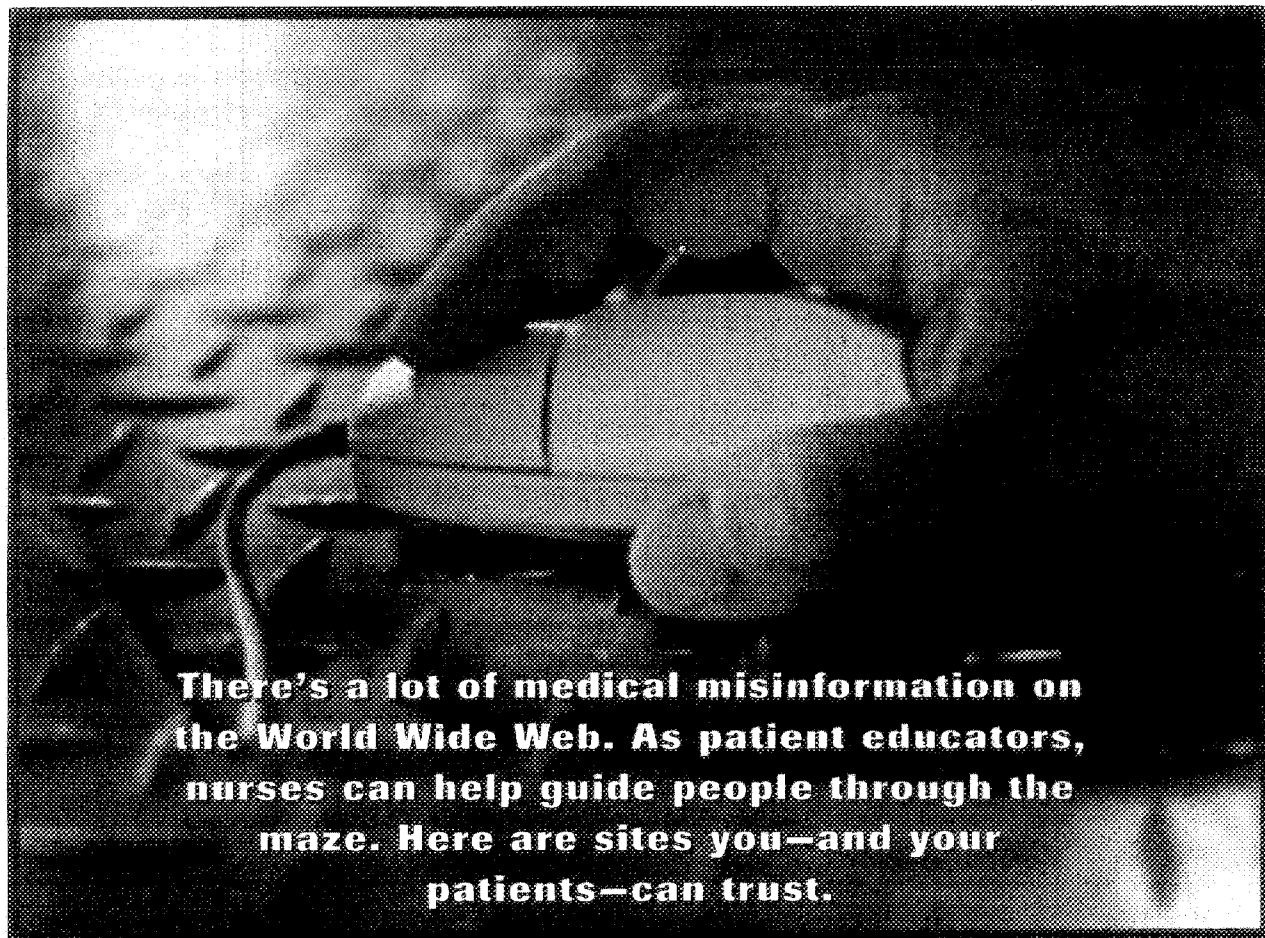


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Help patients surf the Net safely



There's a lot of medical misinformation on the World Wide Web. As patient educators, nurses can help guide people through the maze. Here are sites you—and your patients—can trust.

KEY WORDS

- ▶ internet
- ▶ World Wide Web
- ▶ patient education

Across the country, Web savvy patients are learning about their own medical conditions and bringing that knowledge with them to the doctor's office. Even people who don't have access to computers have family members and friends doing research for them.

Many health professionals welcome the exchange, figuring informed patients take better care of themselves.

But whether you like the trend or not, one thing is for sure, you'll be dealing with more and more Internet-informed patients.

If patients' Internet research makes

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healthcare professionals feel edgy, it might be because there's more than research going on here. Patients who take the trouble to investigate health issues tend to expect a larger degree of participation in the discussion of treatment options and in the decision-making process. That's not necessarily a bad thing. A patient's computer research can save you time and increase your effectiveness—provided they are receiving good information.

Guide patients to the best sites

To help patients become more discerning in general, consider developing a hand-out to guide their Net surfing. (Sending a letter like the one in the box on the facing page is one way to do that.) Tell them that even sites with no advertising may be misguided. Some are the handiwork of people who are champions of a particular approach or therapy. But that individual's enthusiasm is no guarantee that the approach will bring results for your patient.

If the patient is considering a treatment or course of action that's potentially harmful, listen to what he has to say, then mention potential risks—that the medication he wants can cause seizures, for example.

If a patient asks questions you can't answer immediately, tell him you'll speak with someone who knows a little more about the subject and will get back to him. Then make good on your word.

To keep tabs on what's out

**Whether or not you
recommend online
support groups, your
patients will use
them, so be ready to
field questions.**



there, start browsing the Web yourself. Also check out the sites your patients frequent most often. If you don't know what they are, add the question to your patient information form. Then bookmark the sites that provide the best information so you'll be able to reach them easily. Osbourne A. Blake, an "early adopter" of the Internet in his Inglewood, Calif., internal medicine practice, thinks that the best way to steer patients to the most helpful sites is for a medical office to set up its own Web site and put in the links that the staff feels are most helpful.

Encouraging patients to stay informed about their health is the best way to maximize the brief time patients and clinicians spend together, says Donald W. Hackett, president and CEO of drkoop.com (www.drkoop.com), one of the most heavily trafficked health information sites. "When

a patient has knowledge of what ails him, he can begin the discussion at a higher level." In other words, you may spend less time explaining the basics to such a patient and can often launch right into the discussion of the care plan you want to establish.

What about online support groups?

Many patients with chronic or rare disorders have found online support groups invaluable. Physician and online health specialist Tom Ferguson of Austin, Texas, wanted to learn how much patients rely on such groups. Ferguson is the author of *Health Online: How to Find*

Health Information, Support Groups, and Self-Help Communities in Cyberspace (Addison-Wesley, 1996). He's also a professor of health informatics at the University of Texas Health Science Center in Houston, and publisher of *The Ferguson Report*, a free online newsletter.

Ferguson studied the most frequent users of Sapient Health Network's online interactive support groups for people with chronic and serious illnesses. (Sapient is now part of Healtheon/WebMD, a company that connects physicians and consumers with health plans online.) The 191 respondents rated the online support communities as more helpful than physicians in 10 out of 12 categories, including convenience, cost-effectiveness, emotional support, compassion and empathy, help in dealing with death and dying, medical referrals, practical coping, in-depth

information, and "most likely to be there for me in the long run."

Doctors and nurses shouldn't worry much about those results yet, though, says Ferguson. The survey respondents are far more computer literate than the typical patient. However, the results do predict the general trend for the future, he says. And they show how much your sickest patients currently rely on outside support.

The relevant question is whether to refer patients who can use extra support to online groups and, if so, to which ones. Hackett of drkoop.com likens unsupervised chat groups to waiting room conversations, and moderated online discussions to consultations where patients talk one-on-one with a medical expert. He says patients benefit from both. "Individuals value the opportunity to share and learn with others. Certainly the tone changes when there is no trained professional." Support groups at drkoop.com, he says, are all led by someone who has extensive knowledge of a condition, such as a woman who herself has had breast cancer.

Your best bet for finding online support groups you can comfortably recommend is to ask your patients for their top choices, then spend time perusing the discussions. You could also check with national organizations—the American Heart Association, for instance, or the American Cancer Society, or even your local professional organization—you trust to see what they endorse.

Just keep in mind that whether you recommend online support groups or not, your patients will use them and you should be prepared to field questions or cor-

A patient guide to evaluating information on the Net

If you work in a doctor's office, in home care, or in a clinic that has an established patient base, sending out a letter like the one below will help patients separate the useful Web sites from the questionable ones. Hospital-based nurses can make handouts stressing the same material.

Dear Patient,

We want to work with you to help you maintain the best of health. Many people these days are taking the initiative to learn more about responsible self-care for themselves and family members. If you're doing so, I commend you and offer this handout to support your efforts.

Some books, articles, and online information services are reliable, but many are not. You need to distinguish what is helpful from what is harmful. It's important to be aware that many of the online health services were created by companies whose main goal is to make money. Don't be duped by something that serves as an advertisement, even if it doesn't look like the ads on television.

Next time you log on to your favorite healthcare Web site, look for the sponsor and the advertisers. Then consider whether the information those companies are likely to present is in your best interest, or whether it's designed to sell you something. If you'd like, we can point you to sites where all of the healthcare information is reviewed by competent medical professionals.

We suggest you use the following five criteria to evaluate the sites you visit. They were developed by George D. Lundberg, MD, former editor of *The Journal of the American Medical Association*, and health journalist William M. Silberg. Consider any online information unreliable unless you can answer these questions:

1. Who wrote what you're reading? The site should contain the name of a real person.
2. Where does that person work? A university? A Web business? A product manufacturer? Can you easily find that information on the site?
3. Was the information created for the site? If not, is there clear attribution showing where the information originated?
4. Who owns the site, and who pays for it? The source of money and ownership should be clearly identified.
5. Can you tell when the article itself was posted, whether it has been updated, and when?

If you can't answer these questions, you may want to look elsewhere for health information. Even if you can answer the questions easily, there's no guarantee that the information is accurate and unbiased. If you have any questions about anything you find on the Net, we'll be happy to discuss them with you.

Happy (and responsible) surfing!

Sincerely,

rect impressions that have been gained in such groups.

Ferguson stresses, too, that clinicians should help patients develop their clinical judgment so they can filter some of what they hear themselves.

"I think we need to help people be as competent as they can be," says Ferguson. "Our role is not to hold on to the power and control. We need to encourage patients to learn all they can about their health problems, even if that means they disagree with us from time to time. It's a poor student who is afraid to challenge the teacher."

An expert's top sites for patients

The three most heavily trafficked consumer online health sites at the end of last year were OnHealth (www.onhealth.com), [drkoop.com](http://www.drkoop.com) (www.drkoop.com), and America Online's health channel. So these are the three to visit if you don't know your own patients' preferences and want a representative sampling of what's available.

For a physician expert's top sites, we went to pathologist George D. Lundberg, former editor of *The Journal of the American Medical Association* and currently editor-in-chief of Medscape (www.medscape.com). These are his favorites, in alphabetical order.

adam.com, at www.adam.com, is a San-Francisco-based commercial provider of health and wellness information. Among its health advisory panel members are pediatrician Alan Greene, a clinical faculty member at Stanford University and creator of

his own very popular "ask-the-doctor" Web site at www.DrGreene.com.

CancerNet, at www.cancer.net.nci.nih.gov, is a service of the National Cancer Institute. This site provides information on various types of cancer, treatment options, the latest clinical trials, medical journal articles, support groups, and other resources.

Centers for Disease Control and Prevention site, at www.cdc.gov, provides consumers with health news and features on subjects such as HIV testing, safe swimming, and health precautions when traveling outside the United States. There's also a data and statistics section that's useful to physicians.

drkoop.com, at www.drkoop.com, is a commercial site that offers a mix of news, feature articles, and links to online support communities. Headed by C. Everett Koop, MD, former U.S. Surgeon General, it has the Health On the Net Foundation "HONcode" stamp of approval.

healthfinder, at www.healthfinder.gov, is maintained by the U.S. Department of Health and Human Services. This site provides basic self-care information, government health news, and links to a number of different sites.

IntelliHealth, at www.intelihealth.com, is maintained by Aetna US Healthcare and Baltimore's Johns Hopkins University. This site provides physician-reviewed, consumer-friendly articles, an "Ask the Doc" feature, online communities, and a medical dictionary. It, too, has the Health On the Net Foundation "HONcode" stamp of approval.

Mayo Clinic Health Oasis, at www.mayohealth.org, is maintained by the world-renowned Mayo Clinic in Rochester, Minn. Like IntelliHealth, this site provides physician-reviewed, consumer-friendly articles on a wide range of health topics. It also allows users to e-mail questions to clinic physicians.

Medscape, at www.medscape.com and its sister site, CBS HealthWatch (www.cbshealthwatch.medscape.com), are commercial sites. Medscape is the professional site, built around practice-oriented content. CBS HealthWatch, the consumer site, provides news, features, and interactive content.

Oncolink, at www.oncolink.upenn.edu, is maintained by the University of Pennsylvania Cancer Center. This comprehensive site offers news, education on treatment options, reporting on clinical trials, psychosocial support through an active online community, and a listing of useful institutions, organizations, associations, support groups, online journals, book reviews, and other resources for cancer patients and healthcare providers.

RealAge, at www.realage.com, is a commercial site that provides news, an active online support community, and interactive health assessment tools. RealAge, too, has the Health On the Net Foundation "HONcode" stamp of approval.

United States National Library of Medicine, at www.nlm.nih.gov, provides access to the world's largest medical library. To locate information on general health, instruct your patients to use this Web address: www.nlm.nih.gov/medlineplus. □