Women with Epilepsy

A Handbook of Health and Treatment Issues

Edited by
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Introduction: why we wrote this book

Martha J. Morrell

Martha J. Morrell is a Professor of Neurology at Columbia University, College of Physicians and Surgeons in New York City and is Director of the Columbia Comprehensive Epilepsy Center at New York Presbyterian Hospital. She has been elected an International Ambassador for Epilepsy by the International League Against Epilepsy and she chairs the National Epilepsy Foundation. Dr Morrell is the principal investigator on a number of epilepsy research trials examining reproductive health and hormones in women with epilepsy and bone health in women receiving antiepileptic drugs.

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In many ways, epilepsy is a different disease in a woman than in a man. The differences arise because of biological differences between women and men, but also because of the different social roles they play. As a result of these biological and social differences, women with epilepsy face special challenges, especially in the area of reproductive health (Table 1.1).

The experiential differences between women and men with epilepsy became clear to me in the very earliest years of my career as a neurologist specializing in the treatment of epilepsy. My background had been in studying the effects of male and female sex hormones on certain types of behavior, so I was well aware of the significant effects these hormones could have on many brain centers. Therefore, I was not at all surprised when women with epilepsy explained to me that their seizures appeared to vary with their menstrual cycles. Nor was I surprised to hear that many women found that their seizures changed at puberty and with menopause. I was concerned to hear women tell me that their menstrual cycles were irregular and to learn from some of my patients about their difficulties in becoming pregnant. There were also stories of miscarriages and complicated pregnancies. Many women (and men) also shared with me concerns about sexuality – problems with

Table 1.1. Special concerns for women with epilepsy

Hormone effects on seizures
Interactions between birth control pills and antiepileptic drugs (AEDs)
Effects of epilepsy on reproductive health
Effects of epilepsy on sexuality
Effects of AEDs on pregnancy and fetal development
Effectiveness and tolerability of AEDs in women

low sexual desire and sexual responsiveness. When I looked at the literature (now more than 10 years ago), I found that many of these issues were not recognized, not well understood, or not considered significant. Some medical writers believed that menstrual-associated seizures did not even exist. Those physicians who did accept the relationship between hormones and seizures sometimes delivered treatments that we now recognize are ineffective, such as hysterectomy and oophorectomy (removal of the uterus and ovaries).

In selecting antiepileptic treatment, I was dismayed to find that most of the information on the effectiveness and tolerability of the medications had been collected almost entirely from men. There was simply not enough information on whether these drugs worked differently in women, had different side effects, or were safe or not safe to use during pregnancy.

Family planning choices for women with epilepsy must take into account the interaction between hormones used for contraception and some antiepileptic drugs (AEDs). Although for more than 10 years some physicians recognized that some AEDs made birth control pills less effective, this information was not widely known by many neurologists and gynecologists. Therefore, some women with epilepsy have experienced unplanned pregnancies despite their best efforts to use contraception correctly.

One of the chief concerns for many women with epilepsy is that seizures and AEDs may make having children more risky. Women with epilepsy have been told that having children was not advisable because of the risks of transmitting epilepsy to a child and of having a baby with major physical or intellectual problems. Women with epilepsy have also been told that their epilepsy makes them unsuitable parents. Until 1982, there were even laws in some states in the USA restricting the ability of people with epilepsy to marry and have children.

Although it has been known for some time that AEDs can cause birth defects, there has been very little information about how these drugs harm the developing fetus and how treatment can be adapted so that there is as little risk as possible. As many new AEDs become available, we have not had the information that allows us to counsel women of childbearing age appropriately regarding the impact of the medications on reproductive health or the medication's safety during pregnancy. This is because, by government policy, women who are capable of becoming pregnant are excluded from the early phases of drug testing when much of the basic information regarding drug dose, effective pharmacokinetics, and tolerability is gathered. Pregnant and lactating (breastfeeding) women are excluded from any exposure to a drug being tested in order to protect the fetus against possible birth defects (teratogenecity). There are over 800 000 women in the USA with epilepsy who are in their childbearing years and probably one-third continue to have seizures despite efforts to achieve control with the older AEDs. That means that new drugs will be used in women during their reproductive years and while pregnant without health-care providers being fully aware of all the potential risks to reproductive health. Government and health-care providers are currently reassessing these drug development policies.

Fortunately, times have changed. A combination of scientific and social advances has brought issues concerning gender differences in medical illnesses to the attention of the general public, government agencies, and the scientific community. It is now recognized that epilepsy is one of the chronic medical conditions that raise special issues for women. This has increased the educational materials available to health-care providers. However, there is still very little literature available for the nonmedical public that comprehensively addresses the biological, psychosocial, and treatment issues faced by women with epilepsy. The Epilepsy Foundation has recognized the importance of encouraging educational outreach as part of the broader based Women with Epilepsy Initiative launched in 1997. This book is a part of that larger effort.

We have been able to assemble national and international experts to address issues of concern for women with epilepsy. Some are scientists researching the causes and consequences of epilepsy, others are health-care providers treating women with epilepsy, and, finally, we hear from women living with epilepsy. We have attempted to be comprehensive and scientifically

sound, while interpreting what is sometimes confusing and contradictory scientific information. Each author has selected further materials in each topic for the interested reader. These reference materials are not exhaustive, but have been selected as being particularly important, thorough, and clear. Further information can also be obtained through the National Epilepsy Library at the Epilepsy Foundation or from the Epilepsy Foundation's website at www.epilepsyfoundation.org.

Box 1.1

For more information on the
Women with Epilepsy Initiative
contact the Epilepsy Foundation at
www.epilepsyfoundation.org
1-800-EFA-1000

We have also tried to provide information that will permit a woman with epilepsy to educate herself about optimal medical care – not only for epilepsy, but also to maintain the best general and reproductive health. Epilepsy is best managed when there is a partnership between the patient and health-care provider. Family and friends are also an important part of the team. Ultimately, the woman with epilepsy should understand how to access appropriate services, should know enough about epilepsy to ask the important questions, understand the answers, and be able to anticipate health issues that may arise along the way. The woman who knows most about her disease is in the best situation to benefit from treatment. People with epilepsy can also serve as the most effective advocates to ensure that access to high-quality medical care is maintained, that scientific research continues to address topics of importance to people with epilepsy, and that public misconceptions about epilepsy no longer impede social progress.