

Cancer and the Internet

Patient Education Resource Center (PERC)
Information Guide

Recommended Web Sources

- **American Cancer Society** <http://www.cancer.org>
This large site has detailed summaries of specific cancers, and information about living with cancer, making decisions, and coping with side effects and practical issues
- **Cancer.gov** <http://www.cancer.gov>
This site contains PDQ statements -- peer-reviewed summaries on treatment of adult and childhood cancer types, and supportive care topics. Oncology specialists update the statements monthly. The site also had a database of cancer clinical trials.
- **The Cancer Journey** <http://www.thecancerjourney.org>
The focus of the Oncology Nursing Society site is on managing side effects and symptoms during and after treatment.
- **Cancer.net** <http://www.cancer.net/>
The American Society of Clinical Oncology (ASCO) site has research news, treatment guidelines, and online discussions with oncologists.
- **Mcancer.org** <http://mcancer.org/>
The University of Michigan Comprehensive Cancer Center has information about cancer treatment at our center, support services for patients and families and clinical trials.
- **National Comprehensive Cancer Network (NCCN)**
<http://www.nccn.com/>
This alliance of 21 of the world's leading cancer centers creates treatment guidelines for treating specific types of cancer. The site has patient versions of these guidelines and other information about cancer. The University of Michigan Comprehensive Cancer Center is a member of NCCN.

The purpose of this information guide is to direct patients and health care professionals to sources of information on cancer and related topics. This list is not meant to be comprehensive, but rather to provide starting points for information seeking.

The materials can be found at the Patient Education Resource Center of the University of Michigan Comprehensive Cancer Center in room B1-361. An online version of this document can be found at:
http://www.cancer.med.umich.edu/support/information_guides.shtml

Proceed With Caution!

“The Internet is a wild frontier whose landscape changes frequently. It contains all sorts of health information—good and bad, true and false, complete and dangerously incomplete. Before you act on anything you learn online, we recommend that you make sure you check with your doctor.”

--Consumer Reports

- Anyone with a computer can set up a website or publish information through a blog, wiki, medical or social networking sites. It is easier to publish information on the Internet than to publish books, magazines and other traditional forms of communication.
- People and/or commercial companies create sites in order to promote a product or the opinion of the site’s creator. Be aware of the site’s creator’s goals and bias when you read the information.
- It is important to check the credentials of health information providers – just as it is important to check the credentials of your healthcare provider. Find out if the information is provided by a health professional or by a lay person.

If you obtain health information from sites other than the ones listed above, please be sure to evaluate the information according to the following guidelines:

Check the site’s URL (address). The last segment of the URL before the / gives a general indication of the organization sponsoring the site, for example:

- › .edu – site provided by a university or a learning institution
 - › .gov – site provided by a government agency
 - › .com – site provided by a commercial company
 - › .org – site provided by a non-profit organization
- Read the “About us” or “Who are we?” section of the site. A reputable site should include this section. This is where a user can learn about the credentials and intentions of the site’s creator.

- Check the date the information was last revised. Look for sites that offer fresh content that is updated regularly.
- Stick by government or university run sites. Other credible sources include medical associations and hospitals.

Web 2.0 Tools

Many cancer survivors share their wisdom and experience on blogs, wiki's, listservs, medical and social networking sites. Always check to see who provides the information and why. Information that comes from lay people may have errors and the experience of the information provider is not always relevant to the user. Check with your doctor before you make any decisions about your medical care.

Share Information You Found on the Internet with Your Doctor

Cancer is a complex disease with many factors and variables that affect diagnosis, prognosis and treatment decisions. Every cancer patient is a unique case with a different set of circumstances. Even if the information you find on the Internet is accurate and current, it may not be applicable to your specific situation. To understand how the information you find relates to your case, you must consult with your doctor.

The following are suggestions to facilitate efficient and effective communication between you and your doctor:

1. Be organized

Keep your printouts well-organized in a folder or in a set of labeled folders that will enable you to find each piece quickly.

2. Prepare a list

Review the information before the appointment and prepare a set of questions with the most important and relevant ones first. Next to the questions record the information sources on which they are based. These references will help you to pull out a specific piece if the doctor asks for it. Be realistic in planning a reasonable number of questions within the time limit of your appointment.

3. Keep a record of what was said

It is difficult to maintain a conversation and take good notes at the same time. Bring a friend or a family member who can take the notes. You may also ask for permission to tape the conversation. This will help you to recall what was said in the meeting after it is over.

When searching for information on cancer, it is important to establish a good foundation of knowledge about the disease, before focusing the search on treatment options. A good understanding of the disease and its specific aspects such as: sub-typing, staging, tumor markers, etc., will help the information seeker find more relevant information and ask better questions

This document is not intended to take the place of the care and attention of your personal physician or other professional medical services. Our aim is to promote active participation in your care and treatment by providing information and education. Questions about individual health concerns or specific treatment options should be discussed with your physician.

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