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THE INFORMED PATIENT By LAURA LANDRO



Social Networking Comes to Health Care

Online Tools Give Patients Better Access to Information And Help Build Communities

December 27, 2006; Page D1

At DailyStrength.org, patients and caregivers dealing with hundreds of issues, including asthma, celiac disease and depression, can join a support community, start a wellness journal, share advice and recommend doctors, link to news stories and Web sites with disease information, and even send other members a virtual hug.



The CDC has held virtual health fairs on subjects like flu pandemics on the Second Life Web site.

The social-networking revolution is coming to health care, at the same time that new Internet technologies and software programs are making it easier than ever for consumers to find timely, personalized health information online. Patients who once connected mainly through email discussion

groups and chat rooms are building more sophisticated virtual communities that enable them to share information about treatment and coping and build a personal network of friends. At the same time, traditional Web sites that once offered cumbersome pages of static data are developing blogs, podcasts, and customized search engines to deliver the most relevant and timely information on health topics.

The same technologies are making it possible for advocacy groups, government agencies and health-care providers to update consumers on relevant health news and deliver personalized health-awareness messages, reminders and alerts to email accounts, wireless devices and mobile phones. Online collaborations known as wikis, which let different users jointly work on Web-based information such as photo albums and contact lists, are developing to help communities plan for public-health emergencies, such as fluwikie.com, a flu-pandemic planning site. Mainstream advocacy groups and government

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agencies are offering their own specialized health-information "feeds" to consumers, and even experimenting with three-dimensional online computer worlds that use surrogates known as avatars to let visitors interact.

Both the American Cancer Society (cancer.org) and the Centers for Disease Control and Prevention (www.CDC.gov), for example, have been experimenting with virtual computer worlds such as the popular three-dimensional site Second Life (secondlife.com) to test whether so-called social media can help spread the word about such issues as nutrition awareness, cancer screening, and infectious-disease prevention. "We're trying to leverage social networking for health promotion," says Adam Pellegrini, director of online strategy for the cancer society. "Everything is based on communities now."

The CDC has held some virtual health fairs on the Second Life Web site where visitors can learn about subjects like pandemic flu resources. Though Second Life, which resembles a videogame, requires special software to participate and isn't easily available to consumers without high-speed Internet access, the fast growing virtual community offers an alternative to more traditional methods for educating large numbers of people quickly about new treatments or informing them about health dangers such as the recent E. coli outbreak -- especially teens who might not visit a government site like www.CDC.gov.

The American Cancer Society, which plans to open a virtual office on Second Life, used the site this year to help raise \$40,000 for its annual Relay for Life, which attracts millions of participants in local communities who walk, donate or volunteer in an overnight event. The cancer group has also launched a social-networking site of its own for the effort (www.relayforlife.org), and next year plans to launch social-networking sites focusing on tobacco, prevention and volunteerism.

The cancer society, which still wants any information on prevention and treatment to be vetted by experts, next year plans to launch new features such as a "My ACS" portal that allow users to customize their information searches. It is also working on a Health Reminder Assistant that will send health information and guidance via phone, instant messaging and email; an interactive "Great American Health Suite" that will focus on prevention; and desktop "widgets" that can help users find cancer information quickly and interact with other patients.

The rise in social networking and health-care blogging has sparked a nascent movement to set standards and guidelines for "open media" in health care. At a recent health-care blogging summit, Dmitriy Kruglyak, publisher of the Medical Blog Network, which hosts medical blogs, called for guidelines that include conflicts-of-interest disclosure and privacy protection.

The efforts come as more consumers are looking for health

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information online again after three years of little growth, according to Harris Interactive. Use of the Internet to search for health-related information by online U.S. adults increased to 80% in July from 72% in a year-earlier survey, and the total number of adults who have ever searched for health information online rose 16% to 136 million.

But new trends on the Web are taking the search for health information and support "to a whole new level," says Doug Hirsch, the founder of DailyStrength.org. Mr. Hirsch, who had stints building community products such as message boards and chat groups for Yahoo and later worked for Facebook, says that unlike email discussion groups, where users post messages for anyone to read and there is little ability to filter out spam or abusive comments, the social-networking sites make it possible for users to branch into different conversations and create special relationships.

Laurel Simmons, a project director at the nonprofit Institute for Healthcare In leukemia survivor who started one of the first email discussion groups for the Cancer Online Resources (acor.org), says it is still too early to tell whether he social-networking sites will flourish, since they will depend on how vigilant r keeping them going. Social-networking sites "make the space available and w to emerge," she notes. "It is so simple to create your own site these days that t passion may be more interested in starting their own site rather than using the available for them at sites like DailyStrength."

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cancer patients and families, launched a Web site, grouploop.org earlier this y with cancer connect in a private, safe environment. The group says it has reac of the approximately 50,000 teen cancer survivors in the U.S., and is also con nine other countries. In addition to weekly scheduled support groups moderat professional, teens can log in at any time of day to post or read messages in a

site. A comprehensive search engine allows users to search for other teens with cancer on such criteria as age, location, or diagnosis.

Eighteen-year-old Kaitlin Mazik, who is undergoing treatment for non-Hodgkin's lymphoma at M.D. Anderson Cancer Center in Houston, learned of Group Loop from a poster at her doctor's office, and found that many of the teens were already used to connecting online through social-networking sites like Facebook and MySpace.com. "I was pleasantly surprised that it wasn't too downhearted and pessimistic -- we are allowed to have fun and even joke about things, like the special treatment you get when you have cancer," she says.

But the teens also talk about more serious issues, like how their identity has changed as a result of cancer and their anxiety about the future. Though she has never met any of her new friends in person, she says, "we are all going through something similar, and it really is a community."

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