

# A Medical Library for the Public: Starting and Running A Consumer Health Library

by Daniel C. Horne

To set the stage for a discussion of consumer health information and consumer health libraries, I will begin with two quotations. The first is from Dr. Michael DeBakey, the renowned pioneer heart surgeon, who in a speech given at the National Library of Medicine, succinctly and eloquently captured the importance of consumer health information: "Even with our modern advances in health care, I still consider good information to be the best medicine."<sup>1</sup> The second and more matter-of-fact quotation is a definition of consumer health information by Dr. Alan M. Rees, the father of the modern consumer health information movement:

CHI is information on medical topics that is relevant and appropriate for the general public. CHI covers not only information on signs and symptoms, diagnosis, treatment and prognosis of diseases, but also includes information on access, quality, and utilization of health care services.<sup>2</sup>

As librarians, we feel that all information sought by our patrons is important, but few subject areas cause us as much concern as consumer health information because few have such a direct, serious, and potentially profound connection to the well-being of our patrons. Consider the following example, a scenario that will seem familiar to most public reference librarians. A patron needs information on a medical condition. She has a slip of paper with the medical term "myelodysplasia" written down by her physician. You have little or no idea what the term means, but you do what you can with the time and resources available. The patron leaves with some photocopies, but you are left with a nagging feeling that you could have done more, that the information was somehow not quite enough. (There's a trick in the question. For the key, see the last bulleted item near the end of the article.) Public librarians tend to be a little shy of medical questions. After all, most of us were liberal arts majors. We are at ease with history, literary criticism, music, and even economics and basic science, but the world of medical knowledge remains shrouded in mystery and has a complex language all its own. We, along with the rest of society, have learned that medical knowledge is the domain of health professionals, particularly physicians.

The tendency toward a shortage of specialized consumer

health information in public libraries results directly from the library's very nature. Every area of human knowledge must be represented in the collection. Budgets must be distributed in order to ensure collections are developed according to the greater general needs of the patrons. The amount of consumer health information, although extremely important, and therefore warranting some special consideration in the budget, ultimately must be subservient to the mission of the public library — to provide material for all needs and interests. So what is to be done? Currently our options are the same as for any other request for material not found in the collection — interlibrary loan, or referral to another library or agency. The same weaknesses that are inherent in these choices apply, i.e. time and unpredictability of interlibrary loan subject requests and the inability to follow up on referrals to make sure patrons have obtained adequate information. The obvious solution, and one which was recognized by New Hanover Regional Medical Center and the Coastal AHEC Library, is a consumer health library.

Why is detailed and in-depth consumer health information so important that it warrants a library entirely dedicated to it? In answering this question, it is helpful to understand the history of consumer health information. Consumer health information has its roots in two concurrent social forces. The modern consumer movement began in earnest in 1965 with the publication of Ralph Nader's *Unsafe at Any Speed*. In this book, Nader exposed General Motors' production of the potentially lethal Chevrolet Corvair. The public began to question its postwar blind trust that large and powerful corporations had concern for our health, safety, and well-being. The feminist movement of the 1970s was deeply concerned with women's health issues and with women's taking responsibility for their health care. This led to the publication in 1973 of the landmark book *Our Bodies, Ourselves* in which women were given accurate and empowering information on all aspects of health care. The deconstruction of our faith in established corporate order and the seizure of the power to make our own healthcare decisions was fertile soil for the growth and spread of the consumer health information movement.<sup>3</sup>

Since 1973, there has been a steady change in attitude about consumer access to health information for all segments of the population. The importance of this for librarians is that there has been a corresponding increase in the availability and

quality of consumer health publications. Today consumer health information publications, which include not only material on medical conditions but also on related topics such as diet, exercise, aging, health insurance, access to health care, and complementary therapies, enjoy a large market share in nonfiction publication.

In the late 1970s, changes in attitudes toward health care slowly began to appear as official changes in institutions and in the formation of organizations dedicated to consumer health. In 1978, a group of consumer advocates, physicians, educators, and business and cultural leaders joined forces to form Planetree, an organization whose mission was to humanize the hospital experience as well as provide access to consumer health information. (Planetree refers to a kind of Sycamore tree under which Hippocrates taught his medical classes in ancient Greece.) The Planetree Health Resource Center, a full-service consumer health library, opened in San Francisco in 1981. The Center even devised its own materials classification scheme for the cataloging and organization of consumer health materials.<sup>4</sup> In 1982, Dr. Alan Rees published *Developing Consumer Health Information Services*, the first of his several books on the subject. Since then the number of consumer health libraries increased dramatically. Now, the Consumer Health and Patient Health Information Section (CAPHIS) of the Medical Library Association lists 137 consumer health libraries in its Consumer Health Library Directory <capHis.njc.org>.

The increase in the number of consumer publications corresponds to the change in consumer attitudes toward health care. In the past, patients accepted, and indeed were expected to accept, what they were told by physicians and blindly follow prescribed treatments. Now more and more patients are becoming savvy and particular. They want to know as much as they can about their conditions, prognoses, treatments, and options, as well as the cornerstones of wellness, exercise, and nutrition. For these consumers, information and understanding empower them to take control of the healing process and to make healthy lifestyle choices. They are activists who know that knowledge gives them understanding as well as the means to make sound decisions. They do not merely succumb to disease, but consider it their enemy and fight it any way they can. To achieve this, accurate and in-depth medical information must be expressed in the most accessible language possible.

The forces behind the public's change in attitude towards health and the health care system are complex. A significant and measurable factor is managed care. Managed care is a response to the double digit inflation in medical care expenses seen in the 1980s. By 1997, 65% of Americans were enrolled in managed care plans.<sup>5</sup> Managed care makes health care more affordable and encourages people to see their physicians more frequently. But to make managed care economical and to meet the demands placed on the health system by it, the time physicians have to see patients is stretched to the limit. Physician-patient interaction time has an average range between 5 and 10 minutes.<sup>6</sup> It is no wonder people leave office visits bewildered. At the Coastal Consumer Health Library, approximately 25% of our patrons use the library to answer questions that have

arisen, whether they are about diagnosis, terminology, medication, or tests, because office visits are so brief.

The growing realization that quality of life depends to a large extent on good health is also a major factor. Good health is no longer viewed as just the absence of disease. Proper nutrition and exercise, stress reduction, freedom from harmful habits and addictions, interior and exterior environmental health, and spiritual and emotional growth are now emphasized. Parents are concerned about the total health of their children. Young adults and members of the baby boom generation see health and fitness as vital to success in their careers and in family life. People who have reached or who are planning for the end of their careers know that retirement is more than just not having to go to work anymore, but a time when dreams of travel and accomplishments can be realized. Grandparents want to be healthy so they can be a positive force in the lives of their grandchildren. Baby boomers want to make sure they make it to retirement while enjoying health and vitality along the way. As librarians, we know that one of the major keys to success in any endeavor is accurate and current information. Nowhere is this more true than in matters of fighting disease and maintaining health. Good information is truly the best medicine!

In the year that the library has been open, I have enjoyed immensely the challenge of providing medical reference to the public. Becoming self-educated in an entirely new field of knowledge has been a real pleasure and a humbling experience. In conclusion, I would like to share with you some observations I have made in the last several months of providing consumer health information.

- There is a middle area between the general and often too brief descriptions of medical conditions and health concerns found in general consumer health sources and the technical material prepared for health professionals. Most often, people want information that lies within this middle area.
- Men don't generally use the library. Women are avid users for themselves, but they also do the research on medical conditions for the men in their lives. Only



Interior of the Coastal Consumer Health Library, Wilmington, NC.



25% of our library cards have been issued to men.

- Generally speaking, men use the library for themselves most often when they are confronted with prostate cancer, or urological and gastrointestinal problems.
- Consumers do not entirely trust the medical establishment. They are concerned about the quality of doctors and hospitals and resent the often offhand and even rude manner in which they are treated by medical staff.
- Physicians often give the impression that the treatment they prescribe is the only established one, when in reality there may be several options or variations.
- Patrons often tell me about the importance of being your own advocate in negotiating the maze of the health care system. If you don't take responsibility, no one else will.
- Alternative therapies are popular because they offer people the chance to control their own treatments without the intervention of the medical establishment.
- Consumers seek medical information most often to increase their knowledge of treatments and procedures and to reduce fear and anxiety about their conditions. This observation is drawn directly from our surveys.
- When confronted by potentially catastrophic health problems, people very often convey a matter-of-fact attitude and display a sense of humor about their illness.
- When people cry or otherwise display emotion, it is usually over the condition of a loved one rather than their own.
- Some people seem to be shopping for an illness for themselves. This might be hypochondria. These people take their "conditions" very seriously and do not show a sense of humor.
- People want us to give them advice. This is a great danger, and we have to be very careful to phrase our statements in such a way that what we are saying

cannot be in any way considered advice.

- I never realized the extent of what can go wrong with the body and mind. The names of certain diseases are familiar to us all, but there are many, many more. For example, The National Organization for Rare Disorders has information on over 1,100 diseases in its database and The National Cancer Institute's PDQ database lists over 120 kinds of cancer.
- Medical information is usually very precise, but sometimes there are important distinctions so it is always best to consult several sources. For instance, myelodysplasia means a kind of neural tube defect that causes defective development of the spinal cord; however, it also means a disorder of bone marrow that can precede myelogenous leukemia.<sup>7</sup>

The following is a selective bibliography of consumer health information reference sources and periodicals along with a little bit of Internet advice.

### Suggested Core Collection

\*Asterisked Titles = First Choices

#### General Consumer

- Columbia University College of Physicians and Surgeons Complete Home Medical Guide*. 3rd rev. ed. Crown, 1995.
- \**Consumer Health USA*. Vol. 2. Oryx Press, 1997.
- Everything You Need to Know About Diseases*. Springhouse, 1996.
- \**Mayo Clinic Family Health Book*. 2nd ed. Morrow, 1996. Merck *Manual of Medical Information, Home Edition*. Merck, 1997.
- \**Professional Guide to Diseases*. 6th ed. Springhouse, 1998. 0874349265.

#### General Professional

- Cecil Textbook of Medicine*. 20th ed. W. B. Saunders, 1996.
- Conn's Current Therapy*. W. B. Saunders, 1999.
- \**Current Medical Diagnosis and Treatment*. 38th ed. Appleton & Lange, 1999.
- \**Harrison's Principles of Internal Medicine*. 14th ed. McGraw-Hill, 1997.

- Merck Manual of Diagnosis and Therapy*. 17th ed. Merck Research Laboratories, 1999.
- \**Physician's Guide to Rare Diseases*. 2nd ed. Dowden, 1995.

#### Pediatrics

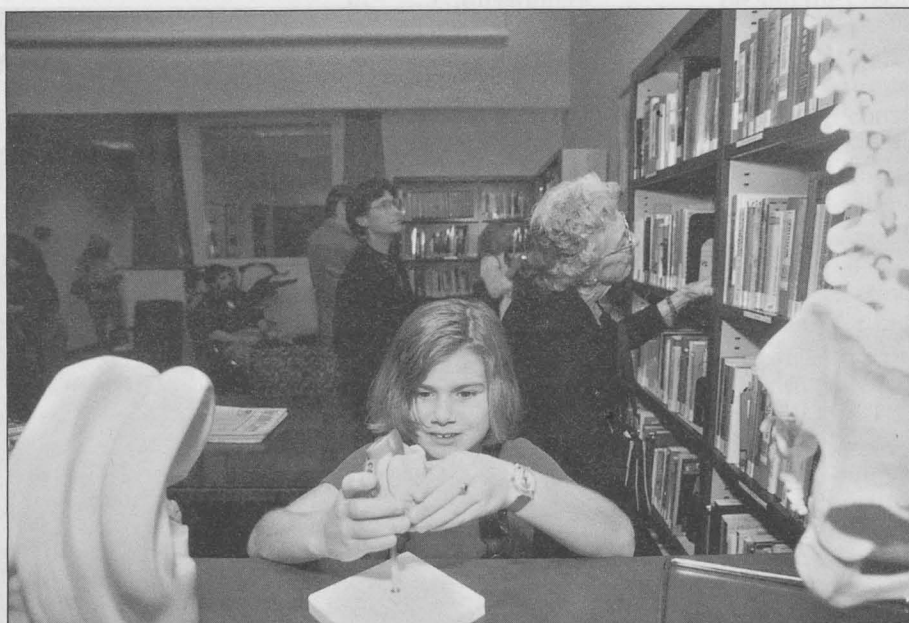
- American Medical Association Complete Guide to Your Children's Health*. Random House, 1999.

#### Dictionaries

- Dorland's Illustrated Medical Dictionary*. 28th ed. W. B. Saunders, 1994.
- Stedman's Medical Dictionary*. 26th ed. Williams & Wilkins, 1995.
- \**Mosby's Medical, Nursing, and Allied Health Dictionary*. 5th ed. Mosby, 1997.
- \**Taber's Cyclopedic Medical Dictionary*. 18th ed. F. A. Davis, 1997.
- \**Dictionary of Medical Syndromes*. 4th ed. Lippincott-Raven, 1997.

#### Mental Health

- Caring for the Mind*. Bantam, 1996.
- \**Diagnostic and Statistical Manual of Mental*



Katherine Flake, a young patron, examines a heart model at the Coastal Consumer Health Library, Wilmington, NC.

Disorders (DSM-IV). American Psychiatric Association, 1994.

\*American Academy of Child & Adolescent Psychiatry *Your Child: What Every Parent Needs to Know*. Harper Collins, 1998.

### Medical Tests

\**Everything You Need to Know About Medical Tests*. Springhouse, 1996.

*The Patient's Guide to Medical Tests*. Facts on File, 1997.

*Mosby's Manual of Diagnostic and Laboratory Tests*. Mosby, 1998.

### Drugs

*Complete Drug Reference*. Consumer Reports, 1999.

*Essential Guide to Prescription Drugs*. Harper Collins, 1999.

\**Mosby's Over-the-Counter Medicine Cabinet Medications*. Mosby Lifeline, 1997.

\**The PDR Family Guide to Prescription Drugs*. 6th ed. Three Rivers Press, 1998.

\**Physicians' Desk Reference*. 53rd ed. Medical Economics, 1999.

### Surgery

*Current Surgical Diagnosis and Treatment*. Appleton & Lange, 1997.

\**The Surgery Book: An Illustrated Guide to 73 of the Most Common Operations*, St. Martin's Griffin, 1997.

### Anatomy

*Gray's Anatomy: The Anatomical Basis of Medicine and Surgery*, 38th ed. Churchill-Livingstone, 1995.

\**The Human Body: An Illustrated Guide to its Structure, Function, and Disorders*. Dorling Kindersley, 1995.

### Nutrition

*The American Dietetic Association's Complete Food & Nutrition Guide*. Chronimed, 1996.

\**Bowes & Church's Food Values of Portions Commonly Used*. 17th ed. Lippincott, 1998.

\**Nutrition Almanac*. 4th ed. McGraw-Hill, 1996.

*Nutrition Bible: A Comprehensive, No-Nonsense Guide to Foods, Nutrients, Additives, Preservatives, Pollutants*. William Morrow, 1995.

### Alternative/Complementary Medicine

*The Medical Advisor: The Complete Guide to Alternative & Conventional Treatments*. Time-Life, 1997.

### Dentistry

\**Columbia University School of Dentistry and Oral Surgery's Guide to Family Dental Care*. W. W. Norton, 1997.

*Oral Health Sourcebook: Basic Information About Diseases and Conditions Affecting Oral Health* (Health Reference Series, v. 30). Omnigraphics, 1998.

### Periodicals

Indexing Codes:

HRC = Health Reference Center (Information Access)

HSP= Health Source Plus (EBSCO)

FT = Full Text

*Child Health Alert* HRC FT 1/95- HSP 1/92-

*Consumer Reports on Health* HRC 1/95- HSP 1/92-

*FDA Consumer* HRC FT 1/95- HSP FT 1/90-

*Harvard Health Letter* HRC FT 1/95- HSP FT 10/90-

*Harvard Men's Health Watch*

*Harvard Mental Health Letter* HRC FT 1/95- HSP FT 1/94-

*Harvard Women's Health Watch* HSP FT 1/94-

*Johns Hopkins Medical Letter: Health After 50*

*Mayo Clinic Health Letter* HRC 1/95- HSP 1/92-

*National Women's Health Report*

*Nutrition Action Health Letter* HRC FT 1/95- HSP FT 1/94-

*University of California at Berkeley Wellness Letter* HRC 1/95- HSP 1/92-

### Internet

Finding quality information on the Internet is always a challenge for reference librarians, but because of its sensitive nature, medical information is a matter of special concern. I'm going to keep it simple. All you really need to do is bookmark *The National Library of Medicine's MEDLINEplus* <www.nlm.nih.gov/medlineplus/>. This site is an excellent new service of NLM and provides most of what you will ever need.

If you want to go further, *Digital Librarian: A Librarian's Choice of the Best of the Web — Health & Medicine* <www.servtech.com/~mvail/health.html> is an extensive and frequently updated listing of Internet health and medicine sites and of the sites of medical organizations and associations. The only drawback is that it is an alphabetical listing with no subject access, so if you are under pressure at the reference desk, you will need to stay calm and take your time.

The Coastal Consumer Health Library has a Web site, too, which can be accessed from New Hanover Regional Medical Center's site <www.nhrmc.org>. Choose "Coastal Consumer Health Library." The first page is brochure information, but at the bottom is a section titled "Internet Links to Consumer Health Sources." Find the link [consumer medical and health information](#), which will take you to my own collection of sites, as well as to the websites of other consumer health information libraries that provide their own sets of links. *Help—The Health Education Library for People* <www.healthlibrary.com/> from Bombay, India, is my favorite.

### Reference Assistance

Please feel free to call the Coastal Consumer Health Library at 1-800-759-7870, if you would like reference help.

### References

<sup>1</sup> Quotation provided by Donna Flake, director of the Coastal AHEC Library, who has received permission for use from Dr. DeBakey.

<sup>2</sup> Alan M. Rees, ed., *The Consumer Health Information Source Book*, 5th ed. (Phoenix: Oryx Press, 1998), 1.

<sup>3</sup> Boston Women's Health Book Collective, *The New Our Bodies Ourselves: A Book by and for Women* (New York: Simon & Schuster, 1998), 8-9; Christiane Northrup, *Women's Bodies, Women's Wisdom: Creating Physical and Emotional Health and Healing*, rev. and updated (New York: Bantam Books, 1998), 3-7; and Michelle A. Spatz, *Planning and Managing the Consumer Health Library: Medical Library Association, CE 201, May 22, 1998* (Material from a continuing education course given at the Medical Library Association Annual Conference, Philadelphia, PA), 6-7.

<sup>4</sup> *Planetree Health Resource Center Information and Policy Manual* (San Francisco: The Planetree Health Resource Center, 1989), 1.

<sup>5</sup> Charles B. Inlander, *The Savvy Medical Consumer* (Allentown, PA: People's Medical Society, 1997), 85.

<sup>6</sup> Barbara M. Korsch and Caroline Harding, *The Intelligent Patient's Guide to the Doctor-Patient Relationship: Learning to Talk So Your Doctor Will Listen* (New York: Oxford University Press, 1997), 269-271.

<sup>7</sup> *Dorland's Illustrated Medical Dictionary* (Philadelphia: W.B. Saunders, 1994), 1089.