



NEWSLETTER ***Winter/Spring 2001***

Index

- **It's Your Choice**
- **Tips for Health Consumers**
- **Informed Decision Making**
- **Solving the Donation Dilemma**
- **New Arrivals**

Tips for Health Consumers

Finding Quality Health Information on the Internet

The Internet can be a useful tool for locating health-related information. But how do you know which web sites to trust? The Internet Healthcare Coalition offers the following guidelines for assessing the reliability of health information available on the Internet:

1. Choosing an online health information resource is like choosing your doctor. You wouldn't go to just any doctor and you may get opinions from several doctors. Therefore you shouldn't rely on just one Internet site for all your health needs. A good rule of thumb is to find a Web site that has a person, institution or organization in which you already have confidence. If possible, you should seek information from several sources and not rely on a single source of information.
2. Trust what you see or read on the Internet only if you can validate the source of the information. Authors and contributors should always be identified, along with their affiliations and financial interests, if any, in the content. Phone numbers, e-mail addresses or other contact information should also be provided.
3. Question Web sites that credit themselves as the sole source of information on a topic, as well as sites that disrespect other sources of knowledge.
4. Don't be fooled by a comprehensive list of links. Any Web site can link to another and this in no way implies endorsement from either site.
5. Find out if the site is professionally managed

Informed Decision Making: Finding Your Path In The Face of Uncertainty

by Nancy Oster and Lucy Thomas

Medical conditions such as diabetes or appendicitis are well understood and usually treated successfully. However, some diseases are not as easily controlled, leading to uncertainty on the part of both the doctor and the patient about the best choice of treatment. Medical situations that warrant research include the following:

No generally successful form of treatment exists,

Standard treatment has failed to check the progress of your disease,

The risks of the treatment might outweigh the potential benefits,

Insurance limitations have restricted your options, regardless of benefit,

You are experiencing unexpected side effects, or

You have been given several treatment options to consider.

In these cases, you and your doctor can work together to evaluate and agree upon the best course of action. Since your doctor's time with you may be limited, you will want to use the time you have together as effectively as possible. Time spent reading about your condition will help you understand the vocabulary, as well as what is known about the disease and, even more importantly, what cannot be predicted about the development and progress of your condition. You can learn why a proposed treatment may or may not work, and what potential short- and long-term risks it includes.

Often as you learn more about your medical condition, the choices become more complex. Instead of finding answers, you may discover there is more uncertainty than you expected. But like everyday decisions, such as whether to drive or fly to a

and reviewed by an editorial board of experts to ensure that the material is both credible and reliable. Sources used to create the content should be clearly referenced and acknowledged.

6. Medical knowledge is continually evolving. Make sure that all clinical content includes the date of publication or modification.
7. Any and all sponsorship, advertising, underwriting, commercial funding arrangements or potential conflicts should be clearly stated and separated from the editorial content. A good question to ask is: Does the author or authors have anything to gain from proposing one particular point of view over another?
8. Avoid any online physician who proposes to diagnose or treat you without a proper physical examination and consultation regarding your medical history.
9. Read the Web site's privacy statement and make certain that any personal medical or other information you supply will be kept absolutely confidential.
10. Most importantly, use your common sense! Shop around, get more than one opinion, be suspicious of miracle cures, and always read the fine print.

Tips reprinted with the permission of the Internet Healthcare Coalition.

The Coalition's web site is

www.ihealthcoalition.org/

[Return To The Top](#)

New Arrivals

Along with the 567 books and audio and video tapes available in the CRCMC library, we have added the following new selections:

Making Informed Medical Decisions: Where to Look and How to Use What You Find
By Nancy Oster, Lucy Thomas and Darol Joseff, MD.
Published by O'Reilly & Associates, Inc.

"This book is impressively clear, accessibly organized, and readable ... well-written and immensely useful."

Marilyn Chandler McEntyre, PhD English
Department Chair, Westmont College, Santa Barbara, CA. Editorial Board Member, Journal of Literature and Medicine, John Hopkins University.

Dr. Susan Love's Breast Book. Third Edition. Fully Revised
By Susan M. Love, MD with Karen Lindsey
Published by Perseus Publishing

"The bible for women with breast cancer."

The New York Times

destination, you will decide by weighing your sense of risk against the urgency of the situation. Asking informed questions helps you develop a realistic perspective on the risks and benefits of the treatments that you are considering.

While it is not necessary to become knowledgeable about every aspect of the disease (just as you do not need to learn to pilot a plane when you fly), you can learn enough about it to decide where to place your trust and when to look further. If you are contemplating a rare complicated surgery, you might look for a center or specialist who performs that surgery on a regular basis. If standard treatment has failed, you might contact a research center and look for appropriate clinical trials. If you are basing a major medical decision on a lab test, you might want to learn more about the reliability of the test.

The decision-making process includes listening to your inner voice. Some of us are risk-takers; some of us are not. Your willingness to take risks may change if your condition worsens. While people around you may encourage you to take certain risks or avoid others, you must make the ultimate decision. You are the one who will live with the consequences.

It is important to communicate your concerns about outcomes, adverse effects, and quality of life to your doctor when you are discussing treatment choices. They can be critical in the decision-making process. For example, radiation to the mouth might affect your ability to taste, a breast reconstruction using the back muscles might affect your ability to play tennis, or chemotherapy might prevent you from having children in the future. If you are a chef, an avid tennis player, or a young person who has not yet had children, the personal impact of these effects must be considered and discussed along with the pros and cons of other methods of treatment.

In essence, research prepares you to ask the questions you need to ask your doctor, discuss the level of risk you are willing to take, and consider which temporary or permanent changes in quality of life you are willing to make. Coming to your medical appointments with a background of information and understanding will greatly enhance your involvement in the treatment planning process.

With patient access to medical information over the Internet, many doctors fear that patients will show up carrying an armload of papers for them to interpret. Most doctors, however, appreciate those patients who read and digest the information and come prepared to ask specific knowledgeable questions and share thoughtful discussion about their options.

Since appointments are often limited to 15-minute sessions, here are some tips for effective use of that time:

Find out how long the appointment will be so you can prepare accordingly. If you feel there is too much to cover in one session, ask for an additional appointment.

Make a list of your questions and concerns.

Prioritize your list. You may not be able to cover every issue in one appointment.

Prepare for Surgery, Heal Faster: A Guide of Mind-Body Techniques

By Peggy Huddleston
Published by Angel River Press

"... should be in the hands of everyone having surgery."

Christine Northrup, MD, Surgeon, past president of the American Holistic Medical Association

A Darker Ribbon: Breast Cancer, Women and Their Doctors in the Twentieth Century

By Ellen Leopold
Published by Beacon Press Books

"I would recommend [this book] to anyone ... as a truly engaged social history of a curious, melancholy, and, until now, untold chapter in medical history."

Katherine A. Powers, *The Boston Globe*

Patient No More: The Politics of Breast Cancer

By Sharon Batt
Published by gynergy books

"A hard-hitting expose ... *Patient No More* is one of the most comprehensive and political books ever written about breast cancer."

Macclean's Magazine

[Return To The Top](#)

It's Your Choice

by Sara O'Donnell
CRCMC's Executive Director

In today's world, when a person hears a diagnosis of cancer from a medical provider, often he or she is sent home with a bewildering array of treatment options to ponder. No longer does the physician make the decision, disregarding input from the patient. This is a good thing, but it also throws the patient into unknown territory. Medical language is foreign to most, and the treatment direction may be unclear to many.

Last year, CRCMC received over 200 requests from first-time callers. Those requests varied according to each person's need. A newly diagnosed woman with breast cancer may have many questions, that when answered, will lead her to an informed decision: Surgical options; mastectomy, lumpectomy, reconstruction? Radiation? Chemotherapy? Acupuncture and herbs? A newly diagnosed man with prostate cancer may face similar decisions: Surgery? Watchful waiting? External-beam radiation?

Give your doctor a copy of the entire list at the beginning of the appointment. That gives your doctor the opportunity to prioritize the elements of discussion too.

Take a friend with you. Ask your friend to take notes so you can focus on the discussion.

Ask if it is okay to tape record the discussion. Often there will be explanations that you will want to listen to more than once, or to share accurately with other members of your family.

Include some time to work together to identify the next step in the decision-making process. Think carefully beforehand about what you want to accomplish at this particular appointment. If you have concerns about negative treatment outcomes, discuss ways to monitor and cope with those possibilities.

As you reach the point where you must make a decision, you will have become informed about each proposed therapy and its positive and adverse effects. Your final decision will incorporate your own personal needs and wishes with the scientific and medical facts you have gathered. You know your own feelings and can sense which option is the best choice for you. As an informed patient, you understand that your medical decisions must be based on research, as well as your own personal needs and intuition, in partnership with medical science.

Nancy Oster is a medical writer, healthcare activist, Internet expert and educator, as well as the founding president of the Breast Resource Center of Santa Barbara. When she has spare time, Nancy cooks gourmet meals, practices yoga, creates websites, gardens and designs quilts.

Lucy Thomas, MLS, is the director of the Reeves Medical Library in the Cottage Hospital in Santa Barbara. She is a distinguished member of the Academy of Health Information Professionals of the Medical Library Association and is on the editorial board for Medicine on the Net. Lucy likes to ski, sail, hike, garden and take long walks on the beach.

Nancy and Lucy actively support access to open and free healthcare and health information. They recently co-wrote a book with Darol Joseff, MD, entitled Making Informed Medical Decisions: Where to Look and How to Use What You Find. The book is available at the CRCMC library.

Nancy plans to present an educational forum, "Making Informed Medical Decisions," for CRCMC on Feb. 7. (See CRCMC Calendar for more information.)

[Return To The Top](#)

Solving the Donation Delima

by Angela Knight

In the electronic gift-giving world, web surfers can donate funds to almost any cause; you can feed the hungry, save endangered species, and cure cancer with the simple click of a

Radiation-seed implants? Chemotherapy? Nutrition and Supplements? These are not small decisions to make.

The final decision is the patient's, and that can be a lonely and frightening road to walk alone. That is where the trained staff and volunteers at CRCMC come in. We understand the importance of making an informed decision; many of us have stood at the crossroads and needed assistance in finding our own direction. Through our personal experiences and training, we are able to provide this assistance in several ways: Our lending library is brimming with up-to-date information; our public access Internet service is open Tuesdays & Wednesdays 9 a.m. to 4 p.m., or by appointment; we have a peer referral network, matching people with similar diagnoses and treatment plans. We are here to listen. We do not give medical advice. We do not encourage a particular course of treatment; that is for you and your medical provider to decide. What we want to provide you with is a light for your treatment path.

This past year many have chosen to participate in our Consultation Planning program, which gives participants a tool to facilitate patient-physician communication. Currently we have five trained consultation planners in Mendocino County who are ready to assist participants with mapping out their questions and concerns in flow-chart form. (Ayn Ruymen, CRCMC's new office manager, is a trained consultation planner). One participant, after her planning session, said, "I had a sense of clarity about the direction I was willing to go with treatment that I didn't have before."

Patient navigation services, like Consultation Planning and the Peer referral network, provided by trained advocates, are at the center of the services we provide. The feedback we have received from both medical providers and patients has shown that an advocate is beneficial for all parties. Dr. Kathleen Persky, a surgeon in Ukiah, says she values the "insightful and caring approach" of CRCMC, as well as its advocates. "CRCMC is taking care of the very important physical and psychological needs of our cancer patients at the time of diagnosis and afterwards," Persky says. She continues to send people to the Center from all over Lake and Mendocino counties.

Nancy Johnson has provided the bulk of the advocacy services to our inland residents for the last five years, as a volunteer. She has worked hard during her off-hours to assist women in navigating the medical system and is a valuable asset to the women she serves as well as to the medical offices she visits. She is one of CRCMC's advisory board members and will soon be the Women's Cancer Advocacy Network (WeCAN!) coordinator. The transition from volunteer to paid staff member can't happen soon enough. Currently, we are writing grants to insure that inland Mendocino County will have a full-time patient advocate in place this year.

We at CRCMC believe it is important for you to be an active participant in your healthcare choices; whether it is deciphering the incredible array of treatment options, or learning how to ask the questions. We want to offer you, your friends and loved ones, the possibility of a partnership with CRCMC to help facilitate your decision-making process.

mouse. While it's true that donating money to charitable organizations has become much easier with the help of the Internet, it also has created complications. The donation choices can be daunting, especially when our mailboxes, electronic as well as traditional, are filled with desperate pleas for money on a daily basis. How do you decide where your valuable donation dollars should go? How do you make informed donation decisions?

It is possible to spend time researching where your donation money should go before you reach for the mouse or your credit card. GuideStar, a website created by the nonprofit Philanthropic Research, Inc., is attempting to provide part of the solution to the donation dilemma. The site claims to offer information on 700,000 nonprofit organizations in the United States. Everything from the American Cancer Society to the Heifer Project, from I-plus to Z Press, Inc., is listed on GuideStar.

By using the site's search feature, potential donors can obtain financial data from their favorite charity, including balance sheets, with assets and liabilities, as well as a copy of its Internal Revenue Service 990 tax form. The breakdown of money spent on programs and administrative costs can give donors a clearer picture of where their donation dollars are being spent.

But what if you don't have a computer or access to the Internet? There is still the telephone. Most non profits have toll-free numbers. The only investment is time, and donors can have a list of questions handy to ask.

What should you look for when assessing a charitable organization? First of all, do you agree with the organization's purpose (which is often reflected in its mission statement)? Is the nonprofit willing to share financial information with donors, including exactly how the money is spent? Is the image that the organization conveys, in printed material and on its website, in keeping with its programs and services?

While educating themselves about the organization, it might be a good idea for potential donors to do a little homework on the actual cause itself. For example, breast cancer is a complex disease, as well as a complicated social and political issue. Many different theories and approaches exist about finding a cure for breast cancer. There is a major difference between donating money to an organization that is looking into environmental links to cancer, versus one that funds breast cancer detection programs.

Along with the postal deluge of donation requests from nonprofit organizations, a wealth of email messages have been circulating about the opportunity to provide a woman with a free mammogram without actually donating a cent. It takes only seconds to perform something called a "daily click" on the Breast Cancer Site, which was founded in October by GreaterGood.com, a private company that operates for profit. The "daily click," which doesn't cost the user any money, gives underprivileged women free mammograms through the National Breast Cancer Foundation, according to the site; GreaterGood's sponsors and advertisers pay for the

We are here to light your way, with information and services. And, always, to listen.

[Return To The Top](#)

mammograms. On the surface, this seems like a good idea. What could be better than a simple charitable act that might possibly save a woman's life? The problem is that the site doesn't offer detailed information about how the program actually works. Before performing the "daily click," it might be a good idea to contact GreaterGood directly and find out who determines which women qualify for the program and whether any treatment funds are available for the women who find out that they have breast cancer.

Recently, Yahoo and the well-known Susan G. Komen Foundation teamed up to offer the "click for the cure." The site was set up so that someone who logs on to the Internet and clicks on the pink ribbon can donate money to the Foundation. Thanks to the efforts of large corporations dedicated to raising money for cancer, donating has become a painless and automatic act. But, where does the money go after that click? How will the Foundation spend your \$1 or \$5 donation?

By taking the time to research nonprofit organizations, and holding them accountable for how they spend their money and the effectiveness of their programs, we can make every donation dollar truly count.

GuideStar's web site is www.guidestar.org/

[Return To The Top](#)