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.

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

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) has3o7 qel. rg /e76hat's there.

doing, which can lead to investigations and prosecutions. You can report suspected scams online at www.consumer.ftc.gov/4 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 Safe⁵?) More information is available on the FDA website (www.fda.gov⁶). 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.htm⁷.

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.org8.

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:

Other organizations offering cancer information*

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

CancerWise From the University of Texas MD Anderson Cancer Center www2.mdanderson.org/cancerwise¹²

Medline Plus The US National Library of Medicine, National Institutes of Health offers easy-to-read information www.nlm.nih.gov/medlineplus/cancers.html¹³

National Cancer Institute (NCI) The NCI is a part of the US National Institutes of Health (NIH) www.cancer.gov¹⁴

National Comprehensive Cancer Network

National Institutes of Health (NIH) www.nih.gov²³

Complementary & alternative therapies*

National Center for Complementary and Integrative Health (part of NIH) http://nccih.nih.gov²⁴

National Cancer Institute www.cancer.gov/cancertopics/cam²⁵

Memorial Sloan-Kettering Cancer Center (MSKCC) *About Herbs, Botanicals & Other Products* <u>www.mskcc.org/cancer-care/integrative-medicine/about-herbs-botanicals-other-products</u>²⁶

Office of Dietary Supplements (part of NIH) http://ods.od.nih.gov/27

*Inclusion on these lists does not imply endorsement by the American Cancer Society.

Hyperlinks

- 1. <u>www.cancer.org/cancer/managing-cancer/treatment-types/complementary-and-integrative-medicine/complementary-and-alternative-methods-and-cancer.html</u>
- 2. <u>www.cancer.org/cancer/managing-cancer/how-to-interpret-news-about-new-cancer-treatments.html</u>
- 3Tv1v0v0c0r1s00r34r.369g41/arrio/le2/d2nTfr0v0-l2eaet11-2cdar0s0.2me 12 Tf 0 0.2me 12 Tf 0 0 1 100per8

- 14. www.cancer.gov/
- 15. www.nccn.org/
- 16. www.oncolink.org/
- 17. www.nlm.nih.gov/
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- 19. www.cdc.gov/
- 20. www.epa.gov/
- 21. <u>www.ftc.gov/</u>19.

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

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