



Childhood Cancer and the Internet

Patient Education Resource Center (PERC)
Information Guide

Website Resources

- **American Cancer Society** <http://www.cancer.org>
Overviews of specific cancer types and topics such as nutrition, coping with side-effects, support and practical issues are offered in this site. Specific articles on coping with childhood cancer may be accessed through the "Patients, Family & Friends" section of the site.
- **Cancer.net** <http://www.cancer.net/portal/site/patient>
The American Society of Clinical Oncology (ASCO) provides an excellent site to keep up with new developments in cancer research and treatment. The site includes a news database, abstracts, treatment guidelines, information from ASCO meetings and online discussions with oncologists.
- **cancer.gov** <http://www.cancer.gov>
This site contains PDQ statements -- peer-reviewed summaries on treatment of adult and pediatric cancer types, and various supportive care topics. PDQ statements are updated monthly by oncology specialists. Also on this site is a database of all cancer clinical trials.
- **Cancer BACUP** <http://www.cancerbacup.org.uk>
The British cancer information service offers news and information on specific cancer types and topics, and an extensive Questions and Answers section offering detailed information written by cancer specialists and nurses.
- **CureSearch.org** <http://www.curesearch.org>
Provided by the National Childhood Cancer Foundation and the Children's Oncology Group this site includes information for children and parents.
- **National Children's Cancer Society (N.C.C.S.)**
<http://nationalchildrenscancersociety.com>
Information about support services to children with cancer and their families. This site includes the full-text of three educational publications: a coloring book for children ages K-3rd, a guidebook for survivors ages 15 to 24 and a guidebook for parents.

The purpose of this information guide is to direct patients and health care professionals to sources of information on cancer and related topics, it does not constitute an endorsement of the information contained in the resources. This list is not meant to be comprehensive, but rather to provide starting points for Information seeking.

All listed 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/learn/percpathways.htm>

- **PED-ONC Resource Center** <http://www.acor.org/ped-onc>
Created and maintained by parents of children with childhood cancer this site focuses on psychosocial and medical issues as well as ways to connect with other parents of children with cancer.

Email Discussion Groups and Chat

- **ACOR** – the Association of Cancer Online Resources (<http://www.acor.org>) provides access to **143 disease-specific cancer email discussion groups**. The ACOR site allows a user to search or browse the archives of the lists.
- Another listing of cancer related email groups (listservs) can be found on **Oncolink**:
 - Go to: <http://www.oncolink.com>
 - Click on: "Coping with Cancer"
 - Click on: "Support"
 - Click on: "Support Groups and Information Resources"

Blogs

- Blogs are online diaries published by users on the world wide web. Many blogs are written by cancer survivors describing their experiences with the disease and its treatment. One must remember that the facts published on blogs may sometimes be erroneous, and the personal experiences of the blogger may not always be relevant to the reader. Information obtained from blogs should be carefully checked for accuracy and currency before making any treatment decisions.

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! It is easier to publish information on the Internet than to publish books, magazines and other traditional forms of communication.

- Some sites on the Internet were created in order to promote a product or the opinion of the site’s creator; therefore the information they present may be biased. It is important to weigh Internet information in the context of the site creator’s motive.
- In a similar manner to checking the credentials of a healthcare provider, it is necessary to check the credentials of an Internet information provider. It is important to know 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 mentioned 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.
- Remember: the information on listservs and chats is anecdotal, and not scientifically proven. Check this information with your doctor.

Sharing 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 physician.

The following are suggestions to promote 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 allow 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 constraints 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 retrieve 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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