

MULTIPLE SCLEROSIS AND AMYOTROPHIC LATERAL SCLEROSIS

INFORMATION FOR CAREGIVERS





BIBLIOAIDANTS®

BETTER INFORMED
TO BETTER HELP®

ABOUT

Biblio-Aidants is a program of the Quebec Public Library Association. Close to 175 municipalities and corporations are members of the Quebec Public Library Association for a total of more than 318 service locations covering 84% of the Quebec population. Biblio-Aidants is available in more than 760 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-Aidants is an initiative of the Charlemagne, L'Assomption and Repentigny libraries. 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-Aidants* booklets and additional information.

www.biblioaidants.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 2020 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-Aidants 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 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-Aidants, please visit www.biblioaidants.ca/criteria

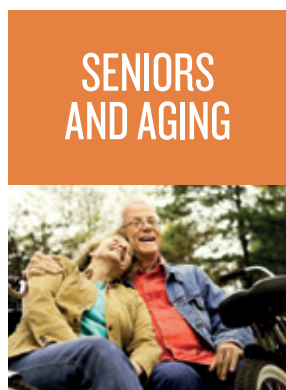
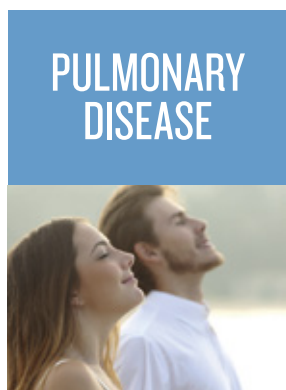
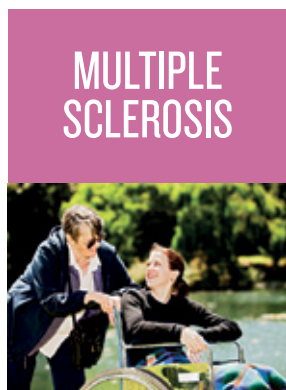
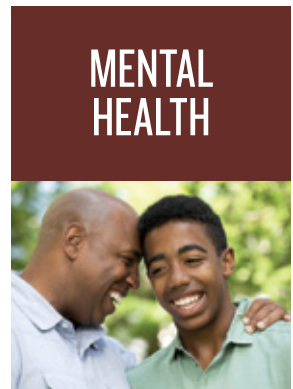
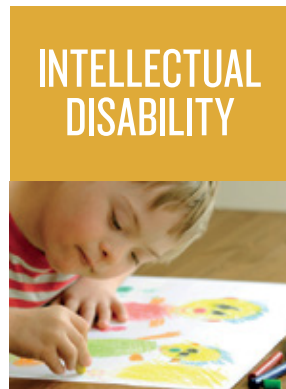
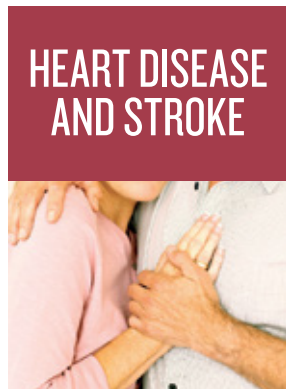
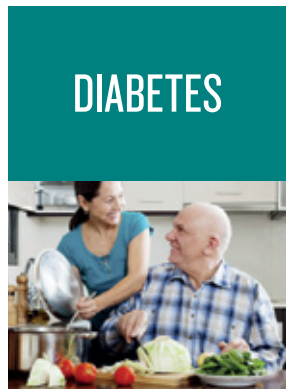
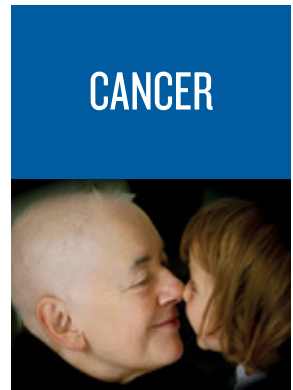
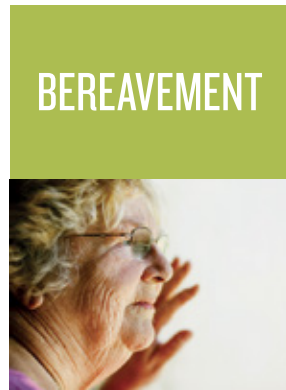
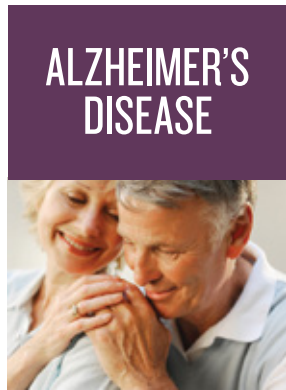
CAREGIVERS



CAREGIVERS BOOKLET

This booklet is complementary to all booklets of the Biblio-Aidants Program. It highlights useful resources to support caregivers and health system users. The resources selection takes into account a patient-partner approach that seeks to make health system users autonomous, thereby helping them to make their own informed choices.

OTHER BOOKLETS AVAILABLE



RESOURCE DIRECTORY



ORGANIZATIONS AND ASSOCIATIONS

CANADA MORTGAGE AND HOUSING CORPORATION

Toll free 1 800 668-2642
Email contactcentre@cmhc.ca
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.

CONSEIL POUR LA PROTECTION DES MALADES

Phone 514 861-5922
Toll free 1 877 276-2433
Email info@cpm.qc.ca
Website www.cpm.qc.ca

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.

KÉROUL

Phone 514 252-3104
Email infos@keroul.qc.ca
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 D'AÎNÉS

Toll free 1 855 852-7784
Email info-aidant@lappui.org
Website www.lappui.org/en

L'Appui pour les proches aidants d'aînés was created in 2009 to help improve the quality of life of those providing care to older adults by facilitating their daily tasks and ensuring that they take full advantage of available resources. We have a strong presence throughout Quebec, thanks to 17 regional Appui offices and a specific agreement for Nunavik. Each regional office supports local organizations promoting caregivers' well-being and providing services adapted to their needs. Each region manages its own fund and invests in a variety of direct services for caregivers of older adults.

MULTIPLE SCLEROSIS SOCIETY OF CANADA

Toll free 1 800 268-7582
Email info@mssociety.ca
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 Chapter

Phone 514 849-7591
Email info.qc@mssociety.ca
Website https://mssociety.ca/division/quebec-division

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

OFFICE DES PERSONNES HANDICAPÉES DU QUÉBEC

Toll free 1 800 567-1465
Email info@ophq.gouv.qc.ca
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
Email info@ranq.qc.ca
Website www.ranq.qc.ca

The Regroupement des aidants naturels du Québec (RANQ) includes about 60 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. Website in French.

REGROUPEMENT PROVINCIAL DES COMITÉS DES USAGERS (RPCU)

Phone 514 436-3744
Email info@rpcu.qc.ca
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

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 ENTERTAINMENT

www.access2card.ca

This site provides information on the Access 2 Entertainment program, a program dedicated to offering more 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

Publications and reports

www.cmhc-schl.gc.ca/en/data-and-research/publications-and-reports

Under the tab “Accessible & Adaptable Housing”, you will find a list of downloadable fact sheets with information on integrating accessibility features to plan safe living spaces.

Affordable Housing Programs in Quebec

www.cmhc-schl.gc.ca/en/developing-and-renovating/develop-new-affordable-housing/programs-and-information/provincial-territorial-programs-information/affordable-housing-programs-in-quebec

The CMHC is responsible for affordable housing programs in Quebec. A number of financial assistance programs are offered, including residential renovation and adaptation.

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

www.cra-arc.gc.ca/disability/

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.aqlph.qc.ca/en/companion-leisure-card/

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.

GOVERNMENT OF QUEBEC – COPING WITH A LOSS OF INDEPENDENCE

www.quebec.ca/en/government/services-quebec/lossofindependence/

This site provides a guide on the various government programs and services for which a person with a disability may be eligible for. It covers topics related to health and social services, housing, home care services, tax credits, justice, work and employment, transportation, and various other topics.

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/home/ovc-20131882

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. The themes of the “MS in focus” guides are: 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

https://mssociety.ca/support-services/programs-and-services/205/youth-programs#_ga=2.44491809.428096161.1586205706-1268710601.1585862367

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)

Publications

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

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

Taking care of myself while taking care of others

www.mcdc.info/uploads/pdf/LivreProchesaidant.pdf

REVENU QUÉBEC - DISABLED INDIVIDUALS

www.revenuquebec.ca/en/citizens/your-situation/disabled-individuals/

This page presents the list of tax credits, exemptions and flexibilities to which a disabled person may be entitled.

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

www.habitation.gouv.qc.ca/english.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>

Provides information of the genetic elements of 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.nlm.nih.gov/medlineplus/medlineplus.html

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>

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.

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.

READING SUGGESTIONS

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

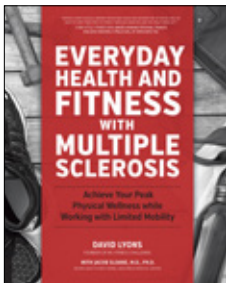
LEARN ABOUT THE
LOAN SERVICE BETWEEN LIBRARIES.

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



NON-FICTION

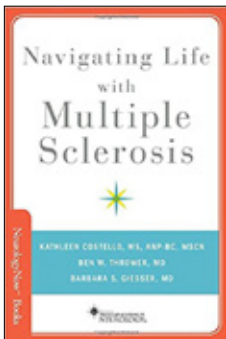
Multiple Sclerosis



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.

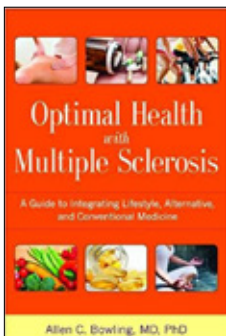
David Lyons' program is designed to help you maintain a healthy lifestyle and includes anecdotes from real people with MS, their limitations and how they followed this plan to reach their fitness goals. Find advice and solutions for overcoming mental hurdles, nutrition fundamentals to properly fuel workouts,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

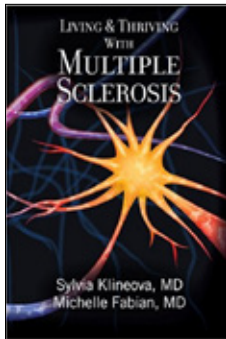
This book is a practical guide for meeting the challenges of this lifelong disease. MS may cause a myriad of symptoms and varies greatly from person to person. The authors demystify MS and offer practical solutions and guidance based upon their extensive combined clinical and research experience. The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

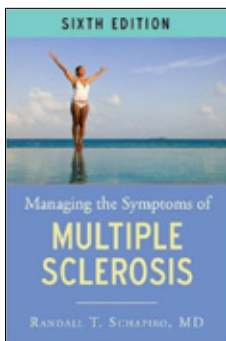
In addition to conventional medicine, many people with MS also use some form of alternative medicine and there is growing evidence and interest in the effects of lifestyle factors, such as diet and exercise on MS. This book provides unbiased and practical information about the MS relevant aspects of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

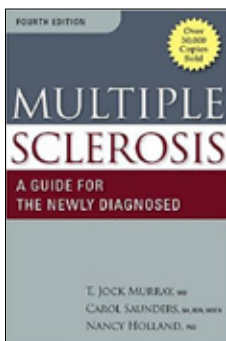
This short book will help you understand the basics of what multiple sclerosis is, what causes it, what the potential associated problems are, and what to expect from medications used for treatment. This book is designed to offer you guidance in easily understandable language. Drs. Kilineova and Fabian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



MANAGING THE SYMPTOMS OF MULTIPLE SCLEROSIS

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

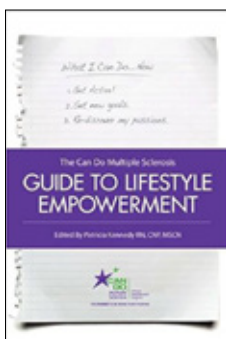
Updated and revised sixth edition of this guide to clinically tested and proven methods for effectively managing the symptoms characteristic of MS and MS treatment. Dr. Randall T. Schapiro provides information to manage both the disease and symptoms, and make everyday life easier. New chapters offer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

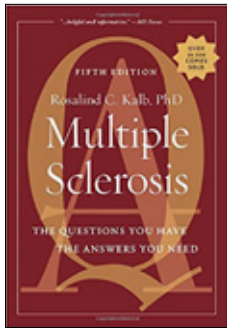
This book has been written specifically for anyone who has been diagnosed with multiple sclerosis, as well as family members and friends. It serves as a guide to learning about the disease, its potential impact on your life, and the medical treatments now available for managing it.



THE CAN DO MULTIPLE SCLEROSIS GUIDE TO LIFESTYLE EMPOWERMENT

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

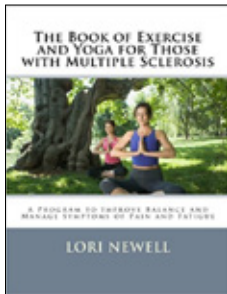
The chapters of this book were contributed by psychologists, doctors, nurses, and occupational and physiotherapists. The philosophy of the book is to help people with MS and those helping them to reclaim a sense of dignity, control and freedom by empowering them with knowledge, skills and confidence.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

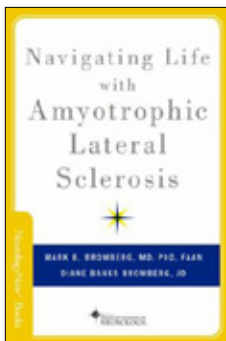


HOME ACCESSIBILITY: 300 TIPS FOR MAKING LIFE EASIER

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.

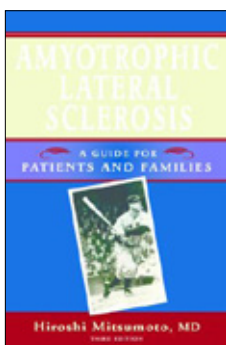
Amyotrophic Lateral Sclerosis



NAVIGATING LIFE WITH AMYOTROPHIC LATERAL SCLEROSIS

Mark B. Bromberg, Diane Banks Bromberg. 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.



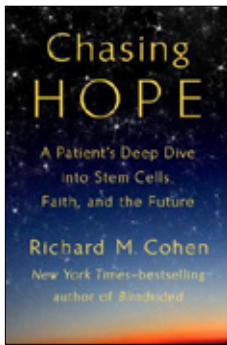
AMYOTROPHIC LATERAL SCLEROSIS: A GUIDE FOR PATIENTS AND FAMILIES

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

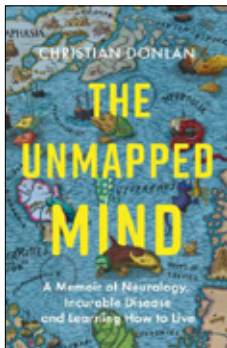
Multiple Sclerosis



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.

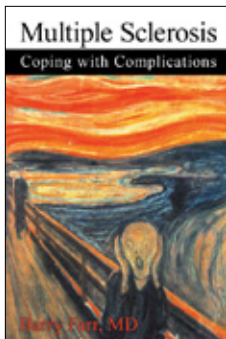
Shortly after his daughter Leontine was born, Christian Donlan's world shifted an inch to the left. He started to miss light switches and door handles when reaching for them. He would injure himself in a hundred stupid ways every day. These strange experiences were the early symptoms of multiple sclerosis,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

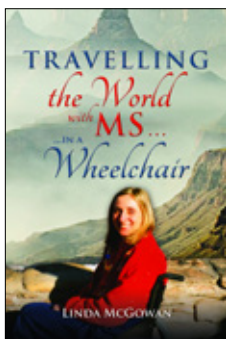
Dr. Farr has battled MS for 24 years. Speaking from personal experience, this book aims to help patients deal with reality of chronic complications of MS. Most of the text deals with Dr. Farr's own challenges, how he dealt with them and then attempts to generalize his experiences to help other people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

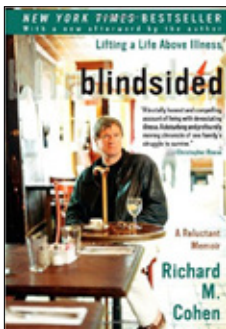
When attorney Jeffrey N. Gingold misplaced his wife on the living room couch, and became lost while driving just blocks from his home, little did he know that he was experiencing a hidden symptom of multiple sclerosis: cognitive difficulties. This book presents a personal account of one man's anguishing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

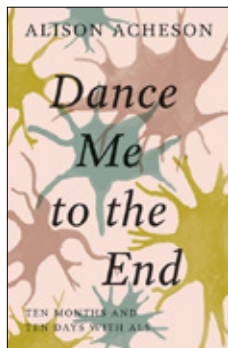


BLINDSIDED: LIFTING A LIFE ABOVE ILLNESS: A RELUCTANT MEMOIR

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.

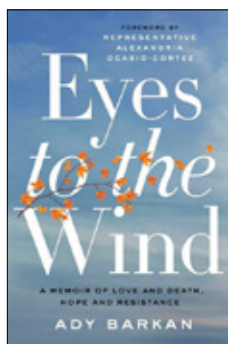
Amyotrophic Lateral Sclerosis



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.



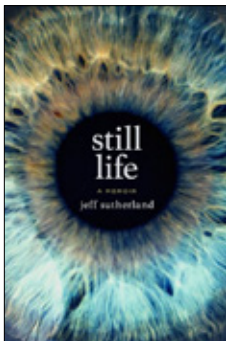
Also available on pretnumerique.ca



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

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

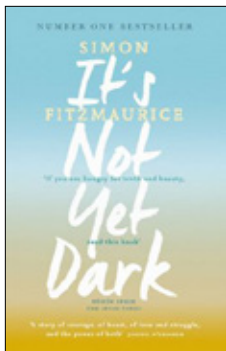
I was alone on that icy cold December day when I received my worst news in 2014... I went for that definitive test, and I wasn't the least bit prepared to be diagnosed with an incurable disease... I didn't know what to do with a prognosis of just a few years to live, growing more and more disabled until 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.

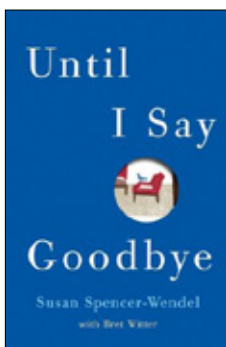
Father, husband, athlete, medical doctor, Jeff Sutherland had built a perfect life for himself and his family... then he noticed that he was losing strength in his left arm. He visited a specialist and from that appointment, he writes, "deep personal loss for some unknown reason wrapped its tentacles 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.

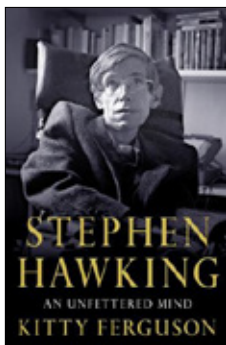
In 2008, Simon Fitzmaurice was diagnosed with Motor Neurone Disease (MND). He was given four years to live. In 2010, in a state of lung-function collapse, Simon knew with crystal clarity that now was not his time to die. Against all prevailing medical opinion, he chose to ventilate in order to stay alive. 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.

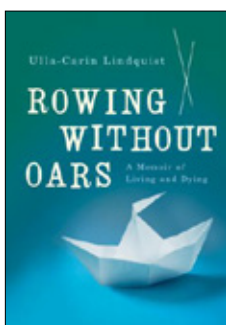
In June 2011, Susan Spencer-Wendel was diagnosed with amyotrophic lateral sclerosis (ALS), more commonly known as Lou Gehrig's disease. It is a disease that systematically destroys the nerves that power muscles; Susan, forty-five years old and a mother of three, already walks with braces and is losing 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.

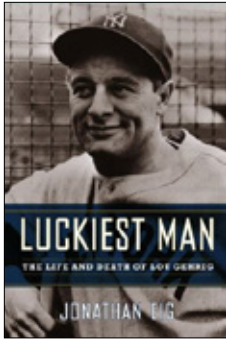
Told in his youth that he would not live past his 20s, Hawking will turn 70 in 2012, and today he continues to inspire millions, drawing rock-concert-sized crowds wherever he lectures. Science writer Kitty Ferguson has been working with Stephen Hawking for decades, and produced an internationally bestselling 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.



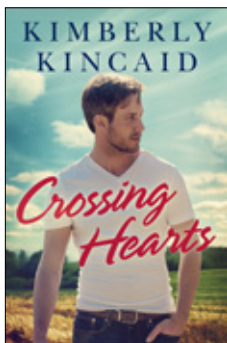
LUCKIEST MAN: THE LIFE AND DEATH OF LOU GEHRIG

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.

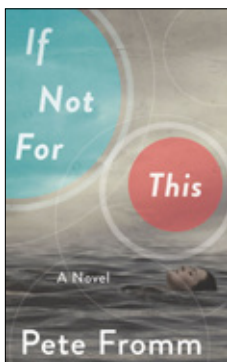
NOVELS

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

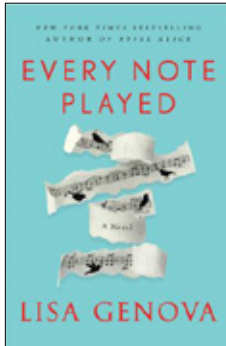
After meeting at a boatman's bash Maddy and Dalt embark on a lifelong affair. An adventurous couple they open their own river business and prosper. Then they confronted with a diagnosis of multiple sclerosis at the same time they find out that Maddie is pregnant.

**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.

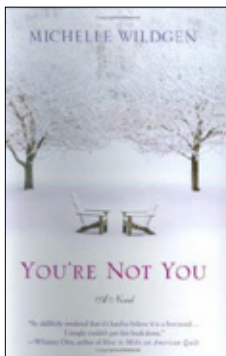
Amyotrophic Lateral Sclerosis



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

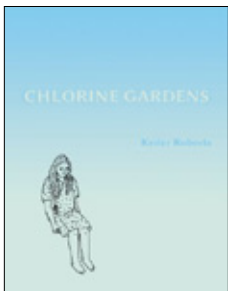
Multiple Sclerosis

**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*

**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.

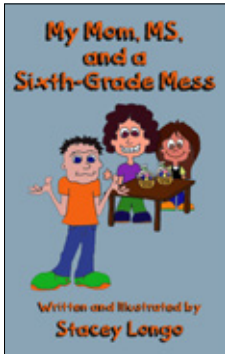
Amyotrophic Lateral Sclerosis

**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.

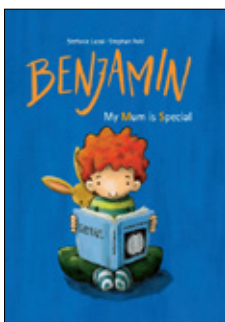


AGES 4 TO 8

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.

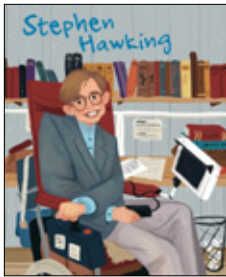


AGES 6 TO 9

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.

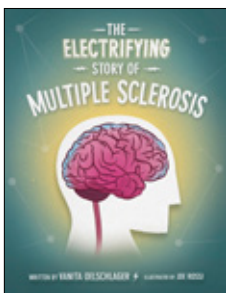


AGES 6 TO 18

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.

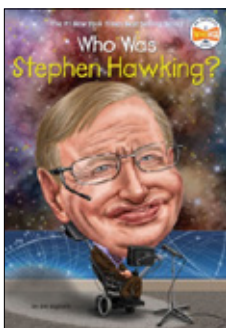


AGES 7 TO 10

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!

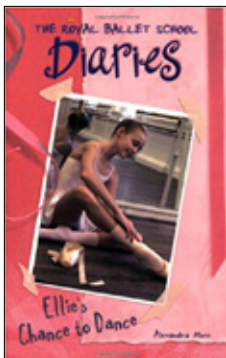


AGES 9 TO 12

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.

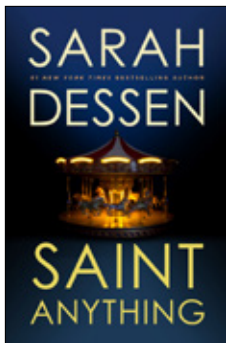


AGES 10+

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.

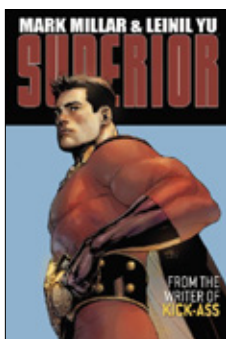


AGES 12+

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.

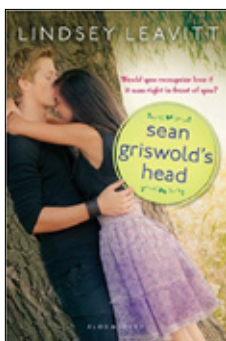


AGES 12+

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+

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.

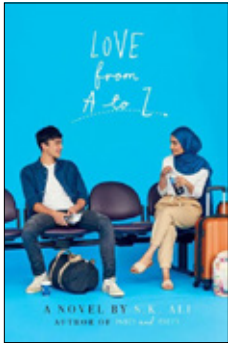


AGES 14+

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.



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 prenumerique.ca

FILM, SERIES AND PROGRAM SUGGESTIONS

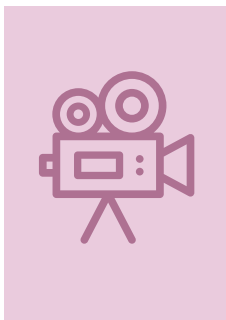
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LIBRARIES HAVE RICH COLLECTIONS OF
DVDS AND BLU-RAYS THAT CAN BE BORROWED.
THEY ALSO OFFER ONLINE ACCESS TO MOVIES,
SERIES AND PROGRAMS. CHECK WITH YOUR
LOCAL LIBRARY.



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.



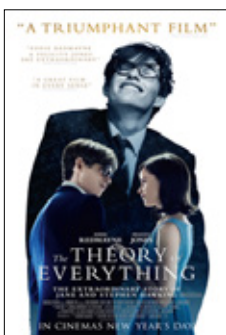
HILARY AND JACKIE

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.

G

DOCUMENTARIES

Multiple Sclerosis



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.

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.

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