

ISSUES IN CANCER SURVIVORSHIP



Accessing helpful information and staying in touch: Social media for cancer survivors

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Social media is playing an increasingly important role in cancer survivorship. Any number of message boards, forums, chat rooms, blogs, and Facebook pages are now devoted to cancer survivors. Cancer organizations use Web pages and other Internet tools for disseminating information to patients as well as oncology professionals. Many of these sites provide their own message boards and other forums that survivors can use to communicate with one other. Here is a necessarily limited selection of some of the more established resources.

CANCER SURVIVORS NETWORK

The American Cancer Society sponsors the Cancer Survivors Network (CSN), an online “community of cancer survivors, families, and friends.” The Web site states, “Our lives have been affected by cancer in ways only those of us who have ‘been there’ can truly understand.” Founded in 1996, this Internet community may be the gold standard of social media for cancer survivors since it has so many built-in options. People register for the free membership with a valid e-mail address in order to access all areas of the CSN Web site. Members are able to

- Find other members and communicate with them using the CSN private and secure internal e-mail service
- Access chat rooms and post to discussion boards

—There are more than 25 discussion boards for specific types of cancer, and other boards as diverse as Caregivers, Gay Men Talk About Cancer, Emotional Support, Humor, Lesbians Talk About Cancer, Long-Term Effects of Treatment, Military Cancer Survivors, and Senior Survivors

- Create their own My CSN Space where they can tell their stories, upload photos and audio files, create blog entries, contribute poems, recommend resources, and more
- Get notified each time they receive new CSN e-mail or new content is added to an area to which they have subscribed
- Create their own personal support community of other CSN members
- Receive a free monthly newsletter from CSN

Of course, CSN members can also link to the American Cancer Society Web

site for information about cancer, community resources, support programs, locating clinical trials, treatment decision tools, and many more topics.

ONCOLINK

OncoLink, the Internet-based cancer resource of the University of Pennsylvania’s Abramson Cancer Center, has won many awards since it was founded in 1994 with a mission “to help cancer patients, families, health care professionals, and the general public get accurate cancer-related information at no charge.”

The site features numerous buttons and hypertext links that ensure ease of navigation through its pages of information on multiple levels. OncoLink is updated daily with news about specific types of cancer, treatments, and advances in cancer research. Among its many links for survivors, OncoLink lists such resources as the Long Term Survivors online group, National LGBT Cancer Network, Young

Links

Cancer Survivors Network: <http://csn.cancer.org>

American Cancer Society: www.cancer.org

OncoLink.org: <http://oncolink.org>

National Children’s Cancer Society: www.nationalchildrenscancersociety.org

CaringBridge: www.caringbridge.org

Beyond the Cure: www.beyondthecure.org

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Survival Coalition, Living Beyond Breast Cancer, and the National Coalition for Cancer Survivorship. One of the more popular features of OncoLink is Ask the Experts, where readers can pose questions to a team of specialists. The information on OncoLink is comprehensive; one expert is a veterinary oncologist who answers questions about cancer in animals on the OncoLink Veterinary Oncology Menu.

THE NATIONAL CHILDREN'S CANCER SOCIETY

Another comprehensive Internet site is provided by The National Children's Cancer Society (NCCS). The NCCS describes their mission as improving the quality of life for children with cancer and their families worldwide. Their Facebook page gets a great deal of activity hosting comments from survivors and their families, as well as postings for many events in the survivor community. On their Web site, NCCS also sponsors the Care to Share Message Board, which is an online support network designed for families and survivors to share experiences, provide encouragement, and connect with others in similar situations.

NCCS also partners with CaringBridge, a free service that helps patients and their families create their own Web sites "to connect family and friends during times of illness, treatment, or recovery." There are numerous Web site templates that enable guests to leave messages in the guestbook, read a journal of the patient's progress, and enjoy photo galleries. The description for this link on the NCCS Web site makes it clear they understand the difficulties of dealing with childhood cancer:

It can be hard to stay connected with family and friends who want to know how you or your child is doing, or perhaps, want to know how coping

with a new treatment or surgery is going. Sometimes it may take too much energy to let everyone know that you are doing OK.

The CaringBridge service currently hosts Web sites for more than 20 million families. Newer features include mobile access, text message journal notifications, an iPhone and iPod Touch app, and Facebook Connect, which links the survivor's Web site with the Facebook pages of family and friends.



Cancer organizations offer Internet tools such as message boards and forums.

BEYOND THE CURE

This is also a program of the National Children's Cancer Society, in partnership with Children's Hospital and Washington University physicians in St. Louis. One of the most visible icons on the Web site's home page is the link for the Care to Share Network message board. There is also a large linked section on late effects of cancer after treatment: "The mission of Beyond the Cure is to help childhood cancer survivors integrate the cancer experience into their new life as survivors and successfully handle the challenges that are ahead of them and to celebrate survivorship."

As a reflection of that, Beyond the Cure sponsors college scholarships that are awarded to 10 survivors each year. Their Web site has links to different aspects of surviving the disease, such as "Finding Meaning in the Cancer Experience," living and eating well, advocacy, and education. One of the most interesting sections on this site offers advice on the value of working in our society and the importance of finding employment when the right time comes. With helpful information on negotiating the job search, interview techniques, dealing with health insurance, and what details to reveal about their illness to whom, this site is especially valuable for newly healthy young adults. The organization encourages its participants to sign up for e-mail, register to join discussion groups, create their own Web pages, and share their stories.

A MULTITUDE OF RESOURCES

There are many more resources that comprise the cancer social media network. Becoming familiar with some of the more popular ones can be helpful for survivors and practitioners alike. ■

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