



2023  
EDITION

# ALZHEIMER'S DISEASE

AND RELATED DISORDERS

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QUALITY HEALTH RELATED INFORMATION CAREFULLY SELECTED BY YOUR LIBRARIES

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 **Biblio-  
Santé**



Better informed to live better.

## **ABOUT**

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

## **ACKNOWLEDGMENTS**

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

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## **VISIT OUR WEBSITE**

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

**[bibliosante.ca](http://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](http://bibliosante.ca/criteria)



### CAREGIVERS

#### **CAREGIVERS BOOKLET**

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

## OTHER BOOKLETS AVAILABLE



**ALZHEIMER'S  
DISEASE**



**AUTISM SPECTRUM  
DISORDER**



**BEREAVEMENT**



**CANCER**



**DIABETES**



**END-OF-LIFE  
CARE**



**HEART DISEASE  
AND STROKE**



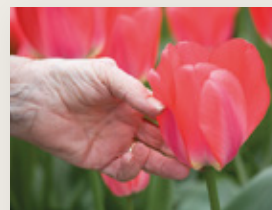
**INTELLECTUAL  
DISABILITY**



**MENTAL  
HEALTH**



**MULTIPLE  
SCLEROSIS**



**PARKINSON'S  
DISEASE**



**PHYSICAL  
DISABILITY**



**PULMONARY  
DISEASE**



**SENIORS  
AND AGING**

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# RESOURCE DIRECTORY

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# ORGANIZATIONS AND ASSOCIATIONS

## General

### ALZHEIMER SOCIETY OF CANADA

**Toll free** 1 800 616-8816  
**Website** [www.alzheimer.ca/en](http://www.alzheimer.ca/en)

Alzheimer Society of Canada is the leading non-profit health organization working nationwide to improve the quality of life of Canadians affected by Alzheimer and to support research. Represented in all provinces, it is active in more than 150 local communities across Canada. Its website provides a broad range of guidance for families affected by the disease.

### BALUCHON ALZHEIMER

**Phone** 514 762-2667  
**Toll free** 1 855 762-2930  
**Website** [www.baluchonalzheimer.com](http://www.baluchonalzheimer.com)

An affordable respite care service for families with loved ones who have Alzheimer's disease. For a period of 4 to 14 days (24 hours a day), an experienced caregiver stays at home with the person being cared for while the caregiver can, in complete confidence, take some personal time. Website in French.

### FEDERATION OF QUEBEC ALZHEIMER SOCIETIES

**Phone** 514 369-7891  
**Toll free** 1 888 636-6473  
**Website** [www.alzheimer.ca/federationquebecoise/en](http://www.alzheimer.ca/federationquebecoise/en)

The Federation is made up of 20 regional Alzheimer societies across Quebec. The regional societies offer telephone support lines, individual and family meetings, psychosocial support and support groups for caregivers. Their contact information can be found on the website of the Federation.

## L'APPUI POUR LES PROCHES AIDANTS

**Toll free**  
**(Caregiver support)** 1 855 852-7784  
**Website** [www.lappui.org/en](http://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.).

## 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

### **ALZHEIMER SOCIETY OF CANADA – NATIONAL RESOURCE LIBRARY**

[www.alzheimer.ca/en/help-support/dementia-resources/national-resource-library](http://www.alzheimer.ca/en/help-support/dementia-resources/national-resource-library)

In the *National resource library* section of the Society's website, you can download several guides and flyers about Alzheimer, the daily life of a person affected, the treatments offered and the resources available to families and caregivers.

### **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 – HOUSING OPTIONS FOR PEOPLE LIVING WITH DEMENTIA**

#### **Volume 1**

<https://www.cmhc-schl.gc.ca/en/professionals/industry-innovation-and-leadership/industry-expertise/senior-housing/housing-options-for-people-living-with-dementia-volume-1>

#### **Volume 2**

<https://www.cmhc-schl.gc.ca/en/professionals/industry-innovation-and-leadership/industry-expertise/senior-housing/housing-options-for-people-living-with-dementia-volume-2>

#### **Volume 3**

<https://www.cmhc-schl.gc.ca/en/professionals/industry-innovation-and-leadership/industry-expertise/senior-housing/housing-options-for-people-living-with-dementia-volume-3>

These PDF files contain information on housing options designed to meet the needs of people living with dementia.

## **DEMENTIA FRIENDS CANADA**

[www.dementiafriends.ca/](http://www.dementiafriends.ca/)

Dementia Friends Canada is a national campaign that's helping Canadians to learn a little about dementia, and then turn that understanding into simple actions that can improve the lives of people living with dementia.

## **DOUGLAS MENTAL HEALTH UNIVERSITY INSTITUTE – ALZHEIMER'S DISEASE: CAUSES, SYMPTOMS AND EVOLUTION**

[www.douglas.qc.ca/info/alzheimer?locale=en](http://www.douglas.qc.ca/info/alzheimer?locale=en)

This fact sheet provides an overview of Alzheimer's disease, including causes, symptoms and evolution.

## **McGILL UNIVERSITY – DEMENTIA: YOUR COMPANION GUIDE**

<https://767b071f.flowpaper.com/DementiaGuidebook/#page=1>

A guide about dementia for people living with dementia and their care partners.

## **NATIONAL INSTITUTE ON AGING – ALZHEIMER'S DISEASE FACT SHEET**

[www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet](http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet)

This fact sheet from the National Institute of Aging provides general information on Alzheimer's disease, including symptoms, diagnosis, treatment, and caregiving. This resource also contains links to further information about the most common cause of dementia in older adults. Website of the U.S. Department of Health & Human Services.

## **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.

## 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/>

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

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

## **GOVERNEMENT DU QUÉBEC – HEALTH**

[www.quebec.ca/en/health/](http://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](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.medlineplus.gov](http://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](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>

## **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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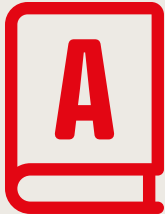
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### **AUDIO AND DIGITAL AUDIO BOOKS**

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

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


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



## DIGITAL BOOKS

Digital books are available via the [pretnumerique.ca](http://pretnumerique.ca) platform.

On the [pretnumerique.ca](http://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](http://pretnumerique.ca)

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

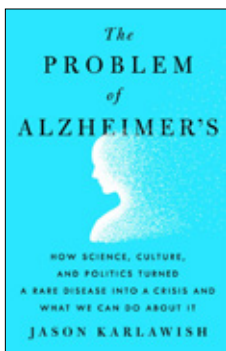
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\*The supply of books in different formats varies from one library to another.

**Find out what your library has to offer!**

# NON-FICTION

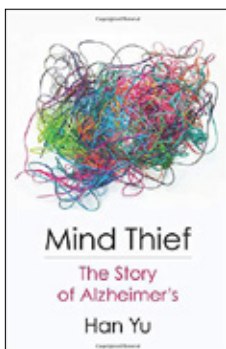
## General works



### **THE PROBLEM OF ALZHEIMER'S: HOW SCIENCE, CULTURE AND POLITICS TURNED A RARE DISEASE INTO A CRISIS AND WHAT WE CAN DO ABOUT IT**

**Jason Karlawish.** New York: St. Martin's Press, 2021, 324 p.

Tracing Alzheimer's from its beginnings to its recognition as a crisis, this account, which highlights decades of missed opportunities in our health systems, also tells the story of the biomedical breakthroughs that may allow Alzheimer's to finally be prevented and treated by medicine. It also presents an argument for how we can live with dementia: how patients can reclaim their autonomy, how families can support their loved ones, and the reforms we can make as a society to give caregivers and patients a better quality of life.



### **MIND THIEF: THE STORY OF ALZHEIMER'S**

**Han Yu.** New York: Columbia University Press, 2021, 360 p.

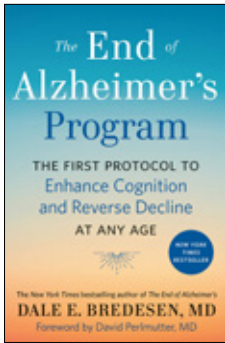
A comprehensive and engaging history of Alzheimer's that demystifies efforts to understand the disease. Beginning with the early twentieth century, Han Yu examines over a century of research and controversy. She presents the leading hypotheses for what causes Alzheimer's, and synthesizes a vast amount of medical literature, historical studies, and media interviews, telling the gripping stories of researchers' struggles while situating science in its historical, social, and cultural contexts.



### **MUSIC AND DEMENTIA: FROM COGNITION TO THERAPY**

**Amee Baird, Sandra Garrido, Jeanette Tamplin.** Oxford: Oxford University Press, 2020, 306 p.

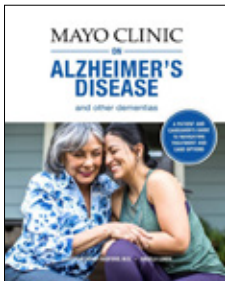
Designed for academics, researchers, students, clinicians, caregivers, and people with lived experience of dementia; The go-to guide for understanding how and why music is beneficial for people living with dementia and those who care for them.



## THE END OF ALZHEIMER'S PROGRAM: THE FIRST PROTOCOL TO ENHANCE COGNITION AND REVERSE DECLINE AT ANY AGE

**Dale E. Bredesen.** New York: Avery, an imprint of Penguin Random House LLC, 2020, 336 p.

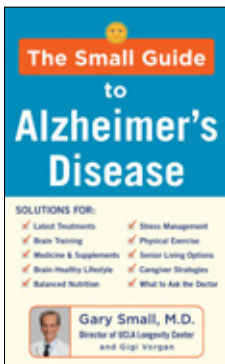
With inspiring stories from patients who have reversed cognitive decline and are now thriving, this book shifts the treatment paradigm and offers a new and effective way to enhance cognition as well as unprecedented hope to sufferers of this now no longer deadly disease.



## MAYO CLINIC ON ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

**Jonathan Graff-Radford and Angela M. Lunde.** Rochester, MN: Mayo Clinic Press, 2020, 414 pages.

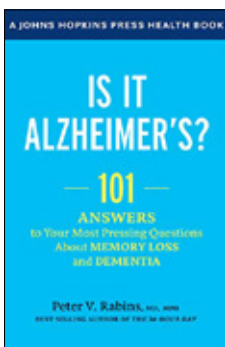
The book presents a comprehensive look at the typical symptoms associated with dementia, current findings regarding common causes of the disease, and gives essential tips for managing the day-to-day challenges of caring for someone with dementia.



## THE SMALL GUIDE TO ALZHEIMER'S DISEASE

**Gary Small.** West Palm Beach, FL: Humanix Books, 2020, 232 p.

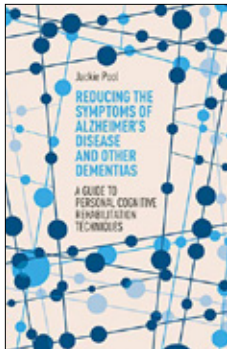
This accessible guide provides readers with an overview of Alzheimer's Disease and dementia: what it is, who gets it, how to recognize it, major causes (genetics, environment, etc.).



## IS IT ALZHEIMER'S?: 101 ANSWERS TO YOUR MOST PRESSING QUESTIONS ABOUT MEMORY LOSS AND DEMENTIA

**Peter V. Rabins.** Baltimore, Maryland: Johns Hopkins University Press, 2020, 160 p.

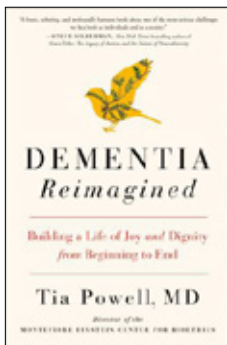
In *Is It Alzheimer's?*, Dr. Peter V. Rabins educates readers by answering 101 often-asked questions about memory loss and dementia. Written in a conversational, easy-to-use Q&A style, the book is organized into seven unique sections.



## REDUCING THE SYMPTOMS OF ALZHEIMER'S DISEASE AND OTHER DEMENTIAS: A GUIDE TO PERSONAL COGNITIVE REHABILITATION TECHNIQUES

**Jackie Pool.** London: Jessica Kingsley Publishers, 2019, 175 p.

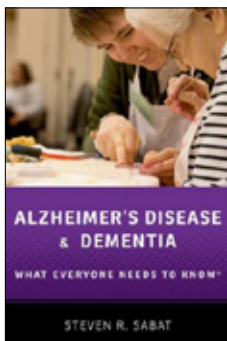
This innovative new book sets out practical guidance for people with dementia, their families and carers on reducing the symptoms of Alzheimer's disease and other dementias. Covering topics such as nutrition, stress, communication, memory and sleep, it provides all the tools and information necessary to build a personalised and flexible self-care plan which will improve and sustain quality of life.



## DEMENTIA REIMAGINED: BUILDING A LIFE OF JOY AND DIGNITY FROM BEGINNING TO END

**Tia Powell.** New York: Avery, an imprint of Penguin Random House, 2019, 310 p.

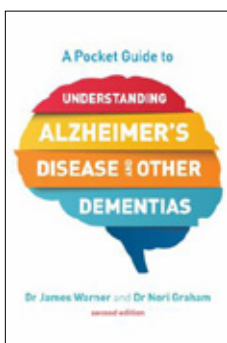
The cultural and medical history of dementia and Alzheimer's disease by a leading psychiatrist and bioethicist who urges us to turn our focus from cure to care.



## ALZHEIMER'S DISEASE AND DEMENTIA: WHAT EVERYONE NEEDS TO KNOW

**Steven R. Sabat.** New York: Oxford University Press, 2018, 272 p.

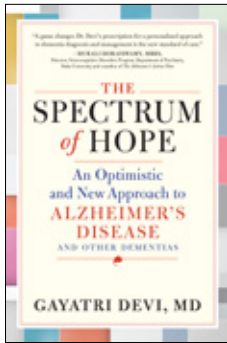
From years spent exploring and observing the points of view and experiences of people diagnosed, Sabat strives to inform as well as to remind readers of the respect and empathy owed to those diagnosed and living with dementia.



## A POCKET GUIDE TO UNDERSTANDING ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

**James Warner and Nori Graham.** London: Jessica Kingsley Publishers, 2018, 160 p.

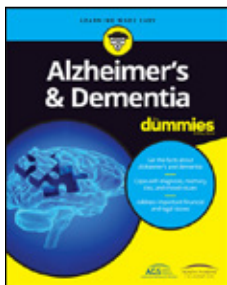
If you or a loved one are worried about Alzheimer's disease or other types of dementia, this pocket guide will help you to better understand the conditions, and how they are diagnosed and treated.



## THE SPECTRUM OF HOPE: AN OPTIMISTIC AND NEW APPROACH TO ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

**Gayatri Devi.** New York: Workman Publishing, 2017, 256 p.

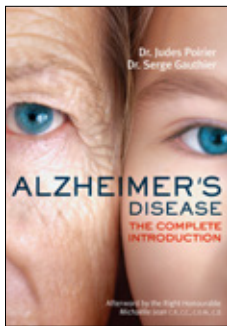
By defining Alzheimer's Disease as a spectrum disorder – like autism, it affects different people differently – Dr. Gayatri Devi offers new hope for its millions of sufferers. A neurologist who's been specializing in dementia and memory loss for more than 20 years, Dr. Devi shares the stories of her patients in the kind of narrative medical writing that grips the reader, humanizes the science, and offers equal parts practical wisdom and advice.



## ALZHEIMER'S AND DEMENTIA FOR DUMMIES

**Consumer Dummies.** Hoboken: John Wiley & Sons, Inc., 2016, 456 p.

Whether you're new to caring for a person affected by Alzheimer's or dementia or just looking for some answers and relief on your journey, this book will help you make sense of the symptoms of dementia and Alzheimer's disease and understand the stages of the illnesses.



## ALZHEIMER'S DISEASE: THE COMPLETE INTRODUCTION

**Judes Poirier and Serge Gauthier.** Toronto: Dundurn Press, 2014, 173 p.

This book is a comprehensive guide to the disease and its effects: getting a diagnosis, the ways it can progress and be managed, strategies for supporting sufferers and accessing care, legal concerns, and more. This guide addresses every aspect of the disease from the first doctor's visit to the long-term measures that can drastically improve the lives of sufferers and those close to them.

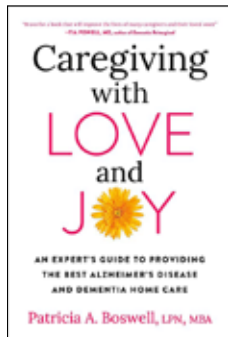


## LOVE, LOSS, AND LAUGHTER: SEEING ALZHEIMER'S DIFFERENTLY

**Cathy Greenblat.** Guilford: Lyons Press, 2012, 176 p.

This book challenges the typical perception of people with Alzheimer's as “empty shells,” lost to themselves and others. Endorsed by Alzheimer's Disease International (ADI), this important work melds uplifting photographs with thoughtful text by the author, care partners, researchers, medical practitioners, social care providers, activists, and people living with dementia diagnoses.

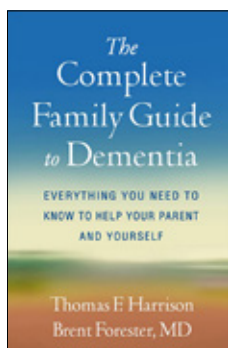
## Accompaniment of a family member or friend



### **CAREGIVING WITH LOVE AND JOY: AN EXPERT'S GUIDE TO PROVIDING THE BEST ALZHEIMER'S DISEASE AND DEMENTIA HOME CARE**

**Patricia A. Boswell.** New York: Avery, an imprint of Penguin Random House, 2022, 284 p.

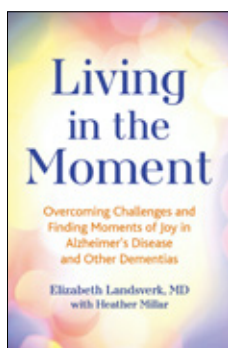
Whether readers are providing the care themselves, managing a caregiver, or sharing the responsibilities, this book presents the most effective tips, tricks, and small changes that can reduce stress and make life easier. This comprehensive guidebook will redefine the caregiving experience as one that can be life-affirming and enjoyable. It offers a singular resource for anyone who is looking to provide or manage outstanding daily care while maintaining – and even enhancing – their own health and mental well-being.



### **THE COMPLETE FAMILY GUIDE TO DEMENTIA: EVERYTHING YOU NEED TO KNOW TO HELP YOUR PARENT AND YOURSELF**

**Thomas F. Harrison and Brent P. Forester.** New York: The Guilford Press, 2022, 243 p.

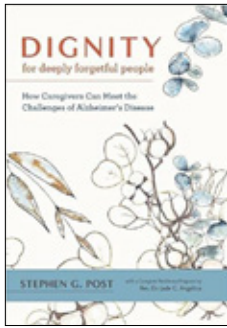
What do you do when your loved one so plainly needs assistance, but is confused, angry, or resistant to your help? Where can you find the vital information you need, when you need it? Journalist Thomas Harrison and leading geriatric psychiatrist Brent Forester show that you don't have to be a medical expert to be a good care provider in this authoritative guide. They explain the basics of dementia and offer effective strategies for coping with the medical, emotional, and financial toll.



### **LIVING IN THE MOMENT: A GUIDE TO OVERCOMING CHALLENGES AND FINDING MOMENTS OF JOY IN ALZHEIMER'S DISEASE AND OTHER DEMENTIAS**

**Elizabeth Landsverk.** New York: Kensington Publishing Corporation, 2022, 272 p.

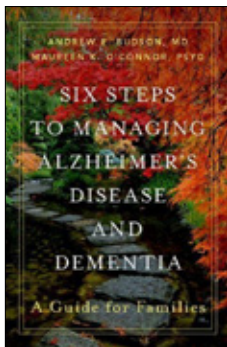
Filled with must-have information, practical advice, and unique and comforting insights, here is everything you need to know about caring for your loved one and making his or her life the best possible – starting now, even as the disease progresses.



## **DIGNITY FOR DEEPLY FORGETFUL PEOPLE: HOW CAREGIVERS CAN MEET THE CHALLENGES OF ALZHEIMER'S DISEASE**

**Stephen G. Post with Rev. Dr. Jade C. Angelica.** Baltimore, Maryland: Johns Hopkins University Press, 2022, 268 p.

In this book, Post offers new perspectives on the worth and dignity of people with Alzheimer's and related disorders despite the negative influence of "hypercognitive" values that place an ethically unacceptable emphasis on human dignity as based on linear rationality and strength of memory. This bias, Post argues, is responsible for the abusive exclusion of this population from our shared humanity. With vignettes and narratives, he argues for a deeper dignity grounded in consciousness, emotional presence, creativity, interdependence, music, and a self that is not "gone" but "differently abled."



## **SIX STEPS TO MANAGING ALZHEIMER'S DISEASE AND DEMENTIA: A GUIDE FOR FAMILIES**

**Andrew Budson.** New York: Oxford University Press, 2021, 330 p.

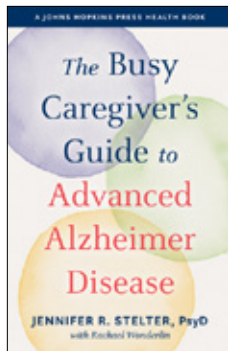
This book explains everything that a caregiver needs to care for their loved one with Alzheimer's disease or dementia, including problems with memory, language, vision, emotion, behaviour, sleep, and bodily functions. Also discussed are medications, the progression of dementia, death, and how to plan for life afterward. Features clinical vignettes and character-based stories that provide examples based on real life.



## **DEMENTIA HOME CARE: HOW TO PREPARE BEFORE, DURING, AND AFTER**

**Tracy Cram Perkins.** Lake Jackson, CA: Behler Publications, 2021, 244 p.

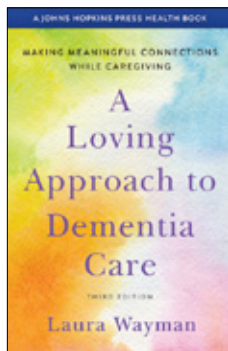
A comprehensive guidebook that teaches caregivers how to use cueing aids, work with hoarding, reduce or prevent wandering, employ distraction and redirection techniques, and much more. Going beyond most dementia caregiving books, its content ranges from teaching first time cooks how to prepare meals for someone with dementia to tips for utilizing medical professionals for the best outcome for your loved one, and how to prepare in advance for emergencies and end of life care.



## THE BUSY CAREGIVER'S GUIDE TO ADVANCED ALZHEIMER DISEASE

**Jennifer R. Stelter, with Rachael Wonderlin.** Baltimore: Johns Hopkins University Press, 2021, 174 p.

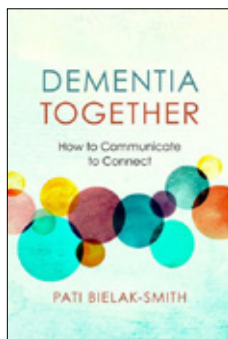
This book presents the Dementia Connection Model, a recipe to connect families in a way that produces positive interactions and preserves their loved one's level of functioning for as long as possible. The model brings together three concepts in dementia care of what is happening to the person with Alzheimer's disease and, more importantly, why these things are happening as the person's condition progresses and how to intervene successfully.



## A LOVING APPROACH TO DEMENTIA CARE: MAKING MEANINGFUL CONNECTIONS WHILE CAREGIVING (3RD EDITION)

**Laura Wayman.** Baltimore: Johns Hopkins University Press, 2021, 190 p.

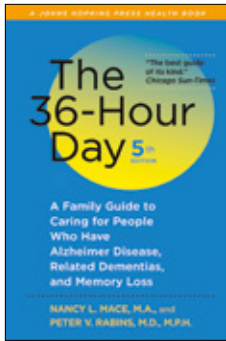
In this third edition of her book, Laura Wayman offers practical, compassionate advice on overcoming caregiving obstacles and maintaining meaningful relationships with loved ones who have dementia and memory loss. Each chapter contains two sections – "Lessons Learned" and "Perceptions and Approaches" – which provide details about how readers can apply lessons from Wayman's stories to their own caregiving practice.



## DEMENTIA TOGETHER: HOW TO COMMUNICATE TO CONNECT

**Pati Bielak-Smith.** Encinitas, California: PuddleDancer Press, 2020, 234 p.

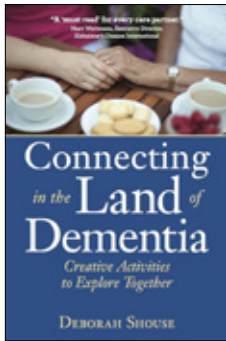
This book is for family members and friends, for spouses, caregivers, and those who simply care. It outlines a path to a life with dementia that includes more life and less illness. With imagination, compassion, empathy, and quiet humor, the real-life stories in *Dementia Together* show you how to build a healthy dementia relationship. Because there are ways to communicate that result in greater capacity to receive as well as to provide both warm connection and practical collaboration.



## **THE 36-HOUR DAY: A FAMILY GUIDE TO CARING FOR PEOPLE WHO HAVE ALZHEIMER DISEASE, OTHER DEMENTIAS, AND MEMORY LOSS**

**Nancy L. Mace and Peter V. Rabins.** Baltimore: Johns Hopkins University Press, 2017, 393 p.

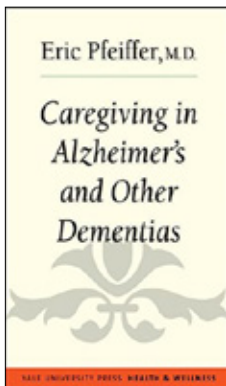
When someone in your family suffers from Alzheimer's disease or other related memory loss diseases, both you and your loved one face immense challenges. Mace and Rabins provide practical and specific advice to make care easier, improve quality of life, and lift the spirits of a family dealing with Alzheimer's disease.



## **CONNECTING IN THE LAND OF DEMENTIA: CREATIVE ACTIVITIES TO EXPLORE TOGETHER**

**Deborah Shouse.** Las Vegas: Central Recovery Press, 2016, 268 p.

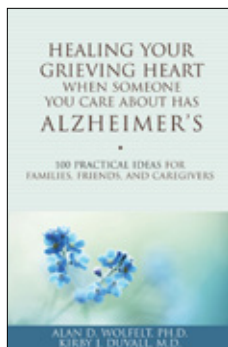
This book offers care partners practical, hands-on ideas for meaningful, creative activities they can do with their patients, family members, or friends who have dementia. It also includes creative tips for busy care partners, offering quick and easy forms of renewal and respite.



## **CAREGIVING IN ALZHEIMER'S AND OTHER DEMENTIAS**

**Eric Pfeiffer.** New Haven: Yale University Press, 2015, 367 p.

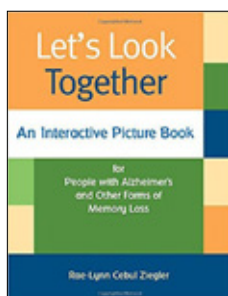
Dr. Eric Pfeiffer, a physician who has devoted thirty years to patients suffering from all forms of dementia, here distills the wisdom of those years for the benefit of caregivers confronting some of life's most challenging days. In these pages are specific tips for all stages of caregiving, from the initial realization of the problem through mild, moderate, and severe stages of dementia, and even beyond, when a caregiver begins to resume a full life after the patient's death. Dr. Pfeiffer identifies specific problems and provides practical solutions. He explains the importance of support groups and many other means of dealing with stressful days.



## HEALING YOUR GRIEVING HEART WHEN SOMEONE YOU CARE ABOUT HAS ALZHEIMER'S: 100 PRACTICAL IDEAS FOR FAMILIES, FRIENDS, AND CAREGIVERS

**Alan Wolfelt.** Fort Collins: Companion Press, 2011, 128 p.

Navigating the challenging journey that families and friends of Alzheimer's patients must endure, this guide reveals how their struggle is as complex and drawn out as the illness itself. Confronting their natural but difficult process of grieving and mourning, the study covers the inevitable feelings of shock, sadness, anger, guilt, and relief, illustrating the initial reactions people commonly feel from the moment of the dementia's onset.



## LET'S LOOK TOGETHER: AN INTERACTIVE PICTURE BOOK FOR PEOPLE WITH ALZHEIMER'S & OTHER FORMS OF MEMORY LOSS

**Rae-Lynn Cebul Ziegler.** Baltimore: Health Professions Press, 2009, 64 p.

Using evocative, sensory-stimulating images, this picture book for adults is to be shared between a family or professional caregiver and a person with memory loss to encourage meaningful emotional connections and conversations that, simultaneously, produce therapeutic brain stimulation.

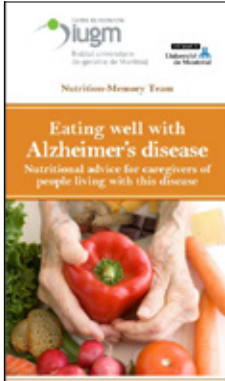


## CREATING MOMENTS OF JOY FOR THE PERSON WITH ALZHEIMER'S OR DEMENTIA: A JOURNAL FOR CAREGIVERS

**Jolene Brackley.** West Lafayette: Purdue University Press, 2008, 331 p.

This book offers many ways to create moments of joy. No matter what the environment or situation is, this book will be a positive tool on a daily basis. This book breaks down the learning process into five sections. Within those five sections are smaller steps. At the end of each step is a place to journal thoughts, ideas, solutions and treasures. With this journal, many moments of joy will be created.

## Healthy living

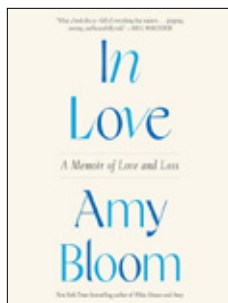


### **EATING WELL WITH ALZHEIMER'S DISEASE: NUTRITIONAL ADVICE FOR CAREGIVERS OF PEOPLE LIVING WITH THIS DISEASE**

**Bryna Shatenstein, Marie-Jeanne Kergoat and Isabelle Reid.** Montreal:  
Nutrition-Memory Team, Institut universitaire de gériatrie de Montréal, 2012, 88 p.

Created for caregivers of people with Alzheimer's disease, this book will serve as a guide throughout the dietary changes that may occur as the illness progresses.

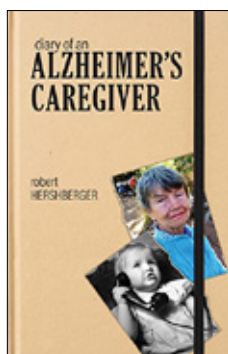
# LIFE STORIES, BIOGRAPHIES AND TESTIMONIALS



## IN LOVE: A MEMOIR OF LOVE AND LOSS

**Amy Bloom.** New York: Random House, 2022, 240 p.

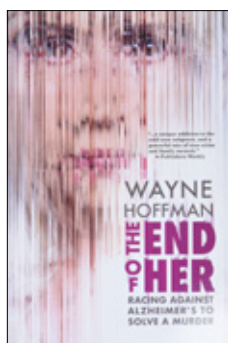
Amy Bloom began to notice changes in her husband, Brian: He retired early from a new job he loved; he withdrew from close friendships; he talked mostly about the past. Suddenly, it seemed there was a glass wall between them, and their long walks and talks stopped. Their world was altered forever when an MRI confirmed what they could no longer ignore: Brian had Alzheimer's disease. In this heartbreaking and surprising memoir, Bloom sheds light on a part of life we so often shy away from discussing – its ending.



## DIARY OF AN ALZHEIMER'S CAREGIVER

**Robert Hershberger.** West Lafayette, Indiana: Purdue University Press, 2022, 194 p.

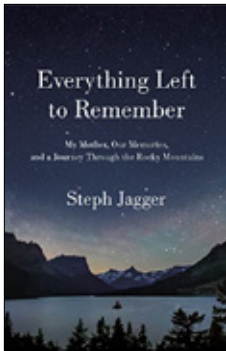
One year shy of her fiftieth wedding anniversary, Dee Hershberger was diagnosed with Alzheimer's disease. Her husband, Bob, serving as her primary caregiver, kept a journal the following four and a half years. *Diary of an Alzheimer's Caregiver* provides an unflinchingly honest and heartbreaking account of what the couple went through.



## THE END OF HER: RACING AGAINST ALZHEIMER'S TO SOLVE A MURDER

**Wayne Hoffman.** New York: Heliotrope Books, 2022, 303 p.

Who was behind the brutal murder of my great-grandmother? wondered Wayne Hoffman, a New York City-based journalist and novelist. The crime wasn't just a family legend – it made headlines across Canada in 1913 – but her killer had never been found. In *THE END OF HER*, Hoffman meticulously researches this century-old tragedy, while facing another: his mother's decline from Alzheimer's.



## **EVERYTHING LEFT TO REMEMBER: MY MOTHER, OUR MEMORIES, AND A JOURNEY THROUGH THE ROCKY MOUNTAINS**

**Steph Jagger.** New York: Flatiron Books, 2022, 257 p.

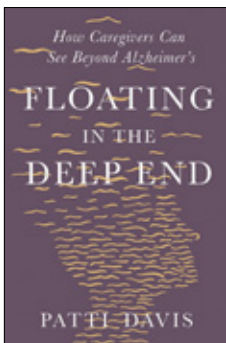
In this heart wrenching and inspirational memoir a woman and her mother, who is suffering from Alzheimer's, embark on a road trip through national parks, revisiting the memories, and the mountains, that made them who they are.



## **MY TWO ELAINES: LEARNING, COPING, AND SURVIVING AS AN ALZHEIMER'S CAREGIVER**

**Martin J. Schreiber with Cathy Breitenbucher.** Nashville, Tennessee: Harper Horizon, an imprint of HarperCollins, 2022, 167 p.

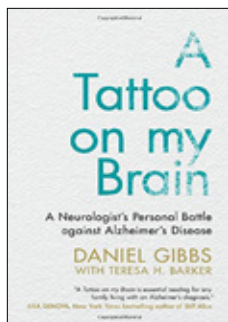
In *My Two Elaines*, author Marty Schreiber, former governor of Wisconsin, watches his beloved wife, Elaine, gradually transform from the woman he fell in love with in high school, and who diligently supported his political career, to the Elaine who knows she is declining and can't remember how to cook a meal, and finally to the Elaine who no longer recognizes Marty or their children.



## **FLOATING IN THE DEEP END: HOW CAREGIVERS CAN SEE BEYOND ALZHEIMER'S**

**Patti Davis.** New York: Liveright Publishing Corporation, a division of W.W. Norton & Company, 2021, 253 p.

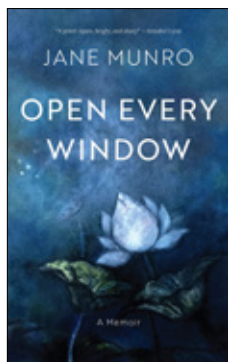
In a singular account of battling Alzheimer's, Patti Davis weaves personal anecdotes with practical advice tailored specifically for the overlooked caregiver. After losing her father, Ronald Reagan, Davis founded a support group for family members and friends of Alzheimer's patients; drawing on those years, Davis reveals the surprising struggles and gifts of this cruel disease. Along the way, Davis shares how her own fractured family came together, and how her father revealed his true self – always kind, even when he couldn't recognize his own daughter.



## A TATTOO ON MY BRAIN: A NEUROLOGIST'S PERSONAL BATTLE AGAINST ALZHEIMER'S DISEASE

**Daniel Gibbs, with Teresa H. Barker.** Cambridge: Cambridge University Press, 2021, 254 p.

Dr. Daniel Gibbs is one of 50 million people worldwide with an Alzheimer's disease diagnosis. Unlike most, however, Dr. Gibbs worked as a neurologist for twenty-five years, caring for patients with the very disease now affecting him. In this highly personal account, Dr. Gibbs documents the effect his diagnosis has had on his life and explains his advocacy for improving early recognition of Alzheimer's. Weaving clinical knowledge with his personal experience of the disease, this is an optimistic tale of one man's journey with early-stage Alzheimer's disease.



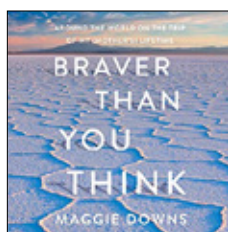
## OPEN EVERY WINDOW: A MEMOIR

**Jane Munro.** Madeira Parks, B.C.: Douglas & MacIntyre, 2021, 256 p.

*Open Every Window* is a genre-bending account of the unraveling of life, when Jane Munro's husband, Bob, is diagnosed with Alzheimer's. The memoir charts a path through sorrow – the pain of seeing a partner age and approach death, the exhaustion of caretaking, and the regret in seeing life's scope narrow and diminish, as Munro grapples with what it means to care for a husband who is gradually but devastatingly deteriorating while her own identity is eclipsed by a single word – *caregiver*.



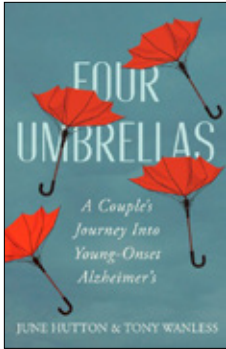
Also available on [prenumerique.ca](https://prenumerique.ca)



## BRAVER THAN YOU THINK: AROUND THE WORLD ON THE TRIP OF MY (MOTHER'S) LIFETIME

**Maggie Downs.** Berkeley, California: Counterpoint, 2020, 285 p.

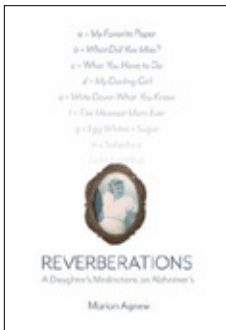
*Braver Than You Think* is the life-affirming story of how Downs, newly married and established in her career as a journalist, quits her job, sells her belongings, and embarks on the solo trip of a lifetime: Her mother's. Over the course of one year backpacking through seventeen countries – visiting all the places her mother, struck with early-onset Alzheimer's disease, cannot visit herself – Maggie faces some of the world's most exotic locales while confronting the slow loss of her mother and the close bond they shared.



## FOUR UMBRELLAS: A WRITING COUPLE'S JOURNEY THROUGH ALZHEIMER'S

**June Hutton.** Toronto: Dundurn, 2020, 224 p.

At the age of fifty-three, Tony walks away from a life of journalism and into an unknown future. June is forty-eight, a writer and teacher, and over the following decade watches as her husband changes – in interests, goals, and behaviour – until Tony has a fall, ending the life they had known.

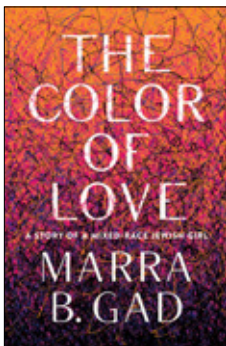


## REVERBERATIONS: A DAUGHTER'S MEDITATIONS ON ALZHEIMER'S

**Marion Agnew.** Manitoba: Signature Editions, 2019, 240 p.

Most people think Alzheimer's disease is the same as memory loss or hope that if they ignore it hard enough, it will go away. That was certainly Marion Agnew's hope when her mother – a Queen's and Harvard/Radcliffe-educated mathematician, nuclear weapons researcher, award-winning professor and researcher, as well as a mother of five – began drifting away from her. This moving memoir looks at grief and family, at love and music. It is a coming-to-terms reflection on the endurance of love and family.

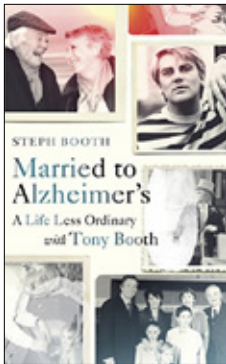
 Also available on [prenumerique.ca](https://prenumerique.ca)



## THE COLOR OF LOVE: A MEMOIR OF A MIXED-RACE JEWISH GIRL

**Marra B. Gad.** Chicago: Bolden, 2019, 233p.

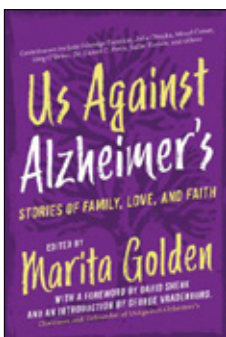
An unforgettable memoir about a mixed-race Jewish woman who, after fifteen years of estrangement from her racist great-aunt, helps bring her home when Alzheimer's strikes.



## MARRIED TO ALZHEIMER'S: A LIFE LESS ORDINARY WITH TONY BOOTH

**Steph Booth.** London: Rider Books, 2019, 256 p.

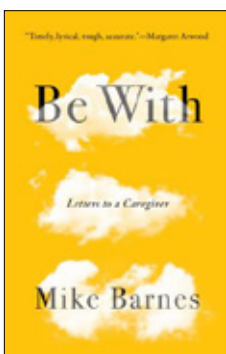
When her husband Tony was diagnosed with Alzheimer's in 2004; Steph Booth had to say goodbye to life as she knew it. The disease encroached into their lives; taking away Tony day by day. Open and honest; but with heart and warmth; Steph reveals and the hardship of caring for Tony and losing herself in the midst of it.



## US AGAINST ALZHEIMER'S: STORIES OF FAMILY, LOVE AND FAITH

Edited by **Marita Golden**; with a foreword by **David Shenk** and an introduction by **George Vradenburg**. New York: Arcade Publishing, 2019, 292 p.

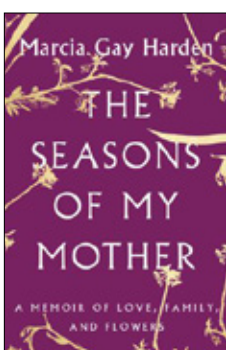
This groundbreaking anthology presents forty narratives, both nonfiction and fiction, that together capture the impact and complexity of Alzheimer's and other dementias on patients as well as their caregivers and family. Deeply personal, recounting the wrenching course of a disease that kills a loved one twice – first they forget who they are, and then the body succumbs – these stories also show how witnessing the disease and caring for someone with it can be powerfully transformative, calling forth amazing strength and grace.



## BE WITH: LETTERS TO A CAREGIVER

**Mike Barnes.** Windsor: Biblioasis, 2018, 149 p.

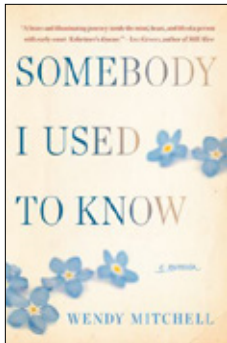
Drawing on the author's seven years of caring for his mother through Alzheimer's, *Be With: Letters to a Caregiver* is what its title promises: four dispatches to an anonymous long-term caregiver. In brief passages that cast fresh light on what it means to live with dementia, Barnes shares trials, insights, solace – and, ultimately, inspiration.



## THE SEASONS OF MY MOTHER: A MEMOIR OF LOVE, FAMILY, AND FLOWERS

**Marcia Gay Harden.** New York: Atria Books, 2018, 325 p.

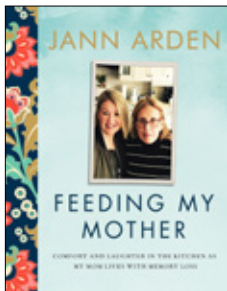
With a razor-sharp wit, as well as the kind of emotional honesty that has made her performances resonate with audiences worldwide, Marcia captures the joys and losses of life even as her precious mother gracefully strives to maintain her identity while coming to grips with Alzheimer's disease.



## **SOMEBODY I USED TO KNOW: A MEMOIR**

**Wendy Mitchell, with Anna Wharton.** New York: Ballantine Books, 2018, 258 p.

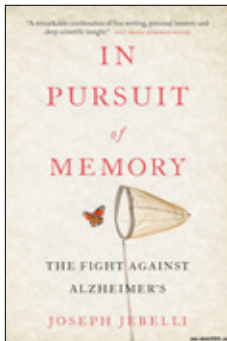
A memoir by a former British National Health Service employee and single parent describes her battles with early onset Alzheimer's, the management techniques she has developed to maintain her independence, and her efforts to make sense of her shifting world.



## **FEEDING MY MOTHER: COMFORT AND LAUGHTER IN THE KITCHEN AS MY MOM LIVES WITH MEMORY LOSS**

**Jann Arden.** Toronto: Random House Canada, 2017, 224 p.

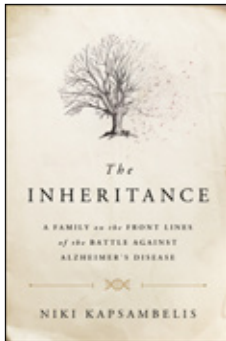
Jann Arden moved into a house just across the way from her parents in rural Alberta to be close to them but also so they could be her refuge from the demands of the music business and a performing career. Since her dad died in 2015, Jann cooks for her mom five or six times a week. Her mom finds comfort in her daughter's kitchen, not just in the delicious food but also just sitting with her as she cooks. And Jann finds some peace in caring for her mom, even as her mom slowly becomes a stranger.



## **IN PURSUIT OF MEMORY: THE FIGHT AGAINST ALZHEIMER'S**

**Joseph Jebelli.** New York: Little, Brown and Company, 2017, 301 p.

A neuroscientist takes readers on a journey around the world and through history, from nineteenth-century Germany to present-day India, to examine the science and scientists working to find a cure for Alzheimer's disease.



## THE INHERITANCE: A FAMILY ON THE FRONT LINES OF THE BATTLE AGAINST ALZHEIMER'S DISEASE

**Niki Kapsambelis.** New York: Simon & Schuster, 2017, 344 p.

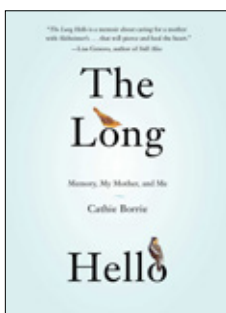
The DeMoe family has the most devastating form of the disease that there is: early onset Alzheimer's, an inherited genetic mutation that causes the disease in 100 percent of cases, and has a 50 percent chance of being passed onto the next generation. Of the six DeMoe children whose father had it, five have inherited the gene; the sixth, Karla, has inherited responsibility for all of them. But rather than give up in the face of such news, the DeMoes have agreed to spend their precious, abbreviated years as part of a worldwide study that could utterly change the landscape of Alzheimer's research and offers the brightest hope for future treatments – and possibly a cure.



## THE SHADOW THIEF: A COUPLE'S JOURNEY OF CHANGED LOVE INTO THE DARKNESS OF ALZHEIMER'S

**Jini A. Wilson.** North Charleston: CreateSpace Independent Publishing Platform, 2017, 114 p.

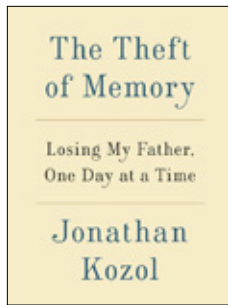
Jini A. Wilson married her husband on his fiftieth birthday. Their lives, as she describes in her new memoir, were perfection. By the time her husband reached his late fifties, he began showing the symptoms of Alzheimer's disease. Jini's sunny days were plunged into shadow, and she had no one to turn to. Jini shares her story from the initial Alzheimer's diagnosis to her heart-wrenching decision to place her husband in long-term care.



## THE LONG HELLO: MEMORY, MY MOTHER, AND ME

**Cathie Borrie.** New York: Simon & Schuster, 2015, 352 p.

*The Long Hello* explores the emotional rewards and challenges that Cathie Borrie experienced in caring for her mother, who was living with Alzheimer's disease, for seven years.



## THE THEFT OF MEMORY: LOSING MY FATHER, ONE DAY AT A TIME

**Jonathan Kozol.** Waterville: Thorndike Press, 2015, 353 p.

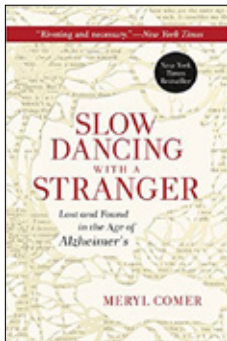
The author tells the story of his father's life and extraordinary career as a noted specialist in neurological and psychiatric disorders of the brain.



## BEFORE I FORGET: LOVE, HOPE, HELP, AND ACCEPTANCE IN OUR FIGHT AGAINST ALZHEIMER'S

**B. Smith and Dan Gasby.** New York: Harmony, 2015, 336 p.

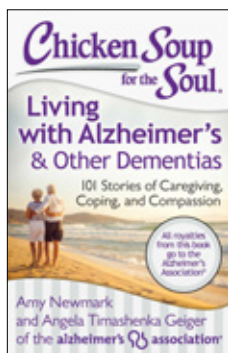
Restaurateur, magazine publisher, celebrity chef, and nationally known lifestyle maven, B. Smith is struggling at 64 with a tag she never expected to add to that string: Alzheimer's patient. She's not alone. Every 67 seconds someone newly develops it, and millions of lives are affected by its aftershocks. B. and her husband, Dan, working with *Vanity Fair* contributing editor Michael Shnayerson, unstintingly share their unfolding story.



## SLOW DANCING WITH A STRANGER: LOST AND FOUND IN THE AGE OF ALZHEIMER'S

**Meryl Comer.** New York: HarperOne, 2014, 224 p.

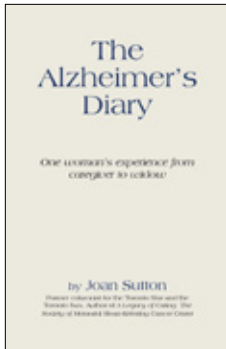
Emmy-award winning broadcast journalist and leading Alzheimer's advocate Meryl Comer's *Slow Dancing With a Stranger* is a personal, unflinching account of her husband's battle with Alzheimer's disease that serves as a much-needed wake-up call to better understand and address a progressive and deadly affliction.



## CHICKEN SOUP FOR THE SOUL: LIVING WITH ALZHEIMER'S & OTHER DEMENTIAS: 101 STORIES OF CAREGIVING, COPING, AND COMPASSION

**Amy Newmark and Angela Timashenka Geiger.** Cos Cob: Chicken Soup for the Soul Publishing, LLC, 2014, 349 p.

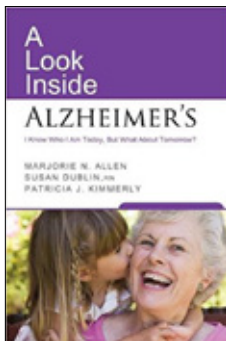
Caring for a loved one with Alzheimer's or another form of dementia? You are not alone. With 101 encouraging and inspiring stories by others like you, this book is a source of support and encouragement throughout your caregiving journey.



## ALZHEIMER'S DIARY: ONE WOMAN'S EXPERIENCE FROM CAREGIVER TO WIDOW

**Joan Sutton.** Bloomington: iUniverse, 2014, 140 p.

In her memoir, author Joan Sutton narrates a moving account of her years as a caregiver to her husband, noting that “Alzheimer’s is a disease of the brain that is paid for with the currency of the heart.” A member of the board of overseers of The Alzheimer’s Drug Discovery Foundation, she stresses the need to develop more effective treatment for the eight million Americans currently diagnosed with this incurable disease, pointing out that for every patient there is a large circle of others also affected.



## A LOOK INSIDE ALZHEIMER'S

**Marjorie N. Allen, Susan Dublin and Patricia J. Kimmerly.** New York: Demos Health, 2013, 138 p.

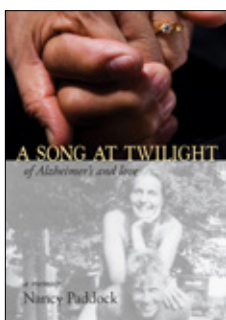
Susan and Patricia share their accounts of their own transformation and deterioration with early-onset Alzheimer’s Disease and Marjorie shares her perspective as the wife of a person living with Alzheimer’s Disease. The book addresses the complexity and emotions surrounding issues such as the loss of independence, unwanted personality shifts, struggle to communicate, and more.



## SUM IT UP: A THOUSAND AND NINETY-EIGHT VICTORIES, A COUPLE OF IRRELEVANT LOSSES, AND A LIFE IN PERSPECTIVE

**Pat Head Summitt and Sally Jenkins.** New York: Crown Archetype, 2013, 416 p.

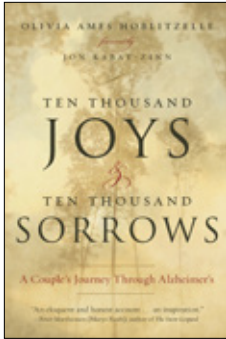
Pat Summitt was only 21 when she became head coach of the Tennessee Vols women’s basketball team. For 38 years, she has broken records, winning more games than any NCAA team in basketball history. Pat’s life took a shocking turn in 2011, when she was diagnosed with early-onset Alzheimer’s disease. Despite her devastating diagnosis, she led the Vols to win their sixteenth SEC championship in March 2012.



## A SONG AT TWILIGHT: OF ALZHEIMER'S AND LOVE

**Nancy Paddock.** Janesville: Blueroad Press, 2011, 301 p.

*A Song at Twilight: Of Alzheimer's and Love* is a feature-length memoir by acclaimed Minnesota poet Nancy Paddock. The book tells the story of her parents’ descent into the netherworld of Alzheimer’s, and the challenges and choices for care that she and her sisters faced while confronting this most baffling and tragic of diseases, now afflicting millions of people and their families.



## TEN THOUSAND JOYS & TEN THOUSAND SORROWS: A COUPLE'S JOURNEY THROUGH ALZHEIMER'S

**Olivia Ames Hoblitzelle.** New York: TarcherPerigee, 2010, 352 p.

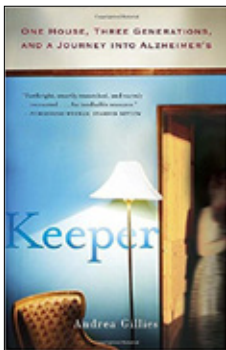
In this memoir, Olivia Ames Hoblitzelle describes how her husband's Alzheimer's diagnosis at the age of seventy-two challenged them to live the spiritual teachings they had embraced during the course of their life together.



## JAN'S STORY: LOVE LOST TO THE LONG GOODBYE OF ALZHEIMER'S

**Barry Petersen.** Lake Forest: Behler Publications, 2010, 224 p.

When CBS News Correspondent Barry Petersen married the love of his life twenty-five years ago, he never thought his vow, 'until death do us part,' would have an expiration date. But early-onset Alzheimer's claimed Jan Petersen, Barry's beautiful wife, at 55, leaving her unable to remember Barry or their life together.



## KEEPER: ONE HOUSE, THREE GENERATIONS, AND A JOURNEY INTO ALZHEIMER'S

**Andrea Gillies.** New York: Broadway Books, 2010, 336 p.

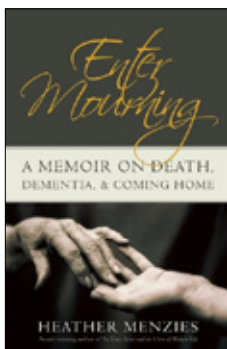
Five years ago, Andrea Gillies seeing that her husband's parents were struggling to cope, invited them to move in. She and her newly extended family relocated to a big Victorian house on a remote, windswept peninsula in the far north of Scotland, leaving behind their friends and all that was familiar; hoping to find a new life, and new inspiration for work. Her mother-in-law Nancy was in the middle stages of Alzheimer's Disease, and *Keeper* charts her journey into dementia, its impact on her personality and her family, and the author's researches into what dementia is. As the grip of her disease tightens, Nancy's grasp on everything we think of as ordinary unravels before our eyes. Diary entries and accounts of conversations with Nancy track the slow unravelling.



## MOTHER IN THE MIDDLE: A BIOLOGIST'S STORY OF CARING FOR PARENT AND CHILD

**Sybil Lockhart.** New York: Simon & Schuster, 2009, 310 p.

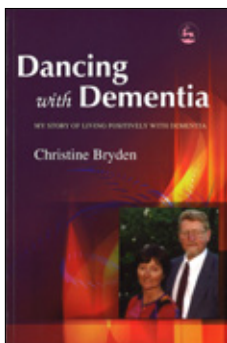
Sybil Lockhart, a Berkeley neurobiologist, became a “mother in the middle” when she was pregnant with her second daughter and her mother was diagnosed with Alzheimer’s disease. What makes Sybil’s story different is that she understood the neurological processes, by turns exciting and devastating, that were taking place in the brains of those she loved.



## ENTER MOURNING: A MEMOIR ON DEATH, DEMENTIA, & COMING HOME

**Heather Menzies.** Toronto: Key Porter Books, 2009, 240 p.

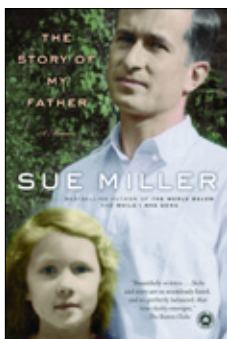
Heather Menzies led a fairly normal life sandwiched between a demanding career and a busy family typical of her baby-boomer generation. Then the ground shifted. Her aging widowed mother was diagnosed with Alzheimer’s. This book chronicles Menzies’s transformative journey with her mother as words fail and the very nature of communication is redefined.



## DANCING WITH DEMENTIA: MY STORY OF LIVING POSITIVELY WITH DEMENTIA

**Christine Bryden.** London: Jessica Kingsley, 2005, 200 p.

Christine Bryden was a top civil servant and single mother of three children when she was diagnosed with dementia at the age of 46. Since then she has gone on to challenge almost every stereotype of people with dementia by campaigning for self-advocacy, writing articles and speaking at national conferences. This book is a vivid account of the author’s experiences of living with dementia, exploring the effects of memory problems, loss of independence, difficulties in communication and the exhaustion of coping with simple tasks.

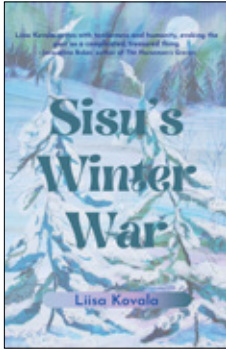


## THE STORY OF MY FATHER: A MEMOIR

**Sue Miller.** New York: Random House Large Print, 2003, 304 p.

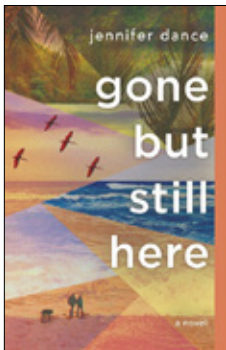
In the fall of 1988, Sue Miller found herself caring for her father as he slipped into the grasp of Alzheimer’s disease. She was, she claims, perhaps the least constitutionally suited of all her siblings to be in the role in which she suddenly found herself, and in *The Story of My Father* she grapples with the haunting memories of those final months and the larger narrative of her father’s life.

## NOVELS

**SISU'S WINTER WAR**

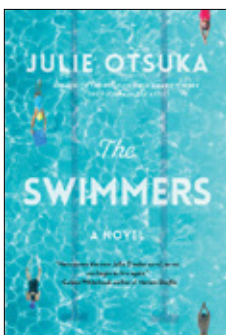
**Liisa Kovalu.** Sudbury, Ontario: Latitude 46, 2022, 350 p.

Meri Saari made a promise to her dying mother she would keep the family together, but she was too young to know how a war can pull people apart. As a teenager responsible for her siblings she finds herself following her father to the front lines during the Winter War when he goes missing in action. Forty years later, living in northern Ontario, Meri's past and present collide when she is diagnosed with early onset Alzheimer's. Responsible for her granddaughter, and navigating a strained relationship with her daughter Linnea, Meri is haunted by the people of her past and by the promises she failed to keep.

**GONE BUT STILL HERE: A NOVEL**

**Jennifer Dance.** Toronto: Dundurn Press, 2022, 380 p.

Coming to terms with advancing dementia, Mary has no choice other than to move into her daughter's home. Her daughter, Kayla, caught between her cognitively impaired mother and her belligerent teenage son, soon finds caregiving is more challenging than she imagined. Sage, the family's golden retriever, offers comfort and unconditional love, but she has her own problems, especially when it comes to dealing with Mary's cat.

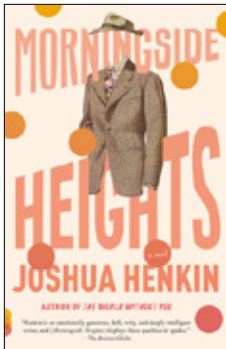
**THE SWIMMERS**

**Julie Otsuka.** New York: Alfred A. Knopf, 2022, 175 p.

Alice is part of a group of recreational swimmers for whom the local pool has become a place of unexpected kinship, freedom, and ritual. Until one day a crack appears beneath its surface... As cracks also appear in Alice's memory, her husband and daughter are faced with the dilemma of how best to care for her, while her daughter also navigates the fractured landscape of their relationship.



Also available on [pretnumerique.ca](https://pretnumerique.ca)

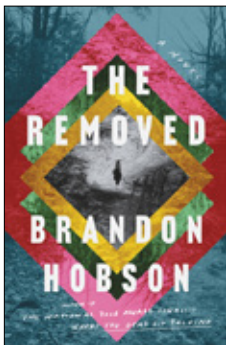


## MORNINGSIDE HEIGHTS

**Joshua Henkin.** New York: Pantheon Books, 2021, 292 p.

When Pru Steiner moves to New York in 1976, she falls in love with and marries Spence Robin, her hotshot young Shakespeare professor. Thirty years later, something is wrong with Spence. He can't concentrate and falls asleep reading *The New York Review of Books*; he is diagnosed with early onset Alzheimer's. With their daughter, Sarah, away at medical school, Pru must struggle on her own to care for him. Meanwhile, Spence's estranged son has come back into their lives. Arlo, a wealthy entrepreneur who invests in biotech, may be his father's last, best hope.

 Also available on [prenumerique.ca](https://prenumerique.ca)



## THE REMOVED

**Brandon Hobson.** New York: Ecco, an imprint of HarperCollins Publishers, 2021, 272 p.

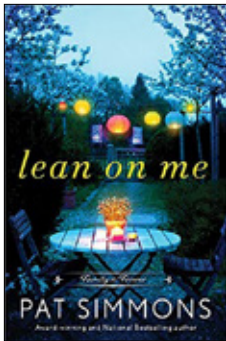
For fifteen years, since their son Ray-Ray was killed in a police shooting, the Echota family has been suspended in grief. The mother, Maria, struggles to manage the onset of Alzheimer's in her husband, Ernest. Their adult daughter, Sonja, leads a life of solitude, punctuated only by spells of dizzying romantic obsession. And their son, Edgar, fled home long ago, turning to drugs to mute his feelings. With the family's annual bonfire approaching—marking both the Cherokee National Holiday and Ray-Ray's death—each of them feels a strange blurring of the boundary between normal life and the spirit world.



## HOW LULU LOST HER MIND

**Rachel Gibson.** New York: Gallery Books, an imprint of Simon & Schuster, Inc., 2020, 324 pages.

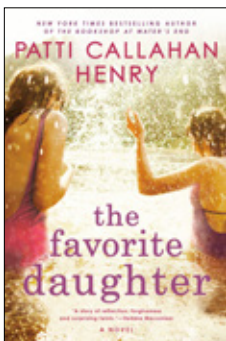
Humorous fiction. Lou Ann Hunter's mother, Patricia, has always had a passionate nature, which explains why she's been married and divorced five times and spooned enough male patients to be ousted from three elderly care facilities. She also has Alzheimer's, which is why she wants to spend her remaining months or years surrounded by memories at her family's decrepit old plantation in Louisiana with her only daughter.



## LEAN ON ME

**Pat Simmons.** Naperville, Illinois: Sourcebooks Casablanca, 2020, 282 p.

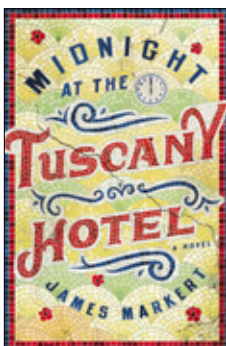
Tabitha Knicely loves her career as a pharmaceutical rep, but even her health care knowledge isn't much help with the daily challenges she now faces caring for her aunt with Alzheimer's. Her once organized lifestyle is in disarray and her patience is tested. When a mystery woman who keeps showing up on his porch turns out to be an elderly neighbor, Marcus is outraged at what he perceives as neglect on the part of her caregiver. Marcus soon learns that being a caregiver is a demanding, compassionate act of kindness that he has never experienced before. After several encounters with Aunt Tweet and Tabitha, his heart is drawn to the family's distress.



## THE FAVORITE DAUGHTER

**Patti Callahan Henry.** New York: Berkley, 2019, 348 p.

On her wedding day ten years ago, Lena Donohue experienced a betrayal so painful that she fled the small town of Watersend, South Carolina, and reinvented herself in New York City. Though now a freelance travel writer, the one place she rarely goes is home – until she learns of her dad's failing health. Returning to Watersend means seeing the sister she has avoided for a decade and the brother who runs their family's Irish pub – and who has borne the burden of his sisters' rift. While Alzheimer's slowly steals their father's memories, the siblings rush to preserve his life in stories and photographs. As his secret past brings Lena's own childhood into focus, it sends her on a journey to discover the true meaning of home.



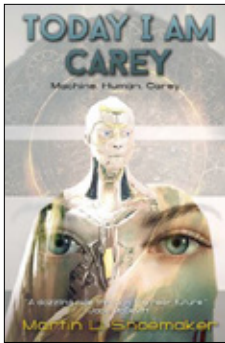
## MIDNIGHT AT THE TUSCANY HOTEL

**James Markert.** Nashville: Thomas Nelson, 2019, 368 p.

A once-beloved hotel and a fountain whose water suddenly can restore lost memories. But is it a miracle, or are there strings attached?



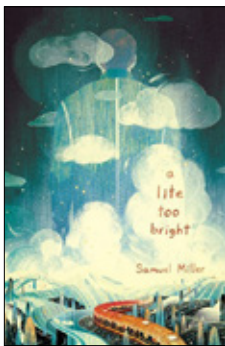
Also available on [prenumerique.ca](http://prenumerique.ca)



## TODAY I AM CAREY

**Martin L. Shoemaker.** New York: Baen Books, 2019, 320 p.

Mildred has Alzheimer's. As memories fade, she acquires the aid of a full-time android to assist her in everyday life. Carey. Carey takes care of Mildred, but its true mission is to fill in the gaps in Mildred's past. To bring yesterday into today by becoming a copy. But not merely a copy of a physical person. A copy from the inside out.

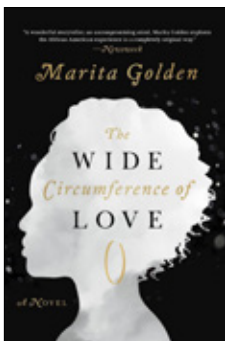


## A LIFE TOO BRIGHT

**Samuel Miller.** New York: Katherine Tegen Books, 2018, 465 p.

Arthur Louis Pullman the Third lives in his grandfather's shadow. The first Arthur Louis Pullman, an iconic Salinger-esque author who wrote the American classic *A World Away*, died in Ohio a week after he disappeared from his family's California home. What happened in that week – and how much his actions were influenced by his Alzheimer's – remains a mystery.

 Also available on [prenumerique.ca](https://prenumerique.ca)



## THE WIDE CIRCUMFERENCE OF LOVE

**Marita Golden.** New York: Arcade Publishing, 2017, 292 p.

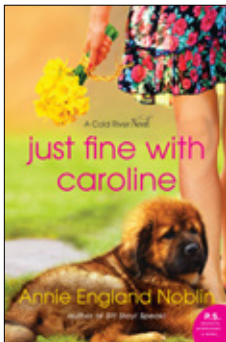
You just can't plan for this kind of thing. Diane Tate certainly hasn't. She never expected to slowly lose her talented husband to the debilitating effects of early-onset Alzheimer's disease. As a respected family court judge, she's spent her life making tough calls, but when her sixty-eight-year-old husband's health worsens and Diane is forced to move him into an assisted living facility, it seems her world is spinning out of control. As Gregory's memory wavers and fades, Diane and her children must reexamine their connection to the man he once was-and learn to love the man he has become.



## THE ALZHAMMER: OR KEEP YOUR FRIENDS CLOSE AND... I FORGET THE OTHER THING

**Joseph Di Prisco.** Los Angeles: Rare Bird Books, 2016, 301 p.

A once powerful mob boss, Mikey is seriously slipping – losing control of his crew and of his mind. His business is sideways, his rivals are coming for him, he's crazy forgetful, and it is a fact his parents suffered miserably with Alzheimer's. He refuses to ride diapered and drooling into the sunset. He is going to whack himself. Problem is, others are trying to whack him and rip off what's left of the family's business.



## JUST FINE WITH CAROLINE

**Annie England Noblin.** New York: William Morrow, an imprint of HarperCollins Publishers, 2016, 328 p.

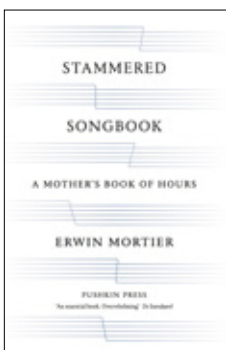
Returning to her small, intrusive Ozark Mountain community, Caroline O'Conner cares for her Alzheimer's patient mother while navigating the challenges of her doctor father's frustrations, her brazen cousin's marital disasters, her deaf dog, a moonshining relative and a troubled ex-veteran.



## THE THINGS WE KEEP

**Sally Hepworth.** New York: St. Martin's Press, 2016, 338 p.

Anna Forster, in the early stages of Alzheimer's disease at only thirty-eight years old, knows that her family is doing what they believe to be best when they take her to Rosalind House, an assisted living facility. She also knows there's just one other resident her age, Luke. What she does not expect is the love that blossoms between her and Luke even as she resists her new life at Rosalind House. As her disease steals more and more of her memory, Anna fights to hold on to what she knows, including her relationship with Luke.



## STAMMERED SONGBOOK: A MOTHER'S BOOK OF HOURS

**Erwin Mortier.** London: Pushkin Press, 2015, 171 p.

Poetry. As Alzheimer's disease sets in and language increasingly escapes her, her son attempts to gather the fragments of what she has become.



## THE MEMORY PAINTER

**Gwendolyn Womack.** New York: HarperCollins Publishers Limited, 2015, 336 p.

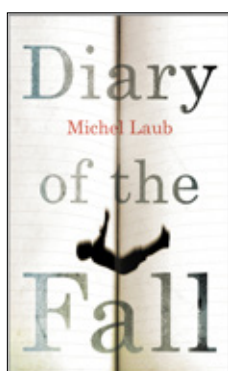
Bryan Pierce is an internationally famous painter. But there's a secret to his success: every canvas is inspired by an unusually vivid dream. When Bryan awakes, he possesses extraordinary new skills – like the ability to speak obscure languages and an inexplicable genius for chess. All his life, he's wondered if his dreams are recollections – if he's re-experiencing other people's lives. Linz Jacobs is a neurogeneticist, absorbed in decoding the genes that help the brain make memories, until she's confronted with an exact rendering of a recurring nightmare at one of Bryan's shows. She tracks down the elusive artist, and their meeting triggers Bryan's most powerful dream yet: visions of a team of scientists who, on the verge of discovering a cure for Alzheimer's, died in a lab explosion decades ago.



## ANGELS WALKING

**Karen Kingsbury.** Nashville: Howard Books, 2014, 384 p.

When former national baseball star Tyler Ames suffers a career-ending injury, all he can think about is putting his life back together the way it was before. He has lost everyone he loves on his way to the big leagues. Then just when things seem to be turning around, Tyler hits rock bottom. Across the country, Tyler's one true love Sami Dawson has moved on. A series of small miracles leads Tyler to a maintenance job at a retirement home and a friendship with Virginia Hutcheson, an old woman with Alzheimer's who strangely might have the answers he so desperately seeks.



## DIARY OF THE FALL

**Michel Laub.** London: Harvill Secker, 2014, 225 p.

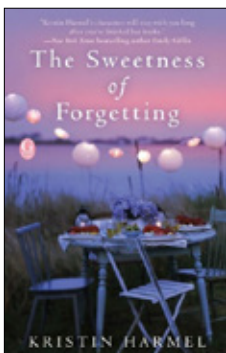
This book is the story of three generations: a man examining the mistakes of his past, and his struggle for forgiveness; a father with Alzheimer's, for whom recording every memory has become an obsession; and a grandfather who survived Auschwitz, filling notebook after notebook with the false memories of someone desperate to forget.



## STARS GO BLUE

**Laura Pritchett.** Berkeley: Counterpoint, 2014, 183 p.

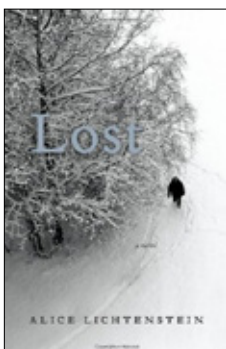
Ranchers Renny and Ben Cross are estranged, elderly spouses living on opposite ends of their sprawling ranch, faced with the particular decline of a fading farm and Ben's struggle with Alzheimer's disease. He is just on the cusp of dementia, able to recognize he is sick but unable to do anything about it – the notes he leaves in his pockets and around the house to remind him of himself, his family, and his responsibilities are no longer as helpful as they used to be.



## THE SWEETNESS OF FORGETTING

**Kristin Harmel.** New York: Gallery Books, 2012, 368 p.

At thirty-six, Hope McKenna-Smith is no stranger to bad news. She lost her mother to cancer, her husband left her for a twenty-two year old, and her bank account is nearly depleted. Her own dreams of becoming a lawyer long gone, she's running a failing family bakery on Cape Cod and raising a troubled preteen. Now, Hope's beloved French-born grandmother Mamie, who wowed the Cape with her fabulous pastries for more than fifty years, is drifting away into a haze of Alzheimer's. But in a rare moment of clarity, Mamie realizes that unless she tells Hope about the past, the secrets she has held on to for so many years will soon be lost forever.



## LOST

**Alice Lichtenstein.** New York: Scribner, 2010, 242 p.

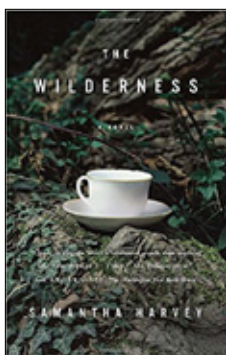
On a cold January morning Susan leaves her husband alone for a few minutes and returns to find him gone. Suffering from dementia, no longer able to dress or feed or wash himself, he has wandered alone into a frigid landscape with no sense of home or direction. *Lost*. From the intersection of three lives emerges an arresting portrait of the shifting terrain of marriage and the devastating effects of physical and psychological damage. Written in spare, beautiful prose, *Lost* explores the lengths we will go to take care of someone and the ways in which responsibility, love, and sorrow can bind people together.



## ISLAND GIRL

**Lynda Simmons.** New York: Berkley Books, 2010, 435 p.

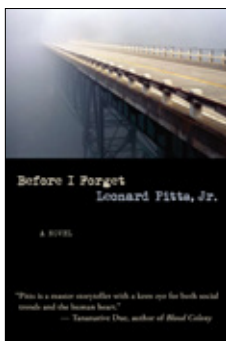
Ruby Donaldson has been diagnosed with early onset Alzheimer's Disease, and she'll be damned if she won't straighten out her troubled family before she no longer knows how.



## THE WILDERNESS

**Samantha Harvey.** New York: Nan A. Talese, 2009, 371 p.

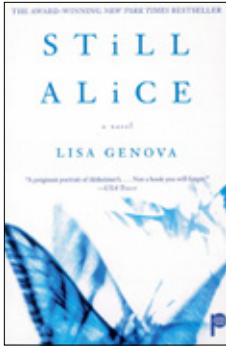
Jake Jameson is a sixty-five-year-old architect who is on the cusp of retirement. One evening he's sitting alone in the office, staring down at an architectural drawing. He can't quite figure out what he's supposed to do with it. Suddenly he remembers a word, one for which he has been searching for days to recall: entropy – for him the singular most interesting theory that exists, a theory that says everything loses, rather than gains, order. This idea underlies this riveting tale of a man whose memories are slowly eroding. As Alzheimer's begins to wear away his sense of identity, Jake builds stories around his life that inform his feelings of blame and responsibility – only to have the stories disintegrate faster than he can capture them.



## BEFORE I FORGET

**Leonard Pitts.** Chicago: Agate, 2009, 365 p.

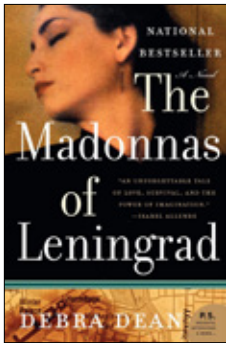
Moses Johnson isn't an old man – though he's a long way beyond his glory days as one of the most popular soul stars of the 70s. But at just about 50, he's shattered to learn that he's developing early-onset Alzheimer's Disease. The prospect is bleak; he's only got a brief amount of time before he loses his memory, and his conscious self, altogether. Mo's been lucky, and he knows it – more successful than most, with at least one unforgettable hit to his name – but there's plenty in his life he regrets.



## STILL ALICE

**Lisa Genova.** New York: Pocket Books, 2008, 293 p.

Alice Howland, happily married with three grown children and a house on the Cape, is a celebrated Harvard professor at the height of her career when she notices a forgetfulness creeping into her life. As confusion starts to cloud her thinking and her memory begins to fail her, she receives a devastating diagnosis: early onset Alzheimer's disease.

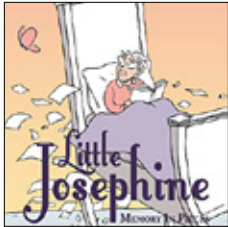


## THE MADONNAS OF LENINGRAD

**Debra Dean.** New York: Morrow, 2006, 231 p.

Bit by bit, the ravages of age are eroding Marina's grip on the everyday. An elderly Russian woman now living in America, she cannot hold on to fresh memories – the details of her grown children's lives, the approaching wedding of her grandchild – yet her distant past is miraculously preserved in her mind's eye. Vivid images of her youth in war-torn Leningrad arise unbidden, carrying her back to the terrible fall of 1941, when she was a tour guide at the Hermitage Museum and the German army's approach signaled the beginning of what would be a long, torturous siege on the city.

## COMICS

**LITTLE JOSEPHINE: MEMORY IN PIECES**

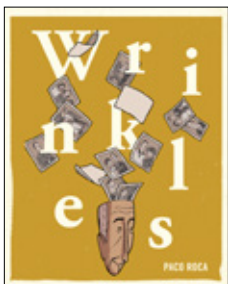
**Valérie Villieu and Raphaël Sarfati.** Los Angeles, California: Life Drawn, 2020, 120 p.

When Valérie first met Josephine, she knew she would be embarking on a unique journey. Though vastly different in age, their connection was instantaneous. Humor quickly became their language, their playground, and despite the debilitating disease that Joséphine faced every single day, they were able to form a beautiful friendship that transcended the reaches of modern medicine.

**EDWIN**

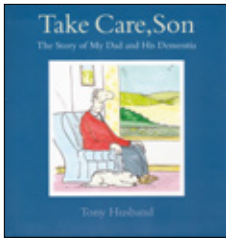
**Roslyn Schwartz.** Toronto: Dumagrad, 2019, 64 p.

*Edwin* is a story in picture book form to be read by caregivers to their Alzheimer's-beset loved ones. It arose from the author's frustration at finding suitable material when she found herself caring for someone who was facing cognitive decline. The story is at once utterly frank about the realities of dementia, yet uplifting.

**WRINKLES**

**Paco Roca.** Seattle: Fantagraphics Books, 2016, 93 p.

Admitted to a home for the elderly because he suffers from Alzheimer's disease, Emilio's community life feels like an ordeal. But soon he accepts his new environment and decides to fight to escape from giving in to his awful destiny. Even as his memory flutters, he and new friend Miguel, an overconfident ladies' man, invent creative ways to enliven their daily routines and strike a blow for personal freedom. It all culminates in a foolhardy, madcap, nighttime joyride... of sorts.



## TAKE CARE, SON: THE STORY OF MY DAD AND HIS DEMENTIA

**Tony Husband.** London: Constable & Robinson Ltd., 2014, 64 p.

This is the illustrated story of Tony's father and how dementia slowly took him away from his family. The title is a reference to his last words to his son – on a day when Tony had spent the day in the care home with no sign of recognition. The book is framed as a chat between Tony and his dad, who fades away through the last few pages of the book.



## TANGLES: A STORY ABOUT ALZHEIMER'S, MY MOTHER, AND ME

**Sarah Leavitt.** Calgary: Freehand Books, 2010.

What do you do when your outspoken, passionate, and quick-witted mother starts fading into a forgetful, fearful woman? In this powerful graphic memoir, Sarah Leavitt reveals how Alzheimer's disease transformed her mother Midge – and her family – forever.



## SAFE RETURN HOME: AN INSPIRATIONAL BOOK FOR CAREGIVERS OF ALZHEIMER'S

**Tom Batiuk and Chuck Ayers.** Kansas City: Andrews McMeel Pub, 1998, 112 p.

A collection of Crankshaft cartoons that feature two characters who suffer from Alzheimer's disease.

# YOUTH LITERATURE



AGES 3 TO 9

## WEEDS IN NANA'S GARDEN: A HEARTFELT STORY OF LOVE THAT HELPS EXPLAIN ALZHEIMER'S DISEASE AND OTHER DEMENTIA

**Kathryn Harrison.** Cobourg: Flipturn Publishing, 2016, 32 p.

A young girl and her Nana hold a special bond that blooms in the surroundings of Nana's magical garden. Extending from the experience of caring for her mother, artist Kathryn Harrison has created this story with rich illustrations to candidly explore dementia diseases, while demonstrating the power of love. After the story, a Question and Answer section about Alzheimer's Disease and other dementia is included.



AGES 4 TO 8

## MY SINGING NANA

**Pat Mora and Alyssa Bermudez** (ill.). Washington, DC: Magination Press, 2019, 32 p.

Billy's beloved Nana's memory is failing but they are "always amigos," so when disaster strikes the day of the family's big summer show, Billy finds a way he and Nana can save the day.

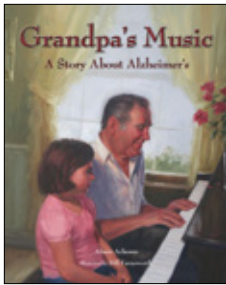


AGES 4 TO 8

## FORGET ME NOT

**Nancy Van Laan and Stephanie Graegin** (ill.). New York: Schwartz & Wade Books, 2014, 40 p.

Young Julia comes to terms with the changes in her beloved grandmother, whose Alzheimer's Disease makes it hard for her to remember people and things.



**AGES 4 TO 8**

## **GRANDPA'S MUSIC: A STORY ABOUT ALZHEIMER'S**

**Alison Acheson and Bill Farnsworth.** Morton Grove: Albert Whitman & Company, 2009, 32 p.

Alison Acheson's thoughtful storytelling and Bill Farnsworth's touching paintings portray a family that learns to adapt to the challenges of Alzheimer's disease while making the very best of their time together.



**AGES 4 TO 8**

## **HUGGING GRANDMA: LOVING THOSE WITH MEMORY DISORDERS**

**Zina Kramer and David Messing (ill.).** Northville: Ferne Press, 2009, 32 p.

What happens when your very own grandma doesn't know it's your birthday? When a little child girl's beloved grandmother develops Alzheimer's disease and can't remember things, how does life go on? Hugs for Grandma provides a positive example of how one child copes with a grandmother who has Alzheimer's disease. Strengthened by the wonderful times they shared together, the child finds ways to help her grandmother still feel useful and needed.



**AGES 4 TO 8**

## **STRIPED SHIRTS AND FLOWERED PANTS: A STORY ABOUT ALZHEIMER'S DISEASE FOR YOUNG CHILDREN**

**Barbara Schnurbush and Cary Pillo (ill.).** Washington: Magination Press, 2006, 32 p.

The author helps children understand how Alzheimer's disease will ultimately change older people they are close to, such as their grandparents, and provides hints for parents to provide ways that they can help their children handle their feelings and worries.

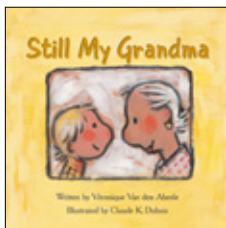


**AGES 4 TO 9**

## GRANDPA MONTY'S MUDDLES

**Marta Zafrilla and Miguel Angel Diez** (ill.). Madrid: Cuento de Luz, 2012, 32 p.

Grandpa Monty is a bit confused: he puts the chicken in the washing machine, he gets towels mixed up with napkins and gloves with socks, and he's always forgetting his grandson's name. Luckily, his grandson loves him very much and is willing to risk getting into a little trouble to try to help him remember. Discussing Alzheimer's and dementia, this story will help both children and parents cope with tough changes in a family. Offering up humor and the potent power of a smile, the book reminds readers of any age that when someone in the family is having trouble remembering things, the most valuable lesson is not to forget the importance of loving them.

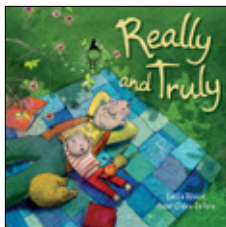


**AGES 4 TO 10**

## STILL MY GRANDMA

**Veronique Van den Abeele and Claude V. Dubois** (ill.). Eerdmans Books for Young Readers, 2007, 28 p.

Camille learns that her grandma is sick, but "not the kind where you cough and blow your nose." Grandma has Alzheimer's disease, which is what makes her do strange things. And even though Grandma has to move out of her house and rely on nurses to care for her, Camille finds a way to continue their special traditions.



**AGES 4+**

## REALLY AND TRULY

**Émilie Rivard and Anne-Claire Delisle** (ill.). Toronto: Owlkid Books, 2011, 24 p.

Charlie is very close to his grandfather, who loves to tell fanciful stories about pirates, witches, and gnomes that amuse Charlie to no end. But lately, Charlie's grandpa doesn't have any new stories to tell. In fact, some days grandpa doesn't even recognize Charlie. A disease has stolen grandpa's memories, his appetite, and even his smile. Charlie wants so much to make his grandpa smile again that he comes up with a plan to tell him stories.

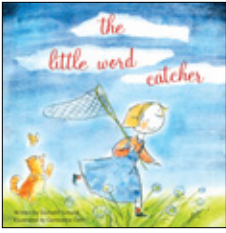


**AGES 5 TO 8**

## MY NEW GRANNY

**Elisabeth Steinkellner and Michael Roher** (ill.). New York: Sky Pony Press, 2012, 32 p.

*My New Granny* is a story about a grandparent who is suffering from dementia and how a grandchild can learn to accept this change in personality in a loved one.

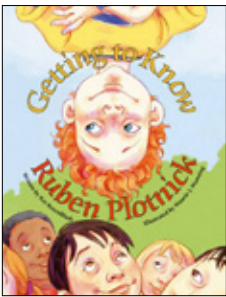


AGES 5 TO 8

## THE LITTLE WORD CATCHER

**Danielle Simard and Geneviève Côté** (ill.). Toronto: Second Story Press, 2008, 32 p.

A little girl tries to help her grandmother by finding the growing number of words that seem to be escaping her. Are the words hiding somewhere? Can she trap them in her net like butterflies? A gentle exploration of the effects of Alzheimer's on the relationships in a family, and the special bond it creates between a grandmother and her granddaughter as the young girl begins to believe that her grandmother has used up all her words and has passed them on to her, as a gift. Award-winning illustrations.

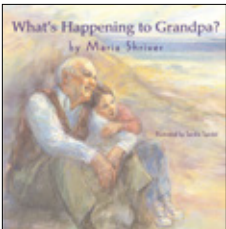


AGES 5 TO 8

## GETTING TO KNOW RUBEN PLOTNICK

**Roz Rosenbluth**. New York: Flashlight Press 2005, 32 p.

David is worried about how zany Ruben Plotnick will react when he meets Grandma Rosie, who often says and does unexpected things. Will Ruben make fun of her to their classmates? Will he imitate her whispery voice? What will he do if Grandma Rosie suddenly wants to dance? This heartwarming story of senility and school-age embarrassment reveals the importance of looking beneath the surface to really get to know someone.

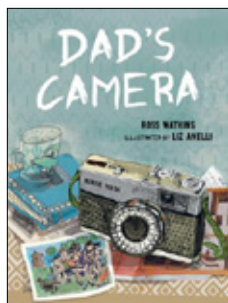


AGES 5 TO 8

## WHAT'S HAPPENING TO GRANDPA?

**Maria Shriver and Sandra Speidel** (ill.). New York: Little, Brown and Co., 2004, 48 p.

Kate has always adored her grandpa's storytelling – but lately he's been repeating the same stories again and again. One day he even forgets Kate's name. Her mother's patient explanations open Kate's eyes to what so many of the elderly must confront: Alzheimer's disease and other forms of memory loss. With special insight derived from her own father's struggle with Alzheimer's, Maria Shriver offers a touching and optimistic story that encourages awareness, acceptance, and dialogue among family and friends.

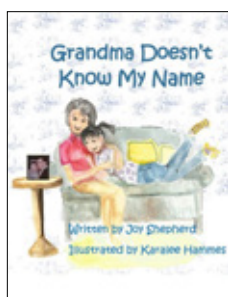


**AGES 5 TO 9**

## DAD'S CAMERA

**Ross Watkins and Liz Anelli** (ill.). Somerville: Candlewick Press, 2018, 40 p.

One day Dad comes home with one of those old cameras, the kind that uses film. But he doesn't take photos of the regular things people photograph. He takes pictures of his keys, his coffee cup, the objects scattered on his desk. He starts doing a lot of things that are hard to understand, like putting items that belong in the fridge in the cupboard and ones that belong in the cupboard in the fridge.



**AGES 5 TO 9**

## GRANDMA DOESN'T KNOW MY NAME

**Joy Shepherd and Karalee Hammes** (ill.). CreateSpace Independent Publishing Platform, 2017, 26 p.

This simple book written in prose helps children understand Alzheimer's disease. A little girl is troubled by her beloved grandmother not remembering her name. The book explains that Alzheimer is not contagious it affects the brain and changes the way things will be done.

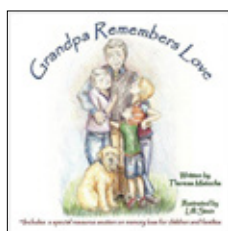


**AGES 6 TO 8**

## COFFEE, RABBIT, SNOWDROP, LOST

**Betina Birkjaer and Anna Margrethe Kjaergaard** (ill.). New York: Enchanted Lion Books, 2021, 36 p.

Stump always has a fantastic time with his grandparents. But one day, his grandfather starts to lose his memory – and his words, which literally fall from him. Stump tries his best to keep the lost words safe, collecting them in a special box. But Grandpa seems to forget more and more everyday, and the situation comes to a head one snowy night when Stump wakes to find Grandpa missing. Together, Stump and Grandma must find new ways to connect with Grandpa, and show him that he's not alone.

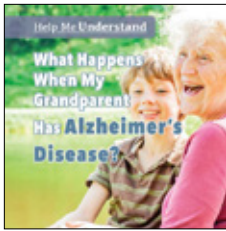


**AGES 6 TO 12**

## GRANDPA REMEMBERS LOVE

**Theresa Matocha**. Bloomington: Authorhouse, 2010, 61 p.

*Grandpa Remembers Love* is a story about connecting with a grandparent who has dementia. With the help of their wise grandmother, Elaine and Teddy begin to understand that an important part of their grandfather's memory has not gone away. And that focusing on what grandpa CAN do creates new opportunities for strengthening the love between them.

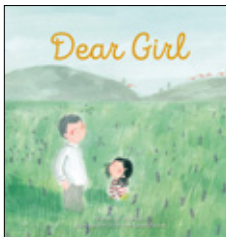


AGES 6+

## WHAT HAPPENS WHEN MY GRANDPARENT HAS ALZHEIMER'S DISEASE?

**Christine Honders.** New York: PowerKids Press, 2020, 24 p.

This book will help young readers understand what Alzheimer's disease is and provide them with healthy coping strategies. Photographs and age-appropriate text aid readers in understanding what's going on and what might be different.

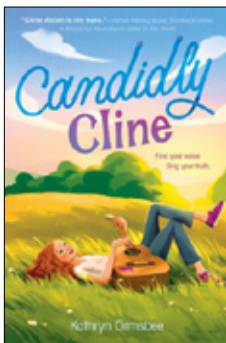


AGES 7+

## DEAR GIRL

**An Swerts and Eline Van Lindenhuisen (ill).** New York: Clavis, 2021, 48 p.

Something is different about Grandpa. He forgets things very easily—he even forgets what simple words mean. Grandpa can remember a lot from his childhood, but his granddaughter, Cathy, knows that something is wrong. Join Cathy and her family as they learn about early-onset dementia and find the things that Grandpa still holds dear, like his dear girl, Cathy.



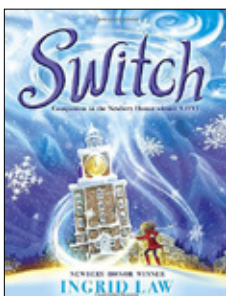
AGES 8 TO 12

## CANDIDLY CLINE

**Kathryn Ormsbee.** New York: Harper, an imprint of HarperCollins Publishers, 2021, 309 p.

Cline Alden's grandmother says that music is in the family's blood, but Cline's mother is dead-set against her daughter's dreams of becoming a country music singer; Cline is determined to find the money to attend a Young Singer-Songwriter Workshop in Lexington, Kentucky, but she also has a lot on her mind—she is hiding things from her mother, is losing her beloved grandmother to Alzheimer's, and she has begun to realize that she is more attracted to girls than boys.

 Also available on [prenumerique.ca](https://prenumerique.ca)

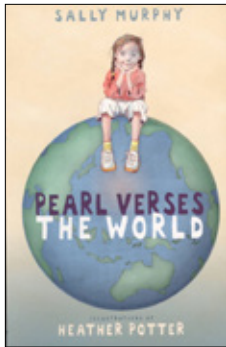


AGES 8 TO 12

## SWITCH

**Ingrid Law.** New York: Dial Books for Young Readers, an imprint of Penguin Group LLC, 2015, 356 p.

Gypsy Beaumont's magical savvy switches to its opposite when she learns that her mean and decidedly non-magical grandma has Alzheimer's and is going to move in with her family.

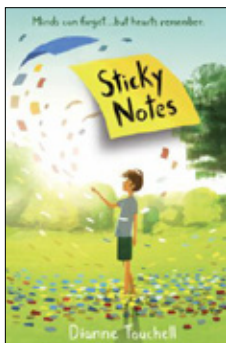


**AGES 8 TO 12**

## PEARL VERSES THE WORLD

**Sally Murphy and Heather Potter** (ill.). Somerville: Candlewick Press, 2011, 80 p.

At school, Pearl is a group of one, and at home her beloved granny is fading. A tale about independence, grief, and finding your place.



**AGES 9 TO 12**

## STICKY NOTES

**Dianne Touchell**. New York: Delacorte Press, 2018, 213 p.

Seven-year-old Foster has always been close to his father, but now his father is changing and forgetting things, Mum is tired and grumpy, and Foster feels invisible.

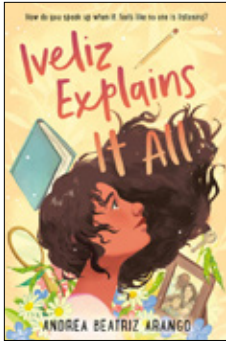


**AGES 9+**

## THE SPACE BETWEEN LOST AND FOUND

**Sandy Stark-McGinnis**. New York: Bloomsbury, 2020, 211 p.

Cassie is determined to give her mom – who has early onset Alzheimer's – one last adventure.



AGES 10 TO 14

## IVELIZ EXPLAINS IT ALL

**Andrea Beatriz Arango and Alyssa Bermudez.** New York: Random House Children's Books, 2022, 268 p.

Seventh grade is going to be Iveliz's year. She's going to make a new friend, help her abuela Mimi get settled after moving from Puerto Rico, and she is *not* going to get into any more trouble at school. Except is that what happens? Of course not. Because no matter how hard Iveliz tries, sometimes people say things that just make her so *mad*. And worse, Mimi keeps saying Iveliz's medicine is unnecessary – even though it helps Iveliz feel less sad. But how do you explain your feelings to others when you're not even sure what's going on yourself?

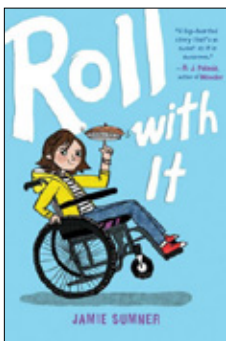


AGES 10 TO 14

## THIS LAST ADVENTURE

**Ryan Dalton.** Minneapolis: Carolrhoda Books, 2022, 298 p.

When Archie's beloved grandpa is diagnosed with Alzheimer's disease, Archie desperately wants to slow the progression of his grandpa's memory loss. Using Grandpa's old journal entries as inspiration, he creates shared role-playing fantasies with epic quests for them to tackle together – allowing Grandpa to live in the present and stay in touch with his fading memories. But as Grandpa's condition gradually worsens, Archie must come to terms with what's happening to his hero. The limits of the fantasies, revelations about Grandpa's past, and a school project about the future force Archie to grapple with what it truly means to live a life worth remembering.



AGES 10 TO 14

## ROLL WITH IT

**Jamie Sumner.** New York: Atheneum Books for Young Readers, 2019, 250 p.

Twelve-year-old Ellie, who has cerebral palsy, finds her life transformed when she moves with her mother to small-town Oklahoma to help care for her grandfather, who has Alzheimer's Disease.

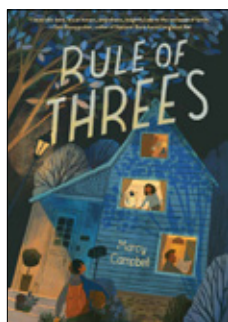


AGES 10 TO 14

## THINGS TOO HUGE TO FIX BY SAYING SORRY

**Susan Vaught.** New York: Simon & Schuster Books for Young Readers, 2016, 342 p.

“Sooner or later, we’re all gonna be okay.” That’s what Dani’s Grandma Beans used to say. But that was before she got Alzheimer’s. Lately, Dani isn’t so sure Grandma Beans was right. In fact, she isn’t sure of a lot of things, like why Mac Richardson suddenly doesn’t want to be her friend, and why Grandma Beans and Avadelle Richardson haven’t spoken in decades. Lately, Grandma Beans doesn’t make a lot of sense. But when she tells Dani to find a secret key and envelope that she’s hidden, Dani can’t ignore her. So she investigates, with the help of her friend, Indri, and her not-friend, Mac.



AGES 10+

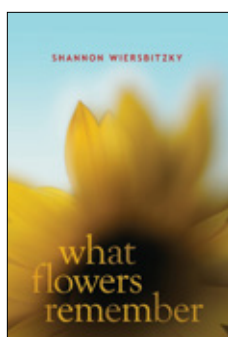
## RULE OF THREES

**Marcy Campbell.** San Francisco: Chronicle Books, 2021, 307 p.

An interior design enthusiast, twelve-year-old Maggie Owens is accustomed to living her life according to her own precise plans. But when she learns about Tony, a mysterious half-brother her own age who needs a place to stay, any semblance of a plan is shattered. Tony’s mom struggles with addiction, and now she’s called upon Maggie’s dad – who is also Tony’s dad – to take him in. On top of everything, Maggie must come to terms with the Alzheimer’s afflicting her beloved grandmother.



Also available on [pretnumerique.ca](https://pretnumerique.ca)

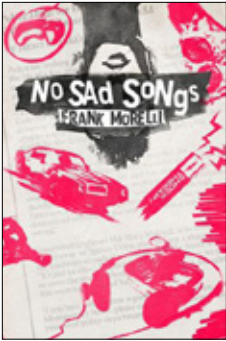


AGES 11 TO 15

## WHAT FLOWERS REMEMBER

**Shannon Wiersbitzky.** South Hampton: Namelos, 2014, 158 p.

Delia and Old Red Clancy make quite a pair. He has the know-how and she has the get-up-and-go. When they dream up a seed- and flower-selling business, well, look out, Tucker’s Ferry, because here they come. But something is happening to Old Red. And the doctors say he can’t be cured. He’s forgetting places and names and getting cranky for no reason. As his condition worsens, Delia takes it upon herself to save as many memories as she can. Her mission is to gather Old Red’s stories so that no one will forget, and she corrals everybody in town to help her.

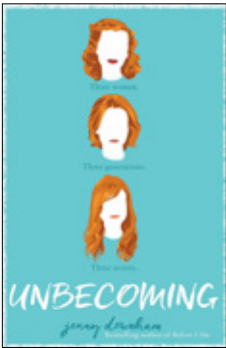


AGES 12+

## NO SAD SONGS

**Frank Morelli.** Ann Arbor: Fish Out of Water Books, 2018, 215 p.

Following a family tragedy, 18-year-old Gabe LoScuda suddenly finds himself thrust into the role of caregiver for his ailing grandfather. Between the shopping trips and the doctor visits with Grandpa, Gabe and his friend John try to salvage their senior year, meet girls, and make the varsity baseball team.



AGES 14 TO 18

## UNBECOMING

**Jenny Downham.** New York: David Fickling Books/Scholastic Inc., 2016, 375 p.

Life has just become very complicated for seventeen-year-old Katie; her father walked out a year ago, her mother is stressed out, her brother is a “special needs” teenager, and she is caring for the maternal grandmother she has never met, who is suffering from Alzheimer’s – and Katie has a secret of her own that she cannot reveal.



AGES 14 TO 18

## WHEREVER YOU GO

**Heather Davis.** Boston: Harcourt, 2011, 309 p.

Seventeen-year-old Holly Mullen, overwhelmed with responsibility at home, grieving over her boyfriend Rob’s tragic death, and confused by the sudden attention of his best friend, Jason, is further upset when her Alzheimer’s-stricken Papa Aldo claims to be having conversations with Rob’s ghost.

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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



13+

**MEMORY****Martin Campbell.** 2022, 113 min.

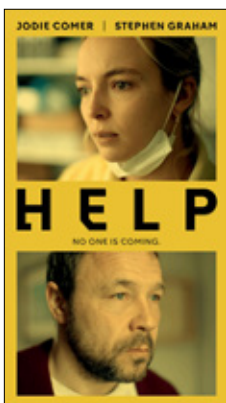
Thriller (United States). Alex, an assassin-for-hire, finds that he's become a target after he refuses to complete a job for a dangerous criminal organization. With the crime syndicate and FBI in hot pursuit, Alex has the skills to stay ahead, except for one thing: he is struggling with severe memory loss, affecting his every move. Alex must question his every action and whom he can ultimately trust.



13+

**IT SNOWS ALL THE TIME****Jay Giannone.** 2022, 80 min.

Drama (United States). Paul did everything a person is supposed to do to keep their mind healthy – until he gets Dementia. As his disease progresses, his family comes together to decide what to do.



16+

**HELP****Marc Munden.** 2022, 102 min.

Drama (United Kingdom). Sarah seems to have found her calling working in a Liverpool care home where she has a special talent for connecting with the residents. Then, in March 2020, the Coronavirus pandemic hits.



G

## SUPERNOVA

**Harry Macqueen.** 2021, 95 min.

Psychological drama (United Kingdom). Sam and Tusker, partners of 20 years, are traveling across England in their old RV visiting friends, family and places from their past. Since Tusker was diagnosed with early-onset dementia two years ago, their time together is the most important thing they have.



G

## THE FATHER

**Florian Zeller.** 2020, 97 min.

Drama (United States). A man refuses all assistance from his daughter as he ages. As he tries to make sense of his changing circumstances, he begins to doubt his loved ones, his own mind and even the fabric of his reality.



## LIVE TWICE, LOVE ONCE

**Maria Ripoll.** 2019, 110 min.

Romantic drama (Spain). A retired academic teacher tries to find the love of his youth after being diagnosed with Alzheimer's.



## A MEDICINE FOR THE MIND

**David Xarach.** 2019, 15 min.

Short film (United States). A new experimental drug for Alzheimer's, gifts 65 year old Sandra Carter, a new opportunity in life - and unexpected new abilities.

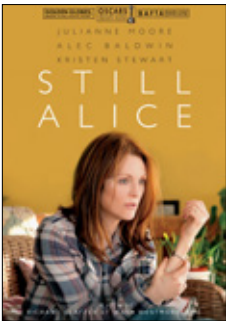


G

## WHAT THEY HAD

**Elizabeth Chomko.** 2018, 101 min.

Drama (United States). When her Alzheimer's-suffering mother, Ruth, wanders into a blizzard on Christmas Eve, Bridget Ertz travels back to her hometown to help her brother, Nicky, convince their father, to put Ruth in a nursing home and face the end of their life-long love affair.

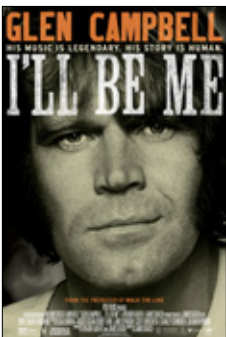


G

## STILL ALICE

**Richard Glatzer and Wash Westmoreland.** 2014, 101 min.

Drama (United States). Alice Howland, a successful and renowned Columbia University linguistics professor, is happily married with three grown children. However, when she receives a devastating diagnosis from her doctor, she and her family struggle to cope with the reality of what their future holds.

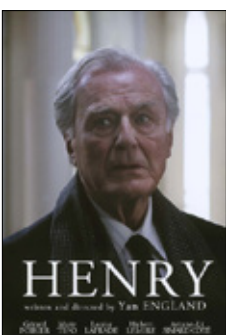


G

## GLEN CAMPBELL: I'LL BE ME

**James Keach.** 2014, 105 min.

Drama (United Kingdom). They thought it would last five weeks. Instead it went for 151 spectacular sold out shows over a triumphant year and a half across America. What made this tour extraordinary was that Glen had recently been diagnosed with Alzheimer's disease. He was told to hang up his guitar and prepare for the inevitable. Instead, Glen and his wife went public with his diagnosis and announced that he and his family would set out on a "Goodbye Tour".



## HENRY

**Yan England.** 2011, 21 min.

Short film, drama (Quebec). Henry, a great concert pianist, has his life thrown in turmoil the day the love of this life, Maria, disappears mysteriously. He'll then discover the inevitable verdict of life.



13+

## EXILE

**John Alexander, BBC One.** (2011- )

TV series (United Kingdom). After his successful London career implodes, journalist Tom Ronstadt returns to his hometown in Lancashire for the first time in 18 years and finds his father Sam in the grip of Alzheimer's. Tom is trying to unravel the mystery that drove him away from home. He persists, unaware that a devastating crime that will reveal unimaginable secrets.



G

## AWAY FROM HER

**Sarah Polley.** 2007, 110 min.

Drama (Canada, United States, Great Britain). Married for 50 years, Grant and Fiona's life together is full of tenderness and humor, their serenity broken only by Fiona's restrained references to the past, complicated further by her increasingly evident memory loss. Moving Fiona into a nursing home specializing in Alzheimer's disease, Grant is not allowed to visit for the first month so she can "adjust".

# DOCUMENTARIES

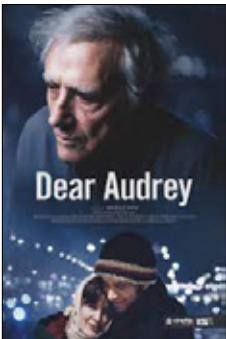
## General



### **DICK JOHNSON IS DEAD**

**Kirsten Johnson.** 2022, 89 min.

Documentary (United States). This docu-fantasia by Kirsten Johnson is a valentine to the director's beloved father, Dick Johnson, made as she has begun to face the reality of losing him to dementia. Tackling taboo questions of aging, mortality, and grief with subversive humor and surprising grace, this is ultimately a triumphant celebration of life and the gentle, funny, unforgettable man at its center.



### **DEAR AUDREY**

**Jeremiah Hayes.** 2021, 89 min.

Documentary (Canada). In Dear Audrey, filmmaker Jeremiah Hayes is a witness to the most important work of Martin Duckworth's life – caring for his wife Audrey after her Alzheimer's diagnosis, and helping his 45-year old daughter, Jacqueline, who has autism, maintain a relationship with her mom.



### **PASSING TIME**

**Lou Colpé.** 2019, 41 min.

I started filming my grandparents in 2007. I was fifteen years old. I really loved my grandfather a lot but as the years went by, I turned my camera more and more towards my grandmother who was suffering from a disturbing illness. Alzheimer's. I filmed a fraction of their lives, as it happens much of it towards the end, the last eight years.



## LE VIEIL ÂGE ET L'ESPÉRANCE

**Fernand Dansereau.** 2019, 87 min.

When old age imposes physical and sometimes mental decay, is there a way to maintain a hopeful attitude towards life and its mysteries? This is the question that the documentary “Le vieil âge et l'espérance” aims to confront not only through specialists such as geriatricians, gerontologists, psychologists and philosophers, but first and foremost through the lived experience of the elderly themselves.



## ALZHEIMER'S: EVERY MINUTE COUNTS

**Elizabeth Arledge, PBS.** 2017, 55 min.

Online: [www.pbs.org/video/alzheimers-every-minute-counts-every-minute-counts/](http://www.pbs.org/video/alzheimers-every-minute-counts-every-minute-counts/)

Documentary (United States). An urgent wake-up call about the national threat posed by Alzheimer's disease. Many know the unique tragedy of this disease, but few know that Alzheimer's is also a major and rapidly growing public health crisis. This high-profile PBS documentary powerfully illuminates the social consequences for America unless a medical breakthrough is discovered for this currently incurable disease.

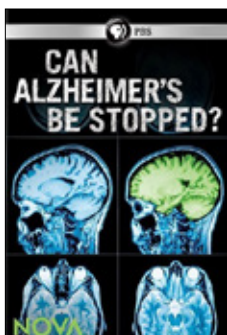


## MUCH TOO YOUNG (FEATURE VERSION)

**Christopher Wynn and Russell Gienapp.** 2017, 88 min.

Online: <https://tvo.org/video/documentaries/much-too-young-feature-version>

Documentary (Canada). What does it mean to be a young adult who becomes a caregiver for an ailing parent? This documentary is a powerful and unflinching look at four families struggling to cope with an unexpected role reversal, and the complications that come with caring for a parent who has been diagnosed with early-onset Alzheimer's disease.



## CAN ALZHEIMER'S BE STOPPED?

**Sarah Holt, PBS.** 2016, 54 min.

Documentary (United States). Alzheimer's disease ravages the minds of over 40 million victims worldwide. The cause of Alzheimer's and whether it can be stopped is one of the greatest medical mysteries of our time. Join courageous patients participating in clinical trials, and then go behind the scenes of the major drug trials to see how researchers target and test therapies that may slow and even prevent Alzheimer's.



## **UNTANGLING ALZHEIMER'S**

**The nature of things, CBC.** 2014, 45 min.

Online: <http://gem.cbc.ca/media/the-nature-of-things/season-53/episode-6/38e815a-0092405a4fe>

David Suzuki has a very personal interest in the disease of Alzheimer's because his mother, aunt, and two uncles died of it. We join David as he explores the newest breakthroughs in research.

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# TAKING PART IN ONE'S HEALTH CARE

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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 CEPPP 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](http://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](http://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/](http://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](http://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](http://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/](http://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](http://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?\\_](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](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](http://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](http://www.educaloi.qc.ca/en/caregivers-practical-legal-tools)

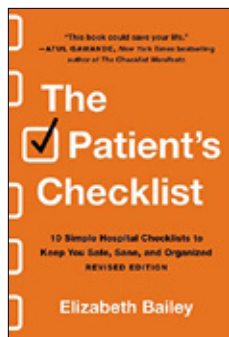
In this web guide, Éducaloi provides clear and useful legal information intended for caregivers.

#### **Health Topics**

[www.educaloi.qc.ca/en/categories/health](http://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](https://prenumerique.ca)



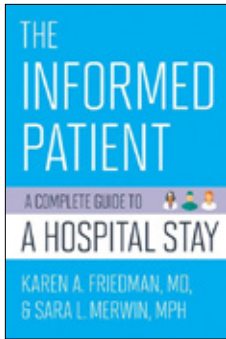
## THE GOOD DOCTOR: WHY MEDICAL UNCERTAINTY MATTERS

**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.



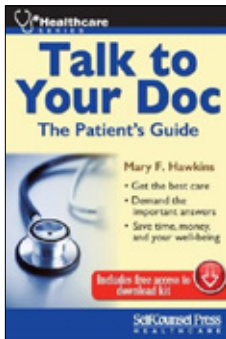
Also available on [prenumerique.ca](https://prenumerique.ca)



## THE INFORMED PATIENT: A COMPLETE GUIDE TO A HOSPITAL STAY

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

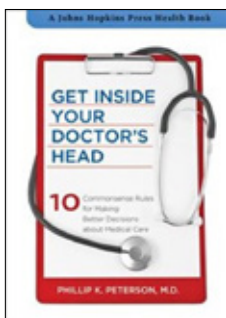
Even the most capable individuals are challenged when confronted with the complexity of the modern hospital experience. *The Informed Patient* is a guide and a workbook, divided into topical, focused sections with step-by-step instructions, insights, and tips to illustrate what patients and their families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