



2021  
EDITION

# END-OF-LIFE CARE

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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 more than 179 member municipalities and corporations, for a total of over 317 autonomous libraries. Biblio-Aidants is available in more than 780 participating public libraries as well as associated health libraries throughout Quebec. Visit our website to see if your library participates in the program.

## **ACKNOWLEDGMENTS**

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

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## **VISIT OUR WEBSITE**

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

**[bibliosante.ca](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 2021 and will be updated on an annual basis.

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## HOW DO WE SELECT THE INFORMATION?

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

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

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

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



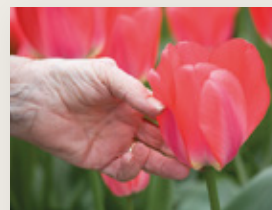
**INTELLECTUAL  
DISABILITY**



**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

## ASSOCIATION QUÉBÉCOISE POUR LE DROIT DE MOURIR DANS LA DIGNITÉ

**Phone** 514 341-4017  
**Website** <https://aqdmd.org/>

The mission of the AQDMD is to ensure respect for the autonomy of every competent adult who drafted his advance medical directives to end his life in dignity and freedom, in accordance with his values. You will find relevant documentation as well as the request form for Medical Assistance in Dying on the website. Website in French only.

## CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION

**Toll free** 1 800 668-2785  
**Website** [www.chpca.ca](http://www.chpca.ca)

This association strives to develop and promote quality palliative care in Canada. The website includes the Canadian Directory of Hospice Palliative Care Services which provides information on the availability of hospice palliative care services across Canada.

## 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. Caregiver Support is a free and confidential phone consultation which aims 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.).

# 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.

## **ADVANCE CARE PLANNING IN CANADA – SPEAK UP**

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

This website was developed by the Canadian Hospice Palliative Care Association to raise the awareness of Canadians about the importance of advance care planning.

## **ALLIANCE DES MAISONS DE SOINS PALLIATIFS DU QUÉBEC – LES MAISONS**

<https://www.alliancempq.com/maisons>

On this page, you will find all of the hospice palliative care homes that are members of the Alliance and a link to their website. Website in French only.

## **CANADIAN CAREGIVER NETWORK**

<https://thecaregivernetwork.ca>

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

## **CANADIAN VIRTUAL HOSPICE**

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

This website provides information and support on palliative and end of life care, loss and grief.

## **ÉDUCALOI - MEDICAL AID IN DYING**

[www.educaloi.qc.ca/en/capsules/medical-aid-in-dying](http://www.educaloi.qc.ca/en/capsules/medical-aid-in-dying)

In Quebec, people at the end of life who are suffering a lot can ask a doctor to give them medication to end their lives. This is called medical aid in dying. You might have heard it called doctor-assisted death, assisted dying, medical help to die or something similar. The law is very strict about when it is allowed. This page explains when it can be given and how patients can ask for it.

## **EHOSPICE**

<https://ehospice.com/canada-english/>

Globally run resource for information on hospice, palliative and end of life care from around the world.

## **GOVERNEMENT DU QUÉBEC – ACT RESPECTING END-OF-LIFE CARE**

[www.quebec.ca/en/health/health-system-and-services/end-of-life-care/act-respecting-end-of-life-care/](http://www.quebec.ca/en/health/health-system-and-services/end-of-life-care/act-respecting-end-of-life-care/)

The *Act Respecting End-of-Life Care* was passed and sanctioned in June 2014. This document outlines the conditions under which certain ill patients may request medical aid in dying.

## **GOVERNEMENT DU QUÉBEC – MEDICAL AID IN DYING**

<https://www.quebec.ca/en/health/health-system-and-services/end-of-life-care/medical-aid-in-dying/procedure/>

The steps to request medical aid in dying are explained on this Web page.

## **GOVERNMENT OF CANADA**

### **End-of-life care**

[www.canada.ca/en/health-canada/topics/end-life-care.html](http://www.canada.ca/en/health-canada/topics/end-life-care.html)

Provides a list of options available to those who are making end-of-life care decisions.

### **Palliative care**

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

Learn about palliative care. Find out how it can help improve your quality of life if you are living with a life-threatening or serious illness.

## **McGILL UNIVERSITY – COUNCIL ON PALLIATIVE CARE**

[www.mcgill.ca/council-on-palliative-care/frequently-asked-questions](http://www.mcgill.ca/council-on-palliative-care/frequently-asked-questions)

The Council on Palliative Care is a not-for-profit organization comprised of volunteer members dedicated to increasing public awareness about palliative care, and public support for its availability within and beyond the McGill University network. The “Frequently Asked Questions” section provides short and concise answers to frequently asked questions about palliative care.

## 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.

## **GOUVERNEMENT 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>

## **CONSUMER HEALTH COMPLETE**

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

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

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

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

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

## **MAGILL'S MEDICAL GUIDE**

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

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

## **SKILLSOFT BOOKS WELL-BEING ESSENTIALS**

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

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

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# READING SUGGESTIONS

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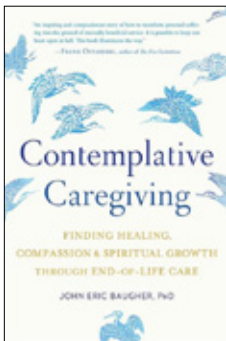
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HAVE THE BOOK THAT YOU  
ARE LOOKING FOR?

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**LOAN SERVICE BETWEEN LIBRARIES.**

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

# NON-FICTION

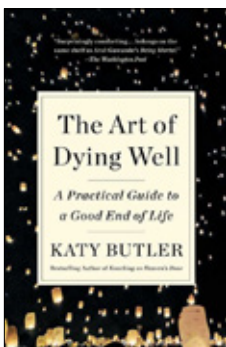
## General works



### **CONTEMPLATIVE CAREGIVING: FINDING HEALING, COMPASSION, AND SPIRITUAL GROWTH THROUGH END-OF-LIFE CARE**

**John Eric Baugher.** Boulder: Shambhala, 2019, 240 p.

After author John Baugher's mother was murdered in 1987, he felt that he was fated to join her killer in life imprisonment – not behind bars, but behind psychological walls of unresolved grief and anger. Baugher turned to hospice volunteering as a way to channel his experience, marking the beginning of a twenty-five year journey of exploration – in both public hospices and prison hospice programs – and the possibility of discovering compassion and even humor in the face of death. In this beautifully written book, Baugher weaves together insights from his experience with those gleaned from interviews with dozens of hospice volunteers from widely varying backgrounds.



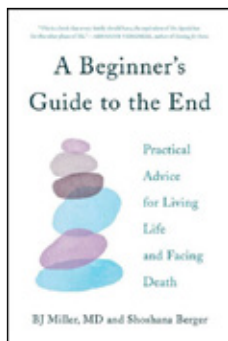
### **THE ART OF DYING WELL: A PRACTICAL GUIDE TO A GOOD END OF LIFE**

**Katy Butler.** New York: Scribner, 2019, 274 p.

The Art of Dying Well is about living as well as possible for as long as possible and adapting successfully to change. Packed with extraordinarily helpful insights and inspiring true stories, award-winning journalist and prominent end-of-life speaker Katy Butler shows how to thrive in later life (even when coping with a chronic medical condition), how to get the best from our health system, and how to make your own “good death” more likely. This handbook of step by step preparations – practical, communal, physical, and sometimes spiritual – will help you make the most of your remaining time, be it decades, years, or months.



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



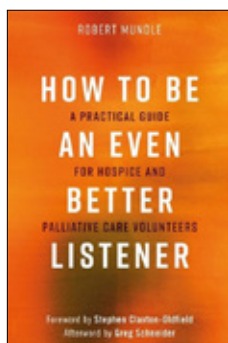
## A BEGINNER'S GUIDE TO THE END: PRACTICAL ADVICE FOR LIVING LIFE AND FACING DEATH

**Bruce J Miller, Shoshana Berger and Marina Luz** (ill.). New York: Simon & Schuster, 2019, 520 p.

Our ultimate purpose here isn't so much to help you die as it is to free up as much life as possible until you do. There is a clear-eyed and big-hearted action plan for approaching the end of life, written to help readers feel more in control of an experience that so often seems anything but. Their book offers everything from step-by-step instructions for how to do your paperwork and navigate the healthcare system to answers to questions you might be afraid to ask your doctor, like whether or not sex is still okay when you're sick. You'll be walked through how to break the news to your employer, whether to share old secrets with your family, how to face friends who might not be as empathetic as you'd hoped, and to how to talk to your children about your will.



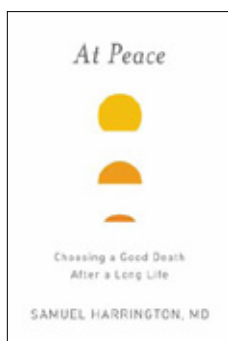
Also available on [prenumerique.ca](http://prenumerique.ca)



## HOW TO BE AN EVEN BETTER LISTENER: A PRACTICAL GUIDE FOR HOSPICE AND PALLIATIVE CARE VOLUNTEERS

**Robert Mundle**. London: Jessica Kingsley Publishers, 2019, 150 p.

Providing guidance and advice on the challenging art of listening, this book responds directly to the expressed learning needs of hospice and palliative care volunteers regarding their communication skills in end-of-life care. Listening can be mentally, physically, and spiritually exhausting, often highlighted in books about hospice and palliative care but never taking the spotlight. This accessible companion provides hospice and palliative care workers with a variety of helpful insights and suggestions drawn from a solid base of current theoretical concepts and clinical research.



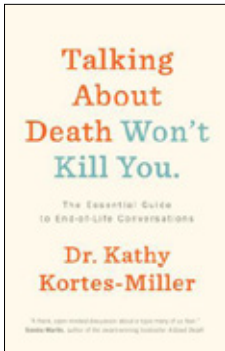
## AT PEACE: CHOOSING A GOOD DEATH AFTER A LONG LIFE

**Samuel Harrington**. New York: Grand Central Life & Style, 2018, 304 p.

Through Dr. Harrington's own experience with his parents and patients, he describes the terminal patterns of the six most common chronic diseases; how to recognize a terminal diagnosis even when the doctor is not clear about it; how to have the hard conversation about end-of-life wishes; how to minimize painful treatments; when to seek hospice care; and how to deal with dementia and other special issues.



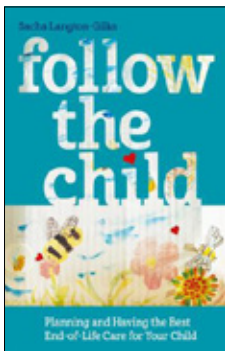
Also available on [prenumerique.ca](http://prenumerique.ca)



## TALKING ABOUT DEATH WON'T KILL YOU: THE ESSENTIAL GUIDE TO END-OF-LIFE CONVERSATIONS

**Kathy Kortés-Miller.** Toronto: ECW Press, 2018, 208 p.

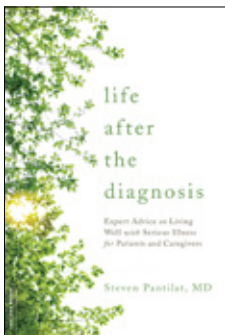
This book is the essential handbook to help navigate personal and medical decisions for the best quality of life for the end of our lives. Noted palliative-care educator and researcher Kathy Kortés-Miller shows readers how to identify and reframe limiting beliefs about dying with humor and compassion.



## FOLLOW THE CHILD: PLANNING AND HAVING THE BEST END-OF-LIFE CARE FOR YOUR CHILD

**Sacha Langton-Gilks.** London: Jessica Kingsley, Publishers, 2018, 229 p.

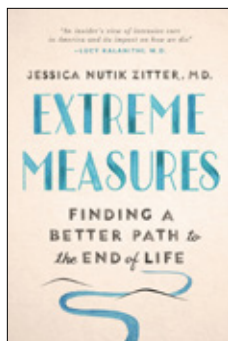
Drawing on her family's own experiences and those of other parents facing the death of a child from illness or a life-limiting condition, Sacha Langton-Gilks explains the challenges, planning, and conversations that can be expected during this traumatic period. Practical advice such as how to work with the healthcare professionals, drawing up an Advance Care Plan, and how to move care into the home sit alongside tender observations of how such things worked in her own family's story.



## LIFE AFTER THE DIAGNOSIS: EXPERT ADVICE ON LIVING WELL WITH SERIOUS ILLNESS FOR PATIENTS AND CAREGIVERS

**Steven Z. Pantilat.** Cambridge: Da Capo Press, 2017, 352 p.

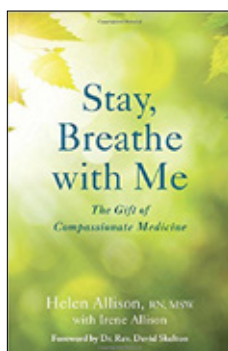
Dr. Steven Z. Pantilat shares innovative approaches for dealing with serious illness, outlines the steps that patients should take, and demystifies the medical system. He covers everything from the first steps after the diagnosis and finding the right caregiving and support, to planning your future so your loved ones don't have to.



## EXTREME MEASURES: FINDING A BETTER PATH TO THE END OF LIFE

**Jessica Nutik Zitter.** New York: Avery, an imprint of Penguin Random House, 2017, 338 p.

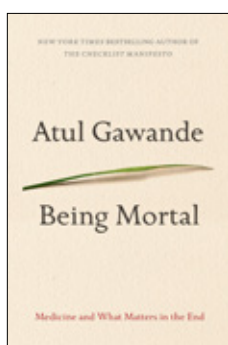
In our current medical culture, the old and the ill are put on what she terms the End-of-Life Conveyor belt. They are intubated, catheterized, and even shelved away in care facilities to suffer their final days alone, confused, and often in pain. In her work Jessica Zitter has learned what patients fear more than death itself: the prospect of dying badly. She builds bridges between patients and caregivers, formulates plans to allay patients' pain and anxiety, and enlists the support of loved ones so that life can end well, even beautifully.



## STAY, BREATHE WITH ME: THE GIFT OF COMPASSIONATE MEDICINE

**Helen Allison and Irene Allison.** Berkeley: She Writes Press, 2016, 265 p.

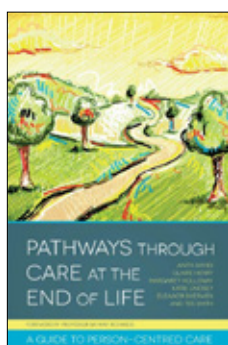
Informed by the voices of the seriously ill, their families, and the lifelong experience of a palliative care nurse and medical social worker, *Stay, Breathe with Me* illuminates the power of the art of care and the need to bring heart and compassion back into health care. Written for both medical professionals and general readers alike.



## BEING MORTAL: MEDICINE AND WHAT MATTERS IN THE END

**Atul Gawande.** Toronto: Doubleday Canada, 2014, 282 p.

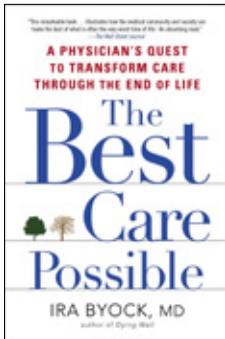
Atul Gawande, a practicing surgeon, follows a hospice nurse on her rounds, a geriatrician in his clinic, and reformers turning nursing homes upside down. He finds people who show us how to have the hard conversations and how to ensure we never sacrifice what people really care about.



## PATHWAYS THROUGH CARE AT THE END OF LIFE

**Anita Hayes, Claire Henry, Margaret Holloway, Katie Lindsey, Eleanor Sherwen and Tes Smith.** London: Jessica Kingsley Publishers, 2014, 223 p.

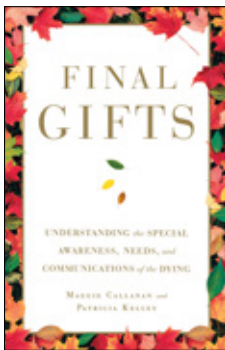
As someone approaches the end of their life, it is vitally important that they receive quality care and support, that their wishes are met, and that they are treated with dignity and respect. This book is a comprehensive guide to providing excellent, person-centred end of life care.



## THE BEST CARE POSSIBLE: A PHYSICIAN'S QUEST TO TRANSFORM CARE THROUGH THE END OF LIFE

**Ira Byock.** New York: Avery, 2012, 320 p.

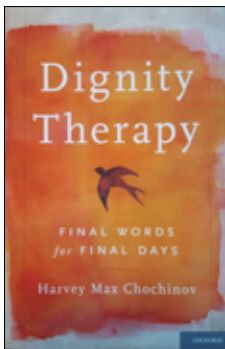
A palliative care doctor on the front lines of hospital care illuminates one of the most important and controversial ethical issues of our time on his quest to transform care through the end of life.



## FINAL GIFTS: UNDERSTANDING THE SPECIAL AWARENESS, NEEDS, AND COMMUNICATIONS OF THE DYING

**Maggie Callanan and Patricia Kelley.** New York: Simon & Schuster Paperbacks, 2012, 221 p.

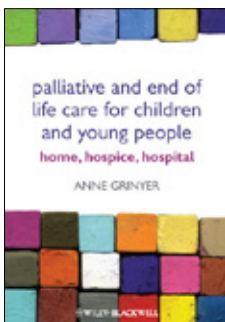
Filled with practical advice on responding to the requests of the dying and helping them prepare emotionally and spiritually for death, this book shows how we can help the dying person live fully to the very end.



## DIGNITY THERAPY: FINAL WORDS FOR FINAL DAYS

**Harvey Max Chochinov.** Oxford; New York: Oxford University Press, 2012, 224 p.

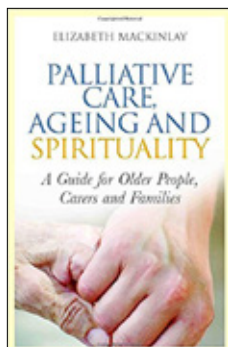
*Dignity therapy*, a psychological intervention developed by Dr. Harvey Max Chochinov and his internationally lauded research group, has been designed specifically to address many of the psychological, existential, and spiritual challenges that patients and their families face as they grapple with the reality of life drawing to a close.



## PALLIATIVE AND END OF LIFE CARE FOR CHILDREN AND YOUNG PEOPLE: HOME, HOSPICE, AND HOSPITAL

**Anne Grinyer.** Chichester: John Wiley & Sons, 2012, 184 p.

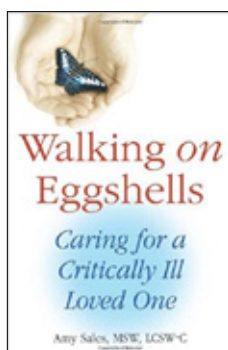
This book provides insights into the choices and experiences of palliative and end of life care for young people with cancer and other life-limiting illnesses. With a focus on palliative care provision across a range of different clinical settings, this comprehensive new resource explores care in the home, the hospice and hospital. It looks at how and where families and young people can access palliative care, and what support is offered to attain their preferred place of death.



## PALLIATIVE CARE, AGEING AND SPIRITUALITY: A GUIDE FOR OLDER PEOPLE, CARERS AND FAMILIES

**Elizabeth MacKinlay.** London; Philadelphia: Jessica Kingsley Publishers, 2012, 141 p.

This book provides older people who are nearing the end of life and their loved ones, as well as the professionals who work with them, with a greater depth of understanding of spiritual issues surrounding death and dying.



## WALKING ON EGGSHELLS: CARING FOR A CRITICALLY ILL LOVED ONE

**Amy Sales.** Far Hills: New Horizon Press, 2012, 227 p.

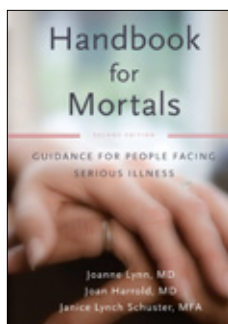
Dealing with a loved one's terminal illness brings difficult and daunting tasks for caregivers. Knowing when and how to say things and what to do becomes frightening. Caregivers often feel they are "walking on eggshells". This practical guide offers comfort, support and advice for managing economic, emotional and daily stressors from day one of the diagnosis.



## PREPARING YOUR CHILDREN FOR GOODBYE: A GUIDEBOOK FOR DYING PARENTS

**Lori A. Hedderman.** CreateSpace Independent Publishing Platform, 2011, 120 p.

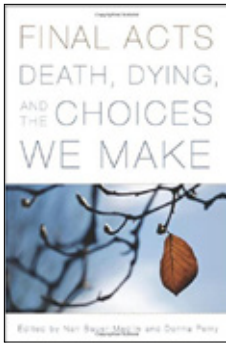
*Preparing Your Children For Goodbye* is a supportive guidebook for parents who are terminally ill. The book will help you plan for your own end-of-life care, prepare your children for your death, and record memories of your life.



## HANDBOOK FOR MORTALS: GUIDANCE FOR PEOPLE FACING SERIOUS ILLNESS

**Joanne Lynn, Joan K. Harrold and Janice Lynch Schuster.** Oxford: Oxford University Press, 2011, 296 p.

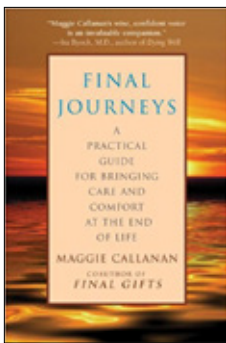
This book is addressed to all those who wish to approach the final years of life with greater awareness of what to expect and greater confidence about how to make the end of their lives a time of growth, comfort, and meaningful reflection.



## **FINAL ACTS: DEATH, DYING, AND THE CHOICES WE MAKE**

**Nan Bauer Maglin and Donna Marie Perry.** New Brunswick: Rutgers University Press, 2010, 326 p.

Today most people die gradually, from incremental illnesses, rather than from the heart attacks or fast-moving diseases that killed earlier generations. Given this new reality, the essays in *Final Acts* explore how we can make informed and caring end-of-life choices for ourselves and for those we love, and what can happen without such planning.



## **FINAL JOURNEYS: A PRACTICAL GUIDE FOR BRINGING CARE AND COMFORT AT THE END OF LIFE**

**Maggie Callanan.** New York: Bantam Books, 2008, 352 p.

For more than two decades, hospice nurse Maggie Callanan has tended to the terminally ill and been a cornerstone of support for their loved ones. From supporting a husband or wife faced with the loss of a spouse, to helping a dying mother prepare her children to carry on without her, Callanan's stories illustrate new ways to meet the physical, emotional, and spiritual challenges of this difficult and precious time. She brings welcome clarity to medical and ethical concerns, explaining what to expect at every stage. Each brief chapter also conveys a home truth about making crucial treatment decisions, supporting the patient's dignity and individuality, and lightening the burden on caregivers.

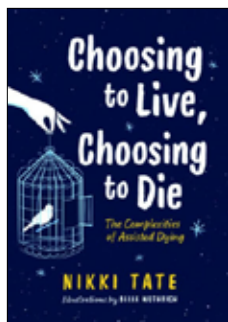
## Medical assistance in dying



## **WHEN MY TIME COMES: CONVERSATIONS ABOUT WHETHER THOSE WHO ARE DYING SHOULD HAVE THE RIGHT TO DETERMINE WHEN LIFE SHOULD END**

**Diane Rehm.** New York: Alfred A. Knopf, 2020, 217 p.

A series of interviews on the topics of end-of-life care and the right-to-die movement.



## CHOOSING TO LIVE, CHOOSING TO DIE: THE COMPLEXITIES OF ASSISTED DYING

**Nikki Tate and Belle Wuthrich** (ill.). Victoria: Orca Books Publishers, 2019, 172 p.

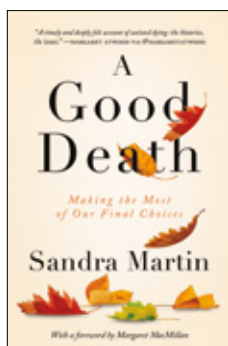
There are few decisions more upsetting than deciding if a when the time is right to end a life. Is it more important to protect life at all costs, or to provide individuals with the right to choose what is best for them? Tate provides teenagers with multiple perspectives on the issue of providing medical assistance in dying. She encourages readers to keep an open mind and reach their own conclusions.



## THE RIGHT TO DIE: THE COURAGEOUS CANADIANS WHO GAVE US THE RIGHT TO A DIGNIFIED DEATH

**Gary Bauslaugh**. Toronto: James Lorimer & Company Ltd., Publishers, 2016, 296 p.

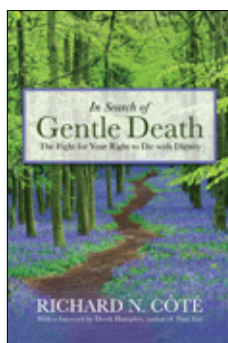
This book explores how the fight for assisted suicide was won in Canada by exploring the stories of the courageous Canadians who fought for the right to a dignified death.



## A GOOD DEATH: MAKING THE MOST OF OUR FINAL CHOICES

**Sandra Martin and Margaret MacMillan**. Toronto: Patrick Crean Editions, 2016, 400 p.

We can't avoid death, but the prospect is a lot less terrifying since the Supreme Court of Canada legalized physician-assisted death. Competent adults, suffering grievously from intolerable medical conditions, will have the right to ask for a doctor's help in ending their lives. This book asks the tough question none of us can avoid: How do we want to die?

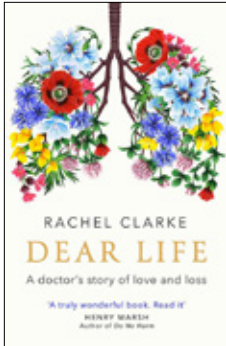


## IN SEARCH OF GENTLE DEATH: THE FIGHT FOR YOUR RIGHT TO DIE WITH DIGNITY

**Richard N. Côté**. Mt. Pleasant: Corinthian Books, 2012, 479 p.

Death is inevitable. But bad deaths, those accompanied by unnecessarily prolonged pain and suffering, often aggravated by immensely costly and frequently futile medical treatments, can be avoided. This book explores the pioneering, highly pragmatic and practical work carried out by the international death-with-dignity movement over the last forty years to eliminate the last bad death.

# LIFE STORIES, BIOGRAPHIES AND TESTIMONIALS



## **DEAR LIFE: A DOCTOR'S STORY OF LOVE AND LOSS**

**Rachel Clarke.** London: Little, Brown, 2020, 320 p.

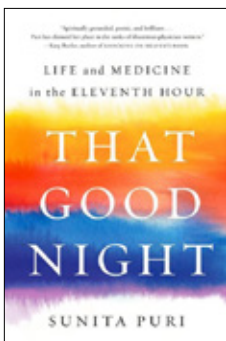
Rachel specialises in palliative care and this book maps her journey into that particular specialism. Her extraordinary powers of empathy are part of what makes her the sort of doctor we would all want on hand for anyone we love, but also give her the ability to write sensitively and beautifully about painful subjects. Here Rachel tells her story – of how death was so conspicuously absent during her medical training, which was focused entirely on learning to save lives and was entirely wanting when it came to helping patients and their families to face death.



## **TEN THOUSAND CROSSROADS: THE PATH AS I REMEMBER IT**

**Balfour M. Mount.** Montreal: McGill-Queen's University Press, 2020, 688 p.

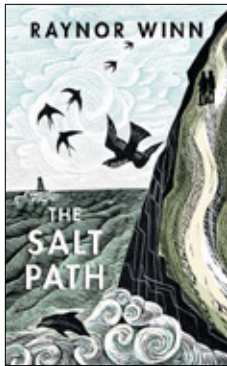
Recognized as the father of palliative care in North America, Balfour Mount facilitated a sea change in medical practice by foregrounding concern for the whole person facing incurable illness. In this intimate and far-reaching memoir, Mount leads the reader through the formative moments and milestones of his personal and professional life as they intersected with the history of medical treatment over the last fifty years.



## **THAT GOOD NIGHT: LIFE AND MEDICINE IN THE ELEVENTH HOUR**

**Sunita Puri.** New York: Viking, 2019, 301 p.

A heart-wrenching and provocative memoir about how the essential parts of one young woman's early life – her mother's work as a surgeon and her spiritual practice – led her to become a doctor and to question the premise that medicine exists to prolong life at all costs.



## THE SALT PATH

**Raynor Winn.** London: Michael Joseph, an imprint of Penguin Books, 2018, 274 p.

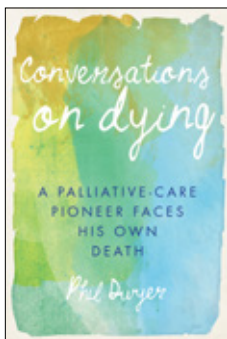
Just days after Raynor learns that her husband of 32 years, Moth, is terminally ill, their home is taken away and they lose their livelihood. With nothing left and little time, they make the brave and impulsive decision to walk the 630 miles of the South West Coast Path, from Somerset to Dorset. The Salt Path is an honest and life-affirming true story of coming to terms with grief and the healing power of the natural world.



## AT DEATH'S DOOR: END OF LIFE STORIES FROM THE BEDSIDE

**Sebastian Sepulveda and Gini Graham Scott.** Lanham: Rowman & Littlefield, 2017, 271 p.

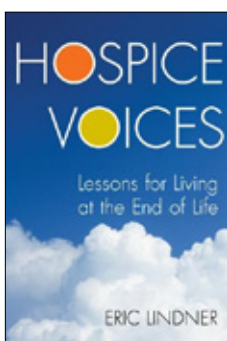
This book tells the story of Sebastian Sepulveda's experiences in working with patients at the end of their lives. Written from the perspective of a medical doctor from years of experience, this personal approach to the end of life explores the many options available to patients and their families and reveals how real people have come to those decisions, and how they play out.



## CONVERSATIONS ON DYING: A PALLIATIVE-CARE PIONEER FACES HIS OWN DEATH

**Phil Dwyer.** Toronto: Dundurn, 2016, 216 p.

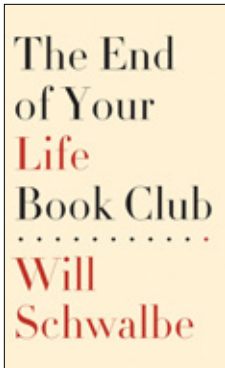
Two men face two very different deaths: One, a renowned palliative care doctor, grapples with the reality he helped so many to confront. The other, an ordinary man, faces an ordinary death. *Conversations on Dying* is a compelling portrayal of two final journeys that challenges you to ask, "What death would I choose?"



## HOSPICE VOICES: LESSONS FOR LIVING AT THE END OF LIFE

**Eric Lindner.** Lanham: Rowman & Littlefield Publishers, Inc., 2013, 210 p.

The author reveals the thoughts, fears, and lessons of those living the ends of their lives in the care of others, having exhausted their medical options or ceased treatment for their illnesses.



## THE END OF YOUR LIFE BOOK CLUB

**Will Schwalbe.** New York: Alfred A. Knopf, 2012, 352 p.

The inspiring story of a son and his dying mother, who form a “book club” that brings them together as her life comes to a close.

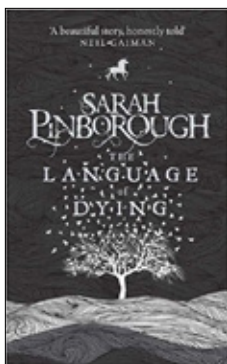


## TWELVE BREATHS A MINUTE: END-OF-LIFE ESSAYS

Edited by **Lee Gutkind.** Dallas: Southern Methodist University Press, 2011, 267 p.

This book features twenty-three personal narratives that examine the way we as a society care for the dying. Here a poet, a former hospice worker, reflects on death’s mysteries; a son wanders the halls of his mother’s nursing home, lost in the small absurdities of the place; a grief counselor struggles with losing his own grandfather; a medical intern traces the origins of time and the quality of our final days; a mother anguishes over her decision to turn off her daughter’s life support and allow her organs to be harvested; and an emergency dispatcher tries to quantify what a stranger’s death should mean.

## NOVELS

**THE LANGUAGE OF DYING**

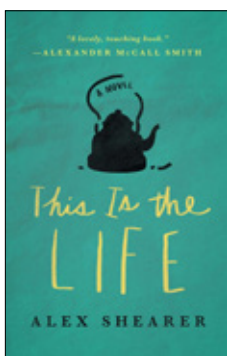
**Sarah Pinborough.** London: Jo Fletcher Books, 2016, 144 p.

In this novella from Sarah Pinborough, a woman sits at her father's bedside, watching the clock tick away the last hours of his life. Her brothers and sisters have all turned up over the past week to pay their last respects. Each is traumatized in his or her own way, and the bonds that unite them to each other are fragile – as fragile perhaps as the old man's health.

**THE LAST DAYS OF RABBIT HAYES**

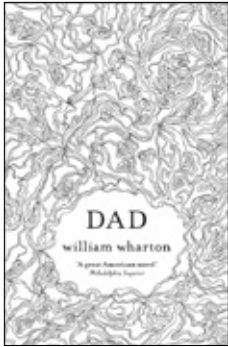
**Anna McPartlin.** New York: St. Martin's Press, 2015, 368 p.

Here is a truth that can't be escaped: for Mia "Rabbit" Hayes, life is coming to an end. Rabbit Hayes loves her life, ordinary as it is, and the extraordinary people in it. She loves her spirited daughter, Juliet; her colorful, unruly family; the only man in her big heart, Johnny Faye. But it turns out the world has other plans for Rabbit, and she's okay with that. Because she has plans for the world too, and only a handful of days left to make them happen.

**THIS IS THE LIFE**

**Alex Shearer.** New York: Washington Square Press, 2015, 240 p.

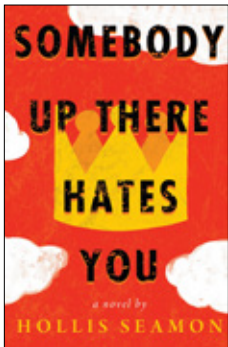
This is the story of Louis, who never quite fit in, and of his younger brother, who always tried to tag along. As they got older, they grew apart. And as they got older still, one of them got cancer, and the other became his caretaker. Then they became close again, two brothers on one final journey together, wading through the stuff that's thicker than water.



## DAD

**William Wharton.** London: The Friday Project, 2014, 448 p.

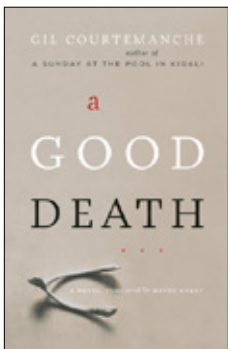
After being summoned home by the news of his mother's heart attack, John Tremont is forced to confront his own middle age. While John's mother begins to make an astonishing recovery, his father deteriorates; having long ago handed over the running of his life to his domineering wife, he is unable to cope without her. With the help of his nineteen-year-old son, John assumes the role of carer. Before long, John finds himself caught between his son's feckless impatience to get on with his life and his father's heartbreaking willingness to let go, as both sons become trapped in the consuming, terrifying and repetitive world of looking after a dying loved one.



## SOMEBODY UP THERE HATES YOU

**Hollis Seamon.** Toronto: Razorbill, 2013, 256 p.

Richard Casey is in most ways a typical seventeen-year-old. Except Richie has cancer, and he's spending his final days in a hospice unit. His mother, his doctors, and the hospice staff are determined to keep Richie alive as long as possible. But in this place where people go to die, Richie has his own plans for how to make the most of the life he has left.

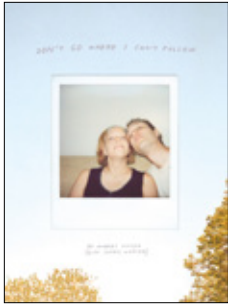


## A GOOD DEATH

**Gil Courtemanche.** Vancouver: Douglas & McIntyre, 2006, 206 p.

On Christmas Eve, a family has gathered around the table for the obligatory dinner. The father, once an imposing figure who terrorized his children, has suddenly fallen prey to Parkinson's. Yesterday's tyrant is now trapped inside a disintegrating body. André, the eldest child, is nearing 60. He has never loved the father who lied too much, abused too much, manipulated too much. But still, this holiday week, André; cannot help but be moved. How should he behave toward a parent to whom all pleasures are forbidden? Should he struggle to prolong the old man's life, or help him end it?

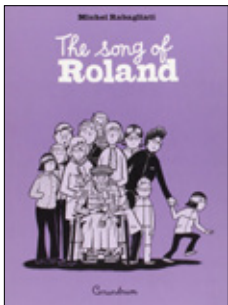
# COMICS



## **DON'T GO WHERE I CAN'T FOLLOW**

**Anders Nilsen.** Montreal: Drawn & Quarterly, 2012, 96 p.

In this collection of letters, drawings, and photos, Anders Nilsen chronicles a six-year relationship and the illness that brought it to an end. The story is told using artifacts of the couple's life together, including early love notes, simple and poetic postcards, tales of their travels in written and comics form, journal entries and drawings done in the hospital in her final days.

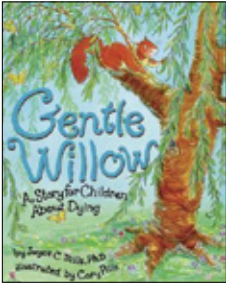


## **THE SONG OF ROLAND**

**Michel Rabagliati.** Wolfville: BDANG, 2012, 187 p.

*The Song of Roland* focuses on the life and death of the father-in-law of Michel Rabagliati's alter ego, Paul. As the family stands vigil over Roland in his hospital bed, Rabagliati weaves a story of one man's journey through life and the legacy he leaves behind.

# YOUTH LITERATURE

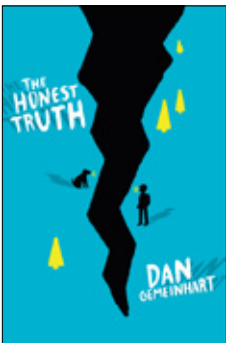


AGES 4 TO 8

## GENTLE WILLOW: A STORY FOR CHILDREN ABOUT DYING

**Joyce C. Mills.** Washington: Magination Press, 2003, 32 p.

Written for children who may not survive their illness or for the children who know them, this tender and touching tale helps address feelings of disbelief, anger, and sadness, along with love and compassion. Amanda and Little Tree discover that their friend Gentle Willow isn't feeling well. Amanda summons the Tree Wizards, who visit Gentle Willow and determine that they can't fix her.



AGES 8 TO 12

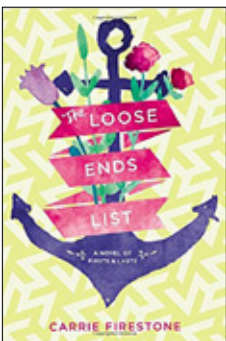
## THE HONEST TRUTH

**Dan Gemeinhart.** New York: Scholastic Press, 2015, 240 p.

In all the ways that matter, Mark is a normal kid. He's got a dog named Beau and a best friend, Jessie. He likes to take photos and write haiku poems in his notebook. He dreams of climbing a mountain one day. But in one important way, Mark is not like other kids at all. Mark is sick. The kind of sick that means hospitals. And treatments. The kind of sick some people never get better from. So Mark runs away. He leaves home with his camera, his notebook, his dog, and a plan to reach the top of Mount Rainier – even if it's the last thing he ever does.



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

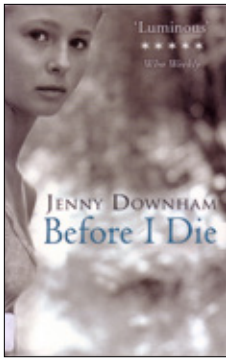


AGES 14 TO 18

## THE LOOSE ENDS LIST

**Carrie Firestone.** New York: Little, Brown Books for Young Readers, 2016, 352 p.

Seventeen-year-old Maddie O'Neill Levine lives a charmed life, and is primed to spend the perfect pre-college summer with her best friends and young-at-heart socialite grandmother (also Maddie's closest confidante), tying up high school loose ends. Maddie's plans change the instant Gram announces that she is terminally ill and has booked the family on a secret "death with dignity" cruise ship so that she can leave the world in her own unconventional way – and give the O'Neill clan an unforgettable summer of dreams-come-true in the process.



AGES 14+

## **BEFORE I DIE**

**Jenny Downham.** New York: David Fickling Books, 2007, 326 p.

A terminally ill teenaged girl makes and carries out a list of things to do before she dies.

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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



## PAUL À QUÉBEC

**François Bouvier.** 2015. 98 min.

Comedy, drama (Quebec). Paul, an aspiring artist, accompanies his wife Lucie and their daughter to celebrate Saint-Jean Day at Lucie's parents home. When Paul notes the declining health of Roland, the bleeding-heart but gruff patriarch, the artist is inspired to make Roland the subject of his first comic strip.



## HONEY

**Valeria Golino.** 2013. 97 min. (original title: Miele)

Drama (Italy). Irene lives alone on the coastline outside Rome. Working under the name of Miele (Honey), her clandestine job is to help terminally ill people to die with dignity by giving them the drug. One day she supplies a new client with a fatal dose, only to find out he's perfectly healthy but tired of life. Irene is determined not to be responsible for his death.



## A FEW HOURS OF SPRING

**Stéphane Brizé.** 2012, 108 min. (original title: Quelques heures de printemps)

Drama (France). Alain Evrard, a trucker who has just finished serving a prison sentence, is forced to temporarily move back to his mother's house. This forced cohabitation causes all the violence of their past relationship to re-emerge. One day, Alain accidentally discovers Yvette, his mother, by a brain tumor and that she has decided to shorten her suffering by resorting to assisted suicide in Switzerland...





**G** UNSUITABLE  
FOR YOUNG  
CHILDREN

## YOU DON'T KNOW JACK

**Barry Levinson.** 2010, 134 min.

Biography, drama (United States). Angel of mercy, or murderous 'Doctor Death'? Jack Kevorkian is one of the most polarizing figures in modern American history, a man whose passionate belief that people have the right to die has brought him both praise and vilification.



**G**

## THE LAST ESCAPE

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

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

# DOCUMENTARIES

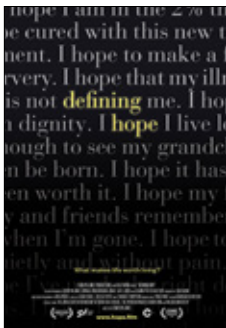
## General works



### END GAME

**Rob Epstein, Jeffrey Friedman.** 2018, 40 min.

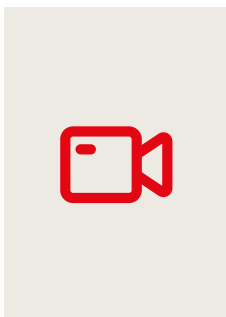
Filmed and edited in intimate vérité style, this movie follows visionary medical practitioners who are working on the cutting edge of life and death and are dedicated to changing our thinking about both.



### DEFINING HOPE

**Carolyn Jones.** 2017, 76 min.

Documentary (United States). We aren't dying the way we used to. We have ventilators, dialysis machines, ICUs technologies that can «fix» us and keep our bodies alive, which have radically changed how we make medical decisions. In our death-denying culture, no matter how sick we get, there is always «hope.» Defining Hope tells the story of patients dealing with life-threatening illness as they move between ICUs, operating rooms, hospice care and home.



### HOW HOSPICE CARE HELPED ONE FAMILY THROUGH A MOTHER'S DEATH

**The National, CBC.** 2017, 17 min.

Online: [www.youtube.com/watch?v=Lw0JJfgwZco](http://www.youtube.com/watch?v=Lw0JJfgwZco)

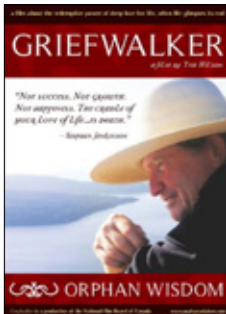
An intimate look at the final days of one woman's life in hospice care.



## EXTREMIS

**Dan Krauss.** 2016, 24 min.

Witness the wrenching emotions that accompany end-of-life decisions as doctors, patients and families in a hospital ICU face harrowing choices.



## GRIEFWALKER

**Tim Wilson, National Film Board of Canada.** 2008, 70 min.

Online: [www.nfb.ca/film/griefwalker/](http://www.nfb.ca/film/griefwalker/)

This documentary introduces us to Stephen Jenkinson, the leader of a palliative care counseling team at Toronto's Mount Sinai Hospital. Through his daytime job, he has been at the deathbed of well over 1,000 people. What he sees over and over, he says, is "a wretched anxiety and an existential terror" even when there is no pain. Indicting the practice of palliative care itself, he has made it his life's mission to change the way we die – to turn the act of dying from denial and resistance into an essential part of life.

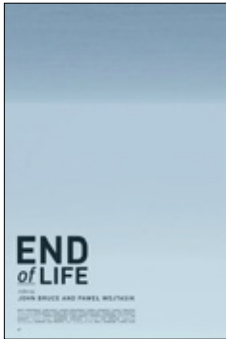


## MAKING EVERY MOMENT COUNT

**Leora Kuttner, National Film Board of Canada.** 2003, 38 min.

Dr Leora Kuttner, an award-winning filmmaker and an international expert in pediatric pain management, brings us this groundbreaking and comprehensive look at the emerging field of pediatric palliative care.

## Medical assistance in dying



### END OF LIFE

**John Bruce and Pawel Wojtasik.** 2017, 91 min.

End of Life is the product of four years spent by John Bruce and Paweł Wojtasik with five individuals at various stages in the process of dying. In preparation for this project, the filmmakers trained to be end-of-life doula and documented hundreds of hours of interactions with their subjects. The Doula works with the dying person, along with those surrounding them, to help design, guide and support their wishes for whatever a “good death” might mean for them.

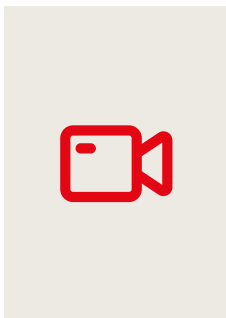


### LAST RIGHT: REFLECTIONS

**The National, CBC.** 2013, 11 min.

Online: [www.cbc.ca/player/play/2421778351](http://www.cbc.ca/player/play/2421778351)

When Duncan McCue and *The National* started this series on the right-to-die debate, their offices were flooded with emails, some of them including very personal stories from viewers whose loved ones have grappled with end-of-life questions. This final segment in the *Last Right* series tells these Canadians' stories.

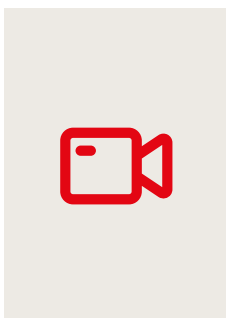


### LAST RIGHT: SANDY TRUNZER'S STORY

**The National, CBC.** 2013, 17 min.

Online: [www.cbc.ca/player/play/2420503474](http://www.cbc.ca/player/play/2420503474)

In this third installment from the documentary series *Last Right*, from *The National*, Duncan McCue meets Sandy Trunzer. She's 49 and dying of a rare disorder. She hoped to respect the laws banning assisted suicide by simply shutting off her pacemaker, but that decision is proving to be problematic.



### LAST RIGHT: HARRIET'S STORY

**The National, CBC.** 2013, 18 min.

Online: [www.cbc.ca/player/play/2415875498](http://www.cbc.ca/player/play/2415875498)

In this second of four parts, *The National's* Duncan McCue continues the series on dying with dignity. All her life, Harriet Scott liked being in the driver's seat. So when her doctor told her she had a terminal case of liver cancer, she was determined to die on her own terms. But would the choice be taken away from her as the disease progressed?

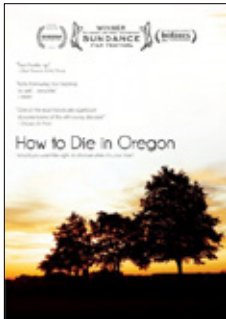


## **LAST RIGHT: ASSISTED SUICIDE IN CANADA**

**The National, CBC.** 2013, 20 min.

Online: [www.cbc.ca/player/play/2414731746](http://www.cbc.ca/player/play/2414731746)

In this first of four parts, *The National* explores the growing demand for new laws governing assisted suicide in Canada. The renewed push comes from baby boomers, a politically active generation that is now aging and demanding more control over their final days. This segment also explores the life of Bill Kennett. A senior Ottawa bureaucrat, he was used to making big decisions, but his last one was shrouded in secrecy.



## **HOW TO DIE IN OREGON**

**Peter Richardson.** 2012, 107 min.

In 1994, Oregon became the first state to legalize physician-assisted suicide. Since then, more than 500 Oregonians have taken their mortality into their own hands. Filmmaker Peter Richardson gently enters the lives of the terminally ill as they consider whether – and when – to end their lives by lethal overdose. Richardson examines both sides of the complex, emotionally charged issue. What emerges is a life-affirming, staggeringly powerful portrait of what it means to die with dignity.

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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

## Legal information

### CHAMBRE DES NOTAIRES DU QUÉBEC

<b>Phone</b>	514 879-1793
<b>Toll free</b>	1 800 263-1793
<b>Website</b>	<a href="http://www.cnq.org/en/home.html">www.cnq.org/en/home.html</a>

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

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

Chat free of charge with a notary.

### COMMUNITY JUSTICE CENTERS

**Website**                            [www.justicedeproximite.qc.ca/en/](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

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

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

## **CURATEUR PUBLIC DU QUÉBEC**

**Phone** 514 873-4074  
**Toll free** 1 844 532-8728  
**Website** <https://www.curateur.gouv.qc.ca/cura/en/>

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

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

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

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

## **INSTITUT DE PLANIFICATION DES SOINS DU QUÉBEC**

**Phone** 514 805-2408  
**Website** [www.planificationdessoins.org](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.

## **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 works

### **CHOOSING WISELY CANADA**

<https://choosingwiselycanada.org/>

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

### **COLLÈGE DES MÉDECINS DU QUÉBEC**

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

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

### **GOVERNEMENT DU QUÉBEC – COPING WITH A LOSS OF INDEPENDENCE**

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

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

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

## **GOVERNEMENT DU QUÉBEC – INFO-SANTÉ 811**

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

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

## **GOVERNEMENT DU QUÉBEC – SERVICE ORGANIZATION**

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

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

## **HEALTHCARE EXCELLENCE CANADA – ENGAGING PATIENTS IN PATIENT SAFETY – A CANADIAN GUIDE**

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

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

## **HEALTHCARE EXCELLENCE CANADA – PATIENT, FAMILY AND CAREGIVER ENGAGEMENT AND PARTNERSHIPS**

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

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

## **HEALTHCARE EXCELLENCE CANADA – SHIFT TO SAFETY**

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

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

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

[www.healthcharities.ca/resources/how-to-health-guide.aspx](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 – GRAND PUBLIC**

[www.opq.org/fr-CA/grand-public/](http://www.opq.org/fr-CA/grand-public/)

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

## **OTTAWA HOSPITAL RESEARCH INSTITUTE – PATIENT DECISION AIDS**

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

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

## **RÉGIE DE L'ASSURANCE MALADIE – CITIZENS**

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

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

## **SANTÉ ET SERVICES SOCIAUX QUÉBEC**

**Quick Reference: I'm taking care of my Health**

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

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

## HAVE YOU HEARD OF DEPRESCRIBING?

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

## WHY RESORT TO DEPRESCRIBING?

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

## HOW DOES IT WORK?

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

Source: Canadian Deprescribing Network

## CANADIAN DEPRESCRIBING NETWORK

[www.deprescribingnetwork.ca](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 RESPONSABILITIES**

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

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

### **ÉDUCALOI – CAREGIVERS: PRACTICAL LEGAL TOOLS**

[www.educaloi.qc.ca/en/caregivers-practical-legal-tools](http://www.educaloi.qc.ca/en/caregivers-practical-legal-tools)

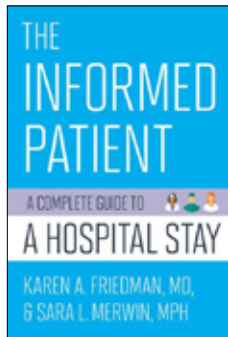
In this web guide, Éducaloi provides clear and useful legal information intended for caregivers.

### **ÉDUCALOI – HEALTH TOPICS**

[www.educaloi.qc.ca/en/categories/health](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.

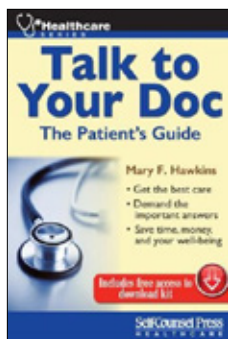
# READING SUGGESTIONS



## THE 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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