

## **tech support Online groups can provide valid information and By Donya Arias**

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LATE AT NIGHT, when Stafford County mom Rosezella Swanson has trouble sleeping, she logs onto her computer and checks out sites that offer advice to parents of children with autism.

From a computer in her Spotsylvania County living room, Sharon Kwiecien has relied on her own cadre of online buddies to help decide whether to undergo gastric bypass surgery--and then to get through the sometimes-rocky aftermath of the procedure.

Barry Gates of Stafford survived such a rare form of brain cancer, the only way he could connect with other survivors and caregivers was to lead an online support group.

No matter what medical condition a person experiences, there likely is an online support group available to help them out.

Two women who met while waiting in an oncologist's office in Buffalo, N.Y., started an online support group for pregnant women with cancer. There's a group for those anticipating or recovering from hip replacement surgery. There's one for men with breast cancer, for people afraid of dentists and for those struggling with alcoholism, depression, gambling addiction or severe anxiety. The list is seemingly endless.

Health experts says there's always a place for face-to-face support and treatment, but getting help and information over the Internet can bridge gaps that might otherwise prevent people from reaching out.

"A lot of times, people take comfort in hearing other people's stories and how they're coping," said John Grohol, a clinical psychologist and publisher of psychcentral .com, a site that maintains a database of more than 4,000 online mental-health and psychology resources.

Grohol finds the booming growth of online support groups "a fantastic development."

"People feel far more comfortable being able to communicate online," especially when faced with a diagnosis they believe is embarrassing, Grohol said.

Think infertility, impotence and the like.

"People just feel safer and are more comfortable doing it," Grohol said.

In Swanson's case, the busy Stafford mother of three young children has a tough time getting out the door to support-group meetings for parents of autistic children. But her computer is always available.

"The good thing is, there is so much out there [online]," said Swanson, mother of a 4-year-old autistic daughter, a 6-year-old son and a 17-month-old daughter.

Swanson has gotten e-mail advice on potty training, and just general support for raising a child with special needs.

Kwiecien of Spotsylvania, occasionally attends local gastric-bypass patient support-group meetings, but she likes the ability to chat online with people she knows she agrees with. And, of course, there's the allure of being able to carry on an online conversation while in pajamas and slippers, a fresh cup of home-brewed coffee at her side.

"I can pick and choose online who I'm talking to," said Kwiecien, who has maintained a 120-pound weight loss since her January 2005 gastric-bypass surgery, but fears regaining the weight.

While she said she always gets a lot out of attending face-to-face support-group meetings, "it's easier to walk over to my computer and type it all in."

'The only place' for support

With an extremely rare medical diagnosis, online support might be a person's only option for connecting with like-minded souls, said Gates of Stafford.

After his diagnosis of and treatment for a rare form of brain cancer, he attended several meetings for brain cancer survivors and patients. He remembers one such meeting in Seattle, where 700 survivors and patients were seated at tables according to their diagnoses. At his lone table for those with central nervous system lymphoma sat Gates and three others.

He then volunteered to facilitate a listserv for survivors, patients and caregivers, which now has about 20 members.

"Certainly, for the more exotic diseases, it [the Internet] is likely to be the only place you find any meaningful support," said Gates, who also has led local face-to-face support groups. "In my case especially, and I'm sure there are many others out there, it's been real good to talk to other people in my situation."

One growing source of online support is the medical profession. Doctors and medical centers have heard their patients say they need to talk to others facing similar health challenges, such as life-threatening surgery.

At Cedars-Sinai Medical Center in Los Angeles, patients come from all over the world for treatment. Doctors there suggested an online support group for the far-flung patients--and caregivers--facing down brain tumors and other brain and spinal cord conditions that require surgery.

"They want to know what it's like from the patient side, and how do I cope as a spouse of someone going through this treatment?" said Dr. Keith Black, chairman of the Cedars-Sinai Neurosurgery Department.

The hospital offers a face-to-face support group as well, but out-of-town patients usually can't attend. "This is just an additional service that we try to offer to give as much support to our patients as possible," Black said.

Authors of the 2003 Pew Internet Project Report noted that "participation in health-related online groups and communities has been steadily rising." They found that in December 2002, 54 percent of Internet users, or an estimated 63 million Americans, had contact with health-related online groups or communities.

As for the effectiveness of such groups, studies back that up. One 2004 study of support groups for caregivers of children with special needs found: "The majority of participants not only obtained what they sought, but found more than expected in terms of insight and people to trust." The results were published in the journal *Pediatric Nursing*.

And a study of 580 back-pain sufferers published in the *Archives of Internal Medicine* found people who used an e-mail discussion group to sympathize with each other and ask questions from medical experts had less pain, better function and fewer doctor visits than those who didn't participate in such online support.

### Late-night support

Even for those who aren't online for peer-to-peer support, the Internet can be a valuable source of information, especially late at night in the face of a scary diagnosis. A recent study found a third of people who go online regularly have sought medical information on the Internet.

Billie Bailey isn't one for support groups, but since her son was diagnosed with developmental delays and then Asperger's Syndrome, sometimes described as a form of mild autism, she has spent hours researching his condition online.

"I think they're [online support groups] important for those who need to talk out the issues," said Bailey, who works as physician recruitment manager for MediCorp Health System in Fredericksburg. "For me, I just needed to arm myself with information and get to work."

For those seeking support, one value of online support groups, Grohol said, is that they can be a portal to face-to-face treatment with a doctor or therapist. He pointed out that

people should seek professional help rather than rely merely on online support if they are "in crisis or suicidal," or feel like they may harm themselves or others.

Online support might not be appropriate for young children, either. Kids who are too young to be Internet-savvy or read well may benefit greatly from a regular, face-to-face support group meeting with friends. One such example: the bimonthly group hosted by Hospice Support Care of Fredericksburg for children ages 5-12 who've lost a loved one. Hands-on craft projects and in-person gab sessions seem to be a big help in easing the children's pain, said Jenna Cooley, children's grief coordinator for Hospice Support Care.

"They have a sense that they're not the only one that's lost a loved one," Cooley said. Parents have even told her their children have benefited more from the group meetings than from individual counseling.

It may seem counterintuitive, but online support is fairly common even for those struggling with computer addiction, or spending so much time online that it interferes with daily life. PsychCentral's Grohol said people with such an addiction may not have a face-to-face support group close to home or may not be able to afford professional therapy, "so it's actually fairly common to join an online support group" for computer or Internet addiction.

Kwiecien, the Spotsylvania woman, believes that the support she gets by checking in with her online message board several times daily is one key to her lasting weight-loss success since her 2005 gastric-bypass surgery.

"I never, ever want to go back to the way I was," said Kwiecien, whose online profile page includes a photo of her at 280 pounds. "It's those people who have no support who gain the weight back."

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