

Section VII

Patient Support Materials, Including Self-Help Group Resources

Many of the general physician associations, specialty and state societies, and other organizations in the preceding sections prepare and distribute patient support materials related to specific health conditions and population groups. Some of these materials have culturally sensitive content or are printed in various languages. Please contact the organizations listed in previous sections for information about their culturally relevant patient support materials. These organizations may also be able to provide you with information about consumer groups related to specific diseases or special populations.

This section provides background information on American Medical Association (AMA) policies and activities and describes some patient support materials, especially self-help group resources, with which physicians may not be familiar. Physicians can contact the American Self-Help Clearinghouse for information about national consumer and self-help groups. Local clearinghouses, such as the Illinois Self-Help Coalition, can provide information about local groups.

Self-help groups have been recognized by federal agencies and health care and educational institutions as important sources of patient/public information and support. A recent survey conducted by Tom Ferguson, MD (doctom@doctom.com) indicates that more and more consumers are consulting online with people with the same condition, not only for emotional support but also for information and treatment options. *Unfortunately, racial, ethnic, and socioeconomically underserved and underrepresented nonmajority populations have limited access to self-help groups and the special kinds of support they provide.*

Although some professionals express concern about the possibility that self-help groups may discourage members from seeking needed medical attention and may encourage the use of unhealthy complementary practices, research studies do not support these concerns. Dr. Ferguson suggests ways in which physicians can cooperate with self-help and other consumer groups to improve patient-centered care and encourage appropriate self-care.

The AMA and Self-Help Groups

The AMA, while acknowledging concerns about the safety and efficacy of self-help groups, has included references to the importance of peer support in several policies, including those related to the environment of medical education. In past years, the National Leadership Development Conference has featured self-help groups for a variety of conditions, and *AMNews* has published numerous articles about the benefits of peer support, including groups specifically for physicians.

In 1986, AMA staff approached then-Surgeon General C. Everett Koop, MD, about devoting one of his Surgeon General's Workshops to the need for improving communication between professionals and self-help groups to maximize the benefits of this underutilized army of volunteers. A self-help group advocate from his early days in practice, when he organized support groups for staff dealing with the loss of pediatric patients, Dr. Koop had incorporated self-help groups in several of his workshops, some of which were attended by AMA leadership. The 1987 Surgeon General's Workshop on Self-Help and Public Health culminated in a publication and a symposium in 1989, cosponsored by the Illinois Self-Help Center and the AMA. The 16 Surgeon General's recommendations continue to serve as a blueprint for encouraging greater understanding of the contributions of self-help groups and their potential for improving the health of the public.

Dr. Koop also supported the organization of the National Council on Self-Help and Public Health, which, during his tenure, succeeded in incorporating self-help group awareness in all eight public health agencies. Several of the agencies now include self-helpers on the panels that determine priorities and funding directions. The National Council was also successful in getting specific objectives related to self-help groups and clearinghouses included in *Healthy People 2000: Objectives for the Nation*. The AMA role in these and others efforts is summarized in *Self-Help Concepts and Applications*, Charles Press, 1992.

Peer Support Stronger Than Willpower

National organizations and federal agencies are continuing to recognize the contributions of peer education and support. A panel established to review how the culture and programs of the National Cancer Institute (NCI) and the National Institutes of Health (NIH) address the needs of ethnic minorities concluded that the agencies fall short in their efforts. The panel recommended that the NCI and NIH tap cancer survivors in ethnic minority groups “as important resources for educating others in the community about cancer” and for providing information about cancer to patients, clinicians, and others in ethnic minority and underserved populations.

The same techniques used to help members cope with the health challenges that drew them together—sharing stories, offering constructive advice, and mentoring—have been found to promote healthy behaviors that can have a positive effect on disease states. The findings of Dean Ornish, MD, about the benefits of meeting with peers with heart disease have been widely publicized through professional and popular media. Many professional associations associated with addictive behavior, from drinking and drug abuse to gambling, have policies indicating the value of 12-step and other types of groups. Physicians appear to be referring patients in ever larger numbers to such groups.

Hundreds of groups exist throughout the nation for most of the specific populations categorized in this Compendium. A case in point is domestic violence. Some groups, such as Parents Anonymous (PA), focus primarily on presenting very specific techniques parents can use to replace their abusive behavior. PA has a long history of testimony and research about how it has reduced risks related to domestic violence and how it educated the public as well as members. The National Committee for Prevention of Child Abuse is among the national organizations that have praised PA for its role in reducing the propensity for future abuse.

The benefits of self-help groups go far beyond stopping harmful or unhealthy behavior. Groups for arthritis, stroke, and diabetes are known for their disease prevention activities, both for their members and for people unaffected by these conditions. Many other groups also sponsor presentations, demonstrations, and even ongoing programs on physical activity, healthy food choices, and other self-care techniques that can improve general health.

Groups formed to help people affected by HIV/AIDS have been recognized by Population Reports (September 1989) as providing the “knowledge, emotions, and skills [that] reinforce healthful changes” and for persuading people “to change their behavior and to maintain new behavior.”

Technology Increases Communication Opportunities

Although it is unlikely that electronic communication will replace the mutual support of face-to-face contact, self-helpers have been among the most aggressive consumers in using online information sources and connections. To supplement their time together during meetings—or as the main source of support for those unable to attend meetings—self-help group members regularly use private online mail sent between two or more individuals; contact discussion list members through broadcast mail; attend online meetings with numerous people signing on to a “chat group” at the same time; access Web-based health information produced by professionals and consumers; use hyperlinks to move to a site with additional health information; consult local clearinghouse listings to find out when and where groups meet locally; or use combinations of the above to organize a group to meet specific needs or respond to a tragedy.

Section Contents

- A. The AMA and Other Organizations
- B. Consumer and Self-Help Publications
- C. Web Sites
 - General Web Sites
 - Specific Web Sites

A. The AMA and Other Organizations

American Medical Association

Policies and Reports

- H-20.977 Reducing Transmission of Human Immunodeficiency Virus (HIV)*
(CSA Rep. C, A-88; amended: BOT Rep. I-93-34)
- H-25.999 Health Care for Older Patients*
(Committee on Aging Report, I-60)
- H-85.967 Good Care of the Dying Patient*
(*JAMA*, February 14, 1996; 275:474-478)
- H-210.986 Physicians and Family Caregivers—A Model for Partnership*
(*JAMA*, March 10, 1993; 269:1282-1284)
- H-295.897 Enhancing the Cultural Competence of Physicians*
- H-295.999 Medical Student Support Groups*

Consumer Books

The emphasis of all consumer books published by or in cooperation with the AMA is on prevention—advocating a working partnership between physicians and patients and showing patients how to take responsibility for their health and well-being. The books also include health information specific to various ethnic and racial groups, such as the incidence of particular diseases within different groups and the risk factors for those groups.

AMA Essential Guides

New York: Pocket Books, 1998
800 223-2336

A series of books that explores one medical topic per volume. Current titles in the series offer consumers information about asthma, depression, hypertension, and menopause. Published by Pocket Books, each guide is easy to read and provides comprehensive information ranging from diagnosis and symptoms to treatments and prevention.

Complete Guide to Women's Health

Kathleen Cahill Allison, Ramona I. Slupik
New York: Random House, 1996

Provides pertinent health information for each of four age ranges—puberty to 18, 18 to 40, 40 to 60, and over 60. Covers health problems that have a unique impact on women, including coronary artery disease, urinary tract infections, osteoporosis, stroke, eating disorders, thyroid problems, autoimmune diseases, and cosmetic surgery. Special chapters also address death and bereavement, as well as sexual assault and family violence.

For a more detailed description, see Section IV.

Complete Guide to Your Children's Health

Donna Kotulak, Dennis Connaughton
New York: Random House, 1996

Includes 700 pages of information on child and adolescent health. Part I, “Your Healthy Child from Birth Through Adolescence,” discusses fundamentals such as nutrition, exercise, and developmental milestones at every stage of a child’s life. Part 2, “Caring for Your Child’s Health,” explains how to keep kids safe, find quality child care, and help children learn to deal with stress. The third and largest part of the book, “Childhood Diseases and Disorders,” is an illustrated A-Z encyclopedia of the most common childhood illnesses. Easy-to-read symptom charts suggest the possible causes and significance of many common symptoms and suggest appropriate measures.

Encyclopedia of Medicine

Charles B. Clayman, MD, ed.
New York: Random House, 1989

Almost 1,200 pages, with 5,000 listings; 2,000 illustrations; descriptions of 2,200 common and uncommon disorders, diseases, conditions, and cures; over 300 symptoms; 2,500 drugs in generic, brand-name, and major groupings; and 600 tests, procedures, and surgical operations. Extensively indexed and cross-referenced.

Family Medical Guide, Third Edition

Charles B. Clayman, MD, ed.
New York: Random House, 1994

Nearly 900 pages of essential health information in one volume, divided into four sections. Part I, "Your Healthy Body," contains specific preventive self-care tips, with advice on diet, exercise, weight loss, stress reduction, and stopping smoking. Part II, "Symptoms and Self-Diagnosis," provides unique diagnostic charts with clear yes/no questions to help users determine what their symptoms mean. Part III, "Diseases, Disorders, and Other Problems," includes detailed articles on more than 650 medical problems. Part IV, "Caring for the Sick," covers the basics of professional medical care, home nursing, and care giving.

JAMA Patient Page

Printed on the last page in each issue of *JAMA*, the *JAMA* Patient Page provides consumer information on a topic related to the content of the particular issue. Recent editions have covered such topics as sickle cell anemia, stroke, blood pressure, and exercise. Also available online at <http://www.ama-assn.org/public/journals/jama/ppindex9.htm>

AMA Web Sites

AMA Adolescent Health On-Line

<http://www.ama-assn.org/adolhlth/adolhlth.htm>

Adolescent Health On-Line, the Web site for the AMA's Child and Adolescent Health Program, is designed to provide information to physicians, health care providers, researchers, parents, and

teenagers on important adolescent health issues. The Web site is regularly updated with the latest scientific information in the field of adolescent health and provides information on the Guidelines for Adolescent Preventive Services (GAPS). It also offers extensive links to other organizations working to improve the health status of young people, as well as information about cultural competence resources developed by the Child and Adolescent Health Program. Adolescent Health On-Line will continue to include more information for adolescents, their parents or guardians, and health care providers striving to provide culturally competent health care.

The site is supported through a cooperative agreement from the Health Services and Resources Administration, Maternal and Child Health Bureau's federal Office of Adolescent Health.

AMA Health Insight

<http://www.ama-assn.org/consumer.htm>

Extensive information for consumers.

JAMA Information Centers

<http://www.ama-assn.org/special/>

Easy-to-use, peer-reviewed collections of resources on specific conditions, including HIV/AIDS, asthma, migraine, and women's health.

Hepatitis C

<http://www.ama-assn.org/med-sci/98oct13b.htm>

Resources on Alcohol and Tobacco

<http://www.ama-assn.org/special/aos/>

See Section IX for a complete list of AMA and other organizations' Web sites.

Alliance of Genetic Support Groups

4301 Connecticut Ave, Ste 404
Washington, DC 20008
800 336-5557 or 202 966-5557
E-mail: info@geneticalliance.org
<http://www.geneticalliance.org>

A June 1985 symposium, Genetic Support Groups: Volunteers and Professionals as Partners, examined how a professional-voluntary partnership could “promote maximum health care and social and psychological functioning for genetically affected individuals and their families.” Tracks devoted to self-help groups were permeated with the concept of networking to communicate with health professionals and the public about the value of self-help groups and to impact on policies related to genetic disorders.

The Mid-Atlantic Regional Human Genetics Network and the National Organization for Rare Disorders subsequently brought together groups related to a number of disorders to strengthen communication with health professionals and the public. The symposium also created a new coalition of voluntary organizations and professionals, the Alliance of Genetics Support Groups. It provides “minority scholarships” to promote participation of diverse ethno-cultural communities at the Alliance Annual Conference.

The Alliance sponsored the 1990 National Conference on Peer Support Training, which brought consumers and professionals together to “strengthen critical working relationships.” The Alliance publishes an information sheet that promotes policies supportive of genetic services and of the role of self-help groups in those services.

Alliance Alert

The Alliance communicates with its constituents, state groups, federal agencies, and the public through its Web site (see above) and its newsletter, *Alliance Alert*. The newsletter contains information about relevant legislation, meetings, and publications, including Web sites with legislative and genetics information.

Partnership for Genetic Services Pilot Program

Since 1997 the Alliance, through its Partnership for Genetic Services Pilot Program, has conducted surveys and focus groups with consumers and professionals in three broad US regions to determine what consumers consider essential to the delivery of quality family-centered, culturally sensitive health care services to people affected by genetic conditions. The fundamental elements of the Partnership Program include the value that “peer support provides valuable resources and emotional nourishment” and that “consumer and provider collaboration is the basis for an *effective* care team.”

Working with 12 Midwest medical schools, the Partnership offers students and consumers an opportunity for dialogue outside the clinical setting and sensitizes providers-in-training to the needs of consumers and to community resources. The Partnership also cooperates with Kaiser Permanente’s Northwest and mid-Atlantic regions, Group Health Cooperative of Puget Sound, and health plans to offer educational and other service interventions to managed care providers.

Culturally Sensitive Consumer Indicators of Quality Genetic Services

Consumer Indicators of Quality Genetic Services, which contains 12 indicators, will be used through the Partnership Program with managed care providers and medical students. One of the activities is to “improve provider access to quality consumer-oriented support group resources—resources that can support, supplement, and enhance services.” Indicator 9 relates most specifically to cultural competence:

“Information about genetic conditions is provided to each consumer in a manner best suited to their needs and culture, which may include:

- their primary language
- an appropriate educational level
- more than one medium”

American Academy of Child and Adolescent Psychiatry

Virginia Q. Anthony, Executive Director
3615 Wisconsin Ave NW
Washington, DC 20016
202 966-7300
202 966-2891 Fax
<http://www.aacap.org>

Your Child: What Every Parent Needs to Know: What's Normal, What's Not, and When to Seek Help

David B. Pruitt, ed.
New York: Harper Collins, 1998
800 242-7737
<http://www.parentshandbooks.org>

A comprehensive guide to emotional, behavioral, and cognitive development from infancy through preadolescence. Guides readers through the developmental milestones of childhood, discussing specific questions and concerns and examining more troublesome problems. Covers topics from choosing a pediatrician to dealing with sleep problems, from monitoring behavior to helping a child develop self-esteem.

Your Adolescent: What Every Parent Needs to Know: What's Normal, What's Not, and When to Seek Help

David B. Pruitt, ed.
New York: Harper Collins, 1999
800 242-7737
<http://www.parentshandbooks.org>

Addresses everyday issues such as peer influence, dating, sexuality, independence, separation anxiety, and responsibility, as well as violent behavior, substance abuse, suicide, and eating disorders.

American Medical Association Alliance

Hazel Lewis, Executive Director
515 N State St
Chicago, IL 60610
312 464-4470
<http://www.ama-assn.org/alliance>

The American Medical Association Alliance (AMA Alliance) is a national grassroots organization of 50,000 physician spouses. As the proactive volunteer voice of the AMA, it promotes the good health of America and the family of medicine. For more than 75 years, Alliance members have participated in numerous local activities and projects that reflect a commitment to health care for diverse populations. The AMA Alliance strongly supports AMA efforts to enhance the ability of physicians to provide culturally effective care.

Programs and Activities

SAVE: Stop America's Violence Everywhere

Since its inception in 1995, the SAVE initiative has been implemented at the grassroots level by more than 700 local Alliances. These programs are tailored to the communities they serve, but all assist victims of violence or teach violence prevention. For the 1999-2000 AMA Alliance year, SAVE activities will focus on situations that threaten the health and safety of children daily—violence in our schools. To help address this growing problem, the AMA Alliance has developed a SAVE Schools from Violence campaign. It encourages Alliances nationwide to adopt a school in their community and provide those students with conflict resolution materials that teach nonviolent behaviors and enhance self-esteem. With the support of the community and the country, the AMA Alliance believes the SAVE program can help break the cycle of violence.

Consumer Education and Resources

Alliance volunteers educate their communities about health-related issues by distributing AMA Alliance publications and resources. Alliance consumer resources include:

Hands Are Not for Hitting—conflict resolution activity book and place mat

Teaches preschool through third grade children positive, nonviolent activities and acceptable ways to treat others. “Hands” identifies what children’s hands should and should not do.

Monitor the Media

Series of brochures that provide suggestions on ways to supervise a child’s television viewing, video game playing, and Internet surfing. Each contains startling statistics and provides a realistic look at what is really coming into your living room through your television and computer.

Shape Up for Life

Series of brochures that address specific health issues and concerns such as child abuse, stress, teen suicide, elder abuse, eating disorders, and drug abuse.

Project Bank: The Encyclopedia of Public Health and Community Projects

Contains more than 500 projects conducted by state and county Alliances nationwide from 1994-1998. Project ideas range from domestic violence posters to teen health fairs, medical marriage seminars to medical textbook collections, and HIV awareness campaigns to elder care programs.

Physician Spouse Series

Series of pamphlets that addresses the needs of physicians’ spouses. Topics include impairment and well-being, marriage, medical family support, working in a spouse’s office, and retirement.

American Self-Help Clearinghouse

Edward Madara, Director
Northwest Covenant Medical Center
Denville, NJ 07834-2995
973 625-9565
<http://www.cmhc.com/selfhelp>

The American Self-Help Clearinghouse serves as a repository and distribution center for information about national self-help organizations, regional clearinghouses, and innovations in online self-help. Founder and director Edward Madara, along with Tom Ferguson, MD, has supported the extensive development of online self-help groups and has provided hundreds of groups with technical assistance. The Clearinghouse has dozens of guides for assisting in developing and maintaining groups.

The Self-Help Sourcebook: Your Guide to Community and Online Support Groups

Published annually by the American Self-Help Clearinghouse. Provides information on more than 800 national groups and networks addressing issues such as abuse, addictions, bereavement, disabilities, rare illnesses, mental health, and parenting.

Forging Connections: An Ethno-Cultural Self-Help Conference

416 487-4355
E-mail: kevin.gosine@utoronto.ca
<http://www3.sympatico.ca/shrc/ethno.html>

This conference serves as a model for collaboration. It was organized by the Self-Help Resource Centre of Greater Toronto; the Anti-Racism, Multiculturalism, and Native Issues Centre (AMNI); and the Ontario Self-Help Network (OSHNET). Each of those organizations can provide specific information related to individual and collaborative efforts to increase access to self-help groups in Canada.

Health Promotion Council of Southeastern Pennsylvania

311 S Juniper St, Ste 308
Philadelphia, PA 19107-5803
215 546-1276
215 545-1395 Fax
E-mail: hpcpa@libertynet.org
<http://www.libertynet.org/hpcpa/>

The Health Promotion Council promotes health to those at greatest risk through publications and training. Pamphlets and audiovisuals for African Americans, Latinos, and Asians, written at or below a sixth-grade reading level, currently cover blood pressure, diabetes, smoking, stress, nutrition, and use of the health care system. The Council has materials in Spanish, Cambodian, Chinese, and Vietnamese. It offers a 7- to 8-week training and curriculum for community-based hypertension and diabetes control in both Spanish and English. Its Health Literacy Project offers teaching materials geared to specific cultural and literacy levels.

Illinois Self-Help Coalition

Daryl Holtz Isenberg, PhD
Wright College South
3400 N Austin Ave
Chicago, IL 60634
773 481-8837
773 481-8917 Fax
<http://www.selfhelp-illinois.org>

For nearly 3 decades, the Illinois Self-Help Coalition (formerly the Illinois Self-Help Center) has been instrumental in planning and conducting national and international forums for promoting understanding and acceptance of self-help groups. Founder Leonard Borman, PhD, attended the 1978 meeting on mental health convened by then-President Carter, and the current director provided administrative support for the 1987 Surgeon General's Workshop on Self-Help and Public Health. The Illinois Self-Help Coalition promotes the development of and access to self-help groups in the state and throughout the nation by:

- publishing a directory guiding consumers in identifying groups that meet their needs (see below)
- partnering with community college and university research and development efforts
- conducting cooperative training sessions for self-help group leaders
- maintaining Web-based resources, including group lists and a newsletter
- providing workshops and in-service training about these and other Web-based resources
- educating health and human service professionals about the utility and availability of groups
- conducting research to fill in the gaps in the support provided by self-help groups, such as enhancing their ability to provide care at the end of life and motivating members to adopt healthy behaviors

Typical projects include partnering with the Rehabilitation Institute of Chicago to provide a variety of self-help options, including Web-based groups and resources, for substance abuse prevention for persons with disabilities.

The Insiders' Guide to Self-Help Groups in Illinois

Includes tips on selecting appropriate self-help groups and provides contact information for more than 2,500 groups for 500 problems. National listings provide access to information about thousands of other groups.

The 43-page narrative introductory section, "The Power of Self-Help," contains titles on topics designed to help newcomers overcome their fears and reservations, such as "You Are Not Alone," "Taking Charge," "Is This Group for Me?," "Supporting Vulnerable Members," "Complementary and Alternative Health Practices," and "Information Age Self-Care."

Last Acts—Care and Caring at the End of Life

The Robert Wood Johnson Foundation
Route 1 and College Road East
Box 2316
Princeton, NJ 08543-2316
609 452-8701
E-mail: mail@rwjf.org
<http://www.rwjf.org>

The Last Acts campaign was established with initial funding from the Robert Wood Johnson Foundation. The campaign's quarterly newsletter, published by the Foundation, reports on such issues as the challenge of patient diversity and how cultural difference is relevant to clinical decision making at the end of life. Major themes include enhancing end-of-life care through communication and decision making, changing health care and health care institutions, and changing American attitudes toward death. Task forces focus on the family, palliative care, service providers, provider education, and financing. Resource committees focus on communication, diversity, spirituality, standards and guidelines, and evaluating outcomes.

Diversity and Palliative Care

<http://growthhouse.net/~lastacts>

The Last Acts Campaign is expanding the dialogue and collaboration among readers, partners, and allies by joining the Inter-Institutional Collaborative Network on End-of-Life Care, sponsored by Growth House, Inc.

This service utilizes state-of-the-art Internet technologies and encourages networking, debate, dialogue, collaboration, and live chat among hundreds if not thousands of end-of-life professionals around the world. Includes a specially focused discussion on "Diversity and Palliative Care."

Last Acts Partners

The Last Acts coalition includes major national organizations, including the AMA, and local groups. Last Acts Partners share the following goals:

- Improve communication between dying people and their loved ones and between dying people, families, and health professionals
- Reshape the medical care environment to better support high-quality end-of-life care
- Change American culture so that people can more comfortably face death and the issues raised by care of the terminally ill.

Partners have the opportunity to:

- demonstrate leadership in end-of-life care
- network with other concerned organizations and individuals through in-person conferences and on-line discussions
- have the Last Acts Web site hotlink to your organization's Web site
- receive quarterly newsletters, weekly e-mail newsletters, policy updates, special mailings of reports and materials, and invitations to meetings and workshops
- receive up-to-date information about end-of-life issues readily usable in their newsletters or Web sites
- get help in planning meeting sessions around end-of-life care
- obtain high-quality materials about of end-of-life issues—caregiving, diversity bereavement, palliative care, policy—to share with their boards, committees, or membership
- promote their organization's activities related to the end of life through articles in the Last Acts electronic and print newsletters, or by listings in the online Resources Directory
- tap into the Last Acts network to locate experts and models of action in end-of-life care

Multi-Cultural Educational Services

Charles LaRue, President
832 104th Lane NW
Coon Rapids, MN 55433
612 767-7786
E-mail: service@mcedservices.com
<http://www.mcedservices.com>

Organization specializing in translating, publishing, and distributing information, including health promotion material, to members of the refugee and immigrant community who have not gained competency in English language skills.

National Mental Health Consumer's Self-Help Clearinghouse

Joseph A. Rogers
1211 Chestnut St, Ste 1000
Philadelphia, PA 19107
800 553-4538
E-mail: infor@mhselfhelp.org
<http://www.mhselfhelp.org>

Funded by the Center for Mental Health Services, the clearinghouse focuses on training and on organizing consumers and survivors to form a collective voice with which to influence such issues as:

- protection of the Americans with Disabilities Act
- consumer rights in managed care
- involuntary commitment and other issues of rights, protection, and advocacy
- the future of community-based systems of care, particularly those managed by consumers

The Clearinghouse has contact information for other consumer-based mental health groups, such as the National Empowerment Center of Lawrence, Massachusetts, and the West Virginia Mental Health Consumers Association in Charleston, West Virginia. Publishes a quarterly newsletter, *The Key*.

National Osteoporosis Foundation Osteoporosis Patient Information Center (OPIC)

1150 17th St NW, Suite 500
Washington, DC 20036-4603
202 223-2226 (9:00am-4:30pm EST)
202 223-2237 Fax
<http://www.nof.org>

The National Osteoporosis Foundation (NOF) is a nonprofit, voluntary health organization dedicated to reducing the widespread prevalence of osteoporosis through programs of research, education, and advocacy. Founded in 1986, the NOF is used by patients, health professionals, and the public for osteoporosis information, programs, and services.

NIH Osteoporosis and Related Bone Diseases - National Resource Center

1232 22nd St NW
Washington, DC 20037-1292
800 624-2663
<http://www.osteoporosis.org>

The NIH Osteoporosis and Related Bone Disease National Resource Center links patients, health professionals, and the public to resources and information. The Center collects information on materials, programs, and support services on metabolic diseases and disseminates this information widely through publications, online services, professional and patient meetings, and general media outreach. The Center has developed fact sheets and annotated bibliographies on osteoporosis for African Americans, Latinos, and Asian Americans, some of which are in Spanish.

National Patient Safety Foundation

515 N State St
Chicago, IL 60610
312 464-4848
312 464-4154
E-mail: npsf@ama-assn.org
<http://www.npsf.org>

Founded in 1997, the National Patient Safety Foundation (NPSF) is an independent, nonprofit research and education organization dedicated to the measurable improvement of patient safety in the delivery of health care. Through the NPSF, health care clinicians, institutional providers, health product manufacturers, researchers, legal advisors, patient/consumer advocates, regulators, and policy makers are working together to make health care safer for patients.

The NPSF Communications Program will explore ways to raise awareness of the influence of cultural competence on patient safety. Activities toward this goal will include an article in the NPSF quarterly newsletter, *Focus on Patient Safety*. NPSF staff are also recommending that cultural competence be addressed at NPSF regional forums, which bring together community and health care leaders for candid discussions of patient safety. Local planners of the Wisconsin regional forum, for example, are considering the topic for a breakout session.

In addition to the NPSF quarterly newsletter, *Focus on Patient Safety*, other resources include the *News Brief*, a semimonthly glance at patient safety activities occurring nationwide; the NPSF Clearinghouse, a repository of information on patient safety and related topics; and the NPSF Web site, an online resource for patient safety literature, activities, and related Web sites.

National Women's Health Information Center

800 994-9662
<http://www.4woman.org>

Provides access to information from federal health clearinghouses and hundreds of private sector organizations.

T'ai Chi Chih Center

3107 Eubank NE, Ste 19
Scottsdale Village
Albuquerque, NM 78111
505 299-2095
<http://www.taichichih.org>

The national headquarters for an easy-to-learn form of t'ai chi originated in 1974 by Justin Stone, offers classes, Justin Stone's Joy Through Movement video and book, and instructional and practice video for Seijaku (an advanced form based on t'ai chi chih), and information about the videotapes created in conjunction with the PBS t'ai chi chih program that is still being aired throughout the country. Described as "meditation in motion," t'ai chi chih has been found to improve balance, reduce the risk of falls, reduce stress, and improve muscle tone. It is taught widely in health care institutions, self-help groups for survivors of life-threatening illnesses, retirement centers, recreation centers for older adults of persons with disabilities, educational institutions from grade school through college, prisons, and recreation programs sponsored by the YMCA and park districts. The Folsom prison program has introduced more than 400 inmates to t'ai chi chih and has been credited with breaking down barriers between inmates from different ethnic and racial backgrounds.

B. Consumer and Self-Help Publications

The American Holistic Health Association Complete Guide to Alternative Medicine

William Collinge
Warner Books, 1996
1271 Avenue of the Americas
New York, NY 10020

Provides an overview of eight major complementary and alternative health care practices. Case examples of each are designed to help readers decide which might suit their needs and how to use them in conjunction with conventional medicine. Evidence of scientific support, strengths and limitations, and guidelines for selecting a practitioner are included for each approach. Readers are cautioned against using the remedies on their own and are advised to consult their health care professionals. Included are concrete data on procedures, techniques, and principles for:

- Chinese medicine
- Ayurveda
- Naturopathic medicine
- Mind/body medicine
- Osteopathic medicine
- Chiropractic
- Massage therapy and bodywork

Bereavement Support Group Program for Children

Beth Haasl, Jean Marnocha
Brunner/Mazel, 1990

Includes a *Leader Manual* and *Participant Workbook*. This comprehensive resource received the National Hospice Organization Award for Excellence.

Consumer Bill of Rights and Responsibilities: Report to the President of the United States

Advisory Commission on Consumer Protection and Quality in the Health Care Industry
November 1997

The Advisory Commission on Consumer Protection and Quality in the Health Care Industry was appointed by President Clinton on March 26, 1997, to “advise the President on changes occurring in the health care system and recommend measures as may be necessary to promote and assure health care quality and value and protect consumers and workers in the health care system.” As part of its work, the President asked the Commission to draft a “consumer bill of rights.” The eight areas of consumer rights and responsibilities includes one on “Respect and Nondiscrimination,” which states that:

- “Consumers have the right to considerate, respectful care from all members of the health care system at all times and under all circumstances. An environment of mutual respect is essential to maintain a quality health care systems.
- “Consumers must not be discriminated against in the delivery of health care services . . . as required by law based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.
- “Consumers who are eligible for coverage under the terms and conditions of a health plan or program or as required by law must not be discriminated against in marketing and enrollment practices based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.”

Directory of National Helplines: A Guide to Toll-Free Helplines, FaxLines, Web Sites, and Other Public Service Numbers, 1998

Consumers Index
Box 1808
Ann Arbor, MI 48106
800 678-2435
<http://www.pierianpress.com>

Many organizations and agencies sponsor toll-free public service helplines in order to provide assistance to persons in need of support and advice. This specialized directory contains nearly 300 social, economic, health, and environmental helplines.

Dr. Tom Linden's Guide to Online Medicine

Tom Linden
New York: McGraw-Hill, 1995

Encyclopedia of Complementary Health Practices

Carolyn Chambers Clark, ed
Springer Publishing Co, 1999

Encyclopedia of Natural Remedies

C. Norman Shealy
Element Books Inc, 1993
160 N Washington St
Boston, MA 02114

C. Norman Shealy, a neurosurgeon, is the founder of the American Holistic Medical Association and director of the Shealy Institute in Springfield, Missouri, a center for health care and pain and stress management. *Natural Remedies* covers natural remedies from eight complementary and alternative health practices:

- Ayurveda
- Chinese herbal medicine
- Traditional home and folk remedies
- Herbalism

- Aromatherapy
- Homeopathy
- Flower remedies
- Vitamins and minerals

The book describes the techniques and practice of each therapy and lists the remedy sources they use, the ailments they treat, and the effects they have been reported to have on health and well-being. It also includes a long list of common ailments and more than 1,000 natural remedies and treatments, as well as a glossary and a comprehensive list of useful addresses and contacts. Illustrated in full color throughout.

The Encyclopedia of Alternative Medicine

Jennifer Jacobs
Journey Editions, 1996
153 Milk St
Boston, MA 02109

Describes the innate self-healing capacity of the body, called "chi" in Chinese medicine and the "vital force" in homeopathic medicine. This ability of the body to heal itself was first recognized by the Greek physician Hippocrates as *vis medicatrix naturae*. Dr. Jacobs contends that this healing energy can be stimulated and enhanced, either directly through therapies such as homeopathy and acupuncture, or indirectly through such practices as nutrition and herbs.

The book includes information on the origins, techniques, safety, practical application, and typical visit for a number of modalities that have not been extensively covered in other publications. Includes chapters on Natural Healing, The Power of Plants, Nutrition and Diet, Mobility and Posture, The Mind, Massage and Touch, and Eastern Therapies.

1996 Guide to Health Care Resources on the Internet

John W Hoben
New York: Faulkner and Gray, 1996

Health Online: How to Find Health Information, Support Groups, and Self-Help Communities in Cyberspace

Tom Ferguson
Addison-Wesley, 1996

This print source opens the door to a universe of technical and personal help, reflecting the author's decades of trying to expand access to resources through interactive telecommunications. The author's profound respect for peer support, which transforms participants from passive victims to empowered helpers, is apparent throughout the book. In preparation for a consumer-centered health care system, the book provides a guided tour of the virtual self-help communities through which thousands of volunteer self-helpers are assisting one another with a wide range of problems. The organization of the book is logical, and the contents are clearly presented. *Health Online* also provides detailed instructions on how to access newsgroups, which permit people to exchange messages. Most of the book is directed to consumers, but professionals are addressed in a small section toward the end, "A Note to Health and Computer Professionals." These four pages present Ferguson's vision for improving and maintaining an effective consumer health information system.

How to Use the Internet

Mark Butler
Berkeley: Ziff-Davis Press, 1994

Palliative Care: Patient and Family Counseling Manual

Aspen Publishers Inc
200 Orchard Ridge Dr
Gaithersburg, MD 20878
800 638-8437
<http://www.aspenpublishers.com>

Features segments on end-of-life care related to many of the special populations included in this *Compendium*. Includes numerous handouts for patients and families and practical applications for practitioners. Provides guidance on training volunteers to deal effectively and caringly with patients from all cultural backgrounds. Covers special issues such as deciding who to listen to if

the parents and partner of a gay patient offer conflicting instructions. Includes:

- Patient and family issues
 - Final stages of life
 - General patient and family education
 - Patient planning guide
 - General guidelines for caregiving
- Pain management
- Grief and psychosocial issues
- Spiritual care
- Nutrition in terminal care
- Professional concerns/volunteer training
- Financial/legal issues
- HIV/AIDS issues

Patient Education in the Medical Encounter: How to Facilitate Learning, Behavior Change, and Coping

UJ Grueninger, FD Duffy, MG Goldstein
In *The Medical Interview: Clinical Care, Education, and Research*
M Lipkin, SM Putnam, A Lazare, eds.
New York: Springer-Verlag; 1995; pp 122-133

Patient Resources on the Internet: A Provider to Patient Resource for On-line Disease Management and Personal Health, 1998-1999

Faulkner & Gray, 800 535-8403
<http://www.faulknergray.com>

Includes the following:

- Keeping Up with Patients On-line
- The Latest in Cyberspace
- Health Care Benefits Move Onto Computer Screens
- Quality of Information on the Internet

- The Web as a Disease Management Tool
- Is the Web Safe Enough?
- Joining the Worldwide Health Care Dialogue
- Web Pages by Providers and Patients
- Preventive Medicine on the Web
- Directory of Online Health Resources

Peaceful Dying: The Step-by-Step Guide to Preserving Your Dignity, Your Choice, and Your Inner Peace at the End of Life

Daniel R. Tobin
New York: Perseus Books, 1999

Presents a 26-step program to guide people through the final stages of life, from “recognizing individuality of disease, individuality of choice” to “dying with tranquility.” Uses a conversational, story-telling style in providing specific tips for taking care of physical, emotional, and spiritual needs in order to live fully and well through the very end of life. Describes techniques for preventing pain and isolation.

Radical Healing: Integrating the World’s Great Therapeutic Traditions to Create a New Transformative Medicine

Rudolph Ballentine
Harmony Books, 1999
201 E 50th St
New York, NY 10022

Radical Healing blends the primary holistic schools of healing, allowing readers to understand their common elements. Drawing on 30 years of medical study and practice, Dr. Ballentine integrates the wisdom of the great traditional healing systems (especially Ayurveda, homeopathy, traditional Chinese medicine, and European and Native American herbology) with nutrition, psychotherapy, and bodywork. *Radical Healing* covers the spectrum from plants, natural substances, diet, exercise, and cleansing to principles of spiritual and psychological interventions. Includes case studies and examples.

The Rights of the Dying: A Companion for Life’s Final Moments

David Kessler
New York: HarperCollins, 1997

Uses 17 “rights of the dying” principles as a framework for guiding people dealing with life-challenging diseases and their supporters in communicating with one another and with physicians and hospital staff. Stresses the importance of allowing dying people to participate in all decisions and express their feelings and emotions.

Self-Help Groups: Empowerment Through Policy and Partnerships

Hannah Hedrick, Daryl Isenberg, Carlos Martini
In: *Self-Help Concepts and Applications*
Alfred Katz, Hannah Hedrick, Daryl Isenberg, eds.
Charles Press, 1992

Focuses on policy and partnership activities related to the growth of autonomous grassroots self-help groups for persons affected by life-threatening conditions. Describes the empowerment provided by peer action orientation and the characteristics and benefits of such groups. Includes 115 references, many to AMA and other health professional publications.

Strategies for Designing Culturally Relevant Client Education Materials

JL Murphy, NJ Giger, R Davidhizar
Journal of Healthcare Education and Training,
1994; 8(3):8-12

Presents strategies for designing and implementing a culturally significant and appropriate client education tool for use with non-English-speaking clients or for any client in a culture different from the mainstream. These strategies include:

- Understanding the relationship between culture and behavior
- Developing a strategic plan
- Gathering demographic data about the setting

- Evaluating the characteristics of the learner
- Developing culturally specific, unique learning materials

Will Online Support Groups Revolutionize Medicine?

Medicine on the Net, May 1999
PO Box 40959
Santa Barbara, CA 93140-0959
<http://www.mednet-i.com>

Medicine on the Net frequently includes articles and editorials on the relationship of self-help groups to consumer health and on the continuing growth of online groups. The May 1999 issue contained two articles of particular benefit to physicians:

- **Getting Up To Speed on Consumer Health Resources:** Describes ten steps that will help health care professionals familiarize themselves with consumer health information resources on the Internet from self-help pioneer Tom Ferguson.
- **The Scoop on Self-Help Medicine—Some of the Leading Sites:** Lists major sites where patients are banding together in online support groups to share medical information, tips for daily living, and emotional support. These patients are calling for a dialogue with their physicians.

Women's Concise Guide to Emotional Wellbeing

Karen Carlson, Stephanie Eisenstate, Terra Ziporyn
Harvard University Press, 1997

Describes psychological disturbances and disorders unique to women.

Women's Concise Guide to a Healthier Heart

Karen Carlson, Stephanie Eisenstate, Terra Ziporyn
Harvard University Press, 1997

Considers questions of cholesterol and diabetes, stress and depression, and diet and smoking as well as diagnostic procedures and surgeries.

C. Web Sites

General Web Sites

For a complete listing of Web sites, refer to Section IX: Virtual Resources.

AMA Health Insight

<http://www.ama-assn.org/consumer.htm>

American Academy of Family Physicians

<http://www.aafp.org/family/patient.html>

Offers consumer health information for 250 topics.

Better Health

<http://www.betterhealth.com/healthwise>

Includes topics researched for accuracy and comprehension by a national medical review board. Enables users to explore health topics and problems and consider options for staying healthy, providing home self-care, determining when medical attention is necessary, and preparing for an appointment with a physician.

Central Illinois

<http://www.prairienet.org/selfhelp>

Family Services/Self-Help Center of Champaign County maintains support group lists for Central Illinois.

DocTom's Online Self-Care Journal

<http://www.healthy.net/othersites/doctom/index.html>

drkoop.com

<http://www.drkoop.com>

Hosts about 100 self-help groups.

General Drug Information

<http://www.rxlist.com>

Provides general drug information on more than 4,000 US drug products to supplement advice provided by physicians.

Go Ask Alice

<http://www.goaskalice.columbia.edu>

This Columbia University site accepts e-mail questions and searches its database for answers.

Healthfinder

<http://www.healthfinder.gov>

A gateway Web site linking consumers and professionals to health and human services information from the federal government and its many partners on more than 1,000 topics.

Health Risk Assessment

<http://www.youfirst.com>

Users fill out a short questionnaire and are then provided with a free, personalized, confidential health assessment report, including healthy lifestyle recommendations.

JAMA Information Centers

<http://www.ama-assn.org/special/>

Easy-to-use, peer-reviewed collections of resources on specific conditions, including HIV/AIDS, asthma, migraine and women's health.

Medicine on the Net

<http://www.mednet-i.com>

National Health Information Center

<http://nhic-nt.health.org>

Clearinghouse providing a central health information referral for consumers and professionals.

National Library of Medicine

<http://www.nlm.nih.gov>

888 FIND-NLM
301 402-1384 Fax
E-mail: custserv@nlm.nih.gov

The National Library of Medicine's MEDLINEplus, the database used by librarians and health professionals for nearly 30 years, is available at no cost, 24 hours a day, 7 days a week. Two Web-based interfaces for searching MEDLINE are available: PubMed and Internet Grateful Med.

Reuters Medical News

<http://www.reutershealth.com>

Publishes 20 full-text online news items every day on recent events from the medical world.

thriveonline.com

<http://www.thriveonline.com>

Provides information to consumers on healthy lifestyles, with diet, sports, medicine, and fitness subsections.

WebMD

<http://my.webmd.com/index.html>

Specific Web Sites

Adolescent Health On-Line

<http://www.ama-assn.org/adolhlth/adolhlth.htm>

Adolescent Health On-Line, the Web site for the AMA's Child and Adolescent Health Program, is designed to provide information to physicians, health care providers, researchers, parents, and teenagers on important adolescent health issues.

Alliance of Genetic Support Groups

<http://www.geneticalliance.org>

American Self-Help Clearinghouse

<http://www.cmhc.com/selfhelp>

Cancer Care

<http://www.cancercare.org>

Offers 1-hour conference calls that provide the latest information from experts in oncology, social work, public policy, and other fields. Teleconference programs feature coping strategies and updates on specific cancers. Register for programs online or by phone at 800 813-HOPE. Also provides information about clinical trials, referrals to related Web sites, and online support groups for patients, partners, and bereavement groups.

Easter Seals

<http://www.seals.com>

Offers rehabilitation and support services for people with disabilities.

Ethics: EPEC Resource Guide

<http://www.ama-assn.org/ethic/epec/rgbuffer.htm>

Hepatitis C

<http://www.ama-assn.org/med-sci/98oct13b.htm>

Illinois Self-Help Coalition

<http://www.selfhelp-illinois.org>

Inter-Institutional Collaborative Network on End-of-Life Care

<http://growthhouse.net/~lastacts>

Last Acts—Care and Caring at the End of Life

<http://www.rwjf.org>

Mental Health Net

<http://www.cmhc.com>

Provides mental health links.

National Mental Health Consumer's Self-Help Clearinghouse

<http://www.mhselfhelp.org>

National Osteoporosis Foundation Osteoporosis Patient Information Center (OPIC)

<http://www.nof.org>

National Women's Health Information Center

<http://www.4woman.org>

NIH Osteoporosis and Related Bone Diseases—National Resource Center

<http://www.osteoporosis.org>

Parent's Handbooks

<http://www.parentshandbooks.org>

Psych Central

<http://www.psychcentral.com>

Part of John Grohol's extensive mental health site, offering a one-stop index for psychology, support, and mental health issues, resources, and people.

Recovery Network

<http://www.recoverynetwork.com>

Recovery Network is committed to serving the 100 million Americans affected by alcoholism, drug abuse, eating disorders, child abuse, depression, or gambling problems. In delivering programming for these populations, this site encourages the partnership of public radio, cable television, and other media. On its Internet site, Recovery Network links hundreds of self-help organizations, 12-step groups, national hotlines, and resources.

Self-Help & Psychology Magazine

<http://www.shpm.com>

Articles on a wide range of self-help topics.

