

# Patient & Family Resource Guide


## Lombardi Cancer Center

*Research \* Education \* Treatment*



A Comprehensive Cancer  
Center Designated by the  
National Cancer Institute



Georgetown  
University  
Hospital 

The name you know.  
The doctors you trust.

## Using this Guide

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The Patient and Family Resource Guide is a compilation of some of the best sites on the World Wide Web providing information and support to patients with cancer and their families. Though we believe the sites we've listed will provide assistance to you, we can not guarantee your ability to access information on each site, nor the accuracy of all content on a given site, as these sites are not maintained by the Lombardi Cancer Center, Georgetown University or Georgetown University Hospital. If you have concerns over various links, please contact them directly with your concerns, as well as notify us, so we might consider removing the site in question from our list. If you have a question with regards to clinical content you find on any of these sites, or require additional information or clarity, please speak with your physician or clinical nurse coordinator. The information provided is not in any way meant to replace interactions with your doctor or other persons on your care team. Your care team may also have additional recommendations of web sites, community organizations or service providers that may best meet your individual needs.

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## The NCI and ACS

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### **National Cancer Institute**

The National Cancer Institute (NCI) is the Nation's primary agency for cancer research. It leads the Nation's fight against cancer by supporting and conducting research in cancer biology, causation, prevention, detection, treatment, and survivorship. The NCI also supports cancer centers, community-based clinical oncology programs, education, and outreach programs.

*The Cancer Information Service (CIS)*, a national information and education network, is a free public service of the NCI. The CIS provides the latest, most accurate information on cancer, interpreting and explaining research findings in a clear and understandable manner. The CIS may be reached at 1-800-4-CANCER, Monday through Friday 9:00 a.m. to 4:30 p.m., or visit them online at <http://cis.nci.nih.gov>.

*The NCI's CancerNet web site*, [www.cancer.gov/cancer\\_information/](http://www.cancer.gov/cancer_information/), provides comprehensive information about cancer by covering topics such as treatment options, clinical trials, coping with cancer, support and resources, and cancer literature. The areas entitled "Coping with Cancer" and "Support and Resources" are especially helpful. It also contains a link to PDQ, a cancer information database.

### **The American Cancer Society (ACS)**

1875 Connecticut Ave., NW  
Washington, DC 20009  
1-800-ACS-2345

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 ACS maintains a toll-free information hotline (number listed above) available 24 hours a day, seven days a week. The ACS, Mid-Atlantic Division's toll-free number, 1-888-ACS-NEED, connects you with one of two local field Resource Centers who can provide comprehensive and current information about ACS programs and services, as well as community resources and information.

The ACS's National web site, found at [www.cancer.org](http://www.cancer.org), is a comprehensive site containing valuable resources on prevention and risk factors, detection, treatment methods, and services for cancer patients and their families. Practical information, ideas, answers to common questions and tips are available, as well as specific resources in your community.

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## General Information

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- Advocacy/Legislation-focused

### **Association of Community Cancer Centers (ACCC)**

[www.accc-cancer.org/main2001.shtml](http://www.accc-cancer.org/main2001.shtml)

11600 Nebel Street, Suite 201

Rockville, MD 20852

(301) 984-9496

ACCC is the national interdisciplinary organization that promotes the entire continuum of quality cancer care for patients and communities. ACCC fulfills their mission by pursuing the following six strategies: Patient Advocacy, Quality and Economic Issues, Research in the Community, Cancer Program Management, Leadership in Policy Development and Promotion, and Support for Members. Their web site includes the latest news on public policy, oncology drugs and products, and state agencies and meetings.

### **Patient Advocate Foundation**

[www.patientadvocate.org](http://www.patientadvocate.org)

The Patient Advocate Foundation is a national non-profit organization that serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job discrimination and/or debt crisis matters relative to diagnosis through case managers, doctors and attorneys. The Patient Advocate Foundation seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of financial stability.

### **U.S. Public Health Service's Office of Women's Health**

[www.4woman.gov](http://www.4woman.gov)

200 Independence Avenue, SW

Room 730B

Washington, DC 20201

(202) 690-7650

This office provides national leadership in women's health through public policy, research, service delivery, and education. Programs include eighteen Centers of Excellence in Women's Health, which serve as models of integrated and comprehensive women's health research and clinical services, including regular screening for breast, ovarian and cervical cancers.

- Informational/Educational-focused

### **Association of Cancer Online Resources (ACOR)**

[www.acor.org](http://www.acor.org)

ACOR provides access to oncology mailing lists and electronic groups; an excellent resource for people with cancer who wish to find others with their same diagnosis.

### **Alpha Cancer Information Resource**

[www.alphacancer.com](http://www.alphacancer.com)

The Alpha Cancer Information Resource is the health education website of the Coalition of National Cancer Cooperative Groups. The site offers articles, book recommendations and webcasts (lectures and discussions via the world wide web) focusing primarily on breast cancer, lung cancer, colon cancer and general cancer awareness.

### **American Society of Clinical Oncologist (ASCO)**

[www.asco.org](http://www.asco.org)

The mission of ASCO is to facilitate the delivery of high quality health care; foster the exchange and diffusion of information and ideas related to cancer, including the biology, diagnosis, staging, treatment, and psycho-social impact of cancer; further the training of all persons in clinical research and in the total care of patients with cancer; and encourage optimal communication among the various specialties concerned with cancer. It is the premier trade association for Oncologists and its web site contains an extraordinary amount of cutting edge information. Though primarily geared towards physicians, patients and family members may find useful information under the section "People Living with Cancer".

### **Association of Community Cancer Centers (ACCC)**

[www.accc-cancer.org/main2001.shtml](http://www.accc-cancer.org/main2001.shtml)

ACCC is the national interdisciplinary organization that promotes the entire continuum of quality cancer care for patients and communities. ACCC fulfills their mission by pursuing the following six strategies: Patient Advocacy, Quality and Economic Issues, Research in the Community, Cancer Program Management, Leadership in Policy Development and Promotion, and Support for Members. Web site includes the latest news on public policy, oncology drugs and products and a hospital locator.

### **Blood and Marrow Transplant Information Network**

<http://bmtnews.org>

This site provides information and emotional support to those contemplating or undergoing blood or marrow transplant and their families.

### **Cancer Care.org**

[www.cancercare.org/index.asp](http://www.cancercare.org/index.asp)

Cancer Care is a non-profit organization whose mission is to provide free professional help to people with all cancers through counseling, education, information and referral, and direct financial assistance. The above link is to their homepage, packed with useful information. This link, [www.cancercare.org/people/education/briefs/index.asp](http://www.cancercare.org/people/education/briefs/index.asp), will get you quickly to short information articles on topics such as treatment and side effects, how to get better medical care, where to go for help, talking to others/caring for yourself, prevention, etc. Information also available in Spanish at [www.cancercare.org/espanol/index.asp](http://www.cancercare.org/espanol/index.asp).

### **Cancer Education.com**

[www.cancereducation.com](http://www.cancereducation.com)

This website's mission is to improve cancer care through the dissemination of up-to-date and accurate educational programming and information for healthcare professionals, cancer patients and their family members. The site has resources for finding physicians and treatment centers, and features video and animation about common types of cancer. The Lombardi Cancer Center is actually a clinical partner to this site as is Cancer Care.

### **CancerHelp**

[www.cancerhelp.8m.com](http://www.cancerhelp.8m.com)

Cancer Help, sponsored by Robert W. Neill Companies, provides a broad list of cancer related web sites, bulletin boards and chat groups. As a partner with Yahoo, this site can direct you to a new area of Yahoo specifically for cancer patients and their families.

### **Cancer News on the Net**

[www.cancernews.com](http://www.cancernews.com)

Cancer News on the Net is dedicated to bringing patients and their families the latest information on cancer diagnosis and treatment. Though not an extremely sophisticated site, it contains various articles on cancer and is packed with links to a variety of other useful sites. Backed by the R.A. Bloch Cancer Foundation, Inc.

### **Cancer Related Links**

[www.seidata.com/~marriage/rcancer.html](http://www.seidata.com/~marriage/rcancer.html)

This web site, put together independently (no organizational affiliation), provides as categorized and comprehensive listing of cancer related web sites throughout the web. It includes everything from governmental sites, organizations, educational institutions and centers, and many, many others.

### **Cancer Source.com**

[www.cancersource.com/index.cfm](http://www.cancersource.com/index.cfm)

The mission of CancerSource.com is to be the most comprehensive and accurate source of cancer information and services available online. Their site is designed for both those affected by the disease, and for professionals. Features include treatment and advocacy information, a consumer drug guide, and support groups. The site is overseen by a medical advisory board led by Dr. Vincent DeVita, Director of the Yale Cancer Center.

### **Complete Home Medical Guide: Cancer**

<http://cpmcnet.columbia.edu/texts/guide/toc/toc17.html>

This website, sponsored by Columbia University, College of Physicians and Surgeons, is a section of their larger Complete Home Medical Guide. It contains general cancer information and other support resources for the layperson.

### **Cycle of Hope**

[www.cycleofhope.org](http://www.cycleofhope.org)

Cycle of Hope is sponsored by the Lance Armstrong Foundation and Bristol Myers Squibb. The site provides information on and promotes early cancer detection, talks about how to reduce fear associated with treatment, and works to encourage a team approach and foster hope in patients and families fighting the disease.

### **Health World.com**

[www.healthy.net/asp/templates/center.asp?centerid=23](http://www.healthy.net/asp/templates/center.asp?centerid=23)

HealthWorld Online is a 24-hour health resource center--a virtual health village where you can access information, products, and services to help create your wellness-based lifestyle. This site deals primarily in natural health, wellness, self-care and alternative medicine. The link above will bring you directly to their cancer area.

### **Facing Our Risk of Cancer Empowered (FORCE)**

[www.facingourrisk.org](http://www.facingourrisk.org)

FORCE is a nonprofit organization for women who are at high risk of getting breast or ovarian cancer due to their family history and genetic status, and for members of families in which a BRCA mutation may be present. The FORCE web site can be a helpful resource for anyone who knows she is at risk, who wonders whether she might be at risk, or who cares about the issues and concerns that face those at risk.

### **Cancer Index.org: A Guide to Internet Resources for Cancer**

[www.CancerIndex.org/clinks1.htm](http://www.CancerIndex.org/clinks1.htm)

Sponsored by the North of England Children's Cancer Research Fund, this site contains links to cancer related information organized by disease, country, treatments, and other topics. Menus for researchers, patients, and a special section for children.

### **HBO's Cancer Evolution to Revolution Website**

[www.hbo.com/cancer/flash\\_home.shtml](http://www.hbo.com/cancer/flash_home.shtml)

Sponsored by HBO, and begun in conjunction with their television program, *Cancer: Evolution to Revolution*, this web site includes details about screening, treatments, and clinical trials, becoming an active patient and finding support groups. A section called "Being and Active Patient" contains practical advice on managing cancer.

### **International Cancer Alliance (ICA)**

[www.icare.org](http://www.icare.org)

4853 Cordell Avenue/Suite 11

Bethesda, MD 20814

800-ICARE-61

(301) 654-8684

Email: [infor@icare.org](mailto:infor@icare.org)

The ICA provides a free cancer therapy review that includes information on specific cancer type, detection and staging, treatment, tests, clinical trials, and more. There is also a cancer breakthrough report sent quarterly that can be ordered through their site.

### **Mayo Clinic**

[www.mayohealth.org/home](http://www.mayohealth.org/home)

Mayo Clinic's web site provides a wide array of health information. By looking up your particular type of cancer, you can access cancer related news updated daily, cancer questions answered by Mayo Clinic specialists, articles from their online library, quizzes to test your cancer knowledge and a glossary of cancer related terms.

### **University of Pennsylvania Cancer Center**

[www.oncolink.upenn.edu](http://www.oncolink.upenn.edu)

Oncolink is designed for the general public to obtain information on various types of cancer, cancer treatment, and research advances with ease. Their "Coping with Cancer" area provides a wide variety of information for patients and caregivers, including book and video reviews, information on cancer and sexuality, and areas for sharing thoughts.

### **Web MD – Cancer**

[http://my.webmd.com/condition\\_center\\_hub/can?z=3074\\_can\\_01](http://my.webmd.com/condition_center_hub/can?z=3074_can_01)

This site provides high quality information and interactive tools to help patients and their families manage their daily personal health. The link above is directly to Web MD's cancer pages. MD Health is committed to providing authoritative medical content written for the consumer as well as access to professional-level content. These articles may compliment information provided by your physician and/or other scientific sites, but is not meant to replace them.

- Newsletters, Books and Other Publications

### **AICR's Bi-Monthly Children's Newsletter**

[www.aicr.org/kidsnl.htm](http://www.aicr.org/kidsnl.htm)

The "good-news-letter" provides kids with an entertaining reminder of how much fun eating healthfully can be.

### **Cancer Book Store**

[www.wellnessbooks.com/cancer](http://www.wellnessbooks.com/cancer)

This site provides information on books on cancer with helpful information on finding a doctor, second opinions, prostate cancer awareness and other subjects, plus links and a bibliography.

### **CONVERSATIONS!**

#### **The International Newsletter for Those Fighting Ovarian Cancer**

[www.ovarian-news.org](http://www.ovarian-news.org)

(806) 355-2565

This site allows you to view a monthly newsletter written by an ovarian cancer survivor. The newsletter reports on treatment options, clinical trials, coping skills, and early detection strategies. It offers a humorous and upbeat tone, as well as a networking service to match women in similar circumstances.

### **CRI HelpBook**

<http://cancerresearch.org/hbintro.html>

This site, sponsored by the Cancer Research Institute, provides access to a variety of publications, including *What to do if Cancer Strikes*. This particular publication provides very useful information about how to talk to your doctor when you are diagnosed, information about treatments and clinical trials, and a resource directory.

### **National Library of Medicine**

[www.nlm.nih.gov](http://www.nlm.nih.gov)

This is the official web site for the National Library of Medicine. On this site you can search a variety of databases for journal articles and books on any are of medical interest.

### **Ovarian Plus: Gynecologic Cancer Prevention Quarterly (newsletter)**

[www.monitor.net/ovarian](http://www.monitor.net/ovarian)

P.O. Box 2831

Springfield, VA 22152-0831

This newsletter has timely information about international research, diagnosis, and treatments for ovarian cancer and other gynecologic cancers. It targets risk reduction, screening, early detection, psychosocial and policy issues, and addresses current events in the ovarian cancer community.

### **What You Need to Know about Cancer**

[www.cancer.gov/cancer\\_information/doc\\_wyntk.aspx?viewid=1a5e47ea-8cdd-4efb-b05c-2988190a8b43](http://www.cancer.gov/cancer_information/doc_wyntk.aspx?viewid=1a5e47ea-8cdd-4efb-b05c-2988190a8b43)

Produced by the NCI, and available at the web link above, *What You Need to Know about Cancer* is a booklet packed with important information about cancer. Chapters include information about diagnosing cancer, treatments, clinical trials and support.

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## Information by Disease

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- Bone Cancer

### **Bone Cancer International, Inc**

[www.bonecancer.to](http://www.bonecancer.to)

Bone Cancer International's mission is to establish and pursue funding for research into the cause, prevention, and cure of primary bone cancer. Their web site offers information about patient support, medical facilities, and professionals who specialize in the care and treatment of bone cancer patients.

- Brain Cancer

### **The American Brain Tumor Association**

[www.abta.org/information/index.html](http://www.abta.org/information/index.html)

This site holds brain tumor information, explanations for treatment, support resources and updates on research.

[www.abta.org/resources/index.html](http://www.abta.org/resources/index.html)

Within the American Brain Tumor Association Website, find help in their "Comfort and Resources" section. Link here to read other people's stories of hope, get information about managing side effects and symptoms, and connect to a pen pal.

### **National Brain Tumor Foundation**

[www.braintumor.org](http://www.braintumor.org)

This non-profit health organization provides information and support to brain tumor patients, family members, and health care professionals.

- Breast Cancer

### **Breast Cancer in Men**

<http://interact.withus.com/interact/mbc/>

This site is dedicated to providing information about male breast cancer. The site includes support resources, FAQs and other medical references.

### **Breast Cancer Online**

[www.bco.org](http://www.bco.org)

This site is mainly for medical professionals. It gives access to conference information and reports, other cancer web sites, medical databases and articles.

### **Breast Cancer Resource Committee (BCRC)**

[www.afamerica.com/bcrc](http://www.afamerica.com/bcrc)

2005 Belmont St. NW  
Washington, DC 20009  
202-463-8040

BCRC is dedicated to educating and supporting the African-American community through a broad-based breast cancer awareness campaign that includes a variety of initiatives. This web site provides more information about their organization and initiatives and other services they provide with regards to breast cancer.

### **Celebrating Life—Wellness**

[www.celebratinglife.org](http://www.celebratinglife.org)

The Celebrating Life Foundation is one of the leading foundations in the nation that promote breast cancer awareness specifically targeting African American women and women of color. Their site provides information about breast cancer, screenings, events and support groups throughout the country.

### **National Breast Cancer Coalition (NBCC)**

[www.stopbreastcancer.org](http://www.stopbreastcancer.org) or [www.natlbcc.org](http://www.natlbcc.org)

1707 L Street NW  
Washington, DC 20036  
(202) 296-7477  
(202) 265-6854 (fax)

This coalition is dedicated to the eradication of breast cancer by action, policy, and advocacy. Their site provides details on the group's legislative activities, , advocacy training, and public policy initiatives. Information is included about members of Congress who have been supportive of NBCC's goals.

### **Susan G. Komen Breast Cancer Foundation**

[www.Komen.org](http://www.Komen.org)

The Komen Foundation's mission is to eradicate breast cancer as a life threatening disease through research, education, screening and treatment. Their web site provides information on research, upcoming events, where to get additional information about breast cancer and how to access community support for patients and families.

### **Mothers Supporting Daughters with Breast Cancer**

[www.mothersdaughters.org](http://www.mothersdaughters.org)

21710 Bayshore Road  
Chestertown, MD 21620-4401  
(410) 778-1982.

This organization is designed to help mothers who have daughters battling breast cancer. Support services are provided free of charge and include contacts with volunteers through email, letters and phone calls as well as a variety of special publications.

### **National Alliance of Breast Cancer Organizations (NABCO)**

[www.nabco.org](http://www.nabco.org)

NABCO is a non-profit coalition of over 370 organizations that provides breast cancer detection, treatment, and care to women. This site provides information about clinical trials, information about resources on the internet, and links to local breast cancer support groups.

### **SHARE: Self-help for Women with Breast or Ovarian Cancer**

[www.sharecancersupport.org](http://www.sharecancersupport.org)

1501 Broadway, Suite 1720

New York, NY 10036

(212) 719-1204

SHARE is a non-profit organization providing information lines in both English and Spanish for breast and ovarian cancer. They offer information, programs and other resources and support.

### **Y-Me National Breast Cancer Organization – Capitol Area**

[www.y-me.org](http://www.y-me.org)

(703) 461-9616

This organization provides general information about breast cancer support services, information on screening and detection, information for men and women with breast cancer, and information for family members and loved ones. Additionally they provide support group services, information and advocacy.

- Colon Cancer

### **Colon Cancer Alliance (CCA)**

[www.ccalliance.org](http://www.ccalliance.org)

This not-for-profit group is dedicated to finding a cure for and increasing awareness of colorectal cancer. Information on the website includes patient support, education and resources, news and research, and advocacy.

- Leukemia/Lymphoma

### **Lymphoma Research Foundation of America**

[www.lymphoma.org](http://www.lymphoma.org)

This site provides educational and emotional support programs for lymphoma patients and their families.

The Leukemia & Lymphoma Society

[www.leukemia.org](http://www.leukemia.org)

The Leukemia & Lymphoma Society's mission is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and to improve the quality of life of patients and their families. Their quite comprehensive web site provides patient aid, family support, and informational resources geared specifically for those with blood-related cancers.

- Lung Cancer

**American Lung Association of the District of Columbia**

[www.aladc.org](http://www.aladc.org)

H St., NW

Washington, DC 20001-2617

(202) 682-5864

(202) 682-5874 (fax)

The mission of the American Lung Association is to prevent lung disease and promote lung health through advocacy, research, public, patient, and professional education. This site is the site of the DC Chapter, providing information about local offers and programs.

**American Lung Association of Virginia, Northern Virginia Office**

9735 Main Street

Fairfax, VA 22031

(703) 591-4131

(703) 591-0082 (fax)

Email: [northern@lungva.org](mailto:northern@lungva.org)

**American Lung Association of Maryland**

1840 York Rd., Suite M

Timonium, MD 21093-5156

(410) 560-2120

(800) LUNG-USA (MD only)

(410) 560-0829 (fax)

Email: [amerlungmd@amlungmd.com](mailto:amerlungmd@amlungmd.com)

**Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE)**

[www.alcase.org](http://www.alcase.org)

ALCASE is a nonprofit organizations dedicated to helping those living with lung cancer and improve the quality of their lives through advocacy, support and education. Their site provides information on three arms of their mission, advocacy, support and education.

**Lung Cancer Online**

[www.lungcanceronline.org](http://www.lungcanceronline.org)

This site serves as a gateway to lung cancer resources for those with lung cancer and their families. The site has links and listservs for resources concerning care, support, treatment, tests, and procedures for lung cancer.

- Gynecological Cancers

**American College of Obstetrics and Gynecology**

[www.acog.org](http://www.acog.org)

This organization serves to promote patient education and serves as an advocate for quality health care in women.

**Corrine Boyer Fund**

620 University Avenue  
Toronto, CA M5G 2L7  
(415) 971-6888

Email: [cbf@cancercare.on.ca](mailto:cbf@cancercare.on.ca)

The Corrine Boyer Fund was established in 1996 to address the neglect surrounding ovarian cancer. Founded by Patrick Boyer in memory of his wife, Corrine, the fund has 2 missions: raising awareness about cancer of the ovary and increasing financial and educational resources to medial and personal efforts to prevent and successfully treat ovarian cancer.

**The Sandra G. Davis Ovarian Cancer Research Program**

1515 Holcombe Boulevard  
Houston, TX 77030  
(713) 792-2765

This research program was established in 1996 to develop effective screening methods and a cure for ovarian cancer through innovative research into causes, prevention, detection, and treatment. It is comprised of clinical care, community relations, and research. For more information, please contact Raana Burnazian, Community Relations Coordinator at the address above.

**Gilda's Club**

[www.gildasclub.org](http://www.gildasclub.org)  
322 Eighth Avenue, Suite 1402  
New York, NY 10001  
(212) 647-9700

The mission of Gilda's Club is to offer social and emotional support for individuals, families, and friends of those affected by ovarian cancer. Although the main facility is in New York, there are clubs in other cities across the country.

**Gilda Radner Ovarian Cancer Familial Registry**

[www.ovariancancer.com](http://www.ovariancancer.com)  
1-800-OVARIAN  
Roswell Park Cancer Institute  
Elm and Carlton Streets  
Buffalo, NY 14263

The registry tracks families with a history of ovarian cancer, offers a help line, education, information, and peer support for women with high risk (family history) of ovarian cancer.

**Gynecologic Cancer Foundation**

[www.wcn.org](http://www.wcn.org)  
This not-for-profit organization is committed to raising funds to support educational and philanthropic programs, as well as for research of gynecologic cancers. The site works to educate and provide information about disease, treatment, and resources.

### **National Cervical Cancer Coalition**

[www.nccc-online.org](http://www.nccc-online.org)

This site distributes information on cervical cancer, provides support services for women and family members, and assists in efforts related to cervical cancer disease research.

### **National Ovarian Cancer Coalition (NOCC)**

[www.ovarian.org](http://www.ovarian.org)

2335 East Atlantic Boulevard, Suite 401  
Pompano Beach, FL 33062  
888-OVARIAN

NOCC is a national membership organization with state chapters. It promotes awareness and education for the general public and medical community and funding for research to find an early detection mechanism. Offers an informational packet containing a variety of information about ovarian cancer issues and resources.

### **Ovarian Cancer National Alliance**

[www.ovariancancer.org](http://www.ovariancancer.org)

1627 K Street, NW 12<sup>th</sup> floor  
Washington, DC 20006  
(202) 331-1332

The Ovarian Cancer National Alliance's purpose is to increase public and professional understanding of ovarian cancer, and to advocate for more effective diagnostics, treatments, and cure. Available materials include awareness information and national policy issue papers.

### **Ovarian Email Support Group**

This email support group provides survivors, families, and others an opportunity to exchange information and support on a daily basis. However, please note that this list is not monitored for medical accuracy. You can subscribe at <http://www.acor.org>, or send email to: [listserv@acor.org](mailto:listserv@acor.org) (Leave subject area blank or put a dash (-). In message area, type: subscribe ovarian First Name Last Name.)

### **The Ovarian Cancer Research Fund, INC (OCRF)**

One Pennsylvania Plaza, Suite 1610  
New York, NY 10119  
(800) 873-9569  
Email: [jlb@mxbhlny.com](mailto:jlb@mxbhlny.com)

OCRF is a not-for-profit organization dedicated to advancing and supporting laboratory and clinical research that promotes the development of new techniques for early detection, screening, and treatment of ovarian cancer. It also provides educational outreach programs and public awareness projects, including videos about ovarian cancer and resource materials.

**SHARE: Self-help for Women with Breast or Ovarian Cancer**

[www.sharecancersupport.org](http://www.sharecancersupport.org)

1501 Broadway, Suite 1720

New York, NY 10036

(212) 719-1204

SHARE is a non-profit organization providing information lines in both English and Spanish for breast and ovarian cancer. They offer information, programs and other resources and support.

**Women's Cancer Network: Gynecologic Cancer Foundation (GCF)**

[www.wcn.org](http://www.wcn.org)

401 N. Michigan Avenue

Chicago, IL 60611

800-444-4441

GCF is a not-for-profit fund-raising organization whose purpose is to support ovarian cancer research, training of cancer specialists in lab research, and to promote a variety of programs in education and public awareness of gynecologic cancers. Individuals can obtain a list of nearby specialists in gynecologic oncology, a nationwide directory of all Society of Gynecologic Oncologists members, and informational literature.

- Male Genital and Urinary Cancers

**American Foundation For Urologic Disease**

[www.afud.org](http://www.afud.org)

300 W. Pratt Street/ Suite 401

Baltimore, MD 21201-2463

Written Requests Only

This foundation oversees the Bladder Health Council, Prostate Health Council, and the Prostate Cancer Survivor's Network. Write to the above address for information.

**Us Too International, Inc.**

[www.ustoo.com/advocacy.html](http://www.ustoo.com/advocacy.html)

Us Too is a prostate cancer support group organization whose goals are to increase awareness in the community, provide information about treatment and disease, and to offer support groups to men who have been diagnosed. Additionally they offer support groups for women whose loved ones are suffering from prostate cancer. They provide the location of groups in every area of the US and Canada, and the name of the appropriate contact person.

- Oral, Head and Neck Cancers

**Oral Cancer Information Center**

[www.oralcancer.org](http://www.oralcancer.org)

This is a resource for professionals as well as the general public. It is designed to bring as much information on topics related to oral cancer into a single site.

**Support for People with Oral, Head, and Neck Cancer, Inc.**

[www.spohnc.org](http://www.spohnc.org)

This is a patient-directed, self help organization dedicated to meeting the needs of oral, head, and neck cancer.

- Skin Cancer

**Melanoma Patients Information Page**

[www.mpip.org](http://www.mpip.org)

This site provides patients with information and support on melanoma.

**The Skin Cancer Foundation**

[www.skincancer.org](http://www.skincancer.org)

The Skin Cancer Foundation is the only national and international organization that is concerned exclusively with the world's most common malignancy -- cancer of the skin. Their web site provides information on how to perform a self-examination, and more detailed information about the three types of skin cancer, melanoma, basal cell and squamous cell, including presentation of various treatment options.

**Skin Cancer Zone**

[www.skin-cancer.com](http://www.skin-cancer.com)

This site is also known as Melanoma.com. Here, you can get information on skin cancer prevention, self-examination, biopsies, skin safety, and nutrition tips.

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## Information for Minorities

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### **The Black Health Network**

[www.blackhealthnetwork.com](http://www.blackhealthnetwork.com)

The Black Health Network provides information health for African Americans. Expanding beyond cancer, it offers a broad array of articles and allows you to search for a minority physician in your area.

### **Breast Cancer Resource Committee (BCRC)**

[www.afamerica.com/bcrc](http://www.afamerica.com/bcrc)

2005 Belmont St. NW  
Washington, DC 20009  
202-463-8040

BCRC is dedicated to educating and supporting the African-American community through a broad-based breast cancer awareness campaign that includes a variety of initiatives. This web site provides more information about their organization and initiatives and other services they provide with regards to breast cancer.

### **Celebrating Life**

[www.celebratinglife.org](http://www.celebratinglife.org)

The Celebrating Life Foundation is one of the leading foundations in the nation that promote breast cancer awareness specifically targeting African American women and women of color. Their site provides information about breast cancer, screenings, events and support groups throughout the country.

### **Office of Minority Health Resource Center**

[www.omhrc.gov](http://www.omhrc.gov)

PO Box 37337  
Washington, DC 20013  
800-444-6472

A service of the Office of Minority Health, this site contains information on a variety of subjects that affect the health of minorities, including cancer.

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## Emotional Support

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### **American Brain Tumor Association**

[www.abta.org/resources/index.html](http://www.abta.org/resources/index.html)

Within the American Brain Tumor Association Website, find help in their “Comfort and Resources” section. Link here to read other people’s stories of hope, get information about managing side effects and symptoms, and connect to a pen pal.

### **Avon Cares Program**

[www.cancercare.org/people/financial/financial\\_18831.asp](http://www.cancercare.org/people/financial/financial_18831.asp)

Avon Cares is a program that will provide financial assistance, education & support services for women with breast, ovarian or cervical cancer. See their site for details.

### **Cancer Care, Inc.**

[www.cancercare.org/index.asp](http://www.cancercare.org/index.asp)

1180 Avenue of the Americans

New York, NY 10036

(212) 302-2400

(800)-813-HOPE

(212) 719-0263 (fax)

Cancer Care is a non-profit organization whose mission is to provide free professional help for people with all cancers through counseling, education, information, referral and direct financial assistance. Within the site you will find opportunities for teleconferences, online professional counseling and facilitated support groups.

### **Cancer Hope Network**

[www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)

Provides support by matching patients with trained volunteers who have themselves undergone a similar experience.

### **FORCE: Facing Our Risk of Cancer Empowered**

[www.brca.com](http://www.brca.com)

This non-profit organization was designed for women who are at high risk of developing cancer due to family history and/or genetic status. The website provides resources, legislation information, chat rooms, and message boards.

### **Gilda’s Club**

[www.gildasclub.org](http://www.gildasclub.org)

322 Eighth Avenue, Suite 1402

New York, NY 10001

(212) 647-9700

The mission of Gilda’s Club is to offer social and emotional support for individuals, families, and friends of those affected by ovarian cancer. Although the main facility is in New York, there are clubs in other cities across the country.

### **Mary Helen Mautner Project for Lesbians with Cancer**

[www.mautnerproject.org](http://www.mautnerproject.org)

This web site provides education about lesbians' cancer risks, needs, care, and support programs in the DC area. The Project also offers counseling and support groups and can provide assistance with medical needs including transportation to appointments, grocery shopping, and childcare.

### **Mothers Supporting Daughters with Breast Cancer**

[www.mothersdaughters.org](http://www.mothersdaughters.org)

21710 Bayshore Road  
Chestertown, MD 21620-4401  
(410) 778-1982.

This organization is designed to help mothers who have daughters battling breast cancer. Support services are provided free of charge and include contacts with volunteers through email, letters and phone calls as well as a variety of special publications.

### **National Coalition for Cancer Survivorship**

[www.cansearch.org/programs/index.html](http://www.cansearch.org/programs/index.html)

Within the National Coalition for Cancer Survivorship website, learn about survivorship programs, including "Ribbon of Hope" and "Cancer Survival Toolbox".

### **The National Self-Help Clearinghouse**

<http://selfhelpweb.org>

The National Self-Help Clearinghouse is a not-for-profit organization that was founded in 1976 to facilitate access to self-help groups and increase the awareness of the importance of mutual support. The web site helps facilitate access to appropriate support.

### **Ovarian Email Support Group**

This email support group provides survivors, families, and others an opportunity to exchange information and support on a daily basis. This list is not monitored for medical accuracy. You can subscribe at <http://www.acor.org>, or send email to : [listserv@acor.org](mailto:listserv@acor.org) (Leave subject area blank or put a dash (-). In message area, type: subscribe ovarian First Name Last Name.)

### **SHARE: Self-help for Women with Breast or Ovarian Cancer**

[www.sharecancersupport.org](http://www.sharecancersupport.org)

1501 Broadway, Suite 1720  
New York, NY 10036  
(212) 719-1204

SHARE is a non-profit organization providing information lines in both English and Spanish for breast and ovarian cancer. They offer information, programs and other resources and support.

**Sibling Support Project**

<http://seattlechildrens.org/sibsupp/>

This support program focuses on the interests of siblings of people with special health and developmental needs.

**The Wellness Community**

[www.wellness-community.org](http://www.wellness-community.org)

The Wellness Community provides a full range of support services for people with cancer and their loved ones, free of charge. Offerings include support groups, networking groups, educational workshops and stress reduction sessions.

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## Health and Wellness

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- General Health and Wellness

### **Encore Plus**

YWCA of the USA/ Office of Women's Health Initiatives  
624 9<sup>th</sup> Street NW/3<sup>rd</sup> floor  
Washington, DC 20001-5394  
(202) 628-3636

Encore Plus provides screening and support services to medically underserved women over 50 and offers a unique combined peer group and support and exercise program. Call for details and eligibility criteria.

### **Estronaut**

[www.estronaut.com/n/cancer.htm](http://www.estronaut.com/n/cancer.htm)

Estronaut is considered a forum for women's health. As a web site, they focus on the many different aspects of health and women. The link above will bring you directly to their site on cancer, which includes a variety of articles and online support groups.

### **Genetics: Building and Understanding Your Medical Family History**

[www.jamesline.com/output/genwkbk/genwkbk.htm](http://www.jamesline.com/output/genwkbk/genwkbk.htm)

This site will aid you in building and understanding your medical family history and assessing your cancer risk. It discusses the importance of doing a medical family tree.

### **Health World Online**

[www.healthy.net](http://www.healthy.net)

This site is an online health resource center that offers information, products, and services that promote a healthy lifestyle.

- Diet and Nutrition

### **American Institute for Cancer Research**

[www.aicr.org](http://www.aicr.org)

1759 R Street NW  
Washington, DC 20009  
1-800-843-8114  
(202)328-7744

Based on the premise that most cancers can be prevented, the American Institute for Cancer Research is a national cancer organization specializing in the field of diet, nutrition, and cancer. On their site you'll find news, research updates, recipes, free publications and tips for good health.

### **Cancer Nutrition Center**

[www.cancernutrition.com](http://www.cancernutrition.com)

The Cancer Nutrition Center site will help you understand that impact of nutrition on your health. Recommendations for diet during treatments are available, as well as general diet and nutrition recommendations.

### **Cyberdiet**

[www.cyberdiet.com](http://www.cyberdiet.com)

The Cyberdiet web site will help you to understand cancer, protective food practices, supportive diets, living well, and resources. Specifics for breast, colorectal & prostate cancer are available on the site.

### **DrKoop.com Diet and Cancer Risk**

[http://digitalcity.drkoop.com/family/mens/nutrition/cancer\\_diet.asp](http://digitalcity.drkoop.com/family/mens/nutrition/cancer_diet.asp)

The site presents the big picture of diet and cancer risk. Articles provide dietary recommendations as well as information on what nutrients can do for you, fat and calories, fiber, non-nutrient food components, protein, selenium, vitamins, effects of other substances and things to avoid.

### **Health Central – General Encyclopedia – Diet for Cancer**

[www.healthcentral.com/mhc/top/002439.cfm?src=ls](http://www.healthcentral.com/mhc/top/002439.cfm?src=ls)

This section of the Health Central web site provides a recommended diet for cancer including food sources, functions, recommendations and using diet to help manage treatment side effects.

### **OncoLink – Cancer Causes, Screening, and Prevention**

[www.oncolink.com/templates/coping/coping.cfm?c=3](http://www.oncolink.com/templates/coping/coping.cfm?c=3)

A section of UPenn's Oncolink, the above is a link to their section on diet and cancer. It includes numerous articles and Q&A.

- Alternative, Holistic and Complimentary Medicine

### **The Academy for Guided Imagery**

[www.healthy.net/agi/index\\_ie.html](http://www.healthy.net/agi/index_ie.html)

The mission of the Academy for Guided Imagery is to teach people to access and use the power of the mind/body connection for healing. On their web site you'll find a directory of certified practitioners, training, books, tapes, and self-healing tools and information.

### **Alternative Medicine**

[www.pitt.edu/~cbw/condit.html#cancer](http://www.pitt.edu/~cbw/condit.html#cancer)

Part of the University of Pittsburgh's Alternative Medicine web site, this specific link will bring you to information in alternative medicine specific to cancer. You'll find information on unconventional, unorthodox, unproven, or alternative, complementary, innovative, integrative therapies.

### **Cancerpage**

[www.cancerpage.com/](http://www.cancerpage.com/)

Created for patients and their loved ones, Cancerpage is a source for the latest news, research, and information on prevention, detection, and cancer treatment. Center for Mind-Body Medicine

[www.cmbm.org](http://www.cmbm.org)

The Center for Mind-Body Medicine is a non-profit, educational organization dedicated to reviving the spirit and transforming the practice of medicine. Their care model combines the precision of modern science with the wisdom of ancient healing, addressing the mental, emotional, social and spiritual, as well as the physical dimensions of health and illness. Through their web site are offered educational programs, support groups and a newsletter on advances in mind-body medicine.

### **Holistic Healing Web page**

[www.holisticmed.com](http://www.holisticmed.com)

This web site contains articles and documents concerning Holistic medicine. There is also assistance in locating a holistic provider in your area.

### **The Mind/Body Connection**

[www.mindbodymed.com](http://www.mindbodymed.com)

This site offers a new approach to health and healing which honors the patient as a "whole" person, addressing the physical, mental, emotional and spiritual components of health and healing.

### **Natural Health and Longevity Resource Center**

[www.all-natural.com](http://www.all-natural.com)

The Natural Health and Longevity Resource Center provides the latest news in natural health, alternative medicine, and other nutritional therapies. A section on recent articles as well as recommendations of books on health is listed.

- **Books and Publications**

*Good Nutrition: Guidebook for the Cancer Patient* (free)

Write to: Central Pennsylvania Oncology Group, C-152  
P.O. Box 850  
The Milton Hershey Medical Center  
Hershey, PA 17033

*Eating Hints: Recipes and Tips for Better Nutrition During Cancer Treatment* (free)

Write to: Office of Cancer Communications  
National Cancer Institute  
Building 31, Rm. 10A18  
Bethesda, MD 20205

Fishman, Joan, and Graham, Joey. *Something's Got to Taste Good*. Andrews and McMeel, 1981. Available in most bookstores.

*Sexuality and Cancer: For the Woman Who Has Cancer and Her Partner.*

*Sexuality and Cancer: For the Man Who Has Cancer and His Partner.*

Available through your local American Cancer Society office.

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## Personal Services

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- Practical Support (financial, equipment, wigs, etc)

### **American Cancer Society (ACS)**

(202) 483-2600

The American Cancer Society offers wigs to those undergoing cancer treatment—FREE OF CHARGE! Call for details.

### **Arlington County Aging and Disability Services**

[www.co.arlington.va.us/dhs/aging/progdsc.htm](http://www.co.arlington.va.us/dhs/aging/progdsc.htm)

Various information on topics such as chronic disease nursing case management, financial assistance, food stamps, prescription medication program and senior centers with congregate meals.

### **Cancer Directory – Products and Services**

[www.cancerdirectory.com/prodsvcs.htm](http://www.cancerdirectory.com/prodsvcs.htm)

Products and services designed for people with special needs, some of which include: skin care, apparel, incontinence, breast forms, prosthetics, hats & turbans, mastectomy products, wigs.

### **Compression Garments**

[www.ghccusa.com/html/cmpdept.html](http://www.ghccusa.com/html/cmpdept.html)

Graduated compression stockings in a wide range of compressions, sizes, styles and colors. Also, a wide variety in ready-to-wear, and certified fitters who can fit custom-made garments.

### **Look Good...Feel Better**

[www.lookgoodfeelbetter.org/1.00.html](http://www.lookgoodfeelbetter.org/1.00.html)

1100 Connecticut Ave, NW

Washington, DC 20036

(800) 395-LOOK

A free, national public service program dedicated to teaching women cancer patients beauty techniques to help restore their appearance and self-image during cancer treatment.

### **Meals on Wheels of Central Maryland**

[www.emsals.org](http://www.emsals.org)

Provides nutritious meals, personal contact and related services.

**Self-Help Clearinghouse of Greater Washington, DC, Northern VA, Southern MD**

C/O Mental Health Association of Northern Virginia

7630 Little River Turnpike #206

Annandale, VA 22003

(703) 941-LINK

This is a hotline providing self-help information and referrals.

- Transportation

**Corporate Angel Network**

[www.corpangelnetwork.org](http://www.corpangelnetwork.org)

914-328-1313

Corporate Angel Network provides FREE air transportation for cancer patients traveling to and from recognized treatment centers in the U.S., without regard to their financial resources. Call or visit their website for details and eligibility criteria.

**Montgomery County Transit Services Division**

[www.dpwt.com/TransSvcDiv/Seniors.htm](http://www.dpwt.com/TransSvcDiv/Seniors.htm)

This web site provides information on transportation services for seniors and persons with disabilities in Montgomery County.

**Washington Elderly Handicapped Transportation Service**

[www.wehts.org](http://www.wehts.org)

This site provides information on basic life support transportation for senior citizens in the District of Columbia, along with information on Call 'N' Ride and Home Delivery Meals.

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## Resources for Professionals

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### **American Brain Tumor Association (ABTA)**

[www.abta.org/professionals/index.html](http://www.abta.org/professionals/index.html)

Within the American Brain Tumor Association website, this link is for professionals. You will find listings of journal links, available funding for research, current ABTA research, patient education tools, and more.

### **American Society of Clinical Oncology (ASCO)**

[www.asco.org](http://www.asco.org)

225 Reinekers Lane, Suite 650

Alexandria, VA 22314

(703) 299-1010

ASCO is the world's leading professional society representing physicians who treat those with cancer. The website has a section devoted to "People Living With Cancer", and presents the latest research presented at ASCO meetings.

### **Cancer Source MD**

[www.cancersourcemd.com](http://www.cancersourcemd.com)

CancerSource MD is designed specifically for physicians and their informational needs. Topics covered include patient education, cancer news, continuing education, drug databases, and reference materials.

### **Cancer Source RN**

[www.cancersourcern.com](http://www.cancersourcern.com)

CancerSource RN is designed specifically for nurses and their informational needs. Topics covered include patient education, cancer news, continuing education, drug databases, and reference materials.

### **Society of Gynecologic Oncologists (SGO)**

[www.sgo.org](http://www.sgo.org)

401 N. Michigan Avenue

Chicago, IL 60601

The SGO is a professional organization of specialists trained in obstetrics and gynecology, and who are all qualified to participate in effective forms of treatment for women with gynecologic cancers.

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## Resources for Caregivers

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### **Administration on Aging – Caregiver Resources**

[www.aoa.dhhs.gov/caregivers/default.htm](http://www.aoa.dhhs.gov/caregivers/default.htm)

Eldercare locator, information for older persons and families, resource directory, etc.

### **Administration on Aging – Caregiver Resources in Spanish**

[www.aoa.dhhs.gov/espanol/default.htm](http://www.aoa.dhhs.gov/espanol/default.htm)

### **Cancer Care’s Section for Caregivers**

<http://www.cancercare.org/managing/caregivers>

Various information about, and for, caregivers such as what does it take to be a successful caregiver, hints for dealing with treatment side effects, emotional issues for caregivers and patients, caregivers and the workplace, and links to online resources.

### **Cancerpage**

[www.cancerpage.com/](http://www.cancerpage.com/)

Created for patients and their loved ones, Cancerpage is a source for the latest news, research, and information on prevention, detection, and cancer treatment.

### **Caregiver Survival Resources**

[www.caregiver911.com](http://www.caregiver911.com)

Information on the cancer survivor series books, organizations, resources, and internet links.

### **Holy Cross Resource Institute, Caregiver Resource Center**

9805 Dameron Drive

Silver Spring, MD

(301) 754-7152

Holds 3 weekly caregiver support groups, a monthly caregiver education program, and holds books and tapes on caregiving and health topics.

### **National Family Caregivers Association**

[www.nfcacares.org](http://www.nfcacares.org)

9621 East Bexhill Drive

Kensington, MD 20895

1-800-896-3650

Provides research, education, support, and respite care to caregivers of cancer patients.

### **Today’s Caregiver Online**

[www.caregiver.com](http://www.caregiver.com)

Contains information about “Today’s Caregiver Magazine”.

**University of Pennsylvania Cancer Center**

[www.oncolink.upenn.edu/templates/coping/coping.cfm?c=1](http://www.oncolink.upenn.edu/templates/coping/coping.cfm?c=1)

This website offers online information for caregivers including courses offered, cancer news, emotional support links, and sign-up for email discussion groups.

- Books and Publications

Beresford, Larry. *The Hospice Handbook*. Little, Brown and Co.; 1993, 165 pages. How to find the right hospice, how to determine eligibility, the right questions to ask, how to get the best care for your money.

Caposella, Cappy, and Warnock, Sheila. *Share the Care*. Fireside Books/Simon & Schuster; 1995, 287 pages. Practical and inspirational guide to setting up support groups.

Carter, Rosalynn. *Helping Yourself Help Others: A Book for Caregivers*. Random House; 1994, 278 pages. Many personal stories explain emotions, medical and family issues. Resource listings.

Heath, Angela. *Long Distance Caregiving*. American Source Books; 1991, 123 pages. Defines caregiving issues, tips for traveling, finding help in the aging network, legal and financial paperwork, care plans, relocation.

Karr, Katherine L. *Taking Time for Me: How Caregivers Can Effectively Deal With Stress*. Prometheus Books; 1992, 179 pages. Personal accounts demonstrate how to renew strength without jeopardizing care.

Lustbader, Wendy. *Counting on Kindness: the Dilemmas of Dependency*. The Free Press; 1994, 206 pages. True stories and quotations explore issues of power and dependency, handling regret, reviving self-esteem.

McFarlane, Rodger, and Bashe, Philip. *The Complete Bedside Companion*. Simon & Schuster; 1998, 544 pages. Chapters explain the health care team, dealing with doctors, essential nursing skills, caring for the caregiver.

McLoed, Beth Writogen. *Caregiving: The Spiritual Journey of Love, Loss, and Renewal*. John Wiley and Sons, Inc.; 1999, 259 pages. Narration of her personal experience for caring for her parents.

Meyer, Maria M. with Derr, Paula. *The Comfort of Home, An Illustrated Step-by-Step Guide for Caregivers*. CareTrust Publications, 1999, 364 pages. Practical, easy-to-follow resource designed to help untrained caregivers understand what help is needed and learn where to find it or how to provide it themselves.

Pitzele, Sefra Kobrin. *Kind Words for Caring People: Daily Affirmations for Caregivers*. Health Communications; 1992, 365 pages. Messages of hope to begin each day.

Pollin, Irene, with Golant, Susan K. *Taking Charge: Overcoming the Challenges of Long-Term Illness*. Times Books; 1994, 255 pages. Sensitively and graphically describes strategies to help patients and families cope.

Sankar, Andrea. *Dying at Home: A Family Guide to Caregiving*. New York: Johns Hopkins University Press; 1991, 257 pages. Making the decision, financial and legal matters, professional caregivers, and caregiver well-being.

Sherman, James R. *Caregiver Survival Series*. Pathway Books, P.O. Box 27790, Golden Valley, MN 55427-0790; 1-800-958-3375; [www.caregiver911.com](http://www.caregiver911.com). All titles \$9.95. Titles include:

- *Preventing Caregiver Burnout*(1997) *Strategies for retaining vitality*.
- *Creative Caregiving*(1997) *How to work smarter, not harder*.
- *Coping With Caregiving Worries*(1997) *Techniques for conquering common caregiver worries such as fear*.

Susik, D. Helen. *Hiring Home Caregivers: the Family Guide to In-Home Eldercare*. Imprint Publishers/American Source Books; 1995, 200 pages. Practical guide to hiring competent, reliable, affordable help at home.

*Today's Caregiver Magazine*. Published 6 times a year/\$18. P.O. Box 21646, Ft. Lauderdale, FL 33335; 1-800-829-2734. Web Site: [www.caregiver.com](http://www.caregiver.com). Helpful information for all family and professional caregivers.

Visiting Nurse Associations of America, *Caregiver's Handbook: A Complete Guide to Home Health Care*. DK Publishing; 1998, pages. Chapters include "Communication", "Healthy Eating & Drinking", and "Adapting the Home"

Williams, Gene B. and Kay, Patie. *The Caregiver's Manual*. Citadel Press; 1995, 366 pages. Chapters on aging, financial and legal matters, family dynamics, how to say good-bye.

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## **Pain and Symptom Management**

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### **American Chronic Pain Association**

[www.theacpa.org](http://www.theacpa.org)

A support and information service for people in chronic pain.

### **American Pain Foundation (Baltimore)**

[www.painfoundation.org](http://www.painfoundation.org)

This site is an online resource for people with pain, their families, friends, caregivers, and the general public.

### **American Pain Society**

[www.ampainsoc.org](http://www.ampainsoc.org)

This is a non-profit information resource and patient advocacy organization serving people with pain.

### **City of Hope Pain & Palliative Care Resource Center**

<http://mayday.coh.org>

The purpose of this center is to make available information and resources that will enable other individuals and institutions to improve the quality of pain management.

### **National Lymphedema Network**

[www.lymphnet.org](http://www.lymphnet.org)

A nonprofit organization providing telephone support, education referral to lymphedema treatment centers and equipment supplies, and a pen-pal program.

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## Pharmacy and Drugs

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### **Captain Chemo**

[www.royalmarsden.org/captchemo/index.asp](http://www.royalmarsden.org/captchemo/index.asp)

The superhero briefs players on the symptoms and treatments of cancer before challenging them to answer a few related questions. Especially good for teenagers.

### **FDA Cancer Liaison Program**

[www.fda.gov/oashi/cancer/cancer.html](http://www.fda.gov/oashi/cancer/cancer.html)

Provides information and help to cancer patients and cancer patient advocacy programs about the FDA drug approval process, cancer clinical trials and access to investigational therapies.

### **Medication Manufacturers' Indigent Drug Programs**

[www.cancercare.org/hhrd/drug\\_assistance.asp#medication](http://www.cancercare.org/hhrd/drug_assistance.asp#medication)

A list of companies that provide medications to people who cannot afford them.

### **State Pharmaceutical Assistance Programs**

[www.cancercare.org/hhrd/drug\\_assistance.asp#state](http://www.cancercare.org/hhrd/drug_assistance.asp#state)

Maryland Pharmacy Assistance Program address and phone number

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## Clinical Trials

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### **Cancer Care's Clinical Trials Information**

[www.cancer.org/managing/trials/index.asp](http://www.cancer.org/managing/trials/index.asp)

Cancer Care's information about clinical trials. Clinical trials available from NCI and also through CenterWatch, Inc.

### **Center Watch Clinical Trials List -Serv**

[www.centerwatch.com](http://www.centerwatch.com)

The CenterWatch Clinical Trials Listing Service has a searchable database of current clinical trials of all areas of medicine, including cancer.

### **Clinical Trials**

<http://clinicaltrials.gov/ct/gui>

Provides patients and family members current information about clinical research studies.

### **NCI's Clinical Trails Information Page**

[www.cancer.gov/clinical\\_trials/](http://www.cancer.gov/clinical_trials/)

Link to NCI's information about clinical trials

### **NCI's Clinical Trials Page for Military Personnel**

[www.cancer.gov/search/clinical\\_trials/va\\_military/](http://www.cancer.gov/search/clinical_trials/va_military/)

Link directly to the National Cancer Institute's search page for clinical trials for military personnel (active/vets) and their dependents.

### **NCI's Clinical Trials Search Page**

[www.cancer.gov/search/clinical\\_trials/](http://www.cancer.gov/search/clinical_trials/)

Link directly to the National Cancer Institute's search page for clinical trials.

### **Patient Centers' site on Clinical Trials**

[www.patientcenters.com/trials/](http://www.patientcenters.com/trials/)

Provides advice for patients considering clinical trials, as well as a number of resources and book listings for those considering clinical trials.

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## Survivorship

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### **The Cancer Survivor's Toolkit**

[www.cansearch.org/programs/toolbox.html](http://www.cansearch.org/programs/toolbox.html)

A free set of audio tapes to help cancer survivors learn how to communicate, find information, solve problems and advocate.

### **Greater Washington Coalition for Cancer Survivors**

[www.gwccs.org](http://www.gwccs.org)

4848 Albemarle Street

Washington, DC 20016-4347

(202) 364-6422

Provides an all-volunteer support network for cancer survivors, their families, friends, and caregivers; disseminates information about cancer care and survivor issues.

### **National Coalition for Cancer Survivorship**

[www.cansearch.org](http://www.cansearch.org)

1010 Wayne Avenue/Suite 300

Silver Spring, MD 20910

1-877-NCCS-YES (1-877-622-7937) or (301) 585-2616

This is a volunteer group concerned by issues faced by people with cancer and people who have recovered from cancer. Their website details public health and policy issues, conferences and events, and media alerts. Provides survivors and patients with a step-by-step guide to the cancer resources found on the web.

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## End of Life Decisions

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### **Advanced Cancer – Living each day**

[www.cancer.gov/cancer\\_information/doc\\_img.aspx?viewid=6f41bff7-8b57-4e2e-9198-4b19b171eba0](http://www.cancer.gov/cancer_information/doc_img.aspx?viewid=6f41bff7-8b57-4e2e-9198-4b19b171eba0)

This online booklet was written to help persons who are struggling with advanced or terminal disease.

### **Before I Die – PBS Online**

[www.thirteen.org/bid/issues.html](http://www.thirteen.org/bid/issues.html)

Before I die: Medical Care & Personal Choices....a PBS online program that explores the medical, ethical, and social issues surrounding end-of-life care.

### **Cancer Care - End of Life**

[www.cancercare.org/managing/concerns/index.asp](http://www.cancercare.org/managing/concerns/index.asp)

To help patients and family members access quality care throughout their cancer experience – especially at the end of life by offering a safe, supportive environment to explore their changing physical, emotional, and spiritual needs.

### **Partnership for Caring**

[www.partnershipforcaring.org/HomePage](http://www.partnershipforcaring.org/HomePage)

Partnership for Caring: American’s Voices for the Dying is a national nonprofit organization that partners individuals and organizations in a powerful collaboration to improve how people die in our society.

### **Growth House**

[www.GrowthHouse.org](http://www.GrowthHouse.org)

This award-winning website provides resources for life-threatening illness and end-of-life care. Its primary mission is to improve quality of life for patients through public education and global professional collaboration.

### **Last Acts**

[www.lastacts.org](http://www.lastacts.org)

“Last Acts” is a call-to-action campaign whose mission is to improve care at the end of life. News on death and dying issues, etc.

- Hospice and Palliative Care Organizations

**Hospice Association of America**

[www.nahc.org/HAA/](http://www.nahc.org/HAA/)

Offers a consumer guide, hospice facts, a hospice bill of rights, and listings by state of member organizations to help you find local services.

**Hospice Net**

[www.hospicenet.org/html/without\\_meds.html](http://www.hospicenet.org/html/without_meds.html)

Provides advice on how to relieve pain without the use of medications.

**The Hospices of the National Capital Area**

[www.hospiceonline.org](http://www.hospiceonline.org)

Links to services offered by the various hospices throughout the National Capital Area, including inpatient hospice care, bereavement services, and corporate and community outreach.

**Homecare Online, Sponsored by the National Association for Home Care**

[www.nahc.org/Consumer/coninfo.html](http://www.nahc.org/Consumer/coninfo.html)

59 C Street NE, Stanton Park

Washington, DC 20002

(202) 547-7424

Information on how to choose providers for home care and hospice care. Ask for a copy of the pamphlet, "How To Select a Home Care Agency" (cost \$1.25).

**National Hospice and Palliative Care Organization**

[www.nhpc.org](http://www.nhpc.org)

Helpline: 800-658-8898

The NHPCO is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for dying patients and their loved ones. They offer information on local hospice and palliative care programs across the country. Go to: <http://www.nhpc.org/Directory/> to search for a hospice in your area.

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## Grief and Bereavement

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- Emotional Support Information

### **AARP's Coping with Grief and Loss Web Site**

[www.aarp.org/griefandloss/home.html](http://www.aarp.org/griefandloss/home.html)

Information from the American Association of Retired Persons on grief, common reactions, and coping strategies.

### **AARP's Widowed Person's Service**

601 E St. NW

Washington, DC 20049

(202) 434-2260

An outreach program in which trained widowed volunteers offer support to newly widowed persons in communities nationwide. Also offers free assistance and resources to communities who wish to develop WPS programs.

### **The Association for Death Education and Counseling**

[www.adec.org](http://www.adec.org)

The Association for Death Education and Counseling is a multi-disciplinary professional organization dedicated to promoting excellence in death education, bereavement counseling, and care of the dying.

### **Bereaved Families Online Support Center**

[www.bereavedfamilies.net](http://www.bereavedfamilies.net)

Online support for people who have lost a family member.

### **Beyond Indigo**

[www.death-dying.com](http://www.death-dying.com)

Provides articles and links for those who have recently lost a loved one.

### **Counseling For Loss**

[www.counselingforloss.com](http://www.counselingforloss.com)

Provides professional services, grief links and resources, and weekly columns dealing with grief and bereavement.

### **Cancer Care**

[www.cancercare.org/managing/grief/index.asp](http://www.cancercare.org/managing/grief/index.asp)

Cancer Care's support for the bereaved. Provides information about grieving.

[www.cancercare.org/forms/general\\_bereavement.asp](http://www.cancercare.org/forms/general_bereavement.asp)

Online Bereavement support group

**Grief and Loss Center**

Hospice of Northern Virginia  
6565 Arlington Blvd. Suite 500  
Falls Church, VA 22042  
(703) 538 – 2047

This center provides counseling and referrals, weekly support groups, bereavement lecture series, camps for grieving children, and more to individuals grieving the loss of a loved one.

**Grief Net**

[www.rivendell.org](http://www.rivendell.org)

Grief Net provides email support groups, assistance for children suffering from grief, and advice about dealing with grief.

**Groww**

[www.groww.org](http://www.groww.org)

GROWW, Grief Recovery Online, is a not-for-profit internet community for anyone who has lost or is losing a loved one to death.

**Hospice Net – Resources for the Grieving**

[www.hospicenet.org/index.html](http://www.hospicenet.org/index.html)

A guide to grief, this site provides suggestions for getting through the holidays, special readings, and much more.

**National Family Caregivers Association Bereavement Kit**

[www.nfcacares.org/brevemnt.html](http://www.nfcacares.org/brevemnt.html)

Bereavement Kit offered for former caregivers whose patients have passed away.

**St. Francis Center**

[www.dccare.org/spsfc.htm](http://www.dccare.org/spsfc.htm)

4880-A MacArthur Blvd., NW  
Washington, DC

(202)333-4880 Contact: Judy Gregory Bowes, MSW

St. Francis Center (non-sectarian) specializes in support to people affected by all types of illness, loss, and grief. Services include counseling for adults and children in individual, family, and group settings; grief awareness and education/training for schools, work places and religious institutions, mental health and health professionals. There is also a volunteer program offering emotional and practical support for children, adolescents, and adults living with illness, loss, or grief.

### **They Help Each Other Spiritually (THEOS)**

717 Liberty Ave.  
1301 Clark Bldg.  
Pittsburgh, PA 15222  
(412) 471-7779

This is a national association assisting widowed persons of all ages and their families to rebuild their lives through mutual self-help.

### **To Live Again**

P.O. Box 415  
Springfield, PA 19064

“To Live Again” is a mutual help organization for widowed women and men supporting themselves through the grief cycle.

### **Tom Golden Website**

[www.webhealing.com](http://www.webhealing.com)

Tom Golden, a licensed clinical social worker from Washington, DC and author of multiple books on the subject of grief and loss, presents his own website with articles, links, discussions, and workshop information.

### **WidowNet**

[www.fortnet.org/WidowNet/index.html](http://www.fortnet.org/WidowNet/index.html)

Created for and by widows and widowers, WidowNet provides useful information for the grieving and lists some local support groups in MD, DC, and VA for those coping with the death of a spouse.

### **William Wendt Center for Loss and Healing**

[www.lossandhealing.org](http://www.lossandhealing.org)

202-333-4880

The William Wendt Center for Loss and Healing is a non-sectarian, non-profit organization offering guidance, information, and support for people living with illness, loss, and bereavement. The Center counsels and supports adults, children, and families. Located right here in DC, the Center provides support groups and resources valuable in coping with the impact of cancer.

- Camps and Retreats

**Point of Hope Camp**

[www.hospiceonline.org/camp.html](http://www.hospiceonline.org/camp.html)

Provides information about “Point of Hope Camp”, sponsored by the Hospices of the National Capital Region for children grieving the loss of a loved one.

- Books and Publications

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Harris Ph.D., Maxine *The Loss That Is Forever: The Lifelong Impact of the Early Death of a Mother or Father*. E.P. Dutton; September 1995, 342 pages.

James, John W. and Friedman, Russell. *The Grief Recovery Handbook - the Action Program For Moving Beyond Death, Divorce, and Other Losses*. HarperTrade; June 1998, 173 pages.

Staudacher, Carol. *Beyond Grief: A Guide for Recovering from the Death of a Loved One*. New Harbinger Publications; April 1987, 264 pages.

Staudacher, Carol. *Men and Grief: A Guide for Men Surviving the Death of a Loved One: A Resource for Caregivers and Mental Health Professionals*. New Harbinger Publications; May 1991, 225 pages.

Wiersbe, Warren W. & David Wiersbe. *Comforting the Bereaved*. Moody Press: September 1985, 150 pages.

Zonnebelt-Smeenge, Susan, DeVries, Robert, DeVries, Bob. *Getting to the Other Side of Grief: Overcoming the Loss of a Spouse*. Baker Book House; January 1999, 208 pages.