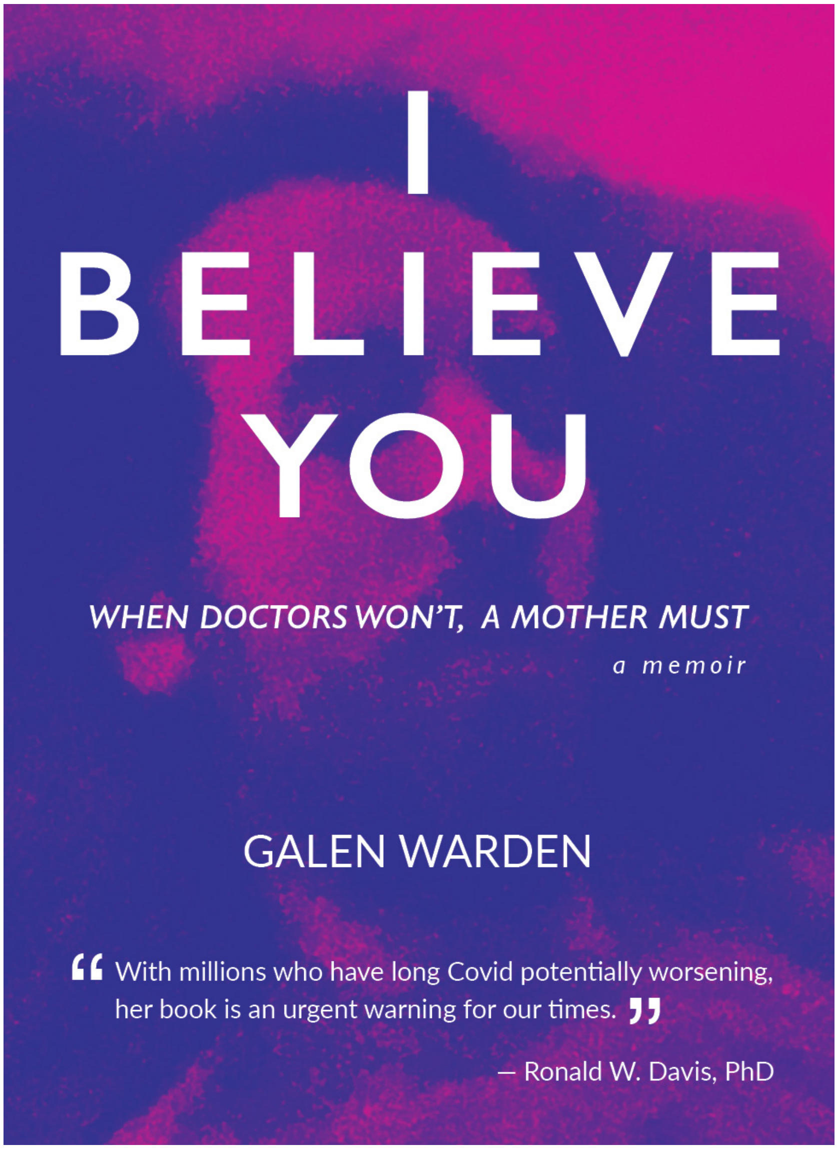

Three pages of selected excerpts from Chapter Five:
Misadventures in Independence

Medical Advice: Lift Weights

I flew back up to New Jersey and took him once again to his doctor. She was kind and empathetic, but she had no idea what was causing his exhaustion, unrefreshing and sporadic sleep, and his inability to walk more than one block or lift a guitar. Exertion or exercise “intolerance” wasn’t something that doctors are inclined to look into. Even if she had, she likely would not have come across myalgic encephalomyelitis. So, like doctors around the world who remain ignorant of ME and its obvious symptoms, she recommended exercise. James was desperate, so he followed his doctor’s orders, his therapist’s orders, any advice from authority figures: those who should know what to do. He bought five-pound weights.

As the saying goes, “You don’t know what you don’t know.” And they just didn’t. And I didn’t.

I did not have the words for what was happening. Maybe the right words would have changed her response, but I doubt it. Looking back, I should have said, “James experiences incapacitating exhaustion after any exertion that’s so severe it prevents any activity, even standing up or walking. Don’t lump it in with being tired or worn out, or with the fatigue you get from an auto-immune disease, anemia, or a thyroid condition. This is not that. Don’t even bother testing for those any more. You’d be aiming a kitchen fire extinguisher at a five-alarm fire that is burning the house down. That’s where we are right now.”

But I didn’t have those words. I was an ill-informed mother then. I didn’t have context. We were adrift in the blackest ocean of the unknown, James worsening steadily, with no help in sight. And, making everything worse for James, I chose to embrace easy, convenient denial and flew back to Beaufort.

It was just not possible that doctors didn’t know about a disease that does something this horrific to a brilliant, motivated, healthy young man. If he was sick, they would have found the sickness by now. He was, therefore, “not sick.” Whatever it was, I had to deny that he would continue to get worse.

When I chose to live in South Carolina and let his siblings move him into his own apartment, that choice was not about James. It was about me wanting to believe he wasn’t sick enough to need me to take care of him. That would be crazy.

The Last Apartment

James' new home was a sweet little attic apartment over a dentist's office in a classic Montclair Tudor, well-manicured and quiet. Had we known what those stairs would do to him, however, we never would have let him make the move. What would turn out to be his last apartment seemed ideal at first.

The living room was a wood-paneled garret with angled ceilings and views out over the quiet tree-lined street. This was where his siblings set up his music studio. His siter Joy's husband Colin, a furniture designer, built James a custom walnut desk for his twen-ty-seven-inch iMac with ProTools and Ableton software. In front of the computer, six rack units for music production were nested into the desk, facing him on an angle above the large flat surface that held his keyboard and accessories. A rack unit by the door held the rest of his electronics and recording equipment.

Acoustic and electric guitars lounged on their stands and his impressive wooden drum set expectantly held out its cymbals and hi-hat. Rhodes, Yamaha, and synthesizer keyboards grinned broadly with their silent mouthfuls, and in the corner a coffee klatch of mic stands tilted forward with pregnant anticipation. It was a still life—a still birth—of musical intention.

I flew north after his siblings moved him in. Once again, I stocked and organized his kitchen. It was an old house, so I cleaned window sills and baseboards. I loaded his clothes into his dressers and found a place for everything.

He had a stool in his kitchen so he could sit while he waited for things to cook—but he lost a lot of weight because he frequently wasn't up to going into the kitchen at all. And if he did, it was just too much to clean the dishes as well.

Having not understood this, I scolded him when I showed up this time to help him move in. I remembered the disaster of his last kitchen and he'd only been here about a week when I came. Why weren't the dishes done? It only takes a minute. I was annoyed with him, as exhausted as he was. To me it seemed like a very minimal effort. Something he could manage if he just stayed on top of it from the start.

"When you use the bathroom no one has to tell you to wipe your ass. You just do it! When you get a pan dirty, just clean it!"

I have regretted those cruel words over and over since then.

When it seemed he was all moved in, I once again ignored the tragedy slowly playing out before my eyes and ran back to South Carolina.

Without a diagnosis, James only rested out of necessity. He could still walk when he'd recover, still participate in life very minimally. In April, his siblings took him out to dinner for his thirty-first birthday. In May he went out for a haircut. When he was up to it, he would still on rare occasions pick up his weights to try to get a little exercise, desperate to do what the doctor said might improve him.

His sister Joy had been spending a lot of time with him, fixing him meals and trying to help him navigate the emotional minefield of losing all of his abilities, especially his ability to make music.

He was fighting constant anxiety over his frighteningly severe condition and the complete lack of help from doctors. In May Joy took him to a sleep specialist, still going on his doctor's theory that better sleep would help his fatigue, and his sleep was so evasive and unrefreshing. They scheduled a sleep study a few months out, but James would never get to it.

Spending most of his time in bed now, James was completely bewildered by his helpless state, and pushing to be active as much as he could, whenever he could, he still continued to decline. He kept a lightweight acoustic Gibson guitar in his room, but it became harder and harder to pick it up, hold his arms in position, and work his fingers to play. It was a crushing milestone when he could not manage to play even one more time. His faithful Gibson had been lying on his queen-sized bed next to him and, for a very short while, he had been able to grab the neck and slowly slide it onto himself to play just a little. The day that he could no longer drag it across the vast disheartening landscape of a foot or two, he lost the final vestige of what made him who he was.

He recently told me how it felt to cross that line. He didn't know what he was going to do without the ability to play guitar.

"I'm only comfortable with a guitar in my hands. It's the ultimate anti-anxiety drug. Whether I was home or at a friend's house, even if I wasn't playing it, I always had a guitar in my hands to make myself feel better. It's been an extension of my body all my life. Losing guitar was like losing an arm."

Ray Charles said, "I was born with music inside me. Music was one of my parts. Like my ribs, my kidneys, my liver, my heart. Like my blood. It was a force already within me when I arrived on the scene. It was a necessity for me—like food or water." This was James.

He waited to get stronger, to be able to play guitar again. But he never could.