Disabilities and Health Issues – Bibliography

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AIDS/HIV

Being Positive: The Lives of Men and Women with HIV. Robert Klitzman, Ivan R. Dee, 1997. ISBN 1566631645

The stories of individuals with HIV and their struggles to come to terms with their HIV status.

Encyclopedia of AIDS: A Social, Political, Cultural, and Scientific Record of the HIV Epidemic. Raymond A. Smith, Penguin Books, 2001. ISBN 0140514864

Provides a comprehensive look at AIDS and its effects on society, politics, law, and health and contains information to help increase awareness and preparedness.

The First Year--HIV: An Essential Guide for the Newly Diagnosed. Brett Grodeck & Daniel S. Berger, Marlowe & Company, 2003. ISBN 1569244901

A guide written in accessible and plain terms, specifically for those newly diagnosed with HIV (the virus that causes AIDS), by HIV-positive patient advocate Brett Grodeck who himself has lived with the virus for many years.

The Guide to Living with HIV Infection: Developed at the Johns Hopkins AIDS Clinic. John G. Bartlett & Ann K. Finkbeiner, Johns Hopkins University Press, 2001. ISBN 0801867444

This guide explains how HIV is transmitted, evaluates available treatment and prevention, provides counsel on coping with the emotional effects of the infection, addresses financial and legal concerns, and discusses the latest research.

ALZHEIMER'S DISEASE

The 36-Hour Day: A Family Guide to Caring for Persons With Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life. Nancy L. Mace, Peter V. Rabins, Warner Books, 2001. ISBN 0446610410

Straightforward advice on medical issues, caregiving, behavior, and legal concerns.

Alzheimer's Activities: Hundreds of Activities for Men and Women With Alzheimer's Disease and Related Disorders. B.J. Fitzray, Ravve Productions, Inc., 2001. ISBN 1877810800

Guide for family members and professional caregivers of those with Alzheimer's to identify appropriate activities for various levels of Alzheimer patients. Describes both daily activities and dealing with special occasions.

Alzheimer's Early Stages: First Steps for Family, Friends, and Caregivers. David M. Bennett, Hunter House Publishers, 2003. ISBN 0897933974

Day-to-day tips that medical professionals may not provide for those caring for family members with dementia and Alzheimer's.

<u>Alzheimer's Essentials</u>. Bretton C. Gordeau & Jeffrey G. Hillier, Carma Publishing, 2005. ISBN 0976958104

This book provides basic information on the essentials of caregiving for someone with Alzheimer's.

Marshall's Journey: The Power Of Understanding Alzheimer's. Vailia Dennis, Authorhouse, 2004. ISBN 1418416703

The author shares the story of brother's struggle with Alzheimer's Disease.

<u>Mayo Clinic on Alzheimer's Disease</u>. Ronald C. Petersen, Editor, Kensington Publishing Corporation, 2002. ISBN 1893005224

This book, prepared by Mayo Clinic experts, covers the basics of brain function; the causes, signs, and symptoms of late-life memory loss; how it is diagnosed; the latest in available treatments; and current research on promising new remedies, as well as details about the effects of memory disorders on the ill person, families, and caregivers.

<u>Talking to Alzheimer's: Simple Ways to Connect When You Visit with a Family Member or Friend</u>. Claudia J. Strauss, New Harbinger Publications, 2002. ISBN 1572242701

Practical guide to communicating with a loved one who has Alzheimer's.

AMPUTEE/CONGENITAL LIMB MALFORMATION

<u>Living with a Below-Knee Amputation : A Unique Insight from a Prosthetist/Amputee</u>. Richard Lee Riley, Slack Incorporated, 2005. ISBN 1556426925

A prosthetist of 22 years looks at the entire spectrum of the below knee experience from amputation to rehabilitation, including surgery, pain, postoperative care, therapy, purpose and design of prosthetics, fittings, maintenance and hygiene, and recreation.

Men of Honor. David Robins, Onyx Books, 2000. ISBN 0451409744

A novel based on the life of Carl Brashear as depicted in the motion picture *Men of Honor*. It is the story of the man who, after losing his leg in an accident, became the first African-American Master Chief Navy Diver.

No One's Perfect. Hirotado Ototake, Gerry Harcourt (Translator), Kodansha International, 2000. ISBN 4770027648

Hirotado Ototake, a 24-year-old Japanese man born without arms and legs, recounts the story of his life and explains how, with the support of his family, he coped with disability and adversity.

AUTISM

<u>The Autism Sourcebook : Everything You Need to Know About Diagnosis, Treatment, Coping, and Healing</u>. Karen Siff Exkorn, Regan Books, 2005. ISBN 0060799889

Karen Siff Exkorn shares the techniques and knowledge she used to help improve the life of her son, Jake, who has autism.

Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder, and Other ASDs. Chantel Sicile-Kira & Temple Grandin, Perigee Trade, 2004. ISBN 0399530479

Based on the author's personal and professional experiences, this comprehensive guide covers all aspects of autism conditions, including Asperger's Syndrome and Pervasive Developmental Disorder.

Emergence : Labeled Autistic. Temple Grandin & Margaret M. Scariano, Warner Books, 1996. ISBN 0446671827

This book is written by a woman who came to understand her own autism and became a successful designer of livestock equipment.

Nobody Nowhere: the Extraordinary Autobiography of an Autistic. Donna Williams. Harper Paperbacks. 1994. ISBN 0380722178

Autobiography of an Australian-born woman who, after a childhood of abuse and isolation, was diagnosed with autism in adulthood and was ultimately able to graduate from college and become an advocate for others.

The Ride Together: A Brother and Sister's Memoir of Autism in the Family. Paul & Judy Karasik, Washington Square Press, 2003. ISBN 0743423364

A sibling's viewpoint of growing up with a brother with autism.

Soon Will Come the Light: A View from Inside the Autism Puzzle. Thomas A. McKean, Future Horizons, 1994. ISBN 1885477112

Written by a man with autism, this book describes the confusion of his childhood, his institutionalization, and his emergence into adulthood. This book won the Autism Society of America's "Literary Achievement Award."

<u>Ten Things Every Child With Autism Wishes You Knew</u>. Ellen Notbohm, Future Horizons, 2005. ISBN 1932565302

A parent, an autism columnist, and a contributor to numerous parenting magazines defines the top ten issues of children with autism.

<u>There's a Boy in Here</u>. Judy & Sean Barron, Future Horizons, 2002. ISBN 1885477864

The story of the Barrons' long fight to "reach" their autistic son and help him live a normal life.

BLIND/VISUALLY IMPAIRED

On Sight and Insight. John Hull, Oneworld Publications, 1997. ISBN 1851681418

The author tells what it is like, emotionally, to go blind. He talks about all aspects of blindness, but the focus on the book is to share how it affected his emotions and his spirituality.

<u>Sight Unseen</u>. Georgina Kleege, Yale University Press, 1999. ISBN 0300076800

Novelist, essayist, and translator Kleege describes how she came to terms with losing her sight after being diagnosed with macular degeneration at the age of eleven.

<u>Touching the Rock: An Experience of Blindness</u>. John Hull, Vintage, 1992. ISBN 067973547X

A university lecturer, who had lived with sight problems from the age of 13, shares the difficult experience of adjusting to loss of vision at the age of 36.

CANCER

<u>Cancer: 50 Essential Things to Do</u>. Greg Anderson, Plume Books, 1999. ISBN 0452280745

Information on recently improved medical treatment options, updated cancer research, and Internet resources.

The Chemotherapy & Radiation Therapy Survival Guide (Chemotherapy and Radiation Therapy Survivor's Guide). Judith McKay & Nancee Hirano, New Harbinger Publications, 1998. ISBN 1572240709

Covers basics about the treatment, how to deal with side-effects, getting good nutrition, support, and bone-marrow transplants.

The Human Side of Cancer: Living with Hope, Coping with Uncertainty. Jimmie Holland & Sheldon Lewis, Harper, 2001. ISBN 006093042X

Explores different styles of coping emotionally, as well as strategies for dealing with physical issues.

When Life Becomes Precious: The Essential Guide for Patients, Loved Ones, and Friends of Those Facing Serious Illnesses. Elise Babcock, Bantam, 1997. ISBN 0553378694

This book includes specific tips for cultivating a support network, avoiding caregiver burnout, managing fear and anger, finding the best doctors and other health care professionals to plan treatment, preparing for hospital visits, and, for the patient, dealing with cancer when at the workplace.

CAREGIVING

<u>American Medical Association Guide to Home Caregiving</u>. Angela Perry, Wiley, 2001. ISBN 0471414093

This volume provides the information on taking the best possible care of an elderly, ill, or disabled person in a home setting. Written by experts from the American Medical Association, the book explains such essentials as how to arrange furniture, give medications, maintain hygiene, monitor symptoms, deal with incontinence, and provide emotional support.

<u>The Caregiver's Essential Handbook : More than 1,200 Tips to Help You Care for and Comfort the Seniors in Your Life</u>. Sasha Carr, Sandra Choron, McGraw-Hill, 2003. ISBN 0071395199

Useful tips for meeting the changing needs of your loved one, such as getting documents and financial issues organized, creating a safe environment, dealing with health and emotional issues, and navigating the medical care system.

The Comfort of Home: An Illustrated Step-By-Step Guide for Caregivers, 2nd Edition. Maria M. Meyer, Paula Derr, Care Trust Publications, 2002. ISBN 0966476735

Takes the reader through all the steps of home care, such as making the home safe and comfortable for people with special needs, handling everyday activities like toileting, bathing, and wheelchair transfers, providing proper nutrition, avoiding infections and illnesses, communicating with health care professionals to get needed services, understanding end-of-life health care documents, and avoiding caregiver burnout.

The Fearless Caregiver: How to Get the Best Care for Your Loved One and Still Have a Life of Your Own (Capital Cares). Gary Barg, Capital Books, 2003. ISBN 1931868565

Addresses issues ranging from wills and powers-of-attorney, to practical tips for dealing with disabilities, to long term care options, to battling stress and depression.

<u>Helping Yourself Help Others : A Book for Caregivers</u>. Rosalynn Carter, Susan Ma Golant, Three Rivers Press, 1995. ISBN 0812925912

The Rosalynn Carter Institute for Human Development was created by the former First Lady to study the caregiving process and find new ways to assist caregivers. This book offers tips for dealing with health professionals, finding a support group (or starting one of your own), recognizing signs of caregiver burnout, and techniques to make life more satisfying for both caregiver and care recipient.

CEREBRAL PALSY

<u>Cerebral Palsy: A Complete Guide for Caregiving</u>. Freeman Miller & Steven J. Bacharach, Johns Hopkins University Press, 1998. ISBN 0801859492

Written by a team of experts associated with the Cerebral Palsy Program at the Alfred I. duPont Institute, this book addresses the complexities and uncertainties of cerebral palsy while providing information about everything that anyone might ever need to know about the condition.

<u>Children With Cerebral Palsy: A Parents' Guide</u>. Elaine, Geralis, Editor, Woodbine House, 1998. ISBN 0933149824

This classic primer for parents, written by a team of medical professionals, provides a complete spectrum of information and advice about cerebral palsy and its effect on their child's development and education.

<u>From Where I Sit: Making My Way With Cerebral Palsy</u>. Shelley Nixon, Scholastic, 1999. ISBN 059039584X

A straightforward look at a young woman with CP looking back on her childhood and adolescence.

<u>I Can't Walk but I Can Crawl : A Long Life with Cerebral Palsy</u>. Joan Ross, Paul Chapman Educational Publishing, 2005. ISBN 1412918723

Joan Ross is an adult with cerebral palsy who shares the story of a childhood before mandatory inclusion, her development as a teenager, and her adult life.

DEAF/HARD OF HEARING

<u>Deaf in America: Voices from a Culture</u>. Humphries & Padden, Harvard University Press, 1990. ISBN 0674194241

The authors, both of whom are deaf, maintain that Deaf people have an authentic language and culture. Among the topics covered: the difference between being "deaf" (lowercase) and "Deaf" (capitalized), the origins of American Sign Language, Deaf theater and poetry, and the work of Deaf filmmaker Charles Krauel, controversies within the Deaf world, and more.

<u>Deaf President Now!: The 1988 Revolution at Gallaudet University</u>. Christiansen & Barnartt, Gallaudet University Press, 1995. ISBN 1563680351

The story of the 1988 student uprising at Gallaudet University, which resulted in the appointment of the school's first deaf president.

<u>Deaf World: A Historical Reader and Primary Sourcebook.</u> Louis Bragg, Editor, New York University Press, 2001. ISBN 0814798535

A collection of essays, speeches, articles, and short stories which provide a self-portrait of the American deaf community. Among the authors are advocates such as Edward Miner Gallaudet, founder of the university bearing his name, deaf playwright Shanny Mow, and a deaf silent film consultant.

Enforcing Normalcy: Disability, Deafness, and the Body. Lennard J. Davis, Verso, 1995. ISBN 1859840078

A historical and cultural perspective on deafness and society's need to judge individuals by their ability to conform to norms.

<u>Everyone Here Spoke Sign Language: Heredity Deafness on Martha's Vineyard</u>. Nora E. Groce, Harvard University Press, 1988. ISBN 067427041X

The story of a unique society that emerged on the Massachusetts island of Martha's Vineyard in the 19th century. One quarter of the population was genetically deaf, resulting in a culture in which deafness was not regarded as a disability.

A Loss for Words: The Story of Deafness in a Family. Lou Ann Walker, Harper Perennial, 1987. ISBN 0060914254

The story of a hearing child raised by deaf parents, detailing the special challenges faced by deaf people in a hearing world.

<u>The Radical Lives of Helen Keller</u>. Kim E. Nielsen, New York University Press, 2004. ISBN 0814758134

A political biography of Helen Keller, which explores her as a complex and often controversial woman who was highly involved in issues that affected people with disabilities, but who advocated for women's suffrage, was a member of the socialist party, and who was a proponent of oralism over sign language for the deaf communication.

<u>Train Go Sorry: Inside a Deaf World.</u> Leah Hager Cohen, Vintage, 1995. ISBN 0679761659

A portrait of a New York City school for the deaf, and the issues facing the deaf community. Analyzes the debate over mainstreaming deaf students, and the value of oralism and whether new cochlear implants rob the deaf of their culture.

DIABETES

1001 Tips for Living Well With Diabetes: Firsthand Advice That Really Works. Judith H. McQuown and Harry Gruenspan, Marlowe & Company, 2004. ISBN 1569244359

Help for parents in coping with a child's type 1 diabetes diagnosis. Addresses medical and dietary issues, dealing with schools, and even becoming comfortable with allowing a child to participate in recreation.

American Diabetes Association Complete Guide to Diabetes: The Ultimate Home Reference from the Diabetes Experts. The American Diabetes Association. 2002. ISBN 1580401619

This guide offers comprehensive and reliable information on preventing diabetesbased complications, achieving blood sugar control, handling diabetes-related emergencies, using a meter, using insulin pumps, the role of nutrition and exercise in diabetes management, sexuality and diabetes, coping with diabetesimposed limitations, even family life, travel, insurance, and pregnancy as they are affected by diabetes.

<u>Diabetes for Dummies</u>. Alan L. Rubin, For Dummies, 2004. ISBN 0764568205

The basics on understanding and living with diabetes.

<u>The First Year Type 2 Diabetes: An Essential Guide for the Newly Diagnosed.</u> Gretchen Becker, Marlowe & Company, 2001. ISBN 1569245460

A basic guide for those newly diagnosed, providing information on management and the latest research.

<u>Type 1 Diabetes: A Guide for Children, Adolescents, Young Adults--and Their Caregivers, Third Edition</u>. Ragnar Hanas & Stuart Brink, Marlowe & Company, 2005. ISBN 1569243964

A comprehensive guide to living a healthy lifestyle with a type 1 diabetes diagnosis and understanding treatment options. Complete with charts and diagrams.

DISABILITY STUDIES/CULTURE

Bending Over Backwards: Essays on Disability and the Body. Michael Berube, New York University Press, 2002. ISBN 0814719503

An examination of the issues concerning the relationship between disability and normality in today's social and political climate.

The Body Silent: The Different World of the Disabled. Robert F. Murphy, W. W. Norton & Company, 2001. ISBN 0393320421

Anthropologist Robert Murphy uses his own experience of quadriplegia, caused by a spinal tumor, to explore issues of identity and society's fears and misconceptions about disability.

<u>Claiming Disability: Knowledge and Identity (Cultural Front Series).</u> Simi Linton, New York University Press, 1998. ISBN 0814751342

An examination of the emerging field of Disability Studies, and the struggle towards a more inclusive society.

<u>The Disability Rights Movement: From Charity to Confrontation</u>. Doris Zames Fleischer and Frieda Zames, Temple University Press, 2001. ISBN 1566398126

A detailed history of the struggle for disability rights in the United States.

<u>The Disability Studies Reader</u>. Lennard J. Davis, Routledge, 1997. ISBN 041591471X

A collection of essays which draws together experts in cultural studies, literary criticism, sociology, biology, and the visual arts to explore the issue of disability and society.

<u>Extraordinary Bodies.</u> Rosemary Garland Thomson, Columbia University Press, 1996. ISBN 0231105177

An examination of how the figure of the disabled body has been used in literature in different periods as a marker or boundary line for defining what the "normal" body is or should be. The author contends that the disabled figure operates to displace anxiety from more "normal" people, and in the process shows how what we consider to be normal functioning changes across historical periods and cultures.

FDR's Splendid Deception: The Moving Story of Roosevelt's Massive Disability-And the Intense Efforts to Conceal It from the Public. Hugh Gregory Gallagher. Vandamere Press. 1999. ISBN 0918339502

The story of the masking of the full extent of President Franklin Delano Roosevelt's mobility impairment as a result of polio.

<u>Health, Illness, and the Social Body</u>. Peter E. S. Freund & Meredith B. McGuire, Prentice Hall, 1999. ISBN: 013098230X

A critical, holistic interpretation of health, illness, and human bodies that emphasizes power as a key social-structural factor in health and in societal responses to illness.

A History of Disability (Corporealities: Discourses of Disability). Henri-Jaxques Stiker, University of Michigan Press, 2000. ISBN 047208626X

This book traces the history of western cultural responses to disability, from ancient times to the present.

Make Them Go Away: Clint Eastwood, Christopher Reeve, and the Case Against Disability Rights. Mary Johnson, Avocado Press, 2003. ISBN 097211890X

Mary Johnson explores what she feels are flaws in the Americans with Disabilities Act which are leading to its misinterpretation and misapplication. From its name to the fact that it is enforceable only by lawsuit, the author demonstrates how the ADA puts people with disabilities in an adversarial position against non-disabled citizens.

<u>Missing Pieces: A Chronicle of Living with a Disability</u>. Irving Kenneth Zola, Temple University Press, 1983. ISBN 1592132448

The author, who has a physical disability and uses a wheelchair, shares his experience of liberation and community while living in the barrier-free Dutch village of Het Dorp.

The New Disability History: American Perspectives (History of Disability). Longmore & Umansky, Editors, 2001. ISBN 0814785646

The editors bring together the contributions of 14 academics from a variety of disciplines to create a broader and more complex understanding of the omission of disability issues from mainstream history.

No Pity: People with Disabilities Forging a New Civil Rights Movement. Joseph P. Shapiro, Times Books, 1993. ISBN 0812924126

An engaging and comprehensive history of the social and political activism that ultimately let to the passage of the Americans with Disabilities Act.

Nothing About Us Without Us: Disability Oppression and Empowerment. James I. Charlton, University of California Press, 2000. ISBN 0520224817

An analysis of the roots of disability oppression which examines its similarities to and differences from racism, sexism, and colonialism.

Ordinary Lives. Irving Kenneth Zola, Editor, Applewood Books, 1982. ISBN: 0918222362

A collection of stories by men and women who have experienced, first hand, a chronic disease or a disability.

The Rejected Body: Feminist Philosophical Reflections on Disability. Susan Wendell, Routledge, 1996. ISBN 0415910471

An exploration, within a feminist framework, of society's perceptions of disability.

<u>Stigma: Notes on the Management of a Spoiled Identity</u>. Erving Goffman, Touchstone, 1986. ISBN 0671622447

An exploration of the sense of self that an individual with a disability develops in response to society's attitudes.

<u>Voices from the Edge: Narratives About the Americans With Disabilities</u> <u>Act</u>. Rogers M. Smith, Oxford University Press, 2003. ISBN 0195156870

This book seeks to challenge the mindset of those who would deny equal protection to those with disabilities, while providing informative analysis of the intent and application of the ADA for those who wish to learn more about disability rights.

Why I Burned My Book and Other Essays on Disability (American Subjects). Paul K. Longmore, Temple University Press, 2003. ISBN 1592130240

The author puts forth an argument for establishing disability as a category of social, political, and historical analysis in much the same way that race, gender, and class already have been. His essays search for the often hidden pattern of systematic prejudice and probe into the institutionalized discrimination that affects the one in five Americans with disabilities.

DWARFISM

<u>Dwarfs Don't Live in Doll Houses</u>. Angela M. Van Ettan, Adaptive Living, 1988. ISBN 0945727801

An examination of how a person of short stature relates to the world.

<u>Dwarfism: Medical and Psychosocial Aspects of Profound Short Stature.</u> Betty M. Adelson & Judith G. Hall, Johns Hopkins University Press, 2005. ISBN 0801881226

As well as listings of dwarfism diagnoses, treatments, and organizations, this book provides personal profiles and divergent opinions of doctors, dwarfs, and parents throughout the world and through the history, and addresses both medical and social issues.

<u>Little People: Learning to See the World Through My Daughter's Eyes</u>. Dan Kennedy, Rodale Books, 2003. ISBN 1579546684

An average-size father's memoir and social commentary on meeting the challenges of raising a daughter with dwarfism.

<u>The Lives of Dwarfs: Their Journey from Public Curiosity Toward Social Liberation</u>. Betty M. Adelson, Rutgers University Press, 2005. ISBN 0815355484

Throughout history, most human cultures have treated dwarfs as oddities or as objects of exploitation. This book chronicles the emergence of cultural identity among "little people", and their progress towards ending stigma and gaining opportunities.

Walking Tall: Overcoming Inner Smallness, No Matter What Size You Are. Peggy O'Neill, Visioneering Group, 2002. ISBN 097101700X

3 foot 8 inch tall author Peggy O'Neill shares advice for people of all sizes on enjoying life and overcoming fear and low self-esteem.

EPILEPSY/SEIZURE DISORDER

<u>The Brainstorms Woman: Epilepsy in Our Lives</u>. Schachter, Krishnamurty, & Cantrell, Lippincott, Williams & Wilkins, 2000. ISBN 0781727499

Accounts from women on how epilepsy impacts the more intimate and important parts of their lives. Offers descriptions of how seizures may fluctuate with changes in female hormones, over the menstrual cycle, and at menopause.

Epilepsy: 199 Answers a Doctor Responds to His Patients' Questions. Andrew N. Wilner, MD, Demos Medical Publishing, 2003. ISBN 1888799706

Consumer text addresses the most common questions asked by those with epilepsy. Written in common language, text discusses what epilepsy is, the many treatment options, various medications available and their side effects, and how to deal with day-to-day living with epilepsy.

<u>Epilepsy: Patient and Family Guide</u>. Orrin Devinsky, MD, F.A. Davis Company, 2001. ISBN 080360498X

This guide for adults with epilepsy and for parents of children with the disorder explains the nature and diversity of seizures, the risks and benefits of the various antiepileptic drugs, and medical and surgical therapies.

Epilepsy and Seizures: Everything You Need to Know (Your Personal Health). Donald F. Weaver, Firefly Books Ltd., 2001. ISBN 1552094529

The director of the epilepsy clinic at Queen's University in Kingston, Ontario, clearly and succinctly summarizes the current medical knowledge about epilepsy from diagnosis to treatment.

<u>Epilepsy: You're Not Alone</u>. Stacey Chillemi, Writer's Showcase Press, 2001. ISBN 0595195261

This is a self-help book that teaches people with epilepsy how to live healthy and productive lives. The book shares encouraging stories and gives readers a workable program for coping with the disorder enabling them to overcome obstacles.

Growing Up With Epilepsy: A Practical Guide for Parents. Lynn Bennett Blackburn, Demos Medical Publishing, 2003. ISBN 1888799749

This book was developed to provide parents of children with epilepsy with an "owner's manual" to help them negotiate the unique challenges that this disorder presents.

<u>Partial Seizure Disorders: Help for Patients and Families.</u> Mitzi Waltz, Patient Centered Guides, 2001. ISBN 0596500033

Partial Seizure Disorders helps patients and families learn how to get an accurate diagnosis, explore therapeutic interventions, and deal with issues such as school difficulties, employment, driving, and advocacy.

Seized. Eve LaPlante, Backinprint.com, 2000. ISBN 0595094317

In this major study, freelance journalist LaPlante, who interviewed scores of patients and doctors, explores Temporal Lobe Epilepsy, a disease that may affect between one and two million Americans.

<u>Seizures and Epilepsy in Childhood: A Guide</u>. John M. Freeman, Eileen P.G.Vining, Diana J. Pillas, Johns Hopkins University Press, 2002. ISBN 0801870518

This award-winning book is the standard resource for parents in need of comprehensive medical information about their child with epilepsy, and includes information on drugs, diet, surgical treatments, insurance issues, and complementary and alternative therapies.

FIBROMYALGIA/CHRONIC FATIGUE

<u>Chronic Fatigue Syndrome Treatment : A Treatment Guide (Quality Medical Home Health Library).</u> Erica F. Verrillo & Lauren M. Gellman, St. Martin's Griffin, 1998. ISBN 0312180667

A self-help manual including personal histories, a symptom and treatment dictionary, and alternative therapies.

The Doctor's Guide to Chronic Fatigue Syndrome: Understanding, Treating, and Living With Cfids. David Sheffield Bell, Addison Wesley Publishing Company, 1995. ISBN 0201407973

A physician's primer on Chronic Fatigue/Immune Dysfunction Syndrome (CFIDS).

<u>Facing and Fighting Fatigue : A Practical Approach</u>. Benjamin Natelson, Yale University Press, 1998. ISBN 0300074018

A professor of neurosciences and director of the New Jersey Chronic Fatigue Syndrome Center shares his clinical and research experience. He discusses stress and depression and emphasizes, above all, the need for a knowledgeable and sympathetic physician.

<u>The First Year--Fibromyalgia: An Essential Guide for the Newly Diagnosed</u> (<u>The First Year Series</u>). Claudia Craig Marek, Marlowe & Company, 2003. ISBN 1569245215

This book guides readers through their first seven days following diagnosis, then the next three weeks of their first month, and finally the next eleven months of their first year—to provide answers and advice that will help everyone newly diagnosed with fibromyalgia come to terms with their condition and the lifestyle changes that accompany it.

<u>Parting the Fog: The Personal Side of Fibromyalgia/Chronic Fatigue Syndrome</u>. Sue Jones, LaMont Publishing, 2001. ISBN 0971217505

A candid, first person account of what it is like to experience fibromyalgia/chronic fatigue syndrome.

<u>Stricken: Voices from the Hidden Epidemic of Chronic Fatigue Syndrome.</u> Peggy Munson, Haworth Press, 2000. ISBN 0789008955

A collection of personal accounts from sufferers of chronic fatigue immune dysfunction syndrome, or CFIDS. This book explores the complex social and political dynamics surrounding the disorder.

MENTAL ILLNESS

<u>The Burden of Sympathy: How Families Cope With Mental Illness.</u> David A. Karp, Oxford University Press, 2001. ISBN 0195152441

A chronicle of the experiences of the family members of the mentally ill, and how hey draw "boundaries of sympathy" to avoid being engulfed by the day-to-day suffering of a loved one. The author reveals similarities that caregivers share in trying to cope with their own feelings and with the complexities of the mental health system.

<u>The Day the Voices Stopped: A Schizophrenic's Journey from Madness to Hope</u>. Ken Steele & Claire Berman, Basic Books, 2002. ISBN 0465082270

A nationally known spokesperson for the mentally ill shares the story of his decades-long struggle with schizophrenia and his remarkable recovery.

<u>I am Not Sick I Don't Need Help!</u> Xavier Amador, Vida Publishers, 2000. ISBN 0967718902

Lack of insight in people with schizophrenia and bipolar disorder is the major cause of many of the worst aspects of their illness. This book prescribes detailed interventions to help families and therapists deal with lack of insight and the many difficulties it causes people with major mental illness.

<u>Speaking of Sadness: Depression, Disconnection, and the Meanings of Illness.</u> David A. Karp, Oxford University Press, 1997. ISBN 0195113861

The author explores the varied effects of depression on fifty different individuals.

<u>Telling is Risky Business: The Experience of Mental Illness Stigma</u>. Otto F. Wahl, Rutgers University Press, 1999. ISBN 0813527244

People with mental illness share their stories of struggling to manage their illnesses while dealing with discrimination and stereotypes.

<u>Transforming Madness: New Lives for People Living with Mental Illness.</u> Jay Neugeboren, University of California Press, 2001. ISBN 0520228758

An examination of the revolution that is taking place in the care and treatment of the mentally ill. While side effects of newer medications are becoming less debilitating, recovery programs, peer support centers, and community treatment options are making it possible for those with severe mental illness to participate more fully in the mainstream community.

<u>The Quiet Room: A Journey Out of the Torment of Madness.</u> Lori Schiller & Amanda Bennett, Warner Books, 1996. ISBN 0446671339

Author Schiller was 17 when she first heard the "voices" that would take over her life. She describes her years of mental illness, substance abuse, and eventual stabilization through proper treatment and medication.

MENTAL RETARDATION/COGNITIVE DISABILITY

Inventing the Feeble Mind: A History of Mental Retardation in the United States (Medicine and Society). James E. Trent, University of California Press, 1994. ISBN 0520082435

A history of popular views of mental retardation which documents society's changing perceptions of the "feebleminded", recounting a history of institutionalization, sterilization, neglect and abuse.

<u>Mental Retardation in America: A Historical Reader (The History of Disability).</u> Noll & Trent, Editors, New York University Press, 2004. ISBN 0814782485

A chronicle of the history of mental retardation, its treatment and labeling, and its representations and ramifications within the changing economic, social, and political context of America.

Riding the Bus with My Sister: A True Life Journey. Rachel Simon, Plume, 2003. ISBN 0452284554

The author accepts her mildly mentally retarded sister's invitation to spend a year riding the city busses with her, and gains a greater appreciation of her sister's challenges and choices.

<u>The State Boys Rebellion</u>. Michael D'Antonio, Simon & Schuster, 2004. ISBN 0743245121

Pulitzer Prize-winning journalist D'Antonio's account of the indiscriminate institutionalization of people with mental retardation during the middle decades of the last century. D'Antonio tells the story of the 1957 uprising in the Walter E. Ferdinand School for the Feebleminded in Massachusetts by a group of young men who were eventually able, with the help of sympathetic outsiders, to free themselves of their involuntary confinement and its abuses.

MULTIPLE SCLEROSIS

As For Tomorrow, I Cannot Say: 33 Years with Multiple Sclerosis. Diana Neutze, New Paradigm Books, 2002. ISBN 1892138069

A New Zealander's personal account of living for three decades with a diagnosis of Multiple Sclerosis.

<u>Climbing Higher</u>. Montel Williams, New American Library, 2004. ISBN 0451211596

Montel Williams, a decorated former Naval intelligence officer and Emmy Awardwinning talk show host, was diagnosed with multiple sclerosis after being baffled by symptoms for twenty years. This is his story of learning to deal with the disease and of becoming a spokesperson for people with MS.

Fall Down, Laughing: How Squiggy Caught Multiple Sclerosis and Didn't Tell Nobody. David Lander, Tarcher, 2000. ISBN 1585420522

In the summer of 1999, actor David Lander of *Laverne and Shirley* revealed publicly that he has multiple sclerosis. This book documents, with humor, his experiences with his condition.

<u>The First Year-Multiple Sclerosis: An Essential Guide for the Newly Diagnosed (The First Year Series).</u> Margaret Blackstone, Marlowe & Company, 2002. ISBN 1569245223

As a "patient-expert," the author guides those newly diagnosed step-by-step through their first year with MS. She provides illustrative charts and tables, crucial information about the nature of the disease, treatment options, diet, exercise, social concerns, emotional issues, networking with others, and much more.

<u>Life on Cripple Creek: Essays on Living With Multiple Sclerosis.</u> Dean Kramer, Demos Medical Publishing, 2002. ISBN 1888799684

The author presents his observations of the emotional aspects of living with the disease.

<u>Multiple Sclerosis Q&A: Reassuring Answers to Frequently Asked</u> <u>Questions</u>. Beth Ann Hill, Avery Publishing Group, 2003. ISBN 1583331743

Drawing from the latest scientific information and from the author's personal experience, this text discusses the symptoms, tests, medical terminology, traditional and complementary treatment options, and lifestyle changes associated with multiple sclerosis.

Waist-High in the World: A Life Among the Nondisabled. Nancy Mairs, Beacon Press, 1997. ISBN 0807070874

A collection of essays on the author's insights into the experience of living with Multiple Sclerosis.

PARENTING

<u>Changed by a Child</u>. Barbara Gill, Main Street Books, 1998. ISBN 0385482434

The author's son has Down Syndrome, and she provides brief meditations and passages about the challenges, hopes, and other feelings and experiences of parents who have children with disabilities.

Reflections from a Different Journey: What Adults with Disabilities Wish All Parents Knew. Stanley Klein & John Kemp, McGraw-Hill, 2004. ISBN 0071422692

Forty stories offering inspiration and advice, written by successful adults who grew up with disabilities.

<u>Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child With a Disability</u>. Robert A. Naseef, Brookes Publishing Company, 2001. ISBN 1557665354

This book illustrates the impact that a child's disability has on the entire family, and helps the reader learn about resources, such as support groups, for working through complex emotions and learning about techniques for communicating effectively with professionals.

A Special Kind of Love: For Those Who Love Children With Special Needs. Susan Titus Osborn & Janet Lynn Mitchell, Broadman & Holman Publishers, 2004. ISBN 0805427279

This book is written for families who live with children with disabilities on a dayby-day basis.

You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children With Disabilities. Kim Schive & Stanley D. Klein, Editors, Kensington Publishing Corporation, 2001. ISBN 1575665603

A collection of narratives from all over the country, offering encouragement and information, by parents of children with special needs.

PARKINSON'S DISEASE

300 Tips for Making Life with Parkinson's Disease Easier. Shelly Peterman Schwarz, Demos Medical Publishing, 2002. ISBN 188879965X

Consumer text filled with tips, techniques, and shortcuts the author learned from her personal experience and from the people around her. Discusses saving time and energy, becoming more organized, and being independent.

<u>Parkinson's Disease: A Complete Guide for Patients and Families.</u> William J. Weiner, Lisa M. Shulman, Anthony E. Lang, Johns Hopkins University Press, 2001. ISBN 0801865565

This book presents known facts and clarification about this degenerative neurological disease. Physical, behavioral, and psychiatric signs and symptoms exhibited during mild, moderate, and advanced stages of the disease are examined, as are diseases that can mimic Parkinson's.

<u>Parkinson's Disease & the Art of Moving</u>. John Argue, New Harbinger Publications, 2000. ISBN 1572241837

Over 100 photographs illustrate exercises derived from yoga and t'ai chi techniques; and theater movement skills show readers how to cope as gracefully as possible with the loss of coordination that Parkinson's patients experience

SEXUALITY & DISABILITY

Enabling Romance: A Guide to Love, Sex, and Relationships for People with Disabilities (and the People who Care About Them). Ken Kroll, No Limits Communication, 2001. ISBN 0971284202

In the tradition of *The Joy of Sex*, this book candidly explores shattering stereotypes, creative sexual variations, building self-esteem, reproduction and contraception, and information on issues specific to several kinds of disabilities.

<u>Sexuality After Spinal Cord Injury: Answers to Your Questions</u>. Stanley H. Ducharme & Kathleen M. Gill, Brookes Publishing Company, 1996. ISBN 1557662657

A basic resource for people with SCI and those with whom they have intimate relationships, set up in question and answer format.

<u>Sexuality and Disability</u>. Maddie Blackburn, Butterworth-Heinemann, 2002. ISBN 0750622520

This book is intended to increase professional awareness and knowledge of the complex issues concerning sexuality and disability. Provides practical advice and tips for professionals supporting and advising people with disabilities. It covers such issues as body image, self-esteem, genetics, continence, abuse, legal matters, and ethics.

<u>Sexuality: Your Sons and Daughters With Intellectual Disabilities</u>. Karin Melberg Schwier & David Hingsburger, Brookes Publishing Company, 2000. ISBN 1557664285

A guide for parents of a son or daughter of any age or with any kind of disability. It provides practical information about sexuality and sexual development with humor and with ways for parents to deal with the topic comfortably and creatively.

The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain and Illness. Cory Silverberg, Miriam Kaufman, Fan Odette, Cleis Press, 2003. ISBN 1573441767

A resource to help people with disabilities think about themselves as sexual beings. It encompasses a wide range of sexual options and also gives information about sex-related topics (such as communication).

SPINA BIFIDA

<u>Children With Spina Bifida: A Parent's Guide (The Special Needs Collection).</u> Marlene Lutkenhoff, Woodbine House, 1999. ISBN 0933149603

This book addresses issues parents will face, from prenatal diagnosis to adulthood legal issues, education, health concerns, treatments, therapies, and causes. It includes an extensive Resource Guide.

<u>Living with Spina Bifida : A Guide for Families and Professionals.</u> Adrian Sandler, MD, University of North Carolina Press, 2004. ISBN 0807855472

Pediatrician Adrain Sandler has written a handbook that addresses patients' biopsychosocial and developmental needs from birth through adolescence and into adulthood.

SPINAL CORD INJURY

<u>Don't Worry, He Won't Get Far on Foot</u>. John Callahan, Vintage, 1990. ISBN 0679728244

Cartoonist Callahan gives a humorous, uncensored account of his life as a quadriplegic and recovering alcoholic.

<u>From There to Here: Stories of Adjustment to Spinal Cord Injury</u>. Karp & Klein, No Limits Communication, 2004. ISBN 0971284229

The personal stories of forty-five individuals who share their experiences of learning to adjust to and live with spinal cord injury.

<u>Moving Violations: War Zones, Wheelchairs, and Declarations of</u> <u>Independence</u>. John Hockenberry, Hyperion, 1996. ISBN 0786881623

News correspondent John Hockenberry, who became a paraplegic after a 1976 car accident, shares stories of what it's like to report on events around the world from a wheelchair.

<u>Still Lives: Narratives of Spinal Cord Injury</u>. Jonathan Cole, MIT Press, 2004. ISBN 0262033151

Author Jonathan Cole presents the narratives of twelve people with spinal cord injuries whom he has asked the simple question of what it is like to live without sensation and movement of the body. He discovers that there is no single or simple answer.

TRAUMATIC BRAIN INJURY

<u>Cracked: Recovering after Traumatic Brain Injury.</u> Lynsey Calderwood, Jessica Kingsley Publishers, 2003. ISBN 18431006657

At 14 the author was in an accident which left her physically unharmed but destroyed her memory. Her book explores her journey through loss of identity, depression, and eating disorders, and addresses the emotional and social issues that are a part of brain injury.

<u>Crooked Smile: One Family's Journey Toward Healing</u>. Lainie Cohen, Ecw Press, 2004. ISBN 1550225731

Within one year, a family copes with one son's traumatic brain injury, a daughter's diagnosis with a degenerative muscular condition, another son's substance abuse, and the death of a grandparent. A resource for families coping with trauma and loss.

<u>I Had Brain Surgery, What's Your Excuse</u>. Suzy Becker, Workman Publishing Company, 2003. ISBN 0761124780

Cartoonist and writer Becker (*All I Need to Know I Learned from My Cat*) uses humor to document her diagnosis of a brain tumor and the subsequent arduous process of recovery from brain surgery.

Objects in the Mirror Are Closer Than They Appear: Inside Brain Injury. Sol Mogerman, People with Disability Press, 2001. ISBN 0595209424

Autobiography of a musician who incurred a brain injury when his car was hit by a drunk driver in 1985.

Over My Head: A Doctor's Own Story of Head Injury from the Inside Looking Out. Claudia L. Osborn, Andrews McMeel Publishing, 2000. ISBN 0740705989

The autobiography of a 45-year-old doctor who must come to terms with her loss of identity and independence, and who has to rebuild her life, after a brain injury.

Where is the Mango Princess? Cathy Crimmins, Vintage, 2001. ISBN 0375704426

Following her husband's traumatic brain injury in a boating accident, the author must cope with his lengthy and complex recovery, and ultimate personality transformation.