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How to evaluate online resources and support for people affected by cancer

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According to a 2009 Pew Research Center Report, 61% of Americans look online for health-related information (www.pewinternet.org/Reports/2009/8-The-Social-Life-of-Health-Information.aspx?r=1). In fact, *cancer* is the second most common word in health-related searches on such highly visited search engines as Google and Yahoo. Many of those users are also seeking information and help with the psychosocial concerns raised by having a serious illness like cancer. And at least one-quarter of those people who have sought medical information online have also joined an online support group.

Like other types of support groups, online groups offer people the opportunity to meet with others in similar circumstances and to learn and share information about their experiences, but without the restrictions of time and place that people often experience with face-to-face groups. Typically, group members exchange valuable tips on how to cope, helpful resources, and solutions to problems—information that contributes to better caring for themselves or their loved ones.

Online groups come in several formats: a chat group, wherein the conversation takes place in real time (ie, chat sessions are scheduled and messages are read and responded to instantly); a listserv, which allows a group's members to e-mail each other with questions

and comments (this format can generate a high number of e-mails, some off topic); and a message board, a type of “closed” group featuring a specific online site, accessible only to members and available 24/7, where people can write comments and questions and can read and respond to other members in the group.

We don't know exactly how many online cancer support groups are operating today. Countless commercial message boards can be found on Yahoo and MSN, among others, are run by volunteers. Several professional and advocacy organizations also host online groups, including *CancerCare*, the American Cancer Society, The Wellness Community, and the Association of Cancer Online Resources (ACOR).

CancerCare's online groups use a message board format, but in contrast to many other message boards, ours are moderated by oncology social workers. Group members are prescreened by a social worker, and those who require more individualized information and support are assigned a primary social worker. Moreover, *CancerCare* offers a variety of online support groups dedicated to cancer type or cancer experience (eg, lung, pancreatic, breast, etc). We also offer groups for specific populations, such as young adult patients and caregivers. All our groups are private (password-

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protected), closed to outside observers, and held for a set period of time. Each member also has the option of retaining anonymity within the group.

Members of CancerCare's online groups actively solicit information from their counterparts about how they are coping and what resources they can recommend. The social worker monitors the conversation, keeping topics on track, correcting misinformation, sharing knowledge, and sometimes refereeing disagreements. The discussion usually starts with the sharing of each individual's medical diagnosis, what tests were performed, and how each is being treated and where. Then, over the course of 4 months—the average operating period for a specific support group—members develop relationships and topics of interest. Under the guidance of the social worker, they establish group goals, with specific objectives they want to meet. Groups can also decide to keep the structure free-flowing, so that people can explore the feelings and concerns that arise as they occur.

When recommending a group to your patient, keep in mind that online support groups will most benefit those who are already comfortable communicating online, enjoy writing, and have easy access to a computer and the Internet. Also consider the format that would be most appropriate for the given patient. Many groups have an

open format, with no set time limit and few restrictions on who can join or when; and a majority are self-help, peer-to-peer groups led by group members or volunteers. A lesser number, like CancerCare's, are moderated by trained professionals. Here is a checklist to help you evaluate what online support group is best for your patient:

- What is the format? Message board? Chat? E-mail listserv?
- Is the group open or closed?
- Does it run for a set period of time?
- Is it confidential, only for approved members?
- Is there a privacy statement or guidelines governing the group?
- Are members' identities protected? If so, how?
- Is there a moderator or group facilitator?
- What are the credentials of the moderator?

Like any gathering of people, online groups can experience conflict, misunderstandings, and differing agendas. Nevertheless, online groups offer a sense of belonging and community that validates and affirms what people are going through, particularly those who, for medical, geographic, and/or social reasons, find themselves isolated. Through online groups, individuals can build bonds, find help, and assist others—just like in the “real” world. ■

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