



# ***SCARY DIAGNOSIS***

*Navigating Fear, Finding  
Strength, and Securing  
the Health Care You Deserve*

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## *Chapter 1*

# ***THE FIRST SHOCK, THEN WAITING FOR ANSWERS***

I'm no mind reader, but I'm pretty certain you are reading this book because you are either waiting for test results or are trying to figure out what a recently received diagnosis means for your health, the health of a family member or friend, and your ability to live the life you want.

You may have never been in a place of such uncertainty before, but I hope this book can help you cope. After absorbing the shock of hearing a scary diagnosis, the time comes to map out a plan to manage it.

Some diagnoses are perfectly clear and virtually immediate. If you are in a car accident, have a heart attack, suffer a stroke, or have a painful kidney stone, a diagnosis will usually be made and confirmed within an hour, perhaps less. You can deal with treatments and will learn how your life will change. But some diagnoses never become clear. This is the case for one of the people you will meet as you read on, Adam Greathouse, a veteran who was gravely injured while serving on the NATO peace-keeping mission in Kosovo. Despite never receiving a definitive

diagnosis, the story of his long struggle is both informative and inspiring.

Adam's condition was likely caused by some type of chemical poisoning. Some diagnoses are never clear. Autoimmune diseases such as lupus, rheumatoid arthritis, or psoriatic arthritis may forever surround you with swirling clouds of hypotheses proposed by doctors, your family, and the self-proclaimed experts on YouTube.

Conditions such as depression or migraine headaches will always be uncertain in origin and unpredictable as to when they flare up. Some questions that may never be answered could include:

- What caused this disease or symptoms?
- Are there any treatments that will cure it?
- Are there any treatments that will make me feel better?
- Does this disease progress and make me sicker?
- Will this become a chronic condition I need to live with for the rest of my life?

Even if these questions are answered, you will have to deal with a significant period of uncertainty until a clear diagnosis is made. For me, it was about six weeks from the MRI that brought the word *transplant* into my daily thoughts to the time I was placed on the transplant list waiting for a match that would cure my liver disease.

Adam, the veteran, was brought to the brink of death even though he never received a definitive diagnosis. Other patients discussed throughout this book visited multiple doctors in multiple specialties only to have some of the scariest diagnoses eliminated, but others that still held multiple dangers were left under active consideration.

Don, who you will meet in greater detail later in the book, is the son and grandson of men who developed Parkinson's disease late in life, so he was primed for indicators. When he noticed a tremor in his right hand as it hung by his side, he strongly suspected that it was Parkinson's, but it took a year and several doctors' appointments until he received a confirming diagnosis.

So here you stand looking past the teeth, down the throat, and into the belly of the beast. Jonah would spend three days and three nights in the belly of the whale that God had sent to save him from drowning. Then God had the whale burp up Jonah onto the beach. You should be so lucky. Jonah's journey took only three days, but that was because God didn't need prior authorization from an insurance company.

Perhaps you are motivated to go to the doctor because of pain or a skin spot that didn't look right. Your journey through the belly of the health-system beast may never have a clear ending. Do your best to come to terms with the process that will now control your thoughts and calendar.

1. You receive the doctor's first impression and hypotheses.
2. You await test results.
3. You see a specialist.
4. You await more test results.
5. You get a second opinion.
6. You await more test results.
7. You decide what action, if any, to take.

Brace yourself. Remember: you are strong. As dreadful as this sounds, prepare yourself for more of the same. One of the reasons you may get caught in a cycle of new doctors, new tests,

and new conclusions is that medical diagnostic errors are shockingly common.

You might even say that this American tradition of diagnostic errors and mistreatments started with George Washington in 1799. At that time, the former president saw a doctor because he was feeling ill with a sore throat and chest congestion. Over the next few days, he was treated by four doctors who, with the patient's acquiescence, drained five pints of his blood—half the blood in the human body! To this day it's unclear if the extreme bloodletting killed Washington or if an undiagnosed infection proved fatal. Certainly removing half his blood was a major medical error and didn't help any possible recovery.

While bloodletting is no longer practiced, medical errors continue.

According to a 2014 report by the Society to Improve Diagnosis in Medicine (SIDM), an estimated 12 million people are affected by medical diagnostic errors in the US every year, resulting in the deaths of between 40,000 and 80,000 patients. Researchers estimate that about half of those errors could be “potentially harmful.”

In a 2017 study of patients seeking second opinions from Mayo Clinic, researchers found that only 12 percent were correctly diagnosed by their primary care providers. More than 20 percent had been misdiagnosed, while 66 percent required some changes to their initial diagnoses.

A 2023 study by the National Institutes of Health estimated that diagnostic errors contribute to about 10 percent of patient deaths and “6 to 17 percent of adverse events in hospitals.”

Some think that second opinions should be mandatory, but not all patients require second opinions. They raise the cost of

care and slow down the process of beginning treatment. Some health insurers—in order to hold down costs—won't cover second opinions from experts outside their networks.

Reducing diagnostic errors means tackling human mistakes to traditional but flawed procedures for treating and diagnosing conditions.

### ***How to Manage the First Steps***

- Accept that you are beginning a process that will be long, complex, and frustrating.
- Be aware that mistakes are made and second opinions and visits to specialists can be worthwhile.
- Understand that you are now on a mission to get answers and you are in charge.