Women with Epilepsy

A Handbook of Health and Treatment Issues

Edited by

Martha J. Morrell and Kerry L. Flynn



PUBLISHED BY THE PRESS SYNDICATE OF THE UNIVERSITY OF CAMBRIDGE The Pitt Building, Trumpington Street, Cambridge, United Kingdom

CAMBRIDGE UNIVERSITY PRESS

The Edinburgh Building, Cambridge CB2 2RU, UK 40 West 20th Street, New York, NY 10011-4211, USA 477 Williamstown Road, Port Melbourne, VIC 3207, Australia Ruiz de Alarcón 13, 28014 Madrid, Spain Dock House, The Waterfront, Cape Town 8001, South Africa http://www.cambridge.org

© Cambridge University Press 2003

This book is in copyright. Subject to statutory exception and to the provisions of relevant collective licensing agreements, no reproduction of any part may take place without the written permission of Cambridge University Press.

First published 2003

Printed in the United Kingdom at the University Press, Cambridge

Typefaces Minion 11/14.5 pt, Formata and Formata BQ System Let TeX 2_E [TB]

A catalogue record for this book is available from the British Library

Library of Congress Cataloguing in Publication data

ISBN 0 521 65224 3 hardback ISBN 0 521 65541 2 paperback

Every effort has been made in preparing this book to provide accurate and up-to-date information that is in accord with accepted standards and practice at the time of publication. Nevertheless, the authors, editors and publisher can make no warranties that the information contained herein is totally free from error, not least because clinical standards are constantly changing through research and regulation. The authors, editors and publisher therefore disclaim all liability for direct or consequential damages resulting from the use of material contained in this book. Readers are strongly advised to pay careful attention to information provided by the manufacturer of any drugs or equipment that they plan to use.

Contents

	List of contributors	page viii
Part I	The woman with epilepsy	
1	Introduction: why we wrote this book Martha J. Morrell	3
2	On being a woman with epilepsy Lisa Zobian Lindahl	7
3	The woman with epilepsy: a historical perspective Orrin Devinsky	17
4	Quality of life issues for women with epilepsy Joyce A. Cramer	35
Part II	Epilepsy diagnosis and treatment	
5	The genetics of epilepsy Melodie R. Winawer and Ruth Ottman	47
6	Epilepsy: epidemiology, definitions, and diagnostic procedures Simon Shorvon and Dominic Heaney	57
7	Antiepileptic drugs and other treatments for epilepsy Jacqueline A. French	68
8	Epilepsy in children and adolescents Patricia Crumrine	77

vi	Contents	
9	Nonepileptic seizures Steven C. Schachter	89
Part III	Hormones and the brain	
10	Brain differences Paula Shear and Rosemary Fama	101
11	Sex hormones and how they act in the brain: a primer on the molecular mechanisms of action of sex steroid hormones Philip A. Schwartzkroin	112
12	Epilepsy and the menstrual cycle Patricia O. Shafer and Andrew G. Herzog	119
13	Menopause and epilepsy Fariha Abbasi and Allan Krumholz	131
Part IV	Health challenges for women with epilepsy	
14	Reproductive health for women with epilepsy Martha J. Morrell	145
15	Sexual dysfunction in epilepsy Martha J. Morrell	152
16	Bone health in women with epilepsy Robert Marcus	164
17	Psychiatric complications in epilepsy Laura Marsh	171
Part V	Family planning, pregnancy, and parenting	
18	Family planning and contraceptive choice Pamela M. Crawford	197
19	Pregnancy risks for the woman with epilepsy Mark Yerby and Yasser Y. El-Sayed	203

vii	Contents	
20	Risks of birth defects in children born to mothers with epilepsy Aline T. Derdiarian and Yasser Y. El-Sayed	215
21	Neurocognitive outcome in children of mothers with epilepsy Kimford J. Meador	222
22	Parenting for women with epilepsy Mimi Callanan	228
Part VI	Living well with epilepsy	
23	The impact of epilepsy on relationships Patricia A. Gibson	237
24	Parenting the daughter with epilepsy Joan Kessner Austin and Janet Austin Tooze	249
25	Safety issues for women with epilepsy Patricia Dean	263
26	Legal issues facing women with epilepsy Jeanne Carpenter	269
27	Work issues and epilepsy Jim Troxell	281
	Appendix The Epilepsy Foundation's Campaign for Women's Health: bringing help and hope to women with epilepsy Elizabeth A. Borda	287
	Index	291

Contributors

Fariha Abbasi, MD

Neurological Center 900 Cox Road Gastonia NC 28054 USA

Janet Austin Tooze, PhD

Biometry Research Group 6130 Executive Boulevard Suite 3131

Bethesda MD 20892 USA

Elizabeth A. Borda

Women and Epilepsy Initiative 4521 Garden City Drive Landover MD 20785

USA

CA 94305

USA

Mimi Callanan, RN, MSN

Department of Neurology and Neurological Sciences Stanford University Medical Center Stanford Hospital 300 Pasteur Drive Stanford

Jeanne Carpenter, JD

McDermott, Will & Emery 600 13th Street, NW Washington DC 20005 USA

Joyce A. Cramer

Yale University School of Medicine VA Connecticut Health Care System 950 Campbell Avenue West Haven CT 06516 USA

Pamela M. Crawford, MD

Department of Neurology Special Centre for Epilepsy York District Hospital Wigginton Road York YO3 7HE England

Patricia Crumrine, MD

Department of Neurology Children's Hospital of Pittsburgh 3705 5th Avenue at DeSoto Street Pittsburgh PA 15213 USA

Patricia Dean, MSN, ARNP

Maimi Children's Hospital Department of Neuroscience

3100 SW 62nd Avenue

USA

Miami FL

Aline T. Derdiarian

California USA

Orrin Devinsky, MD

Department of Neurology

NYU Comprehensive Epilepsy Center

560 First Avenue

Rivergate New York NY 10016 USA

Yasser Y. El-Sayed, MD

Department of Gynecology and Obstetrics

Stanford University Medical Center

Stanford Hospital 300 Pasteur Drive

Stanford CA 94305

Rosemary Fama, PhD

SRI International

333 Ravenswood Avenue

Menlo Park CA 94025 USA

Kerry L. Flynn, MA

Columbia Comprehensive Epilepsy Center

The Neurological Institute 710 West 168th Street

New York NY 10032 USA

Jacqueline A. French, MD

Department of Neurology

Hospital of University of Pennsylvania

3400 Spruce Street Philadelphia PA 19104 USA

Patricia A. Gibson, MSSW

Department of Neurology

Bowman Gray School of Medicine

Wake Forest University Medical Center Blvd Winston-Salem NC 27157 USA

Dominic Heaney, MD

The National Hospital for Neurology and

Neurosurgery

National Society for Epilepsy

Gerrards Cross Chalfont Centre for

Epilepsy

Chalfont St Peter

Buckinghamshire SL9 ORJ

England

Andrew G. Herzog, MD, MSc

Beth Israel Deaconess Medical Center

Harvard Neuroendocrine Unit

330 Brookline Avenue

Boston MA 02215 USA

Joan Kessner Austin, DNS

Indiana University School of Nursing

1111 Middle Drive Indianapolis IN 46202 USA

Allan Krumholz, MD

Department of Neurology

University of Maryland Medical System

22 South Greene Street

Baltimore MD 21201 USA

Lisa Zobian Lindahl

112 Clay Point Colchester VT 05446 USA

Robert Marcus, MD

VA Palo Alto Health Care 3801 Miranda Avenue

Palo Alto CA 94304 USA

Laura Marsh, MD

Department of Psychiatry

Johns Hopkins University School of

Medicine

600 N. Wolfe Street

Baltimore MD 21287 USA

Kimford J. Meador, MD

Department of Neurology Georgetown University Hospital 3800 Reservoir Road, NW Washington DC 20007

USA

Martha J. Morrell, MD

Columbia Comprehensive Epilepsy Center The Neurological Institute 710 W. 168th Street

New York NY 10032 USA

Ruth Ottman, PhD

Columbia University GH Sergievsky Center 630 W. 168th Street

New York NY 10032 USA

Steven C. Schachter, MD

Beth Israel Deaconess Medical

Center

Comprehensive Epilepsy Center

300 Brookline Avenue

Boston MA 02215 USA

Philip A. Schwartzkroin, PhD

Department of Neurological Surgery University of California at Davis

One Shields Avenue

Davis CA 95616 USA

Patricia O. Shafer, RN, MN

Beth Israel Deaconess Medical Center

Comprehensive Epilepsy

Center

300 Brookline Avenue

Boston MA 02215 USA Paula Shear, PhD 4351 Garden City Drive

Department of Psychiatry
University of Cincinnati

MD 20785
Cincinnati

USA

OH 45221

USA Melodie R. Winawer, MD, MS

Columbia University
Simon Shorvon, MD Sergievsky Center

Simon Shorvon, MD Sergievsky Center
The National Hospital for Neurology and 630 W. 168th Street

Neurosurgery New York National Society for Epilepsy NY 10032

Gerrards Cross Chalfont Centre USA

for Epilepsy

Chalfont St Peter Mark Yerby, MD

Buckinghamshire SL9 ORJ North Pacific Epilepsy Research
England 2455 Northwest Marshall Street

England 2455 North
Portland
Jim Troxell OR 97210

Epilepsy Foundation USA

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.

MJM

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.