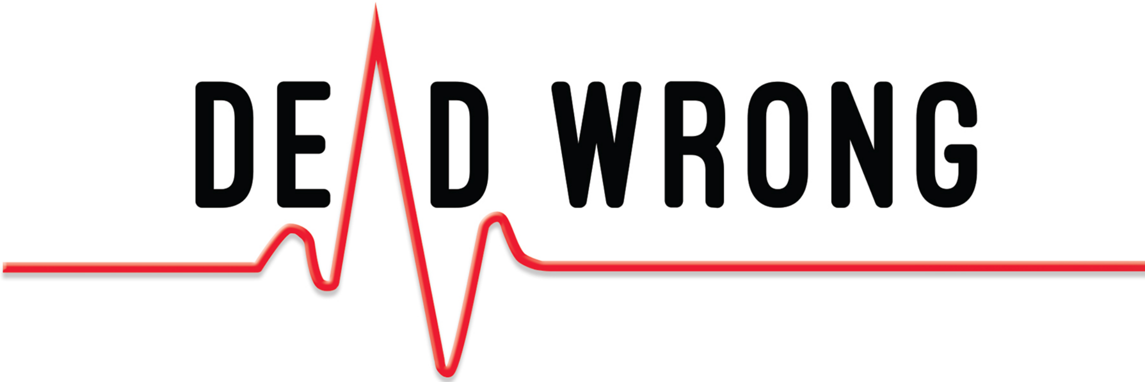
GEETA 'DR.G' NAYYAR, MD

WITH TOM CASTLES AND JACK MURTHA

DEAD WRONG



Diagnosing and Treating Healthcare's Misinformation Illness

WILEY

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For my mom and dad,

For teaching me that the truth always matters

For inspiring me to pursue a career in medicine

For showing me that you can have grit and grace at the same time

For giving me your strength at my weakest moments

For giving me my name

For making the American Dream my reality and now my daughter's reality

For believing in me and supporting ALL my dreams

For being a modern progressive woman long before your generation and country

For inventing Shake and Bake tandoori chicken

For loving my mom

For loving my dad

For convincing me I'm worth 1,000 sons

This book is dedicated to the healthy and the sick. The knowledgeable and the ignorant. The rich and the poor. The old and the young. To those who believe in God and those who do not. To every patient I had the privilege to care for or will care for in the future. To every person and family who lost a life during the Covid-19 pandemic. To anyone who has been vaccinated. To anyone who has not been vaccinated. To anyone who has ever been curious about their health. To anyone who ever used Google to answer a question about the human body. This book is for you.

CONTENTS

Foreword by Dr. Joseph Kvedar *vii*

Preface *ix*

Chapter 1 A Fatal Misconception 1
Chapter 2 Pandemic of Lies 19
Chapter 3 Our Tainted History 35
Chapter 4 New Traumas, Old Wounds 53
Chapter 5 A Shock to the Healthcare System 69
Chapter 6 Trust and Empathy 87
Chapter 7 Reverse-Engineering Dark Magic 107
Chapter 8 Healthcare's Human Stories 125
Chapter 9 The Pursuit of Change 143
Chapter 10 Doing No Harm 165

Notes *177*

Acknowledgments *199*

About the Authors *205*

Index *207*

FOREWORD

By Dr. Joseph Kvedar

I REMEMBER WHEN Dr. Geeta Nayyar told me she was writing *Dead Wrong* in early 2021. The Covid-19 pandemic was killing thousands of Americans each day. We all struggled to separate truth from fiction. Misinformation was everywhere.

Now, the pandemic is over (even though, at the time of writing, Covid kills one person every four minutes[1]). And yet misinformation remains.

Thus, the zeitgeist of our time is perfect for this book. The bedlam of the pandemic has hardly passed and already new vehicles for viral misinformation have emerged. Artificial intelligence, a tool that many predict will usher in the future of healthcare, promises to liberate the industry from rote work, identify lifesaving treatments, and deliver critical insights. But behind that promise lurks a more sinister possibility: that the agents of disinformation will co-opt this powerful tool to do harm, or that the tool itself will simply reinforce our biases.

The lesson, as Geeta and her coauthors aptly suggest throughout this book, is that misinformation is not the product of new tools or new times. Rather, it's timeless. Its latest forms feel novel, but they're merely mutations of a persistent phenomenon—a misinformation illness—that has always plagued healthcare. Diagnosing and treating that illness means acknowledging how it harms us, accepting our responsibility to address it, and intervening right now, including through innovative solutions such as artificial intelligence.

There's no better team to guide readers through that journey than Geeta Nayyar, a physician and healthcare-technology leader, and her coauthors, Jack Murtha and Tom Castles, two writers and former journalists. They anchor the chapters in this book on the best available scientific literature and interviews with luminaries, thought leaders, and frontline clinicians. Each interview shines on its own as an immersive story, radiant with lessons learned. When tied together, these interviews provide the context needed to understand and confront the problems misinformation poses.

This year marks my 40th in patient care. I'm a professor of dermatology at Harvard Medical School, past chair of the board at the American Telemedicine Association, and editor-in-chief of *npj Digital Medicine*. I've practiced medicine since graduating medical school in 1983. I cared for patients during the HIV/AIDS epidemic, prior to the advent of the highly active antiretroviral therapy that turned HIV into a chronic illness. I also cared for patients during the Covid pandemic.

I relate to Geeta's portrayals of the patients she cared for during these difficult times. Her words jump from the page when she, and many of the clinicians interviewed in this book, explain how complicated misinformation makes their jobs—and how it results in direct harm to our patients.

What can we do to prevent that harm? There's no panacea to misinformation. But the authors offer the next best thing: true stories that illuminate a promising path forward.

May this book represent the first step on your journey down that path.

PREFACE

We live in a scientific age, yet we assume that knowledge of science is the prerogative of only a small number of human beings, isolated and priest-like in their laboratories. This is not true. The materials of science are the materials of life itself. Science is part of the reality of living; it is the what, the how, and the why of everything in our experience. It is impossible to understand man without understanding his environment and the forces that have molded him physically and mentally. The aim of science is to discover and illuminate truth.

—Rachel Carson

All leaders in healthcare have a level of access, familiarity, and comfort with medical care that vastly exceeds that of the average patient. Consequently, as healthcare providers, we have to ask ourselves this question: What stories are we not hearing? If we don't keep ourselves honest and consider the voice of the patient not in the room, we overlook opportunities to improve care for a substantial number of people.

—Dr. Sachin Jain

As my mom has said, when one person is unhappy, it usually means two people are unhappy but that one has not come to terms with it yet.

—Mindy Kaling

THE TRUTH IS ON LIFE SUPPORT. It didn't start with cries of "fake news" and "alternative facts" or even the World Health Organization's decision to label Covid-19 an "infodemic."

Americans' fascination with conspiracy theory and conjecture runs deeper than that. It encompasses the moon landing, one of this nation's greatest achievements, and the president who inspired us to get there. Our obsession blanketed 19th-century politics with whispers of coups and patronage, at one point instigating a recession.[1] The trouble went all the way back to the country's infancy, when a minister appealed to fears about the moral compass of a young nation, claiming that a dark and secret society was coming for god and government.[2] Much has changed since then. Centuries of scientific research and innovation matured our understanding of the world and ourselves, and the internet placed that knowledge at our fingertips. And yet the aggressive reach and power of falsehoods persists.

Misinformation today doesn't just continue an unfortunate tradition. It tears at the fabric of society. Social media platforms, people's dwindling trust in institutions, neighbors with different political beliefs, and regimented groups that produce highly effective disinformation feed the evolution of falsehoods. They have become endemic, and most of us can *feel* them doing damage. In 2019, 85 percent of Americans told the Pew Research Center that widespread disagreement over core facts about current events was either a "moderately big" or "very big" problem.[3] When Covid-19 arrived, the disconnect between perception and reality only grew wider. Consequences became painfully obvious, manifesting as stubborn and reemerging virus hotspots, hospitals pushed to capacity and forced to ration care, and pandemic deniers' attacks against doctors and nurses. Although we may never learn its precise effect, misinformation appears to have raised the death toll.[4]

The phenomenon may spike and subside during crises, but it will never fade away on its own. Still, the US healthcare system has refused to reckon with the implications of pervasive misinformation for its business: the business of getting and keeping people healthy. Many industry leaders think their roles are about damage control. Politics, media, technology, and the rest of society cause the problem, while medicine keeps its head down and shoulders the effects, like a martyr. That view has to change. Healthcare leaders have a responsibility—to their patients, clinicians, shareholders, and themselves—to understand how misinformation hurts their mission and to stop the sickness. That's essential to any effort to protect and nurture good health.

I decided to write this book because I wanted to help healthcare leaders see misinformation's real-world repercussions for the nation and the industry. I also hoped to serve up promising solutions. I set out to help people *see* what was happening because I need readers to hear *and* feel the call to action. That led me to dozens of conversations—with experts, fellow doctors, patients, and many more—and hundreds of journal articles and news reports. I did it all to make it easy for executives, physicians, and patients to acknowledge the challenge and come together to take corrective action at scale. A few good doctors isn't enough. Healthcare must make sweeping, systemic moves to diagnose and treat our systemic illness.

The first five chapters of *Dead Wrong* uncover rich human stories highlighting that problem. In Chapter 1, I share my personal connection to misinformation in the clinic before setting off on our journey. Chapter 2 reveals physician hardships surfaced during the Covid-19 pandemic, while Chapter 3 traces healthcare's relationship with falsehoods to the distant past. Patients and the unconscionable burden they face define Chapter 4. Chapter 5 shows what's at stake for clinicians, healthcare organizations, and the entire system.

The next four chapters target solutions, complete with steps leaders can take to make a difference today. In Chapter 6, we examine trust and how to scale the doctor-patient relationship. Chapter 7 takes us to digital transformation, showing how data, technology, and the right strategy can move us forward. Marketing and communications guide Chapter 8, which delivers insights into consumer intelligence and engagement that far surpass industry expectations. Chapter 9 takes a microscope to health policy's role in misinformation and hard-earned lessons from a recent shift that forever altered healthcare, for better or worse.

Finally, in Chapter 10, I place healthcare's future in your hands.

This book isn't only for the brave and committed or the well-resourced and innovative. It's also for the doubtful and the unconvinced, the cash-strapped and the hesitant. This book is for everyone who has a say in healthcare and patients' lives. It's for anyone who cares to pursue positive change today. It's for everyone who cares.

Chapter 1

A FATAL MISCONCEPTION

THE INTERNET CAN TAKE YOU to some strange places. Ever since a new strain of the coronavirus emerged in Wuhan, China, and spread through the world killing millions, we've seen just how weird—and how *real*—our online lives can get.

In early 2020, Covid-19 punctured the digital realm, already rife with "misinformation," a term for falsehoods spread in earnest, and disinformation, which describes lies maliciously designed to manipulate people. Covid-related misinformation and disinformation caused real-world ripple effects that formed a toxic tsunami rivaling the emerging pandemic in speed and scope. Donald Trump, then the president of the United States, dismissed scientists and spread social media hype around unproven "cures" such as hydroxychloroquine, over and over again. In the US and around the globe, some elected officials followed suit, feeding sickness and false narratives with each misguided post.

As we doomscrolled our way through extended lockdowns, unhealthy information spread across online communities like a noxious gas wafting over a battlefield. Left-leaning new-age influencers took militant stances against Covid-19 vaccines, while veteran right-wing conspiracy theorists injected new anti-mask sentiment into old tropes of sinister cabals that secretly run the world. Off-beat uncles became insufferable former Facebook friends. Anti-vax spouses threatened to leave their partners should they get the jab—because their "sources" on Instagram claimed the vaccines would poison children who had yet to be conceived.

Socially distanced and working from home, I gobbled up every rumor I found. Not because I believed them, but because I couldn't look away. The more I read, the more I became convinced that the internet can't only take you to strange places. It can take *your life*.

In the summer of 2020, the former Republican presidential primary candidate Herman Cain died after testing positive for Covid. His passing captured the public's attention because he had downplayed the pandemic's risks and attended a Trump rally unmasked in Tulsa, Oklahoma, shortly before being hospitalized. The apparent link between misinformation and Cain's death galvanized an online movement that set out to showcase similar stories of cause and effect, most notably in a Reddit community named /r/HermanCainAward, which chronicled people's descent into Covid denialism and their subsequent deaths. "I should have had my shots. My wife had hers. She kept telling me to get mine. I'm going to die, aren't I?" one man told a doctor, in a post published on the Reddit forum. The patient died alone in an intensive care unit three days later.

Americans had proven their susceptibility to misinformation and disinformation in profound and visible ways. Thanks to the internet, we could see their journey to sickness and preventable deaths. They weren't mere data points in a survey. Some people scoffed at those who believed misinformation, but I viewed them differently. They were victims. They had tried to make sense of a bewildering pandemic, and disinformation producers had led them astray. Maybe the dead even got their information from a close friend who considered sharing a conspiracy theory helpful. Misinformation's victims were trying to take control of their health. They did what they thought was right. If only a reliable source had won their trust.

Me as a doctor in training in the early 2000s at George Washington University.

Conspiracy theory and conjecture weren't new in medicine at all. Anyone who's ever worn scrubs could tell you that. By the time Covid came along, I had been a physician for nearly two decades. Although it had been years since I stopped practicing rheumatology full time in favor of corporate roles, I continued to teach medical school students at the University of Miami and treat patients at a clinic for people with low incomes, primarily Haitian immigrants, in Miami. After spending my pandemic year on the internet, I noticed misinformation creeping into my real-world patient encounters.

One young man, in particular, stood out. He looked healthy enough. He was smart and established in his career. But he said he felt awful all the time. When he proudly ran down the list of vitamins, herbal supplements, and energy drinks he consumed daily, I explained how that might have harmed his health. He was surprised, like he expected me to confirm that this twisted cocktail he built while cruising the internet would boost his immune system, as if he were taking a proactive step doctors only *wished* every patient would mimic.

Despite misinformation's destructive grip on patients and the clinicians who treat them, I hardly registered its stubborn presence in the clinic until it became impossible to ignore. Soon, I doubted whether I had spent a single day as a physician without bumping up against a falsehood that jeopardized patient health.

"You're in big pharma's pocket, so of course I'm not going to take my meds."

"I heard smoking weed cures cancer. Is that right, doc?"

"I've done my research, and it's pretty clear that vaccines cause autism. Polio and measles aren't really problems anymore, anyway."

Misinformation was more than a side effect of our new smartphone-obsessed, social media–saturated culture. The internet in the age of Covid only complicated a challenge no one seemed prepared or eager to solve. In healthcare, we didn't consider it systemic. It was an individual, patient-by-patient challenge. It was public health's problem, no matter how underfunded state and local agencies were. But all that changed when the pandemic struck and more people started paying for their ignorance and healthcare's inaction. Reflecting on my clinical career, I came to understand that misinformation had been with me—been with us all—from the start. Unless the healthcare system did something about it, the problem could be with us forever.

MY PATIENT WAS DEAD before we even met.

Not by clinical standards, of course, but by that gut feeling that comes with experience—one every physician comes to know after spending enough time at the threshold of life and death. The patient, Jerome, was still breathing when I entered his room. He struggled to move, enshrouded by the stark white hospital bed sheets, his clavicles jutting upward from his frail, wasting body. It was the early 2000s in Washington, DC. I was young, but I had seen enough to perform the rapid-fire calculations that led me to an inevitable conclusion: Jerome didn't have much time.

He had developed a severe case of coccidioidal meningitis, a fungal infection that preys on people with compromised immune systems. Fungus isn't supposed to grow on your brain like it does on bread, but brain cell by brain cell, Jerome's infection spread, debilitating him as it went. It might take days, weeks, or months, but meningitis would consume him.

I was an ambitious and dedicated intern working as many as 100 hours a week and regularly spending 24- to 48-hour shifts on call at George Washington University Hospital. I obsessed over doing whatever I could to help my patients walk out alive and well. So I held out hope I would find a lifesaving data point that everyone else had missed, something that could reverse Jerome's condition. I analyzed his CT scans and his chart and met with attending physicians. But my investigation only confirmed my suspicions: He was dying because he had AIDS. Patients with the virus often developed coccidioidal meningitis, in what's called an "opportunistic infection."

Jerome came to the ER in an ambulance after a public seizure, which prompted a stranger to call 911. His case was typical for DC during that era. Just a few years older than me, Jerome was a

Me and my dad, in front of the George Washington University Hospital, where I did my residency and fellowship.

20-something Black man from a rough neighborhood, where hard drugs, governmental neglect, and the HIV/AIDS crisis had ravaged the community for more than two decades. He was a frequent flier—one of many patients from the nearby low-income neighborhoods, where access to preventive care was scant, who ended up in our hospital *a lot*. I had seen tragic endings for too many patients like Jerome in my brief time as a medical resident. Still, I always found a way to press on, to preserve hope. Was it optimism or naiveté? All I knew was that the energy seemed to drain out of me as I stood near Jerome. Everything I learned during my training—my whole life—now seemed futile in this quiet, dimly lit room.

I understood Jerome's condition, but I had to dig deeper before I could treat him. I pepped myself up to fire off a long list of questions to a man who could hardly think—a man whose brain was inflamed by fungus. As I approached, I avoided eye contact to manage my own emotional discomfort. He avoided eye contact because his coccidioidal meningitis caused photophobia, an intense sensitivity to any sort of light, including the faint fluorescent rays that sneaked their way from the hallway into the hospital room. Jerome couldn't have looked at me if he wanted to.

We were both upset. Who wouldn't be? Jerome was young, but instead of preparing for a future and a family, he lay decimated in a hospital bed. I was a young doctor who suddenly felt like some hardened veteran.

When I asked him about his life, Jerome found the strength to speak with his eyes firmly shut. He had grown up in a rough neighborhood, with a tight social circle, and he had just come off a scorched-earth adolescence. I asked him if he used drugs. Yes, he injected heroin, but he didn't do it every day, he told me. Then I dug into his sexual history. Not long ago, Jerome said, he was a charmer with plenty of girlfriends. Then I asked him whether he used condoms. "Sometimes," he responded, "sometimes not."

I realized Jerome collected risk factors like kids catch colds. Although he used clean needles, he never considered that condoms might defend his body against the virus that was killing him.

"Dr. G," he said, "no one told me I could get AIDS. I thought you had to be gay to get AIDS. I'm not gay. This can't happen to me."

The shriveling man before me looked much older than his age, but I pictured a fuller, vibrant version of Jerome laughing at a family barbecue or flirting his way across a dark, crowded bar as music blared. Before this, he was healthy. No medications or allergies. His family history of disease didn't raise any red flags. The more Jerome talked, the clearer it became that he shouldn't have developed a terminal disease before his 30th birthday. But he had—and it was all because of a wild misconception.

At the time, Jerome's confusion about how he got HIV didn't strike me. When you're in the trenches treating people who were raised with the world's ills bearing down on them, it's common to hear rumors passed off as fact and to see illusions turn deadly. I didn't know it then, but Jerome's insistence that he couldn't have been infected with HIV because he had never had sex with a man would echo through my mind for the next 20 years. It will probably stick with me for the rest of my life. It's impossible to forget a man on his deathbed pleading with his doctor to explain