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Web 2.0: What Does This Mean for Young Adults with Cancer [1]

Editor's Note: This is part of a series of Patient Advocate Guest Columns and Podcasts, launched as a forum for patient advocates to address a topic, issue, or trend within the cancer community through Cancer.Net, the patient information website of the American Society of Clinical Oncology (ASCO).

Listen to theSpecial Cancer.Net Podcast: Web 2.0 - What Does this Mean for Young Adults with Cancer? with Heidi Adams, Planet Cancer [2], adapted from this column.

Web 2.0: What Does This Mean for Young Adults with Cancer?

A Patient Advocate Guest Column by Heidi Adams, Founder and Executive Director, Planet Cancer (www.planetcancer.org[3]).

In the Fall of 2008, I had the pleasure of giving the closing keynote at the national conference for the Association of Pediatric Hematology/Oncology Nurses. The night before, I posted a question on my blog for the members of *My Planet*, our social networking community, asking them what I should tell nurses about caring for young adult cancer patients.

Among many replies, Lindsey, a college student from Pennsylvania, compiled a highly entertaining list that included ?Break the rules on visiting hours? and ?Do not comment about my dietâ€"I have cancer. Heart disease is not my main concern.? But the number one item she listed was: ?Figure out a way to let me have Facebookâ€¦.it's my lifeline to the outside world.?

Although it sounds dramatic, ?lifeline? is probably not exaggerated in this case. The web and, specifically, social networks, are where young adults in their teens, 20s and even 30s live and breathe these days. And when cancer knocks a young adult out of their ?normal? life, this is where they go to try to manage, share, and process the experience.

The geeky expression for this brave new world is ?Web 2.0,? but it's really just about a new level of interactivity and interconnectedness in the way people use the Web. For cancer patients, it's a way to get and share information, find and give support, and access tools to help manage their experience.

We launched *My Planet* because we were serving young adults and we knew this was the space where they wereâ€”and we know it works because we've seen our membership jump to almost 3,000 in the first 10 months. But it turns out that there are unique aspects of social networking that makes it especially well-suited to providing support for young adults with cancer, who have typically been overlooked and underserved on all fronts.

First of all is the **value of community.** There's nothing worse than being a young adult with cancer and never seeing anyone else your own age in the hospitals or waiting rooms. Everyone is either five years old, or your grandparents' age. Online, that isolation vanishes as you find peers all around the countryâ€”or the world!â€”who share your issues and concerns: dating with cancer, insurance issues, preserving fertility, supporting your partner, or even what kind of music is best for MRIs.

Second of all, social networks allow the young adult patient to **define their own experience.** Maintaining your own identity is critically important for a young adult, because it's just at this time of life that you're actually *creating* that identityâ€”and no one wants to end up being defined as ?The Cancer Girl/Guy.?

Social networks give back control by allowing people to set the terms of their own experience. They allow the individual to decide *what* information to focus on and share (your diagnosis, personal information, treatment, fears, and issues) as well as *how* to reveal it and *to whom* (such as a blog, photo, forum posting, private message, or group membership).

On *My Planet*, people can form groups aroundâ€¦well, pretty much anything. In addition to the expected groups forming around diagnosis or geography, we have people who congregate in groups such as ?Cancer Made Me a TV Addict? to ?Ostomy Peeps? to ?People who couldn't have gotten through this without their pets.? In addition, users can communicate about all this at their own pace and on their own schedule. Which leads me toâ€¦

Support on demand. In today's world of 24/7 access, young adults want support when *they* want it. If they wake up with the heebie-jeebies at 3 a.m., they will go online to find someone else who is up, whether they're across town or halfway around the world. They are also usually hell-bent on maintaining their ?real? lives: seeing friends, going out to dinner and keeping up with school or work. Accommodating those things may take up their increasingly precious free time and energy during the treatment process, leaving little time or desire to attend a formal support group. As one member said, ?I'm not one for support groups in a room at a building (I'd feel like I'm in AA!), and/or going to counselors, so this site is perfect for me.? It's not that they don't *want*

support; it's just that, in their world, the structure around that support looks different.

Last but not least, one of the key things to remember about social media is that, in successful social networks, the emphasis is always on the ?social? rather than the ?media.? It's the *people* who make it work, so they should always come first.

Or, as one Planet Cancer member put it:

"While surrounded by people who loved me more than anything, I had never felt so alone. The people here know what that's like and they make me feel like it's okay for still struggling. Just knowing that there are other people out there who are out of treatment and still encounter problems, still ask WHY, still feel shaken to their cores over all of this... that makes me feel less crazy and more like I've found the one place that is going to help me get my life back in order. With everyone's support here, I feel like there's nothing I can't do.

See, that's the thing about Planet Cancer. You get to be painfully honest and you get to share things you never thought you'd ever be able to share with anyone. I don't know HOW it works, but it does. So let's just go with it, shall we?"

As in so many other cases?cancer treatment included, for health care providers out there!â€”if you just give people respect and control, magic happens. And I think we'll go with that.

Planet Cancer (www.planetcancer.org[3]) is an online community of young adults with cancer and includes a social networking community, My Planet, where patients and survivors can connect with each other.

If you are a patient advocate interested in authoring a future Patient Advocate Guest Column and Podcast, please contactpatientadvocates@asco.org[4] or 571-483-1358.

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[1] http://www.cancer.net/research-and-advocacy/patient-advocates/patient-advocate-guest-columns-and-podcasts/web-20-what-does-mean-young-adults-cancer
[2] http://www.cancer.net/sites/cancer.net/files/planet_cancer.mp3
[3] http://www.planetcancer.org
[4] mailto:patientadvocates@asco.org