

Advance Care Planning

Prepare for Serious Illness by
Sharing Your Wishes for Future
Health and Personal Care

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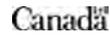
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Notice to Readers

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Introduction: Advance Care Planning

This book is for every person, at any age, and stage of life and health. It is about taking back control of your body and your health decisions; learning how to better communicate with your health-care teams; and while important and often ignored, planning for serious illness and, eventually, for the end of your life.

The concepts of “patient-centered care” and “shared decision making” have been a part of medical theory for at least 30 years but in our fast-paced, overburdened health-care system, the person who is patient gets left behind. This is a basic guide that will help you be a part of your own care and decision making so that you are hopefully not one of the unfortunate ones left behind.

As a health-care navigator and patient advocate, my clients are often in crisis. I have tried to summarize and give all patients and families the same advice I would as if I were in the room with them.

When you are seriously ill and your health-care team is not listening to you, or have told you what you are experiencing is “all in your head,” this book may help, but you will likely need advice that is beyond what is offered here. I will give you some ideas in Chapter 1 on how to find resources that might help.

Part 1 of this book is about the basics of patient and caregiver empowerment. Part 2 is a deep-dive into planning for serious injury, illness, or end of life — whether you’re still healthy, facing illness and frailty, or in the midst of a health crisis that is life-threatening.

As we begin to look at becoming empowered, it’s interesting to look back and see the road of the empowered patient.

The empowered patient movement began in earnest in the 1960s and 1970s when women started to have a choice about their bodies and control of their lives. First came the birth control pill, and suddenly women had a choice over when, if, and how many children they would have. Birth rates plummeted in the Western world and as that happened, women slowly began to move into male-dominated careers, including medicine.

In 1979, I was a senior nursing student in Victoria, BC, doing one of my rotations in maternity. A massive change — almost an earthquake — was taking place at that very moment. In nursing classes, we were learning about Lamaze and other natural birthing methods, and that women were pushing to go back to using midwives and having home births. As students, we had vigorous debates over rights and choice versus the safety of mothers and babies.

And then we stepped into the real world of antiquated deliveries and I could see why mothers wanted to go back to delivering in their own homes and beds. Birthing was a cold, sterile, and uncomfortable experience. I remember everything being white, from the walls to the bedding. The beds were uncomfortable and there were no options for a more comfortable labour: there were no baths, no showers, and no other labour assistance tools. Women were behind closed doors, without spouses or birth coaches, and were encouraged to “labour quietly.” When they were finally ready to push, we ran for a stretcher and between heavy contractions would whip the mother onto the stretcher and down the hall to the sterile birthing room and place her on a medieval contraption that was no different than a gynecologist’s table with stirrups. She would push, with her

feet in the horrible contraptions until she delivered — sometimes two or three hours later.

The maternity ward was another regimented unit, where babies were bundled tightly, put on a cart like a bunch of adorable sausages, and delivered to their mothers every four hours. They were left for 30 minutes to feed and cuddle, and then bundled back up and taken back to the nursery. If babies needed to be fed in between, we gave them sugar water or formula. New moms were in hospital for four to six days.

I had just gotten married and was thinking about having babies, but I knew I didn't want to have them like that. It turned out a lot of other women didn't want it either. Within four years, every maternity ward and hospital began to change. Beautiful and comfortable birthing suites became the norm and rooming-in with babies became standard. Within seven years, most new moms and their babies were going home within 24 hours.

While the old guard of nurses and doctors did not go willingly or happily into the good night, it was a mother-driven uprising.

Now, this same group of adults is changing the way we want health care delivered and how we want the end of our lives to look. We keep pushing for choice and we're not prepared to stop.

It shouldn't be surprising that almost all those who attend my Empowered Patient and Advance Care Planning workshops are women. They have been the mothers and the caregivers and they have seen what happens when we don't plan.

Women are still not being taken as seriously as men when we are sick. It is much more likely that our symptoms will be dismissed or that we will receive a psychiatric diagnosis. It is a theme that has gone back centuries. Through social media, women are fighting back. An example is an incredible video, produced in BC and viewed, as of this writing, almost 18 million times in 190 countries. It is *A Typical Heart* (Distillery Film Company, 2019), about the underdiagnosis and undertreatment of women and heart disease — the leading cause of death in women currently. It will change the way women are treated in cardiac care.

In Canada, we are at the forefront in change for choice at the end of our lives. Medical Assistance in Dying (MAiD) began as a grass-roots

movement with Sue Rodriguez asking for the right to assisted death in 1993 (Assisted Suicide in Canada: The Rodriguez Case [1993]: www.thecanadianencyclopedia.ca/en/article/rodriguez-case-1993). It's been a legal choice since 2016 and that choice is changing everything. We want to get all the care and treatment Western medicine can offer us, but then we can choose to say, "That's enough. I'm ready to die."

Informed and responsible choices along our health-care journeys are the basis of being empowered patients and caregivers. We need to assertively ask for a seat at our own health-care discussions and decisions.

"What you feel is real and important and you should never feel afraid to communicate that." (Dr. Doreen Rabi, Clinical Endocrinologist, University of Calgary — in *A Typical Heart*.)

For many of us, the thought of being in a care facility for severe disability or advanced dementia is untenable. Advance care planning, detailed advance directives, and the option of MAiD, gives us options as far as how we choose the ends of our lives to look.

Our society is in a health-care crisis. There are not enough hospital beds, nurses, doctors, or allied health professionals. But there is an antidote: Educate yourself; be an active participant in your own care; be responsible for your own body and mind; and be respectful as you communicate, plan ahead through advance care planning conversations, and document and proactively communicate with all involved in your care.

1. How This Book Works

The first step in working this book to ensure your rights and desires are taken care of is to know your patient rights. While each province has developed its own health care legislation to be discussed throughout the book, there is a national framework in Canada that, when broken down, ensures very CAPABLE adult has the right to —

- be fully informed of all treatment options,
- have his or her Substitute Decision Maker recognized,
- have his or her Advance Directive (a document that can go by other names as well, see Chapter 8) followed,

- pain and symptom management,
- refuse treatment,
- end his or her own life, and
- assisted death.

There are two parts to the book. Part 1 is about the basics of empowerment and navigating the health-care system. Part 2 is about determining what your wishes are and deciding how best to communicate them to loved ones and health-care providers.

There is also a downloadable forms kit included with more resources for you to use (see URL at the back of this book to access it).

Communication and preparation are the two biggest keys to successfully navigating our complex health-care system. The work required of readers in the upcoming chapters is not easy, but it's incredibly rewarding to come out the other end with a lot of knowledge and a plan.

PART ONE

Empowered Patients and Caregivers: Navigating the Canadian Health-Care System

In this first part of the book, we will discuss how to –

- be an active participant in your own or your loved one's health care,
- improve communication at all points in the health-care journey,
- effectively navigate the health-care system,
- prepare for medical emergencies, and
- prepare financially for serious illness, injury, and disability.

