



THE DETERMINED PATIENT

Become a Powerful Self-Advocate No Matter What
Your Health Condition

Question and Answers

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The Guide to Becoming a Powerful Self-Advocate No Matter What Your Health Condition

What is a “self-advocate for health care”?

All of us are forced into engagement with the health care system at some point in our lives. Even if you are rarely ill or in need of medical care, you might find yourself dealing with a loved one or friend who develops an illness or condition or suffers a trauma such as a debilitating accident. You want to be able to find the best resources and access the best possible medical care. And most importantly, you want to minimize the possibility of medical errors, misdiagnoses, deteriorating health, and less-than-optimal outcomes and maximize the likelihood of returning to a previous state of good health. A determined patient self-advocates, or advocates for others, to achieve these goals.

What makes it hard for a person to access the best medical care even if they have good health care coverage?

The medical system is exceedingly complex. When you need to use it to obtain the best health outcome you can, you can be barraged with so many possible options, opinions, doctors, hospitals, and treatments that you soon feel confused and overwhelmed. How can you process all of the information with which you are confronted and make the best decisions?

The reality is that many people in need of medical help often get less-than-optimal medical care and treatment *even if they have fantastic health care coverage* (which many don't). They may not be accessing the right doctor for them. They might be receiving treatment for the wrong condition because they were misdiagnosed. Worse, they might be receiving a treatment that is ineffective or even dangerous for them.

Excellent communication among physicians and other treatment providers is much more likely to happen when you are a determined patient who recognizes how to stay on top of what is happening with your health. Doctors try their best, but they see dozens of patients a day and operate within a complex system where mistakes happen. *The Determined Patient* provides explanations and practical strategies for partnering with medical professionals. Your doctor wants you to be a determined patient because it's often the determined patients who get the best care and experience the best outcomes.

What do determined patients do differently that makes them such powerful advocates for themselves or others?

Determined patients take charge of their health care. They become experts on how their body is experiencing a particular disease or condition. They pay attention to their symptoms and to what does and doesn't work for them. They make sure they're informed about medical news, including research, related to their condition. When they get a vague answer, they press for details. When they get no answers, they keep asking questions, even if they have to go to a different source to get the information and guidance they need. Determined patients do not take "I guess you'll just have to live with this" for an answer.

What can you do to help yourself when confronted with a new or difficult medical issue?

Simply stated, quite a lot! We wrote *The Determined Patient* because as practicing physicians—Dr. Danziger is a cardiologist and Dr. Gellens is a nephrologist—we know that determined patients often achieve optimal outcomes. We want readers to have the tools they need to get the best out of our complex health care system.

If you have a very difficult to treat disease or one without a known cure, you might not know what new treatments and clinical trials can benefit you. We explain how to turn over every stone—and then some—in your quest for the best possible treatments. If you aren't sure whether a new medication or an old one is better for you, and you're relying solely on your doctor's opinion, you might be taking the wrong drug—and you might not need it at all. If you're considering surgery, you might want to think twice. We want you to become a determined patient and learn more so that your decisions are the most educated ones they can be and so that you feel confident in asking for what you want and need.

You do not have to simply trust your doctors. In fact, many doctors admit they wish their patients took more responsibility for their health care, reporting any problems with compliance or treatment promptly and asking good questions. Medical mistakes and misdiagnoses happen. They don't have to happen to you, and we offer strategies to help you make sure they don't.

Most people think that their options in the health care system and their treatment are limited, but are there choices they don't realize they have?

There are some obvious choices every patient makes:

1. The choice of health care provider
2. The choice of the facility in which to be treated
3. The choice of specialists with whom to consult

However, determined patients are conscious of some other choices available to them:

4. **The choice to use the same sources of information as health-care providers do.** A determined patient can access the same source materials, including websites and clinical guidelines, that medical professionals use for their information and continuing education—and learn how to interpret them. For example, in *The Determined Patient*, we teach readers how to read a research study so that they don't have to rely on a reporter's interpretation of the study's results and validity and so they can apply the findings to their unique situations.
5. **The choice to look for current cutting-edge clinical research and trials to inform decision-making.** Many patients do not know how to learn about new or alternative treatments they can benefit from (and don't know that new is not always better!). *The Determined Patient* provides guidance on researching studies, trials, and standards for treatment.
6. **The choice to look for new possibilities for treatment on the horizon.** Knowing what is coming just around the corner and how the newest advances are relevant to you can help you remain encouraged, hopeful, proactive—and determined.

What are the primary barriers receiving optimal care for a medical condition or disease?

It used to be that when you were sick and concerned about your health or that of a loved one, you went to your primary care physician and left it up to this M.D. to manage your medical care. However, in recent years there has been an exponential increase in medical information, medical professionals, and health care providers. Your primary care “doctor” might not be a doctor but a physicians' assistant or nurse practitioner. It might take many months to get in to see a specialist, and when you do, you want to be prepared and knowledgeable so you get the best out of your partnership with this physician.

For some patients, accessing highly specialized and new treatments and diagnostic tests becomes a major impediment to optimum care. For many patients, even just knowing that other options for their care exist may lead to them achieving better care.

And we have to mention compliance. Determined patients are compliant with their treatment protocols and honest with their physicians and medical care providers. They know the best treatment isn't going to work if they don't follow the doctor's orders, so if there's a problem, they speak up.

What does a “Determined Patient” do to improve their care and ensure the best possible treatments?

Most lay people who are confronted with a disease or health issue find it very difficult to navigate the labyrinth of options available to them in the medical system—options ranging from hospitals, doctors, payments, treatments, and so on. Some of their options become clear right away but others are hidden until a determined patient takes charge of their health care and becomes proactive in asking questions and researching what’s available to help them in achieving better health. Using the approaches and strategies in *The Determined Patient*, readers will become empowered to make their way through the maze and feel confident they are getting the best possible care available. They might need to find a new primary doctor, add a specialist or two to their team, identify a leading specialty hospital or medical center where they can be evaluated to ensure they have the correct diagnosis, determine what clinical trials are ongoing, and discover what recent or current research might apply to their situation. Trials and new treatments might save your life, and getting the correct diagnosis might help you return to the best possible health for you.

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