

cancer

How Technology Sparked a Medical Revolution

Over the past decade the Internet has changed the way people find music, mattresses, and even mates. It has also transformed cancer.

Nearly 90 percent of Americans spend time online regularly, up from about half in 2000. Health care has moved online along with the public. Patients, doctors, and researchers now have a much easier time finding information – and one another. The online universe has improved the patient experience, though determining which information is reliable and which is not can be challenging.



BY PAIGE ALLEN
AND ANDREW BECKER



In the Beginning

When LeAnn Lamb was diagnosed with GIST, a cancer of the digestive system that affects less than half of one percent of cancer patients, she hadn't heard of the disease. She certainly didn't know anyone else who had it.

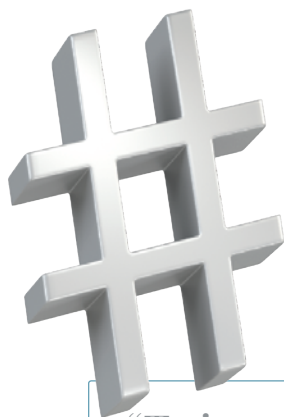
As she began treatment at Fox Chase Cancer Center, she looked for a patient support group but came up empty. It was the early 2000s and she wasn't very computer-savvy, but her husband suggested that she create her own support group online.

"GIST is so rare and very few people know what it is or even where to go," said Rick Lamb, LeAnn's husband. "GIST Support International evolved out of that need."

Within six months, 500 GIST patients had joined. As the Internet became more commonplace, the group swelled. LeAnn later created a Facebook group that now has more than 3,000 members.

"Mom told me about her website ... but I never really knew her impact until she passed," said LeAnn's daughter, Megan Craig.

When Lamb died in September



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DAVID Y.T. CHEN, UROLOGIC SURGEON AT FOX CHASE

2017, her family received an outpouring of support from around the world. Megan was so moved by the messages that she shared some of them at the funeral.

"Up until she lost her ability to speak, she was still trying to talk about her experience and share her journey," Craig said. "She couldn't always remember what day it was but she knew she wanted to communicate to that group. A lot of people have gained a lot of life from this support group."

The Soapbox Goes Virtual

With the rise of social media, people are finding their voices amplified exponentially. Patients can share personal experiences and post reviews of doctors in the same way they might rate a restaurant or hair salon. Many doctors and scientists use social media to share news and connect with colleagues.

"Twitter is such an interesting platform because how far your voice goes is potentially unlimited," said David Y.T. Chen, a urologic surgeon at Fox Chase.

Chen regularly interacts with other physicians on Twitter, which he likens to a virtual doctors lounge, where meaningful conversations take place as participants rotate in and out. He also belongs to a doctors-only robotic surgery consortium on Facebook that allows him to view surgical procedures and learn ways to improve his technique.

"Somebody out there has seen it before," he said. "In a lot of situations that are rare or uncommon, it's hard to hear how people did or what transpired unless it's been published. With social media, you can put a call out asking if anybody has ever seen this?"

Like Chen, Wafik El-Deiry, deputy cancer center director and head of translational research at Fox Chase, embraces social media. Across Twitter, LinkedIn, and Facebook, he has more than 20,000 followers.

Social media has made it easy to find support and information, but El-Deiry and Chen say doctors and patients should proceed with caution and a healthy skepticism.

"Take the feedback with the level of weight you think is appropriate," Chen said. "For patients, there's a trove of information out there. As physicians, we need to be able to help discern which sites give legitimate information and which ones are less valid."

When patients believe incorrect information, it can create problems in the exam room.

"Google is not your doctor," said El-Deiry. "There's an art to the profession of medicine and doctors spend many years honing their skills. Internet research can make you well informed but it doesn't mean you've figured out your diagnosis or treatment. Medicine is not just fact. There are preferences, and wishes, and judgments that have to be made."

Information Can Move Mountains

After John Schroettner's stomach cancer diagnosis in 2013, he and wife Danielle found reliable information online that helped influence his treatment options. As John prepared to start chemotherapy, Danielle researched the drugs his doctor prescribed and discovered that neuropathy was a common side effect.

"John already had some problems with neuropathy and he didn't need aggravation," she said. "I mentioned that to the doctor and he changed to a drug that didn't have that particular side effect."

Later, when John needed surgery, the couple wanted to travel from their home in Hawaii to Fox Chase in Philadelphia because they had family nearby. Their insurance company urged them to find an in-network surgeon in Honolulu or Los Angeles.

"Both the American Cancer Society and National Comprehensive Cancer Network recommended that we select a surgeon who has a fairly high volume of doing those procedures," Danielle said. "The surgeon at Fox Chase did between 15 and 20 of these surgeries every year and had done more than 100 over the years."

The fight with the insurance company threatened to delay

John's surgery, so the couple paid out of pocket for the surgery at Fox Chase while appealing the decision. Danielle sent eight pages of research to the company handling the appeal.

"The day after John was discharged, we found out we won the appeal," she said. "The research I did on the Internet helped me to bolster my case and we won."

John eventually died from his cancer, but Danielle has remained connected to Fox Chase despite the distance, making yearly donations and following the Center on social media.

Intervention via Internet

Beyond facilitating better access to information and support, online communication has driven improvements in patients' quality of life.

Kuang-Yi Wen, an assistant professor in the Cancer Prevention and Control Program at Fox Chase, developed a text message program to help alleviate side-effect symptoms in breast cancer patients undergoing chemotherapy.

"Chemotherapy is a journey," Wen said. "Patients are dealing with nausea, vomiting, hair loss, body changes, and a lot of emotion. Text messaging was a way to connect the gap when they're home."

Patients in Wen's recent study received two text messages every day with content developed from the Fox Chase Resource and Education Center, the American Cancer Society, the National Cancer Institute, and other leading groups.

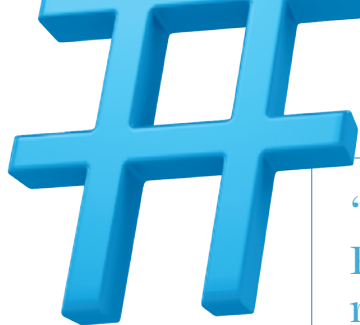
"They were getting bursts of information over time rather than all at once, and it was always on their phone to go back and look at," Wen said.

Wen said the reaction was overwhelmingly positive. Some asked for a program to guide them through other phases of treatment, including radiation and surgery.

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"They want to feel supported, empowered, and in control," Wen said. "One patient told us the text messages were a daily support that she did not have otherwise."

Coming Full Circle Online

In 2007 Lawrence James created an online prayer network for his Philadelphia church. The church had been sending out prayer requests via email, and James knew it wasn't the most efficient method. His company, Connexus Technology, built a software tool to receive prayer requests and distribute them to large groups. When it caught on, they built a more advanced web-based program, called PrayerConnexus, so more churches could use it.

"The church was using it and it spread around the city and around the world," he said. The vision was to unite people around the world in prayer and have a birds-eye view of how to strategically pray for people."

About a year after building PrayerConnexus, James found himself in need of prayers after he was diagnosed with a germ cell tumor. After initially keeping the diagnosis to himself, James went public on Facebook and PrayerConnexus, where he sent his own prayer request.

"In my experience, there's a tipping point when it comes to sharing your diagnosis," he said. "You're kind of guarded and private for a while but at some point, the cancer and what you're going through becomes part of who you are. When I hit that point, I wanted people to know so they could pray for me."

Sharing his experience as a cancer patient with others going through the same thing is something James values greatly.

"Cancer can be a very lonely thing. I felt like I was in the same world as everyone else but I was on time out while others moved forward," he said. "If there's anything I can share to help others, I will. I'm a survivor and an advocate for survivors. I will be that forever and I voice that on social media." ♦

