. In the meantime, if you have been diagnosed with advanced breast cancer, seek to manage your breast cancer like a chronic disease, and plan to turn to the many new and better treatments for the disease and for its symptoms that are now becoming available, more rapidly than at any other time in the history of breast cancer.

(Revised January 2007, YSC - This information was originally developed and published by the National Alliance of Breast Cancer Organizations (NABCO) and made available by agreement with NABCO prior to its closing in June 2004.)

When Cancer Returns

(National Cancer Institute, 2005)

www.cancer.gov or (800) 4-CANCER

This booklet from the NCI focuses on a recurrence of cancer, the adjustment period, decision-making, coping, feelings, setting goals and family and friends.

Recurrence or Metastasis

(WomenStories, 2004, free online or available on VHS for \$5.00)

www.womenstories.org or (800) 775-5790

When breast cancer patients receive a diagnosis of recurrence or metastasis they often need as much, or more, encouragement and support as they did for their original diagnosis. This video tells the stories of five women and how they and their families coped with recurrent or metastatic breast cancer.

Diagnosis and treatment of advanced/metastatic breast cancer

See more resources for living with advanced breast cancer on page 126.

Advanced Breast Cancer: A Guide to Living with Metastatic Disease, 2nd Edition

by Musa Mayer (Patient Centered Guides, 1998, \$24.95)

This book deals honestly with the realities of metastatic disease, yet offers hope and comfort. All aspects of dealing with the disease are covered, including: coping with the shock of recurrence, seeking information and making treatment decisions, communicating effectively with medical personnel, getting emotional support from other patients, friends, and family and finding new ways to discover meaning in the midst of adversity. The author, a respected patient advocate, also maintains a website of advanced breast cancer resources at www.advancedbc.org.

BCMets.org

The largest online list serv to offer support and information for women living with advanced breast cancer, their families and friends. Although this list is for women of all ages, there are a number of young women who contribute regularly. Archives are searchable on the website.

The Beautiful Eight: Young Women Learning to Live with Advanced Breast Cancer

Directed and produced by Beth Murphy (Principle Pictures and Young Survival Coalition, DVD, 2006)

www.youngsurvival.org or (877) YSC-1011

An intimate discussion among eight young women diagnosed with metastatic breast cancer. Join them on this journey filled with hope, fear, laughter, anxiety and determination to live life to the fullest. *The Beautiful Eight* connect you with a community of young women who openly share their experience of living with advanced breast cancer.

Club Mets Metastatic Breast Cancer Online Support Group

<http://listserv.acor.org/archives/club-mets-bc.html>


One of the largest listserves for women living with advanced breast cancer with searchable archives and an active group of women and men who post to the list.

I Still Buy Green Bananas

(Y-ME National Breast Cancer Organization, 2006)

www.y-me.org/publications/generalpubs/greenbananas.pdf or (800) 221-2141

Comprehensive booklet based on advice from people who are living with advanced breast cancer—how they face each day, make medical decisions, give and get support from their families and friends, and how the experience of living with cancer has changed their lives.

 Networking Sessions for Young Women with Metastatic Breast Cancer
ywabc@youngsurvival.org or (877) YSC-1011 to register

Telephone-based Networking Sessions enable young women living with advanced (metastatic) breast cancer to connect with others in similar situations and gives newly-diagnosed participants the opportunity to gain valuable insight as well as practical information from long-term survivors of this disease. These calls are facilitated by an oncology social worker to ensure appropriate information and supportive exchanges.

The Patient Active Guide to Living with Advanced Breast Cancer
(Wellness Community and Living Beyond Breast Cancer, 2006)
www.lbbc.org or (888) 753-5222

This 58-page booklet contains information on how to improve your quality of life by actively participating in the choices you and your healthcare team make about treatment. Learn about the latest treatments, side effects and side effect management, as well as how to cope with the social and emotional challenges of your diagnosis.

Recurrence or Metastasis
(WomenStories, 2004, free online or available on VHS for \$5.00)
www.womenstories.org or (800) 775-5790

When breast cancer patients receive a diagnosis of recurrence or metastasis they often need as much, or more, encouragement and support as they did for their original diagnosis. This video tells the stories of five women and how they and their families coped with recurrent or metastatic breast cancer.

Clinical trials

Clinical trials are research studies designed to answer questions about new techniques for screening, preventing, diagnosing, treating, or improving life for people living with a disease such as cancer. Currently, fewer than five percent of breast cancer patients receive treatment for their disease as part of a clinical trial. There are many misconceptions about clinical trials, but they offer the best way for researchers to learn how to improve breast cancer treatment for all patients in the future. Advances might occur more rapidly if a greater number of people participated in clinical trials. Many doctors do not routinely offer patients clinical trial information, so any interested breast cancer patient should ask her physician and oncology team about clinical trials that may be appropriate.

American Cancer Society
www.cancer.org/docroot/ETO/ETO_6.asp or (800) 303-5691

Confidential online clinical trial matching service provided by the American Cancer Society. This online resource supplies valuable information about the importance of clinical trials, how they may benefit you and what you should ask your doctor.

ClinicalTrials.gov
www.clinicaltrials.gov or (800) 4-CANCER

A service of the National Institute of Health, this website has a searchable database of current clinical trials, gives details about the trial's purpose, who may participate, locations and contact information.

Coalition of Cancer Cooperative Groups
www.cancertrialshelp.org or (877) 520-4457

Offers clinical trial information and a matching system for trials being conducted at CCG-affiliated centers as well as other useful information about clinical trials.

Cancerbackup

www.cancerbackup.org.uk/trials/search or 0808 800 1234

Online search engine for breast cancer research trials available to patients in the United Kingdom and Europe.



Young Survival Coalition

www.youngsurvival.org/research/current-studies or (877) YSC-1011

The YSC has a website listing with updated links to ongoing research specific to young women.

Breast surgery

Lumpectomy: A Patient Guide

(American Cancer Society, 2005)

www.cancer.org or (800) ACS-2345

This booklet aims to answer questions about lumpectomy, provide practical information about follow-up after surgery and communication with others including healthcare teams and family.

Mastectomy: A Patient Guide

(American Cancer Society, 2005)

www.cancer.org or (800) ACS-2345

This booklet aims to answer questions about mastectomy, provide practical information about follow-up after surgery and communication with others including healthcare teams and family.

Surgical Choices

(WomenStories, 2002, \$5.00 VHS or watch online for free at www.womenstories.org)

This video tells the stories of seven women and the choices they made for surgery. Not all the choices presented in the video are appropriate or available for every person with breast cancer, but the video shows the range of possibilities and the individual processes that women go through to come to their decisions.

Exercises After Breast Surgery

(American Cancer Society, 2001)

www.cancer.org or (800) ACS-2345

Regardless of the type of surgery, it is important to do exercises so that any side effects of surgery can be lessened. This booklet covers a few key exercises and when to start them to regain range of motion.

Chemotherapy

Chemocare.com

A project of the Scott Hamilton CARES initiative, this website with content from the Cleveland Clinic Cancer Center, is a source for chemotherapy, side effects and chemotherapy drug information.

Chemo Chicks

4320 Kenyon Avenue

Los Angeles, CA 90066

(310) 439-1490

info@chemochicks.com

www.chemochicks.com

Chemo Chicks is a resource for practical, innovative and uplifting products, helpful resources and simple solutions to women undergoing chemotherapy, radiation and related treatments.

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Treatment

Chemotherapy

(WomenStories, 2002, \$5.00 VHS or watch online for free at www.womenstories.org)

www.womenstories.org or (800) 775-5790

In this video breast cancer survivors tell their stories about coping with chemotherapy.

Chemotherapy and You: A Guide to Self-Help During Cancer Treatment

(National Cancer Institute, 1999)

www.cancer.gov/cancerinfo/chemotherapy-and-you or (800) 4-CANCER

This 56 page booklet, in question-and-answer format, addresses problems and concerns of patients receiving chemotherapy including what to expect, eating well and getting the support you need.

Coping with Chemotherapy and Radiation

by Daniel Cukier, MD, FACR, Frank Gingerelli, MD, Grace Makari-Judson, MD, and Virginia E. McCullough

(McGraw-Hill, 2005, \$14.95)

This book aims to answer questions and offer guidance about diet and lifestyle adjustments that will ease the discomfort of chemotherapy and radiation.

Understanding and Managing Chemotherapy Side Effects

by Richard J. Gralla, MD; Nancy G. Houlihan, RN, MA, AOCN; Rebecca Pick, MSW (CancerCare, Inc., 2006)

This booklet helps patients find out about common side effects, practical information, improving the quality of life and the role of the health care team.

Understanding Chemotherapy: A Guide for Patients and Families

(American Cancer Society, 2006)

www.cancer.org or (800) ACS-2345

This booklet contains answers to common questions about chemotherapy. Also available in Spanish.

Radiation

Radiation Therapy and You: A Guide to Self-Help During Cancer Treatment

(National Cancer Institute, 1999)

www.cancer.gov/cancerinfo/radiation-therapy-and-you

This 52-page booklet addresses common concerns of patients receiving radiation therapy. The emphasis is on explanation and self-help. Available on the NCI website.

Radiation

(WomenStories, 2006, \$5.00 VHS or watch online for free at www.womenstories.org)

www.womenstories.org or (800) 775-5790

This video tells the stories of several women and how they address the main issues of radiation therapy.

These women offer insight and advice about how they coped with this treatment and its impact on their lives.

Complementary therapy

Annie Appleseed Project
annieappleseedpr@aol.com
www.annieappleseedproject.org

Annie Appleseed provides information, education, advocacy and awareness for people with cancer, family and friends interested in complementary, alternative medicine “CAM” and natural therapies from the patient perspective.

Complementary and Alternative Medicine in Cancer Treatment: Questions and Answers
(National Cancer Institute, 2006)

www.cancer.gov/cancertopics/factsheet/therapy/CAM or (800) 4-CANCER

This guide is designed to help patients understand complementary and alternative therapies.

Healing Outside the Margins: The Survivor’s Guide to Integrative Cancer Care
by Carole O’Toole, with Carolyn B. Hendricks, MD (LifeLine Press, 2002, \$21.95)

This book provides explanations of different complementary cancer therapies as well as guidelines for constructing your own “action plan” for choosing complementary therapy.

Memorial Sloan Kettering Cancer Center
www.mskcc.org/mskcc/html/11570.cfm

The Integrative Medicine Service at Memorial Sloan-Kettering Cancer Center offers this online resource to provide evidence-based information about herbs, botanicals, supplements and more.

National Center for Complementary and Alternative Medicine
PO Box 7923

Gaithersburg, MD 20898

(888) 644-6226

www.nccam.nih.gov

NCCAM is the Federal Government’s lead agency for scientific research on complementary and alternative medicine. The agency provides descriptions of complementary and alternative medicine therapies and provides information to help patients make informed decisions about using such therapies during and after treatment.

Office of Cancer Complementary and Alternative Medicine (OCCAM)

National Cancer Institute

6116 Executive Blvd, Suite 609, MSC 8339

Bethesda, MD 20892

(888) NIH-NCAM

www.cancer.gov/cam

The NCI’s Office of Cancer Complementary and Alternative Medicine coordinates the Institute’s research program in complementary and alternative medicine. The OCCAM offers guidelines for evaluating complementary alternative medical therapies as well as CAM clinical trial information.

M. D. Anderson Cancer Center’s Complementary/Integrative Medicine Education Resources (CIMER)

www.mdanderson.org/departments/cimer

CIMER aims to help patients and physicians decide how best to integrate complementary and alternative medicine into their care.

Thinking About Complementary and Alternative Medicine

(National Cancer Institute, 2005)

www.cancer.gov/cancertopics/thinking-about-CAM or (800) 4-CANCER

An easy to read online pamphlet about complementary and alternative medicine.

Managing side effects

Few women receive breast cancer treatment without experiencing some physical and psychological side effects. While the impact and severity of some side effects are known, others are understood less, and are the subject of ongoing study. Offering clear and understandable information about potential side effects is an important aspect of treatment that is often abbreviated or overlooked. Women with breast cancer should be encouraged to learn about the side effects of treatment for the disease, and to be prepared to discuss the subject with a medical professional who can answer their questions and suggest effective practical and medical interventions.

Recent literature about breast cancer treatment side effects has included these observations:

- Studies have demonstrated that pre-treatment education about what to expect and how to manage side effects tends to lessen their impact. Well-informed patients who can anticipate the effects of treatment on their everyday life are often able to plan and adjust daily work and home activities. In some women with breast cancer, the education process alone has been shown to reduce the incidence and severity of certain side effects.
- After certain phases of active treatment are completed (such as chemotherapy cycles), some women with breast cancer report feeling more vulnerable once they are “on their own.” In other surveys and in support group sessions, these patients frequently express increased uncertainty about their health and overall well-being. Continued interactive monitoring of side effects by the patient’s healthcare team is an integral part of active treatment.
- A survey of young women diagnosed with breast cancer showed that only 72% were given any indication about ways in which their cancer treatments could affect their fertility and of those women, 26% felt their fertility concerns had not been adequately addressed.

The introduction of new therapies has contributed to significant progress in treating breast cancer, and has extended survival. With these new agents, including targeted biologics with innovative mechanisms of action, new side effects profiles have begun to emerge. In addition, in both the adjuvant and advanced-stage settings, standard and new hormonal and chemotherapy agents are being used to treat breast cancer in a variety of doses, sequences and combinations, which increasingly complement diagnostic, surgical and radiation therapy interventions. As a result, a growing number of women are now being treated with regimens whose intermediate and long-term effects are either unknown or still under investigation.

It is important for all women being treated for breast cancer to keep track of any potential side effects of their treatment, and to report these to their doctor or nurse. Very often, side effects that cause pain or discomfort are only temporary and can be prevented, treated or alleviated. The following questions may be useful in initiating a discussion between doctor and patient:

- With this treatment, what side effects should I expect?
- How can I prevent or prepare for potential side effects?
- What side effects are considered serious, and when should I call the doctor?
- Are there treatments available for the side effects I will experience?

(Revised January 2007, YSC - This information was originally developed and published by the National Alliance of Breast Cancer Organizations (NABCO) and made available by agreement with NABCO prior to its closing in June 2004.)

Fertility

For more information on becoming a parent after breast cancer, see page 136.

2006-2007 Cancer & Fertility Resource Guide

(Fertile Hope, 2006)

www.fertilehope.org or (888) 994-HOPE

National directory of resources for fertility preservation techniques, parenthood options and support services available before, during and after cancer treatments.

American Fertility Association

305 Madison Avenue, Suite 449

New York, NY 10165

(888) 917-3777 (Support line)

info@theafa.org

www.theafa.org

A national organization dedicated to educating, supporting and advocating for men and women concerned with reproductive health, fertility preservation, infertility and all forms of family building. Their website has information as well as bulletin boards for information on fertility preservation, infertility, adoption and other topics.



Breast Cancer and Fertility

(Fertile Hope, 2006)

www.fertilehope.org or (888) 994-HOPE

Booklet that outlines fertility risks and options for women affected by breast cancer.

Cancer and Fertility: A Guide For Young Adults

(Fertile Hope, 2004)

www.fertilehope.org or (888) 994-HOPE

Booklet that presents fertility risks and options for young adults with cancer.

Fertile Hope

65 Broadway, Suite 603

New York, NY 10006

(888) 994-HOPE

info@fertilehope.org

www.fertilehope.org

A national, non-profit organization dedicated to providing reproductive information, support and hope to cancer patients whose medical treatments present the risk of infertility.

InterNational Council on Infertility Information Dissemination, Inc. (INCIID)

PO Box 6836

Arlington, VA 22206

(703) 379-9178

www.inciid.org

A non-profit organization that helps individuals and couples explore their family-building options. INCIID provides current information and immediate support regarding the diagnosis, treatment, and prevention of infertility and pregnancy loss, and offers guidance to those considering adoption or childfree lifestyles.

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RESOLVE: The National Infertility Association
7910 Woodmont Avenue, Suite 1350
Bethesda, MD 20814
(888) 623-0744
(301) 652-8585
www.resolve.org

Provides support and information to people who are experiencing infertility and aims to increase awareness of infertility issues through public education and advocacy.

Sexuality and Fertility After Cancer

By Leslie R. Schover, PhD (John Wiley & Sons, Inc., 1997, \$15.95)

Comprehensive book that presents options after treatment in regards to fertility and renewed sexuality. Also presents information on sexual problems men and women face after treatment, infertility treatment options, and risks for unplanned pregnancy.

Sharing Hope Financial Assistance Program

(FertileHope, 2006)

www.fertilehope.org or (888) 994-HOPE

Brochure that outlines the Fertile Hope financial assistance program for fertility preservation.

Menopause

Early Menopause Guidebook

(North American Menopause Society, 2003, \$20 or online for free)

www.menopause.org or (440) 442-7550

This comprehensive guidebook aims to promote the understanding of the physical and emotional changes that accompany early menopause as well as the health issues later in a woman's life that may be related to menopause. Contains extensive information on menopause-related changes, post-menopausal health, menopause treatments and a resource section.

EarlyMenopause.com

www.earlymenopause.com

A website and support community for women who are experiencing early menopause due to natural early menopause; premature ovarian failure; surgery (hysterectomy and oophorectomy); cancer treatments, such as chemotherapy or radiation; autoimmune disorders or other causes.

North American Menopause Society

PO Box 94527

Cleveland, OH 44101

(440) 442-7550

(800) 774-5342

www.menopause.org

Provides resources on menopause and its related issues, menopause clinicians, discussion groups and publishes the *Early Menopause Guidebook*. See listing this page.

Our Bodies, Ourselves: Menopause
(Touchstone, 2006, \$15.00)

The Boston Women's Health Book Collective known for the women's health classic *Our Bodies, Ourselves*, provides a comprehensive look at menopause. Though not focused on early menopause, there are sections on bone and heart health, getting a good night's sleep, changes in sexual desire, mood swings and memory changes, and politics and women's health.

Sudden Menopause: Restoring Health and Emotional Well-Being
by Debbie DeAngelo, RNC, BSN (Hunter House Publishers, 2001, \$16.95)

This book, written by an ovarian cancer survivor with a background in women's health care, gives young women facing early menopause the information and support that they need to adjust to the impact it has on their lives. With discussion about topics such as hot flashes, emotional and cognitive changes, osteoporosis and heart disease, the author shares personal experiences and information from interviews with other young women. This book includes discussion of Hormone Replacement Therapy (HRT) and the use of herbal therapies as a treatment for premature menopause; some of the therapies discussed may not be appropriate for breast cancer survivors.

Sexuality and intimacy

Sexuality and Fertility After Cancer

by Leslie R. Schover, PhD (John Wiley & Sons, Inc., 1997, \$15.95)

Comprehensive book that presents options after treatment in regards to fertility and renewed sexuality. Also presents information on sexual problems men and women face after treatment, infertility treatment options and risks for unplanned pregnancy.



Sexuality and Intimacy: Issues Addressed, Questions Answered
A Young Perspective Teleconference, June 21, 2006

www.youngsurvival.org/programs/survivor-programs/telecons

A teleconference featuring Sage Bolte, LCSW and Patty Brisbane of Pure Romance held to discuss the impact and the effects of cancer treatments with information on options, tips and ideas for maintaining intimacy. Transcript of the teleconference is available online.

Intimacy

(WomenStories, \$5.00 VHS or watch online for free at www.womenstories.org)

This video examines issues of intimacy, sexuality and body image from the perspective of breast cancer survivors and their partners.

No Less A Woman, Femininity, Sexuality and Breast Cancer

by Deborah Hobler Kahane (Hunter House, Inc., Publishers, 1995, \$14.95)

This book focuses on some of the major issues breast cancer patients face by presenting interviews with ten women.

Pure Romance
161 Commerce Blvd
Loveland, OH 45140
(513) 965-7017
(866) ROMANCE
www.pureromance.com/sss

Pure Romance offers an exclusive line of heighteners, lubricants and bedroom accessories for relationship enhancement including products specifically for women affected by breast cancer. *Sensuality, Sexuality, Survival* focuses on helping women recapture their sensual and sexual selves following cancer diagnosis or treatment.

Sexuality and Cancer: For the Woman Who Has Cancer, and Her Partner
(American Cancer Society, 2004)

www.cancer.org or (800) ACS-2345

This booklet offers facts that can help you lead as healthy a sexual life as possible, even with cancer in your present or past.

Sexuality and Fertility After Cancer

Leslie R. Schover, Ph.D (John Wiley & Sons, Inc., 1997, \$15.95)

Comprehensive book that presents options after treatment in regards to fertility and renewed sexuality. Also presents info on sexual problems men and women face after treatment, infertility treatment options, and risks for unplanned pregnancy.

Body image

No Less A Woman: Femininity, Sexuality and Breast Cancer (Revised Second Edition)

By Deborah Hober Kahane (Hunter House, Inc., Publishers, 1995, \$14.95)

This book focuses on some of the major issues breast cancer patients face by presenting interviews with 10 women.

Shop Well with You Guide to Body-Image and Cancer

(Shop Well With You, Inc., 2004)

www.shopwellwithyou.org/guide.cfm

This booklet is designed to accompany its user not only to the mall, but to her own closet, allowing her to find clothing in her own wardrobe to improve her quality of life during and after treatment.

The Look Good, Feel Better Program

www.lookgoodfeelbetter.org or (800) 395-LOOK

This program is an opportunity for people undergoing cancer treatment to develop skills to cope with appearance changes.

Facing the Mirror with Cancer: A Guide to Using Makeup to Make a Difference

by Lori Ovitz with Joanne Kabak (Belle Press, LLC, 2004, \$24.95)

This book offers a practical guide for patients coping with changes that occur as a result of cancer treatment. The models shown in the book share their personal stories and discuss how taking control of their appearance helped to improve their quality of life.

Ramy Gafni's Beauty Therapy: The Ultimate Guide to Looking and Feeling Great

by Ramy Gafni (M. Evans and Company, Inc., 2005, \$24.95)

This book offers tips to help you look your best during your treatment for cancer. The author offers information on finding stylish head coverings, and teaches how to thicken thinning eyebrows and lashes and camouflage damaged skin.

Breast reconstruction and prostheses

After a mastectomy, some women may choose to wear a prosthesis (breast form), have breast reconstruction—either at the same time as the mastectomy or later on—or do nothing to disguise their surgery. What is right for one woman may not be right for another and each option has its pros and cons. There are several procedures that are used to reconstruct the breast including the use of implants (either saline or silicone) or the use of tissue moved from another part of the woman's body. Deciding on the type of reconstruction that is best depends on a woman's body type, and the type of surgery that she has had. A woman should discuss the risks and benefits of each type of reconstructive surgery with her plastic surgeon. The YSC feels that with reconstruction seeing can be very beneficial in reducing anxiety and managing expectations. Most doctors can show pictures of their work. Also, look on the YSC bulletin board to find images of reconstruction and discussions about women's feelings about their reconstruction results.

(Revised January 2007, YSC - This information was originally developed and published by the National Alliance of Breast Cancer Organizations (NABCO) and made available by agreement with NABCO prior to its closing in June 2004.)

6.

Treatment

Reconstruction

Breast Reconstruction Following Mastectomy

American Cancer Society, 2001)

www.cancer.org or (800) ACS-2345

This booklet is a basic guide to the options for breast construction after mastectomy.

My Hope Chest

3395 South Jones, #298

Las Vegas, NV 89146

www.myhopechest.org

My Hope Chest focuses on the need of breast reconstruction for uninsured and underprivileged women believing that this surgery is truly "the final step in breast cancer treatment." By enabling women who desire reconstruction to have it, My Hope Chest aims to help women return their normal life with feelings of self-worth and completeness.



Myself: Together Again (M:TA)

One Young Woman's Story of Breast Cancer Recovery and Reconstruction

PO Box 6451

Raleigh, NC 27628-6451

www.myselftogetheragain.org

This project features images of delayed breast reconstruction following double mastectomy surgery from before reconstruction and after as well as the entire process between. The Myself: Together Again story was created so that other young women can get an idea of what to expect all along the way.

Prostheses

Amoena

www.amoena.com

Amoena makes breast forms, intimate apparel, swimwear, symmetry shapers, and post-operative products.

Women's Personal Health.net

(877) 463-1343

(845) 321-1961

www.womenspersonalhealth.net

Website where women dealing with the side effects of cancer treatment can purchase personal items for life after (and during) chemotherapy, radiation, and surgery.

How to find post-mastectomy products

Prostheses (breast forms) It is recommended that you be fitted by an experienced fitter the first time you purchase a prosthesis and again anytime after if you have gained or lost a significant amount of weight. The lingerie areas in some department stores employ professional fitters who will help you find a comfortable and suitable prosthesis, and a bra to wear with it. Smaller lingerie boutiques in major cities often perform this function — check the yellow pages under “Lingerie” or “Brassieres,” or in larger cities, under “Breast Prostheses.” Also contact department stores in your area to see if they offer a fitting service. Prostheses may also be ordered from selected surgical supply stores, often listed under “Surgical Appliances and Supplies.” Temporary prostheses can be ordered by mail. Women who cannot afford a prosthesis may contact the Y-ME Prosthesis Bank at (800) 221-2121 or the Breast Cancer Resource Center of the Princeton YWCA at (609) 497-2126.

Bathing suits and lingerie Contact the sources mentioned above. In addition, a number of specialty boutiques sell clothing with post-mastectomy needs in mind, although there is not a large national chain. Consult the yellow pages under “Lingerie” or the Shop Well with You resource guide at www.shopwellwithyou.org. If you have difficulty locating a local retailer, contact the Reach-to-Recovery volunteer at your nearest American Cancer Society office; ask at a local breast cancer support group; or contact the Department of Social Work at your largest local hospital.

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Hair loss

Facing the Mirror with Cancer: A Guide to Using Makeup to Make a Difference

by Lori Ovitz with Joanne Kabak (Belle Press, LLC, 2004, \$24.95)

This book offers a practical guide for patients coping with changes that occur as a result of cancer treatment. The models shown in the book share their personal stories and discuss how taking control of their appearance helped to improve their quality of life.

Adaptations, Inc.

5 F Street, SW

Ardmore, OK 73401

(866) 353-3506

(580) 226-3506

www.adaptations4u.com

Adaptations offers a variety of hats, headwear and wig options for people experiencing chemotherapy related hair loss. The headwear selection includes many stylish hats, turbans, scarves and sleep caps specifically selected with cancer-chemotherapy patients in mind.

Doma Designs, Inc.

426 East Bissell Avenue

Oil City, PA 16301

(888) 603-1206

(814) 676-5033

www.domadesigns.com

Offers a wide selection of head coverings that are exclusively designed for hair loss. Hats are designed to give full coverage of the head. The “No-Fuss” Bandana has rounded ties, tailored sides and a longer tail that give a softer, more feminine look than a traditional bandana. The “Do-dana” is a versatile one-size fits all head covering that can be worn ten different ways.

Hats, Scarves and More

PO Box 7446

Spokane, WA 92207

(509) 484-2095

www.hatsscarvesandmore.com

Website for cancer patients featuring designer hats, scarves and sleep caps that appeal to younger women. Over 100 different styles selected by a hair designer who is an ovarian cancer survivor diagnosed at 35.

Hip Hats With Hair

108 West Adalee Street

Tampa, FL 33603

(877) 447-4287

(813) 229-2377

www.hatswithhair.com

Offers alternatives to wearing a full wig, including underhair that can be worn under any hat, cap or scarf and a one piece cap with a ponytail and bangs.

Headcovers Unlimited

Carol Galland

35B Tiffany Plaza

Ardmore, OK 73401

www.headcovers.com

Founded by a breast cancer survivor, this website offers a variety of headcovers that completely cover the head and are chosen for women experiencing hair loss including hats, scarves, turbans, sleep hats and swim caps. Also offers false eyelashes, eyebrows and wig accessories.

Janas Bandanas

(480) 947-2323

www.janasbandanas.com

Founded by a young woman with permanent alopecia, this website offers unique headwear for women experiencing hair loss that focuses on comfort and ease. There is an instructional video on the website that shows you how to tie the bandana.

Turbans Plus

13692 Newhope Street

Garden Grove, CA 92843

(800) 552-0589

(714) 530-9590

www.turbansplus.com

Offers high quality headwear for medically-related hair loss. Selection includes turbans, scarves, hats, sleepcaps, headwraps, petal hats and cloches. All products are fitted, adjustable and soft to the touch.

Ramy Gafni's Cancer Beauty Therapy: The Ultimate Guide to Looking and Feeling Great While Living with Cancer

by Ramy Gafni (M. Evans and Company, Inc., 2005, \$24.95)

This book offers tips to help you look your best during your treatment for cancer. The author offers information on finding stylish head coverings, and teaches how to thicken thinning eyebrows and lashes and camouflage damaged skin.

"TLC" - Tender Loving Care
PO Box 395
Louisiana, MO 63353-0395
(800) 279-2018
www.tlcdirect.org

This non-profit patient service of the American Cancer Society is intended to help people cope with the side effects of cancer treatment. The website has an online store and catalogue for women dealing with breast cancer that offers wigs, hats, sleep caps, scarves and turbans.

Women's Personal Health.net
(877) 463-1343
(845) 321-1961
www.womenspersonalhealth.net

Offers a secure web site where women dealing with the side effects of cancer treatment can purchase personal items for life after (and during) chemotherapy, radiation, and surgery.

Nausea

Cancernausea.com
www.cancernausea.com

A website for people experiencing nausea associated with cancer treatment that provides useful information on symptom relief and treatment options. It also contains a simple list of diet "do's and don'ts," a symptom diary and a printable practical guide for patients.

Cancernutritioninfo.com
www.cancernutritioninfo.com

This online resource provides simple nutrition tips to help manage nausea associated with cancer treatment. See articles listed under treatment symptom management.

Eating Hints for Cancer Patients: Before, During and After Treatment
(National Cancer Institute, 2003)
www.cancer.gov/cancerinfo/eatinghints

This booklet provides information and recipes to help patients meet their needs for good nutrition during treatment and to help cope with side effects that may affect eating. It is available online and copies may also be ordered from the National Cancer Institute website.

Nausea and Vomiting Treatment Guidelines for Patients with Cancer – Version III
(National Comprehensive Cancer Network and American Cancer Society, 2005)
www.nccn.org, www.cancer.org or (888) 909-NCCN, (800) ACS-2345
Patient guide to nausea and vomiting associated with cancer treatment.

Fatigue

Cancer-Related Fatigue and Anemia Treatment Guidelines for Patients:
Finding New Ways to Cope with Fatigue – Version III
(National Comprehensive Cancer Network and American Cancer Society, 2005)
www.nccn.org, www.cancer.org or (888) 909-NCCN, (800) ACS-2345
Patient guide to fatigue and anemia associated with cancer treatment.

Cancersymptoms.org
www.cancersymptoms.org

The Oncology Nursing Society's website designed for patients and caregivers to provide information and learning about the ten most common cancer treatment symptoms, including fatigue.

Managing Lymphedema

Lymphedema (lim-fa-DEE-ma) is a painful swelling of the arm that can result from having underarm lymph nodes removed surgically (axillary lymph node dissection). Lymph node dissection is currently a standard component of breast surgery for invasive breast cancer. A less invasive sampling technique called Sentinel Lymph Node Biopsy (SLNB) is increasingly common, and may reduce the incidence of lymphedema. Radiation therapy that includes the underarm region can also cause or worsen lymphedema. Many women never get lymphedema, some have only a mild case, but others have a more severe experience, resulting in discomfort and physical limitations.

Lymphedema can develop at any time after surgery, and once present, it seldom disappears completely. Some women have not been properly taught about the basic precautions that should always be taken, including protecting against sunburn, heavy lifting, constriction, blood drawing, and infection of the affected arm or hand. If you have lymphedema, ask your surgeon about your therapeutic options and how it should be treated.

- **Elastic Sleeves.** Medical equipment dealers and surgical supply stores often carry products used to treat lymphedema. Elastic sleeves should be custom-fitted. Consult your breast surgeon to discuss the products you may need; a prescription is necessary for insurance reimbursement.
- **A Lymphedema Alert Bracelet or Necklace** can be worn to remind medical providers not to treat the affected arm for any medical procedures which could trigger the onset of lymphedema. These are available for \$15.00 each from the National Lymphedema Network (see next page).
- **Physical Therapy or Lymphedema Therapy.** Physical manipulation of the arm and lymph system by a specially-trained professional may help to treat lymphedema, but it is important that the professional be qualified. Many insurance plans do not cover this therapy. To find a local therapist, consult your breast surgeon, or call the National Lymphedema Network. Manual lymph drainage is a specialized procedure; referrals may not be possible in all locations.

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Lymphedema

Living Well With Lymphedema

by Ann Ehrlich, Alma Vinje-Harrewijn, PT, CLT, Elizabeth McMahon, PhD (Lymph Notes, 2005, \$39.95)

A comprehensive resource covering the physical aspects of lymphedema, including prevention, diagnosis, treatment, self-care, insurance, nutrition, and much more.

Lymph Notes

www.lymphnotes.com

Online resource and support for people with lymphedema including their families, friends, and therapists.

Lymphatic Research Foundation

100 Forest Drive

East Hills, NY 11548

(516) 625-9675

lrf@lymphaticresearch.org

www.lymphaticresearch.org

The Lymphatic Research Foundation is a non-profit organization whose mission is to advance research of the lymphatic system and to find the cause of and cure for lymphatic diseases, lymphedema, and related disorders.

Lymphedema: A Breast Cancer Patient's Guide to Prevention and Healing

by Jeannie Burt & Gwen White, PT (Hunter House, 1999, \$12.95)

Complete with over 50 illustrations, this book tells the stories of women who have dealt with lymphedema.

It describes the options that people have for preventing and treating lymphedema with an emphasis on self-help.

Lymphedema Awareness Foundation

172 Lakeside Circle

Sanford, FL 32773

(407) 324-3255

laf@elymphnotes.org

www.elymphnotes.org

Provides advocacy and support in the promotion of lymphedema awareness. Has an established referral network and outreach programs for health care professionals and lymphedema patients.

National Lymphedema Network

Latham Square Building

1611 Telegraph Avenue, Suite 1111

Oakland, CA 94612-2138

(800) 541-3259

(510) 208-3200

nln@lymphnet.org

www.lymphnet.org

Provides education and guidance to lymphedema patients, health care professionals and the general public by disseminating information on the prevention and management of lymphedema.

Overcoming the Emotional Challenges of Lymphedema

by Elizabeth McMahon, PhD (Lymph Notes, 2005, \$34.95)

A self-help book on the psychological aspects of lymphedema for patients, family, parents, and caregivers.

Understanding and Managing Lymphedema after Cancer
(American Cancer Society, 2006, \$16.95)

www.cancer.org or (800) ACS-2345

This guide addresses precautions that may help prevent lymphedema, how to detect it early, your role in diagnosis and effective treatment options. It also includes information regarding practical challenges such as treatment cost, finding treatment and insurance issues.

What Every Woman Facing Breast Cancer Should Know About Lymphedema
(American Cancer Society, 2004)

www.cancer.org or (800) ACS-2345

This booklet educates women about the risks of lymphedema and ways to prevent it. It is also available in Spanish.

Osteoporosis

National Osteoporosis Foundation (NOF)

1232 22nd Street, NW

Washington, DC 20037-1292

(202) 223-2226

www.nof.org

Offers education, information, and support to those affected by osteoporosis. Resources include several brochures, booklets and an exercise video.

National Institute of Health Osteoporosis and Related Bone Diseases National Resource Center
National Institute of Health

2 AMS Circle

Bethesda, MD 20892-3676

(800) 624-BONE

(202) 223-0344

www.niams.nih.gov/bone

Provides link to resources and information on osteoporosis and related disorders.

Pain management

Cancer Pain: Treatment Guidelines for Patients – Version II

(National Comprehensive Cancer Network and American Cancer Society, 2005)

www.nccn.org, www.cancer.org or (888) 909-NCCN, (800) ACS-2345

This booklet shows patients how cancer pain is treated at the nation's leading cancer centers. It includes information about what causes pain, treatment of pain, side effects of pain medications as well as pain assessment tools.

Managing cancer pain

A woman with breast cancer is likely to experience at least some discomfort or pain associated with surgery, which usually goes away completely. In advanced disease, pain from the cancer itself must be managed. Surveys show that many cancer patients, their family members, and even clinicians have a poor understanding of pain and pain relief, and that patients suffer needlessly. Cancer pain can often be relieved safely and effectively, while maintaining good function and an alert mood. Patients have the right to be as comfortable as possible at all times.

There are many false beliefs about pain relief that can lead to pain being treated improperly. Some of these are:

Myth – Pain-relieving medications lead to addiction.

Fact – In studies involving tens of thousands of cancer patients, fewer than one percent exhibit signs of addiction.

Myth – Use of opioid drugs (e.g., morphine) slows breathing to a dangerous level.

Fact – Respiratory depression is rarely problematic, and can be quickly reversed if necessary.

Myth – “Giving in to pain” and treating it is a sign of weakness.

Fact – Treating pain is a crucial part of successfully treating disease. Unrelieved pain can inhibit mobility, disturb sleep, lead to a depressed mood, slow healing and stress to the body’s systems.

Myth – Pain medications make you too sleepy to conduct normal work and home activities.

Fact – Correctly administered, patients on many regimens are alert and feel able to maintain normal daily routines.

Each patient has a responsibility to tell her doctor or nurse that she has pain, how bad it is, and what seems to make it better or worse. Rating pain from 0 to 10, where 0 equals no pain and 10 equals the worst pain imaginable, is a simple and effective way to report pain. If your doctor isn’t responding to your requests for pain relief, ask to see a pain specialist.

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Pain Control: A Guide for People With Cancer and Their Families

(National Cancer Institute and American Cancer Society, 2000)

www.cancer.gov/cancertopics/paincontrol

For cancer patients and families who want to learn more about pain control and methods, medicines for cancer pain, and non-drug treatments for cancer pain. Available online.

Understanding Cancer Pain

(National Cancer Institute, 2000)

www.cancer.gov/cancertopics/understanding-cancer-pain

Online guide to understanding and managing cancer pain. This easy to read online tool also includes a pain diary. It is also available in Spanish.