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# Kids with cancer bond online

Updated 4/10/2006 7:58 PM ET

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[Enlarge](#) By Martin E. Klimek for USA TODAY

From her bedroom in Walnut Creek, Calif., Simone Weinstein, 16, who has cancer, instant-messages with her friend Lauren Sharp, 16, in Versailles, Mo.

By Liz Szabo, USA TODAY

*More than 10 million Americans are cancer survivors. That number is expected to grow as the population ages, as improved therapies help people live longer and as screenings identify the disease earlier. In this occasional series, USA TODAY examines how a cancer diagnosis changes people's lives and outlooks.*

Cancer has consumed 2½ years of Simone Weinstein's young life.

It took her hair, her eyebrows and her eyelashes.

At times, cancer has even taken away her friends.

Simone, 16, often has been afraid to see or even call them. Chemotherapy makes her nauseous, and she's terrified of throwing up in front of other kids. A lifesaving medication called prednisone causes turbulent mood swings that make it hard to control her temper. Rather than risk snapping at people who care about her, Simone often chooses to be alone.

"I was so afraid of doing something gross in front of people," says Simone, of Walnut Creek, Calif., who is scheduled to finish treatment this spring.

Yet Simone is never afraid to talk to Lauren Sharp of Versailles, Mo. The girls, who have both been treated for acute lymphoblastic leukemia, met at a website for teen cancer patients called Group Loop.

They are among thousands of patients with cancer and other serious illnesses who use technology to cope. Some patients create blogs. Others record their stories through podcasts that can be downloaded onto iPods. Many follow online discussion boards.

## FAMILIES FIND A LIFELINE

A number of hospitals recognize the power of online support, making it easy for patients and their families to connect through the Internet or even create their own blogs.

Tony Scilingo of Edison, N.J., had never used the Internet before his son was diagnosed with bone cancer. But he now files Web updates about his son's progress every week, thanks to a site called [caringbridge.org](http://caringbridge.org).

Scilingo learned about the site, which was designed with families in mind, from New York's Memorial Sloan-Kettering Cancer Center. Scilingo says the site spares him from having to repeat the same news to dozens of well-wishers. It also allows him to keep up with his tech-savvy 15-year-old son, Anthony.

"He's teaching me how to copy and paste," Scilingo says.

Karen Grant of Methuen, Mass., has been teaching senior citizen patients about podcasts. Grant, 31, has survived mesothelioma, a rare

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and deadly lung cancer typically found in older people who were exposed to asbestos. She volunteers at the International Mesothelioma Program at Brigham and Women's Hospital in Boston.

The hospital has recorded video testimonials from survivors on its website. She says the online videos reach patients who may never meet another person with mesothelioma. Grant passes out iPods in the hospital so that anxious patients can listen to the testimonials.

"As tough as it is, I try to help them have a smile on their face and relax and know it's OK," Grant says.

Lori Todaro says she pours her heart into her son's site at carepages.com. She found it through The Children's Inn at the National Institutes of Health, where her 7-year-old son, Nino, is being treated for a rare disease called periodic fever syndrome.

"It was so helpful to be able to go back to the inn and just dump everything on those pages," says Todaro, who travels to the NIH every four weeks from her home in Carlisle, Pa. "I was able to just leave my worries and my tears there, because I couldn't be down for Nino."

*By Liz Szabo*

One of the best-known sites, the Cancer Survivors Network of the American Cancer Society, has 72,000 members, most of whom are adults.

The Internet has special appeal for adolescent patients, says Jennifer Ford, an assistant attending psychologist at New York's Memorial Sloan-Kettering Cancer Center. Young cancer patients have grown up with technology, and many already have their own websites and blogs. Other popular sites, she says, include [teenswithcancer.org](http://teenswithcancer.org) and [planetcancer.org](http://planetcancer.org), which is geared toward young adults.

Girls seem especially drawn to these sites; they make up about two-thirds of the users at Group Loop, says Mitch Golant, the site's vice president for research and development. Women generally are more likely than men to use support groups, he says.

Online communities can be especially important for teens because their disease is so rare, Ford says. The 12,400 patients under 20 who are diagnosed with cancer each year make up less than 1% of the 1.4 million new annual cases of the disease, the American Cancer Society says. Loneliness is a common problem for these young patients, many of whom, like Simone, sometimes isolate themselves.

Sometimes, after a visit with classmates, Simone says, "I would just collapse from the pressure of holding it all in."

Battling cancer is grueling at any age, but Ford says the disease can be particularly tough on teens. At this age, even healthy children worry about their bodies, their looks and fitting in.

The last thing that teens want is to be taken away from home and set apart from everyone else.

Lauren, 16, was the only child with cancer in her hometown in Missouri. She wishes she had known about Group Loop when she was in treatment. She was 11 when she began treatment, which made her swell up and gain weight. At school, Lauren hid her puffy cheeks by walking through the hallways with her hands in front of her face.

Lauren says she understands the agony of patients still going through therapy.

Now, in their hours online and on the phone, Lauren and Simone air their resentment of medications that punish patients in order to cure them. They can speak freely without the fear of boring anyone, without anyone staring.

Like Lauren, Simone is sensitive about her appearance. On a discussion board last year, she wrote of being ashamed of her "big, fat hideous cheeks." Yet Simone also has found courage to poke fun at herself, choosing "chpmnkcheekz" as her screen name.

"When I talk to Lauren, I don't have to explain," says Simone, who discovered the website shortly after being diagnosed. "Whenever I am sad or depressed, I always feel like she can help."

The two girls, who have been friends for two years, met in person last summer at Simone's house. They plan to meet at Lauren's home in a few months.

It's important for teens to have their own support systems, Ford says, because teens' concerns are so different from those of other patients. Unlike adults, teens rarely worry about death, she says. They focus more on immediate threats: appearance or missed opportunities, such as going to the prom.

Teens also have close ties to familiar places, such as their schools and neighborhoods, Ford says. They suffer when they are plucked out of that environment, especially if sent hundreds of miles away to a specialty pediatric hospital, a common practice.

### **Connected by cellphone**

Emily Bye, who was treated for bone cancer at 17, often spent five days at a time in the hospital.

Every day felt the same, she says, until time no longer seemed to matter. The hospital charged high fees for the Internet and forbid the use of cellphones — a hardship for a generation accustomed to sending dozens of text messages a day.

To Emily's teen classmates, even the vocabulary of cancer — platelets, catheters and sarcomas — seemed foreign. "I felt like I wasn't normal," says Emily, now a 19-year-old sophomore at Virginia's James Madison University.

She heard about Group Loop during treatment, but didn't become a regular member at the site, which doesn't charge a fee, until she left the hospital and finished therapy.

"I found there were other people out there like me," she says. "I felt normal in that way. It was nice to know that they had gone through the same thing."

Some hospitals make a special effort to help patients stay in touch.

Memorial Sloan-Kettering allows cellphones and text paging and even provides laptops and high-speed Internet connections. Kids can use teleconference facilities to follow along with their classes at home, says Nina Pickett, administrator of the hospital's pediatrics department.

One of the hospital's patients, 15-year-old Anthony Scilingo, says he's never far from his laptop. He carries his cellphone in one of the many pockets of his cargo pants.

Yet Anthony, who is undergoing chemo for bone cancer, spends much of his day waiting to talk. His old friends in Edison, N.J., don't get out of school, and back online, until 4 p.m.

### **A natural distance**

Ford notes that the Internet fills another crucial need for kids with cancer: It gives them a place to complain about their parents.

Adolescent cancer patients sometimes lose the opportunity to become independent, Ford says. Kids usually spend their teen years staking out an identity distinct from their parents and bonding with their peers.

Cancer, however, makes teenagers dependent on their parents, sometimes for the most basic and embarrassing of needs, such as getting dressed.

Many parents end up sleeping in their child's hospital room. websites for teen cancer patients can give kids a place to put a little healthy distance between themselves and their caregivers, Ford says.

Yet she cautions against spending too much time on the Web. Chatting online can't replace face-to-face interactions with peers, Ford says. Kids who spend too much time at the computer may become even more isolated.

And in the end, no technology can make cancer easy.

Emily says her online buddies understand cancer, but they don't know her as well as her longtime friends.

She also is reluctant to really bond with other young patients. One of her online friends has relapsed. A friend with cancer died of an infection.

"It's hard to get close to people because you know they all have cancer and that something could happen to them," she says. "As much as we talk, I sort of restrain myself."

Posted 4/10/2006 7:54 PM ET

Updated 4/10/2006 7:58 PM ET

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