

The doctor is In(ternet)



JOHN MAJOR, THE OTTAWA CITIZEN

When Ayala Ravek couldn't find any helpful information on the Internet about reflex sympathetic dystrophy, she started her own Web site. She says the support and feedback she gets is 'inspiring.'

When Ayala Ravek learned she had reflex sympathetic dystrophy, a rare syndrome that causes acute and lasting pain, she turned to the Internet for information.

She couldn't find anything helpful: no message boards, no personal stories. Everything she found was written from a medical perspective, too difficult for her to understand at age 11. That's when she decided to start her own Web site at www.nopainzone.com -- a place where people of all ages could read about the disease and share their experiences.

"Two years ago I was very, very depressed, in the hospital, thinking 'What's the point of living because I'm in so much pain.' And now, you wouldn't even know I'm the same person. The support, the inspiring e-mails I get, it's very inspiring and emotional," says Ayala, now 13, from her home in Ottawa.

Ayala says her site now generates "tons of feedback" -- a sign, perhaps,

Amidst the screens of Web sites dedicated to health issues, where's a person to go for reliable information?

Bev Wake answers the question.

of the growing demand for online health information. In response, new Web sites are being launched every day, including one this week called www.medistudy.com, touted as Canada's newest online source for clinical information.

But, as Ayala's experience suggests, finding relevant, accurate and understandable information isn't always easy. Wading through the vast amount of material online, and analysing its quality, can be a daunting task. Experts in the field, however, say there are thousands of helpful sites like Ayala's online that could offer around-the-clock access to anonymous self-help and support -- if people only knew how to find them.

Dr. Froggie's Favourite Links (www.froggie.org) is another popular site, also offering a directory to Internet health sites. Designed by Dr. Arlette Lefebvre at the Hospital for Sick Children in Toronto, it was created as a reference for children with chronic diseases or disabilities and their parents.

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As people become more informed about health care, Dr. Skinner (a professor in the University of Toronto's department of medicine) explains, it demystifies the world of medicine -- and that has the potential to change practitioners. The internet, he explains, could open up the "hidden health care system" of self-help and support.

"We're in the midst of a huge transformation. We just don't know it yet", he says.

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Ayala, however, insists her Web site has already transformed her life. Since launching her site, she's taken over responsibility for the teen component of the Canadian RSD Network's site and has been asked to write a chapter about her experiences for a book to be published next year.

She's had e-mails from people as young as nine and as old as 65 -- and has put reflex sympathetic dystrophy sufferers in touch with one another. Ayala, at least, feels her Web site plays a small role in educating one person at a time.

"I want people to leave there and have a smile on their face, learning about the disease and knowing they're not alone," she says.