



2023
EDITION

PARKINSON'S DISEASE

QUALITY HEALTH RELATED INFORMATION CAREFULLY SELECTED BY YOUR LIBRARIES



Better informed to live better.

ABOUT

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

ACKNOWLEDGMENTS

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

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VISIT OUR WEBSITE

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

bibliosante.ca

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

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HOW DO WE SELECT THE INFORMATION?

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

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

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

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



CAREGIVERS

CAREGIVERS BOOKLET

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

OTHER BOOKLETS AVAILABLE



**ALZHEIMER'S
DISEASE**



**AUTISM SPECTRUM
DISORDER**



BEREAVEMENT



CANCER



**CHRONIC
PAIN**



DIABETES



**END-OF-LIFE
CARE**



**HEART DISEASE
AND STROKE**



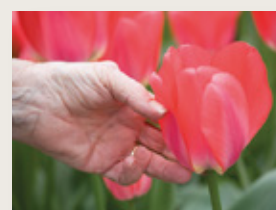
**INTELLECTUAL
DISABILITY**



**MENTAL
HEALTH**



**MULTIPLE
SCLEROSIS**



**PARKINSON'S
DISEASE**



**PHYSICAL
DISABILITY**



**PULMONARY
DISEASE**



**SENIORS
AND AGING**

RESOURCE DIRECTORY

ORGANIZATIONS AND ASSOCIATIONS

General

CANADA MORTGAGE AND HOUSING CORPORATION (CMHC)

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

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

DAWN CANADA

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

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

KÉROUL

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

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

L'APPUI POUR LES PROCHES AIDANTS

Toll free

1 855 852-7784

Website

www.lappui.org/en

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

PARKINSON CANADA IN QUÉBEC

Toll free

1 800 565-3000 extension 3411

Website

www.parkinson.ca

Parkinson Canada provides support services and education while financing research and promoting the rights of people with Parkinson's disease.

PARKINSON QUEBEC

Toll free

1 800 720-1307

Website

<http://parkinsonquebec.ca/en/>

Parkinson Quebec supports people with Parkinson's disease and their caregivers. The organization is involved in biomedical research. It also promotes services and educational programs, represents the Parkinson's disease patients and works to increase public awareness about the disease. The website provides reliable and up-to-date information on all aspects of the disease for the needs of people with Parkinson's disease and their caregivers and healthcare professionals.

PROCHE AIDANCE QUÉBEC

Phone

514 524-1959

Website

<https://procheaidance.quebec/>

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

INTERNET RESOURCES

A few tips for critically assessing information found on the Internet

THE SOURCE OF THE INFORMATION (AUTHOR OR AUTHORS)

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

THE QUALITY OF THE INFORMATION SOURCE

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

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

General

ACCESS 2 CARD

www.access2card.ca

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

BRAINXCHANGE – “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.

CANADA MORTGAGE AND HOUSING CORPORATION – ACCESSIBLE AND ADAPTABLE HOUSING

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

This page offers extensive information about affordable and accessible housing.

COMPANION LEISURE CARD

www.carteloisir.ca/en

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

DAVIS PHINNEY FOUNDATION FOR PARKINSON'S

Living Well Challenge

<https://davisphinneyfoundation.org/event/live-well-today-webinars/>

The *Living Well Challenge* is an educational webinar series featuring movement disorder experts speaking on topics of interest to people affected by Parkinson's disease. Topics include cognitive and non-motor symptoms of Parkinson's, deep brain stimulation, exercise, and many more.

Parkinson's Worksheets, Checklists & Assessments

www.davisphinneyfoundation.org/parkinsons-worksheets

The Davis Phinney Foundation is a nonprofit organization dedicated to improving the lives of people with Parkinson's disease. This page includes worksheets for people with Parkinson's disease, and their caretakers, on topics such as motor and non-motor symptoms, dental health, therapies, medications and treatments, emotional well-being, nutrition, lifestyle, sleep, and exercise. These sheets provide tips for better living.

FINANDICAP

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

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

GOVERNMENT OF CANADA

Caring for someone who is ill

www.canada.ca/en/financial-consumer-agency/services/caring-someone-ill.html

In this page, you will find different resources that will help you being prepared financially and avoid financial challenges in the future.

Disability benefits

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

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

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.

GOUVERNEMENT DU QUÉBEC – PEOPLE WITH DISABILITIES

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

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

HEALTHLINKBC – PARKINSON'S DISEASE

<https://www.healthlinkbc.ca/illnesses-conditions/disease-and-disease-prevention/parkinsons-disease>

An overview of what Parkinson's Disease is, how it is treated, its symptoms, as well as a dedicated Frequently Asked Questions section. Published by the British Columbian service HealthLink BC.

KÉROUL

Québec for all

<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.

KIDS HEALTH – PARKINSON'S DISEASE

<http://kidshealth.org/en/kids/parkinson.html#>

A resource for young children which explains what Parkinson's Disease is, what causes it, who gets it, and what are its symptoms.

MUHC PATIENT EDUCATION OFFICE

Parkinson's Disease: An Introductory Guide

www.muhcpatienteducation.ca/DATA/GUIDE/313_en~v~parkinson-s-disease-pdf-.pdf

This patient-friendly web resource is intended to help you understand Parkinson's Disease and prepare you for the treatments ahead. Other than tremor, slowness and stiffness, those diagnosed with Parkinson's Disease may experience other changes. These other changes, known as non-motor symptoms, can also impact your quality of life. Many patients may also not realize that these other symptoms are linked to Parkinson's disease. As a result, they go untreated. This resource will help you learn about these symptoms and discuss how you can recognize them. It will provide information on treatments and strategies to help you manage these symptoms, any serious problems to watch out for, as well as when and how to get more help. This resource includes a non-motor symptom questionnaire called *NMS-Quest*, which can be found on the last page of this online booklet.

PARKINSON CANADA

Care Partnering

www.parkinson.ca/about-parkinsons/care-partnering/

This section aims to prepare the loved ones of someone with Parkinson's disease to accompany the latter. It offers advice for communication, day-to-day life as well as resources to deal with daily difficulties.

Parkinson Post

<http://parkinsonpost.com/>

For Canadians living with Parkinson's. The online publication of Parkinson Society Canada.

PARKINSON QUEBEC

Parkinson's Disease

www.parkinsonquebec.ca/en/parkinsons-disease

This section provides detailed information on Parkinson's disease, outlining the symptoms, treatments and psychological aspects related to the diagnosis and support of the person with Parkinson's disease. It also includes an information package for people with Parkinson's disease under the age of 40.

PROCHE AIDANCE QUÉBEC

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

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

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

RÉGIE DE L'ASSURANCE MALADIE

Domestic help

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

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

Domestic help social economy businesses

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

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

REVENU QUÉBEC – TAX CREDITS

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

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

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

Disabled individuals

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

Refundable tax credit for medical expenses

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

Tax credit for caregivers

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

Work premium tax credit

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

SOCIÉTÉ D'HABITATION DU QUÉBEC – RESIDENTIAL ADAPTATION ASSISTANCE PROGRAM

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

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

WORLD PARKINSON'S PROGRAM – EDUCATION

www.pdprogram.org/education

The World Parkinson's Program's website includes video lectures on various topics related to Parkinson's Disease and brochures on a variety of topics such as treatment, caregiving, driving, better sleep, and so on, that are available in 14 different languages.

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.

GOUVERNEMENT DU QUÉBEC – HEALTH

www.quebec.ca/en/health/

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

MAYO CLINIC

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

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

MEDLINEPLUS

www.medlineplus.gov

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

HEALTH DATABASES

Open access databases

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

PUBMED CENTRAL

www.ncbi.nlm.nih.gov/pmc

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

Databases with access restricted to subscribers

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

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

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

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

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

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

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

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

MAGILL'S MEDICAL GUIDE

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

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

READING SUGGESTIONS

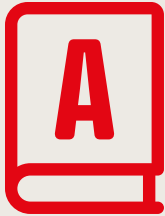
YOUR LIBRARY DOESN'T
HAVE THE BOOK THAT YOU
ARE LOOKING FOR?

LEARN ABOUT THE
LOAN SERVICE BETWEEN LIBRARIES.

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THE DOCUMENT YOU WOULD LIKE
FROM ANOTHER LIBRARY.

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LARGE PRINT BOOKS

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



AUDIO AND DIGITAL AUDIO BOOKS

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

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

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



DIGITAL BOOKS

Digital books are available via the pretnumerique.ca platform.

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



Also available on pretnumerique.ca

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

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

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

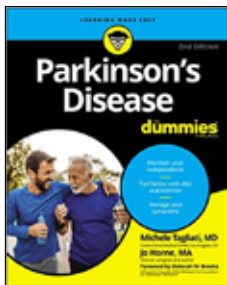
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NON-FICTION

General works



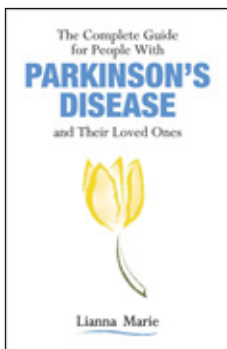
PARKINSON'S DISEASE FOR DUMMIES

Michele Tagliati and Jo Horne. Hoboken, NJ: John Wiley & Sons, Inc., 2022, 424 p.

Maintain a take-charge attitude and live your life to the fullest with Parkinson's. Whether the diagnosis is yours or that of a loved one, Parkinson's Disease for Dummies contains everything you need to know about living with this disease. This book is an easy-to-understand, straightforward, and sometimes humorous guide that offers proven techniques for coping with daily issues, finding the right doctors, and providing care as the disease progresses.



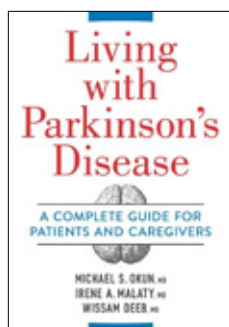
Also available on prenumerique.ca



THE COMPLETE GUIDE FOR PEOPLE WITH PARKINSON'S DISEASE AND THEIR LOVED ONES

Lianna Marie. West Lafayette, Indiana: Purdue University Press, 2020, 223 p.

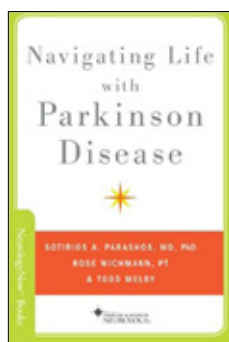
A trained nurse and primary caregiver for her mother, who was diagnosed with Parkinson's disease in 1991, Lianna Marie draws upon over twenty years of education, research, and direct experience. Written in straightforward and easily accessible language, this essential guide aims to help patients better understand their role in their treatment so that they may continue to lead happy and hopeful lives.



LIVING WITH PARKINSON'S DISEASE: A COMPLETE GUIDE FOR PATIENTS AND CAREGIVERS

Michael S. Okun, Irene A. Malaty and Wissam Deeb. Toronto: Robert Rose, 2020, 256 p.

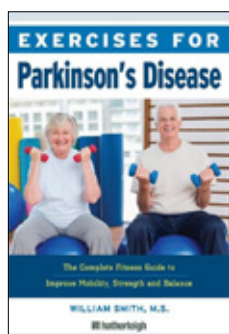
Worldwide, there are more than 10 million people living with Parkinson's disease (PD). Internationally renowned as both a neurologist and a leading researcher, Dr. Okun has been referred to as a world authority on Parkinson's disease. His positive and optimistic approach has helped countless people manage their symptoms and achieve happiness despite them. This approach, detailed in *Living with Parkinson's Disease*, is a critical resource for Parkinson's disease patients and their families. Presented in a friendly and easy-to-understand way, this book addresses PD-related issues and symptoms along with emerging therapies.



NAVIGATING LIFE WITH PARKINSON'S DISEASE

Sotirios A. Parashos and Rose L. Wichmann. New York: Oxford University Press, 2020, 326 p.

Navigating Life with Parkinson's Disease is a guide for anyone affected by Parkinson's, providing useful information to those with Parkinson's and their caregivers, family, and friends. Discussing available treatments and providing practical advice, this book emphasizes lifestyle adjustments that provide a better quality of life for patients and their loved ones.



EXERCISES FOR PARKINSON'S DISEASE: THE COMPLETE FITNESS GUIDE TO IMPROVE MOBILITY AND WELLNESS

William Smith. Long Island City : Hatherleigh, 2019, 137 p.

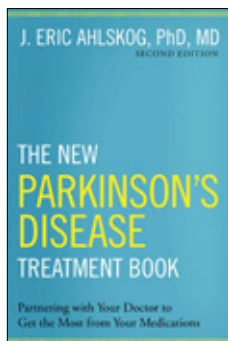
Exercises for Parkinson's Disease is the authoritative exercise guide for men and women who suffer from Parkinson's Disease. Studies have found exercise improves fitness and energy levels as well as relieves pain in people with Parkinson's Disease. *Exercises for Parkinson's Disease* features easy-to-follow exercises and workout plans that optimises mobility, increases strength, and minimises pain. Designed with safety as its number one priority, the exercises in the book are clearly photographed in easy-to-follow sequences and contain complete descriptions.



ESSENTIAL PURÉE: THE A TO Z GUIDEBOOK

Diane Wolff. Gourmet Puree LLC, 2016, 240 p.

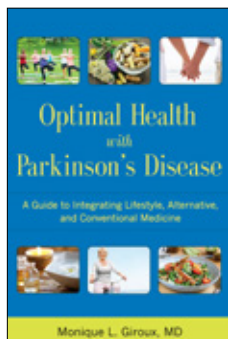
Puréed recipes for anyone with swallowing disorders, including three levels of Dysphagia (Soft Diet, Modified Soft Diet and Puree Diet). Provides a system for setting up and running a purée kitchen. Taking the guesswork out of the setup, the *Essential Purée* system is fast, easy, organized and smart.



THE NEW PARKINSON'S DISEASE TREATMENT BOOK: PARTNERING WITH YOUR DOCTOR TO GET THE MOST FROM YOUR MEDICATIONS

J. Eric Ahlskog. New York: Oxford University Press, 2015, 544 p.

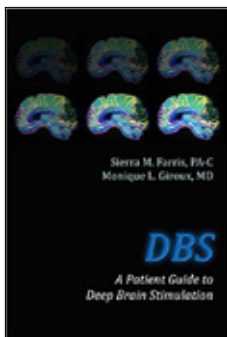
Dr. Ahlskog, a Parkinson's Disease specialist, aims to educate patients so that they can better team up with their doctors to do battle with the disease, streamlining the decision-making process and enhancing their treatment. To do this, Dr. Ahlskog offers a gold mine of information, distilled from more than 30 years of experience treating people with Parkinson's at the Mayo Clinic. In addition to providing a comprehensive account of Parkinson medications, this book also examines additional aspects of treatment, such as the role of nutrition, exercise, and physical therapy.



OPTIMAL HEALTH WITH PARKINSON'S DISEASE: A GUIDE TO INTEGRATING LIFESTYLE, ALTERNATIVE, AND CONVENTIONAL MEDICINE

Monique L. Giroux. New York: Demos Health, 2015, 320 p.

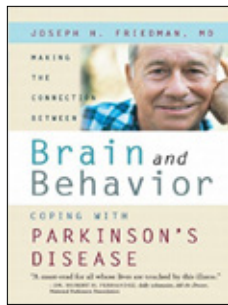
Written by a board-certified neurologist and expert in mind-body medicine, this book provides a thorough and up-to-date guide to a variety of therapies so that you and your health care team can make informed decisions to help you achieve optimal health.



DBS: A PATIENT GUIDE TO DEEP BRAIN STIMULATION

Sierra M. Farris and Monique L. Giroux. CreateSpace Independent Publishing Platform, 2013, 132 p.

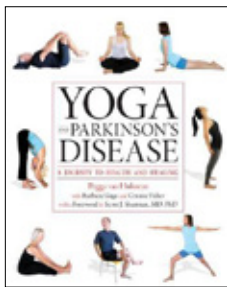
This book distills a high-tech brain surgery into understandable terms for every reader. This guide offers a wealth of information whether new to DBS or already living with DBS. The authors bring 14 years' experience working as a DBS team in treating over 1000 DBS patients. Their easy to read format is packed with practical tips in a patient-centered approach.



MAKING THE CONNECTION BETWEEN BRAIN AND BEHAVIOR: COPING WITH PARKINSON'S DISEASE

Joseph H. Friedman. New York: Demos Health, 2013, 264 p.

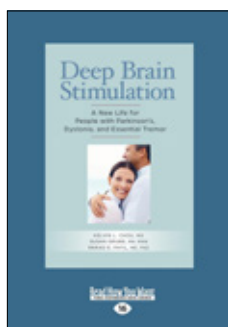
Complete and up-to-date book addressing the most common behavioral symptoms of Parkinson's Disease (PD), including depression, anxiety, hallucinations, disrupted sleep, and compulsive behavior.



YOGA AND PARKINSON'S DISEASE: A JOURNEY TO HEALTH AND HEALING

Peggy Van Hulsteyn, Barbara Gage and Connie Fisher. New York: Demos Medical Publishing, 2013, 116 p.

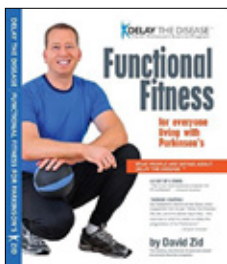
Yoga is a complementary therapy for Parkinson's Disease (PD), helping to increase flexibility, correct posture, loosen tight, painful muscles, build confidence, and in general, enhance the quality of life. Peggy van Hulsteyn, who was diagnosed with PD over a decade ago, has experienced these benefits firsthand. In *Yoga and Parkinson's Disease*, van Hulsteyn draws on her 40-year yoga practice, collaborating with two certified yoga teachers to provide a guide for bringing the benefits of yoga into your life, even if you've never done yoga before.



DEEP BRAIN STIMULATION: A NEW LIFE FOR PEOPLE WITH PARKINSON'S, DYSTONIA AND ESSENTIAL TREMOR

Kelvin L. Chou, Susan Grube and Parag G. Patil. New York: Demos Health, 2012, 200 p.

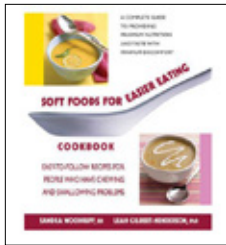
Everything you need to know about deep brain stimulation. From the first consideration to long-term care, this is a resource that patients, their families, and their physicians will want at their fingertips.



DELAY THE DISEASE – FUNCTIONAL FITNESS FOR PARKINSON'S

David Zid and Jackie Russell. Columbus: Delay the Disease LLC, 2012, 80 p.

This book features 15 fitness plans for those with Parkinson's Disease. Each plan is geared toward a daily living activity (moving through crowds, getting out of the car, dressing, etc.) and includes exercises to help improve your mobility and functionality.

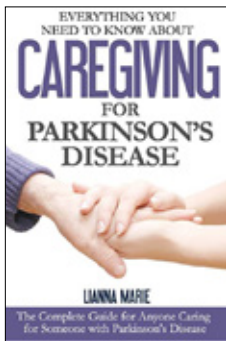


SOFT FOODS FOR EASIER EATING COOKBOOK: EASY-TO-FOLLOW RECIPES FOR PEOPLE WHO HAVE CHEWING AND SWALLOWING PROBLEMS

Sandra Woodruff and Leah Gilbert-Henderson. New Hyde Park: Square One, 2009, 320 p.

Nutritionists Sandra Woodruff and Leah Gilbert-Henderson have written this guide that offers maximum nutrition and taste with minimum discomfort.

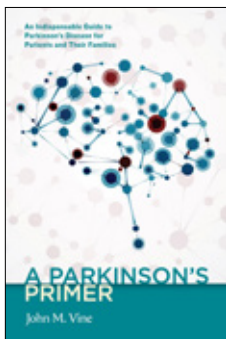
Accompaniment of a family member or friend



EVERYTHING YOU NEED TO KNOW ABOUT CAREGIVING FOR PARKINSON'S DISEASE

Lianna Marie. West Lafayette, Indiana: Purdue University Press, 2020, 206 p.

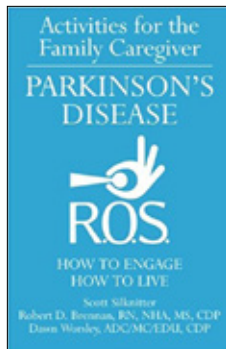
Lianna Marie served as her mother's caregiver for more than twenty years after she was diagnosed with Parkinson's disease. Drawing on firsthand experience, her training as a nurse, and the many stories of others she has helped and counseled over the years, Marie shares her wisdom and advice-practical and emotional.



A PARKINSON'S PRIMER: AN INDISPENSABLE GUIDE TO PARKINSON'S DISEASE FOR PATIENTS AND THEIR FAMILIES

John M. Vine. Philadelphia: Paul Dry Books, Inc., 2017, 154 p.

This is a book describing the personal experiences of many individuals, including the author, living with Parkinson's disease. It captures the fact that although there are many possible symptoms in this disease, each person experiences different symptoms and copes with them in various ways. This book is a clear, non-technical, personal guide written from the patient's perspective.



ACTIVITIES FOR THE FAMILY CAREGIVER: PARKINSON'S DISEASE: HOW TO ENGAGE / HOW TO LIVE

Scott Silknitter, Dawn Worsley and Robert Brennan. Greensboro: R.O.S. Therapy Systems, 2015, 136 p.

This book offers information and insight to enhance quality of life through improved social interactions as well as activities of daily living, safety and general caregiver information. Learn new communication and activity strategies to improve time spent with your loved one. Gain new insight as you learn the “How To’s,” “Why’s,” and techniques of activities – daily living and leisure.

Accessibility



THE ACCESSIBLE HOME: DESIGNING FOR ALL AGES AND ABILITIES

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

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



HOME ACCESSIBILITY : 300 TIPS FOR MAKING LIFE EASIER

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

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

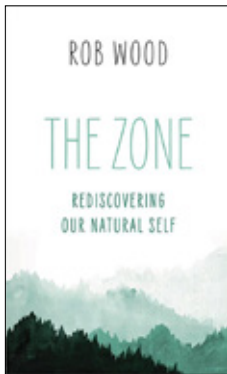
LIFE STORIES, BIOGRAPHIES AND TESTIMONIALS



DANCING IN SMALL SPACES: ONE COUPLE'S JOURNEY WITH PARKINSON'S DISEASE AND LEWY BODY DEMENTIA

Leslie A. Davidson. Victoria, BC: Brindle & Glass, 2022, 240 p.

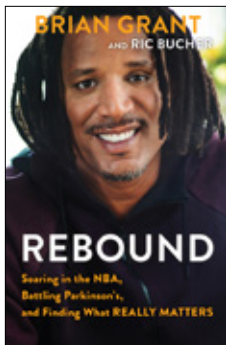
In 2011, Leslie Davidson and her husband Lincoln Ford were enjoying retired life to the fullest as ardent outdoor enthusiasts, energetic travellers, and soon-to-be grandparents. But when Lincoln's confusion became a concern and Leslie began to experience a hesitant leg and uncontrollable tremors in one arm, a devastating double diagnosis completely changed their life. In this personal and unstintingly honest memoir, Leslie recounts the years that follow the diagnoses – her Parkinson's and Lincoln's Lewy body dementia – charting physical changes, mastering medications (and sometimes flubbing it), the logistical puzzles of caregiving, and the steady support of their close-knit community in the small town of Grand Forks in south central British Columbia.



THE ZONE: REDISCOVERING OUR NATURAL SELF

Rob Wood. Victoria, BC: RMB Rocky Mountain Books, 2022, 112 p.

This book is an autobiographical account that details the emotional and physical struggles of renowned mountaineer, naturalist, and architect Rob Wood as he deals with the ravages of Parkinson's disease on his body and mind. With an unshakeable faith in the power of nature and our own need to reconnect with the natural world, Rob Wood takes the reader on a step-by-step journey documenting how – through the author's deep connection to what he calls a "universal consciousness" – even the most difficult physical limitations can be dealt with effectively and successfully, with limited medical or pharmaceutical support.



REBOUND: SOARING IN THE NBA, BATTLING PARKINSON'S, AND FINDING WHAT REALLY MATTERS

Brian Grant. Chicago: Triumph Books, 2021, 356 p.

After 12 years of playing basketball at the highest professional level, Brian Grant could have been forgiven for thinking that the hardest part of his life was behind him. But soon after his retirement from the NBA, Grant was diagnosed with young-onset Parkinson's disease, ushering in a challenge greater than any he'd faced before. With writer Ric Bucher, Grant candidly shares his story, taking readers to Sacramento, Portland, Miami, and beyond; to the airplane where he first came to understand the source of the tremors in his hand; and to the summit of Mount St. Helens alongside five others with PD, where he once again put himself to the test and defied expectations.



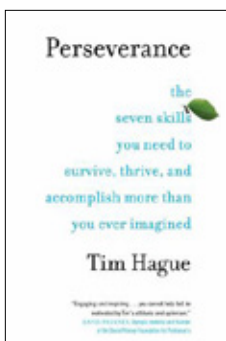
NO TIME LIKE THE FUTURE: AN OPTIMIST CONSIDERS MORTALITY

Michael J. Fox. New York: Flatiron Books, 2020, 238 p.

The actor shares personal stories and observations about illness and health, aging, the strength of family and friends, and how perceptions about time affect the consideration of mortality.



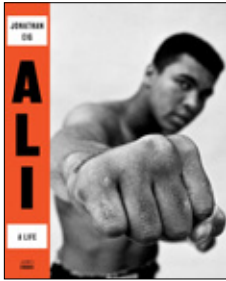
Also available on pretnumerique.ca



PERSEVERANCE: THE SEVEN SKILLS YOU NEED TO SURVIVE, THRIVE AND ACCOMPLISH MORE THAN YOU EVER IMAGINED

Tim Hague. Toronto: Viking Canada, 2018, 272 p.

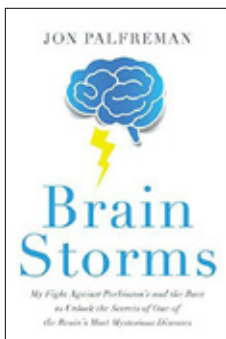
After starting a family and flourishing in his career, Tim Hague was struck by misfortune. The irritating tremor in his foot turned out to be early onset Parkinson's disease. He was only 46 years old. But what seemed to be an end became a new beginning. Just three years later, Hague won the inaugural *The Amazing Race Canada* (with his son, Tim Jr., as his teammate). His remarkable life story shows that perseverance is not just a matter of willpower: it is a skill that can be learned and honed.



ALI: A LIFE

Jonathan Eig. Boston: Houghton Mifflin Harcourt, 2017, 623 p.

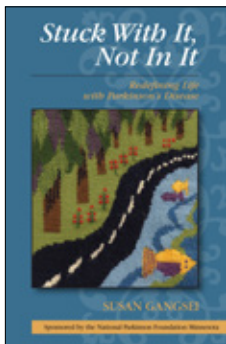
Based on more than 500 interviews, including Muhammad Ali's closest associates, and enhanced by access to thousands of pages of newly released FBI records, this is a thrilling story of a man who became one of the great figures of the twentieth century.



BRAIN STORMS: MY FIGHT AGAINST PARKINSON'S AND THE RACE TO UNLOCK THE SECRETS OF ONE OF THE BRAIN'S MOST MYSTERIOUS DISEASE

Jon Palfreman. New York: Collins, 2015, 288 p.

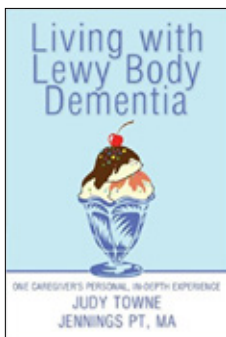
Seven million people worldwide suffer from Parkinson's – with sixty thousand new cases diagnosed each year in the US alone – and it remains an enigma, with doctors, researchers and patients hunting for a cure. In *Brain Storms*, journalist Jon Palfreman tells their story, a story that takes on urgency when he is diagnosed with the debilitating illness.



STUCK WITH IT, NOT IN IT: REDEFINING LIFE WITH PARKINSON'S DISEASE

Susan Gangsei. Minneapolis: Aston Group, 2014, 86 pages.

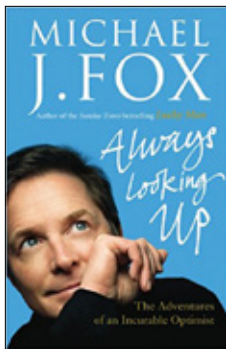
A collection of stories from people with Parkinson's disease (PD), family members of people living with the illness, volunteers for Parkinson's-related organizations, and professionals specializing PD. Each story is personal and has a message. The stories tell how people faced the disease, stared it down and found new ways of going forward. They refocused and redefined their purpose in life. They learned lessons that they want to share with others – anyone who lives with Parkinson's or wants to understand what life is like for people dealing with a chronic disease.



LIVING WITH LEWY BODY DEMENTIA: ONE CAREGIVER'S PERSONAL, IN-DEPTH EXPERIENCE

Judy Towne Jennings. Bloomington: WestBow Press, 2012, 160 pages.

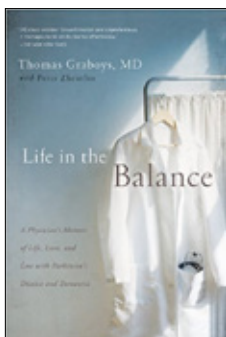
Living with Lewy Body Dementia presents readers with an accurate description of what caregiving for this disease requires. This book serves as a resource for patients and caregivers, and provides insight into the experiences gained of living with someone affected by Lewy Body Dementia. The author is a physical therapist.



ALWAYS LOOKING UP: THE ADVENTURES OF AN INCURABLE OPTIMIST

Michael J. Fox. New York: Hyperion, 2009, 279 p.

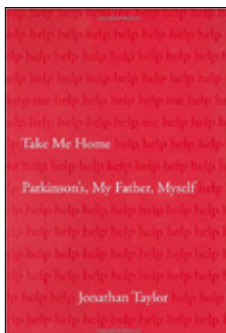
The popular film and television actor evaluates the personal philosophy that has enabled his positive outlook in spite of his battle with degenerative Parkinson's disease, in an uplifting account that considers how he has become a happier and more satisfied person by recognizing the gifts of everyday life.



LIFE IN THE BALANCE

Thomas B. Graboys, MD and Peter Zheutlin. New York: Union Square Press, 2008, 201 p.

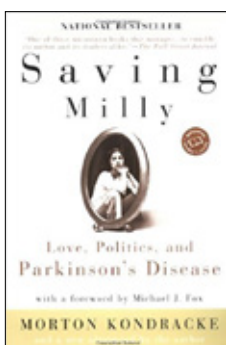
Chronicles the author's descent from a top cardiologist to a patient slowly succumbing to Parkinson's disease and dementia, including how he struggles with the feelings he experiences daily and the impact of the diseases in his life.



TAKE ME HOME: PARKINSON'S, MY FATHER, MYSELF

Jonathan Taylor. London: Granta, 2007, 274 p.

When Jonathan Taylor was eight, he began to find his father puzzling. Doctors diagnosed Parkinson's disease, and Jonathan became one of his father's carers, taking it in turn with his family to look after him. This is the story of a son's struggle for recognition from a father who is being transformed mentally and physically by the disease.

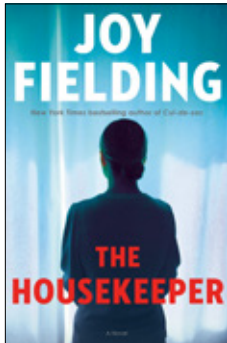


SAVING MILLY: LOVE, POLITICS, AND PARKINSON'S DISEASE

Morton Kondracke. New York: PublicAffairs, 2001, 288 p.

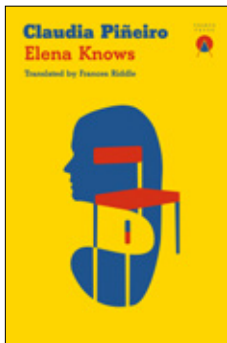
Morton Kondracke never intended to wed Millicent Martinez, but the fiery daughter of a radical labor organizer eventually captured his heart. They married, raised two daughters, and loved and fought passionately for twenty years. Then, in 1987, Milly noticed a glitch in her handwriting, a small tremor that would lead to the shattering diagnosis of Parkinson's Disease. *Saving Milly* is Kondracke's powerfully moving chronicle of his vital and volatile marriage, one that has endured and deepened in the face of tragedy; it also follows his own transformation from careerist to caregiver and activist, a man who will fight all the way, without pause or rest, to save his beloved Milly.

NOVELS

**THE HOUSEKEEPER: A NOVEL**

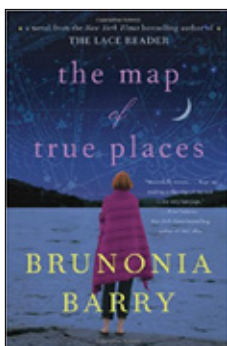
Joy Fielding. Toronto: Doubleday Canada, 2022, 351 p.

Jodi's father, Vic, now seventy-nine and retired, is a very controlling man. His wife, Audrey, was herself no shrinking violet. But things changed when Audrey developed Parkinson's eight years ago, and Vic retired to devote himself to her care. But while still reasonably spry and rakishly handsome, Vic is worn down by his wife's deteriorating condition. Exhausted from trying to be all things to all people, Jodi finally decides she's had enough and starts interviewing housekeepers to help care for her parents.

**ELENA KNOWS**

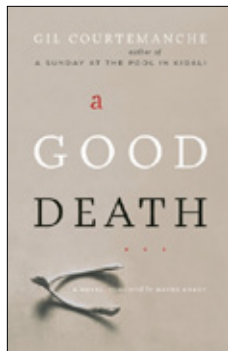
Claudia Piñeiro. Edinburgh: Charco Press, 2021, 143 p.

After Rita is found dead in the bell tower of the church she used to attend, her death is ruled a suicide and the official investigation into the incident is quickly closed. Her mother Elena, who suffers from Parkinson's disease, is the only person still determined to find the culprit, despite her debilitating illness. Chronicling a difficult journey across the suburbs of the city, an old debt and a revealing conversation, *Elena Knows* unravels the secrets of its characters and the hidden facets of authoritarianism and hypocrisy in our society.

**THE MAP OF TRUE PLACES**

Barry Brunonia. New York: HarperCollins, 2010, 406 p.

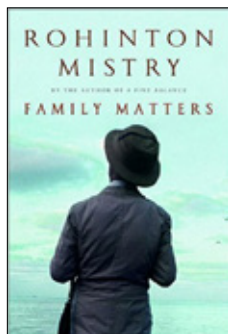
Zee Finch, a respected psychotherapist, must remap her life after returning to Salem for a patient/friend's funeral only to find her father dealing with Parkinson's disease; his companion, Melville has moved out and the untimely death of her mother, results in an awkward and strained relationship.



A GOOD DEATH

Gil Courtemanche. Vancouver: Douglas & McIntyre, 2009, 208 p.

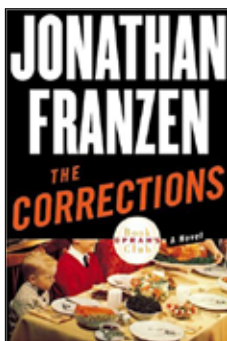
On Christmas Eve, a family has gathered around the table for the obligatory dinner. The father, once an imposing figure who terrorized his children, has suddenly fallen prey to Parkinson's. Yesterday's tyrant is now trapped inside a disintegrating body. André, the eldest child, is nearing 60. He has never loved the father who lied too much, abused too much, manipulated too much. But still, this holiday week, André cannot help but be moved. How should he behave toward a parent to whom all pleasures are forbidden? Should he struggle to prolong the old man's life, or help him end it? Around the dinner table, opinions are divided. At once intimate and universal, in it, Gil Courtemanche once again asks readers to confront the question that lay at the heart of his first novel: Why live? Why die?



FAMILY MATTERS

Rohinton Mistry. Toronto: McClelland & Stewart, 2002, 504 p.

Set in Bombay in the mid-1990s, *Family Matters* tells a story of familial love and obligation, of personal and political corruption, of the demands of tradition and the possibilities for compassion. Nariman Vakeel, the patriarch of a small discordant family, is beset by Parkinson's disease and haunted by memories of his past. He lives with his two middle-aged stepchildren but the burden of the illness worsens the already strained family relationships.



THE CORRECTIONS

Jonathan Franzen. New York: Farrar, Straus and Giroux, 2001, 567 p.

After almost fifty years as a wife and mother, Enid Lambert is ready to have some fun. Unfortunately, her husband, Alfred, is losing his sanity to Parkinson's disease, and their children have long since flown the family nest to the catastrophes of their own lives. Desperate for some pleasure to look forward to, Enid has set her heart on an elusive goal: bringing her family together for one last Christmas at home.

COMICS

**DAD'S NOT ALL THERE ANY MORE**

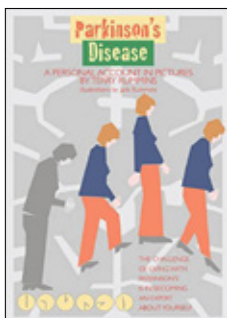
Alex Demetris. London: Singing Dragon, 2015, 32 p.

When Pete started hallucinating clowns in the corner, his son knew something wasn't quite right. Here, Alex Demetris draws on his father's experience of Lewy Body Dementia (LBD) to shed light on the condition. Exploring both physical and mental changes, this comic shows how LBD symptoms affect people with the condition and their loved ones.

**MY DEGENERATION: A JOURNEY THROUGH PARKINSON'S**

Peter Dunlap-Shohl. Pennsylvania: Pennsylvania State University Press, 2015, 96 p.

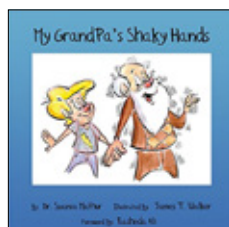
How does one deal with a diagnosis of Parkinson's Disease at the age of forty-three? *My Degeneration*, by former *Anchorage Daily News* staff cartoonist Peter Dunlap-Shohl, answers the question with humor and passion, recounting the author's attempt to come to grips with the "malicious whimsy" of this chronic, progressive, and disabling disease. This graphic novel tracks Dunlap-Shohl's journey through depression, the worsening symptoms of the disease, the juggling of medications and their side effects, the impact on relations with family and community, and the raft of mental and physical changes wrought by the malady.

**PARKINSON'S DISEASE: A PERSONAL ACCOUNT IN PICTURES**

Terry Rummins and Jack Rummins (ill.). Leicester: Troubador Publishing Ltd, 2015, 42 p.

Parkinson's Disease: A Personal Account in Pictures is Terry Rummins' story of living with the disease and told in a graphical style, with humor. In over 400 color illustrations, Jack Rummins, Terry's husband, has produced an original interpretation of her story. From the shock at receiving the diagnosis to feelings of inadequacy, anger, joy and finally to hope, the illustrations show, in a very direct manner, what it means to have this paradoxical disorder. Terry has dealt with this situation in an individual way for many years. She tells how she developed a new understanding of herself and how this has helped with the daily challenges of Parkinson's and the prognosis.

YOUTH LITERATURE

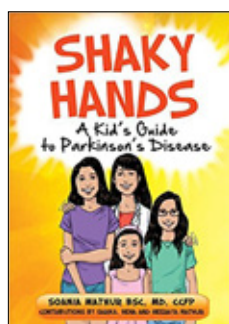


AGES 3+

MY GRANDPA'S SHAKY HANDS

Soania Mathur and John T. Walker (ill.). CreateSpace Independent Publishing Platform, 2014, 34 p.

This story is about a boy who can only see the positive in what others perceive as his grandfather's disability and also portrays the optimistic and determined attitude of a grandfather as he continues to find joy in life despite the physical challenges that Parkinson's disease brings.

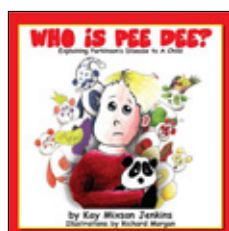


AGES 5+

SHAKY HANDS: A KID'S GUIDE TO PARKINSON'S DISEASE

Soania Mathur. CreateSpace Independent Publishing Platform, 2015, 58 p.

When a child learns that a loved one has Parkinson's Disease, it can be a frightening time for them because they don't understand what a diagnosis such as this actually means. This book hopes to address the questions that may naturally arise. What is Parkinson's Disease? How does it feel to have Parkinson's? How is it treated? How do I deal with all the feelings I have as I see the one I love change? What can I do to help? Reading the information contained and encouraging open dialogue will help children cope with a loved one's journey with Parkinson's.

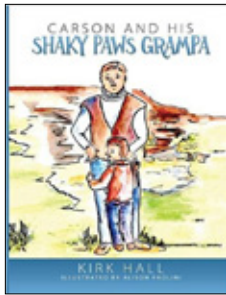


AGES 5+

WHO IS PEE DEE?: EXPLAINING PARKINSON'S DISEASE TO A CHILD

Kay Mixson Jenkins and Richard Morgan. Smyrna: UCB, Inc., 2008, 24 p.

When you live with a devastating illness like Parkinson's Disease (PD), it affects your entire family — especially your kids. In PD families, children witness the debilitating symptoms first-hand, and they may have many questions and concerns. But what are the best answers to give? Follow the adventures of a boy named Colt and his toy panda bear, "Pee Dee", and learn how families can better live with the disease.

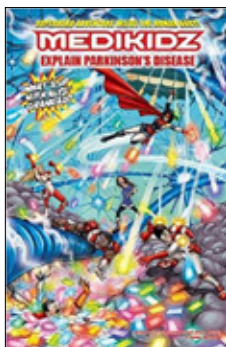


AGES 7+

CARSON AND HIS SHAKY PAWS GRAMPA

Kirk Hall and Alison Paolini (ill.). Collierville: Innovo Publishing LLC, 2011, 24 p.

A story designed to help parents and grandparents talk about the symptoms of Parkinson's with their children. Based on the author's personal experience with Parkinson's. Also includes information to address common questions and concerns that children may express.

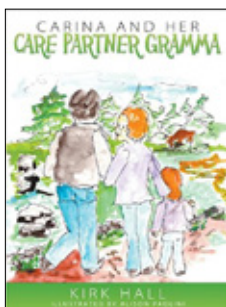


AGES 8+

WHAT'S UP WITH ALYS' GRANDDAD? MEDIKIDZ EXPLAIN PARKINSON'S DISEASE

Kiml Chilman-Blair and Shawn DeLoach. London: MediKidz, 2013, 32 p.

Alys loves spending time with her grandad, and they share many interests, especially inventing! Recently, however, grandad seems to be slowing up, and Alys feels frustrated and confused, as she doesn't understand what's going on for him. The Medikidz are on hand to take Alys on an exciting trip to Mediland, where she learns all about Parkinson's Disease. Join Alys on her journey, as she gets to explore the brain, nerves, and chemical messengers! At the end, you, like Alys' will know all about Parkinson's Disease, what it is, how it affects the body, and what can be done to help!

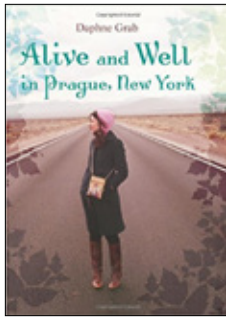


AGES 8+

CARINA AND HER CARE PARTNER GRAMMA

Kirk Hall and Alison Paolini (ill.). Collierville: Innovo Publishing LLC, 2013, 26 p.

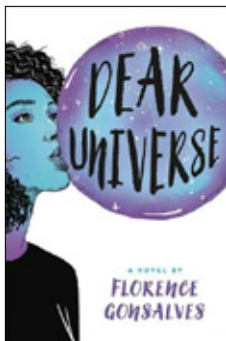
This story about Carina's admiration for her grandmother who is a care partner to her husband who has Parkinson's disease is designed to help adults talk to children about caring for someone with Parkinson's.

**AGES 12+**

ALIVE AND WELL IN PRAGUE, NEW YORK

Daphne Grab. New York: Laura Geringer Books, 2008, 247 p.

Manhattanites Matisse Osgood and her artist parents move to upstate New York when her father's Parkinson's disease worsens, and Matisse must face high school in a small, provincial town as she tries to avoid thinking about her father's future.

**AGES 14+**

DEAR UNIVERSE

Florence Gonsalves. New York; Boston: Little, Brown and Company, 2021, 342 p.

It's senior year, and Chamomile Myles has whiplash from traveling between her two universes: school (the relentless countdown to prom, torturous college applications, and the mindless march toward an uncertain future) and home, where she wrestles a slow, bitter battle with her father's terminal illness—untreated Parkinson's disease. Enter Brendan, a man-bun-and tutu-wearing hospital volunteer with a penchant for absurdity, who strides boldly between her worlds—and helps her open up a new road between them.

FILM, SERIES AND PROGRAM SUGGESTIONS

DID YOU KNOW?

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

FICTION



KINETICS

Tom Martin. 2018, 51 min.

Online: <https://vimeo.com/248010160>

When Rose is diagnosed with early-onset Parkinson's she meets Lukas, a frustrated young pupil who finds his release through Parkour. An odd coupling brought together by their desire to move.



PARKINSON - ANIMATION SHORT FILM

Oriane Thibault, Audrey Von Hatten, Benjamin Lucas. 2018, 3 min 57 s.

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

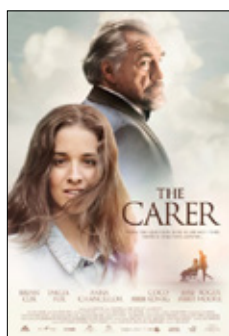
The evolution of a grandpa's life through sickness, linked with his little daughter.



NEVER STEADY, NEVER STILL

Kathleen Hepburn. 2017, 112 min.

A mother struggles to take control of her life in the face of advanced Parkinson's disease, while her son battles his sexual and emotional identity amongst the violence of Alberta's oil field work camps.



THE CARER

János Edelényi. 2016, 89 min.

Comedy, drama (United Kingdom). Diagnosed with a rare form of Parkinson's Disease, ailing theatrical legend Sir Michael Gifford (Brian Cox) is terminally ill. He's also foul-mouthed, irascible, and highly resistant to the concept of allowing a full-time care giver into his home. Out of sheer necessity but hardly convicted at the notion herself, Sir Michael's daughter Sophia (Emilia Fox) reluctantly brings in a candidate to interview for the job. Into this fraught household comes Dorottya, who is greeted coldly by Sophia and Michael's estate manager and former lover Milly (Anna Chancellor) but nevertheless manages to convince them to allow her a chance.



A LATE QUARTET

Yaron Zilberman. 2012, 105 min.

Drama (United States). On the eve of an important concert, Peter (Academy Award-winner Christopher Walken), lead cellist of a veteran string quartet, receives some very disturbing news. When he announces his pending retirement, competing egos and uncontrollable passions threaten to derail years of friendship and collaboration within the tightly knit group.



LOVE AND OTHER DRUGS

Edward Zwick. 2010, 112 min.

A young woman suffering from Parkinson's befriends a drug rep working for Pfizer in 1990s Pittsburgh.



THE LAST ESCAPE

Léa Pool. 2010, 91 min. (Original title: La dernière fugue)

Drama (Quebec, Luxembourg). Christmas approaches and the Levesque family has once again gathered for their traditional celebration. But this time there is a mixture of emotions running through each person. The patriarch of the family suffers from a combination of Parkinson's disease and heart failure. His life reduced in every way, the end approaches and there are unhappy memories of his once violent and authoritarian past.

DOCUMENTARIES

General



THE PARKINSON'S DRUG TRIAL: A MIRACLE CURE?

BBC Documentaries. 2019

Filmed over six years, this program follows a group of volunteers with Parkinson's as they take part in a groundbreaking medical trial testing an experimental drug called GDNF. Forty-two volunteers undergo complex brain surgery and months of drug infusions via a port embedded into the side of their skull. Can this clinical trial give hope to the estimated 10 million affected by Parkinson's globally? In the second episode, cameras continue to follow the lives of the Parkinson's sufferers who agreed to take part in an invasive clinical trial – testing a drug that could be the first to halt progression, or even reverse their condition.



SHAKE WITH ME

Zack Grant. 2019, 32 min.

Online: <https://vimeo.com/273256248>

Art, health and the will to cope; Debra Magid is an artist living with Parkinson's Disease. A documentary film through the eyes of her son, Zack Grant.



THE 5TH DEMENTIA

Serene Meshel-Dillman. 2019, 97 min.

The 5th Dementia, is a diverse band featuring former professionals from a range of socioeconomic and educational backgrounds who now struggle to remember anything at all due to their illnesses. Alzheimer's, Dementia, Parkinson's. They come together to play and sing a list of songs compiled by their bandleader. When the music starts, they are transformed. The rhythms and melodies stir something deep within them. These men and women, leading lives with almost no social interaction who show very little emotion outside the rehearsal space, dive right into songs from their generation without a single page of sheet music. Memories otherwise entirely unreachable are unlocked. The music has a euphoric and quality of life changing impact. Through uniquely personal stories, from inspiring daily triumphs to the sobering toll of slow mental decline, viewers of *The 5th Dementia* Documentary will see an emotional, revealing look at this inexplicable phenomena.



LIVING WITH PARKINSON'S

PBS. 2018, 29 min.

Online: <https://www.pbs.org/video/kvie-viewfinder-living-parkinsons/>

Examine how Parkinson's Disease is now approached with a new perspective, thanks to doctors, researchers, and patients who are driving the science. Meet men and women from all walks of life who struggle to delay their disease progression, including former Sacramento Kings power forward Brian Grant.

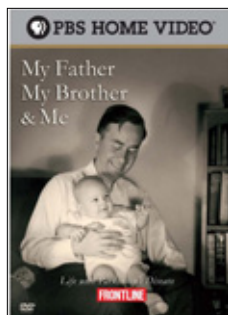


THE ADVENTURES OF AN ASPIRING ROCKSTAR

Sam Oldmeadow. 2017, 34 min.

Online: <https://vimeo.com/189961472>

From a very young age, Cosimo Mauro dreamt about being a rockstar. It was a dream he would briefly realise in his twenties. But what he could not have predicted was that at age forty he would be diagnosed with Parkinson's disease. On the surface the film provides an intimate window into the life of a man struggling psychologically and physically with a debilitating illness but if we look closer we soon understand that Parkinson's is just an exaggeration of the universal themes of ageing and the comparisons we are eventually forced to make between a life we used to dream about and the lives we actually lead.



MY FATHER, MY BROTHER AND ME

Dave Iverson and Michael Schwarz, Frontline. 2009, 60 min.

In 2004, journalist Dave Iverson received the same news that had been delivered to his father and older brother years earlier: He had Parkinson's disease. In *My Father, My Brother and Me*, Iverson sets off on a personal journey to explore the scientific, ethical, and political debate that surrounds Parkinson's. And he has intimate conversations with fellow Parkinson's sufferers like actor Michael J. Fox and writer Michael Kinsley.

TAKING PART IN ONE'S HEALTH CARE

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

WHAT DOES PATIENT-AS-PARTNER MEAN?

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

Source: Faculté de médecine de l'Université de Montréal

ORGANIZATIONS AND ASSOCIATIONS

General

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

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

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

HEALTHCARE EXCELLENCE CANADA

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

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

INSTITUT DE PLANIFICATION DES SOINS DU QUÉBEC

Phone 514 805-2408
Website www.planificationdessoins.org

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

Legal information

CHAMBRE DES NOTAIRES DU QUÉBEC

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

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

COMMUNITY JUSTICE CENTERS

Website www.justicedeproximite.qc.ca/en/

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

CONSEIL POUR LA PROTECTION DES MALADES

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

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

CURATEUR PUBLIC DU QUÉBEC

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

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

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

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

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

JURISTES À DOMICILE

Phone 514 944-9929
Website www.juristesadomicile.com

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

PROTECTEUR DU CITOYEN

Toll free

1 800 463-5070

Website

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

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

REGROUPEMENT PROVINCIAL DES COMITÉS DES USAGERS (RPCU)

Phone

514 436-3744

Website

www.rpcu.qc.ca/en/

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

INTERNET RESOURCES

General

CANADIAN MEDICAL ASSOCIATION – PATIENT VOICE

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

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

CHOOSING WISELY CANADA

<https://choosingwiselycanada.org/>

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

COLLÈGE DES MÉDECINS DU QUÉBEC

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

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

GOVERNMENT OF CANADA

How older adults can use social media safely

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

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

GOVERNEMENT DU QUÉBEC

Coping with a loss of independence

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

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

Info-Santé 811

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

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

Service Organization

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

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

HEALTH BOOKLET

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

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

HEALTHCARE EXCELLENCE CANADA

Engaging Patients in Patient Safety – a Canadian Guide

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

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

Patient, Family and Caregiver Engagement and Partnerships

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

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

Shift to Safety

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

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

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

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

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

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

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

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

INSTITUTE FOR SAFE MEDICATION PRACTICE CANADA – SAFEMEDICATIONUSE.CA

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

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

MCGILL UNIVERSITY HEALTH CENTER

Patient Safety and Physical Restraints: What You Need to Know

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

This booklet aims to help you understand physical restraints.

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

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

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

ORDRE DES PHARMACIENS DU QUÉBEC – PROTECTION DU PUBLIC

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

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

OTTAWA HOSPITAL RESEARCH INSTITUTE – PATIENT DECISION AIDS

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

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

RÉGIE DE L'ASSURANCE MALADIE – CITIZENS

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

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

SANTÉ ET SERVICES SOCIAUX QUÉBEC

Quick Reference: I'm taking care of my Health

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

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

SENIORS' GUIDE TO STAYING CYBER SAFE DURING COVID-19

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

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

HAVE YOU HEARD OF DEPRESCRIBING?

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

WHY RESORT TO DEPRESCRIBING?

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

HOW DOES IT WORK?

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

Source: Canadian Deprescribing Network

CANADIAN DEPRESCRIBING NETWORK

www.deprescribingnetwork.ca

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

Legal information

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

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

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

ÉDUCALOI

Caregivers: Practical Legal Tools

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

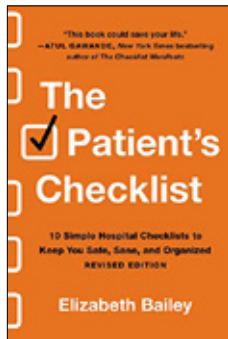
In this web guide, Éducaloi provides clear and useful legal information intended for caregivers.

Health Topics

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

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

READING SUGGESTIONS



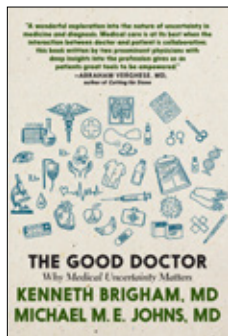
THE PATIENT'S CHECKLIST: 10 SIMPLE HOSPITAL CHECKLISTS TO KEEP YOU SAFE, SANE, AND ORGANIZED

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

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



Also available on prenumerique.ca



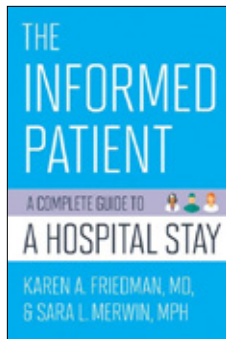
THE GOOD DOCTOR: WHY MEDICAL UNCERTAINTY MATTERS

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

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



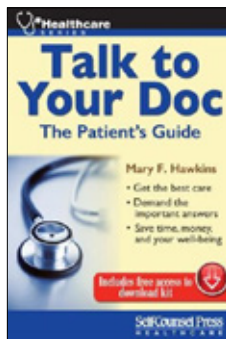
Also available on prenumerique.ca



THE INFORMED PATIENT: A COMPLETE GUIDE TO A HOSPITAL STAY

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

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



TALK TO YOUR DOC: THE PATIENT'S GUIDE

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

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



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

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

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

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