



2023
EDITION

MULTIPLE SCLEROSIS

QUALITY HEALTH RELATED INFORMATION CAREFULLY SELECTED BY YOUR LIBRARIES

 **Biblio-
Santé**



Better informed to live better.

ABOUT

Biblio-Santé is a program of the Quebec Public Library Association. The ABPQ is made up of 182 member municipalities and corporations, for a total of 320 autonomous libraries. Biblio-Santé is available in more than 660 participating public libraries as well as associated health libraries throughout Quebec. Visit our website to see if your library participates in the program.

ACKNOWLEDGMENTS

Biblio-Santé is an initiative of the Charlemagne, L'Assomption and Repentigny libraries that was started under the name Biblio-Aidants. The Quebec Public Library Association would like to thank these three cities for allowing it to extend the program to the rest of Quebec by transferring the copyright.

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VISIT OUR WEBSITE

You will find all of the Biblio-Santé booklets and additional information.

bibliosante.ca

The information provided does not replace a diagnosis or medical examination by a physician or qualified health professional. The content of this booklet was verified in the spring of 2023 and will be updated on an annual basis.

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HOW DO WE SELECT THE INFORMATION?

Each document for inclusion in the Biblio-Santé thematic booklets is evaluated with impartiality, based on Librarianship practices in place in public libraries, using various general selection criteria.

First, the booklets are carefully designed to primarily meet the needs and interests of health system users and caregivers. Every title is evaluated according to relevance and quality of its content for the general public, in the Quebec context. If of equal value, Quebec materials are always preferred. The credibility and reputation of the author, creator, illustrator, publisher or producer are also of great importance. Furthermore, special attention is given to the timeliness and long-term relevance of the subject as well as the accuracy of the information.

With regard to documentaries, works by health professionals (doctors, nurses, occupational therapists, psychologists, etc.) are given preference. However, titles based on lay or experiential knowledge are not rejected outright, especially those involving support by a caregiver.

Finally, each thematic booklet is considered as a whole in order to respect the diversity of the topics covered and allow for a balanced presentation of viewpoints. For more information on the selection criteria for Biblio-Santé, please visit bibliosante.ca/criteria



CAREGIVERS

CAREGIVERS BOOKLET

This booklet is complementary to all booklets of the Biblio-Santé Program. It highlights useful resources to support caregivers.

OTHER BOOKLETS AVAILABLE



**ALZHEIMER'S
DISEASE**



**AUTISM SPECTRUM
DISORDER**



BEREAVEMENT



CANCER



**CHRONIC
PAIN**



DIABETES



**END-OF-LIFE
CARE**



**HEART DISEASE
AND STROKE**



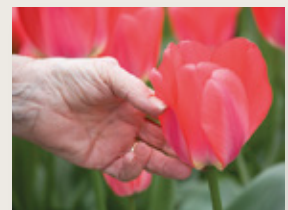
**INTELLECTUAL
DISABILITY**



**MENTAL
HEALTH**



**MULTIPLE
SCLEROSIS**



**PARKINSON'S
DISEASE**



**PHYSICAL
DISABILITY**



**PULMONARY
DISEASE**



**SENIORS
AND AGING**

RESOURCE DIRECTORY

ORGANIZATIONS AND ASSOCIATIONS

General

CANADA MORTGAGE AND HOUSING CORPORATION (CMHC)

Toll free 1 800 668-2642
Website www.cmhc-schl.gc.ca/en/

The Corporation's website gives access to a number of information leaflets covering different issues that require consideration to make housing units accessible.

DAWN CANADA

Phone 514 396-0009
Toll free 1 866 396-0074
Website <https://www.dawncanada.net/>

DAWN Canada is an organization that works towards the advancement and inclusion of women and girls with disabilities and Deaf women in Canada. It offers resources for and about women with disabilities and their concerns.

KÉROUL

Phone 514 252-3104
Website www.keroul.qc.ca/en/home.html

Kéroul is a non-profit organization dedicated to informing, representing, developing and promoting accessible tourism and culture. Visit the website to get information on different aspects of accessible tourism (tourism outside Quebec, transportation, associations, etc.) and to find specially adapted accommodation.

L'APPUI POUR LES PROCHES AIDANTS

Toll free 1 855 852-7784
Website www.lappui.org/en

The 17 regional Appui offices offer a professional helpline as well as support and reference services tailored to the needs of caregivers serving seniors. Each region provides information, training and respite services. The goal of the Caregiver Support hotline is to provide caregiver support, help you through the different steps, and offer guidance on resources available in your community. The website also includes a directory in which you can search by region and type of need required (respite, psychosocial support, etc.)

MULTIPLE SCLEROSIS SOCIETY OF CANADA

Toll free 1 800 268-7582
Website <https://mssociety.ca>

The Multiple Sclerosis Society of Canada promotes the rights and interests of people with the disease and their relatives and friends, informs the population and supports research.

Multiple Sclerosis Society of Canada – Quebec Division

Phone 514 849-7591
Website <https://mssociety.ca/division/quebec-division>

The Quebec Division coordinates the activities of the Multiple Sclerosis Society of Canada in the province. There are about 20 regional chapters in the province of Quebec.

OFFICE DES PERSONNES HANDICAPÉES DU QUÉBEC (OPHQ)

Toll free 1 800 567-1465
Website www.ophq.gouv.qc.ca

The Office des personnes handicapées du Québec provides support, advice and assistance to people with disabilities and their families. It publishes information brochures for family caregivers that can be downloaded in the “Publications” section of the website.

PROCHE AIDANCE QUÉBEC

Phone 514 524-1959
Website <https://procheaidance.quebec/>

Proche aideance Québec brings together 124 community organizations whose mission is to improve the living conditions of caregivers. You will find the complete list of organizations by region on the Proche aideance website. Website in french.

INTERNET RESOURCES

A few tips for critically assessing information found on the Internet

THE SOURCE OF THE INFORMATION (AUTHOR OR AUTHORS)

- Who created the site?
- Is it possible to obtain information about the author or the owner of the site?
- Is it a government or university site or one belonging to a recognized organization?

THE QUALITY OF THE INFORMATION SOURCE

- What is the objective (to inform or sell)?
- Are the sources referenced?
- Are there links to similar sources (to verify the accuracy and objectivity of the information)?
- How frequently is the information updated?

Keep an eye open! Information is shared very quickly, and false news travel just as fast. We should not always rely on content shared online, especially on social networks. You may find articles in which the information is false or exaggerated. It is therefore important to check the quality of information before you believe it and share it.

General

ACCESS 2 CARD

www.access2card.ca

This site provides information on the Access 2 Card program, a program dedicated to offering more entertainment, cultural and recreational opportunities for persons with disabilities and their attendants, without added financial burden. The site provides an application form, as well as a list of all venues in Quebec and the rest of Canada where the card is recognized.

AMERICAN ACADEMY OF NEUROLOGY – MULTIPLE SCLEROSIS

www.aan.com/Guidelines/home/ByTopic?topicId=18

Includes up-to-date information and tools for people with Multiple Sclerosis centered around practice guidelines for health professionals.

BRAINXCHANGE

Learning How to Get the Help You Need: How Caregivers can Navigate the Health & Social Care Network

<https://vimeo.com/168664929>

This online webinar will teach caregivers how to take charge and identify key issues in order to find and get the help they need as well as implement a self-advocacy plan so that they can continue to provide the best care they can to their family member or friend.

Taking Care of Yourself through the Ups and Downs of Caregiving

<https://vimeo.com/148894704>

Caregivers play a major role taking care of family members with neurological health conditions like Alzheimer's disease, Parkinson's and Multiple Sclerosis. Many caregivers would not have it any other way. Yet, caregivers need help to see to their own needs. We know that stress can be a serious issue and can lead to poorer health for caregivers. This webinar goes over the physical and emotional changes that can come with each stage of caregiving, typical range of feelings (the ups and the downs) as a natural part of caregiving, ways to spot stress and other mental health concerns, and tips to staying healthy and well.

Working it out: MS and Employment

<https://vimeo.com/157296362>

This online webinar will help participants navigate through employment issues that arose with someone living with Multiple Sclerosis.

**CANADA MORTGAGE AND HOUSING CORPORATION –
ACCESSIBLE AND ADAPTABLE HOUSING**

<https://www.cmhc-schl.gc.ca/en/developing-and-renovating/accessible-adaptable-housing>

This page offers extensive information about affordable and accessible housing.

**CANADA REVENUE AGENCY – TAX CREDITS AND DEDUCTIONS FOR
PERSONS WITH DISABILITIES**

www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities.html

Find information on Canadian tax credits and deductions that are available to persons with disabilities, their supporting family members, and their caregivers.

**CANADIAN SOCIETY FOR EXERCISE PHYSIOLOGY –
CANADIAN PHYSICAL ACTIVITY GUIDELINES FOR ADULTS
WITH MULTIPLE SCLEROSIS**

<https://csepguidelines.ca/>

Basic information on the preferred amount and types of physical exercise for a person with Multiple Sclerosis.

COMPANION LEISURE CARD

www.carteloisir.ca/en

This website provides information regarding the Companion Leisure Card (CAL). This card gives free access (in participating institutions) to the companions of people aged 12 and older with a permanent disability and who require assistance. A permanent disability includes, but is not limited to, physical, intellectual, developmental and sensory disabilities, as well as mental illness.

FINANDICAP

<https://finandicap.com/en/home/>

Finandicap is a firm that offers you the RDSP, a savings plan that allows people with disabilities and their families to save to ensure a better quality of life in the long term.

GOVERNEMENT DU QUÉBEC – PEOPLE WITH DISABILITIES

<https://www.quebec.ca/en/people-with-disabilities>

This section of the Government of Quebec website presents the programs, measures and services for people with disabilities, their families and caregivers.

GOVERNMENT OF CANADA – DISABILITY BENEFITS

www.canada.ca/en/services/benefits/disability.html

Find information on disability pensions, savings plans, education funding, and other benefits.

KÉROUL

Québec for all website

<http://quebecforall.com>

Quebecforall.com features more than 1,700 tourism businesses assessed by Kéroul and certified as fully or partially accessible, along with local merchants and businesses.

MAYO CLINIC – MULTIPLE SCLEROSIS

www.mayoclinic.org/diseases-conditions/multiple-sclerosis/symptoms-causes/syc-20350269

Mayo Clinic's MS program has earned a national reputation as a top diagnostic and treatment center (Mayo Clinic website). This page contains information on many different elements of Multiple Sclerosis.

MULTIPLE SCLEROSIS INTERNATIONAL FEDERATION (MSIF)

www.msif.org

The site summarizes what multiple sclerosis is. It presents statistics on its prevalence in the world and offers various downloadable guides about fatigue, pharmacological treatments, complementary therapies, pain, family, sexuality, caregiving, etc.

MULTIPLE SCLEROSIS SOCIETY OF CANADA

MS Canada magazine

<https://mssociety.ca/resources/semi-annual-magazine>

The Multiple Sclerosis Society of Canada publishes the MS Canada Magazine twice a year. The magazine features articles on the advances in research, Living Well with MS, as well as stories of people affected by MS and their loved ones. Past issues are available online for consultation and subscribing to the publication is also possible when becoming a member of the MS Society.

Information Library

<https://mssociety.ca/resources/library>

This webpage gives you access to all the Multiple Sclerosis Society of Canada publications. Topics covered include health and well-being, work and finance, family, youth, etc.

Support & Services

<https://mssociety.ca/support-services>

In this section, you will find the list of services offered to people with MS, their loved ones, caregivers and health professionals, as well as a link to the regional offices contact information. The majority of regional offices offer a confidential support line, support groups, conferences, information sessions and rights advocacy.

ONROULE.ORG

<https://onroule.org/en/>

OnRoule.org is a non-profit organization whose mission is to contribute to the well-being and greater autonomy of people with reduced mobility or with functional limitations. The organization centralizes and distributes information on accessibility on its website, listing accessible public places and businesses, accessible, adaptable and/or adapted accommodation and homes, and assistance and referral organizations.

PROCHE AIDANCE QUÉBEC

Taking care of yourself... while taking care of your loved one

<http://ranq.qc.ca/wp-content/uploads/2014/02/GuideLavalanglais.pdf>

The need for caregivers to take care of themselves no longer has to be demonstrated. By consulting this guide, you will know that you are not the only ones living with this commitment, and that numerous resources have been set up to help you take care of yourself while taking care of a loved one.

RÉGIE DE L'ASSURANCE MALADIE

Domestic help

<https://www.ramq.gouv.qc.ca/en/citizens/aid-programs/domestic-help>

The Financial Assistance Program for Domestic Help Services allows you to benefit from a reduction in the hourly rate charged for domestic help services by social economy businesses. These services include housekeeping work, laundering, meal preparation and accompanying you when shopping. On this page, you will find the steps to follow when requesting domestic help.

Domestic help social economy businesses

<https://www.ramq.gouv.qc.ca/en/citizens/aid-programs/domestic-help/social-economy-businesses>

On this page, you will find a directory of social economy businesses in domestic help recognized by the Ministère de la Santé et des Services sociaux.

REVENU QUÉBEC – TAX CREDITS

This site provides information on different tax credits and on financial support.

Amount for a severe and prolonged impairment in mental or physical functions

<https://www.revenuquebec.ca/en/citizens/tax-credits/amount-for-a-severe-and-prolonged-impairment-in-mental-or-physical-functions/>

Disabled individuals

<https://www.revenuquebec.ca/en/citizens/your-situation/disabled-individuals/>

Refundable tax credit for medical expenses

<https://www.revenuquebec.ca/en/citizens/tax-credits/refundable-tax-credit-for-medical-expenses/>

Tax credit for caregivers

<https://www.revenuquebec.ca/en/citizens/tax-credits/tax-credit-for-caregivers/>

Work premium tax credit

<https://www.revenuquebec.ca/en/citizens/tax-credits/work-premium-tax-credits/>

SOCIÉTÉ D'HABITATION DU QUÉBEC (SHQ) – RESIDENTIAL ADAPTATION ASSISTANCE PROGRAM

www.habitation.gouv.qc.ca/english/detail_du_programme_english/programme/residential_adaptation_assistance_program.html

Provides information and residential adaptation assistance programs for people with a disability. An information brochure is available online.

U.S. NATIONAL LIBRARY OF MEDICINE – MULTIPLE SCLEROSIS

<https://ghr.nlm.nih.gov/condition/multiple-sclerosis>

www.medlineplus.gov/genetics/condition/multiple-sclerosis/

HEALTH INFORMATION PORTALS

Sources offering reliable and quality information about health and healthy lifestyle habits.

GOVERNMENT OF CANADA – HEALTH

www.canada.ca/en/services/health.html

Offers reliable, easy-to-understand health and safety information for Canadians.

GOVERNEMENT DU QUÉBEC – HEALTH

www.quebec.ca/en/health/

Offers simple, practical and reliable information to help manage health problems and make better use of Quebec's health services.

MAYO CLINIC

www.mayoclinic.org/patient-care-and-health-information

The Patient Care and Health Information section of the Mayo Clinic offers the general public factual, practical and objective information on disease prevention and adopting healthy lifestyle habits. With the collaboration of 3,300 physicians, scientists and researchers, this site offers quality content.

MEDLINEPLUS

www.medlineplus.gov

MedlinePlus is an authoritative resource offering detailed information on many health issues and is produced by the National Library of Medicine (Maryland, United States).

HEALTH DATABASES

Open access databases

Here is a selection of resources to help you find relevant information. **The databases below are accessible at no charge and no subscription is required.**

PUBMED CENTRAL

www.ncbi.nlm.nih.gov/pmc

PubMed Central (PMC) is a digital repository of scientific health-related articles that were submitted to a peer review process (collective activity of researchers who critically assess the work of other researchers). Articles are freely accessible.

Databases with access restricted to subscribers

Would you like to refine your search for health information? Bibliothèque et Archives nationales du Québec (BAnQ) offers remote consultation of several health databases. We have selected those aimed at a large audience. Please note that certain resources are only in English. The interface language and the language of the content of the resource are indicated at the end of each description.

In order to access the BanQ databases, you must subscribe to remote services.

To subscribe: www.banq.qc.ca/formulaires/abonnement

To view the resources available in the BAnQ digital collection, log in first using your subscriber number and password for the library.

Guides and a selection of essential resources are available to help you find your way around on the platform: <http://numerique.banq.qc.ca/apropos/debuter.html>

E-CPS (COMPENDIUM DES PRODUITS ET SPÉCIALITÉS PHARMACEUTIQUES EN LIGNE) / COMPENDIUM OF PHARMACEUTICALS AND SPECIALTIES ON LINE

<http://numerique.banq.qc.ca/ressources/details/6020>

This database provides access to more than 2,000 monographs of drugs, vaccines and natural products available in Canada. It contains information such as indications, contraindications, warnings, adverse reactions, drug interactions and dosage. This resource also includes directories (poison control centres, health organizations, manufacturers), a product identification tool and glossaries. Bilingual resource.

MAGILL'S MEDICAL GUIDE

<http://numerique.banq.qc.ca/ressources/details/5809>

Magill's Medical Guide gives online access to articles that are easy to understand for the general public on various medical topics: diseases, disorders, treatments and preventive measures. Contains an alphabetical index on the subjects covered as well as capsules on recent developments in medical science. Interface and content in English.

READING SUGGESTIONS

YOUR LIBRARY DOESN'T
HAVE THE BOOK THAT YOU
ARE LOOKING FOR?

LEARN ABOUT THE
LOAN SERVICE BETWEEN LIBRARIES.

YOUR LIBRARY CAN THEN OBTAIN
THE DOCUMENT YOU WOULD LIKE
FROM ANOTHER LIBRARY.

Books available in different formats

Did you know that you can borrow books in different formats for free from your libraries?



LARGE PRINT BOOKS

Large print books are designed to optimize reading comfort for the visually impaired, the sick, people with eye strain and young dyslexics. You will find many of them in public libraries.



AUDIO AND DIGITAL AUDIO BOOKS

Audio and digital audio books are voice recordings of the text of a book made by a narrator. These books are read by recognized interpreters. They are recommended for both beginning readers and people with visual impairments.

Audio books are recorded on CD or MP3 CD and can be found on the shelves of libraries that offer them.


Digital audio books are available on the prenumerique.ca platform. They can be listened to on all devices using a recent version of a web browser and a reliable Internet connection. This does not require the installation of a reader application.



DIGITAL BOOKS

Digital books are available via the pretnumerique.ca platform.

On the pretnumerique.ca website of libraries participating in the Biblio-Santé program, you will find the **digital Biblio-Santé collection**. Each book suggested in the booklets that is available in digital format is identified by the following mention:

 Also available on pretnumerique.ca

These digital books are chronodegradable, that is to say that they deactivate automatically at the end of the loan period. Downloaded books can be read on different devices: e-readers, tablets, computers, smartphones, etc. The service is accessible anytime and anywhere, as long as you have access to an Internet connection.

[Pretnumerique.ca](http://pretnumerique.ca) also offers a dedicated free reading application, available in iOS (Apple) and Android format. This allows you to consult the digital catalog of your libraries as well as to borrow, reserve and easily read your digital books and your digital audiobooks from the same application.

Your reading device gives you access to features to promote its accessibility and facilitate your reading.

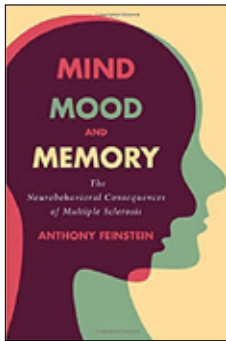
For help borrowing an eBook, visit the [Aide en ligne Prêt Numérique](#) page.

*The supply of books in different formats varies from one library to another.

Find out what your library has to offer!

NON-FICTION

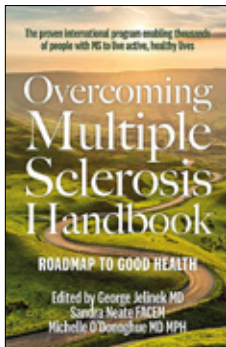
General works



MIND, MOOD, AND MEMORY: THE NEUROBEHAVIORAL CONSEQUENCES OF MULTIPLE SCLEROSIS

Anthony Feinstein. Baltimore: Johns Hopkins University Press, 2022, 240 p.

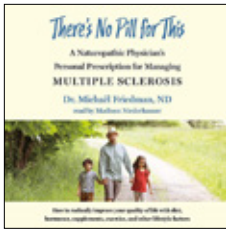
The author provides a comprehensive, current review of the major behavioral abnormalities associated with multiple sclerosis. Disorders of cognition, mood, and affect are described with findings from the neuropsychological, brain imaging, and treatment literature, complemented by detailed, eloquent case histories.



OVERCOMING MULTIPLE SCLEROSIS HANDBOOK: ROADMAP TO GOOD HEALTH

George Jelinek, Sandra Neate and Michelle O'Donoghue. Sydney: Allen & Unwin, 2022, 366 p.

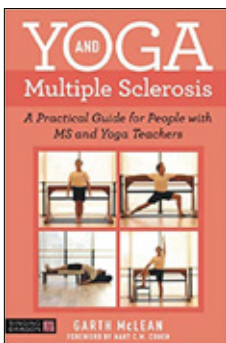
This book explains what MS is, and outlines the scientifically credible and evidence-based 7 step self-management program originally devised by Professor George Jelinek. It covers all aspects of living on the program, from first diagnosis to later life, with chapters from medical specialists and other experts on choosing your healthcare team, improving resilience, work, pregnancy and progressive MS.



THERE'S NO PILL FOR THIS: A NATUROPATHIC PHYSICIAN'S PERSONAL PRESCRIPTION FOR MANAGING MULTIPLE SCLEROSIS

Michaël Friedman. White River Junction, Vermont: Chelsea Green Publishing, 2020, 229 p.

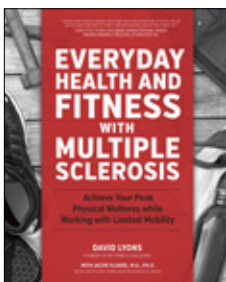
Most of us take for granted the little things in life-like walking out to the mailbox, socializing with friends, or enjoying a mug of hot coffee. But what if each daily activity required intensive planning and effort? That's what living with multiple sclerosis is like, and author Michaël Friedman knows this from first-hand experience. Since his diagnosis of multiple sclerosis a decade ago, Dr. Friedman has been searching for a cure for the disease. After years of research, he realized that he had some of the answers right in his naturopathic medicine toolbox, and others, surprisingly, lay in the realm of conventional medicine.



YOGA AND MULTIPLE SCLEROSIS: A PRACTICAL GUIDE FOR PEOPLE WITH MS AND YOGA TEACHERS

Garth McLean. Philadelphia: Jessica Kingsley Publishers, 2020, 368 p.

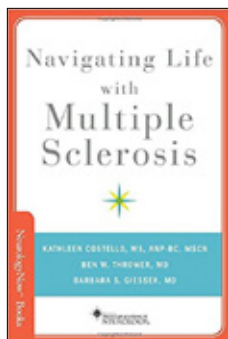
By providing an overview of key yoga postures and basic breathing techniques, this book demonstrates how people with multiple sclerosis can manage symptoms, and create a regular yoga practice in order to enhance physical and mental wellbeing. The book includes photos to demonstrate the yoga poses, as well as case studies and testimonials that depict the benefits and impact of a regular practice that can be carried out at home with minimal equipment or household objects.



EVERYDAY HEALTH AND FITNESS WITH MULTIPLE SCLEROSIS: ACHIEVE YOUR PEAK PHYSICAL WELLNESS WHILE WORKING WITH LIMITED MOBILITY

David Lyons and Jacob Sloane. Beverly: Fair Winds Press, 2017, 192 p.

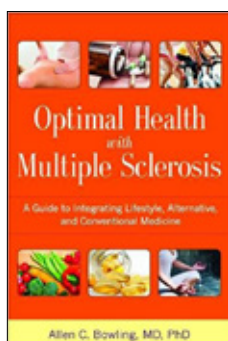
David Lyons' program is designed to help you maintain a healthy lifestyle and includes anecdotes from real people with MS, their limitations and how they followed this plan to reach their fitness goals. Find advice and solutions for overcoming mental hurdles, nutrition fundamentals to properly fuel workouts, easily adaptable exercises, and motivation.



NAVIGATING LIFE WITH MULTIPLE SCLEROSIS

Kathleen Costello, Ben W. Thrower and Barbara S. Giesser. New York: Oxford University Press, 2015, 192 p.

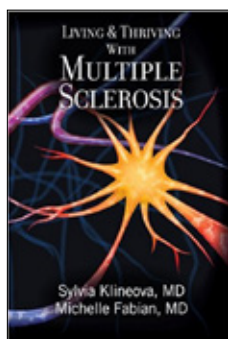
This book is a practical guide for meeting the challenges of this lifelong disease. MS may cause a myriad of symptoms and varies greatly from person to person. The authors demystify MS and offer practical solutions and guidance based upon their extensive combined clinical and research experience. The book tackles many of the common symptoms experienced by the person with MS and looks into the future to explore where research is headed. The authors are a nurse practitioner and two doctors all of whom specialize in multiple sclerosis. Some of the financial planning details are mostly directed to a U.S. audience.



OPTIMAL HEALTH WITH MULTIPLE SCLEROSIS: A GUIDE TO INTEGRATING LIFESTYLE, ALTERNATIVE AND CONVENTIONAL MEDICINE

Allen C. Bowling. New York: Demos Medical Publishing, 2014, 402 p.

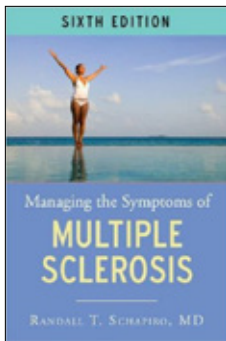
In addition to conventional medicine, many people with MS also use some form of alternative medicine and there is growing evidence and interest in the effects of lifestyle factors, such as diet and exercise on MS. This book provides unbiased and practical information about the MS relevant aspects of these non-medication approaches. Dr. Bowling is a specialist in MS and alternative medicine.



LIVING AND THRIVING WITH MULTIPLE SCLEROSIS

Sylvia Klineova and Michelle Fabian. Greenacres: Provenir Publishing, 2014, 60 p.

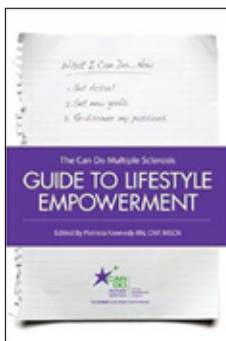
This short book will help you understand the basics of what multiple sclerosis is, what causes it, what the potential associated problems are, and what to expect from medications used for treatment. This book is designed to offer you guidance in easily understandable language. Drs. Klineova and Fabian are MS specialists.



MANAGING THE SYMPTOMS OF MULTIPLE SCLEROSIS

Randall T. Schapiro. New York: Demos Medical Publishing, 2014, 232 p.

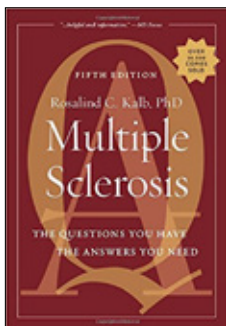
Updated and revised sixth edition of this guide to clinically tested and proven methods for effectively managing the symptoms characteristic of MS and MS treatment. Dr. Randall T. Schapiro provides information to manage both the disease and symptoms, and make everyday life easier. New chapters offer advice for those newly diagnosed with the disease, and those who experience more symptoms with age.



THE CAN DO MULTIPLE SCLEROSIS GUIDE TO LIFESTYLE EMPOWERMENT

Edited by **Patricia Kennedy.** New York: Demos Medical Publishing, 2013, 180 p.

The chapters of this book were contributed by psychologists, doctors, nurses, and occupational and physiotherapists. The philosophy of the book is to help people with MS and those helping them to reclaim a sense of dignity, control and freedom by empowering them with knowledge, skills and confidence. A very small amount of financial planning information is directed to a U.S. audience.



MULTIPLE SCLEROSIS: THE QUESTIONS YOU HAVE – THE ANSWERS YOU NEED

Rosalind Kalb. New York: Demos Medical Publishing, 2012, 448 p.

This is a guide for those who have MS and those who share their lives with someone who has it. It covers a wide range of topics in a question-answer format. The chapters cover everything from treatment to emotional, sexual and employment issues. Rosalind Kalb, PhD. is a clinical psychologist at the National Multiple Sclerosis Society in the U.S. This book is comprehensive and useful although some of the resources are specifically related to the U.S.

Accessibility



THE ACCESSIBLE HOME: DESIGNING FOR ALL AGES AND ABILITIES

Deborah Pierce. Newtown: Taunton Press, 2012, 224 p.

The Accessible Home goes beyond ramps and grab bars to help aging boomers, or those faced with disabilities, accomplish home accessibility on a deeper level. With a focus on closing the gap between home and homeowner, architect Deborah Pierce leads readers through the steps of universal design—from hiring the right architect to creating a pleasing space with the final details. Plus, an insider's look at 25 case studies shows that the best design is built in, not tacked on, and that «accessible» can be both beautiful and functional.

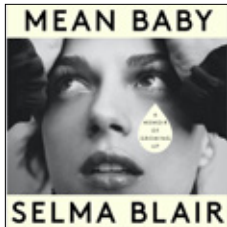


HOME ACCESSIBILITY: 300 TIPS FOR MAKING LIFE EASIER

Shelley Peterman Schwarz. New York: Demos Health Publishing, 2011, 144 p.

This book is designed to help people with chronic illness, physical disability, temporary or permanent (including low vision, blind, hard of hearing, the Deaf, and others), and age-related limitations make their homes safer and more accessible without costly remodeling or structural changes. Shelley Peterman Schwarz shares practical tips, techniques, and shortcuts. She has learned from personal experience, to adapt, organize, and simplify life.

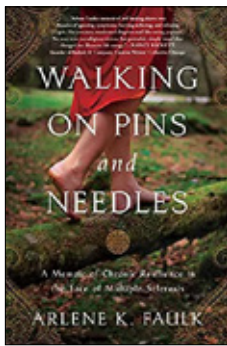
LIFE STORIES, BIOGRAPHIES AND TESTIMONIALS



MEAN BABY: A MEMOIR OF GROWING UP

Selma Blair. New York: Alfred A. Knopf, 2022, 320 p.

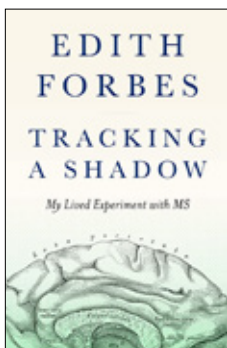
Over the course of this beautiful and, at times, devastating memoir, Selma lays bare her addiction to alcohol, her devotion to her brilliant and complicated mother, and the moments she flirted with death. There is brutal violence, passionate love, true friendship, the gift of motherhood, and, finally, the surprising salvation of a multiple sclerosis diagnosis.



WALKING ON PINS AND NEEDLES: A MEMOIR OF CHRONIC RESILIENCE IN THE FACE OF MULTIPLE SCLEROSIS

Arlene K. Faulk. Austin, TX: River Grove Books, 2022, 251 p.

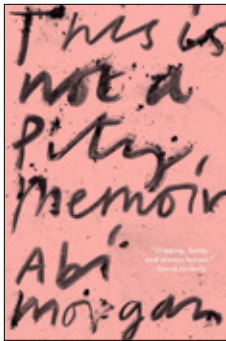
In this memoir of one woman's years-long struggle to understand and conceal her debilitating symptoms as she ascends the corporate ladder in a major airline comes a story of perseverance, rediscovery, and hope in light of multiple sclerosis. As she jumps into the unknown, Faulk finds comfort and healing through Chinese medicine and Tai Chi. Her inspiring story demonstrates how a chronic and debilitating health condition lacks the power to control our lives and stop us from moving in the direction of possibility.



TRACKING A SHADOW: MY LIVED EXPERIMENT WITH MS

Edith Forbes. Seattle: Girl Friday Books, 2022, 141 p.

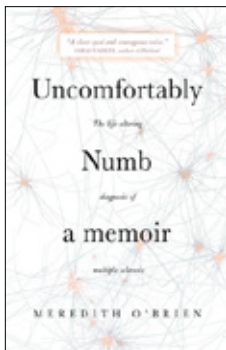
After her MS diagnosis, Forbes turned her fear into action, immersing herself in the medical literature to search for ideas. Finding an unexpected connection between the medical information and her own knowledge of agriculture, she embarked on a self-designed experiment that continues to this day. Tracking a Shadow weaves together the story of Forbes's personal twenty-five-year medical experiment with a memoir of the mother whose constant determination to look for better answers shaped the author's unique approach to her disease.



THIS IS NOT A PITY MEMOIR

Abi Morgan. New York: HarperCollins, 2022, 246 p.

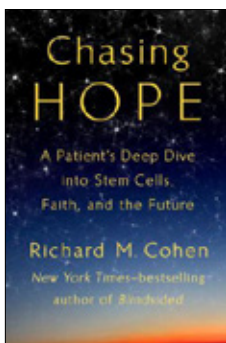
This is a story about love and family. Abi describes with unflinching honesty and nuance the extraordinary and terrifying challenge of caring for a loved one in the wake of devastating illness.



UNCOMFORTABLY NUMB: A MEMOIR

Meredith O'Brien. Deadwood, OR: Wyatt-MacKenzie Publishing, 2020, 247 p.

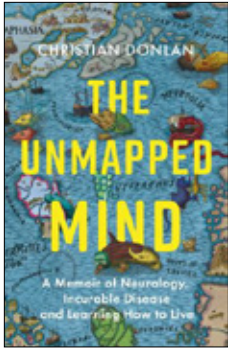
It begins with numbness on her left leg. Then it spreads. Even though an MRI finds a 'mass' on her brainstem, it takes two more years for Meredith O'Brien to learn what is causing that numbness. Months after her 65-year-old mother dies from a fast-moving cancer, weeks after her father is hospitalized and she experiences an unexpected job change, she learns she has multiple sclerosis. Suddenly, Meredith, a married mother of three teens, has to figure out how to move forward into a life she no longer recognizes. Reimagining her life as a writer and an educator, as a mother and a spouse, she has to adjust to the restrictions MS imposes on her.



CHASING HOPE: A PATIENT'S DEEP DIVE INTO STEM CELLS, FAITH, AND THE FUTURE

Richard M. Cohen. New York: Blue Rider Press, 2018, 279 p.

In 2012, Cohen and his wife, Meredith Vieira, were invited to host and chair an adult stem cell conference at the Vatican. A believer in the power of denial and determination over faith and hope, Cohen was caught off guard by what he learned. Medical technology had advanced further and more quickly than Cohen had known. Could there be a chance his health could improve? Could MS be cured?



THE UNMAPPED MIND: A MEMOIR OF NEUROLOGY, INCURABLE DISEASE AND LEARNING HOW TO LIVE

Christian Donlan. London: Viking, 2018, 292 p.

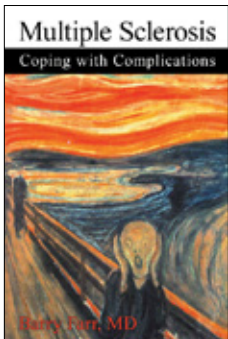
Shortly after his daughter Leontine was born, Christian Donlan's world shifted an inch to the left. He started to miss light switches and door handles when reaching for them. He would injure himself in a hundred stupid ways every day. These strange experiences were the early symptoms of multiple sclerosis, an incurable and degenerative neurological illness. As his young daughter starts to investigate her environment, he too finds himself exploring a strange new landscape, the shifting and bewildering territory of the brain.



JUST JEN: THRIVING THROUGH MULTIPLE SCLEROSIS

Jen Powley. Winnipeg: Fernwood, 2017, 178 p.

Jen Powley was diagnosed with multiple sclerosis at fifteen. By thirty-five, she had lost the use of her arms and legs. *Just Jen* is a memoir that tells the story of Powley's life at the time of her diagnosis, and the infinite, irrevocable ways it has changed since.



MULTIPLE SCLEROSIS: COPING WITH COMPLICATIONS

Barry M. Farr. Bloomington: Archway Publishing, 2016. 450 p.

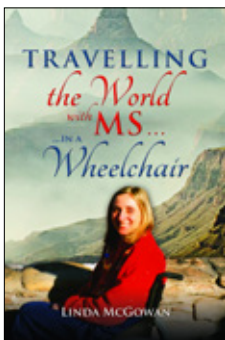
Dr. Farr has battled MS for 24 years. Speaking from personal experience, this book aims to help patients deal with reality of chronic complications of MS. Most of the text deals with Dr. Farr's own challenges, how he dealt with them and then attempts to generalize his experiences to help other people with similar problems. The book is large a very detailed and could be helpful with ideas about dealing with everyday problems of people who are seriously affected by MS and their caregivers.



TAKING CONTROL TOGETHER: REAL LIFE STORIES FOR CARING FOR YOURSELF & A LOVED ONE WITH MULTIPLE SCLEROSIS

Jullian Kingsford Smith. Take 20 Publishing, 2015, 170 p.

A guide that gets to the heart of how you can overcome feeling isolated or alone with caring for someone with chronic illness. Chronic disease affects far more than just the person diagnosed. It can be a steep learning curve and a very confusing and emotional time for those closest to the person living with the illness.



TRAVELLING THE WORLD WITH MS...IN A WHEELCHAIR

Linda McGowan. North Vancouver: Influence Publishing 2014, 366 p.

Since her diagnosis with multiple sclerosis in 1983, Linda McGowan has tenaciously pursued her dream of travelling the globe. From viewing the top of the world from a basket on the back of a porter at the Annapurna base camp in Nepal, to hob-knobbing with emperor penguins at the end of the world on the Falkland Islands, Linda describes her exploits and encounters while travelling through vastly different countries. Using creativity, patience and an open mind, Linda shows how she conquered unique challenges and enjoyed a plethora of wondrous sights, people, food and experiences, all from the apparent vulnerability of her wheelchair.



FACING THE COGNITIVE CHALLENGES OF MULTIPLE SCLEROSIS

Jeffery N. Gingold. New York: Demos Health, 2011, 209 p.

When attorney Jeffrey N. Gingold misplaced his wife on the living room couch, and became lost while driving just blocks from his home, little did he know that he was experiencing a hidden symptom of multiple sclerosis: cognitive difficulties. This book presents a personal account of one man's anguishing struggle with this aspect of the disease.



KEEPING BALANCE: A PSYCHOLOGIST'S EXPERIENCE OF CHRONIC ILLNESS AND DISABILITY

Katherine Cuthbert. Leicester: Matador, 2010, 269 p.

This memoir provides a personal account of living with multiple sclerosis, rooted in psychological knowledge.



BLINDSIDED: LIFTING A LIFE ABOVE ILLNESS: A RELUCTANT MEMOIR

Richard M. Cohen. New York: Perennial, 2005, 242 p.

Traces the veteran journalist's struggles with multiple sclerosis and cancer while raising three children alongside his television host wife Meredith Vieira.

NOVELS



SOPHOMORES

Sean Desmond. New York: G.P. Putnam's Sons, 2021, 374 p.

It's fall 1987 and life as normal is ending for the Malone family. With their sterile Dallas community a far cry from the Irish-American Bronx of their youth, Pat and Anne Malone have reached a breaking point. Pat, faced with a debilitating MS diagnosis, has fallen into his drinking. Anne, his devoutly Catholic wife, is selected as a juror for a highly publicized murder trial, one that raises questions she has buried her entire life. Together, they try to raise their only son, Daniel, a bright but unmotivated student who is shocked into actual learning by an enigmatic English teacher. For once, Dan is unable to fly under the radar, and is finally asked to consider what he might want to make of his life.

 Also available on pretnumerique.ca



CROSSING HEARTS

Kimberly Kincaid. Seattle: Montlake Romance, 2017, 310 p.

Hunter Cross has no regrets. Having left his football prospects behind the day he graduated from high school, he's happy to carry out his legacy on his family's farm in the foothills of the Shenandoah. Emerson Montgomery has secrets. Refusing to divulge why she left her job as a hotshot physical therapist for a pro football team, she struggles to readjust to life in the hometown she left behind. The more time she spends with Hunter, the more Emerson finds herself wanting to trust him with the diagnosis of MS that has turned her world upside down.



IF NOT FOR THIS

Pete Fromm. Pasadena: Red Hen Press, 2014

After meeting at a boatman's bash Maddy and Dalt embark on a lifelong affair. An adventurous couple they open their own river business and prosper. Then they are confronted with a diagnosis of multiple sclerosis at the same time they find out that Maddie is pregnant.

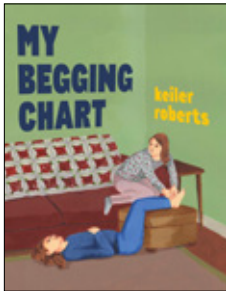


ROCK & ROLL NEVER FORGETS: A JP KINKAID MYSTERY

Deborah Grabien. New York: St. Martin's Minotaur, 2008, 278 p.

Musician John “JP” Kinkaid, a guitarist with the rock band Blacklight, is confronting his own set of problems—his intensely private partner of many years, Bree; his long-estranged wife, Cilla; and multiple sclerosis—a situation complicated by a muckraking writer, Perry Dillon, and a murder in which Bree becomes the prime suspect.

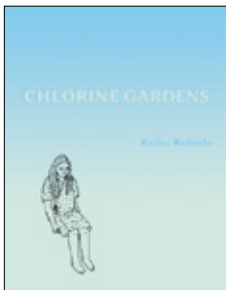
COMICS



MY BEGGING CHART

Keiler Roberts. Montreal: Drawn & Quarterly, 2021, 153 p.

With this book, Keiler Roberts delivers an affecting and funny account of what it means to simultaneously exist as a mother, daughter, wife, and artist. Roberts can get lost in the rewarding melodrama of playing Barbies with her daughter and will momentarily snap out of her depression. Her harmless fibs to get through the moment are brought up by her daughter a year or two later, yet without hesitation Roberts will request that her daughter's imaginary friend not visit when she is around. Her MS diagnosis lingers in the background.



CHLORINE GARDENS

Keiler Roberts. Toronto: Koyama Press, 2018, 128 p.

Dealing with pregnancy, child-rearing, art-making, mental illness, and an MS diagnosis, the parts of Chlorine Gardens' sum sound heavy, but Keiler Roberts' gift is the deft drollness in which she presents life's darker moments. She doesn't whistle past graveyards, but rather finds the punch line in the pitiful.

YOUTH LITERATURE



AGES 2 TO 5

SOME DAYS: A TALE OF LOVE, ICE CREAM, AND MY MOM'S CHRONIC ILLNESS

Julie A. Stamm and Chamisa Kellogg (ill.). New York: The Experiment, 2021, 32 p.

Even when Wyatt's mom isn't feeling her best, he still thinks she's a superhero! Rosie and Wyatt go on adventures every day: On sleepy days, they build a cozy pillow fort just for two. On wobbly days, Wyatt gets out Rosie's magical walking stick and they cast spells on his toys. And on one super-special day, the whole family heads to town for the big "funraiser"! Warm and uplifting, *Some Days* is the perfect story to share with your child about life with multiple sclerosis—or any chronic illness. Although some days are fast and some are slow, Rosie and Wyatt fill each one with love, excitement, and fun... not to mention ice cream!



Also available on pretnumerique.ca

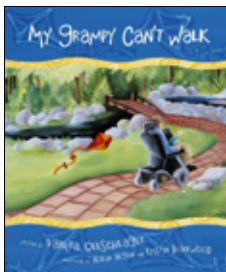


AGES 4 TO 8

MY MOM HAS MS

Stacey Longo. Connecticut: Farmer's Daughter Press, 2015, 30 p.

When Patrick's mother is diagnosed with multiple sclerosis, everyone in the family pitches in to help out more. But Patrick is too little to do the laundry or help with the cooking. What can he do to help his mom? A heartwarming tale based on a true story proving that nothing's more important than family. This book is also an important tool to help start the discussion with young children about multiple sclerosis.

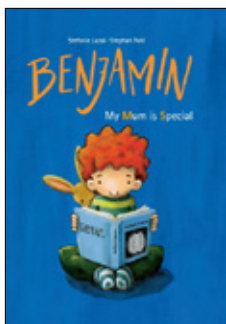


AGES 4 TO 8

MY GRAMPY CAN'T WALK

Vanita Oelschlager, Robin Hegan (ill.) and **Kristin Blackwood** (ill.). Cleveland: Cleveland Clinic Press, 2006, 36 p.

Grampy can't walk anymore because he has multiple sclerosis. But his MS doesn't slow him down. And it doesn't keep him from doing some pretty spectacular things with his grandchildren! This is a story celebrating the vitality of people who use a wheelchair for ease of mobility.

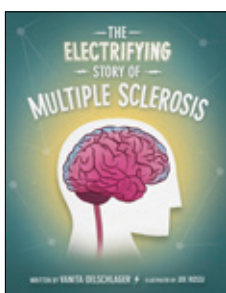


AGES 6 TO 9

BENJAMIN: MY MUM IS SPECIAL

Stephanie Lazar and Stephan Pohl. Edmonton: Multiple Sclerosis Society of Canada, 2005, 42 p.

Benjamin's mother is unwell. She is constantly forgetting or losing things and suddenly she has trouble walking, suffers blurred vision and is no longer able to dress herself. Benjamin's mother has multiple sclerosis and Benjamin is learning for the first time what it means when she suffers a relapse.



AGES 7 TO 10

THE ELECTRIFYING STORY OF MULTIPLE SCLEROSIS

Vanita Aelschlager. Akron: Vanita Books, 2015, 40 p.

The Electrifying Story of Multiple Sclerosis is written to help people understand what it feels like to have the disease, how to help, and what symptoms people feel.



AGES 8 TO 15

WHAT'S UP WITH RYAN'S MUM? MEDIKIDZ EXPLAIN MULTIPLE SCLEROSIS

Kim Chilman-Blair and Ian Rimmer. London: MediKidz, 2012, 32 p.

Ryan's mum is a taekwondo champion and Ryan's hero. With another championship almost in the bag, her arm suddenly stops moving during the final bout, and she is defeated. The doctor diagnoses multiple sclerosis, but Ryan doesn't really understand what is going on, or how he can help. Luckily, the Medikidz are on hand to take Ryan on a trip to Mediland where they see up close what happens to the body in MS, and send up in the middle of a ferocious battle. How will they escape the attack from the body's own immune cells? Will they avoid being sucked up by a giant needle? Join Ryan and the Medikidz in finding out about how nerves work, and how his mum can defend herself best from another attack from MS!

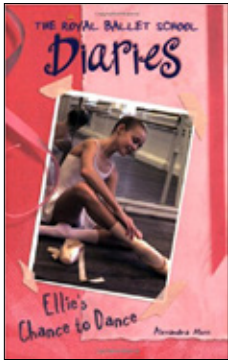


AGES 9 TO 12

THE MEANING OF MAGGIE

Megan Jean Sovern. San Francisco: Chronicle Books, 2014, 220 p.

Eleven-year-old Maggie Mayfield is an A-plus student with big plans for herself, but is facing a lot of problems like starting middle school and figuring out how to help her father who is out of work and in a wheelchair due to his multiple sclerosis.

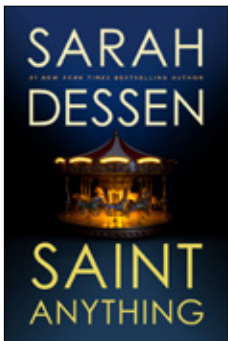


AGES 10+

ELLIE'S CHANCE TO DANCE

Alexandra Moss. New York: Grosset & Dunlap, 2005, 141 p.

After moving from Chicago to Oxford, England, ten-year-old Ellie worries about making new friends at school and caring for her mother who has multiple sclerosis, while also preparing to audition for the resident dancer's training program at London's Royal Ballet School.

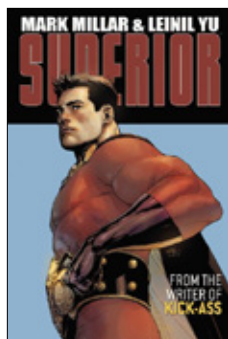


AGES 12+

SAINT ANYTHING

Sarah Dessen. New York: Viking, Penguin 2015, 432 p,

Peyton, Sydney's charismatic older brother, has always been the star of the family, receiving the lion's share of their parents' attention and — lately — concern. When Peyton's increasingly reckless behavior culminates in an accident, a drunk driving conviction, and a jail sentence, Sydney is cast adrift, searching for her place in the family and the world. When everyone else is so worried about Peyton, is she the only one concerned about the victim of the accident? Enter the Chathams, a warm, chaotic family who run a pizza parlor, play bluegrass on weekends, and pitch in to care for their mother, who has multiple sclerosis. Here Sydney experiences unquestioning acceptance. And here she meets Mac, gentle, watchful, and protective, who makes Sydney feel seen, really seen, for the first time.

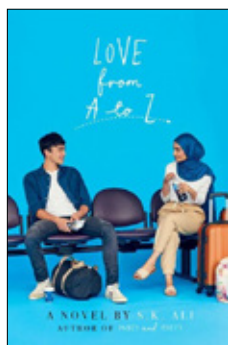


AGES 12+

SUPERIOR

Mark Millar and Leinil Francis Yu (ill.). New York: Marvel, 2012, 200 p.

Simon Pooni was a normal kid with a great life until multiple sclerosis hit. He lost the ability to walk, went blind in one eye and sometimes barely had the muscle control to speak. Every night, Simon would pray his multiple sclerosis somehow would go away. “Somehow” turned out to be a magic monkey named Orman, who granted Simon one wish. And the 12-year-old boy stood transformed into a real-life version of Superior, the legendary comic-book hero. As Superior, Simon spent one glorious week saving those in need, averting natural disasters – becoming the most beloved man on the planet. But Orman ominously cautioned Simon all would be explained in one week.

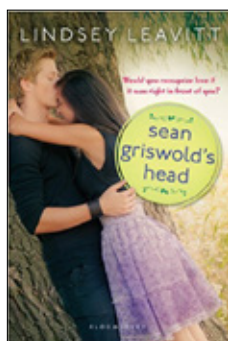


AGES 14 TO 17

LOVE FROM A TO Z

S.K. Ali. New York: Salaam Reads, 2019, 342 p.

Zayneb’s teacher won’t stop reminding the class how “bad” Muslims are. But Zayneb, the only Muslim in class, isn’t bad. She’s angry. When she gets suspended for confronting her teacher, and he begins investigating her activist friends, Zayneb heads to her aunt’s house in Doha, Qatar, for an early start to spring break. Her path crosses with Adam’s. Since he got diagnosed with multiple sclerosis in November, Adam has stopped going to classes, intent on keeping the memory of his mom alive for his little sister. They’ve been playing roles for others, keeping their real thoughts locked away in their journals... until they meet.



AGES 14+

SEAN GRISWOLD'S HEAD

Lindsey Leavitt. New York: Bloomsbury, 2012, 276 p.

After discovering that her father has multiple sclerosis, fifteen-year-old Payton begins counseling sessions at school, which lead her to become interested in a boy in her biology class, have a falling out with her best friend, develop an interest in bike riding, and eventually allow her to come to terms with life’s uncertainties.

**AGES 14+**

MERCY LILY

Lisa Albert. Woodbury: Flux, 2011, 232 p.

While navigating first love, friendship, and other typical worries faced by high school sophomores, Lily must make an excruciating decision when her mother, who has multiple sclerosis, asks for Lily's help in ending her life.

FILM, SERIES AND PROGRAM SUGGESTIONS

DID YOU KNOW?

LIBRARIES HAVE RICH COLLECTIONS OF DVDS AND BLU-RAYS THAT CAN BE BORROWED. THEY ALSO OFFER ONLINE ACCESS TO MOVIES, SERIES AND PROGRAMS. CHECK WITH YOUR LOCAL LIBRARY.

FICTION

**TIMMY'S JOURNEY TO UNDERSTANDING MS**

National Multiple Sclerosis Society. 2007, 15 min.

Animated cartoon (United States). *Timmy's Journey to Understanding MS* is an animated cartoon that shares a little boy's adventure learning about MS. David Lander is the voice of Captain Kip S'myelin, Timmy's guide on his journey. The cartoon is an excellent resource to talk with children about MS. Developed for children ages 5-12.

**HILARY AND JACKIE**

Anand Tucker. 1998, 121 min.

Biography (Great Britain). The tragic story of world renowned classic cellist Jacqueline du Pré, as told from the point of view of her sister, flautist Hilary du Pré-Finzi.



DOCUMENTARIES

General



PREDICTING MY MS

Jason DaSilva. 2022, 30 min.

Online: <https://www.youtube.com/watch?v=m8Qy3YX2oVU>

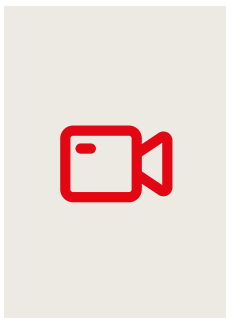
Documentary (United States). In 2005, filmmaker Jason DaSilva was diagnosed with primary progressive multiple sclerosis, a rare type of MS that has no known cure and inflicts progressively debilitating symptoms. In this moving personal film, DaSilva looks back on the challenges he's faced, delves into the science behind MS, and investigates the potential risk factors that may—or may not—have contributed to his rare diagnosis.



INTRODUCING, SELMA BLAIR

Rachel Fleit. 2021, 94 min.

Actress Selma Blair gives an intimate, raw look at her life as she adapts to living with multiple sclerosis. After revealing her diagnosis on social media, Selma becomes a platform for disability and takes risks to slow the disease's progression.



BENEATH THE SURFACE

David Kuhn. 2020, 30 min.

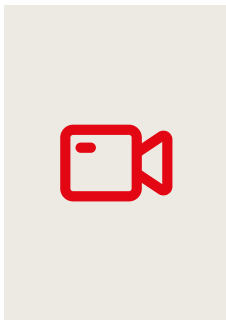
Beneath The Surface tells the stories of people in America living with multiple sclerosis at various stages of progression, who open their homes and their hearts, share what it felt like at diagnosis, and how dreams survive albeit most quite altered from “original plans.” They are empowered, graceful, in some cases depressed and lonely, and always people for whom compassion and understanding change how we view and care for them.



WHEN WE WALK

Jason DaSilva. 2019, 78 min.

Filmmaker Jason DaSilva has been living with a severe form of multiple sclerosis for over 10 years. When his son moves 1700 miles away to Austin, Texas, he is unable to cope with this loss. He attempts to relocate to Austin which reveals to him the extent of the broken Medicaid system. He discovers that state-run Medicaid would require him to live in a nursing home. *When We Walk* documents a devoted father and filmmaker with an indestructible drive to keep the cameras rolling no matter what and to show his son what it means to never give up.



CAN YOU STOP MY MULTIPLE SCLEROSIS?

Panorama, BBC. 2016, 30 min.

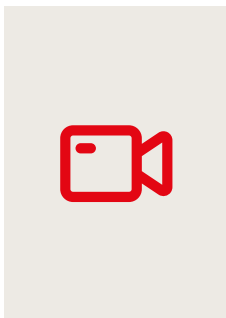
Multiple sclerosis affects a hundred thousand people in the UK, most of them diagnosed in their '20s and '30s. Now there is hope that a bone marrow stem cell transplant usually given to cancer patients could stop MS in its tracks preventing lifelong disability.



WHEN I WALK

Jason DaSilva. 2013, 84 min.

In 2006, 25-year-old Jason DaSilva's legs stopped functioning and he collapsed. Months earlier, doctors had diagnosed him with multiple sclerosis, which can lead to loss of vision, muscle control, and a myriad of other complications. As his illness worsens, Jason picks up the camera, turns it on his declining body, and sets out on a worldwide journey in search of healing, self-discovery, and love.



MS TREATMENT IN QUESTION

The National. 2013, 3 min.

Online: www.cbc.ca/player/play/2358361019

More evidence is in for so-called multiple sclerosis liberation therapy, but the answers remain unclear.



BUT YOU STILL LOOK SO WELL: LIVING WITH MULTIPLE SCLEROSIS

Kevin J. Lindermuth. 2012, 143 min.

Two films profiling four individuals with multiple sclerosis, who, despite there being no obvious signs of their having the disease, must deal with invisible symptoms such as numbness, tingling and pain in their limbs, fatigue, headaches, and vision and cognitive problems. Medical professionals offer insight and advice.



MS BLOGGER'S SURGERY JOURNEY

CBC NEWS. 2010, 13 min.

Watch multiple sclerosis blogger Ginger MacQueen who decides to go to Katowice, Poland, to have her veins checked, and follow her into the operating suite.

TAKING PART IN ONE'S HEALTH CARE

This section can be found in every Biblio-Santé thematic booklet. The resources have been selected with a patient-as-partner approach that aims to help the health system users to actively participate in their health care and to make informed decisions.

WHAT DOES PATIENT-AS-PARTNER MEAN?

A patient-as-partner is a person who progressively becomes able as they receive treatment to make informed and independent health choices. Their experience related knowledge is recognized and their care related competences are developed with help from the team. Respected in all aspects of their humanity, they are a full member of this team when it comes to the care and services offered to them. While fully recognizing the expertise of the team members, the patient-as-partner can direct the team's concern towards their particular needs and long term well being.

Source: Faculté de médecine de l'Université de Montréal

ORGANIZATIONS AND ASSOCIATIONS

General

CENTRE OF EXCELLENCE FOR PARTNERSHIP WITH PATIENTS AND THE PUBLIC (CEPPP)

Phone 514 890-8000, ext. 15488
Website <https://ceppp.ca/en/>

The CEP PP aims to make collaborating with patients and the public a science, a culture and the new standard to improve the health of all and the (health) experience of each. Its purpose is to integrate the patient into their care team and the citizen into their healthcare system.

HEALTHCARE EXCELLENCE CANADA

Toll free 1-866-421-6933
Website <https://www.healthcareexcellence.ca/en/>

Healthcare Excellence Canada is an organization with a relentless focus on improving healthcare, with – and for – everyone in Canada. It brings together the Canadian Patient Safety Institute and Canadian Foundation for Healthcare Improvement. Several of its programs are aimed directly at patients and their families in order to improve their safety and the quality of health services.

INSTITUT DE PLANIFICATION DES SOINS DU QUÉBEC

Phone 514 805-2408
Website www.planificationdessoins.org

The Institute's mission is to help people with loss of autonomy or suffering from a degenerative disease to plan their health care. It notably offers different tools as well as lectures and online training. Website only in French.

Legal information

CHAMBRE DES NOTAIRES DU QUÉBEC

Phone 514 879-1793
Toll free 1 800 263-1793
Website www.cnq.org/en/home.html

The Chambre des notaires offers basic legal information, including information about powers of attorney, mandates in case of incapacity, wills and successions.

COMMUNITY JUSTICE CENTERS

Website www.justicedeproximite.qc.ca/en/

The Community Justice Centers provide services in six regions in Quebec. They inform you about your legal rights and obligations. They support you by helping you in the identification of your legal needs and the options available to address them. They also refer you to the legal resources available related to the legal system or the community, so you can choose the service that best suits your needs.

CONSEIL POUR LA PROTECTION DES MALADES

Phone 514 861-5922
Toll free 1 877 276-2433
Website <http://cpm.qc.ca/en/home/>

You can contact this organization free of charge to get information about the rights of sick people or to report an abuse or a situation which affects the rights of health and social service network users. Every call will be kept strictly confidential.

CURATEUR PUBLIC DU QUÉBEC

Phone 514 873-4074
Toll free 1 844 532-8728
Website quebec.ca/en/government/departments-and-agencies/curateur-public

The Curateur public ensures the protection of incapacitated persons. It educates the public about the protection needs associated with incapacity and supports families and close friends who are representing incapacitated persons, administering the property of an incapacitated person or a minor, or serving as members of a tutorship council. The site provides information about incapacity (protection mandate, tutorship, curatorship, etc.).

FÉDÉRATION DES CENTRES D'ASSISTANCE ET D'ACCOMPAGNEMENT AUX PLAINTES

Toll free 1 877 767-2227
Website <https://fcaap.ca/en/>

Complaint assistance and support centers assist the user in any process to file a complaint with an establishment, a CISSS, a CIUSSS or the Protecteur des usagers. They accompany the user for the duration of the appeal, including when the complaint is referred to the Council of Physicians, Dentists and Pharmacists of an establishment. You can find on the FCAAP website the list of assistance centers as well as information on your rights.

JURISTES À DOMICILE

Phone 514 944-9929
Website www.juristesadomicile.com

Juristes à Domicile guides and supports its members who find themselves in a difficult situation, or who are vulnerable, when it comes to ensuring that their rights are respected. The organization can also facilitate access to low cost legal services, if needed. As the name of the organization suggests, the team's lawyers come to their homes. Website only in French.

PROTECTEUR DU CITOYEN

Toll free

1 800 463-5070

Website

<https://protecteurducitoyen.qc.ca/en>

The Protecteur du citoyen conducts investigations into complaints or reports involving individuals, groups, organizations or undertakings who claim that they were treated unfairly or improperly by a Quebec Government department or public agency, or by Health and Social Services network authorities. The Quebec Ombudsman is independent of the government, neutral and unbiased. All complaints are treated as confidential. The services are free and easily accessible.

REGROUPEMENT PROVINCIAL DES COMITÉS DES USAGERS (RPCU)

Phone

514 436-3744

Website

www.rpcu.qc.ca/en/

The Regroupement provincial des comités des usagers defends and protects the rights of all users of the Health and Social Services network. Visit the website of the Regroupement for more information on the rights and recourse of the loved one you support.

INTERNET RESOURCES

General

CANADIAN MEDICAL ASSOCIATION – PATIENT VOICE

<https://www.cma.ca/patient-voice>

Patient Voice is a group of patients who lend their perspectives and experience to the Canadian Medical Association's (CMA) advocacy work. The 15-member group offers ideas on how to make Canadians healthier and contribute to the medical profession, highlighting issues that matter to the public and giving insight into the best ways for the CMA and physicians to engage with patients. Their web page features information about the group's current members, contact information for obtaining more information or getting involved, as well as a definition of Patient Partnered Care.

CHOOSING WISELY CANADA

<https://choosingwiselycanada.org/>

Choosing Wisely Canada is the national voice for reducing unnecessary tests and treatments in health care. The website provides information related to treatments and medication. It offers recommendations and resources by specialty for health professionals and patients. Patient Pamphlets are also available under the "Patient Resources" tab.

COLLÈGE DES MÉDECINS DU QUÉBEC

<http://www.cmq.org/hub/en/services-au-public.aspx>

The "Services for the public" section of the Collège des médecins du Québec provides information on various aspects of consultations with a doctor (access to a doctor, medical fees, complaints, etc.) and on the role of other health professionals.

GOVERNMENT OF CANADA

How older adults can use social media safely

<https://www.getcybersafe.gc.ca/en/blogs/how-older-adults-can-use-social-media-safely>

This blog post gives tips on how to navigate social media safely.

GOVERNEMENT DU QUÉBEC

Coping with a loss of independence

<https://www.quebec.ca/en/family-and-support-for-individuals/loss-of-independence/loss-of-independence>

This guide provides comprehensive information on government programs and services for individuals experiencing a loss of autonomy and their caregivers. Topics covered include health and social services, housing, home care services, tax credits, justice, work and employment, and transportation. Note also that the forms necessary to obtain the aforementioned services and programs are available on this site.

Info-Santé 811

<https://www.quebec.ca/en/health/finding-a-resource/info-sante-811/>

Info-Santé 8-1-1 is a free and confidential telephone consultation service. Dialling 8-1-1 promptly puts you in contact with a nurse in case of a non-urgent health issue. The service is available 24 hours a day, 365 days a year. Anyone living in Quebec can call Info-Santé 8-1-1 for themselves or a family member.

Service Organization

<https://www.quebec.ca/en/health/health-system-and-services/service-organization/>

This web page of the Government of Quebec presents a portrait of the organization of services in Quebec as well as relevant information for each service offered.

HEALTH BOOKLET

<https://carnetsante.gouv.qc.ca/portail>

The Québec Health Booklet is your one-stop reference to your health information, accessible anywhere. It gives you access to the results of your medical imaging examinations, the history of your pharmacy medications and the results of your samples, including blood and urine tests. It allows you to schedule an appointment for family medicine online.

HEALTHCARE EXCELLENCE CANADA

Engaging Patients in Patient Safety – a Canadian Guide

<https://www.patientsafetyinstitute.ca/en/toolsresources/patient-engagement-in-patient-safety-guide/pages/default.aspx>

The Engaging Patients in Patient Safety Canadian guide is presented to you in detail on this web page. You will discover who is this guide for, its purpose and what is included inside. You also have the option to download it.

Patient, Family and Caregiver Engagement and Partnerships

<https://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement/PatientEngagementResourceHub/Results.aspx>

On this page of the Canadian Foundation for Healthcare Improvement, you will find information about the participation and collaboration of patients in their health care, including the Bridge-to-Home project that allows improve the quality of care, as well as the experience of patients, caregivers and providers during transitions from hospital to home.

Shift to Safety

<https://www.patientsafetyinstitute.ca/en/about/programs/shift-to-safety/pages/public.aspx>

The “Public” section of SHIFT to safety program aims to help you take an active part in the safety of your healthcare. It offers resources on a range of topics for making informed care choices, links to other patients, and tips for working with health care providers based on personal needs.

HEALTH CHARITIES COALITION OF CANADA – “HOW TO” HEALTH GUIDE

www.healthcharities.ca/resources/how-to-health-guide.aspx

The “How To” Health Guide was developed to assist patients, caregivers, friends and families in managing information about the Canadian health care system, which can often be challenging to navigate. If you, or someone you love and care for, are trying to find health services, support or information for an illness or disease, there are actions you can take to help get the best possible health care. The Guide provides basic information about how to speak to those working within the system on a range of issues. A link to download a copy of the guide is available at the bottom of the page.

HEART & STROKE FOUNDATION – BEING A PARTNER IN YOUR HEALTH CARE

https://www.heartandstroke.ca/heart-disease/recovery-and-support/talking-to-your-doctor?_

This section of the Heart & Stroke foundation website provides an overview of what you need to know to prepare well for a medical appointment.

INSTITUTE FOR SAFE MEDICATION PRACTICE CANADA – SAFEMEDICATIONUSE.CA

<https://safemedicationuse.ca/newsletter/index.html>

ISMP Canada SafeMedicationUse.ca newsletters contain information for consumers to promote the safe use of drugs in all areas of health. One of their objectives is to make recommendations to prevent medication-related accidents.

MCGILL UNIVERSITY HEALTH CENTER

Patient Safety and Physical Restraints: What You Need to Know

http://www.muhcpatienteducation.ca/DATA/GUIDE/349_en~v~patient-safety-and-physical-restraint.pdf

This booklet aims to help you understand physical restraints.

MERCK MANUAL (CONSUMER VERSION) – MAKING THE MOST OF HEALTH CARE

<https://www.merckmanuals.com/en-ca/home/fundamentals/making-the-most-of-health-care>

This web page offers you valuable tips for participating actively in your health care, such as when to see your doctor, how to get the most out of a consultation, and investigating a disease.

ORDRE DES PHARMACIENS DU QUÉBEC – PROTECTION DU PUBLIC

<https://www.opq.org/protection-du-public/que-fait-lordre-pour-me-proteger/>

The “Protection du public” section of the Ordre des pharmaciens du Québec website allows you to find a pharmacist, obtain advice related to the protection of the public as well as better understand the role of the pharmacist and what pharmaceutical care is. Website only in French.

OTTAWA HOSPITAL RESEARCH INSTITUTE – PATIENT DECISION AIDS

<https://decisionaid.ohri.ca/AZinvent.php>

The A to Z Inventory of Decision Aids is designed to help you find a decision aid to meet your needs.

RÉGIE DE L'ASSURANCE MALADIE – CITIZENS

<https://www.ramq.gouv.qc.ca/en/citizens/health-insurance/Pages/health-insurance.aspx>

The RAMQ website provides you information on health insurance, prescription drug insurance, aid programs and temporary stays outside Quebec. You will find the services available online as well as the forms necessary to benefit from the services offered.

SANTÉ ET SERVICES SOCIAUX QUÉBEC

Quick Reference: I'm taking care of my Health

<https://publications.msss.gouv.qc.ca/msss/fichiers/2016/16-909-01A.pdf>

This checklist offers you some tips to help you prepare for meetings with health professionals.

SENIORS' GUIDE TO STAYING CYBER SAFE DURING COVID-19

<https://www.getcybersafe.gc.ca/en/resources/seniors-guide-staying-cyber-safe-during-covid-19>

This guide helps seniors protect their identity by helping them create strong passwords, enable multi-factor authentication, and warn them about phishing attempts.

HAVE YOU HEARD OF DEPRESCRIBING?

Deprescribing means reducing or stopping medication. Its goal is to maintain or improve quality of life.

WHY RESORT TO DEPRESCRIBING?

Medication controls symptoms, cures illness and can even extend lifetime. However, it can cause side effects or interactions that can be harmful. The more medication we take, the higher the risks of negative effects. It's also important to know that as we get older, changes in the body make us more sensitive to medications, which increases the risk of suffering from negative side effects.

HOW DOES IT WORK?

For all these reasons, it's recommended to regularly review your medication with your health care provider. They will be able to determine whether the risk of taking a specific medication is higher than its benefits and if deprescribing is an option. **Deprescribing is a planned process that must always be done with the help of your doctor, nurse or pharmacist.**

Source: Canadian Deprescribing Network

CANADIAN DEPRESCRIBING NETWORK

www.deprescribingnetwork.ca

The Canadian Deprescribing Network provide you information about medication safety, deprescribing and safer alternatives to risky medications. Different articles and resources on the subject are proposed on the website of the Network.

Legal information

COMITÉ DES USAGERS DU CENTRE DE SANTÉ ET DE SERVICES SOCIAUX DE LAVAL – THE RIGHTS AND THE RESPONSIBILITIES

<http://www.cucssslaval.ca/user/the-rights-and-the-responsibilities>

The various rights in terms of health and well-being in Quebec and everyone's responsibilities in this area are grouped together on this web page.

ÉDUCALOI

Caregivers: Practical Legal Tools

www.educaloi.qc.ca/en/caregivers-practical-legal-tools

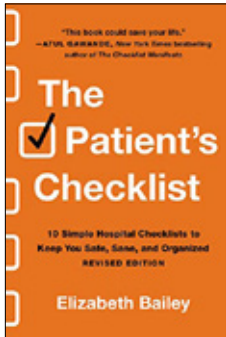
In this web guide, Éducaloi provides clear and useful legal information intended for caregivers.

Health Topics

www.educaloi.qc.ca/en/categories/health

This section of the Éducaloi website clearly explains the rights and responsibilities of doctors, patients, partners, caregivers, etc., within the Quebec health care system. Topics covered include the public health system, filing a complaint, access to medical records, making medical decisions, incapacity, and loss of autonomy.

READING SUGGESTIONS



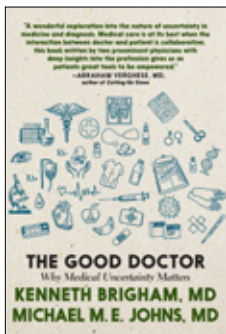
THE PATIENT'S CHECKLIST: 10 SIMPLE HOSPITAL CHECKLISTS TO KEEP YOU SAFE, SANE, AND ORGANIZED

Elizabeth Bailey. New York: Hachette, 2020, 161 p.

Whether you're addressing the rising chaos of a pandemic or preparing for a scheduled surgery, having checklists prepared to guide you through a hospital visit can often mean the difference between comfort and pain, personal and distant care – and even life or death. In today's hospital system, you can face a series of obstacles to satisfactory care, from overworked healthcare providers to understaffed facilities. This series of essential, easy-to-use checklists will help you better manage, monitor, and participate in your own healthcare. These include: Before You Go, What to Bring, Master Medication List, Discharge Plan, and more. It is more important than ever to have a protocol, including a detailed plan for hygiene and communications while hospitalized. You can trust the medical staff, but you also need to trust yourself or a loved one to be your own best advocate.



Also available on prenumerique.ca



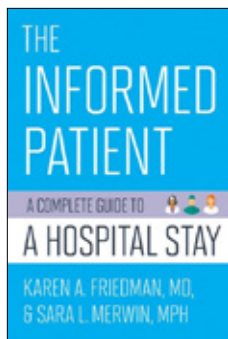
THE GOOD DOCTOR: WHY MEDICAL UNCERTAINTY MATTERS

Kenneth Brigham and Michael M.E. Johns. New York : Seven Stories Press, 2020, 238 p.

What makes a good doctor? It's not what people think. A doctor willing to face their own uncertainty in the face of illness and treatment might just be the best medicine. In *The Good Doctor*, Ken Brigham, MD, and Michael M.E. Johns, MD, argue that we need to change the way we think about health care if we want to be the healthiest we can be. Counterintuitive as it may seem, uncertainty is integral to medicine, and you want a doctor who knows that: someone who sees you as the unique case you are, someone who knows that data isn't everything, someone who is able to change her mind as the information changes.



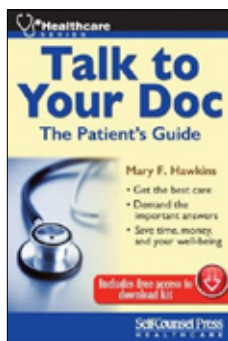
Also available on prenumerique.ca



THE INFORMED PATIENT: A COMPLETE GUIDE TO A HOSPITAL STAY

Karen A. Friedman and Sara L. Merwin. Ithaca: ILR Press, 2017, 228 p.

Even the most capable individuals are challenged when confronted with the complexity of the modern hospital experience. *The Informed Patient* is a guide and a workbook, divided into topical, focused sections with step-by-step instructions, insights, and tips to illustrate what patients and their families can expect during a hospital stay. Anyone who will experience a hospital stay – or friends or family who may be in charge of a patient's care – will find all the help and advice they could need in the detailed sections that cover every aspect of what they can expect.



TALK TO YOUR DOC: THE PATIENT'S GUIDE

Mary Hawkins. North Vancouver: Self-Counsel Press, 2015, 163 p.

Doctors are busier than ever and the Internet produces more information than ever for patients. Getting the right treatment can be challenging if you don't have the right approach. Mary Hawkins helps patients advocate for the best care with a guide on how to discuss your condition with your doctor.



GET INSIDE YOUR DOCTOR'S HEAD: 10 COMMONSENSE RULES FOR MAKING BETTER DECISIONS ABOUT MEDICAL CARE

Phillip K. Peterson. Baltimore: The Johns Hopkins University Press, 2013, 130 p.

In simple direct language Dr. Peterson tells readers how to understand their doctors' recommendations and ask intelligent questions about their validity.



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