

How to manage epilepsy instead of letting it manage you.

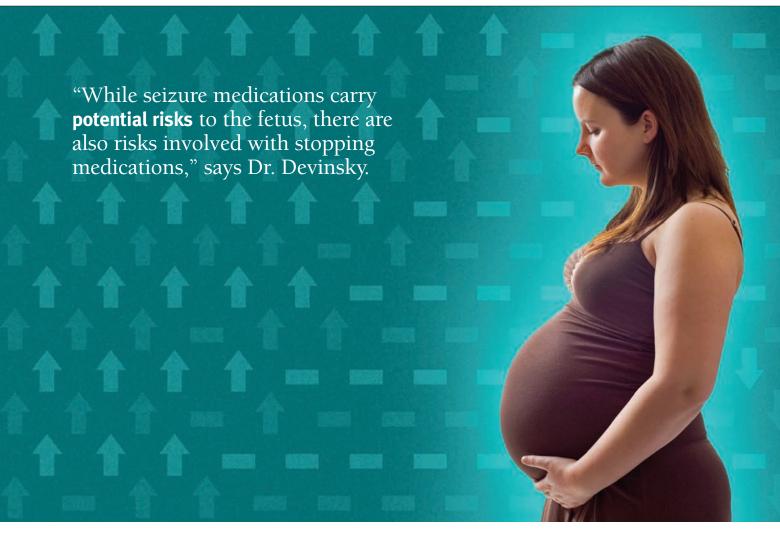
BY KATE HUVANE

pilepsy treatment has come a long way since the nineteenth century, when women with seizures often underwent hysterectomies or ovariectomies. The logic was that by eliminating the menstrual cycle—which was linked with a higher seizure frequency at certain times—seizures would be eliminated as well. The strategy didn't work; in fact, it only made women less likely to consult with physicians.

Fast-forward a couple of hundred years, and things couldn't be more different. The management of epilepsy is far more sophisticated, and our knowledge of the condition is expanding at a rate that is astounding, even to those within the neurology community.

When Martha Morrell, M.D., first became an epileptologist, she noticed that many of her female patients had concerns about how having epilepsy might affect things like the ability to conceive a child. "There wasn't a whole lot of information that gave them answers," says Dr. Morrell, now a clinical professor of neurology at Stanford University in Palo Alto, CA, and chief medical officer at Neuropace in Mountain View, CA. "But in the last five or 10 years, there has been such interest in this area on the part of neurologists. We're in a much different place."

Thanks to data from clinical trials, registries, and other research, we now know that epilepsy—along with the medications used to treat it—impacts women uniquely throughout



their adult lives. As a result, women with epilepsy should consider their condition when making important life decisions, such as planning for a baby.

The good news is that women can manage epilepsy instead of letting it manage them—by educating themselves about the condition, maintaining an open line of communication with their physicians, and taking an active role in their treatment.

ONE PATIENT'S EXPERIENCE

For Shannen Soldate, a 38-year-old woman with epilepsy, finding a physician who would give her answers was a critical step in taking control of her condition.

Soldate had visited a number of neurologists over a period of several years before being diagnosed with epilepsy at age 28. Prior to that, she had been prescribed various medications to control her seizures, including painkillers like diazepam (Valium) and acetaminophen and hydrocodone (Vicodin). The one thing she wasn't given was a definitive diagnosis. That changed when she was referred to an epilepsy specialist at the University of California—San Francisco Medical Center who confirmed that she did in fact have epilepsy and put her on a medication regimen that finally controlled her seizures.

"I wish I would have found a good doctor sooner," Soldate says, "but I didn't know enough about my own condition to ask the questions I needed to ask."

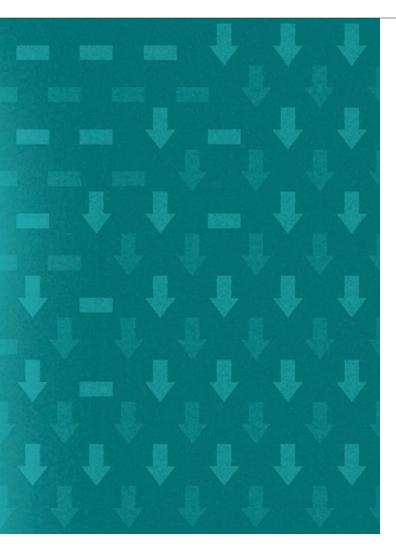
SEIZURES AND THE MENSTRUAL CYCLE

Soldate first started having seizures at age 16. This is not uncommon, according to Allison Pack, M.D., assistant professor of clinical neurology and Columbia University Medical Center in New York, NY. "There are epilepsy syndromes that start around the time of puberty," says Dr. Pack. Often, women first notice a pattern between their seizures and the menstrual cycle around the time they begin having their periods.

"Data suggest that anywhere between 25 and 30 percent of women have seizures that are exacerbated during particular points in their menstrual cycle," Dr. Pack says. Those particular times, according to the Comprehensive Epilepsy Center at New York University Medical Center, are:

- ▶ Just before and/or at the onset of bleeding
- ▶ At ovulation (in the middle of the cycle)
- During the second half of the cycle, particularly in women with abnormal cycles

The reason that seizures are more pronounced during these times, says Dr. Pack, is probably due to the relationship between the two main sex hormones, estrogen and progesterone, each of which affects brain cells differently. Estrogen, which is responsible for the start of bleeding and for ovulation, has proconvulsant properties, making seizures more likely. Progesterone, which keeps the uterine lining rich in preparation for a



fertilized egg, has anticonvulsant properties. When a woman is at a time of her cycle when the increase in estrogen is high in relation to the increase in progesterone, she is more susceptible to having seizures.

Because of this, "it's important for women to keep track of their periods and their seizure frequency," advises Dr. Pack. Possible interventions include increasing a medication's hormone dosage, taking an anticonvulsant, regulating the menstrual cycle, or considering a progesterone injection. However, Dr. Pack strongly emphasizes that none of these actions should be taken without consulting a physician first.

SEX AND SEIZURES

As women enter adulthood, they may have to confront several issues arising from the use of anti-epileptic drugs. One of these is sexual function. "Women with epilepsy are more likely to complain about sexual desire and arousal," Dr. Morrell says. One reason for this is that depression, which is common in people with epilepsy, can cause sexual dysfunction. Another factor is that anti-epileptic drugs can interact with hormones that are important for sexual function. The best thing a woman can do in this case is to speak with a neurologist specializing in epilepsy, who can review her medications.

Another hot button issue is contraception. According to Dr. Pack, a number of studies have shown that certain anti-epilep-

ADVICE FOR NEW MOTHERS

We know that women with epilepsy face obstacles during pregnancy, but what happens after pregnancy can be just as challenging. During this time, it's crucial that women obtain answers to their important questions:

Do I have to stop taking anti-epileptic drugs if I want to breastfeed? The American Academy of Pediatrics recommends that women who choose to breastfeed do not stop taking anti-epileptic drugs. Breast milk provides many benefits for a baby's health. In addition, the baby has already been exposed to anti-epileptic drugs through the pregnancy, and the possible exposure during breastfeeding is considerably less, according to Dr. Morrell. "Antiepileptic drugs cross into breast milk to varying degrees, but it's important to note that when the baby breastfeeds, the baby does not absorb the drug completely. In general, the blood levels of anti-epileptic drugs are quite low," Dr. Morrell says. She recommends that women make their own decision about whether to breastfeed. If they have any concerns, a blood level can be drawn and they can switch to bottle feeding.

What if I have a seizure while I'm caring for my baby? Many women continue to have seizures after delivering. While this shouldn't be cause for panic, it does mean that certain precautions need to be taken. For women with infants who experience seizures, Dr. Pack advises the following:

- ► Don't walk across the room with an infant. Put the baby in a stroller, even if it's for a short distance.
- ▶ Never bathe the baby alone—always have someone with you.
- ▶ Don't ever hold the baby in a position where he or she can get hurt. For example, don't cook over a hot stove while holding the baby.
- When you're with the baby, ask yourself this question: If I were to have a seizure right now, would my baby get hurt?

"This is a really important issue," says Pack. "So many women focus on getting pregnant and having a healthy baby, and now all of a sudden they have to take care of the baby. If women are continuing to have seizures, there are certain precautions that they have to take, particularly if they're alone."

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tic drugs may reduce the efficacy of hormonal contraceptives, including the birth-control pill, patch, and ring. She advises women who are taking the pill to inquire about increasing the estrogen dose or consider using a barrier method as a back-up.

"Often the best methods are those such as an intrauterine device, where there is absolutely no interaction," says Dr. Pack.

When considering which method of birth control is optimal, women should make an appointment not just with an OB-GYN but also with a neurologist, who are "more tuned in to the unique concerns of women with epilepsy," according to Dr. Morrell.

"It's critical that women maintain close contact with an epileptologist, who is in the best position to understand issues of reproductive health and epilepsy and to coordinate her care," Dr. Morrell says.

PREGNANCY AND ANTI-EPILEPTIC DRUGS

Pregnancy seems to cause the most anxiety in women with epilepsy. Questions commonly addressed to physicians include whether medications can be taken during pregnancy and how seizures might affect the fetus.

Most experts recommend that as soon as a woman even

PREGNANCY REGISTRIES

The North American Anti-Epileptic Drug Pregnancy Registry was established in 1997 for pregnant women in the U.S. and Canada.

The goal of this registry is to gather and publish information on the rate of major malformations, such as heart defects, spina bifida, and cleft lip, in infants whose mothers had taken anti-epileptic drugs during pregnancy, and to determine the safety of seizure medications.

As of February 2008, nearly 6,000 women have participated, but more participation is needed in order to enable health care professionals to obtain the most accurate information possible so that women with epilepsy can become better educated on this very important topic.

Participants will be interviewed at the time of enrollment, at 7 months' gestation and postpartum (up to 8 to 12 weeks after the expected date of delivery).

To enroll in the registry, call the toll-free number at 1-888-233-2334 or visit the aedpregnancyregistry.org.

starts to consider conceiving, she should meet with her doctors to develop a health regimen that meets her specific needs and to determine whether anti-epileptic drugs can be continued—and if so, at what dosage.

"The first time to consider epilepsy in pregnancy is well before the woman becomes pregnant," says Orrin Devinsky, M.D., director of the New York University Comprehensive Epilepsy Center and founder of an organization called "Finding a Cure for Epilepsy and Seizures."

It can be difficult to determine how a women's seizure pattern may change during pregnancy. About one-third of women experience fewer seizures, one-third don't see any change, and one-third have a higher frequency, according to Dr. Morrell. If a woman is in the first two groups, she may be able to lower the dose of her anti-epileptic drug significantly. But this decision, says Dr. Devinsky, "should be made ahead of time, not when the woman is six or eight weeks pregnant," because many medications pose the highest risks for birth defects during the first trimester.

While the specific risks for each of the individual antiepileptic drugs are not yet known, data from four registries suggest that the risk of major malformation (birth defect) associated with the anti-seizure drug valproate "is somewhere between 10 and 20 percent," according to Dr. Morrell. Dr. Devinsky agrees, adding that children who are born to mothers taking valproate face higher rates of learning disorders such as autism in addition to the risk for malformation.

Another anti-epileptic drug, phenobarbital, was shown in an *Archives of Neurology* study in May 2004 to carry a significantly increased risk of fetal abnormalities. The overall risk of major malformation in women who are taking any anti-epileptic drug is around four to six percent, says Dr. Morrell, which is about twice that of the general population.

But while all seizure medications do carry potential risks, there are also risks involved with stopping medications, says Dr. Devinsky. "Many women would rather suffer and have a seizure or two as opposed to putting the baby at risk of a malformation," he says, emphasizing that this isn't always the best plan—especially if these women drive cars or are involved in any other activities that could place them in danger in the event of a seizure.

Many neurologists, including Dr. Devinsky, suggest that women work with their physician to establish the lowest possible dose of their anti-epileptic drug that will prevent seizures while also posing the least possible risk to the fetus.

"You have to carefully balance the risks and try to minimize the number of drugs and the dosage of drugs. But think long and hard

Ask yourself: If I were to have a seizure right now, would my baby get hurt?

before you consider getting off the drugs," Dr. Devinsky says.

Like all pregnant women, those with epilepsy are strongly encouraged to avoid caffeine and tobacco and to take folic acid supplements. The American Academy of Neurology guidelines suggest that women take anywhere from 0.4 to 4.0 milligrams per day of folic acid. Dr. Pack advises that women taking anti-epileptic drugs take a higher dose of folic acid, since epilepsy medications can reduce levels of folic acid in the body. "I would suggest that if they're taking valproate, they should be taking closer to 4 milligrams," Dr. Pack says.

Pregnant women should also try to "reduce stress and seizure-provocative factors, and seek medical care from both an OB-GYN and a neurologist more regularly than they've done before, to make sure there's a solid dialogue among all three parties," says Dr. Devinsky.

It's the kind of advice that could have made Shannen Soldate's pregnancy a little easier.

"I really wish now that I had asked more questions about my meds, what I was up against, and any kind of supplements I could have taken," says Soldate, who hopes that other women can learn from her experience. "You have to communicate with your doctors. You can't expect your OB-GYN to be educated about epilepsy. You have to take that initiative."

Although Soldate continued to take seizure medications during her pregnancy—a fact that her OB-GYN was aware of but did not monitor—she was able to have a relatively healthy pregnancy, and her daughter was born without any birth defects.

BONE HEALTH

While the reproductive years can be challenging for women with epilepsy, the problems associated with the condition don't disappear at menopause. Sometimes they get more serious. Seizures can become more severe during menopause because women's bodies undergo dramatic changes in hormone levels during this time, according to Dr. Devinsky. Women should keep their physicians informed of any changes.

Around the time if menopause—and often earlier—women may also begin to experience bone loss. While all women need to be conscious of bone health, those with epilepsy need to be particularly vigilant because certain anti-epileptic drugs are associated with a higher risk for bone loss.

In a study conducted among women with epilepsy who were taking one of four anti-epileptic drugs over the course of a year (with no changes in their medications), it was shown that those taking phenytoin (Dilantin) experienced 3 percent loss of the bone mass in their hip in one year. The results of the study, which was published in the journal *Neurology* in April 2008,

were eye-opening for co-author Dr. Morrell (Dr. Pack was the lead author).

"A typical menstruationaged woman should lose much less than half of a percent, so this is six times the amount of bone loss you should lose," Dr. Morrell says. "If you add up three percent of bone loss year after year, pretty soon you're talking about a pathological fracture. If a woman is on this medication, she should have her bone density followed closely and have a screening test."

Fortunately, there are preventive measures that women can take. Dr. Pack advises that women talk to their physicians about getting enough

calcium and vitamin D, incorporate weight-training exercises into their fitness routines, and avoid risk factors for bone loss like smoking and chronic alcohol use.



No matter what stage of life a women is in, the best thing she can do to improve both her seizure control and her overall health is to take an active role in her treatment.

"Women should be educated about their condition, about the medications that they're on, and about the potential effects of those medications," says Dr. Devinsky.

One of the best ways to do this is by searching the Internet. But you have to find trustworthy sources of information.

"There are a lot of resources out there now that are reliable and up-to-date," says Dr. Morrell, who identifies the Epilepsy Foundation site (epilepsyfoundation.org) and Epilepsy.com as "consistently up-to-date and trustworthy." The American Academy of Neurology's main Web site (aan.com) and patient site (brainmatters.org) are also excellent.

For Soldate, sites like the one run by the Epilepsy Foundation of Northern California provide an outlet to speak with others who have epilepsy. Some of these sites have proven helpful in educating her friends and loved ones about her condition. "As my daughter has gotten older, she's gotten a better understanding of epilepsy," says Soldate. "When she was





younger, she was fearful of it. Those Web sites have helped her tremendously."

Nothing, however, is more helpful in educating family members than direct communication, says Soldate. But isn't always easy.

"The hardest thing has always been to let people know how I'm feeling," she says. "Even with my husband and my daughter, if we're out somewhere, I don't want to ruin anyone's good time and let them know I'm going to have a seizure."

While Soldate was out to dinner several years ago with other families from her daughter's softball team, she felt a seizure coming on. Instead of letting someone know, she excused herself from the table. On her way to the bathroom, she started having a seizure.

"I didn't want to make a scene," says Soldate, whose instinct to protect her daughter prevailed over a desire to ask for help. As a result, she put herself in danger unnecessarily, but learned that letting fear dictate her actions can result in worse consequences than simply voicing her concerns. "Make sure you don't hold back when you're not feeling well. Don't fear epilepsy."

Kate Huvane is a writer specializing in health topics such as Alzheimer's disease, obesity, pulmonary disorders, disease disparities among racial and ethnic groups, and health literacy.



For more information on women and epilepsy, please see RESOURCE CENTRAL on page 37.

READ MORE ABOUT EPILEPSY

Epilepsy, Patient and Family Guide, 3rd edition, by Orrin Devinsky, M.D. (Demos, 2008). This book provides a comprehensive overview of epilepsy for patients, physicians, families, and caregivers, focusing on the nature and diversity of seizures, how to prevent them, the benefits and risks of modern medicines and surgical therapies, and how the disorder affects employment and transportation.

Epilepsy, by Elaine Wyllie, M.D. (Cleveland Clinic, 2008). Written by the director of the Cleveland Clinic's Center for Pediatric Neurology, this slim but informative and easy-to-read book covers the basics of epilepsy and treatment and provides helpful diagrams, real case studies, and a glossary. Whole chapters are devoted to epilepsy in children, women, and seniors.

The Epilepsy Foundation:

epilepsyfoundation.org/about/faq/index.cfm Visit this site for general epilepsy information as well as for their women's section, which includes an online community and an online magazine called Between Us. —*Elizabeth Stump*