

the
PATIENT'S
SURVIVAL GUIDE

SEVEN KEY QUESTIONS for
NAVIGATING THE MEDICAL MAZE

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BEAUFORT
BOOKS

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PREFACE

In a sense, this guide has been about seventy years in the making. I had an early experience of medically induced complications (now called iatrogenic disease) at a time when they were relatively rare. You might even say I was a “drug-reaction pioneer.”

In 1949, when I was in second grade in Springfield, Delaware County, Pennsylvania, our family doctor prescribed a sulfonamide antibiotic, one of the earliest “miracle” antibiotics, for a common childhood infection.

After a few days on this drug, this seven-year-old came down with acute nephritis (kidney inflammation). Renal function dropped, edema

set in, and I ended up in Philadelphia Osteopathic Hospital while doctors figured out what to do.

There was actually very little to do at the time except pray, hydrate, avoid salt (Epsom salts instead), and rest. Lots of rest. In fact, it was deemed I should “rest” for a whole year. So I spent all of third grade resting on a chaise longue and reading. (I’m still not good at sports!)

But the upsides of that year were my full recovery, my later interest in iatrogenic matters, and the development of my reading and academic ability. I had finished second grade reading just at grade level but finished third grade reading at the tenth-grade level—with a vocabulary to match.

So this unfortunate incident has helped me all my life. Being a voracious reader has helped me through my nineteen years as a communicator for General Electric senior executives, twenty-two years as CEO of New York’s Bowery Mission, and now, finally, in my own consulting practice on leadership. And now it is helping me come full circle with this guide.

Throughout my life, I have kept myself informed not only on the amazing and lifesaving explosion of medical knowledge, treatments, and technology, but also on the more ominous development of aggressive Big Pharma, risky diagnostics, low productivity mass screenings, and aggressive protocols substituted for clinical judgment. These profit-fueled and patient-endangering practices have grown into a monster—a national emergency that has become the third leading cause of death in America. More on that in the next chapter.

There are a few courageous doctors out there talking about these things, like the more than thirty authors in the “Further Reading” section. But they mostly get no mainstream media attention. The electronic media, with the commendable exception of the focus on the opioid crisis, seem uninterested in stories on our broken medical system and its thousands of unnecessary deaths, stories that will cross their Big Pharma sponsors; instead they extol high-tech medical breakthroughs that benefit very few and feature milquetoast advice for better health. The print media have done somewhat better, but to little effect, and the

younger generation consumes mostly electronic media.

Hence, I decided to get practical and construct this guide with the hope that it will help prevent medical tragedies and extend a friend or a family member's longevity. That's why I'm writing.

The need for this kind of skeptical wisdom has risen exponentially in the past two decades. Overtreatment and medical mistakes have multiplied into the premature deaths of hundreds of thousands. We explain how in chapter 1. A couple of examples close to home:

My father died in 1991 at seventy-five years of age of metastatic prostate cancer. I show in this guide how it is probable that he didn't need to die that young.

In 1999, my wife was diagnosed with stage 1 breast cancer, had a lumpectomy, some local radiation, and no chemotherapy. Two hospitals, including one of the leading cancer hospitals in the nation, recommended a full round of chemotherapy, even though there was no lymph node involvement. When I asked for any studies on five-year recurrence of stage 1 breast cancer, with or without chemotherapy, first there were raised eyebrows that I would question their clinical judgment and established protocols. Second, I was told there were no such studies. Finally, a small study was proffered, which showed a 2% absolute difference in recurrence, which is not statistically significant in a study that small. When asked why they would not save "the big guns" for when and if the cancer returned and help keep my wife's immune system intact, there was further patronizing talk—talk of killing every last remaining cancer cell—a totally improbable and unverifiable goal. We walked. Twenty-one years later there has been no recurrence.

One more story ripened my conviction that I should write about this. I had my own brush with becoming a heart patient. In October of 2018, I noticed some shortness of breath and angina-like symptoms when taking the subway stairs quickly in New York City, as I usually do. Chest discomfort during exercise is never a good thing, although it can have multiple causes, as I was about to learn. I saw our family physician, who praised me for coming in and sent me right over to an

interventional cardiologist. I suggested a non-invasive stress test on a treadmill with an echocardiogram as a first step, and he agreed. But the stress test results were not “normal” and led to a recommendation for angiography to see the extent of any artery blockages. The possibility of implanting a stent was mentioned.

A caution light went on in my head, and I told him we would get back to him. The next few days of research were eye-opening. I had a cardiologist friend in New York read the echocardiogram and EKG and review the notes as a first step.

And in the following nights, I googled “unnecessary heart stents” and was literally knocked back by page after page of results, both from popular sources like the *New York Times* and from peer-reviewed journals. The upshot, as reported later in this book: there’s a \$2.9 billion heart stent industry in North America¹ with a million angioplasty procedures performed in 2019²—life-saving procedures if performed during heart attacks but apparently of zero worth in reducing mortality if used prophylactically. In addition, the blood thinners required after implantation have caused thousands of complications.

I declined the procedure, took statins and a baby aspirin for a few months, added cardio-exercises three times a week, and lowered my sugar intake. One year later, the symptoms are gone. This does not mean that anyone should ignore chest pain or refuse all suggested interventions. It does mean that we should proceed with caution and wisdom when interventional cardiology is recommended.

I am well aware that medical harm has been going on since the time of Hippocrates and his famous admonition to physicians to “first do no harm.” And I am also aware that medical harm has been going on in this country since George Washington’s physicians bled him profusely during his final illness. But I think we should all be shocked by how the cautious approach of the Hippocratic oath that all new doctors take has been replaced by the notion that an aggressive medical approach is almost always the best for the patient and certainly for the doctor in this litigious climate. The harvest of this notion is detailed in the next chapter.

I realize that many people will be skeptical. Most people believe that medical harm has declined as ignorance-based treatments have disappeared. Would that it was so! To the contrary, medical harm has ballooned into an epidemic as new dimensions of unintended consequences take over medicine—rooted in overdiagnosis, overtreatment, flawed pharmaceutical studies, and doctors worried about lawsuits. In today's American medical system, many incentives for health care providers are misaligned with the interests of the patient.

As a side note, most of this country's doctors, nurses, and medical leaders are caring, compassionate, and skilled people. But they are working in a broken system. David Goldhill, one-time CEO of Game Show Network, lost his father to medical mistakes in a New York hospital, and in 2013, wrote a book about our medical system, entitled *Catastrophic Care: How the American Medical System Killed My Father*. He says it well:

Accidentally, but relentlessly, America has built a health-care system with incentives that inexorably generate terrible and perverse results. Incentives that emphasize health care over any other aspects of health and well-being. That emphasize treatment over prevention. That disguise true cost. That favor complexity, and discourage transparent competition based on price and quality. That result in a generational pyramid scheme rather than sustainable financing. And that—most importantly—removes consumers from our irreplaceable role as the ultimate insurer of value.

It is my hope that this guide will touch off a movement of skepticism and wisdom in confronting some of life's most difficult choices. If it extends one life or changes one end-of-life course, I will be excited.

PART I

**THE MEDICAL ENVIRONMENT IN
AMERICA AND YOUR RESPONSE**

CHAPTER 1

A BROKEN SYSTEM AND A NATION GOING BACKWARDS IN LONGEVITY

First, do no harm

—HIPPOCRATES OF KOS

If you really want to understand what's going on in American medicine today, don't just follow the science, follow the money.

The scene is played out tens of thousands of times each year in American hospitals. A patient lies helpless in an intensive care unit, heavily sedated, sometimes restrained, and often intubated so he cannot speak. He is isolated from family members. Meanwhile, his loved ones sit waiting, hoping against hope that technology can give him another shot at life, as sincere critical-care specialists offer shreds of hope and describe flashes of improvement, only to eventually admit defeat.

In August 2012, in Fairfield, Ohio, this scene happened to someone who was no ordinary citizen. Lying in the intensive care unit, clinging to life, was the first man to set foot on the moon, Neil Armstrong. He

was a person of faith and a vigorous eighty-two-year-old. A few days earlier, he had walked into his family doctor's office with some moderate heart symptoms. He ended up in the local hospital, where he was advised to undergo coronary bypass surgery. He signed the papers, the surgery was performed, and then a cascade of postoperative procedures and complications left him nonviable even before he went off to the ICU for more than a week.¹ An appalling story, you say, but what does it have to do with the overall care system in this country? To lower his operative risk, perhaps Armstrong should have gone right down the road to Cleveland Clinic, the world pioneer in heart bypass surgery, instead of letting his local hospital talk him into having the procedure done in his hometown?

No, his tragedy was not selecting the wrong hospital to have the surgery performed—it was agreeing to have the surgery performed at all. He made the assumption, based on unsubstantiated advice, that bypass surgery was indicated for his condition and that arduous coronary artery bypass grafting (CABG), would likely extend his life *more than conservative treatment*.² As you can see in our footnote and in our heart chapter, that's a dubious and unwise assumption. That's what we mean by overtreatment! Would Cleveland Clinic also have recommended CABG for Armstrong? We'll never know. We do know that this American hero didn't get the medical wisdom he needed.

David S. Jones of Harvard University points out in his book *Broken Hearts: The Tangled History of Cardiac Care* that even though CABG rates in the United States are five to six times higher than in Ontario, Canada, the two have completely comparable heart disease survival rates. Armstrong, who never had a heart attack, made the mistake of assuming that the \$75,000 procedure he was being offered was his very best option for an extended life.

Because of his fame, world hero status, and the loyalty of his two sons, Neil Armstrong's family got a \$6 million payment from the hospital, in return for no admission of fault and a confidentiality agreement. But that small comfort did not remove his family from the ranks of tens of

thousands of other families who made a series of fateful medical decisions—decisions that seemed wise at the time, but ultimately ended with premature death or death under agonizing circumstances.

A recent *New York Times* article about the Armstrong family's tragedy treats Armstrong's death as an unfortunate but somewhat anomalous event, perhaps rising to the level of substandard care.³ But cases like his are not rare anomalies. Armstrong's fate and other celebrity cases that make it to the popular press—like comedienne Joan Rivers's throat endoscopy that went very wrong,⁴ Andy Warhol's gallbladder removal that turned tragic through a horrifying mistake in post-op care in 1987,⁵ and comedian Dana Carvey's cardiac bypass in 1998, in which the wrong artery was bypassed, show us that anyone can be a victim. They are symbols of a pervasive problem that has overtaken American medicine. In the context of huge growth in complicated procedures and increased use of multiple interacting drugs, medical mistakes have become the third leading cause of death in the United States.

That startling assertion has moved past marginalized circles and into the mainstream literature of medicine. And it means that you and I need to shift our approach to medical care or risk being part of this national tragedy. It has become a life-or-death matter for us.

In 2000, an organization called Institute of Medicine (IOM) released a study of patient harm called "To Err Is Human: Building a Safer Health System." It posited up to 98,000 preventable deaths per year in hospitals. The report created a few press ripples and then faded away. The breakthrough into mainstream medical reporting has come through the impassioned efforts of Dr. Martin Makary of Johns Hopkins University School of Medicine. His study was published in one of the "big five" medical journals, the *British Medical Journal*, in May of 2016.⁶ It estimated that annually more than 250,000 hospital deaths in the US alone are caused by medical errors, far ahead of car crashes and every other cause of death except heart disease and cancer. It wasn't easy for Dr. Makary to assemble statistics for this landmark conclusion when the previous information had been mostly anecdotal. And here's why.

The Johns Hopkins team explains that the Centers for Disease Control and Prevention's (CDC) way of collecting national health statistics fails to classify medical errors separately on death certificates. The researchers at Johns Hopkins are advocating for updated criteria in true cause of death on death certificates. "Incidence rates for deaths directly attributable to medical care gone awry haven't been recognized in any standardized method for collecting national statistics," writes Makary. He goes on to explain that the international classifications adopted in 1949 did not include any recognition for iatrogenic (physician-caused) disease because it was not recognized as a problem at the time. According to the CDC in 2013, more than 611,000 people died of heart disease, 584,000 died of cancer, and 149,000 died of chronic respiratory disease—the top three causes of death.

But this newly calculated figure for medical errors in hospitals alone would move this cause of death to number three according to Makary—behind heart disease and cancer, but ahead of respiratory disease. The rank of a cause of death as reported by the CDC is the basis for funding priorities. Since medical mistakes don't appear on the list, it is understandable that very few resources have been allocated to solving them.

After Makary's work brought medical errors into the mainstream, CNBC reporter Ray Sipherd did a commendable follow-up in February of 2018 pointing out that appeals to the CDC to change the way it collects data from death certificates have not been answered.⁷ To the date of this writing, no changes have been made.

The CNBC report also points out that the 250,000 deaths include only hospital-related deaths, so it substantially underestimated the issue by any measure, perhaps by an order of magnitude. This had already been recognized by the *Journal of Patient Safety*.⁸ In 2013, the *Journal* put the inpatient and outpatient total of preventable deaths in the US at more than 400,000 per year.

And then medical columnist Dr. Gary Kohls points out that even these numbers do not take into account the 50,000 opioid overdose deaths annually, many of which were prescribed by health care providers.

Nor do the numbers account for the thousands of suicides associated with psychiatric drugs, the thousands of heart attacks from NSAIDs, or the thousands of premature deaths from chemotherapy, which are currently included in the cancer death category. Says Dr. Kohls, “One also wonders that if accurate figures were available, combining inpatient and outpatient iatrogenic deaths together (a rational approach) it would cause heart and cancer deaths to drop to number 2 and number 3.”⁹

Joe and Teresa Graedon, bestselling authors of *The People’s Pharmacy*, came up with the highest annual iatrogenic death total of all, an astounding 788,558—all footnoted with full citations in their newest book.¹⁰ That number, if believable, would catapult medical mistakes and unnecessary deaths to first place, ahead of heart disease in the US. That number would not make the medical establishment happy, but it would indicate the profession’s need to get a handle on this problem.

Not only do many of us die early, but many of us “die badly.” Dr. Ira Byock, director of a Robert Wood Johnson program on end-of-life care, also leads a team that treats and counsels patients with advanced illnesses.¹¹ He says modern medicine has become so good at keeping the terminally ill alive at tremendous expense by treating the complications of underlying disease that the inevitable process of dying has become much harder and is often prolonged unnecessarily.

An overwhelming number of people—93% in one study—say they want to die at home surrounded by people they love.¹² Only 25% get to do that. Seventy-five percent of Americans die in a hospital. An astounding 18 to 20% die in an ICU, isolated from everyone they know.¹³ And this was before the coronavirus pandemic and the national rush to create thousands of ICU beds and manufacture hundreds of thousands of excess ventilators.

“Families cannot imagine there could be anything worse than their loved one dying. But in fact, there are things much worse. Most generally, it’s having someone you love, die badly,” Byock says.

A NATION GOING BACKWARDS

All of this has taken a toll on the position of the US in terms of world health indicators, based on longevity. Of course, America is a much larger and more diverse society than some countries it is compared to. But of thirteen countries in a recent comparison, the US ranks twelfth for sixteen available health indicators, including longevity.¹⁴ In another study, the US ranks fifteenth amongst twenty-five industrialized countries on some of the same health indicators.¹⁵

This is often explained away by saying that the American public engages in bad behaviors: smoking, drinking, drug use, poor eating habits, and perpetrating violence. That's clearly always been a factor in America. But those issues turn out to be a stable factor, not an increasing one. Another factor often cited in American health concerns is income inequality and limited access to health care. That is an alarming social injustice that must be corrected on a high-priority basis. But access to health care among the poor has actually improved marginally over recent years, studies say. For instance, in 2010, 37 million people were uninsured in America; by 2018 that number had shrunk to 23 million.¹⁶ Increasingly, it is recognized that neither of these causes is the driver in declining longevity. David Goldhill states, "Increasingly, researchers are being driven to the recognition of the harmful effects of health care interventions and the likely possibility that they account for a substantial proportion of the excess deaths in the US compared with other comparably industrialized nations."¹⁷

All these excess and premature deaths show up in individual disease categories because they don't have their own category, making data collection on this topic difficult but not impossible. The data is hiding in plain sight. But you have to know where to look.

For most leading causes of death, mortality rates are higher in the US than in comparable countries. That includes infant mortality and maternal mortality. And then, to add insult to injury, other wealthy countries spend about half as much per person on health care as the US spends.

In the next chapter, we will lay out the principles that enable us to confront proposed treatments with wisdom and discernment. And the following chapters will explore the epidemic of unnecessary diagnostics, drugs, treatments, and devices that most often lead to cascades of adverse events. The purpose of this guide is to prevent heartache and regret and to allow wise and discerning people to live lives uninterrupted by the third leading cause of death in the US, iatrogenic disease. We leave the reformation of the runaway American medical system to others. Our goal is simpler: to protect the lives of those who want to pursue medical wisdom.

— FURTHER READING —

Robert Pearl, MD, *Why We Think We're Getting Good Healthcare and Why We're Usually Wrong* (Philadelphia: Perseus Books, 2017).

Dr. Pearl's book is the most recent of the potential blockbusters that have somehow failed to start a reformation movement even though they have the potential to do so. Dr. Pearl is a caring reconstructive surgeon who was CEO of Kaiser Permanente Medical Group, one of the nation's largest health care providers. He is on the faculty at both Stanford Medical School and Stanford Business School. He went through the untimely death of his father, which occasioned the book. Dr. Pearl's book has been endorsed by bestselling physician-author Atul Gawande. The facts in the book and the credentials of the author have all the makings of a reformation movement. The lack of popular press attention and the peer silence demonstrate just how entrenched this problem is.