

orlandosentinel.com/orl-support1207aug12,0,3901942.story

OrlandoSentinel.com

The stressed, ill and alone find solace in online support groups

Tyeesha Dixon

Sentinel Staff Writer

August 12, 2007

Taking care of her 87-year-old mother had become a 24-hour-a-day job for Pat Byrd.

When Byrd was overwhelmed and needed someone to talk to, she felt her family and friends didn't understand. Although a local support group for caregivers met once a month, the [Deltona](#) woman couldn't leave her mother -- who has Alzheimer's disease -- to attend.

Then, about a year ago, Byrd found an e-mail-based support group on Caregiving.com.

Now, she doesn't feel alone.

"I feel like there are other people living my life," said Byrd, 58.

Online groups have burgeoned in recent years to offer support for everyone from rare-cancer patients to those with narcissistic personalities. Experts say more people are seeing the benefits of these cyber-support systems -- not just patients with rare conditions, as in the past.

Users say the groups are immediate, anonymous and abundant, offering an outlet for people with any condition imaginable. What's more, online groups have become so specialized that users can talk to others who know exactly what they're going through.

Although online support groups have been around for more than 20 years, their audiences have changed, said John Grohol, publisher of the mental-health network PsychCentral.com and spokesman for the International Society for Mental Health Online.

Versatile support

Grohol said early groups started for people with rare conditions who couldn't find local support groups, as well as mental-health patients who wanted to avoid being stigmatized.

But as more people discover the benefits of online groups, they are popping up for all sorts of issues, he said.

"Ten years ago you wouldn't find an [online] support group for fairly common conditions," Grohol said. "And now, we're pretty much finding groups for every concern."



Deb Lee Gould started a traditional support group in 1991 with her husband for fatty oxidation disorders after their 1-year-old daughter died of one of the rare genetic conditions a few years earlier.

Gould said they decided to offer online groups a few years later, allowing families from as far away as England and Australia to connect through the Michigan-based Web site.

"It's just a good way to network and seek support and get practical information, especially about issues that are related to our disorders," said Gould, director of the FOD Family Support Group. "We thought we were the only ones out there. I can speak to families all over the world now."

But the variety of online groups is not their only advantage, experts say.

"Due to what psychologists call the 'online disinhibition effect,' people also often tend to be more honest and open about themselves in cyberspace, which can be an important asset in a support group," said John Suler, psychology professor at Rider University in New Jersey and author of the online book *The Psychology of Cyberspace*.

"This effect stems from the anonymity that people can experience when they communicate with text."

Suler said another advantage of online groups is their accessibility from home, which is especially helpful for those who are too ill or busy to leave.

Byrd said that's one reason she loves her online support group.

"I have nobody supporting me or relieving me," said Byrd, who takes care of her mother for about six months of the year. Byrd's sisters, who live in Ohio, take turns caring for their mother the rest of the time. "We need more programs here for respite or day care," she said.

Other caregivers in the group can relate to Byrd's frustrations and offer advice, she said -- and she doesn't have to wait for a face-to-face group to meet when she wants to vent.

"They know where you're coming from, and they know the ins and outs of how to deal with stress," she said.

Not for everyone

Despite the ease and convenience of online groups, traditional groups are still better for some patients, experts say. Many online groups are not moderated by professionals, which can lead to misinformation, Suler said.

At [Florida Hospital](#) face-to-face cancer support groups for recently diagnosed patients include an oncology nurse educator and social worker, said Charles Miceli, social-work supervisor and oncology social worker for the Florida Hospital Cancer Institute.

And some companies use online groups to sell products to people who are emotionally vulnerable, said Dr. Al Musella, founder of the Musella Foundation for Brain Tumor Research and Information, which offers online support groups.

Byrd said one disadvantage of online communication is the misunderstanding that can occur through misspellings and lack of body language. She said it can also be difficult to sense irony or sarcasm.

But overall, Byrd said, her online support group has become a lifeline.

"I never looked further after I found this group," she said. "It's been just amazing."

Tyeesha Dixon can be reached at tdixon@orlandosentinel.com or 407-540-4225.

Copyright © 2008, [Orlando Sentinel](#)