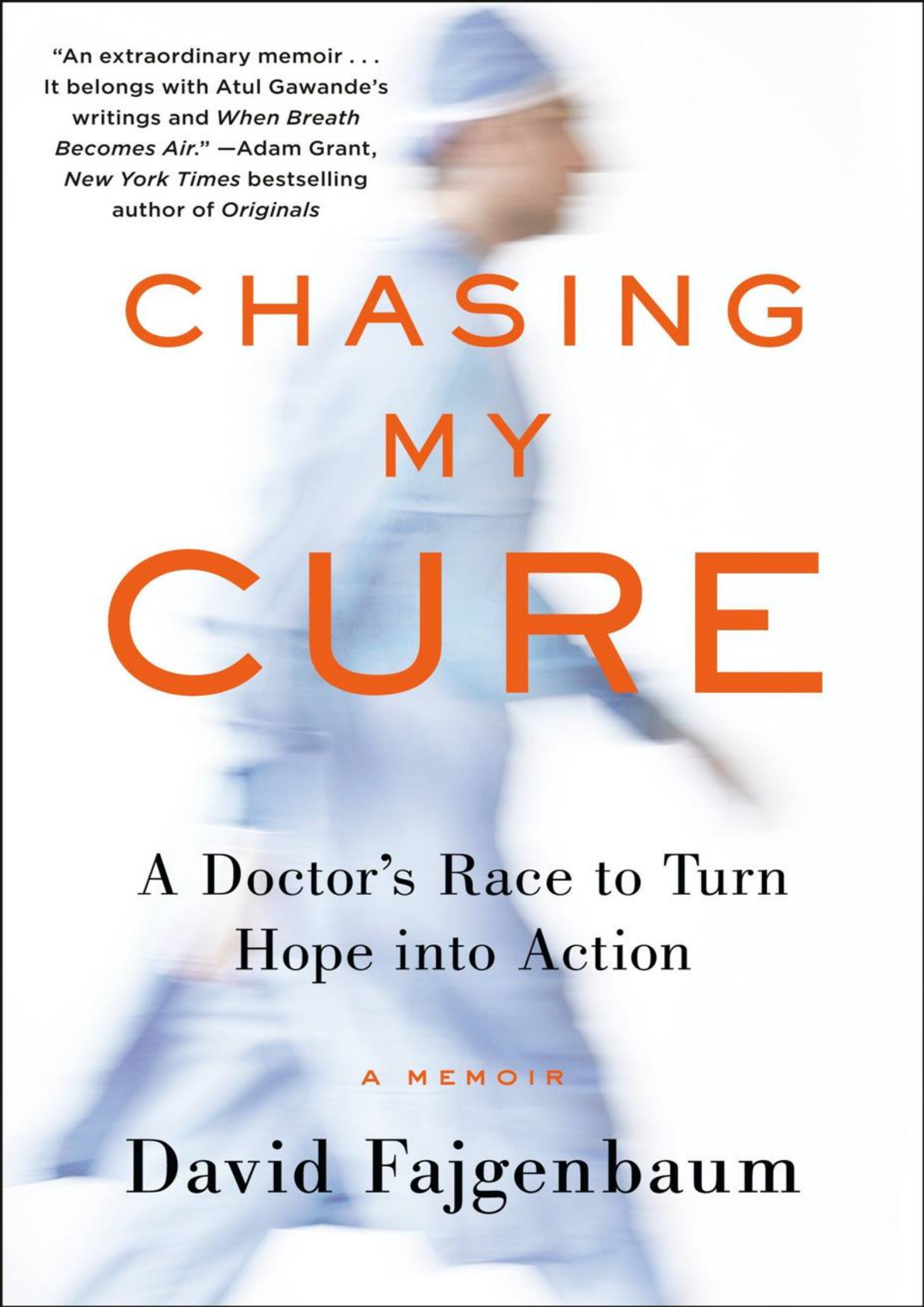

"An extraordinary memoir . . . It belongs with Atul Gawande's writings and *When Breath Becomes Air*." —Adam Grant, *New York Times* bestselling author of *Originals*

CHASING MY CURE

A Doctor's Race to Turn Hope into Action

A MEMOIR

David Fajgenbaum

ADVANCE PRAISE FOR *CHASING MY CURE*

"I could not put this book down. Dr. Fajgenbaum is an inspiration, and *Chasing My Cure* is a page-turning chronicle of living, nearly dying, and discovering what it really means to be invincible in hope."

—ANGELA DUCKWORTH, *New York Times* bestselling author of *Grit*

"This book is so gripping that I read it in one sitting—and so moving that I can't stop thinking about it months later. It's an extraordinary memoir, filled with wisdom, by a doctor who came face-to-face with his own mortality. It belongs in rare company with Atul Gawande's writings and *When Breath Becomes Air*."

—ADAM GRANT, *New York Times* bestselling author of *Give and Take* and *Originals* and co-author of *Option B*

"*Chasing My Cure* is a medical thriller that grapples with supreme stakes—real love, bedrock faith, and how we spend our time on earth. Fast-paced and achingly transparent, David Fajgenbaum's deeply thoughtful memoir will have you rethinking your life's priorities."

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"This is a riveting story of a remarkable journey of one persevering through illness to medical discoveries and recovery. It's a tribute to Dr. Fajgenbaum's rare qualities of spirit and intellect, the support of his family and friends, the power of modern science, and the role that patients can play to find new treatments.

Chasing My Cure is mesmerizing."

—J. LARRY JAMESON MD, PhD, dean of the Perelman School of Medicine, University of Pennsylvania

"This is a fascinating true-life story of a young doctor who, stricken with a rare, life-threatening disease, takes matters into his own hands and, with total focus, finds a cure….An informative and inspiring read."

—ANDREW WEIL, MD

"I was riveted from the very first to the very last page of this extraordinary story of life, assumed death, resilience, and hope. I am convinced that through his incredible journey, David Fajgenbaum has acquired 'superpowers' that will no doubt shape the lives of others, now and well into the future."

—NICOLE BOICE, founder of Global Genes

"*Chasing My Cure* is an extremely powerful story about turning fear into faith and hope into action. David Fajgenbaum's ferocious will to survive and his leadership in the face of his rare disease provide a model pathway for others to follow when searching for cures of their own."

—STEPHEN GROFT, PharmD, former director of the Office of Rare Diseases Research, National Institutes of Health

"A remarkable and gripping story of how a potentially fatal and rare illness inspired the patient to commit himself as a physician/scientist to search for its cause and cure. Dr. Fajgenbaum's description of his journey is a tale of courage, dedication, and brilliance that will enthrall and fascinate its readers."

—ARTHUR H. RUBENSTEIN, professor of medicine, the Perelman School of Medicine, University of Pennsylvania

"Inquiring physicians have discovered much from studying patients with rare diseases, but rarely has the physician been the patient. Dr. Fajgenbaum tells the remarkable story of his own

mysterious, nearly fatal multisystem disease and his brilliant deduction that a long-known drug may be the cure. This book—part detective story, part love story, part scientific quest—shows how one indefatigable physician can bring hope to patients who suffer from a rare disease that is barely on the radar screen of medical science."

—MICHAEL S. BROWN, MD, recipient of the Nobel Prize in Medicine, 1985

"David Fajgenbaum, a self-proclaimed 'rare disease quarterback,' shares with us his extraordinary story of assembling a team and a framework to conduct unprecedented collaborative research. In his deeply personal memoir, he makes plain the urgency of hope, and explores how the human spirit might transcend suffering to inspire communities to take collective action against seemingly insurmountable odds."

—JOHN J. DEGIOIA, president, Georgetown University

"Dr. Fajgenbaum has taken a tragic personal situation and turned it into a story that provides a model for all those who want to improve treatment of rare disease. Indeed, the lessons are not only good for people concerned about rare disease, but also for anyone dealing with illness or considering doing something to change the biomedical science enterprise."

—ROBERT M. CALIFF, MD, former commissioner, U.S. Food and Drug Administration

CHASING MY CURE

A DOCTOR'S RACE TO TURN HOPE INTO ACTION

A MEMOIR

DAVID FAJGENBAUM

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Chasing My Cure is a work of nonfiction. Some names and identifying details have been changed.

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INTRODUCTION

AFTER YOU'VE MASTERED the basics of technique—hand placement, head tilt, and timing—and after you've accepted the inevitable feeling of shattering ribs beneath the heels of your hands, the hardest thing about performing CPR is knowing when to stop.

What if one more pump could do it?

Or one more after that?

When—no matter how hard you push, how hard you hope and pray—that pulse just will not return, then what comes next is entirely up to you. The life has already been lost. But hope hasn't been, not necessarily. You could keep *that* alive at least. You could keep doing compressions until your arms and shoulders are too worn out to continue, until you can't push hard enough to make a difference, much less break another rib.

So—how long do you try to bring someone back?

Eventually you will remove your hands from the body, eventually you'll have to—but *eventually* isn't a number. It isn't guidance. You won't see it in a CPR diagram. And it doesn't even really answer "when" so much as "why." When you *eventually* stop, you stop because there's no more hope.

That's what makes the decision so difficult. Your effort allows you to hope that life is possible, and your hope inspires you to push even harder. The three of those things—hope, life, and effort—chase one another, keep one another moving around a track.

I have performed CPR twice in my life. Both times, the patients were nearly dead when I began my relentless chest compressions and prayers. And both ended up dying. I didn't want to stop. I wish I was still going right now. And I continued to hope that I'd see a pulse appear on the heart monitor even after I had stopped my chest

compressions. But hoping and wishing are often not enough. Hope can be a force; but it isn't a superpower. Neither is any part of medicine, much as we'd like it to be.

It can feel like one, though.

When I set out to be a doctor, I had already borne witness to incurable disease and inconsolable sadness—my mother had died of brain cancer when I was in college—but I was still optimistic about the power of science and medicine to find answers and cures. Because to be honest, long after I could reasonably blame it on youth and naïveté, I basically believed in the Santa Claus theory of civilization: that for every problem in the world, there are surely people working diligently—in workshops near and far, with powers both practical and magical—to solve it. Or perhaps they've already solved it.

That faith has perverse effects, especially in medicine. Believing that nearly all medical questions are already answered means that all you need to do is find a doctor who knows the answers. And as long as Santa-doctors are working diligently on those diseases for which there are not yet answers, there is no incentive for us to try to push forward progress for these diseases when they affect us or our loved ones.

I know better now. I've had a lot of time over the past few years to think about doctors, and they've had a lot of time to think about me. One thing I've learned is that every one of us who puts on a white coat has a fraught relationship with the concept of *authority*. Of course, we all train and grind for years and years to *have* it. We all *want* it. And we all seek to be the trusted voice in the room when someone else is full of urgent questions. And the public expects near omniscience from physicians. But at the same time, all of that education, all those books, all those clinical rotations, all of it instills in us a kind of realism about what is and what is not ultimately possible. Not one of us knows all there is to know. Not even nearly. We may perform masterfully from time to time—and a select few may really *be* masterful at particular specialties—but by and large we accept our limits. It's not easy. Because beyond those limits are mirages of omnipotence that torture us: a life we could have saved, a cure we could have found. A drug. A diagnosis. A firm answer.

The truth is that no one knows everything, but that's not really the problem. The problem is that, for some things, no one knows *anything, nothing* is being done to change that, and sometimes medicine can be frankly wrong.

I still believe in the power of science and medicine. And I still believe in the importance of hard work and kindness. And I am still hopeful. And I still pray. But my adventures as both a doctor and a patient have taught me volumes about the often unfair disconnect between the best that science can offer and our fragile longevity, between thoughts and prayers and health and well-being.

This is a story about how I found out that Santa's proxies in medicine didn't exist, they weren't working on my gift, and they wouldn't be delivering me a cure. It's also a story about how I came to understand that hope cannot be a passive concept. It's a choice and a force; hoping for something takes more than casting out a wish to the universe and waiting for it to occur. Hope should inspire action. And when it does inspire action in medicine and science, that hope can become a reality, beyond your wildest dreams.

In essence, this is a story about dying, from which I hope you can learn about living.

CHAPTER ONE

IN MY SECOND year of medical school I was sent out to a hospital in Bethlehem, Pennsylvania, an old steel town that had bottomed out in the nineties but had since bounced back into a vibrant, small community. I could relate. I had also gone through my own dark valley—losing my mother to cancer six years prior—and now I felt like I had climbed up and out onto the other side. My mom's death had inspired me to go into medicine in the first place; I had dreamed of helping patients like her, and I yearned to take revenge on her disease.

Picture me as a warrior in the battle against cancer, training so I could lay waste to the so-called emperor of all maladies, the king of terror. Picture me sharpening my tools and arming for war, stoic and full of wrath.

But first picture me on my obstetrics rotation, and absolutely terrified. On this particular day, I felt less like a warrior than like an actor. I had to keep rehearsing over and over in my head what I needed to do. I reviewed my steps, practiced my lines, worked through my checklist, and tried to remember how to play doctor. It really did feel like I was about to go onstage. The hospital room curtains had been thrust open, and the sun was streaming in, throwing a heavenly kind of spotlight on the first-time parents and all over the blue covering the nurse had just put down. Though both prospective parents were beaming with excitement, the mother's forehead glistened with sweat; I'm sure mine did too.

This husband-and-wife team were in their late twenties, which made them older than I was. It crossed my mind that Caitlin, then my girlfriend of three years, and I could find ourselves in this very same position soon enough, and that was a happy, calming thought. But perhaps I looked even more nervous than I thought I did,

because the father asked, “This isn’t your first time, is it?”

A scary thing about medicine is that everything in it has a first—every drug has a first patient, every surgeon has a first surgery, every method has a first try—and my life at the time was dominated, daily, by first times and new challenges.

But no, I assured this father-to-be I’d done this before. What I didn’t say was: *once* before.

Then I was in position. My second Red Bull of the morning had kicked in, and I was ready.

As I cycled through the stages of labor in my mind, I was interrupted by the first sign of the baby—his head.

Don’t drop it, Dave. Don’t drop it, Dave. Don’t drop it, Dave.

And that was that. I guided the baby safely into the world (it’s actually easier than you might think), and I watched him take his first full breath of life. A profound sense of purpose spread through my body, into my limbs, and overwhelmed my senses so that I couldn’t even notice the smell of feces and blood that attends every delivery. It didn’t look like it did in movies. There was a lot more winging it, a lot more fear, a lot more relief.

There would be many times, later on, when I would remember that baby I delivered. What I did wasn’t heroic or complicated or extraordinary by any measure. It was routine. But I had helped new life take flight and that was extraordinary. Too often hospital medicine isn’t about new life—when doctors, nurses, and patients are assembled in a room, the reason is usually dire.

My first rotation working in a hospital where I could see this firsthand had been in January 2010, only a few months before my Bethlehem (Pennsylvania) baby. After four years of pre-med, a master’s degree, and a year and a half of medical school coursework, it was finally time to apply my medical knowledge in situ. No more shadowing, no more observing. I might actually help save lives. I got about three hours of sleep the night before my first day—I couldn’t remember being that amped up since my days of playing football. It was below freezing and before dawn when I got up to go to the hospital, but my adrenaline practically carried me there. I’d walked through the same entrance and atrium of the Hospital of the University of Pennsylvania many times before, but today it was

totally different. The floors shone brighter. It was larger—or I was smaller. I smiled and waved at the security guards, who met my glee with dutiful reciprocity. They had likely seen dozens of glowing medical students that morning. Each of us, of course, dreaming that we'd be cracking cases and helping patients today like in an episode of *House*.

My first stop was the psychiatry resident call room, where I was supposed to meet up with what's called the psychiatry consult service. Basically our job would be to visit patients throughout the hospital whose treating physicians had decided they could benefit from additional psychiatric assistance. Some patients were simply delirious after surgery, but others had said they wanted to hurt themselves, or other people.

Psychiatry wasn't what I really wanted to be ultimately doing—all I could think about doing was fighting cancer—but I was eager to begin my clinical career on a good note. So I attacked the day with egregious enthusiasm. I greeted a woman a few years older than I—one of the residents—who was already engaged deeply in something on her computer screen. I extended my hand, introduced myself, and announced—unnecessarily—that this was my first rotation.

Then, as now, I was terrible at masking my mood. It has always been so achingly obvious. The resident could probably *smell* the nervousness on me.

Another medical student came in after me. Well, as I soon learned, he wasn't exactly a medical student, even though our role there in the consult service would be the same. He was already an oral surgeon; he'd already completed dental school *and* dental residency. He was now coming back to undertake a few medical school rotations that are mandatory to practice as an oral surgeon. I was competing against someone in his eighth year of medical training.

And—yes—it was a competition. We were both dressed like the plebs we were: in the same short white coats, just barely reaching our waists. This set us apart (as it was intended to do). The attending physician and other resident both arrived resplendent in coats that nearly reached the floor. My legs never felt so naked. Especially because Oral Surgeon over there actually could have

worn the longer coat if he'd really wanted to. He'd already earned it. He'd already made his way through the gauntlet. Becoming a physician requires first acing premed courses in undergraduate, and then grinding through four years of medical school. That's step one. After that, you *technically* get your long coat, but you still need to complete residency and possibly fellowship training, which can last from three to more than twelve years—depending on specialty—before you can finally practice on your own as an attending. I still had a long way to go. But a first day was a first step.

Our morning greetings and introductions (and my private ruminations) were interrupted by the beeps of a pager. Our first mission of the day. We rushed down the hall in order of rank—Oral Surgeon and I took up the rear.

When we got to the patient's room, a lump immediately rose in my throat. The room was dark. The patient was very sick. His cheeks were swollen from the corticosteroid treatments he'd been on, which reminded me of the way my mom had looked when being treated (also with corticosteroids) for her cancer. Her swollen cheeks had exaggerated her smile. The memory was bittersweet. I knew that I was going to struggle if I constantly thought of my mother. But I couldn't shut those memories out. I didn't want to—remembering her smile with those big cheeks made me smile.

This patient wasn't just sick; he was critically ill, and our goal was to evaluate whether or not he had the capacity to make medical decisions for himself. A woman sat beside the bed, holding the patient's hand. His wife, we soon learned. Tears dripped down her face, untouched, and eventually made their way down between her hands, where she'd gathered some blanket. A small piece of comfort, now also damp with her sadness. The patient was confused, and he struggled to answer our questions on the mental status exam.

"Where are we?"

"I'm in New…"

We were in Philadelphia.

"What year is it?"

"Nineteen seventy-seven."

It was 2010.

We huddled outside the room, but the decision wasn't difficult and the discussion was brief. The patient didn't have capacity to make his own medical decisions; his wife should make them for him.

Of course, medicine isn't always so binary. It's not just life or death, joy or despair. A middle ground exists where joy is possible in the face of death.

My time as a member of the psychiatry consult service would be distinguished neither by duration nor by any particular talent. That is to say: When my two weeks on psychiatry consult were up, I happily transferred to working on the inpatient psychiatric ward, a locked unit in Pennsylvania Hospital. It was an intimidating place for a young doctor in training, a place for patients on the edge: struggling with depression, bipolar disorder, schizophrenia, and suicidality. Though this rotation was a necessary step toward becoming a doctor, I didn't expect it to actually hone any future cancer-fighting skills.

My first patient there was George. Aged fifty-two, divorced, tall with broad shoulders, George had been diagnosed with glioblastoma, an aggressive brain cancer—the worst kind, and the kind my mom had had. One side of his face drooped, and he walked with a limp. But that's not why he was in the hospital. He was in the psychiatric ward for depression and his stated wish to commit suicide. Just that week he'd been told he had two months to live.

My resident told me that George had not wanted to talk to anyone since he arrived and that he had stayed in his room almost all day, every day. She asked me to perform a mental status exam on him to round out his admission paperwork. Despite having a rapidly growing brain tumor, he scored a perfect 30 out of 30. Most of the patients that I evaluated who didn't have tumors growing in their brains scored around 25.

He was anything but dour when I showed him the results.

"I aced it, Doc! Do I get anything special for it?"

"I know. Way to go. Let me get back to you on your prize." I grinned.

He walked away with more confidence than when he'd come in. It was visible even in his stride, in his carriage. His limp looked

more like a strut.

But later that day, I saw him lying in his bed without the TV on. He was just staring at the wall. It seemed that the high I'd helped him get to with the test score was only temporary. *Okay, even if it was only temporary, it could be repeated.* There wasn't any reason I couldn't help him strut again. If that was the best we could hope for, it seemed eminently worth trying.

I searched the Internet to find a new mental status exam that I could administer. This time he scored 28 out of 30, nearly as good as before, and well above the normal threshold of 25. Again, George smiled from ear to ear. The next morning, I didn't see him lying in bed—I found him at the nurses' station, bragging to all who would listen about how well he'd done on the two previous tests.

I ended up giving George a mental status exam each afternoon he was in the hospital. They weren't necessary for his care and none of them ever went in his chart, but that was hardly the point. George's transformation from suicidal to upbeat had turned a routine piece of hospital paperwork into a joyful routine for both of us. In time, it led to something more.

One part of the mental status exam instructs the patient to write any sentence he wants to on a piece of paper. Each time, George would write something about his daughter, Ashley. On Monday he wrote "I love Ashley." On Tuesday: "It was Ashley's birthday Saturday." On Wednesday he wrote "I miss Ashley." On Thursday: "I love Ashley!" The pattern was clear: Ashley was important to him. So I asked him about her. I learned that he hadn't talked with her in a while but that he left voicemails with her every day. I am not naïve: I knew the situation was much more complicated than I could appreciate. I knew that estrangement has many causes, and many contributors. But at the same time, sitting in the psychiatric ward, watching a man spend his last days writing simple notes to his daughter that she would never see and leaving voicemails that she would not return—it wasn't too complicated to untangle. I asked George if I could call Ashley simply to tell her how well he was doing, about his great tests and the notes, and about what it was like for me when my mom had brain cancer. He agreed. So I called and left her my own voicemail.

The next day I saw George and asked him how he was doing.

“I’m doing great! Ashley called last night!”

When I rounded the corner, out of his sight, I gave a fist pump. This was the first time that I may have really helped one of my patients. And it wasn’t even some complicated procedure or coup of surgical dexterity. I hadn’t uncovered a medical mystery. I simply let my hope and desire for George to be happy during his final days direct my actions. George and I had gotten to a breakthrough by doing some paperwork. That’s all it was. The things that sustain us need not be anything more.

While I had witnessed pure joy for the new parents and devastating despair for the incapacitated patient and his wife, I actually helped to bring about joy in the face of sadness for George.

And it felt so good. I wanted more.

Luckily for me, this phase of medical training is pretty much set up to give you more, and more, and more, and more. More than you can ever really handle.

CHAPTER TWO

I SHOULD HAVE been too tired to do much of anything outside the hospital, but the endless hours and high pressure were actually energizing for me and pumped me up to take on more. In between grueling rotations and long hours on the wards, my best friends from medical school and I would steal time to hit the gym. Between exercises, we practiced what we called dynamic rest—we grumbled about rotations, hospital staff, and, for me in the first weeks, Oral Surgeon.

Since I'm a shell of my former self today, I don't feel like it's bragging for me to share that I could bench-press 375 pounds back then. My friends started calling me the Beast. Even as a Division I college football player, I had never been more Beastly.

One night, a group of my friends were watching a Phillies game in my apartment while I studied in my room. I came out for a study break just as Ryan Howard was up to bat. At the time, he was one of the top power hitters in Major League Baseball. The commentator said that Howard could bench-press 350 pounds. My friend Aaron looked at me and said, "Howard's using his three-hundred-fifty-pound bench press to hit homers. What are you using your bench press for? Holding back the skin during surgery?" Everyone laughed. Perhaps sensing that my laughter was a little forced, Aaron emailed me the next day with a link to a bench-pressing contest in Stanardsville, Virginia, with the words "Put that bench press to use." I'm still not sure if he was entirely serious, but I took him up on the challenge: A few weeks later, nine of us packed into two cars to drive five hours from Philadelphia to Stanardsville, a town of about five hundred residents. I would be the only one competing, but my friends were willing to squander their precious downtime to show their support. Luckily for me, this particular league required

participants to give a same-day urine sample, so I wouldn't be competing against anyone using illegal performance enhancers. All I took were my requisite three Red Bulls—totally legal.

I wasn't hitting home runs for the Phillies, but I did win the bench-pressing contest that year for my weight class in Stanardsville. I missed the state record by five pounds. My friends cheered "Beast! Beast!" We celebrated hard that night.

Maybe my bench-press adventures prove what some who know me would tell you: I'm a bit of a glutton for punishment. Which may be one reason that the constant demands of being a young doctor in training suited me perfectly. It felt like the more that was asked from me, the more I was able to put into everything I did, both in work and in play. Seeing what I could do to help people like George pushed me to focus on everything else I could do. It felt like I was finally discovering potential I had buried or put into cold storage during my first couple years of medical school.

It was an old, good feeling. What had always truly helped me the most, back in school, back on the field, was that I could *focus* better and work harder than anyone. It's the only way I ever got to excel in football; I played quarterback at Georgetown very much despite my God-given lack of foot speed.

After struggling following my mom's death, I was back up. I had the bull by the horns. I was healthy, I was thriving. I was the Virginia bench-pressing champion in my weight class, and I had a wonderful girlfriend, Caitlin, who had been a pillar of strength and support for me while I coped with my mother's death and was now —even at a distance (she was living in Raleigh, North Carolina, finishing up her final year of college)—every bit as supportive of my drive to become a doctor. And here I was making strides toward one day defeating the disease that had killed my mother. I felt like I was conquering the world.

But I was leaving worlds behind.

One night, just a couple weeks after Stanardsville, I was studying for my neurology rotation—flash card after flash card after flash card—when my phone rang. It was Caitlin. We traveled between Philadelphia and Raleigh nearly every other weekend to see each other and had just spent a long holiday weekend together. It

occurred to me that maybe she'd just come from a Fajgenbaum family dinner—she went to these even when I wasn't in Raleigh to join them—and was calling to fill me in on family happenings. Or maybe she'd just come home from work and had something funny to share—when she wasn't in class, she worked at my sister's clothing store or babysat my three-year-old niece, Anne Marie. No matter the topic, these calls always seemed to help me feel good.

Immediately, this one felt different.

"Hey," she said, "we need to talk." Even though she'd said only five words, she sounded uncharacteristically sad and anxious. Now I wondered if she'd gotten bad news at work, had something go wrong in class, or if something had happened to her parents or brother, all of whom I cared deeply for. Then eight more words that felled me: "I think we need to take a break."

It was a stunning blow. In no iteration of my life plan was Caitlin not there. Didn't she know that? Had I neglected to tell her? I needed her by my side. I thought, I assumed, she knew that and wanted me by her side too. I was at a loss for words.

So, eventually and lamely, I just said, "Okay." Then there was a long pause.

It strikes me now that my reluctance to probe further and ask *why* was because I already knew but didn't want to hear it. My torpedo-like focus, that thing that had helped me in so many ways and would help me so much in the future, was rarely directed at Caitlin.

So, she filled the strange silence herself. "I think we need a break because you're just not making me a priority."

I knew what she was saying, but I couldn't help thinking: *You knew all of this. You knew what I had to do, and what we were getting into. We have made it work for three years. We managed to keep this relationship alive—and have some of the happiest times of our lives together—despite time and geographic constraints: while I was at Georgetown and you were four hours away in Raleigh. I went away for a whole year to get a master's in England and I worked my tail off to complete it in less than one year so I could return to the States to be closer to you. I've been seven hours away at medical school for two years already. I've had*