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Chapter **1**

Finding Your Compass Through the Healthcare Maze

Welcome to the sometimes frustrating journey of health-care advocacy. Whether you're advocating for yourself or for a loved one, this process can be difficult, but this book can help you along the journey. This book is for patients, their caregivers, including friends, family, and others — anyone who helps someone else manage and navigate the healthcare system. Whether you are reading this book to advocate for your own health or you are an active participant in helping someone else manage this experience, this book can help.

The U.S. healthcare system is complicated and multifaceted. It's sometimes nearly impossible to figure out what's best for your care and how that corresponds with what you can afford. In order to be an effective advocate during the healthcare journey, you need to be educated and understand the diagnoses, treatment plans, side-effects, costs, and more. The goal of this book is to help you become the best advocate you can — for your own care as well as for your loved ones'.

Participating in Your Own Care

If you're like most patients, the idea of "consuming" the health-care system probably sounds a bit odd. Healthcare doesn't feel like something you consume, right? You get sick, go to a doctor, they tell you what to do, you follow along, and you hope to get better. That's the classic model of paternalistic medicine, which is the way the process worked for years. But things have shifted, and health-care professionals now lean toward *participatory care*. Here's the thing: Not all patients have caught on to this change, and that disconnect can make all the difference in your healthcare experience.

Being a *participant* in your care isn't about pushing your doctor around or being demanding — it's about understanding that you have a right to safe, accurate, and effective care. Whether you're paying with insurance or out-of-pocket, you're investing in a service, and like any consumer, you have the right to expect a standard of quality.

However, to participate fully, you do need continually educate yourself about your condition and possible treatments; keep your records, medications, and treatments organized; and have the time and peace of mind to ask the right questions. If that sounds daunting, you are not alone (see Figure 1-1). It might be time to seek out an advocate who can help.



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FIGURE 1-1: If you find trying to understand and advocate for your own healthcare daunting and stressful, finding a professional advocate is a great idea.

Understanding Patient Advocacy

Patient advocacy, at its core, is a simple concept: it's about helping a patient achieve the outcomes they want and need in their care. Anyone — family, friends, healthcare professionals, and patients themselves — can step into the role of a patient advocate. But while anyone *can* advocate, the quality and impact of advocacy varies greatly depending on who's providing it and how it's done. Just like anything else, effective advocacy requires understanding, commitment, and a genuine focus on the patient's best interests.

Patient advocacy as a patient

Patient advocacy, when you're doing it for yourself — what I call *patient self-advocacy* — is all about standing up for your own best interests regarding your healthcare. To do this properly, you need to:

- » Stay informed about your health
- » Ask questions about your care plans
- » Understand how each part of your healthcare journey support your well-being

You may not realize it, but you're probably already advocating for yourself in many ways. For example, when you tell your clinician that you're having stomach pain and you'd like to know why and seek treatment, you're taking an active role in seeking the care you need.

Patient advocacy as a support partner

When you advocate for a patient as a support partner — whether you're their spouse, friend, family member, or someone else who you care about — you're there to help ensure they receive the care they need and deserve.

Your role is about actively supporting them: asking questions they might miss (with their permission, of course), keeping them accountable to their care, and helping them feel confident and understood as they navigate their healthcare journey. It's about being their voice when needed, but also respecting their wishes, making sure that the care they receive aligns with their values and preferences.

Patient advocacy as a provider

Many healthcare providers — doctors, nurses, nurse practitioners, and physician assistants — advocate for their patients by going beyond simply performing their clinical duties. They make sure their patients don't slip through the cracks in complex healthcare processes.

For instance, a provider may recognize that a patient's symptoms call for a specialist and actively push for that referral, ensuring the patient gets the targeted care they need. They might also step in to help navigate insurance challenges, advocating for coverage when claims are denied or costs become a barrier to necessary care.

Providers bring not only their expertise but also a commitment to their patients' best interests, often working behind the scenes to secure the resources and attention their patients require.

Differentiating Types of Patient Advocates

The term *patient advocate* is used widely across different healthcare roles, often creating some confusion. In some companies, customer service representatives are called patient advocates, while hospitals might give this title to financial liaisons, care managers, or other staff. While these roles do involve advocacy for patients, it's useful to understand that the nature of their advocacy can vary based on their responsibilities, their employer, and their relationship to your care.

Institutional/hospital patient advocates

You may have heard about someone called a patient advocate who works for the hospital. Sometimes these professionals are called case managers, care coordinators, or navigators, among other names. These are individuals employed by the hospital to help patients connect their care between providers, answer questions, and improve the patient's experience. The work that these professionals do is very meaningful, especially for patients admitted to the hospital who have many moving parts to their care.

It's important to recognize, however, that these individuals are employed by and work for the hospital. That means their assistance only stretches so far. When a patient is discharged from the hospital, or transferred to another facility, this hospital employee may no longer provide any hands-on assistance.

They're there to help patients have a better healthcare experience, but they ultimately still work for the hospital. They can be a resource for you as an advocate, but you can't rely on them to be a full patient advocate as you (or your loved one) navigate different stages of care.



TIP

You may also hear the term patient advocate used in other spaces too, such as for the representative who helps you when you call your insurance company, or the individual who works at a hospital ombudsman office to help you file a complaint. This term is used in many areas to mean anyone who might help a patient with healthcare issues.

Private patient advocates

Private or independent patient advocates provide patient advocacy services independent of a healthcare system and are often contracted or hired directly by the patient or their family to provide personalized assistance, regardless of where the patient is receiving care.

Many private and independent patient advocates provide different types of services depending on the needs of their clients and the advocate's area of expertise. If they don't provide the service that you're looking for, ask if they have any recommendations of advocates that do. The work that these professionals do is extremely collaborative and that doesn't just mean with the healthcare teams their clients work with — they may also collaborate with other patient advocates and know of different contacts to help you with a specific need.

Some private patient advocates carry industry certifications to show that they have demonstrated expertise and specialize knowledge in different areas of the healthcare navigation process, along with the bonus of showing how committed they are to the provision of high-quality advocacy.

» A private patient advocate who has achieved the credential Board Certified Patient Advocate or BCPA, has met specific

competencies established by the Patient Advocate Certification Board (PACB) that speaks to their knowledge of the healthcare system, their grasp on patient rights, the role of a patient advocate on a healthcare team with a patient, and more.

- » Some advocates hold the Certified Case Manager or CCM certification that is awarded to them by the Commission for Case Manager Certification (CCCM) proving that they have mastered case management skills, like care coordination.
- » Advocates that hold the certification of Certified Senior Advisor or CSA, have a passion for working with older and aging patients as clients and have demonstrated their understanding of the unique needs, both clinically and otherwise, that specifically affect seniors in the health-care system.

Do your research and learn as much as you can about the private patient advocate you are considering working with. One size does not fit all and you want to make sure you have a connection with, and work well with, the professional you add to your healthcare team.

Most advocates require that you complete a consultation call for meeting with them so that they can fully understand your needs, your expectations, your currency, and what your goals are. Some advocates don't charge for consultations, while others do.

Friends and family members as advocates

When a friend or loved one gets sick, it's common for their loved ones, such as family members and friends, to step in and support their journey to wellness. Having someone by your side who is familiar and can support you as you navigate the healthcare system is very important, and patients often find solace in members of their support network.

Family and friends do a wonderful job supporting their loved ones, to the extent that they're able. However, the healthcare system is confusing, even if your loved one or friend has experience with it. As you involve your loved ones in your care, manage everyone's expectations about what that support looks like. As well-meaning as they may be, you might need more help ensuring your health-care journey moves along smoothly.

Navigating the Healthcare System

You likely realize by this point that the U.S. healthcare system is quite flawed. However, there's also a great deal of people who are committed to making it work. The aim of this book is not only to educate you but also to empower you with the realization that you don't have to always take what you're given or navigate your journey alone.

Remember, you have options, you have power, and your perspective is important and relevant to your care. This book is now one of your resources to navigate that journey.

