

# 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 165 municipalities and corporations are members of the Quebec Public Library Association for a total of more than 310 service locations covering 80% of the Quebec population.

*Biblio-Aidants* is available in more than 850 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.

## COORDINATION - QUEBEC PUBLIC LIBRARY ASSOCIATION

Fannie Labonté, Executive Assistant  
Eve Lagacé, Executive Director

## BIBLIOGRAPHIC RESEARCH

Gabrielle C. Beaulieu, Project manager  
Magali Boileau-Morin, Consultant librarian, ABPQ  
Dahlal Mohr-Elzeki, McGill University Health Centre  
Eileen Beany Peterson, Montreal Neurological Institute and Hospital  
Cassandra Ricafort, Montreal Children's Hospital  
John Vogas, Montreal Neurological Institute and Hospital  
Olivia Yu, Cedars CanSupport Resource Centre

## LAYOUT AND DESIGN

Steve Poutré DGA

## VISIT OUR WEBSITE

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

[www.biblioaidants.ca](http://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 2019 and will be updated on an annual basis.

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Association des bibliothèques publiques du Québec  
1453, rue Beaubien Est, bureau 215, Montréal (Québec) H2G 3C6  
info@abpq.ca | www.abpq.ca

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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](http://www.biblioaidants.ca/criteria)

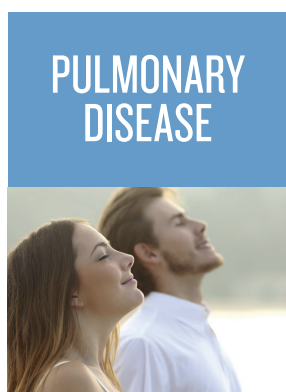
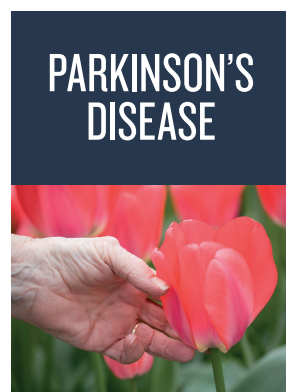
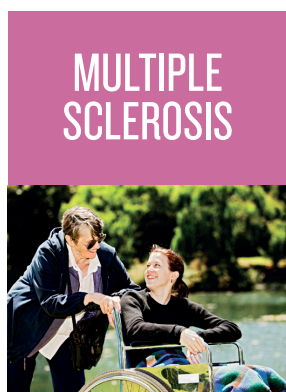
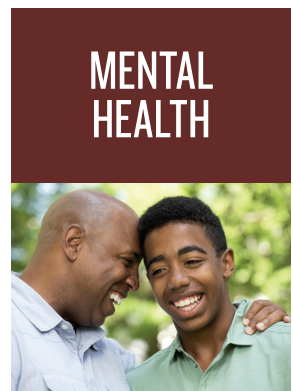
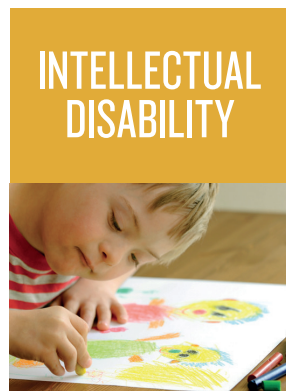
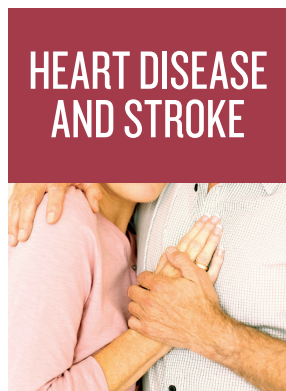
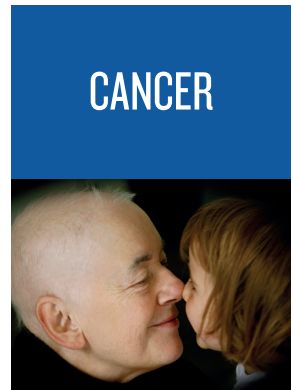
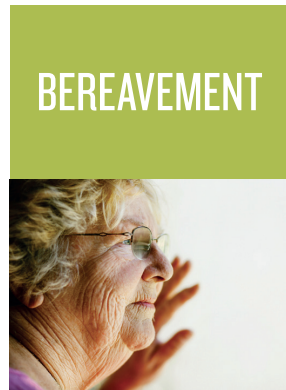
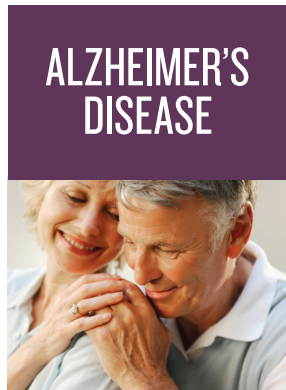
### CAREGIVERS



### CAREGIVERS BOOKLET

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

## OTHER BOOKLETS AVAILABLE



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# RESOURCE DIRECTORY

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## ORGANIZATIONS AND ASSOCIATIONS

### CANADA MORTGAGE AND HOUSING CORPORATION

**Toll free** 1 800 668-2642  
**Email** [contactcentre@cmhc.ca](mailto:contactcentre@cmhc.ca)  
**Website** [www.cmhc-schl.gc.ca/en/](http://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 CPM-AIDE (276-2433)  
**Email** [info@cpm.qc.ca](mailto:info@cpm.qc.ca)  
**Website** [www.cpm.qc.ca](http://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](mailto:infos@keroul.qc.ca)  
**Website** [www.keroul.qc.ca](http://www.keroul.qc.ca)

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](mailto:info@ranq.qc.ca)  
**Website** [www.ranq.qc.ca](http://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](mailto:info@rpcu.qc.ca)  
**Website** [www.rpcu.qc.ca/en/index.aspx](http://www.rpcu.qc.ca/en/index.aspx)

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.

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

**Toll free** 1 800 463-4315  
**Website** [www.habitation.gouv.qc.ca/english.html](http://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.

## **THE CAREGIVER NETWORK**

**Website** <https://thecaregivernetwork.ca/>

The Caregiver Network brings together partners from all across Canada, with a common goal of providing information and supporting caregivers, healthcare beneficiaries and professionals with the help of distance learning technologies.



# 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](http://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](http://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**

<https://www.cmhc-schl.gc.ca/fr/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**

<https://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/](http://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 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](http://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.

## **GOVERNMENT OF CANADA – DISABILITY BENEFITS**

[www.canada.ca/en/services/benefits/disability.html](http://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/home/ovc-20131882](http://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 SOCIETY OF CANADA**

### **MS Canada magazine**

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

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

### **Information Library**

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

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

### **Support & Services**

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

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

## **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](http://www.mcdc.info/uploads/pdf/LivreProchesaidant.pdf)

## **SERVICES QUEBEC – COPING WITH A LOSS OF INDEPENDENCE**

<https://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.

## **TOURIST AND LEISURE COMPANION STICKER**

<http://www.vatl.org/en/>

This site provides information on the tourist and leisure companion sticker, a sticker which gives free access to companions of people aged 12 and over with a permanent disability. The site explains how one can apply for the sticker, as well as a list of tourist and leisure sites that accept the companion sticker in the provinces of Quebec and Ontario.

## **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.

## HEALTHY CANADIANS

[www.canada.ca/en/services/health.html](http://www.canada.ca/en/services/health.html)

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

## MAYO CLINIC

[www.mayoclinic.org/patient-care-and-health-information](http://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](http://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).

## PORTAIL SANTÉ MIEUX-ÊTRE

[www.sante.gouv.qc.ca/en/](http://www.sante.gouv.qc.ca/en/)

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

# 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](http://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](http://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.

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# READING SUGGESTIONS

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

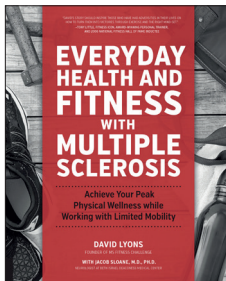
LEARN ABOUT THE  
**LOAN SERVICE BETWEEN LIBRARIES.**

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



# NON-FICTION

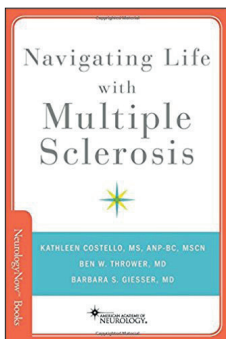
## Multiple Sclerosis



### **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.

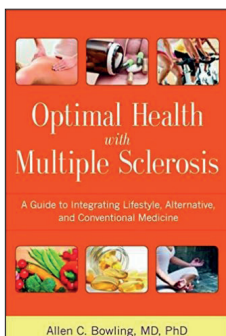
David Lyons' program is designed to help you maintain a healthy lifestyle and includes anecdotes from real people with MS, their limitations and how they followed this plan to reach their fitness goals. Find advice and solutions for overcoming mental hurdles, nutrition fundamentals to properly fuel workouts,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

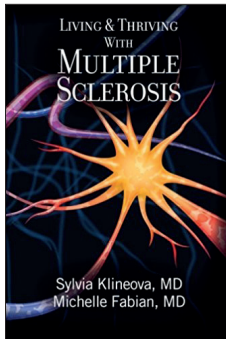
This book is a practical guide for meeting the challenges of this lifelong disease. MS may cause a myriad of symptoms and varies greatly from person to person. The authors demystify MS and offer practical solutions and guidance based upon their extensive combined clinical and research experience. The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

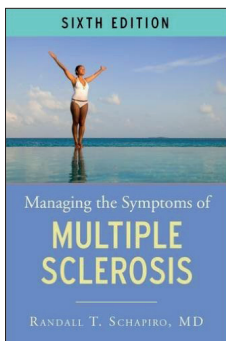
In addition to conventional medicine, many people with MS also use some form of alternative medicine and there is growing evidence and interest in the effects of lifestyle factors, such as diet and exercise on MS. This book provides unbiased and practical information about the MS relevant aspects of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

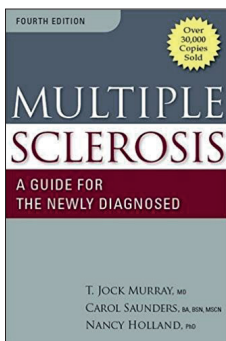
This short book will help you understand the basics of what multiple sclerosis is, what causes it, what the potential associated problems are, and what to expect from medications used for treatment. This book is designed to offer you guidance in easily understandable language. Drs. Kilineova and Fabian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



## MANAGING THE SYMPTOMS OF MULTIPLE SCLEROSIS

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

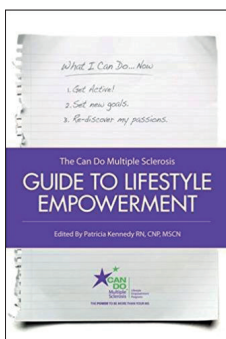
Updated and revised sixth edition of this guide to clinically tested and proven methods for effectively managing the symptoms characteristic of MS and MS treatment. Dr. Randall T. Schapiro provides information to manage both the disease and symptoms, and make everyday life easier. New chapters offer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

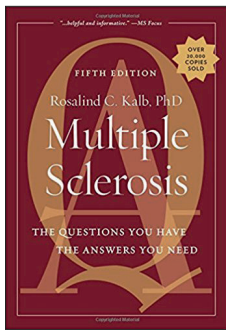
This book has been written specifically for anyone who has been diagnosed with multiple sclerosis, as well as family members and friends. It serves as a guide to learning about the disease, its potential impact on your life, and the medical treatments now available for managing it.



## THE CAN DO MULTIPLE SCLEROSIS GUIDE TO LIFESTYLE EMPOWERMENT

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

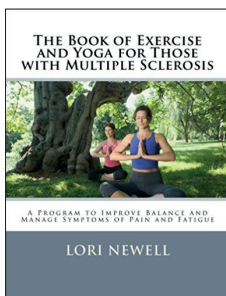
The chapters of this book were contributed by psychologists, doctors, nurses, and occupational and physiotherapists. The philosophy of the book is to help people with MS and those helping them to reclaim a sense of dignity, control and freedom by empowering them with knowledge, skills and confidence.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

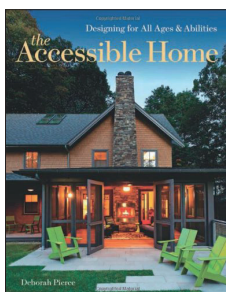


## THE BOOK OF EXERCISE AND YOGA FOR THOSE WITH MULTIPLE SCLEROSIS: A PROGRAM TO IMPROVE BALANCE AND MANAGE SYMPTOMS OF PAIN AND FATIGUE

**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.

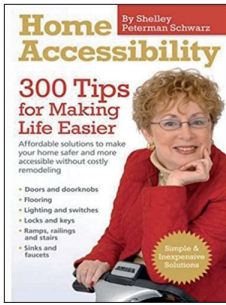
## Accessibility



## 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.

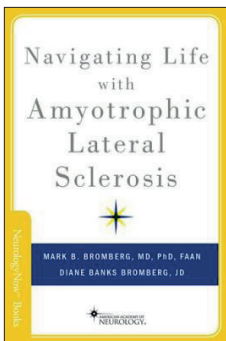


## HOME ACCESSIBILITY: 300 TIPS FOR MAKING LIFE EASIER

**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.

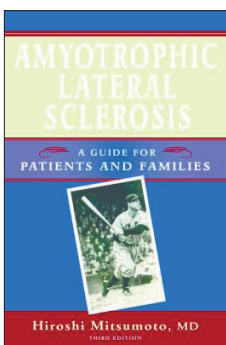
## Amyotrophic Lateral Sclerosis



## 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.



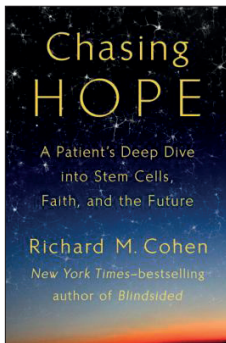
## AMYOTROPHIC LATERAL SCLEROSIS: A GUIDE FOR PATIENTS AND FAMILIES

**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

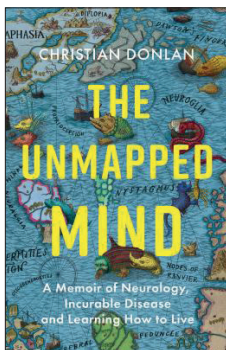
## Multiple Sclerosis



### **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.

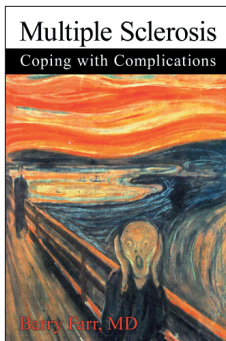
Shortly after his daughter Leontine was born, Christian Donlan's world shifted an inch to the left. He started to miss light switches and door handles when reaching for them. He would injure himself in a hundred stupid ways every day. These strange experiences were the early symptoms of multiple sclerosis,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

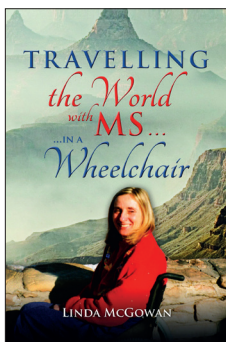
Dr. Farr has battled MS for 24 years. Speaking from personal experience, this book aims to help patients deal with reality of chronic complications of MS. Most of the text deals with Dr. Farr's own challenges, how he dealt with them and then attempts to generalize his experiences to help other people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

**Jillian 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.

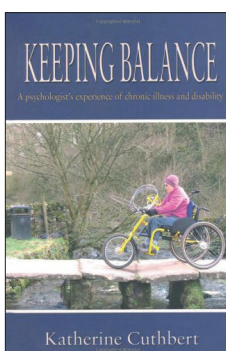
Since her diagnosis with Multiple Sclerosis in 1983, Linda McGowan has tenaciously pursued her dream of travelling the globe. From viewing the top of the world from a basket on the back of a porter at the Annapurna base camp in Nepal, to hob-knobbing with emperor penguins at the end of the world on the 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.

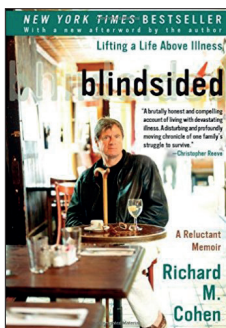
When attorney Jeffrey N. Gingold misplaced his wife on the living room couch, and became lost while driving just blocks from his home, little did he know that he was experiencing a hidden symptom of multiple sclerosis: cognitive difficulties. This book presents a personal account of one man's anguishing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

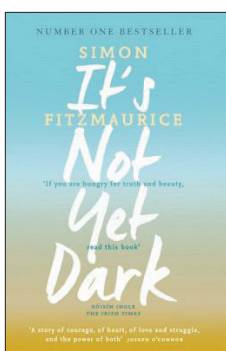


## BLINDSIDED: LIFTING A LIFE ABOVE ILLNESS: A RELUCTANT MEMOIR

**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.

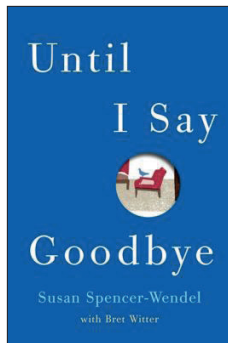
# Amyotrophic Lateral Sclerosis



## IT'S NOT YET DARK

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

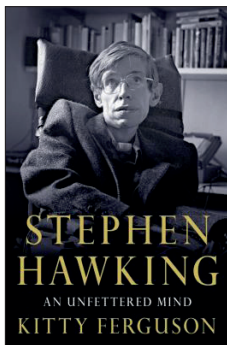
In 2008, Simon Fitzmaurice was diagnosed with Motor Neurone Disease (MND). He was given four years to live. In 2010, in a state of lung-function collapse, Simon knew with crystal clarity that now was not his time to die. Against all prevailing medical opinion, he chose to ventilate in order to stay alive.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

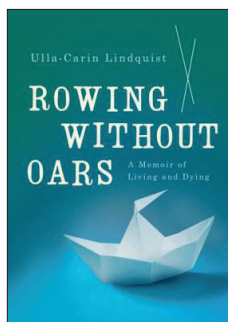
In June 2011, Susan Spencer-Wendel was diagnosed with amyotrophic lateral sclerosis (ALS), more commonly known as Lou Gehrig's disease. It is a disease that systematically destroys the nerves that power muscles; Susan, forty-five years old and a mother of three, already walks with braces and is losing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

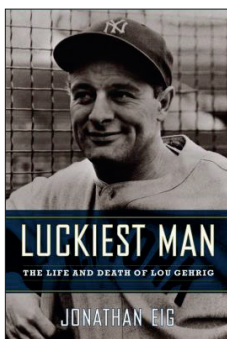
Told in his youth that he would not live past his 20s, Hawking will turn 70 in 2012, and today he continues to inspire millions, drawing rock-concert-sized crowds wherever he lectures. Science writer Kitty Ferguson has been working with Stephen Hawking for decades, and produced an internationally bestselling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



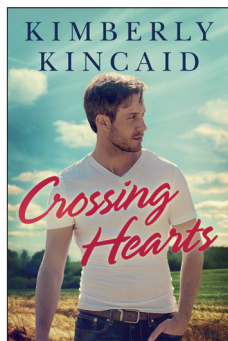
## LUCKIEST MAN: THE LIFE AND DEATH OF LOU GEHRIG

**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

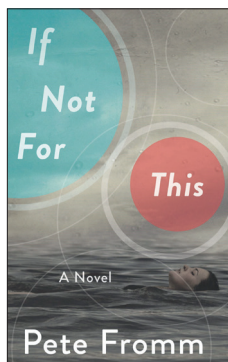
## Multiple Sclerosis



### **CROSSING HEARTS**

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

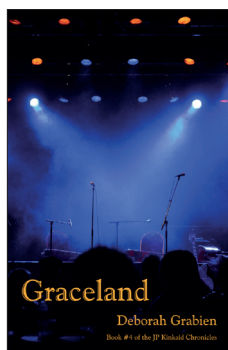
Hunter Cross has no regrets. Having left his football prospects behind the day he graduated from high school, he's happy to carry out his legacy on his family's farm in the foothills of the Shenandoah. Emerson Montgomery has secrets. Refusing to divulge why she left her job as a hotshot physical therapist 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.

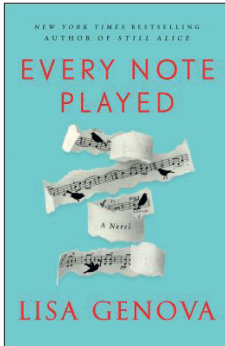


### **ROCK & ROLL NEVER FORGETS: A JP KINKAID MYSTERY**

**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.

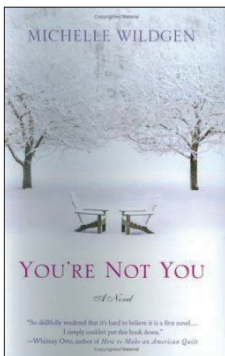
## Amyotrophic Lateral Sclerosis



### 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.



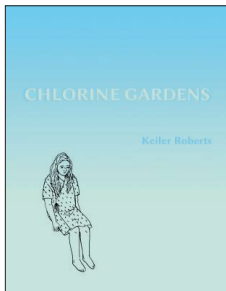
### YOU'RE NOT YOU

**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

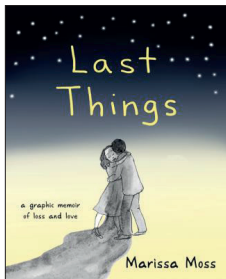


### **CHLORINE GARDENS**

**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

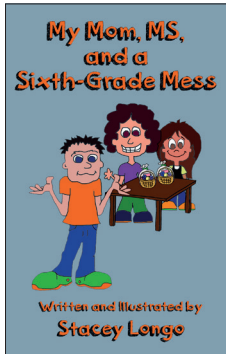


### **LAST THINGS: A GRAPHIC MEMOIR OF LOSS AND LOVE**

**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.

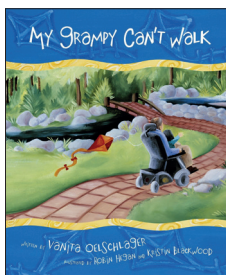
## YOUTH LITERATURE



AGES 4 TO 8

**MY MOM HAS MS****Stacey Longo.** Connecticut: Farmer's Daughter Press, 2015, 30 p.

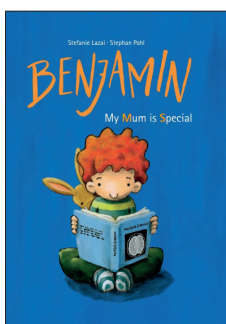
When Patrick's mother is diagnosed with multiple sclerosis, everyone in the family pitches in to help out more. But Patrick is too little to do the laundry or help with the cooking. What can he do to help his mom? A heartwarming tale based on a true story proving that nothing's more important than family.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

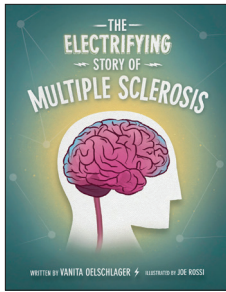
Grampy can't walk anymore because he has multiple sclerosis. But his MS doesn't slow him down. And it doesn't keep him from doing some pretty spectacular things with his grandchildren! This is a story celebrating the vitality of people who use a wheelchair for ease of mobility.



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 7 TO 10

## THE ELECTRIFYING STORY OF MULTIPLE SCLEROSIS

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

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



AGES 8 TO 15

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

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

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

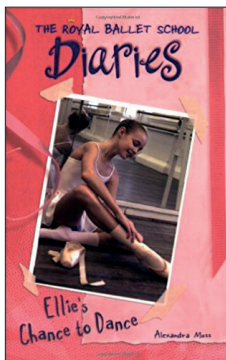


AGES 9 TO 12

## THE MEANING OF MAGGIE

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

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

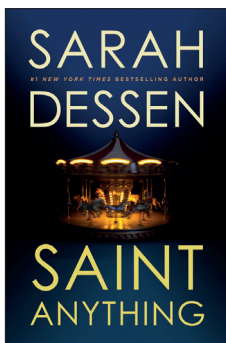


AGES 10+

## ELLIE'S CHANCE TO DANCE

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

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

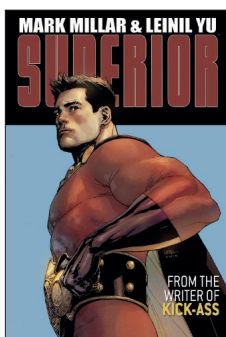


AGES 12+

## SAINT ANYTHING

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

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

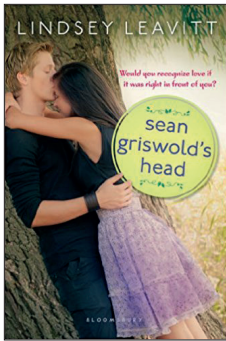


AGES 12+

## SUPERIOR

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

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

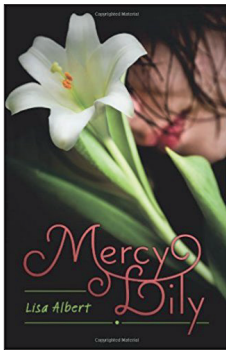


AGES 14+

## 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.

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# FILM, SERIES AND PROGRAM SUGGESTIONS

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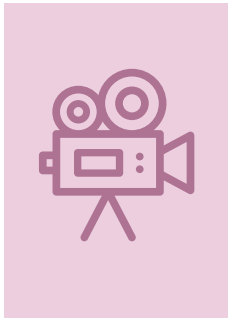
## DID YOU KNOW?

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.



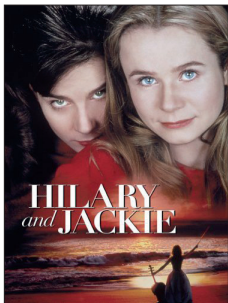
## FICTION

## 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.



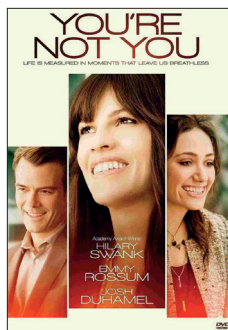
## Amyotrophic Lateral Sclerosis

**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



### **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.

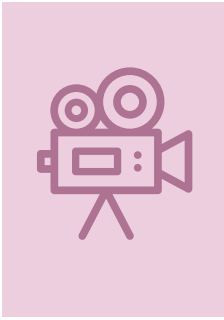
In 2006, 25-year-old Jason DaSilva's legs stopped functioning and he collapsed. Months earlier, doctors had diagnosed him with multiple sclerosis, which can lead to loss of vision, muscle control, and a myriad of other complications. As his illness worsens, Jason picks up the camera, turns it on his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

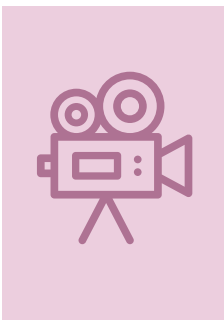
More evidence is in for so-called multiple sclerosis liberation therapy, but the answers remain unclear.



## **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.

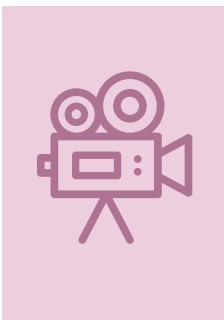


## **MS BLOGGER'S SURGERY JOURNEY**

**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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TO BETTER HELP<sup>©</sup>



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