



Excerpt from *The Life You Save* by Patrick Malone

Chapter 1: This Book Could Save Your Life

The sound patients make when they fall off the earth is so quiet that hardly anyone can hear it.

For one of my clients, Richard Semsler, a forty-six-year-old attorney, the sound was a thin rustle, as his internist handed him a sheet of paper that told him his life was ruined for no good reason.

He already knew that the mole on his lower back, which had recently turned a mottled blue-brown, had proven to be an aggressive cancer, a melanoma. But now the newly discovered paper told him that a dermatologist had recommended the mole be excised eight years before, long before it turned deadly. Somehow, no one had notified the patient.

Richard stared at the eight-year-old letter which his internist had resurrected from the thick jumble of papers documenting twenty years of routine internal-medicine treatment: for headaches, high cholesterol, poison ivy, and the painful boils on his back that had led to several referrals to the dermatologist. Inside, Richard was screaming. Outside, all was hushed. It would be impolite to make any noise.

So it goes with many hundreds of thousands, even millions, of Americans each year. When a person learns that a preventable medical mistake has stolen his health and that it is too late to do anything, the shock of being twice victimized—first by a curable disease and then by the caregivers who were supposed to help—causes a dizzy feeling, like everything securing him to the earth has let go. Caregivers turn from allies to adversaries.

Could this happen to you?

The odds are unsettling: Medical catastrophes have been documented to so pervade the American healthcare system that a realistic risk of needless death or serious injury confronts every family in the United States at some point.

But there's good news too: You can do a lot to protect yourself and to secure for you and your loved ones the best that our fragmented, expensive system has to offer.

This book gives voice to victims of bad and mediocre health care and to patients who have successfully navigated the American healthcare system. You will see how tragedies could have been averted.

And you will watch as the successful patients-many of whom were victims first-enlist doctors and nurses to help them care for themselves.

- They clear up miscommunications before harm occurs.
- They persist in looking for cures when doomsayers have told them to give up.
- They refuse to accept "It's all in your head" and learn how to unlock the puzzles of their bodies' strange signals.
- They politely decline to have their bodies cut open by mediocre surgeons and negotiate access for themselves to the best surgeons and hospitals.
- They become literate in the statistics of their diseases and figure out how to use numbers to make wise decisions.

In the process, they learn that the best way to win the longest, healthiest lives for themselves is to take charge of their own health care and not merely turn their bodies over to an impersonal and broken medical industry.

"The life you save," as the novelist Flannery O'Connor once wrote, "may be your own."

To learn how to work the system, you need guidance from an expert in the system. And that's where I come in. Over the last twenty-five years, I have represented hundreds of patients and their families who lost their health to the health-care system. In each case, I've done a legal "autopsy" to figure out what went wrong with the patient's health care and why he or she was injured or killed.

Before I became a lawyer, I spent a decade as a journalist covering both the best and the worst of the American medical system. In both careers, I've learned how to find the best medical care

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and avoid the worst. I've learned that you don't have to have a degree in medicine to understand enough to make smart medical choices. I've learned that you do need common sense, curiosity, and persistence.

And you need a plan. And that's what I have put together in these pages.

American Health Care: Amazingly Good and Stunningly Bad

Americans spend more on their medical care than people anywhere in the world, by a long shot. A large chunk of that extra expense is leached out to feed the paper shufflers in the health-insurance bureaucracy, who add no real benefit. But some of the money gives us amazing technology that lets doctors peer into the deepest recesses of our bodies without cutting and perform treatments on the cellular level that would have been unthinkable only a few years ago.

Yet critics routinely describe this same health-care system as broken. Frightening statistics abound:

- Every year, some 100,000 people die and hundreds of thousands more are injured unnecessarily.
- Medical mistakes claim more lives each year than breast cancer, AIDS, and motor-vehicle crashes combined.
- Apollo astronaut Pete Conrad rocketed to the moon and back safely in 1969 but died of poor emergency room care thirty years later.
- Medication errors alone kill more people each year than die in all the workplace accidents across the country.

It's like a jumbo jet crashing every day. Arresting statistics, yes?

And all of them came from a 1999 report from the Institute of Medicine, part of the National Academies of Science.¹

The authors worked hard to dress up their otherwise wonkish report with sexy, alarming numbers, and across the country the report sparked pilot projects dedicated to saving lives and reducing errors.

Just the name of one project will give you an idea of the scope of the problem—the 5 Million Lives campaign of the Institute of Healthcare Improvement projected that American hospitals could save 5 million patients from harm over two years by implementing just twelve specific strategies.

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Five million!

The same institute estimates that 40,000 incidents of medical harm happen every day in the United States.² These episodes can and do happen anywhere. Anyone who thinks it cannot happen to me because my doctor went to a brand-name medical school and works at a prestigious hospital is badly mistaken.

The people who cause these deaths and injuries are not evil. Nor did they necessarily graduate at the bottom of their medical-school or nursing-school classes. Many are the best and the brightest.

In a way, they are victims too: of a system that has antiquated safety mechanisms and a paternalistic philosophy out of sync with twentyfirst- century life, a system that propagates injury-causing errors and then does little to fix them-or even own up to them honestly.

The "Half-Notes" of American Medical Care

What may be worse than all the breathtaking errors is the inconsistent quality of the day-to-day care that Americans receive. The best estimate by quality experts is that Americans get about half the medical care recommended by consensus lists of what works and what doesn't work for the most common physical and mental diseases.³

Half the recommended preventive care, like early screening for cancer or vaccinations. Half the care recommended for emergencies like heart attacks, strokes, and fractures. Half the care recommended for long-term issues like cancer, diabetes, high blood pressure, and depression.

A grade of 50 percent is a flunking score in most schools, but in American health care, it's business as usual.

Happily for us patients, doctors and nurses across the country are doing pioneering work to figure out how to bring high-quality care to more of us (hint: it's a lot more than having a good insurance plan) and to determine how errors happen and how they can be prevented.

Some hospitals are taking big steps to transform the culture of medical care to make safety and quality for patients the top priorities, to insist on accountability for results, and to be open and honest with patients when mishaps occur despite best efforts.

But unless you go to a place like the Veterans Administration for health care (yes, the VA has some of the most honest, accountable, and organized care in the country), the chance of your getting consistently excellent care with a minimum of errors is just a spin of the roulette wheel.

So I will give you some tools to get out of the health-care casino and win for yourself and your family the reliably high-quality care we all deserve, care that is available virtually everywhere in

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the country, but that you have to work to find.

Many of us otherwise intelligent, informed adults engage in what can only be called delusional thinking when it comes to our own medical care. We read reports about how America's health indicators- infant deaths and life expectancy, to take two prominent examples-lag behind those of most other wealthy countries, and we rationalize that our own health care must be just fine and that it must be someone else's low-quality care that is bringing down the average. It's the uninsured patients, or the racial disparities in quality, we assume.

The fact is that poor quality and medical mistakes are democratically distributed; we're all at risk, insured and uninsured, rich and poor, black and white.

But top-quality care, indeed, some of the best in the world, is also democratically distributed in the United States and is available to everybody who has the tools to recognize the best and make sure they get it.

My job in this book is to give you the tools, teach you how to use them, and motivate you for an exciting journey.

But there's one big problem we have to confront first: "We have met the enemy and he is us," as Walt Kelly's Pogo famously said. It's one thing to vow, "I will take charge of my own health care"; quite another, to put the plan into action.

It can feel wrong to ask too many questions of the doctors and nurses who care for us. We have a condition we might call white-coat-intimidation-itis. The paternalistic model of health care is deeply imprinted in our psyches, for one very good reason: Sickness is scary, and everything that goes with it- needles, tubes, beeping monitors, masked humans-can be scary too.

So when someone comes along in a hospital and promises to take care of us, treating us like the children we once were, it can be enormously comforting to just let go, ask no questions, and pull up the blanket snugly.

Evolutionary psychologists also teach that, much as we prize our independence, deference to authority is ingrained deep in our DNA because it has proven such a successful survival strategy over the millennia. Only now are we understanding that in technologically complex, flawed systems like hospitals and clinics, deference to authority can be fatal.

The point is, the time to read this book is now, before you or someone in your family faces a health crisis. And because we're all mortal, we know (but often pretend otherwise) that that crisis looms in each of our futures.

The Necessary Nine

This book is organized around the critical moments when you as a patient or as an advocate for a loved one can make a difference before it's too late. The order proceeds logically from basic building blocks to more complex issues.

The safety strategy that informs the book, as you will see, starts with something the medical-care industry has begun to learn from the aviation industry:

- that we are all human, doctor and patient alike;
- that we all make mistakes;
- that the way we catch errors before they cause tragedy is to enlist a second and third set of eyes on whatever we're doing; and
- that the most effective way to collaborate on our common health mission is to boil down complex processes into simple checklists of what needs to happen and then check off the lists, item by item.

Thus do we extend our lives, one checkmark at a time.

Here are the Necessary Nine steps (with their corresponding chapters):

1. Get your medical records, read them, and organize them (Chapter 2).

By gathering and reading your own medical records, you will gain insight into that most fascinating of topics-yourself-and you will prevent the kind of miscommunication that led to Richard's fatal melanoma and many other preventable tragedies.

It doesn't take a medical degree to help your doctors avoid tragic errors. An inquisitive mind is the main ingredient needed. This first step paves the way for every other step you need to take.

2. Learn how to talk to your doctor efficiently and effectively. Make a list, leave a list, and take a list (Chapters 3 and 4).

You can plan how to talk to your doctors to give them the information they need to diagnose what's wrong with you and prescribe the best treatment. These chapters offer communication strategies to prevent misdiagnosis and arrive at the right answer-because clear communication, not fancy tests, is still the best way for you and your doctor to find out what's wrong with your body and carry through to an effective plan to deal with it.

The most effective way to clearly communicate is in writing: by making a list of your concerns and symptoms; leaving the list with your doctor; and taking home another list, the doctor's action plan.

When even that doesn't work and your doctor seems to be floundering, Chapter 4 offers more strategies for finding the answer.

3. Team up with the best primary-care doctor you can find (Chapters 5 and 6).

What if the communication strategies you've learned from Chapters 3 and 4 don't seem to be working with your current primary-care doctor? Then it might be time to look for another one, because the ability to listen well is one of the hallmarks of a top doctor, particularly when it comes to diagnosing what ails you.

And an excellent internist or family doctor is one of your prime protectors against mediocre care and medical error.

I will talk about some of the telltale tip-offs that help you scout out the best and avoid mediocre or downright dangerous doctors.

4. Learn the safe, sensible-and skeptical-approach to using medicines (Chapter 7).

There are good drugs, which can save your life and ease your pains. Then there are fad drugs, useless drugs, and dangerous drugs. I'll talk about the scandal of drug-industry propaganda that too many busy doctors rely on for their pharmaceutical education.

This chapter also offers practical tips for getting unbiased information about medicines and how to take them safely.

5. Understand why all medical tests are flawed, and seek a second or third opinion at every major crossroads of health care (Chapters 8 and 9).

No medical test can be perfectly accurate; they all generate false alarms and sometimes-false reassurance. In Chapter 8, I teach you how to understand the statistics behind testing error rates, so you can make intelligent choices about tests and treatments.

Chapter 9 goes on to consider the related issue of second opinions. Many lives every year are saved when patients have the gumption to say, "I'd like another opinion."

We're trained to think of the "second opinion" as an option only when considering elective surgery, but the concept of enlisting a second pair of expert eyes to focus on your case works for

much, much more than just surgery.

6. Choose a surgeon by experience and team structure, and learn the checklists for safe surgery (Chapters 10 and 11).

When you're thinking about surgery or some other major treatment, you are most vulnerable to mediocre care and error. These chapters will show you how to find the right surgeon and teach you what you must know before letting someone cut you open.

I also explain the importance of check- lists for safe surgery and how patients can improve their odds for a good outcome by checking off the key steps that doctors and nurses should do in front of the patient before they're put under anesthesia.

7. Have an advocate with you at every significant health-care encounter, especially in the hospital (Chapter 12).

When you are sick, it's not only your physical defenses that are down. Your mental defenses-your ability to think things through, to exercise good judgment, to hear the advice people are giving you-suffer too. Having an ally and advocate with you at all times is the only way to go.

This chapter recounts stories of injuries, which an advocate can help prevent, and also shows how an advocate can spur a health-care team to give better care and get you home faster. You will also learn how to become an effective advocate for your sick family members.

8. Learn how to steer clear of the major hazards of hospitals and how to find hospitals that work to maximize your safety (Chapters 13 and 14).

It's a cliché that hospitals are dangerous places, but what many people don't realize is that some are a lot more dangerous than others. Infections are such an important source of preventable injury, they deserve their own chapter (Chapter 13).

Chapter 14 turns more generally to hospital quality and reviews the currently available quality-rating guides from the government, nonprofit agencies, and commercial raters. I will show why one of the most simple and down-to-earth measures-patient ratings of their satisfaction with the hospital-may be about the best.

9. If you develop a chronic disease, educate yourself in what you need and learn how to audit your care to make sure you get it (Chapters 15 and 16).

The right approach to chronic disease starts with the right attitude, so I begin this final step with stories from patients who have tamed their own chronic-disease issues with determination and curiosity. Then I go on to address the uneven quality in the delivery of care, which plagues the patients who need doctors the most.

For most of the common serious medical conditions, expert specialty organizations have developed checklists that they use to audit care quality. You can use the same checklists to do your own audit, and if your care or a loved one's care comes up short, you can find a better doctor before it's too late.

Putting It All Together

Once you learn the **Necessary Nine** steps to finding the best health care, you'll meet some of the heroes and champions of the patientsafety movement in Chapter 17.

Finally, the *Epilogue* gives you some steps to follow when you believe that to you or a family member has suffered a needless medical injury. I will show you how to pull straight answers from health-care providers after something has gone wrong with medical treatment, so you can push the care back onto the right course.

And if all else fails, I will help you figure out if you have a legal case worth pursuing and how to find the best lawyer.

But my fervent hope is to generate less business for lawyers by helping readers secure the best, safest care, so you never need an attorney.

A final word: Most health-advice books are written by doctors for patients. This book is different, because I believe the experts in finding the best health care are the patients who have learned how to become their own best advocates, not so much those who dish out the care. So the advice you'll read here comes mostly from patients themselves (backed up by plenty of current scientific studies).

And there's a stronger point to be made. As the Internet democratizes access to high-quality medical information, there is no reason to defer blindly to the authority of those with MDs or DOs behind their names. Doctors should be our allies, not our dictators; they should be our coaches, not our parents. Patients who take this book's lessons to heart will help make that happen for all of

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us, because we can help doctors see where their most effective and humane role lies.

A note about names: Many of the patients featured in this book agreed to let me use their real names. (Those who preferred otherwise had very good reasons to keep their names private.) So you will see a lot of real names in this book.

On the other hand, for the most part (except when the legal cases have gone all the way to trial in a public courtroom), I do not use the real names of the doctors, nurses, and hospitals involved with injuries and deaths. This helps my publisher sleep at night, but it also underlines one of my main points.

Bad things happen everywhere in our health-care system, so knowing the exact place where something awful occurred is not going to help you, the reader.

What can help is to understand why and how our system doesn't work well and what you can do to patch the holes in the medical care that you and your loved ones receive.

Notes

1. Institute of Medicine, *To Err Is Human: Building a Safer Health System* (Washington, D.C.: National Academy Press, 1999) p. 1.
2. <http://www.ihl.org/IHI/Programs/Campaign/Campaign.htm?TabId=1>
3. Elizabeth McGlynn, et al., "The Quality of Health Care Delivered to Adults in the United States," *New England Journal of Medicine* 348 (June 26, 2003): 2635-45.