

Dear Seizure Diary

How and why to record your epileptic seizures.

BY LISA PHILLIPS

ne of the most important tools a neurologist has for the treatment of epilepsy and other seizure disorders can only be provided by the patient: a record of seizure activity in day-to-day life.

Seizure diaries, as they are often called, are a way for physicians to get an idea of how many seizures a patient is having between office visits. Depending on how detailed the diary is, it may also give insight into a patient's seizure triggers and medication side effects.

"If you don't know the frequency of seizures, you don't know whether the patient is responding to medication or not," says Jacqueline A. French, M.D., professor of neurology and director of the Clinical Trials Consortium at New York University's Comprehensive Epilepsy Center.

Without a record, Dr. French has to rely on a patient's memory of seizure activity—and memory can be unreliable. "If a patient is convinced a medication won't work, they may remember more seizures than they actually had," she says. "If they are sure the medication will work, they may remember fewer."

"You come into the office when you're not actively seizing," says Shlomo Shinnar, M.D., Ph.D., professor of neurology, pediatrics, and epidemiology and director of the Comprehensive Epilepsy Management Center at Montefiore Medical Center and Albert Einstein College of Medicine. "So I rely on what you're telling me to decide if I should switch medication or change your dosage. In epilepsy, you need a reliable history in order to guide treatment. In many cases a diary is a critical component of this."

BETTER SEIZURE CONTROL

Methods of monitoring seizures vary widely. Many physicians' offices distribute forms or booklets. Some patients simply put check marks on a piece of



paper on the refrigerator. Others keep detailed written journals in a notebook. A newer option is electronic record keeping, through computer calendar programs and Web sites.

For Sabrina Cooke, 43, the opportunity to document her seizures online transformed her from someone who was "not good" at self-monitoring into a diligent record keeper. Cooke first investigated **seizuretracker.com**, a free online seizure diary, because she thought members of her epilepsy support group would find it useful.

"The site gives all the prompts," Cooke says. "You can choose from a list of triggers in a drop-down menu instead of writing a summary. It's not hard to use."

After three months of using seizuretracker.com, Cooke gave her physician an eight-page printout with graphs detailing her seizure activity. He noticed that she had a lot of seizures in the mid-afternoon, so he prescribed her an afternoon dose of medication. The change made a big difference, according to Cooke.

"I'd never gone a full week without seizures in my life," she says. "But now at times I can go up to six days without one."

Cooke often uses her cell phone, which is Web-enabled, to enter data on seizuretracker.com. Sheryl Haut, M.D., M.S., associate professor of clinical neurology and director of the adult epilepsy program at Montefiore Medical Center and the Albert Einstein College of Medicine, has found that hand-held devices seem to be the most effective technology for keeping diaries. They can serve as portable alarms, she says, reminding patients to enter data or take medication. In her research, patients using electronic

However, Dr. Haut says, the screen size and ease of use of any technology are important considerations, particularly for older patients who may not be comfortable using a computer.

ONLINE TOOLS

Robert Moss, a commercial photographer and co-founder of seizuretracker.com, developed the Web site because none of the diaries he found worked to keep track of the many daily seizures suffered by his son Evan. At age two, Evan was diagnosed with tuberous sclerosis complex, a genetic condition associated with epilepsy.

"We are advocates of seizure logging at any level," Moss says. "It gives people a sense of control."

Seizuretracker.com now has 2,500 users, with about 200 new users logging on every month and a new mobile optimized site. So far, the work Moss and others have put into the site has been volunteer, but he is seeking foundation grants that would allow him to work on it full-time. The site's current business plan does not include advertising as a funding source, he says.

Other online options are available. Some pharmaceutical companies offer tools on Web sites for epilepsy medication. In October, the Epilepsy Therapy Project, a non-profit organization dedicated to accelerating new therapies for people living with epilepsy and seizures, launched My Epilepsy Diary, a new seizure-tracking tool on **epilepsy.com** with applications for iPhones and other smart phones.

A NEW TOOL FOR RESEARCH?

Like Moss's site, My Epilepsy Diary is free and allows patients to enter details about their seizures, medicines, side effects, and possible triggers. Though the tool's primary purpose is to help paAfter using seizuretracker.com, Cooke gave her physician an eightpage printout with graphs detailing her seizure activity.

tients with their medical care, the site will also be used for research purposes, says Dr. Robert Fisher, M.D., Ph.D., editor-in-chief of epilepsy.com and professor of neurology and director of Stanford Comprehensive Epilepsy Center at Stanford University.

"We might use the information on an anonymous basis to learn something about seizures," Dr. Fisher says. "Most of the information we have about seizures and side effects are from artificial controlled studies. This could be a way of making observations about medication in the real world."

Dr. Fisher adds that epilepsy.com is not covered by the Health Insurance Portability and Accountability Act (HIPAA) or Institutional Review Boards (IRBs) because the site does not provide medical care or sell medical products. But, he emphasizes that the site takes privacy "very seriously." The My Seizure Diary tool does not ask for any identifying information such as names or telephone numbers.

Though certain pages on epilepsy. com do accept advertising, Dr. Fisher says e-mail addresses are not used for commercial mailing lists. Only legitimate medical researchers will use the database, not corporations. "We're not interested in having the database be a corporate marketing tool," he says.

Moss says data from users of seizuretracker.com would never be shared outside the site without prior consent from the user.

Dr. French questions whether the data collected from online seizure diaries will be valid for research purposes. "There could be an enormous selection bias," she says. In other words, "People in tune with their illness are going to be more likely to fill out seizure diaries than some other people. You'll end up with information that pertains to people who are obsessive about their seizures and no one else."

No seizure-tracking system is perfect, Dr. French points out. The very nature of seizures, which can cause memory problems, makes dairies a flawed tool at best. Nevertheless, maintaining some kind of diary is still a worthwhile use of your time—and remembering what happened within the last 24 hours is easier than remembering what happened six months ago while sitting in an exam room. "Seizure diaries are the worst possible form of tracking seizures—except for everything else," Dr. French says.

ONLINE SEIZURE-TRACKING TOOLS

- My Seizure Diary, developed by the Epilepsy
 Therapy Project: epilepsy.com/seizurediary
- ► Seizure Tracker: **seizuretracker.com** (see image)
- Interactive Seizure Diary on the Keppra Web site: keppra.com/pc/talking_to_your_doctor/seizure_diary.asp
- ► EpiTrax, a software program for tracking seizures (\$49.99): **neomedsoft.com**
- ► Live Beyond Epilepsy's downloadable paper epilepsy diary: livebeyondepilepsy.com/resources/specialist-information

NOTE: PLEASE CHECK EACH SITE FOR DETAILED INFORMATION ON PRIVACY AND HOW DATA IS USED, AS POLICIES MAY VARY