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Finding Cancer Information on the Internet

For many people, the Internet has become the first place to go when looking for information. You can get instant access to almost any topic you can think of – including a lot of cancer information. People facing cancer often use this information to make decisions about their illness and treatment. Some of this information is more reliable than the rest, but it can be hard to tell at first glance.

On many websites you can find basic facts about certain types of cancer, find current clinical trials, and find support in dealing with cancer. You can also get vast amounts of information on research studies, doctors and hospitals, cancer treatment guidelines, drugs, and complementary and alternative treatment methods. But a lot of what passes for cancer information on the Internet is made up of opinion, salesmanship, and testimonials, and is not grounded in careful science. It may take some extra time and effort, but you need to find accurate information. The wrong information can hurt you when it comes to cancer.

Here are some ideas on what to look for and what to avoid as you look for the information you need to make the best possible decisions.

User beware

Cancer information on the Internet comes from many different sources – expert health organizations, government agencies, universities, merchants, interest groups, the general public, and scam artists. Anyone can post any kind of information online and some people may be passing along information that's limited, inaccurate, or just plain wrong. Some even try to deceive you.

Scam artists and other dishonest people use the Internet for 2 main reasons: low cost

and relative anonymity (no one knows who they are). What's more, the message or product gets out to people all over the world.

The nature of the web makes it easier to mislead people. For example, if you saw a sign in front of a small, run-down store that claimed it was the largest supplier of medical devices in the United States, you'd probably be suspicious right away. But if you saw a professional-looking site on the Internet making the same claim, you might have a harder time deciding if it was real.

This is not to say that you shouldn't trust anything on the Internet – just that you have to choose your sources carefully. Even on trusted, highly regarded websites, it's important to note that the health information is just general information that might not apply to you at all. **Always remember that the information found online should not take the place of medical advice.** If you have a health-related problem, please talk to a doctor. There's no other way to get the same experience and care as sitting down with a health care provider who can look at your health history, your unique medical situation, examine you, and talk with you about how you've been feeling.

Searches give you commercial results, too

Keep in mind that most search engines return “sponsored” findings with their search results. Often, these links are at the top of the result list. They may be in a box, in a different color, above a line, off to one side, or below a header, but you should be able to tell these links from your true search results. The sponsored results are actually ads for other websites that are related to your search. Sometimes you might find the links helpful, but many of the sponsors are trying to sell a product to make money. Seller information can be helpful for many products, but it's probably not the kind of information you want to use in choosing your cancer treatment.

How can I be sure that what I read on the web is true?

In many cases, there isn't a simple way to be sure. The list of questions below is adapted from a list developed by the National Cancer Institute (NCI). Ask these questions when trying to decide if you can trust a source of cancer information. The answers should be easy to find on the website itself.

Who runs this website? Who pays for it?

Is the site run or paid for by an individual or by an organization? What type of organization – business, government agency, or non-profit organization?

Any honest, health-related site should make it easy for you to find out who is responsible for the information on it. Often this can be found by clicking on “About Us,” which can usually be found at the top or bottom of the site’s main (home) page.

You can get an idea about who runs a site by looking at the letters at the end of the URL address, called *top level domain names*.

- *.edu* means that the source of the information is part of an educational system (such as a college or university)
- *.org* usually means that the source is a non-profit organization
- *.gov* means that the source is a part of a national or state government
- *.com* or *.biz* usually means the site is run by a commercial (for-profit) or private source

Knowing whether the information came from a business, a university, or a non-profit group can be useful because it could give you some insight into why the individual or organization is providing that information. There are other top level domain names, but these are among the oldest in use that might apply to health information sources.

Although the US doesn’t do it, other countries usually have a 2-letter code that comes after the end of the basic URL. For example, India uses *in* and Australia uses *au*. You might notice information from a British government agency includes *.gov.uk*, and a Rwandan business might use *.com.rw* in their URLs. It’s important to know where information comes from, because while the general information might be good, treatment information, treatment availability, and cancer statistics in other countries can be very different from those of the US.

In the US, the most reliable sources of health information tend to be government agencies, hospitals, universities, and major public health and health advocacy organizations, such as the American Cancer Society. These groups use information that’s reviewed by noted experts and updated often.

Who’s funding the site should also be easy to figure out. It’s important, because it can affect what’s presented on the site and how it’s presented. If the source is a commercial business, such as an advertiser or provider of a service or product, there may be some bias or prejudice in the information. Government sites, universities, and public health groups generally seek only to educate the reader. But even on non-profit websites, if the site is full of ads or is supported or funded by an outside company, it’s important to ask yourself whether the information there might be biased in some way. This isn’t always the case, but it should make you more cautious.

What's the purpose or mission of this website?

It's important to know the mission or purpose of the site – it's usually related to who runs the site. In most cases, this information can be found by clicking on "About This Site" or "About Us," which is usually at the top or bottom of the main (home) page.

Again, websites designed to promote or sell products may be more likely to have slanted or inaccurate health information than sites designed to simply provide information. Some sites try to do both, but you should look at these carefully, too. Remember that if a website's main purpose is to sell products, it will only contain the information the seller wants you to read.

Intended audience

Another thing to think about: who is the website is written for? It should clearly state whether the health information is meant to be used by lay consumers (patients and families) or health professionals.

Some health information websites have 2 different areas – one for consumers and one for professionals. The site should be designed so that you can choose the one you want to read. The information in both areas should be much the same, but the patient information should be written in a way that makes it easier to understand without using a lot of medical terms.

Where does the information on this website come from? How is it documented?

Can you tell where the information came from? Is it based on scientific facts, or is it based on opinions or personal experiences? Personal stories, often called blogs, testimonials, or anecdotal reports, may be quite moving, but they may not apply to you. And, a few people saying that they've done well on a certain treatment (which may not even be true) doesn't mean that most people will.

Good information comes from studies that are done on large groups of volunteers, using careful methods to be sure that the result actually reflects what's being tested. Testimonials can be exciting, but they usually can't be checked for accuracy. And testimonials describing another person's experiences with a different kind of cancer (or even the same type of cancer, in a different stage or in someone with different medical problems) may not be related to the choices you are facing.

Can you tell what research was done to back up what's being said? More reputable

websites will list references from scientific journals that support the information they give you.

Does the information seem biased? Is only a single viewpoint presented?

Information should be balanced, giving the pros and cons of a subject or treatment. If the information describes a treatment, know that all treatments have unwanted effects in some people. If none are listed or discussed, that's often a warning sign.

Also, look for a disclaimer saying that the content is intended for information and not as medical advice. Information on the Internet cannot replace medical care.

How is the information reviewed? Who writes or reviews it?

Does the site tell you how the information is reviewed to be sure it's correct? For example, is the information reviewed by experts in the field? How often is it reviewed?

Who writes the material on the site? Try to identify the authors. If the authors are listed, are their credentials included?

You might even want to try typing the names of authors and experts into a search engine to learn more about them.

How up-to-date is the information?

How often is the information updated? Information in the field of cancer treatment changes almost every day. The standard of care a couple of years ago may no longer be the standard of care today. Web pages should include the date the information was posted. If information on cancer treatment is more than a couple of years old, you may want to look for and compare it to more recent information.

Does the website ask for your information? Why?

If the site collects your personal information, can you find out how this information is to be used? Can you look up cancer information without giving any personal information? Does the information you're asked to give fit the purpose stated? If the answer to these questions is no, then you might want to look elsewhere.

The site's privacy policy (usually linked from the top or bottom of the site's home page) should be easy to get to and clearly explained. Some websites may automatically place you on email lists, or even sell your information to other organizations or companies.

Know where your information may be used before giving it out, especially if you have included anything of a personal or financial nature.

Websites that exist only for health information should not ask for information like your social security number, credit or debit card numbers, driver's license number, date of birth, or mother's maiden name. This kind of personal information should only be given when you have a trusted business relationship with the website and are sure you are on a secure page.

How do users interact with this website?

Is there a way for users to make suggestions and comments on the website? Most websites will offer you a way to give feedback on their site. If the site has a chat room, blog, or message board, is there a moderator or someone who monitors user interaction? Does the moderator check facts or just remove offending posts?

Tips for finding reliable information

Links to other websites

Some websites also have links you can click on to go to similar types of sites. Once you find a website you trust and that meets your needs, you may be able to look for links on that site that take you to other useful and credible sites.

Warning signs

It may not be easy to get answers to the questions listed above. Even some reputable websites may fall short in certain areas. Another helpful way to size up a website is to look closely at what's there.

The US Federal Trade Commission (FTC) has developed a list of claims that should make you suspicious of a website:

- Claims of a "scientific breakthrough," "miraculous cure," "secret ingredient," or "ancient remedy"
- Claims that a product can cure a wide range of illnesses (No one product can do this.)
- Stories of people who've had amazing results, but no clear scientific data
- Claims that a product is available only from one source, especially if you must pay

in advance

- Claims of a “money-back” guarantee (While this may make the product seem risk-free, it’s often impossible to actually get your money back.)
- Websites that don’t list the company’s name, street address, phone number, and other contact information (It may exist only offshore, away from US laws and regulators.)

Problems in any of these areas should raise a red flag – a warning – to the user that the site may contain information that’s not based on careful science and cannot be trusted. This may be especially important when looking at sites promoting complementary or alternative cancer treatments. (See [Complementary and Alternative Methods and Cancer](#)¹ and [Learning About New Cancer Treatments](#)² for more information on this.)

Health On the Net Foundation

Another way to check the quality of a website is with the Health On the Net Foundation (HON). HON is an organization based in Switzerland whose mission is to guide people to useful and reliable online medical and health information.

To be allowed to display the HON logo, participating websites must agree to abide by an ethical code of conduct. The HON code tries to improve the quality of medical information on the Internet through some basic principles which cover things like authorship, documentation of materials, and sponsorship of the site.

HON also tries to actively promote effective Internet use with specific medical search engines that give you reliable and scientifically sound information. For more information, visit the HON website at www.hon.ch³.

Reporting inaccurate information

You can help make sure that health information on the Internet is correct. If you see something on a web page you know is wrong, let those at the website know about it so that it can be fixed. This can usually be done by using the “Contact Us” link.

If someone is making false claims on purpose, or trying to deceive people while selling a product, they may be breaking the law. You can use this link to find special information about online [cancer scams](#)⁴, or you can contact the US Federal Trade Commission (FTC) at 1-877-FTC-HELP (1-877-382-4357).

The FTC does not resolve complaints, but tracks them to detect patterns of wrong-

doing, which can lead to investigations and prosecutions. You can report suspected scams online at www.consumer.ftc.gov⁵ by choosing “File a consumer complaint.”

The Food and Drug Administration (FDA) is responsible for regulating all drugs (prescription and over-the-counter) and sets standards for dietary supplements (such as herbs, vitamins, and minerals) as well as the claims that can be made about them. The FDA has different standards of proof for supplements than for medicines, in that they do not review the effects of supplements on the body. (You can read more about this in [Dietary Supplements: What Is Safe](#)⁶?) More information is available on the FDA website (www.fda.gov⁷). If you have a concern about unproven claims on a website, such as claims that a supplement has the same effects as a drug, or that it can prevent or cure an illness, you can let the FDA know through their website at www.fda.gov/Safety/MedWatch/HowToReport/default.htm⁸.

Online support groups, mailing lists, blogs, and chat rooms

Online support groups are groups of people who share information and support over the Internet through blogs, chat rooms, discussion boards, or mailing lists. These websites allow people to connect with others like them who might otherwise be difficult to reach. They also allow a person to keep their real identity private if they want to do so.

Some people find online support groups emotionally helpful. It may be comforting to share your experiences with other people who are facing the same things you are. Still, these places may not be the best sources of health information. You should discuss any information you get with your cancer care team to see if it applies to you. You should also be aware that sometimes researchers monitor the conversations of online support groups.

The Cancer Survivors Network[®]

The American Cancer Society’s Cancer Survivors Network (CSN) is a secure online community created by and for cancer survivors and their families to share their cancer-related experiences, support one another, and exchange practical tips learned while living with the challenges of cancer. It’s available online at csn.cancer.org⁹.

The CSN is free and available around the clock. An easy and quick registration is all you need to access all areas of the community and take part in its many interactive features. Members may search for people with similar cancer experiences or interests, either by entering certain information (such as age range and cancer type) or by using keywords.

Interactive features of the CSN include: discussion boards, chat rooms, blogs, safe and secure internal CSN email, an Expressions Gallery with member photos, poems, audio, and more. CSN members are also able to create a personal page to share their story and to contribute to the member-created CSN Resource Library if they so wish.

Finding other online support groups

Here are some ways to find other online support groups:

- [The Association of Cancer Online Resources, Inc.](#)¹⁰(ACOR), maintains a large collection of cancer-related Internet mailing lists. ACOR supports the mailing lists, and develops and hosts Internet knowledge systems that allow the public to find and use accurate, relevant information. They also try to educate users about privacy issues in Internet health care.
- Many of the websites listed in the “Cancer information websites” section below also offer support to people with cancer and their families.

What about the e-mails I get?

If you share your contact information, e-mails may start pouring in. Well-meaning friends and family may also send you e-mails with cancer information and various cancer treatment options. Carefully evaluate these messages. Consider the source of the message and its purpose. Many companies and organizations use e-mail to advertise or attract people to their websites. The accuracy of the information may be influenced by their desire to promote their product or service.

One way to sift through the information you get is to identify respected, reliable sources of health information and use them as your main resources. You can learn more about this in our documents called [Learning About New Cancer Treatments](#)¹¹ and [Learning About New Ways to Prevent Cancer](#)¹².

Cancer information websites

The following are more specific examples of cancer information websites. These sources should only be used to get information. If you have a health-related problem, please see a health care provider.

This list is not all-inclusive, and inclusion here does not imply endorsement by the American Cancer Society.

Other organizations offering cancer information*

Along with the American Cancer Society, other sources of cancer information and support include:

Cancer.Net Oncologist-approved cancer information from the American Society of Clinical Oncology (ASCO) www.cancer.net¹³

CancerWise From the University of Texas MD Anderson Cancer Center www2.mdanderson.org/cancerwise¹⁴

Medline Plus The US National Library of Medicine, National Institutes of Health offers easy-to-read information www.nlm.nih.gov/medlineplus/cancers.html¹⁵

National Cancer Institute (NCI) The NCI is a part of the US National Institutes of Health (NIH) www.cancer.gov¹⁶

National Comprehensive Cancer Network An alliance of 21 of the country's leading cancer centers www.nccn.org¹⁷

Oncolink From the Abramson Cancer Center of the University of Pennsylvania www.oncolink.org¹⁸

Searching for specific cancer-related medical research articles*

These sites allow you to search the medical literature for scientific articles published in medical journals. They are not helpful in searching for other websites or other types of information.

National Library of Medicine (main page allows access to several different databases) www.nlm.nih.gov¹⁹

PubMed/MEDLINE www.ncbi.nlm.nih.gov/PubMed²⁰

US Government sites (not just for cancer information)*

Centers for Disease Control and Prevention (CDC) www.cdc.gov²¹

Environmental Protection Agency (EPA) www.epa.gov²²

Federal Trade Commission (FTC) www.ftc.gov²³

Food & Drug Administration (FDA) www.fda.gov²⁴

National Institutes of Health (NIH) www.nih.gov²⁵

Complementary & alternative therapies*

National Center for Complementary and Integrative Health (part of NIH)
<http://nccih.nih.gov>²⁶

National Cancer Institute www.cancer.gov/cancertopics/cam²⁷

Memorial Sloan-Kettering Cancer Center (MSKCC) *About Herbs, Botanicals & Other Products* www.mskcc.org/cancer-care/integrative-medicine/about-herbs-botanicals-other-products²⁸

Office of Dietary Supplements (part of NIH) <http://ods.od.nih.gov>²⁹

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Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/complementary-and-integrative-medicine/complementary-and-alternative-methods-and-cancer.html
2. www.cancer.org/treatment/treatments-and-side-effects/how-to-interpret-news-about-new-cancer-treatments.html
3. <http://www.hon.ch>
4. <http://www.consumer.ftc.gov/articles/common-health-scams>
5. www.consumer.ftc.gov/
6. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/complementary-and-integrative-medicine/dietary-supplements.html
7. <http://www.fda.gov/>
8. <http://www.fda.gov/Safety/MedWatch/HowToReport/default.htm>
9. <http://csn.cancer.org/>
10. listserv.acor.org/scripts/wa-ACOR.exe?INDEX
11. www.cancer.org/treatment/treatments-and-side-effects/how-to-interpret-news-about-new-cancer-treatments.html
12. www.cancer.org/healthy/cancer-facts/how-to-interpret-news-about-ways-to-prevent-cancer.html

13. <http://www.cancer.net/>
14. <http://www2.mdanderson.org/cancerwise/>
15. medlineplus.gov/cancers.html
16. <http://www.cancer.gov/>
17. www.nccn.org/
18. <http://www.oncolink.org/>
19. www.nlm.nih.gov/
20. <http://www.ncbi.nlm.nih.gov/PubMed>
21. <http://www.cdc.gov/>
22. www.epa.gov/
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Written by

The American Cancer Society medical and editorial content team
(www.cancer.org/cancer/acs-medical-content-and-news-staff.html)

Our team is made up of doctors and oncology certified nurses with deep knowledge of cancer care as well as journalists, editors, and translators with extensive experience in medical writing.

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