Advance Care Planning

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

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Contents

Introduction: Advance Care Planning xiii

PART ONE: Empowered Patients and Caregivers: Navigating the Canadian Health-Care System 1

CHAPTER ONE: Become an Empowered Patient or Caregiver 3

1. Becoming and Remaining an Empowered Patient 5
   1.1 Build your team 6
   1.2 The power of empowered caregivers 7

2. Becoming a Caregiver after Serious Injury and During Illness 8
   2.1 Who is who 9
   2.2 Caregiving when loved ones have chronic illness and increasing frailty 10

3. When You Need to Hire a Professional Navigator-Advocate 11

4. Empowered Patients and Caregivers (a Review) 15
CHAPTER TWO: Empowered Communication

1. No One Should Be Alone in the Health-Care System
2. The Power of a Notebook
3. The Power of Being Respectfully Assertive
4. The Power of Staying Logical in Doctors’ Appointments
5. Effective Communication in Hospital Saves Lives
6. Communication in Preventing Common Medical Errors
   6.1 Infection is the number one cause of hospital-induced disease and death
   6.2 Medication and treatment errors
   6.3 Report any change in the status, and stay with the patient if you’re looking after someone else
7. Patient Rights in Balance with Patient Responsibility
8. When You Hit a Communications Wall
9. Communicating with Dismissive, Arrogant, or Bad Doctors
10. Effective Communication Is a Lot of Work, and It’s Harder When You’re Sick

CHAPTER THREE: Navigating the Health-Care System

1. How to find a GP or Nurse Practitioner If You Don’t Have One
   1.1 A note about walk-in clinics
2. Improve Care at Appointments
3. Get Faster Testing and Referrals to Specialists
4. Improve Care at the Emergency Room
5. Improve Care in Hospital
   5.1 Discharge planning
6. Transitions of Care — Sometimes Referred to as the Chain of Care
7. Importance of Obtaining and Maintaining your Health-Care Documents
   7.1 We forget details and dates
   7.2 Important documents are often lost or archived
7.3 We don't know what's important 39
7.4 We don't know what other doctors and health-team members have reported 40
7.5 You are entitled to your health records 40
7.6 Most of us don't know how to read medical imaging and laboratory reports 40
7.7 Immediate lab results 40
7.8 Put your documents together 41
7.9 Obtain your hospital records 41
8. If You Need to Make a Complaint 41
8.1 A special note about assault 42
8.2 A note of caution about going to the media 43
8.3 Take a witness 43
8.4 Complaints about nursing staff (RNs, LPNs, care aides) 43
8.5 The complaint process 44
8.6 Complaints about doctors 45

CHAPTER FOUR: In Case of Emergency (ICE): A Form That Communicates When You Can’t
1. ICE Form 48
2. Review and Update Your Information Regularly 59

CHAPTER FIVE: Financial Planning for Serious Illness, Injury, and Disability 61
1. Common Health Expenses Not Covered by Provincial Health Plans 62
2. Financial Planning for Those Who Are Still Working: Adults 18 to 65 63
   2.1 Benefits packages 64
   2.2 For the self-employed 65
   2.3 For those who have a low reportable income or if you are a stay-at-home spouse 65
3. Our Most Expensive Health Years Are after 65 66
4. Powers of Attorney (POAs) and Enduring Powers of Attorney (EPOAs) 68
   4.1 When do you need an EPOA? 69
5. Elder Financial Abuse 69

PART TWO: Advance Care Planning: Why and How to Use It 71

CHAPTER SIX: Advance Care Planning: Definition and Conversations 73
   1. The Advance Care Planning Process 76
   2. The Importance of Advance Care Planning and Dementia 77
      2.1 Opportunities for conversation 77

CHAPTER SEVEN: Choose Who Will Speak for You When You Cannot Speak for Yourself 83
   1. What If You Are Alone? 84
   2. Choose Who Will Speak for You 84
      2.1 Legal hierarchy of Substitute Decision Makers 85
      2.2 Determine who is best to speak for you 86
      2.3 Talk to your Substitute Decision Makers 87
      2.4 When your Substitute Decision Makers can step in to make decisions 87
   3. Write a Formal Substitute Decision Maker Document (at Any Age) 88
      3.1 Formal Substitute Decision Makers by province 89
   4. Reasons to Consult an Estate or Elder-Law Lawyer 90
   5. Where You Should Keep SDM Documents 91

CHAPTER EIGHT: Determine Your Values, Beliefs, and Preferences for Future Care 93
   1. Think about Your Values and Beliefs 94

CHAPTER NINE: Determine Where You Are in Your Health Journey 99
CHAPTER TEN: Advance Directives: Considering and Writing Your Wishes for Future Care

1. A Quick Review of the Difference between Advance Care Planning and Estate Planning 106
3. Understanding Resuscitation and “No CPR” 109
4. Understanding Hospital Medical Orders of Levels of Care 111
5. Level of Care — Glossary of Terms 113
6. Determine the Appropriate Level of Care 116
7. Write Your Advance Directive 116
8. Final Steps with Your Advance Directive 123

CHAPTER ELEVEN: Vital, Ongoing Conversations with Those You Love and Those Who Will Care for You

1. Talk to the People You Love 130
   1.1 A few ways to start your script 131
   1.2 When you are speaking to your loved ones 133
2. When We Are Old and Frail: Conversations When We Are Coming to the End of Our Natural Lives 134
3. Talk to Your Physicians and Health-Care Providers 135

CHAPTER TWELVE: Considerations for an Empowered End of Life

1. Choice When Approaching a Natural End of Life 143
2. Choice at End of Life 143
3. End-of-Life Options 144
   3.1 Palliative care and hospice 144
4. Medical Assistance in Dying (MAiD) 145
   4.1 When the people you love don't support your decision (or you don't support your loved one’s decision) 146
5. A Few Growing Professions and Options for Your Life’s Ending 147
   5.1 End-of-life doulas 147
   5.2 Alternatives in death ceremony 147
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SAMPLES

1  ICE Form Sample  49
2  Determine Your Values, Beliefs, and Fears  96
3  Determine the Stages of Life and Health  101
4  Determine Your Level of Care  125

TABLES

1  Health Information Resources by Province  12
2  Legal Substitute Decision Maker by Province  91
3  Advance Directive Terms by Province  106
4  No CPR/DNR Forms by Province  112
5  In-Hospital Levels of Care Documents by Province  114
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,
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.