

# **Who Says I Can't**

**A two-time cancer-surviving amputee and entrepreneur who fought back, survived, and thrived**

*Chapter 1 for free preview*

**Jothy Rosenberg**

## Preface

*One of the most difficult things everyone has to learn is that for your entire life you must keep fighting and adjusting if you hope to survive. No matter who you are or what your position is, you must keep fighting for whatever it is you desire to achieve.*

—George Allen, football coach

“You have zero chance of survival.” That is what my nineteen-year-old brain heard as my doctor told me that the cancer that took my right leg three years previously had now spread to my lung, two-fifths of which had also just been removed. What he probably said was, “No one has ever survived once this type of cancer spreads through the bloodstream.” That was over thirty-five years ago. I survived. And then some.

This book is about what effect hearing those words has on someone’s personality and how one can not only survive, but also fight back, recover, and thrive. This is not a “cancer book.” Those are written when the survival is new and fresh and the experience is raw. Instead, this book, written with more than a thirty-five-year perspective, is about human perseverance, adaptability, and strength. People ask me all the time how my personality of today would be different had the cancer, amputation, loss of a lung, and death threat not

occurred. I try to answer that in this book, but I do not believe anyone can say for sure what their personality would be like at age fifty if something had not happened to them at age sixteen or nineteen.

I am not famous and have not changed the world. But I have a story to tell, one that might help others. I was as devastated as one can possibly be after losing a leg at age sixteen, losing a major portion of a lung at age nineteen, having a year of chemotherapy, and all the while thinking I would die any day. I used athletics to redevelop self-confidence and became a double black diamond skier. I have ridden a bicycle, one-legged and one-lunged, from Boston to New York City three times, as well as 192 miles across Massachusetts seven times over a ten-year period to raise more than \$100,000 for charity. I swim across San Francisco Bay every year in what is considered the most grand and intimidating competitive open water swims—also to raise money for charity. I have been married for more than twenty-eight years, adopted my wife’s son, and had two more kids after Carole and I married, as well as one grandchild, all before I turned fifty. I earned a PhD in computer science, have written two technical books, and have started six high-technology companies, where I have been Chief Executive Officer, Chief Operating Officer, Chief Technology Officer, or Vice President. In starting those six companies, I raised more than \$85 million in venture capital, with two of those companies providing a return of more than \$100 million each. I could not have done all these startup companies if I had not developed the will power, determination, and focus that came from what happened to me, and if people had not kept saying, “I bet you can’t,” every place I turned.

Cancer is a devastating disease for sure. However, there are many other conditions that threaten people’s lives and create some kind of disability: heart disease, diabetes, emphysema, cystic fibrosis, multiple sclerosis, and countless others. In the not-too-distant past, polio was the most dreaded disease; it disabled thousands. What polio survivors always seem to have in

common is a drive to excel in the face of physical disability. Studies have compared them to the hard-driving, over-achieving individuals associated with Type A personality. In the words of one survivor, as captured by David M. Oshinsky in *Polio: An American Story*: “We were [taught] to be tough and gritty. I did what was expected. . . . I needed to have a disciplined life with a no-quit attitude. That was what worked.” Lance Armstrong has said similar things about his cancer and how without his near-death experience and recovery he never would have gone on to win seven Tour de France races. I share these sentiments and feel that my experiences equipped me to tackle more and do better than I believe I would have otherwise.

There are 1.4 million new cases of cancer in the United States per year. There are 1.8 million Americans living with limb loss. There are 45 million disabled Americans. It is hard to imagine a single adult alive whose life has not been touched by cancer or disability. People who are knocked down by life need help and hope to fight back and win. Perhaps my story can provide a bit of that help and hope.

I cannot say that I have “cracked the code” on how to deal with adversity, the kind of adversity others have dealt with wonderfully well. However, many people over the years have told me that my story is inspirational to them. It took me a long time to look outside myself and my struggles and realize that I can motivate others around me. Maybe, with this book, I can shorten the recovery time for some people. I know I would have liked a book like this when I was a sixteen-year-old lying on my back in the hospital, wondering what—if anything—I would be able to do next and wondering how—if ever—I could be “normal.”

I took the strength and fortitude I gained in fighting back from two bouts with cancer and a permanent disability and turned it toward business. High-tech startups are one of the toughest and riskiest flavors of business, yet I was drawn to them. So many things can go wrong in an early-stage startup. No startup I have heard of has ever realized success precisely according to plan. Change is inevitable and constant from the moment of formation. Being the leader of such risky ventures is by far the scariest and most challenging thing I have done in

my professional life. I could not have kept going in the face of all the adversity I experienced starting six companies if not for the perspective I gained from surviving cancer and a permanent disability.

I have another message as well. I have endured a psychological adversity that has never gone away: the negative aspect of the word “considering.” No one wants to hear, “You are good *considering*” in any circumstances. Whether it is because of gender, race, age, or a disability, “considering” neutralizes what would otherwise be a strong comment, a confidence builder—a compliment. “Considering” is a take-the-wind-out-of-your-sails word. It puts you in a different group, a separate-but-not-equal group. People with any sort of disability or disadvantage do not want to be part of that group. They work hard to be “normal.” In fact, they have to work harder than the “normal” people whom they are trying to join. But the truth is, their disability actually gives them an edge. It makes them more focused, more disciplined, more determined. If their accomplishments are nullified with “considering,” they are shoved right back into the unwanted realm of pity and sympathy. It crushes the confidence built up through all their hard work. “Considering” is an insulting word. It demeans disabled people. It demeans minorities. It demeans children, women, ethnic groups, overweight people, the developmentally disabled, and on and on. I have heard the word all of my life. It has angered me and made me work harder. I have strived to ban it from any description of me, yet still I hear it.

Everyone falls into the trap and uses it, even friends. As in, “You ski pretty well . . . considering you have only one leg.” “You sure throw a ball well . . . considering you are a girl.” The examples are endless. “Great job you were offered . . . considering you are black.” “You ran that mile pretty fast . . . considering you are only twelve.” No one likes to deal with these put downs, but the disabled can never escape them. The existence of the word “considering” should motivate us all to shatter the boundaries the world places on us.

When someone tempers your accomplishments with the word “considering” or rejects your aspirations with the phrase, “I bet you can’t,” the best defense is to show them that you can and you will. This book is about how I did just that and the insights with which I subsequently emerged. If these stories help just one person, I will have achieved my goal.

Within the limitations and frailties of human memory, I have tried to be accurate and factual in all incidents. In general, I have used people’s actual names, but in some cases, names of people and companies have been changed to “protect the guilty.”

*Success is to be measured not so much by the position that one has reached in life as by the obstacles which one has overcome.*

— Booker T. Washington, political leader

Jothy Rosenberg

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# One

## A Maverick to Replace a Leg

*The whole world loves a maverick.*

— Kevin Patterson, author

*The only disability in life is a bad attitude.*

— Scott Hamilton, skater

*Being defeated is often a temporary condition. Giving up is what makes it permanent.*

— Marilyn vos Savant, journalist

It didn't seem like a life-changing event when it happened. It was October. I was sixteen, jumping rope in gym class at Wylie E. Groves High School in the Birmingham suburb of Detroit. While in midair, my right knee locked up, as a searing pain shot up my leg, and I fell writhing to the cushioned mat. The class froze, sensing this was no minor injury. The pain was like nothing I had ever felt. It was blazing, sharp, and intense, focused in my knee, but with electric shock waves radiating up and down my entire leg if I moved it even a hair. After a while, I was able to get up with help, and the school called my parents to take me home.

Like always when we had medical issues, my father, a surgeon, was our primary physician. He examined me in our family room and saw no cause for alarm. "This is what happens to big, fast-growing boys who are very athletic," he said. "Your knee hurts. You fall. You twist a joint. It needs to be wrapped for support, and then you take it easy until it heals."

That was the diagnosis. He expertly wrapped my knee in an ace bandage, and just as he had said, it improved a little each day.

Soon I was playing touch football, working in the yard, and running around our neighborhood. My strong, young body did a brilliant job of compensating for and adapting to what we did not know at the time: I had an extremely rare form of cancer that was destroying the healthy cells of the femur in my knee joint. The bone structure was disintegrating.

A few weeks later in November, at home in the yard, I was heading to the barn and needed to get over the paddock fence in a hurry. At the top of the fence, my knee locked up again. I fell, and it was even more painful this time than the incident in gym class. I landed in a lump on the other side. It took a while before I could get up and limp back to the house. Dad wrapped it again and said I really had to take it easy this time to give it a chance to get better. I promised I would, and I meant it because this was getting to be a drag.

We had an amazing Golden Retriever named Lobo. He was officially my brother Michael's dog, but since Mike was off at college, Lobo became my constant companion. He was smart and well trained. I became the one who took him to a field for a run after school every day. I loved those runs. I was so proud of him, and he was a great substitute for not having any close high school friends since I had recently moved to a new school. I talked to him constantly while we wandered together through our favorite hiking area. He was so smart that I could just gently speak simple directions and he knew what I meant.

Christmas vacation came. On a wet, icy day in early winter, Lobo and I drove over to Franklin Village Green—a field about a mile from our house—for an afternoon walk. Although my knee was still wrapped, I was walking well, if a bit stiffly.

It was raining, and water was standing on the icy patches all over the Village Green, making it as slippery as a Teflon frying pan. Lobo blasted out of the car like a golden rocket. He was obedient to my voice commands, so I never leashed him. A proud, aggressive dog, he

bounded through the field, sniffing and marking his territory. I opened my umbrella and followed him, gingerly traversing the slick ground.

Two hundred yards into the field, I hit an ice patch and my feet slipped out from under me. I must have looked like the cartoon character that slips and hangs suspended horizontally in midair before crashing to the ground. The pain from my previous falls didn't begin to compare to what I felt this time around. It was hard to breathe; I saw stars. It was raining and I had fallen into a puddle, which is probably all that kept me from going unconscious.

Lobo came right over and stayed by my side as I crawled and hopped back to the car. My right leg was useless, in excruciating pain. I struggled to lift it into the car and stay conscious. The car had a standard transmission, so I used the umbrella to press the accelerator and my left foot to work the clutch and brake. When I pulled into our driveway, I blasted the horn and kept blasting. The look on my father's face as he came running from the house took my breath away; it conveyed that he had—perhaps subconsciously—feared something like this might happen.

"Same knee," I managed to croak out when he asked me what had happened. "Hurts so bad. Can't walk."

No ace bandage this time. My parents mobilized into a flurry of activity to get me into the hospital for a biopsy that night. I suspect they (my mom especially, being a pathologist) had a feeling that it was bone cancer. But not wanting to worry me before they knew for sure, they didn't tell me anything. Being a sixteen-year-old, I assumed immortality. I did not think horrible things could possibly happen to me. Parents always worried too much, so I discounted their grim faces.

My father wrapped the knee tightly for the drive to the offices of Dr. Angelo Giambertoni, "Dr. G." I called him, in downtown Detroit.

Dr. G., Detroit's top orthopedist, quickly examined me. X-rays clearly showed the tumor and the irreparable damage the cancer had done to my knee. Still, my parents and Dr. G. needed to be certain.

On the short drive to Grace Hospital, my mother, a pathologist who specialized in tumors, explained that I needed a biopsy of the femur. "During the biopsy," she explained, "a long needle is inserted into the knee bone to take a very small sample of tissue for analysis so we will know for sure what's going on in there."

"You won't feel a thing," my father added. "You'll be under general anesthesia. It's quick, so you'll only be out for a short time."

The hospital quickly admitted me, and the nurses whisked me into surgery. I awoke to find my parents and Dr. G. hovering over me.

"I'm afraid we have some very bad news," said Dr. G. "The biopsy came back malignant, which means we have to amputate tomorrow at 7 a.m. Nurses will be here momentarily to begin prepping you for the surgery. Any questions?"

*Malignant. Cancer. Amputation. Any questions? Was he kidding?* I looked at my silent parents who couldn't make eye contact with me.

"It's just a sore knee from being a big active kid," I sputtered, throwing my dad's diagnosis back at them. "I promise to be more careful with it in the future."

I knew in my heart it was much more than that, but I wanted to buy time.

"The biopsy is definitive," Dr. G. continued. "It reveals the presence of a type of bone cancer called 'osteogenic sarcoma' in the femur side of your knee. We have to take your leg off above the knee to get the cancer out, and we have to move quickly so the cancer cells don't enter your blood stream and spread."

In my simplified view of the world, smoking caused cancer. It afflicted old people. How could it be inside me? And Dr. G. wanted to cut off my leg! I was beyond petrified. Dr. G. was waiting for my consent before he put the staff in motion to prep me for surgery.

“I’m not letting you take my leg unless my mom tells me there is no alternative,” I said.

My mother would realize my condition was not all that serious when she looked at the biopsy. I had total faith in her. Over the years, I had heard her colleagues gush about what a rock star doc she was.

It may seem cruel and self-centered to have involved my mother, but anyone going through the kind of ordeal I went through should be allowed to be selfish at times. The newly disabled, those diagnosed with life-threatening illnesses, and those who have suffered a tremendous loss, need time within themselves to recover psychologically. That kind of self-centeredness is crucial in order to reclaim your life. If you don’t focus on yourself, you may not find the inner strength you need to fight back.

In *Lucky Man: A Memoir*, Michael J. Fox writes about his reaction to his Parkinson’s diagnosis: “Nobody would ever choose to have this visited upon them. Still, this unexpected crisis forced a fundamental life decision: adopt a siege mentality—or embark upon a journey.”

A journey is a wonderful way to view life after a diagnosis like Fox’s or mine. At sixteen, however, there was no way I had that level of maturity. It was only years later, many years into adulthood, that I was able to see that my diagnosis was actually the beginning of a journey toward the meaning and purpose of my life. A journey we all have to take, disabled or not.

My mother obtained permission to look at my biopsy tissue, although I was not officially her case. I waited anxiously for her return, hoping she would spare me.

Mom had a commanding presence, thin and standing six feet tall. She was stoic—a reserved New Englander who rarely showed emotion. I had never so much as seen her shed a tear, but when she returned to my room, she was pale and trembling. She stood next to my hospital bed, and I will never forget her words. “Jothy,” she said, “there is no choice but to amputate your leg.”

My father, typically a pillar of strength, was also on the verge of tears. Seeing them struggle to keep their composure terrified me. I began to weep, and at that point, they couldn't hold back their tears any longer.

I eventually regained enough composure to give Dr. G. my formal consent to amputate my leg.

My mother reiterated that the cancer could get into the blood stream and latch on somewhere else, which is why the surgery had to happen immediately. I assumed the chance that the cancer had entered my bloodstream was remote and that they just liked covering their bases no matter how unlikely the scenario. Little did I know.

I would later learn that my type of bone cancer, osteogenic sarcoma, now more commonly known as "osteosarcoma," strikes only nine hundred people in the United States each year, almost all of them children. It is fifty percent more likely to occur in boys than girls, possibly because it may be related to rapid bone growth. It is deadly. If the cancer cells get into the blood stream, they like to metastasize to new sites. "Metastasize" means to spread from one part of the body to another. When cancer cells metastasize and form secondary tumors, the cells in the metastatic tumor (called "mets") are like those in the original (primary) tumor. With many types of cancers, the most common site for mets is the lungs, which are the first place cells land after venous blood returns to the heart.

In 1973, when this particular cancer metastasized to a lung, it was a death sentence. My physician parents both knew this. As they looked down at their weeping son, I now understand that they saw not just the loss of a leg, but also the potential loss of their child.

Early the next morning, a busy dance of nurses, orderlies, and doctors began. My parents, who exuded an overwhelming sense of sadness, had to stay out of the way. I was on strong pain meds, sedated to blunt the inevitable terror of what was coming. They put me on a gurney and wheeled me to the operating room. Someone placed a mask over my mouth and told me to count backwards from ten. I was out by the time I got to five.

As I began to regain consciousness from the deep fog of anesthesia, I found myself in a dark, quiet recovery room. All I saw were curtains near my bed and some nurses studying monitors and papers on their desks just across from where I was lying. All I could hear were machines making quiet, high-tech whirring and beeping noises. I knew what was supposed to have happened, so I looked down. It was gone. A large bandaged stump was all that was left of my right leg. The anesthesia numbed my shock and horror of that first sighting, but an overwhelming sense of loss and sadness settled over me. Although my brain was too foggy to crisply analyze the situation, the nurses focused me on practical matters right away. Unless I could pee on my own, they threatened, they would insert a catheter to drain my bladder. Two sets of strong arms stood me up on my one leg. I was weak and dizzy, but finally the urine came.

Peeing on my own was actually a critical first step. *At least, I thought, I have been able to accomplish that.* It was something on which to build a return to a normal life.

I desperately wanted to be normal. For a new amputee, normalcy is an elusive dream. It is like grabbing for the Crisco-covered watermelon in the pool games I played at summer camp. You can see the watermelon. You can almost touch it. But then, as soon as you grab hold of it, it squirts away and you have to chase after it all over again.

The feeling of being normal is especially important to the child or teenage amputee. Being part of the group and able to do what the rest of the kids are doing is vital. But sports, dancing, and dating seemed completely out of reach for someone looking down at a stump where his leg once was.

As I was grappling with my new body, trying to pee, and dealing with the horrible feeling in my gut that I would never again fit in, I also had to face the fact that the amputation had not gone well.

As it turned out, Dr. G. usually did amputations on elderly patients with poor circulation and weak muscles. He was unfamiliar with strong, young legs with normal blood flow, and, because of that, he had almost lost me on the operating table.

In elderly people with poor circulation, a tourniquet placed above the cut line for the amputation is sufficient to stop any bleeding. For a leg with healthy musculature and vasculature, however, the recommended technique is to cut toward the bone, tie off all the major blood vessels, and then cut a little deeper. This procedure is much more time consuming than using a tourniquet, which may have been one of the reasons Dr. G. elected not to use it.

As Dr. G. must have quickly discovered, however, it is difficult to secure the air-filled tourniquet around well-toned muscles. Worse, because one's thigh narrows as it gets closer to the knee, the tourniquet has a tendency to slip downward. When that happens, the tourniquet loosens, taking pressure off the deeper arteries in the lower leg. It is still tight enough, however, to occlude the venous return vessels that are closer to the surface. That, in turn, raises the pressure in the arteries, causing them to bleed even more profusely.

The old rule of thumb when doing an amputation for bone cancer was to make sure there was a joint between the amputation site and the cancerous bone. That would have meant cutting my leg off at the hip. Wearing a prosthesis with no stump at all is problematic, so Dr. G. elected to leave me with part of my thigh, but still cut high enough up the leg to put some distance between the cut point and the tumor. When the tourniquet slipped and the bleeding increased, I was continuously transfused as Dr. G. raced to finish the amputation. On the table, I bled out six of my sixteen units of blood and ended up with a five-inch stump, which is way too short to work well with a prosthesis.

To make matters worse, Dr. G. bent my leg at the hip so it would be easier to work on. Imagine lying flat on your back with your legs straight out. If Dr. G. had amputated in that position, my stump would have lined up with my upper body and left leg. But he bent my right leg, flexing the hip, and removed it midway between the hip and knee as he tied off all

the muscles. That bend in my hip became permanent, and it has been a nightmare for me ever since. In the language of amputees, this is called “flexion contracture.” The muscles in the front of my leg are tied off shorter than the muscles in back, and no amount of physical therapy or stretching can ever make my residual limb (or stump) stay straight, which makes fitting a prosthesis exceedingly difficult.

Giambertoni’s decision to cut so far up the leg was also a bad one. Every millimeter of residual limb becomes vitally important for leverage inside the socket of an artificial leg. The more leverage, the more control. The more control, the less limping. My short, flexed stump has given me a pronounced, unavoidable, and permanent limp.

I wish I could tell you this was the extent of my challenges, but the extreme blood loss and excessive tourniquet tightness, and a fight against time to finish the amputation, caused an unusually high degree of tissue trauma, massive swelling, and bleeding—all of which contributed, post surgery, to horrific phantom pain.

Calling pain “phantom” makes it sound unreal. Let me assure you, that is not at all the case. It is a cruel joke at the expense of the amputee. Fifty to eighty percent of the roughly two million amputees in the United States feel as though they have pain coming from a body part that no longer exists.

American military surgeon Silas Weir Mitchell first coined the term “phantom limb” in 1871. It was much earlier, in 1551, that the French military surgeon Ambroise Paré wrote, “For the patients, long after the amputation . . . say that they still feel pain in the amputated part.” Until recently, many believed this post-amputation phenomenon was a psychological problem. Amputees were told that if they felt pain in a missing limb, they had mental problems and should see a psychiatrist.

It was not until the early 1970s that researchers learned from brain mapping that the nerves firing in the residual limb after an amputation are transmitted to the somatosensory

cortex, the part of the brain responsible for the movement and exchange of sensory and motor information, including pain. The pain amputees feel from these traumatized nerves is just as real as the pain you feel when you cut your finger with a knife.

The part of the somatosensory cortex responsible for phantom sensation is similar to a hard-wired telephone switchboard, with a plug for every nerve coming from the body's surface. This area is not part of the conscious brain, and it does not know where its signals originate. A signal from a nerve on the stump that once extended all the way to the foot is routed through the somatosensory cortex, which tells the conscious brain there is a sensation in the foot. The conscious brain, which knows full well that the foot is gone, is powerless to override these signals.

Phantom pain can feel like burning, stinging, or worst of all, shooting electric shocks. It is worse in people who experience pain before or right after their amputation. It is now recognized that pain management in both cases is critical. Jonathan Cole at the The Wellcome Trust, who has studied phantom pain extensively, describes it as “often excruciating and almost impossible to treat,” adding that it can be “intractable and chronic.”<sup>†</sup>

In my case, the phantom phenomenon, pain included, has turned out to be permanent. Even thirty-six years after my amputation, I can still try to wiggle my non-existent toes. My stump aches and tingles, sometimes severely, almost every night, which makes me a poor sleeper. Sometimes waves of what feel like high-voltage electric shocks shoot through my body, reminding me (as if I needed reminding) of the trauma of my operation. Occasionally, these debilitating waves can last an entire day, completely taking me out of commission. There is no rhyme or reason to when a bad day is going to occur. Psychologically, phantom pain

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<sup>†</sup> Cole, Jonathan, *Phantom Limb Pain*,

<http://www.wellcome.ac.uk/en/pain/microsite/medicine2.html>

drains you; you feel like you already “paid the price,” and yet the pain never lets up. You keep paying and paying. Sometimes it makes you want to scream. Or cry.

Once I came out of anesthesia, I needed morphine, but I was given Demerol. In 1973, the medical community feared putting patients on narcotics would turn them into drug addicts. I was sure glad when my father changed the orders on my chart, even if it may have violated medical protocol. On Demerol, I had been sluggish, cloudy, dazed, and still in agonizing pain. On morphine, I was clear-headed, sharp-witted, and the pain was almost gone. It is now generally accepted in the medical community that narcotics administered for pain for a short time, especially when self-administered, do not cause addiction.

The hospital staff stood me on one leg so I could start relearning balance and be able to pee without support. But as hard as I tried, I could not remain upright without my crutches. My body and brain played tricks on each other. My brain remembered how balance felt before the amputation, when I had stood on one leg while I still had the other leg to move around as a counterbalance. It sent the same signals as it always had to the muscles in both my legs. The muscles on the left side did as told. On my right side, however, there were no muscles to receive my brain’s signals. As I lilted to one side, my inner ear became unbalanced and sent that signal to the brain, which would futilely try to get my missing right leg to do its part to regain my balance. Fortunately, the brain relearns quickly and within weeks I was balancing unconsciously again.

I had the weird idea when I began to think more clearly that they should weigh the amputated leg. I wanted to be able to quote an extrapolated weight. They reported my limb weighed twenty-five pounds. Today, when someone asks me how much I weigh, I have to figure from three different possible answers. My as-is, no-clothing, one-legged, six feet two inch weight is 185 pounds. My two-legged, *extrapolated* weight is 210 pounds, which more closely resembles what people think when they see me. My weight wearing my prosthesis is

197 pounds. The one I usually quote to avoid confusion is the extrapolated, guesstimate weight.

As I began to recover, I started asking questions. When would I get a prosthesis? How long would it take to relearn how to walk? Would I be able to ski? Ice skate? No one could give me answers.

When I told my first joke, which was silly and a little bit morbid, people acted as though it was a huge deal. “You finally found a cure for the athlete’s foot problem I had on my right foot,” I quipped. It was a sign that I was rediscovering my personality and doing what I always did: trying to make light of whatever it was that was stressing me. I was emerging from the fog of self-pity and beginning to deal with what had happened.

Stephen Hawking, the world famous physicist and bestselling author who, at age twenty, was diagnosed with Amyotrophic Lateral Sclerosis (also referred to as “Lou Gehrig’s Disease”), has spent almost fifty years in a wheelchair. He spoke frequently about the attitude that has sustained him. “It is a waste of time to be angry about my disability,” Hawking said in a 2005 interview with *The Guardian* newspaper. “One has to get on with life, and I haven't done badly. People won't have time for you if you are always angry or complaining.”

Hawking and everyone else who has faced a limiting physical condition knows how easy it is to slip into self-pity. We are all prone to it, disabled or not. We would all do well to listen to people like Hawking, for whom self-pity is anathema. The definition of self-pity in Merriam-Webster’s online dictionary is “a self-indulgent dwelling on one's own sorrows or misfortunes.”

Regaining confidence is where our personal fight begins. It’s rare to find a person—able-bodied or disabled, healthy or sick—who has not been knocked down by life at one time or another. Regaining confidence is particularly difficult when we face a debilitating physical

challenge, but we need to transcend our human propensity for self-pity if we want to feel fully alive and live up to our potential.

I've always found that my confidence is boosted when I push my body to the limit—skiing, riding my bike, swimming long distances—and deal with the physical pain. Win one victory; go on to the next battle; and win that too. Pretty soon, these little victories start to add up to confidence. At that point, self-pity becomes but a distant memory.

It was depressing to me then, but looking back now, it's just plain shocking that one and only one friend had the guts to visit me in the hospital. Jane Pince was a friend from junior high that went to the high school across town. She visited me several times in the hospital and then at the house before I was able to go back to school. Teenagers are self-focused and afraid of illness in others, but Jane still recognized that when something this devastating happens, the victim needs support and friendship more than ever. When I talk to teenagers now about disability, I make a specific point to challenge them: What would you do if your friend got whacked like that and was in the hospital? I hope that times have changed and the teenagers of today would behave differently than the teenagers of 1973.

As it turned out, I spent only five days in the hospital. During that time, I began to develop an attitude that has sustained me through my life. When the doctors said I would need to stay in the hospital for two weeks, I took it as a challenge to beat their estimate. "Who says I can't be ready in one?" I asked myself. It was the first of many times I would sound my new rallying cry.

Glad as I was to leave Grace Hospital behind, the real world felt like a strange and scary place in which I no longer belonged. I had absolutely no idea how I was going to cope as I looked out the window of our station wagon on the ride home.

As we pulled into the driveway, there was a green Ford Maverick with a ribbon around it. I immediately knew it was for me. What sixteen-year-old boy, even if he had lost his leg

only five days before, wouldn't jump (dare I say hop) for joy at the sight? Tears welled up in my parent's eyes as they acknowledged my excitement and appreciation. It was the first of many examples of how they intuited just the right amount of help to provide, balanced with an equal amount of challenge, to make me stretch and grow.

Even the Maverick couldn't take away the pain, however, once I was back home, off morphine, and relying solely on codeine. The pain was intense, sharp, and throbbing. There was no relief. I couldn't sleep, watch television, read, or even carry on a conversation.

I tried not to look at the stump when my dad changed my dressings once a day. I did see, however, that there was a giant incision across the end of what was left of my leg. It was red, bruised, swollen to twice its normal size, and crisscrossed with stitches. It frightened and appalled me, and I couldn't accept that it was part of me and would be for the rest of my life.

Looking down at myself, I was beginning to become accustomed to seeing my right leg missing. But I hated looking at myself in the mirror; reflected back at me, the difference in my body was extreme. I felt like a freak.

I slept fitfully for short durations. The pain always seemed worse at night. I would lie in bed, unbearably lonely, crushed by the searing waves of pain, acutely aware of my deformed body, cursing my fate, and asking myself over and over, "Why me?"

Music was an escape from the nightmare of my new body. My method of escapism could have been much more extreme. Believe me, I know how strong the temptation is to use drugs to blunt the pain and anxiety of a life that has been severely compromised. I was lucky to be able to lose myself instead in "Locomotive Breath" by Jethro Tull, "Riders on the Storm" by The Doors, "Stairway to Heaven" and "Kashmir" by Led Zeppelin, and "In the Court of the Crimson King" by King Crimson. I listened to the albums with those songs over and over. When I hear that music today, it still evokes powerful feelings of healing and recovery.

Chronic pain is much better understood now than it was then. But even in the early 1970s, it was known that a “cognitive busy signal” could be created in the brain to block or suppress the sensation of pain. Intense focus on a task can create this kind of busy signal. Solitaire, puzzles, models, and building a stereo from a kit created the busy signals I needed and kept me focused.

True to form, I pushed and pushed, and my parents and doctors finally relented and let me go back to school after just three weeks at home—five weeks less than the eight they had told me I would have to endure. I wanted to go back to school not only to begin leading a normal life again, but also to smash through the limits being placed on me and to exceed everyone’s expectations. When they said, “you can’t,” I was determined to show them I could. I would beat their predictions if it killed me.

I went back to school on crutches. In those days, they waited six months between amputation and fitting an artificial leg to allow complete muscle atrophy and de-swelling of all the soft tissues in the stump. Today it’s different. A new amputee is immediately fitted with a prosthesis because it actually helps decrease the swelling of the stump by placing it snugly inside a hard plastic socket. This also gives the amputee a head start on the challenge of relearning to walk.

Groves High was an E-shaped building with 2,100 students in three grades. The spine of the E was the main hall from which feeder halls branched. Between classes, the main hall was packed with kids at their lockers, talking in groups, and coupling up. It was a loud, busy place. But not on my first day back. When I swung through on crutches, it was like the parting of the Red Sea.

While I had been in the hospital, there had been a detailed public address announcement about my plight. All Groves’ 2,100 students—most of whom had no idea who I was—now knew the tragic story of the one-legged guy in their midst. They jumped out of my

way as I approached, became suddenly quiet, and gawked. No one talked to me. No one even made eye contact.

I felt their pity and discomfort—it was sickeningly thick in the air—as I focused with all my might on trying not to stumble. Their pity infuriated me. It forced me away from them, away from their healthy, two-legged, mobile, athletic lives. I felt isolated, freakish, and singled out. I was still me, but I felt utterly and completely defined by my missing leg.

The anger I felt at people's pity and my determination to defy expectations spurred me to become a wiz on crutches. I refused to let people hold doors for me. Instead, I figured out how to smash school-building horizontal bar openers with my foot. I came at a door full speed, pivoting back and balancing on my crutches so that my one leg was almost horizontal with my hips, and fired my foot into the bar. The door flew open and I swung on through. Luckily, no one was ever opening the door from the other side at the same time. But I was not really thinking too much about other people. It was all about me and about counteracting the horrible feelings of pity I felt from all sides. I was angry and scared, and I had a big chip on my shoulder.

My body began to adapt to its new form. My balance improved. Walking on crutches is essentially walking on your arms, and my arms and remaining leg naturally grew stronger.

I cruised along at a good clip. Stairs slowed me down, so I invented special stair adaptations. Going up, I took stairs two at a time, leading with my foot and following with the crutches. I went down even faster. After taking two steps down, leading with the crutches, I landed on the same step as the crutches with my foot; a little hop and a slide off the edge of that step got me down one extra step, while the crutches moved down two more steps. So it was two steps plus one extra each cycle—a very fast stair descent indeed. Incredible as it may seem, in thirty-six years of doing this I have never fallen.

The doctors were probably right: It was a bit early to be back in school. I was anemic from blood loss, tired, and unable to concentrate in class. The phantom pain was severe. Fortunately, the school let me come and go as I pleased. The Maverick made that easy. What mattered to me was that I was back much earlier than anyone had thought possible. Who said I couldn't? Just winning that battle alone gave me confidence.

I had lost a leg during my Christmas vacation, but that winter I began to find ways to fight back from what felt like a complete and crushing defeat. I had no idea what was in front of me, and I often fell back into feelings of self-pity and despair. I was angry much of the time, and I felt very much on my own. I began to set goals and work hard at them.

I celebrated even the smallest victories. Smashing open doors. Going up and down stairs. Relearning to drive. Taking Lobo for a hike on crutches. Each one of those little things felt like a fight to me because I was being constantly tested, knocked down, and pushed up against my limitations. I was in constant pain and struggling to learn how to live with that pain and accept my new body. And I was beginning to find a new way to move through the world—the way of the amputee, the disabled, the cancer survivor.

A portion of the proceeds from this book go to the O'Brien Osteosarcoma fund at the Dana-Farber Cancer Institute in Boston.