



2021
EDITION

MULTIPLE SCLEROSIS

AND AMYOTROPHIC LATERAL 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 more than 179 member municipalities and corporations, for a total of over 317 autonomous libraries. Biblio-Aidants is available in more than 780 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 2021 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



DIABETES



**END-OF-LIFE
CARE**



**HEART DISEASE
AND STROKE**



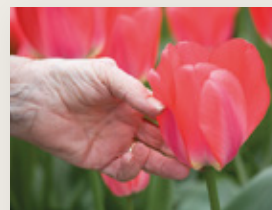
**INTELLECTUAL
DISABILITY**



**MENTAL
HEALTH**



**MULTIPLE
SCLEROSIS**



**PARKINSON'S
DISEASE**



**PHYSICAL
DISABILITY**



**PULMONARY
DISEASE**



**SENIORS
AND AGING**

RESOURCE DIRECTORY

ORGANIZATIONS AND ASSOCIATIONS

CANADA MORTGAGE AND HOUSING CORPORATION

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.

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

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.

REGROUPEMENT DES AIDANTS NATURELS DU QUÉBEC (RANQ)

Phone 514 524-1959
Website www.ranq.qc.ca/en

The Regroupement des aidants naturels du Québec (RANQ) includes about 111 organizations and associations providing direct services to Quebec caregivers: volunteer centres, caregivers regional groups, etc. A complete list of organizations by region can be found on the website of the Regroupement.

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.

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 CAREGIVER NETWORK

<https://thecaregivernetwork.ca/>

The Canadian Caregiver Network mission is to bring caregivers together to share their experiences. With Huddol, their social platform dedicated to caregivers, you can join a community committed to your well-being where you can exchange with professionals and others like you.

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

www.csep.ca/CMFiles/Guidelines/specialpops/CSEP_MS_PAGuidelines_adults_en.pdf

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.

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

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.

Programs and Services - Youth Programs

www.mssociety.ca/support-services/programs-and-services/205/youth-programs

This section presents various resources for young people whose parent has multiple sclerosis, including publications, Espoir Famille Youth Program and the MS Camp.

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.

REGROUPEMENT DES AIDANTS NATURELS DU QUÉBEC (RANQ)

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

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

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.

SOMEONE LIKE ME

<https://someonelikeme.ca>

Virtual community of teens and young adults living with multiple sclerosis, either because they have it themselves or because they have a personal connection to it. Testimonials, frank discussions and information on all aspects of life with multiple sclerosis.

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>

CONSUMER HEALTH COMPLETE

<http://numerique.banq.qc.ca/ressources/details/5278>

A database of periodicals, reference material and diverse medical sources gathered to meet the needs of users and not health professionals. It covers topics related to health, such as medicine, cancer, drugs, physical training, nutrition, child health as well as alternative medicines. Resources in several languages.

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.

SKILLSOFT BOOKS WELL-BEING ESSENTIALS

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

Books on health and well-being available online. This collection covers several topics, including hygiene, nutrition, stress management, work, work-life balance, relationships, family, consumption, etc.

READING SUGGESTIONS

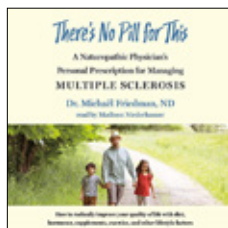
YOUR LIBRARY DOESN'T
HAVE THE BOOK THAT YOU
ARE LOOKING FOR?

LEARN ABOUT THE
LOAN SERVICE BETWEEN LIBRARIES.

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

NON-FICTION

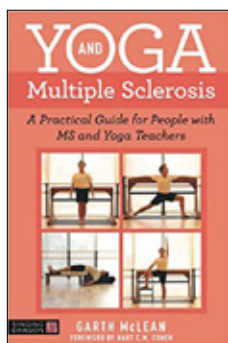
Multiple sclerosis



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.

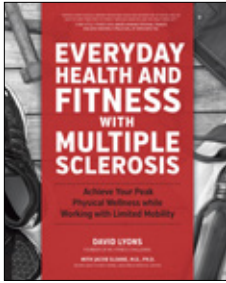
Most of us take for granted the little things in life—like walking out to the mailbox, socializing with friends, or enjoying a mug of hot coffee. But what if each daily activity required intensive planning and effort? That's what living with multiple sclerosis is like, and author Michaël Friedman knows 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.

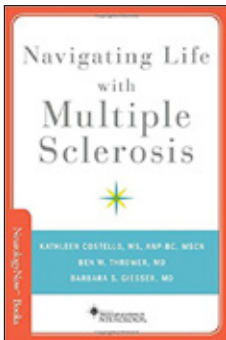
By providing an overview of key yoga postures and basic breathing techniques, this book demonstrates how people with Multiple Sclerosis can manage symptoms, and create a regular yoga practice in order to enhance physical and mental wellbeing. The book includes photos to demonstrate the yoga poses, as 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.

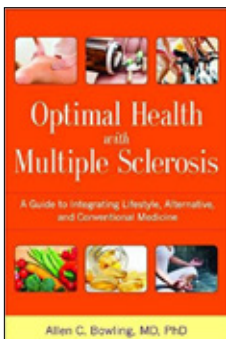
David Lyons' program is designed to help you maintain a healthy lifestyle and includes anecdotes from real people with MS, their limitations and how they followed this plan to reach their fitness goals. Find advice and solutions for overcoming mental hurdles, nutrition fundamentals to properly fuel workouts,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

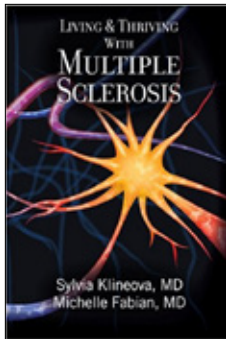
This book is a practical guide for meeting the challenges of this lifelong disease. MS may cause a myriad of symptoms and varies greatly from person to person. The authors demystify MS and offer practical solutions and guidance based upon their extensive combined clinical and research experience. The 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.

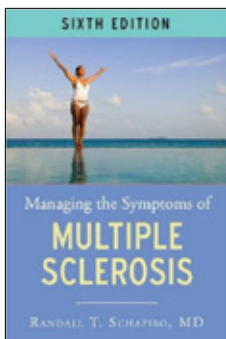
In addition to conventional medicine, many people with MS also use some form of alternative medicine and there is growing evidence and interest in the effects of lifestyle factors, such as diet and exercise on MS. This book provides unbiased and practical information about the MS relevant aspects of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



LIVING AND THRIVING WITH MULTIPLE SCLEROSIS

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

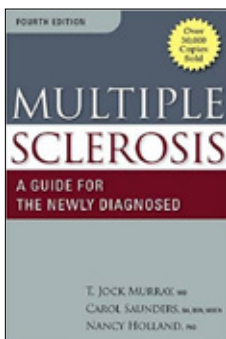
This short book will help you understand the basics of what multiple sclerosis is, what causes it, what the potential associated problems are, and what to expect from medications used for treatment. This book is designed to offer you guidance in easily understandable language. Drs. Kilineova and Fabian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



MANAGING THE SYMPTOMS OF MULTIPLE SCLEROSIS

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

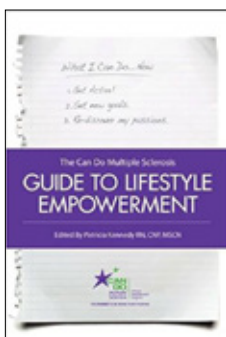
Updated and revised sixth edition of this guide to clinically tested and proven methods for effectively managing the symptoms characteristic of MS and MS treatment. Dr. Randall T. Schapiro provides information to manage both the disease and symptoms, and make everyday life easier. New chapters offer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



MULTIPLE SCLEROSIS: A GUIDE FOR THE NEWLY DIAGNOSED

Nancy J. Holland, T. Jock Murray and Stephen C. Reingold. New York: Demos Health, 2013, 265 p.

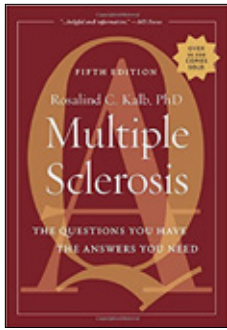
This book has been written specifically for anyone who has been diagnosed with multiple sclerosis, as well as family members and friends. It serves as a guide to learning about the disease, its potential impact on your life, and the medical treatments now available for managing it.



THE CAN DO MULTIPLE SCLEROSIS GUIDE TO LIFESTYLE EMPOWERMENT

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

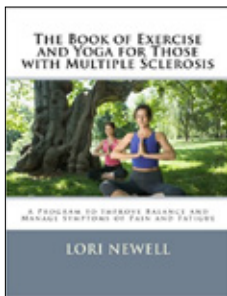
The chapters of this book were contributed by psychologists, doctors, nurses, and occupational and physiotherapists. The philosophy of the book is to help people with MS and those helping them to reclaim a sense of dignity, control and freedom by empowering them with knowledge, skills and confidence. 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.



THE BOOK OF EXERCISE AND YOGA FOR THOSE WITH MULTIPLE SCLEROSIS: A PROGRAM TO IMPROVE BALANCE AND MANAGE SYMPTOMS OF PAIN AND FATIGUE

Lori Newell. North Charleston: CreateSpace Independent Publishing, 2011, 288 p.

This book based on the author's experience outlines a comprehensive program specifically geared to those with Multiple Sclerosis. This book covers a wide variety of movement therapies such as range-of-motion exercises, low to no-impact aerobics, strength training, and yoga. This book offers many movement techniques that are specifically geared to and helpful for those with MS.

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.

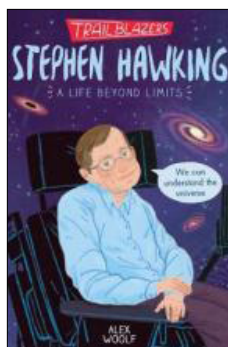


HOME ACCESSIBILITY: 300 TIPS FOR MAKING LIFE EASIER

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.

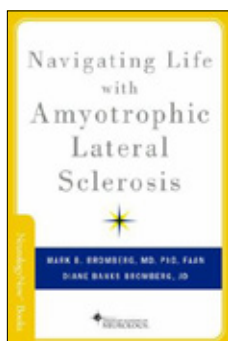
Amyotrophic lateral sclerosis



STEPHEN HAWKING: A LIFE BEYOND LIMITS

Alex Woolf. New York: Random House Children's Books, 2020, 168 p.

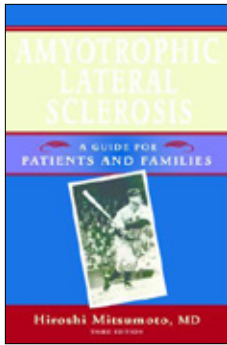
With spot art, charts, and graphic panels, this biography celebrates the life and accomplishments of Stephen Hawking



NAVIGATING LIFE WITH AMYOTROPHIC LATERAL SCLEROSIS

Mark B. Bromberg, MD, PhD, FAHA, Diane Banks Bromberg, JD. New York: Oxford University Press, 2017, 250 p.

This guide covers all aspects of managing ALS, from the onset of symptoms, diagnosis, treatments, and coping strategies, to the use of home health care or hospice, and new research in the field. It also covers two perspectives: one author is a neurologist with 30 years of experience treating ALS patients, and the other author experienced first-hand the issues in providing care for a parent with ALS.



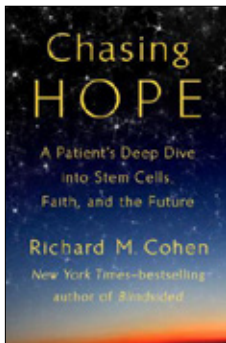
AMYOTROPHIC LATERAL SCLEROSIS: A GUIDE FOR PATIENTS AND FAMILIES

Hiroshi Mitsumoto. New York: Demos Health, 2009, 475 p.

ALS, also known as Lou Gehrig's disease, cannot be cured but it can be treated. A great deal can be done to treat the symptoms of ALS, to improve an individual's quality of life, and to help families, caregivers, and loved ones to cope with the disease. This extensively revised and rewritten new edition of the bestselling guide addresses all of those needs, and brings up-to-date important information to those living with the reality of ALS.

LIFE STORIES, BIOGRAPHIES AND TESTIMONIALS

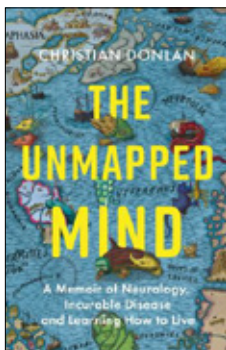
Multiple sclerosis



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.

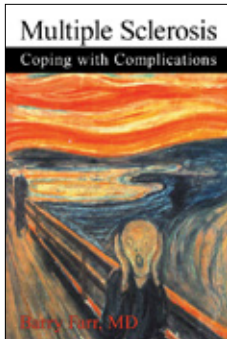
Shortly after his daughter Leontine was born, Christian Donlan's world shifted an inch to the left. He started to miss light switches and door handles when reaching for them. He would injure himself in a hundred stupid ways every day. These strange experiences were the early symptoms of multiple sclerosis, 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.

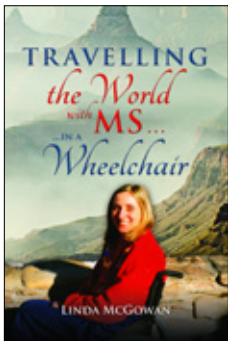
Dr. Farr has battled MS for 24 years. Speaking from personal experience, this book aims to help patients deal with reality of chronic complications of MS. Most of the text deals with Dr. Farr's own challenges, how he dealt with them and then attempts to generalize his experiences to help other people 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.

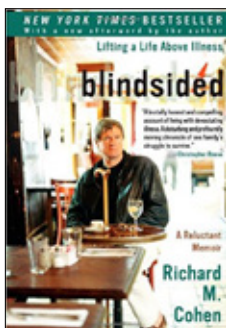
When attorney Jeffrey N. Gingold misplaced his wife on the living room couch, and became lost while driving just blocks from his home, little did he know that he was experiencing a hidden symptom of multiple sclerosis: cognitive difficulties. This book presents a personal account of one man's anguishing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

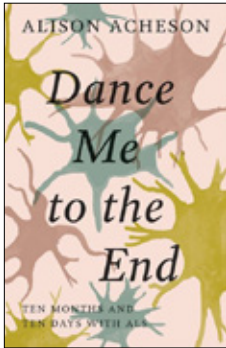


BLINDSIDED: LIFTING A LIFE ABOVE ILLNESS: A RELUCTANT MEMOIR

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.

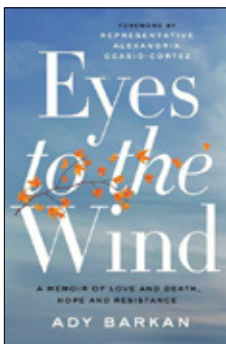
Amyotrophic lateral sclerosis



DANCE ME TO THE END: TEN MONTHS AND TEN DAYS WITH ALS

Alison Acheson. Victoria: Brindle & Glass, 2019, 314 p.

A profoundly honest and intensely personal story of a woman who cares for her husband after the devastating terminal diagnosis of ALS. Marty, age 57, was given a preliminary diagnosis of ALS by his family doctor. Seven weeks later, the diagnosis was confirmed by a neurologist. Ten months and ten days later, Marty passed away. *Dance Me to the End* is an evocative memoir about the emotional impact of witnessing a loved one suffer from a neurological, degenerative, and terminal disease. This is a detailed account of grief, shock and pain coexisting with the levity, laughter and love shared with her husband and sons in those final months of Marty's life.



EYES TO THE WIND: A MEMOIR OF LOVE AND DEATH, HOPE, AND RESISTANCE

Ady Barkan. New York: Atria Books, 2019, 281 p.

At thirty-two, Ady Barkan had everything he wanted: a fulfilling career in the progressive movement, a brilliant wife, and a beautiful newborn son. Then his luck ran out. What he thought might be carpal tunnel was in fact ALS, a neurological disease that would probably paralyze and kill him quickly. But then, with his life slipping away and American democracy under grave threat, he turned a devastating diagnosis into his most potent tool. [This book] is a rousing memoir featuring intertwining narratives about determination, perseverance, and now to live a life of purpose. The first traces Ady's battle with ALS. The second shows his journey from a goofy political nerd to a prominent figure in the progressive movement, becoming one of today's most vocal advocates for social justice.



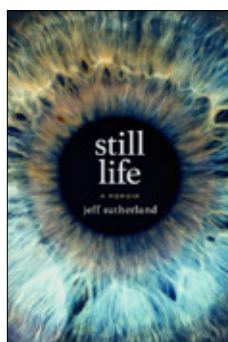
Also available on pretnumerique.ca



THE BEST OF THE WORST NEWS: TALES FROM AROUND THE WORLD AND MY LIFE WITH ALS

Norm MacIsaac. London: Insomniac Press, 2019, 324 p.

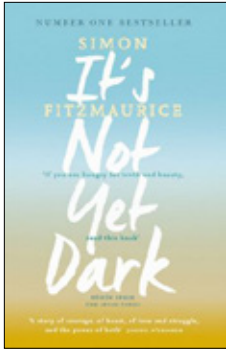
I was alone on that icy cold December day when I received my worst news in 2014... I went for that definitive test, and I wasn't the least bit prepared to be diagnosed with an incurable disease... I didn't know what to do with a prognosis of just a few years to live, growing more and more disabled until I could no longer move, swallow and, ultimately, breathe. I looked for a book that would guide me through this process. I wondered what to expect, how to share this news with colleagues, kith, and kin. Would I get angry? Sad? Depressed? How long would I remain in denial? But I never did find that book. Instead, I began writing it.' Norm MacIsaac writes in the opening of *The Best of the Worst News*. Written over several years as the disease progressed, the author explores living with amyotrophic lateral sclerosis (ALS), commonly referred to as Lou Gehrig's disease. This is a series of intertwined autobiographical tales set in over a dozen different countries spanning nearly half a century. It's not about the disease, but the emotional and psychological journey that accompanies such an earth-shattering diagnosis. Travel with him around the world and back in time as he tells stories of the people and places that inspired him to defy this incurable, degenerative disease, to embrace a positive perspective and live every day to the fullest.



STILL LIFE

Jeff Sutherland. Toronto: Sutherland House, 2019, 181 p.

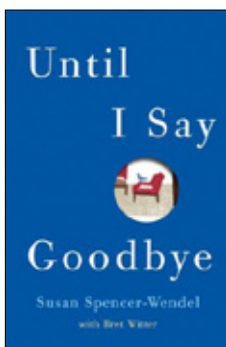
Father, husband, athlete, medical doctor, Jeff Sutherland had built a perfect life for himself and his family... then he noticed that he was losing strength in his left arm. He visited a specialist and from that appointment, he writes, "deep personal loss for some unknown reason wrapped its tentacles around me and my family." Diagnosed with ALS, he lost his abilities to walk and speak within two years and, confined to a wheelchair, was forced to retire from his life's work as a physician at forty-three. Not long after, he was locked in his own inanimate body, unable to eat, drink, or breathe without assistance. His meals were delivered through a feeding tube, and a ventilator controlled his lungs through an opening in his throat. The only parts of his body he was able to move voluntarily were his eyes. Despite these extreme limitations, Sutherland made peace with his disease and, surrounded by his loving family, found happiness again – only to suffer another soul-shattering loss. His eldest son, Zachary, passed alongside his girlfriend in a freak kayaking accident in the river behind the family home. "Despite everything I lost through ALS," he says, Zachary's death was worse. Yet again, through a long process of suffering and healing, Sutherland was able to accept his loss and find a renewed sense of purpose and meaning in his constricted life.



IT'S NOT YET DARK

Simon Fitzmaurice. Dublin: Hachette Books Ireland, 2015, 176 p.

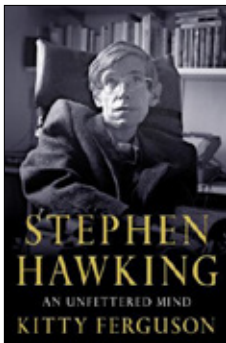
In 2008, Simon Fitzmaurice was diagnosed with Motor Neurone Disease (MND). He was given four years to live. In 2010, in a state of lung-function collapse, Simon knew with crystal clarity that now was not his time to die. Against all prevailing medical opinion, he chose to ventilate in order to stay alive. Here, the young filmmaker, a husband and father of five small children draws us deeply into his inner world.



UNTIL I SAY GOOD-BYE: MY YEAR OF LIVING WITH JOY

Susan Spencer-Wendel and Bret Witter. Toronto: HarperCollins Canada, 2013, 256 p.

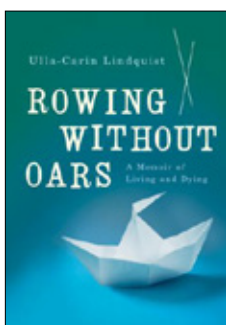
In June 2011, Susan Spencer-Wendel was diagnosed with amyotrophic lateral sclerosis (ALS), more commonly known as Lou Gehrig's disease. It is a disease that systematically destroys the nerves that power muscles; Susan, forty-five years old and a mother of three, already walks with braces and is losing her ability to speak. Though Susan cannot stop the rapid decline of her body, she refuses to let her life stop before its time.



STEPHEN HAWKING: AN UNFETTERED MIND

Kitty Ferguson. New York: Palgrave Macmillan, 2012, 310 p.

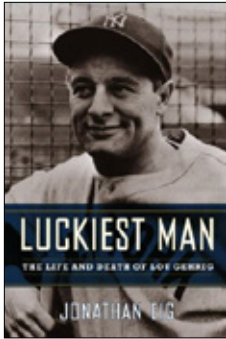
Told in his youth that he would not live past his 20s, Hawking will turn 70 in 2012, and today he continues to inspire millions, drawing rock-concert-sized crowds wherever he lectures. Science writer Kitty Ferguson has been working with Stephen Hawking for decades, and produced an internationally bestselling biography of his life in 1992. Now, she brings his life as well as his scientific discoveries up to date.



ROWING WITHOUT OARS

Ulla-Carin Lindquist. New York: Viking, 2006, 197 p.

Ulla-Carin Lindquist was happily married with four adoring children and a successful career as a newscaster. All of that changed when, as her fiftieth birthday drew near, she began to notice small failures of strength and strange numbing sensations in her hands and arms. As she set out to understand her illness, she began a journal recounting her failing health. Soon the diagnosis became terribly clear: she was suffering from ALS, or Lou Gehrig's disease.



LUCKIEST MAN: THE LIFE AND DEATH OF LOU GEHRIG

Jonathan Eig. New York: Simon & Schuster, 2005, 420 p.

Lou Gehrig was the Iron Horse, baseball's strongest and most determined superstar -- struck down in his prime by a disease that now bears his name. But who was Lou Gehrig, really? How did he cope with the illness that abruptly ended his career and drained him of his legendary power? Drawing on dozens of new interviews and hundreds of pages of Gehrig's personal and previously unpublished letters, this definitive biography gives us a deeper, more intimate understanding his life.

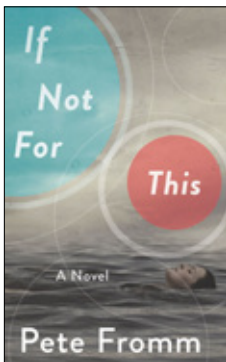
NOVELS

Multiple sclerosis

**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

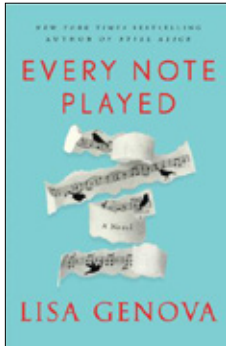
After meeting at a boatman's bash Maddy and Dalt embark on a lifelong affair. An adventurous couple they open their own river business and prosper. Then they confronted with a diagnosis of multiple sclerosis at the same time they find out that Maddie is pregnant.

**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.

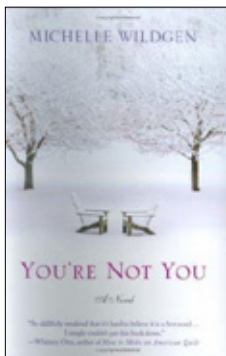
Amyotrophic lateral sclerosis



EVERY NOTE PLAYED

Lisa Genova. New York: Scout Press, 2018, 307 p.

A once accomplished concert pianist, Richard now has ALS. As he becomes increasingly paralyzed and is no longer able to live on his own, Karina becomes his reluctant caretaker. As Richard's muscles, voice, and breath fade, both he and Karina try to reconcile their past before it's too late.



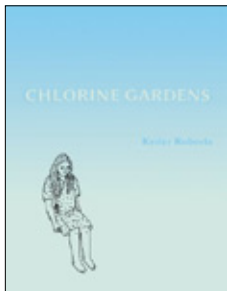
YOU'RE NOT YOU

Michelle Wildgen. New York: Thomas Dunne Books, 2006, 274 p.

College student Bec is dangerously adrift. Self-conscious and increasingly uncertain about her long-term plans, she's studying a major that no longer interests her and is caught up in a bewildering affair with a married professor. In an impulsive attempt to redeem herself, she answers a want ad seeking a caregiver. What she finds is a wealthy, cultivated woman in her midthirties, Kate, who is now in the advanced stages of ALS (Lou Gehrig's disease). Bec is soon a vital part of her employer's household, and their increasing closeness transforms both women's lives and their relationships.

COMICS

Multiple sclerosis

**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.

Amyotrophic lateral sclerosis

**HAWKING**

Jim Ottaviani, Leland Myrick (ill.) and Aaron Polk (ill.). New York: First Second, 2019, 298 p.

From his early days at the St Albans School and Oxford, Stephen Hawking's brilliance and good humor were obvious to everyone he met. A lively and popular young man, it's no surprise that he would later rise to celebrity status.

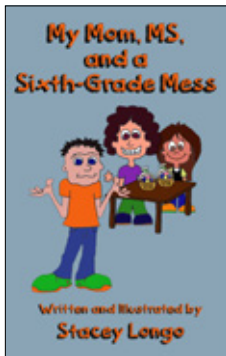
 Also available on prenumerique.ca

**LAST THINGS: A GRAPHIC MEMOIR OF LOSS AND LOVE**

Marissa Moss. Newburyport: Conari Press, 2017, 173 p.

After returning home from a year abroad, Marissa's husband, Harvey was diagnosed with ALS. The disease progressed quickly and Marissa was soon consumed with caring for Harvey while trying to keep life as normal as possible for their children. This is not a story about the redemptive power of terminal illness.

YOUTH LITERATURE

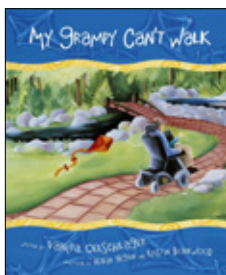


AGES 4 TO 8

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.

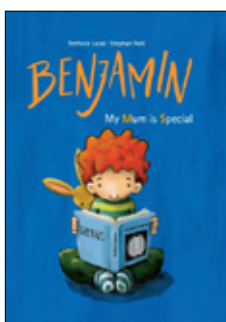


AGES 4 TO 8

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.

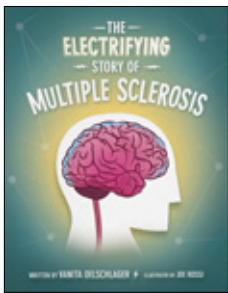


AGES 6 TO 18

THE LIFE OF STEPHEN HAWKING

Jane Kent and Isabel Muñoz (ill.). Milan: White Star Kids, 2019, 44 p.

Describes the life and accomplishments of the world-famous English physicist who suffered from amyotrophic lateral sclerosis.

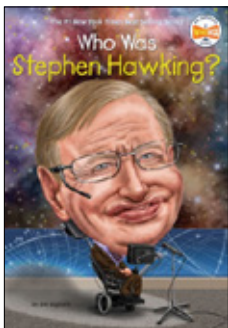


AGES 7 TO 10

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 12

WHO WAS STEPHEN HAWKING?

Jim Gigliotti and Gregory Copeland (ill.). New York: Penguin Workshop, 2019, 106 p.

Learn more about the renowned British scientist, professor, and author who spent his entire career trying to answer the question: “Where did the universe come from?” Stephen Hawking was born exactly three hundred years after the death of the scientist Galileo, so maybe it was written in the stars that he would become a famous scientist in his own right. Although he was diagnosed with a neurological disease at age 21, Stephen did not let the illness define his life. Known for his groundbreaking work in physics, and identified by his wheelchair and computerized voice system, Stephen continued his research until his death in 2018. He is best known for his black hole theories and his best-selling book *A Brief History of Time*. Stephen Hawking is an example of a person who had a great mind, but an even greater spirit.



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!

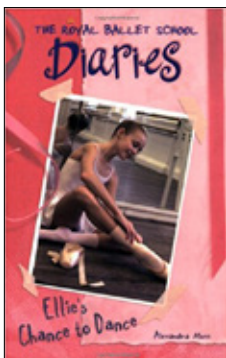


AGES 9 TO 12

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.

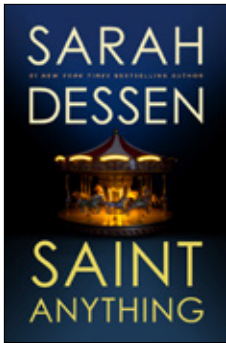


AGES 10+

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.

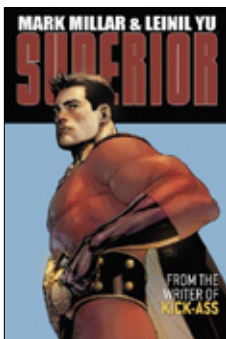


AGES 12+

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.

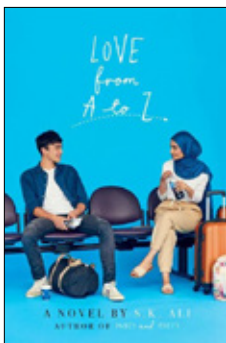


AGES 12+

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

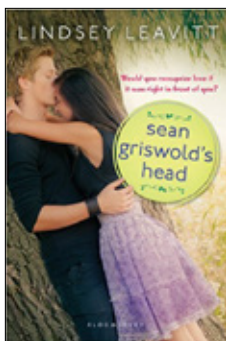
LOVE FROM A TO Z

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.



Also available on pretnumerique.ca

**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

Multiple sclerosis



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.



Amyotrophic lateral sclerosis

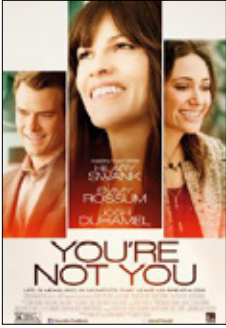


THE THEORY OF EVERYTHING

James Marsh. 2014, 123 min.

A look at the relationship between the famous physicist Stephen Hawking, who suffered from ALS, and his wife.





YOU'RE NOT YOU

George C. Wolfe. 2014, 102 min.

Drama (United States). A brash college student and aspiring rock star takes a job assisting a classical pianist just diagnosed with ALS.



DOCUMENTARIES

Multiple sclerosis



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.

Amyotrophic lateral sclerosis



GLEASON

Clay Tweel. 2016, 111 min.

After he is diagnosed with ALS, former professional football player Steve Gleason begins making a video diary for his unborn son, as he, his wife, and their friends and family work to raise money for ALS patients as his disease progresses.



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

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.

Toll free line **1-800-NOTAIRE (668-2473)**

Chat free of charge with a notary.

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 <https://www.curateur.gouv.qc.ca/cura/en/>

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.

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.

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 works

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.

GOVERNEMENT DU QUÉBEC – COPING WITH A LOSS OF INDEPENDENCE

<https://www.quebec.ca/en/government/services-quebec/lossofindependence/>

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.

Finally, you may choose to fill out the “My personalized itinerary” questionnaire to obtain a list of steps to take to benefit from the government programs and services intended for you that is specific to your situation.

GOVERNEMENT DU QUÉBEC – 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.

GOVERNEMENT DU QUÉBEC – 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.

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.

HEALTHCARE EXCELLENCE CANADA – 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.

HEALTHCARE EXCELLENCE CANADA – 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 – GRAND PUBLIC

www.opq.org/fr-CA/grand-public/

The “Grand 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.

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 RESPONSABILITIES

<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

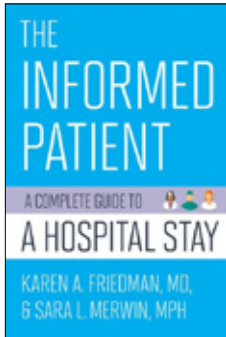
In this web guide, Éducaloi provides clear and useful legal information intended for caregivers.

ÉDUCALOI – 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.

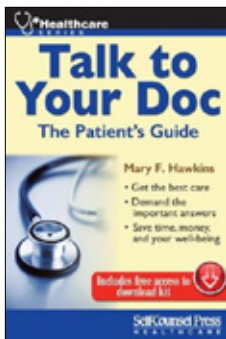
READING SUGGESTIONS



THE INFORMED PATIENT: A COMPLETE GUIDE TO A HOSPITAL STAY

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

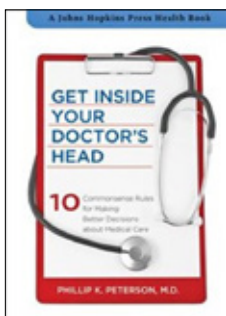
Even the most capable individuals are challenged when confronted with the complexity of the modern hospital experience. The Informed Patient is a guide and a workbook, divided into topical, focused sections with step-by-step instructions, insights, and tips to illustrate what patients and their families 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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