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MDs note the rise of e-patients

Seriously ill find help, hope online

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BY KELLY HEYBOER

Barbara Earl was a marathon-running, mountain-climbing fitness enthusiast when her doctor gave her a shocking diagnosis last fall: She had Stage 3 esophageal cancer.

As soon as she got home, the South Plainfield resident sat down at her computer and typed "esophageal cancer" into Google. She found a flood of treatment information, survivors' blogs, patients' forums and other online resources that helped her feel a little less overwhelmed.

"When you're told you have cancer, you can't think straight," said Earl, 54. "It helped me formulate my questions for the doctor. It was reassuring."

Earl, who is doing well after surgery and chemotherapy, is what researchers have dubbed an "e-patient." They are the growing number of seriously or chronically ill people who are increasingly turning to the Internet to help research their own health problems, make treatment decisions and connect with others with the same illnesses.

A study released yesterday by the Pew Internet & American Life Project confirmed what most doctors already know: The number of e-patients is growing.

About 51 percent of those living with a disability or chronic disease go online, compared to 74 percent of the rest of the population, according to the study. But once those with illnesses get online, they become some of the most avid Internet users.

Three-quarters of e-patients say information they found on the Web affected decisions about their treatment, according to the study. Nearly 69 percent said something they found on the Internet led them to ask their doctors new questions or get a second opinion.

The health care industry, which once discouraged people from doing Internet research, is beginning to take notice of the e-patients' rise, said Susannah Fox, associate director of the Pew Internet & American Life Project, a Washington, D.C.-based nonprofit group.

"I've seen a significant change since we started studying this seven years ago," Fox said. "What a difference seven years has made."

Medical organizations are starting their own Web sites and steering patients toward credible online health information, Fox said. Doctors who once advised patients to stay off the Internet have begun handing out lists of Web sites along with each diagnosis.

At the Cancer Institute of New Jersey in New Brunswick, patients can leave their doctors' offices and go directly to the computers in the facility's Resource and Learning Center to do their own research.

"I've offered classes here on how to evaluate Web sites," said Janet Lasin, the center's medical librarian. "The more information they can get, the better."

Though online health information is getting more credible, there are still plenty of pitfalls. The Pew study found an alarming 67 percent of e-patients say they don't always check the source or date of the health information they pull from the Internet. That often leaves frustrated doctors the task of talking patients out of trying the latest miracle cure they found online.

Geoffrey Hogan of Lavallette used the Web to help him made decisions during seven years of surgeries, radiation and chemotherapy treatments for prostate cancer. But, in the end, he found that talking to his doctors, reading medical journals and doing old-fashioned book research to be more helpful.

"These sources available through the Internet were not particularly effective. They didn't tell me anything I didn't know," said Hogan, 67, who has a doctorate in toxicology and pharmacology.

Still, many patients say the Internet gives them a sense of instant empowerment when facing a life-changing diagnosis. Jane Haszko of Bridgewater was online looking for Web sites within hours of being told she had breast cancer.

"It made you feel like you could take action," said Haszko, 55. "I had a list of questions for the doctor and I was able to start plotting out my plan."

Now that she is recovering, Haszko still goes online regularly to study statistics about cancer reoccurrence and watch video and read transcripts from oncologist conferences.

Kathleen Toomey, an oncologist and medical director of the Steeplechase Cancer Center at Somerset Medical Center in Somerville, said patients may be getting more and more of their information online. But it remains the doctor's job to put it all in perspective.

"Our job now is to make sure it's in a form they can understand and digest," Toomey said. "They still need that one-on-one. It still takes a village of nurses, doctors and dietitians to educate our patients."