The Medical Library Association Guide to Finding Out about Heart Disease

The Best Print and Electronic Resources

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Terry Paula Hoffman

Chicago  2013

www.alastore.ala.org
The information in this book is intended to help the reader locate information about heart disease. It is not intended to replace the advice of a qualified health care professional. While every effort has been made to ensure accuracy and currency of the facts presented, this information should not be used to make decisions about medical care. Please consult with your physician before making any decisions regarding medical treatment.

Contact information and URLs listed in the book were accurate at the time the manuscript went to press.

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Preface

Heart disease is the leading cause of death in the developed world. As physicians have increasingly limited time to spend with justifiably distressed patients and their families and friends, people are turning to the Internet for information and answers without knowing how to determine the credibility of online resources. A guide to reliable information resources for the public is necessary and important.

“I cannot give you a new heart.” That’s what one of the most preeminent physicians in a Midwestern state told my grandfather before discharging him as a patient in the early 1940s. While my mother was still in elementary school, my grandfather had a massive heart attack and spent nearly two years in bed. At that time, bed rest was the only treatment for heart disease. My grandfather took his health into his own hands and eventually got of bed, went back to work, and, luckily, lived long enough to play with me.

—Jeanette de Richemond

My dad died in his forties within minutes of having coronary thrombosis; he was slender and active. Back in 1964, my dad did not feel well for a few days. He went to his doctor for a checkup, but no serious cardiovascular results were identified. My dad died only a few days later. Both of my brothers, while in their fifties, developed classic symptoms and needed immediate quintuple bypasses. Both being slender and active, most likely, saved their lives. I am also slender and very active, and although symptomless, my LDL doubled in one year and my blood pressure jumped from a typical normal range to 150/100. It is safe to say that cardiovascular disease runs in my family. Understanding the importance of screening, preventive medicine, and lifestyle changes to lower my family’s and my own risk of heart attack and stroke is vital.

—Terry Paula Hoffman

You are in the doctor’s office. Your physician has just informed you that you have heart or cardiovascular disease and then asked, “Do you have any questions?” Regardless of whether your situation is immediately life-threatening or the beginning of a progressive disease, you might think of a few questions, your mind might go momentarily blank, or you might not feel informed enough to know what to ask. You say to yourself, “Tonight, I will go online and search the web.”
When you begin your web search, you quickly discover there is an overwhelming amount of information about your condition on the Internet. Advertising-type websites pop up first; many of them cleverly resemble official medical sites. As you continue to scroll down or click from page to page, you ask yourself, “How do I know which are the reliable sites?”

The purpose of this book is to provide carefully selected, trustworthy, consumer-friendly resources that are easy to understand for patients and their families and friends; the related goal is to present knowledge that patients will need to be able to ask appropriate questions of their physicians. Included are sections on various types of heart and cardiovascular diseases, cardiac tests, treatments, including drug therapy and procedures, and related issues.

This book is intended to provide basic background information on heart and cardiovascular diseases, offering quality, vetted resources for librarians, health care personnel, and consumers. This information will allow consumers to be knowledgeable about heart basics and will assist in their consultations with physicians. Included are books (some in print, some as e-books), brochures, and websites.

Before changing careers to become a medical information specialist, I spent more than twenty years as a health/medical writer. During that time, I attended the scientific sessions of the American Heart Association and the American College of Cardiology for many years so I could report on the sessions for health professionals and for the general public. I also wrote a Coping column for a major newspaper on dealing with medical problems. I believed then as I believe now that “information is the antidote to anxiety.”

—Jeanette de Richemond

I spent many years teaching secondary science as well as being a product development chemist before my career evolved toward becoming a medical information specialist. One might say educating, researching, and searching for information, as well as enabling others’ empowerment through knowledge, is in my blood.

—Terry Paula Hoffman
Chapter 1

Introduction

How to Use This Book

The purpose of this book is to provide medical librarians, public library librarians, and laypersons with a basic understanding of heart disease and its treatment and management and to direct them to knowledgeable, accurate, and credible resources for further detailed information.

Within each chapter, each topic begins with a definition and description to explain any issues needed to further its clarification. This is followed by the section Resources for Further Information, which includes, if available and as current as possible, books; brochures, booklets, and other short print publications; carefully chosen websites; and patient support groups/organizations. Some chapters include just one resource section for the chapter overall and others provide separate condition-specific resource sections as well as a section for the chapter overall. Because the goal of this reference book is to be completely consumer friendly, each chapter can be viewed in any order and independently, and each contains its own set of instructions intended for the non-professional who is searching for relevant references.

The goal of this book was to identify books and websites that offer evidence-based health care information on heart and cardiovascular diseases. According to the Cochrane Library, evidence-based health care “is the conscientious use of current best evidence in making decisions about the care of individual patients or the delivery of health services. Current best evidence is up-to-date information from relevant, valid research about the effects of different forms of health care, the potential for harm from exposure to particular agents, the accuracy of diagnostic tests, and the predictive power of prognostic factors” (http://www.cochrane.org/about-us/evidence-based-health-care).

Authors’ Note

This book is not intended to substitute for interaction with a patient’s doctor or cardiologist. Learning about the aspects of heart disease will help patients discuss the issues of their disease with a doctor. Only a doctor can guide patients through the many steps needed to diagnose, treat, recover from, and live with heart disease.
Chapter One

This first chapter explains how to use this book and its resources; it provides guidelines and strategies for conducting a heart disease reference interview, evaluating reference sources, and locating information. Chapter 2 explains how the heart works as part of the circulatory system. Many people are unaware they have a heart disease, and they often find out from a physician’s diagnosis. Chapter 3 provides an understanding of the various types of heart and cardiovascular diseases. Chapter 4 provides an understanding of the various types of congenital heart disease. Chapter 5 describes diagnostic tests, treatments, and procedures. Chapter 6 describes the various types of risk factors and preventive measures. Chapter 7 describes lifestyle changes to help reduce risk or delay the onset of some heart diseases, as well as manage and control the progression or recovery of heart disease. Women have different heart problems and symptoms than do men; Chapter 8 explains women’s heart issues. The book concludes with a glossary that provides the reader with basic definitions of heart and cardiovascular disease terminology.

Many references include animations, videos, audios, slide presentations, tutorials, and interactive charts. Many websites offer guides to what questions to ask your doctor, how to get a second opinion, latest clinical trials accepting patients, guides to health care costs and comparisons, patient discussions forums, and how to find the top doctors and top hospitals in cardiology your area, rated by the prestigious

Daily Evidence-Based Health News Updates

The physician-led Insidermedicine Project (http://www.insidermedicine.com/) “allows patients, doctors and medical students to keep up on the latest medical information by watching” videos created each weekday by their team of medical experts, allowing anyone to receive daily evidence-based health and medical updates. Previously created videos are available and free to view or download. Under the heading “Programs,” click the category “By Disease or Symptom,” scroll through the list of conditions, and click on a heart or cardiovascular topic. Also under the heading “Programs,” click on “Universities and Hospitals” for links to “University and Hospital News Segments.”

HealthDay—News for Better Living (http://consumer.healthday.com/) is a consumer-friendly expertly written health website that is updated several times a day. The HealthDay website also produces HealthDay TV, which provides a “daily [Monday through Friday] video recap of the latest consumer health research . . . for insight into the latest news published in major medical journals and new research presented at medical conferences . . . [in] short, easy-to-understand commentary that translates highly technical language into a concise and compelling report for medical consumers.” Also available is a free, weekly HealthDay newsletter that can be customized for specific topics, such as heart health.

www.alastore.ala.org
U.S. News and World Report magazine; and several top U.S. hospital websites include an “Ask the Doctor” answered by a cardiologist or other heart specialist that you can call or e-mail. There are numerous free e-mail sign-ups for consumer-friendly, heart-healthy newsletters from trusted sites, such as the Hospital of the University of Pennsylvania, Harvard University–Harvard Medical School’s Harvard Heart Letter, and the American College of Cardiology’s CardioSmart.org. In addition, most of these trusted websites include links to their own social media, such as Facebook and Twitter accounts. There is also information specifically written for teens and for children. Included are links to consumer-friendly sections from Medicare.gov, the “Official U.S. Government Site for Medicare.”

Because some heart conditions affect a higher percentage of the population than others do, such as high blood pressure and Marfan syndrome, the number of trusted references identified for each topic varies.

Although heart disease can be associated with other major diseases, such as diabetes, this book is limited to heart and cardiovascular diseases. However, exploring the resources provided can lead to more information on directly related health care topics. For example, at the American Heart Association website (http://www.heart.org/), if you click on the category “Conditions” at the top of the screen, you will be directed to a website that contains a link to a list of heart and cardiovascular disease conditions, such as arrhythmia, high cholesterol, and heart attack. It also includes a link to more information on diabetes.

See CHAPTER 5 for more detailed information on these rankings.
Recommended books are mostly for background information; however, because websites are continuously being updated with the latest information, user-friendly instructions are designed to help ensure you find these references, even if the original website address (URL, or uniform resource locator) changes. For example, currently at WebMD there is information on atrial fibrillation at http://www.webmd.com/heart-disease/atrial-fibrillation/default.htm. However, you can also find this webpage by going to WebMD’s homepage at http://www.webmd.com/and typing “atrial fibrillation health center” in the Search box at the top of the page. Likewise, whenever possible the various topics in this book are cross-referenced so you can find additional information relating to your primary topic in other sections.

Many complex terms are explained in the individual sections; the final section of this book also provides a glossary of terms. Many medical terms are composed of common phrases that might aid in comprehension. For example, cardiac refers to the heart, and coronary refers to the blood vessels and nerves associated with the heart. However, some terms that seem similar are not related. For example, myocardial infarction or heart attack is different from heart failure, which is also different from sudden cardiac arrest.

Heart Disease Reference Interview

Most medical librarians recognize a reference interview requires excellent listening skills, sensitivity, insight, tolerance, and discretion toward the user. For identifying the latest information, searching the Internet makes the most sense. Six basic steps are recommended:

- Establish a rapport with the user, and make good eye contact.
- Negotiate the question.
- Develop a successful search strategy and communicate it to the user.
- Locate the information and evaluate it.
- Provide information in a useful format (presentation of results).
- Ensure that the question is fully answered.

A patient, family member, or friend of the patient may likely be apprehensive, not fully informed, and uncertain as to what is wanted. Keeping users calm and reassuring them that you will be able to assist them in finding valuable resources will be helpful. Extracting key information from the users, such as symptoms, doctor’s comments, or diagnosis, is a starting point. The librarian should provide only the information requested by the patient or family member and avoid providing negative information unless specifically requested to do so. Gently remind the user that you are a librarian and not a doctor; your goal is to offer the information, not analyze it. Never give advice, suggest a diagnosis, or recommend a particular treatment or
physician. The librarian should be an impartial guide to the information needed to satisfy the user. For further details on working with patients and family members, refer to the Medical Library Association’s policy of providing health care information to the public at the Consumer and Patient Health Information Section (CAPHIS) at http://caphis.mlanet.org/.

Websites in this guide were selected for their high quality and reliability. Although the selection of resources follows the Medical Library Association guidelines of CAPHIS, for evaluating the quality of health-related web resources users should always check on the applicability of any information with the physician who knows the patient’s condition. This caveat applies to making lifestyle changes, such as diet and exercise, as well; the physician should be consulted before such changes are made. Most of the websites listed in this book hone in on a specific topic. Although the majority of these sites are written and developed for layperson use, included are a few clinical sites, such as Medscape and PubMed, which might assist the medical librarian in expanding on answers to a consumer’s medical question, if needed, or aid health care professionals (e.g., physicians or nurses) who are looking for information for their patients. After the librarian guides the user to relevant websites and/or books, the interview can likely be closed.

Strategies for Locating Information

Searching for basic, background details about the user’s question might be needed to enhance the search strategy for effectively finding the best information. Be sure to determine the correct spelling of the relevant search terms. The glossary and index of this book offer many terms, as do the specific chapters.

Jumping to Chapter 3 might be a good starting point for locating current information if answers about a specific condition, such as cardiomyopathy, are requested. Another option is going first to Chapter 6 if the user is interested in lifestyle changes for managing heart disease. Each chapter offers a wide variety of areas to peruse for patient-friendly information.

Providing nurses or physicians with information for a quick general overview may be sufficient, such as directing them to PubMed, MedlinePlus, drug suppliers’ websites, and medical device suppliers’ websites. Evidence-based websites that were used in searching for information on heart and cardiovascular diseases include MedlinePlus (http://www.medlineplus.gov/), the American Heart Association (http://www.heart.org/), the American College of Cardiology (http://www.acc.org/), the National Heart, Lung, and Blood Institute (http://www.nhlbi.nih.gov/), the Mayo Clinic (http://www.mayoclinic.com/), Medscape Reference (http://emedicine.medscape.com/), Medscape (http://www.medscape.com/), and PubMed (http://www.ncbi.nlm.nih.gov/pubmed/). The Medical
Library Association’s CAPHIS also provides a list of the top 100 websites that can be trusted (http://caphis.mlanet.org/).

**Guidelines for Evaluating Reference Sources**

Numerous websites, journal and newspaper articles, and medical texts were examined. Heart disease is an expanding and ever-changing subject. New studies are published every day; websites containing medical information are updated on a regular basis. Therefore, cross-checking several sources will ensure the information is current and accurate. Remember that with various diagnostic screening tools, treatment options, and preventive measures recommended for heart and cardiovascular diseases, it is important for patients to discuss all information with their health care professionals.

Drug information is complex; consumer-friendly websites on drug treatments provide the detail to be able to understand a specific drug treatment’s pros and cons. A drug treatment may be effective; however, its adverse effects might be too risky for a particular patient. Websites were also selected specifically for the non-medical professional for easy-to-understand descriptions of all areas discussed in this book.

See **resources for further information** for general medical information in print (e.g., complete home medical guides, medical encyclopedias and dictionaries, overviews of medical conditions, and guidance on making informed medical decisions) as well as gateway websites to information about a disease, drug, or treatment that may be more useful to searching librarians. Websites listed in other chapters provide more specific, topic-driven information, such as on individual heart and cardiovascular diseases, which may be more beneficial to patients.

**Resources for Further Information**

**Books**


A solid reference filled with illustrations and pictures, this book is good to have on hand despite the utility of the Internet.


This 778-page reference book on human anatomy and physiology is in alphabetical order, with more than 1,000 topics, including 150+ illustrations and 20 color plates. Carefully written for the professional and nonprofessional, the book features “full cross-referencing [and] comprehensive indexing.”


Chenzbraun, a cardiologist who specialized in echocardiography at Stanford University Medical School, wrote this guide in a reader-friendly format that covers what heart disease is, types of heart disease, and treatment options.


This guide for Latinas in English and Spanish includes common conditions and medical decision making.


This seminal dictionary includes almost 124,000 medical terms and 1,525 illustrations. The e-book version contains 35,000 audio versions of medical terms.


This guide translates medical knowledge into clear terms. Key points are highlighted in orange boxes throughout the book. The index includes entries under both common and medical terms, suggests additional search terms, and directs readers to key pages for each topic.


Editor Gersh’s book includes information on the prevention, diagnosis, and treatment of cardiovascular disease, the number-one killer of women as well as men in the United States. Advances in minimally invasive surgeries; the risks and benefits of in-the-news topics, such as fish oil and margarine; insights about cardiac disease in women; the controversy surrounding appetite suppressants and heart damage; and even gene therapy are discussed in full, as are many more subject areas.

This book lists relevant journal articles after discussions of diseases; it is updated and published annually.

While this dictionary is not as authoritative as others, it is useful as it explains medication terms in easy-to-understand language.

Here are tools for health-information seekers who face critical health care decisions. This book guides readers through the world of medical information in print, on the Internet, and through contact with medical experts and other patients, and it gives practical advice on reading and understanding medical journal articles and understanding variations in standard treatments.

The book gives a comprehensive and accurate description of the heart and heart diseases and is helpful to readers from cardiovascular professionals to patients and families.

This book, written by a diverse group of health care experts, provides a detailed overview of diseases and conditions for the consumer.

This detailed guide by Riegelman provides information about how to understand medical journal articles, such as finding the limits to the study; understanding the results, data, and interpretations; and rating the study’s value of evidence-based medicine. The book is arranged in a “step-by-step, active-participation approach to reading the medical evidence.”

This 2,100-page comprehensive medical dictionary contains over 107,000 terms and definitions, with pronunciations, and includes about 1,500 images and illustrations. The book also features a list of common prefixes, suffixes, and other medical term fragments that compose “90 to 95% of medical vocabulary.”

Although bound to be pocket-sized, this 1,184-page book contains more than 38,000 defined terms derived from *Stedman's Medical Dictionary* and *Stedman's Medical Dictionary for the Health Professions and Nursing*. E-versions that include audio pronunciations are available.

➢ Younger-Lewis, Catherine, ed. *The Canadian Medical Association Complete Home Medical Guide*. 2nd ed. Toronto, Ontario, Canada: Dorling Kindersley, 2001. Print. Comprehensive and accurate, the *Canadian Medical Association Complete Home Medical Guide* was created in collaboration with the Canadian Medical Association to be an accessible source of up-to-date medical information for those who want to participate effectively in their own health care.

**Gateway Websites**

The following gateway sites will provide overall information about a disease, drug, or treatment and are likely to be useful to the searching librarian; websites in the other chapters provide specific, topic-driven information, such as individual heart and cardiovascular diseases, which will likely be more beneficial to a patient.


**Online Search Tips**

The following are brief, helpful, searching hints for accessing online resources:

- If you click on a link (e.g., a title) and nothing happens, try this: right-click on the link and then left-click on the option “Open in new window.”
- To view an animation, you might be asked to allow the installation of a common Internet plug-in called Shockwave Player by Adobe ([http://www.adobe.com/products/shockwaveplayer/](http://www.adobe.com/products/shockwaveplayer/)).

Because the Internet is an ever-evolving resource, some direct links to resources may break over time. To help offset this, we provide alternate paths of access to the resources, but even these may change as websites modify their layout and content.
The Better Medicine website offers links to “Anatomy of the Heart,” with separate links to “Heart, Blood, and Circulation Topics,” and “Expert Advice from Harvard Medical School,” which provides a Heart Disease Center with access to a range of heart disease articles; click on “Forums,” scroll down to “Conditions,” and click on “Heart Conditions.” According to the Better Medicine website, “All content is medically reviewed by at least one medical professional. Our content is backed by evidence from sources, such as articles in peer-reviewed journals, government bodies, objective health organizations and medical groups of specialists. The name and credentials of the medical reviewer(s) are printed at the end of the article.”

The goal of this website is to offer a limited number of resources that meet CAPHIS’s quality criteria for currency, credibility, content, audience, and so forth.

MedlinePlus, a component of the National Institutes of Health and produced by the federal National Library of Medicine, is updated regularly. This website is for patients and their families and friends to access information about diseases, conditions, and wellness issues in easily understandable language. MedlinePlus contains articles on the latest treatments, information on drugs and supplements, definitions of terms, and medical videos and illustrations. It provides links to the latest medical research and clinical trials on all manner of diseases and conditions.

There is a light blue box in the lower center of the homepage. Choose the left-hand column under “Public” to search the disease and conditions index. Choose from the search results. Each page on a disease has information on the nature of the condition, types, causes, risk factors, signs and symptoms, diagnosis, treatments, living with the condition, clinical trials, key points, and links to additional information. The homepage also has links to a variety of important topics under the “Public” Search box. As a federal government agency, the NHLBI’s website is the gateway for the information provided on heart, lung, and blood diseases. To access the “Heart and Vascular Diseases” webpage, the URL is http://www.nhlbi.nih.gov/health/public/heart/index.htm. NHLBI provides global leadership for research, training, and education programs to promote the prevention and treatment of heart, lung, and blood diseases and enhance the health of all individuals.
➢ WebMD—“Heart Disease Health Center.” http://www.webmd.com/heart-disease/default.htm; alternate path: http://www.webmd.com/, search for “heart disease health center,” and click on “Heart Disease Health Center Guide.” This consumer-oriented website offers the latest information on heart disease, using articles, slide presentations, videos, FAQs, discussions groups, and expert blogs. According to the website, “WebMD News is an independent media service designed to provide news, information, and educational material to consumers and physicians. News content created by WebMD is free from influence by sponsors, partners, or other sources.”

➢ WebMD—“Medscape Topics.” http://www.medscape.com/medscapetoday/resource; alternate path: http://www.medscape.com/, in lower left column under “Other Sites,” click on “Medscape Today,” and then at top right of the new page click on “More.” WebMD’s alphabetical gateway has information on many diseases and related topics. Users must register and registration is free. Topic portal pages have the latest news on the topic and links to pages on specific issues on the topic. The information is geared more toward physicians or those with a deeper knowledge of medicine.

➢ WebMD, Medscape Reference—“Drugs, Diseases, and Procedures.” http://emedicine.medscape.com/. The Medscape Reference gateway leads to clinical references for a variety of diseases and medical specialties. The information is geared more toward physicians or those with a deeper knowledge of medicine. Its specific webpages are very thorough and are written by physicians knowledgeable in their subject areas.

Databases

➢ CINAHL Plus with Full Text. EBSCO Publishing. http://www.ebscohost.com/academic/cinahl-plus-with-full-text; alternate path: http://www.ebscohost.com/, click on “Public Libraries,” and then under “Products” scroll down and click on any of the CINAHL databases. Paid subscription; available at some hospitals or public libraries. According to the website, “This is the world’s most comprehensive nursing and allied health research database, providing full text for more than 770 journals.”

➢ Embase Biomedical Answers. Elsevier. http://www.embase.com/. Paid subscription. This database has citations to more European and drug studies than PubMed/MEDLINE, and according to the Embase website, it contains indexed records from more than 7,600 peer-reviewed journals.

Produced by the U.S. National Library of Medicine, the MEDLINE database is widely recognized as the premier source for bibliographic and abstract coverage of biomedical literature. MEDLINE provides information from the fields of medicine, nursing, and dentistry, as well as coverage in the areas of allied health, biological and physical sciences, humanities and information science as they relate to medicine and health care, communication disorders, population biology, and reproductive biology. The database contains more than 12 million citations from 4,600 biomedical journals published in the United States and other countries.

  Ovid is a database service available at hospitals and some public libraries. According to Ovid, the website contains “more than 4,500 ebooks, including 60 book collections, including archive collections of critical historical material, publisher collections, and topical collections; over 1,200 premium, peer-reviewed journals—with no embargoes! Plus 50 journal collections, including archive collections and packages based on publisher or subject; and over 100 bibliographic and full-text databases.”

  According to the website, PsycINFO “is an expansive abstracting and indexing database with more than 3 million records devoted to peer-reviewed literature in the behavioral sciences and mental health, making it an ideal discovery and linking tool for scholarly research in a host of disciplines.” Subscription databases are available at hospitals and public libraries. This is a database of literature on behavioral health.

  Available via the National Center for Biotechnology Information (NCBI) Entrez life sciences retrieval system, PubMed was developed at the National Library of Medicine, located at the U.S. National Institutes of Health. Entrez is the text-based search-and-retrieval system used at NCBI for services including PubMed, Nucleotide and Protein Sequences, Protein Structures, Complete Genomes, Taxonomy, OMIM, and many others. PubMed provides access to bibliographic information that includes MEDLINE and OLDMEDLINE. PubMed coverage also includes out-of-scope citations (e.g., articles on plate tectonics or astrophysics) from certain MEDLINE journals, primarily general science and chemistry journals for which the life sciences articles are indexed for MEDLINE. A PubMed overview
page and a tutorial page are available. Check out the main page (http://www.nlm.nih.gov/) for additional databases.

Webliography


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