

Introduction:

Rules for Navigators

Wouldn't it be wonderful if the only time we had to worry about navigating our way through the health care system was when our own health *was* at stake?

But this is not reality. The fact is that each one of us called upon to help our loved ones—children, parents, spouses, and friends—when they need to interact with a complex, almost cryptic health care system. And our health care system is becoming even more complex day by day. This complexity has its roots in new treatments, new drugs, and changing coverage rules. And most of us are utterly ill-equipped to provide such direction when it is needed most. For this reason, this user guide to the Canadian health care system takes you on a walk through the stages of life:

- The early years (including pregnancy)
- The middle years
- The senior years

It provides a guide to navigating the system more effectively. It will equip you with information on how things work and what to expect so you can provide greater support for yourself and your loved ones.

The lyric poet John Masefield wrote in "Sea Fever," "All I ask is a tall ship and a star to steer her by" In the modern age of ocean sailing, it is more common to rely on Global Positioning Systems (GPSs) to know precisely where you and your ship are sailing, rather than relying on seeing the stars. In simpler times you could successfully navigate the health system just by having a good family doctor and knowing the location of the nearest hospital. Today that is not enough. Health care has become far more complex. Your *successful* navigation will be enormously aided by information, by insight into the ways of the system, by a questioning attitude, and by advocacy

There are five rules for successfully navigating the health care system.

Rule One: Stay Healthy

You will fare better, no matter what your condition, if you take better care of yourself. It seems almost pedestrian to recite the simple things you can do to improve the status of your health, but here they are in case you haven't read a newspaper or watched a television in the past 20 years. First, smoking is actually bad for you. You should quit. The good news is that there are lots of quite effective smoking-cessation aids—everything from the patch to counselling—to get you off the noxious weed. Second, being physically active can reduce your risk of heart disease or cancer. Physical activity could be as easy -, as walking more or as challenging as going to a gym and working out. Being involved in an active sport will help.

The third in this trinity of things that make you a healthy navigator is what you eat. What you eat is what you are, and there are both good and bad things you can eat. Despite newspaper stories that seem to vacillate on some subjects—for example, whether coffee is good or bad for you—for a long period of time medical evidence has consistently shown the virtues of a balanced diet. There is lots of evidence on the virtues of dark leafy vegetables and an abundant wealth of information on why eating greasy fast food will not increase your health—in fact, it will have the opposite effect.

If you find it hard to believe that fast food is so damaging, take a trip (please walk) to the nearest video store and rent the movie *Super Size Me*. It will likely put you off everything but the salads at McDonald's, Burger King, and Wendy's for the rest of your life. On second thought, be careful of even the salad dressings—the ones at McDonald's contain more fat than the cheeseburgers.

Increasingly, the health care system is trying to save you from yourself and your choices. This is not an act of altruism. Facing rising costs, health care professionals want to postpone your need for treatment for as many years as possible. You can help by staying healthy and making better choices.

Rule Two: Know as Much as
You Possibly Can

You need to become informed not only about the condition or disease that you are coping with, but also

about the resources in the health system. You need to know how to find care, and find it swiftly. You need to know how to determine if care is safe and high quality. You need to know your insurance coverage, whether that is coverage paid for by your tax dollars through government or supplementary private insurance paid by your employer, or whether you're going to pay out of your own pocket.

You have more and more choices to make, important choices that will affect your health care. You need to know what to expect in your treatment and what you can do to improve your chances of a good outcome. The good news is that this information is often available on the Internet. Because information on the Internet can be disorganized and of uneven quality, you need to separate the good information from the not so good. Today, many reputable organizations and institutions provide basic and reliable information on their websites. Being an informed sailor is the most important rule of navigation and that rule applies if you're a patient travelling through the health care system. It may be true that ignorance is bliss, but not when it comes to your health or health care. In health care, ignorance can make your patient journey longer and more difficult and your outcome worse.

Just as a good sailor needs to know the winds and currents of the ocean, you need to know the winds and currents of the health system. Having a good knowledge of the health care system, particularly those centres of

excellence within it, can be the difference between getting *first-class* care and waiting a long time for care that wasn't worth the waiting.

Find out what you need and what is covered in your province or territory. Like real estate, health care services have a lot to do with "location, location, location." We often confuse "universality" with "uniformity." We might have a "universal" health care system, in which every resident and citizen is entitled to medicare, but we do not have a system in which the services and products to which we are entitled are the same from coast to coast. Nor is there a guarantee that you will automatically get what you are entitled to receive.

Rule Three: Organize Your Care Team

Your care team will likely start with your family doctor, but as you age, you need to expand that team far beyond just your doctor. Simply finding a family doctor is a challenge for many Canadians. In addition, many of us now take a complex set of medications, so the pharmacist with whom you deal is a vital member of your team. Befriend your pharmacist! A pharmacist is quite capable of being a solid adviser on the use of not only prescription medication but, more important, the over-the-counter remedy that is often the best option for minor ailments. The pharmacist may be your first and only stop for treating minor rashes, illnesses, and aches and pains. However, beyond the physician and pharmacist, you may also need the services of a nurse, nurse-practitioner,

dietitian, nutritionist, physiotherapist, or massage therapist. For example, if you are managing lower back pain and wish to avoid surgery that will leave you with a rigid spine, you may need a prescribed *set* of exercises. The point here is that as medicine and health care become more complex, so does the range of skills you need access to—hence the team! Look to all members of the team for coaching in the management of illness, particularly chronic illness. Remember that you will spend a few hours a year with your team and over 8000 hours a year self-managing your condition.

Rule Four: Have an Advocate

You need someone who is in your corner, particularly if you are dealing with hospitalization or a serious illness. During your patient care journey, you may not always be sufficiently strong or focused or even conscious to deal with what's coming at you. You need someone who has the dual qualities of caring deeply about you and not taking no for an answer. You need your advocate to ask the questions that you may forget to ask. You need your advocate to write down the answers you may forget. In most cases, your advocate will be a family member or close friend. If you do not have a close family member or friend, you may need to seek the support of a professional patient advocate.

Rule Five: Take Control of Your Care--

Don't Be a Passive Patient

You need to adopt a questioning, skeptical attitude. Don't presume that all your care providers know your full history. Don't presume they know your allergies. Make a careful point of communicating fully. Often one specialist is unaware that another specialist is treating you with medication, and drugs can interact in negative ways. You need to be in control and keep your care team fully informed.

You also need to own and control your health record. You should not be at the mercy of paper-based medical records systems that make it difficult to retrieve essential test results, X-rays, and other information. Sometimes important records are lost or are not available when needed. Build your own medical record either electronically or in a simple file. Keep track of illnesses, medications, test results, and your family's medical history. You'll learn more about this in Chapter 4.

If you have drawn up an advance directive or living will, you need to ensure all those caring for you are aware of your choices. Only then can you be assured your wishes will be respected and implemented.

Embarking on Your Journey

A few last notes before we take you on a life journey through the Canadian health care system:

This book was created using a mix of information from interviews with leading experts and from some very credible websites. Although good information is accessible through a number of sources, many people don't know where to look and are unsure about how to assess the credibility of what they find. Look up "cancer" with a computer search engine, for example, and you will find websites from reputable, peer-reviewed organizations, but you may also find websites for dishonest organizations professing to cure cancer through a snake oil that you rub on your belly. The purpose of our book is to take what we considered to be important information from credible sources and provide you with a "one-stop shopping place." The resource guides at the end of each chapter highlight the best health-organization websites we have come across, as well as essential books. But there are many other good sources of information—our resource guides are not meant to be exhaustive or exclusive.

This book provides an interpretation of what we, through our own experiences and the experiences of friends, have actually found to be true about the health care system. Where there is evidence, we cite it. Some of you will have had different experiences. Some of the advice we provide may be met with criticism from the "purists" in the health professional community. But these reflect our opinions, and we reserve the right to share them and to pass on some of the tips and tricks we've picked up along the way. This book is meant to

provide you with some added practical ammunition for your journey through the health care system in Canada. Your patient care journey will be unique. This book is about helping you to improve that journey.