

Pandora's Box: The Book of Infinite Questions

By Candice Carnes

This is a memoir about my death: Except I didn't die. If you ask a hundred people who knew me—at the moment my illness reached its climax—you would get one hundred different answers about what happened. Some people were relieved when I was finally admitted at UNMH (the University of New Mexico Hospital) because I had been sick for so long I was running out of energy to fight. I was in the process, not of giving up, but of letting go.

I was 32 years old.

I didn't want to write this book. I wanted to snap my fingers. And I wanted to skip away. And I wanted to forget. The last thing I wanted to do, when I finally began to recover from illness, was to waste more time thinking about it, and I felt ashamed for letting it get so bad in the first place. I might have worked as a nursing assistant, but I didn't know how to communicate with my own doctors. I didn't know how to navigate the healthcare system as a patient, and I was too independent for my own good.

If I've learned anything, it's how to ask for help.

As early as my mid-twenties, my body began to betray me, at first in small ways: a kidney infection, a kidney stone that hurt like hell to pass (some have described it as being more difficult and painful than giving birth), a fever, extreme fatigue, cold sweats, extreme weight loss, followed by extreme weight gain, and always the vomiting. Every day I vomited, and by the time I turned thirty, it seemed as commonplace as doing laundry or paying bills, just another burden of adult life.

I had seen so many doctors, and because I didn't know what to tell them, or because they didn't know how to listen, or because I looked like such a hardy young woman with glowing skin, nothing came of most of those visits. I had seen too many doctors and I had not seen enough. My life sprouted a paradox, and because I didn't know what was wrong I got scared, and because I got scared, I got stupid.

What did I know when this all began? What does any 25-year-old know about serious illness? In school, they taught me about history. They taught me about geometry, how to drive, and even sex, but no one ever told me what to do if I became seriously ill. That was something to worry about later when my skin began to sag. No one told me the dangers of a frail body with a young temperament.

This is a memoir about my death, because if I didn't finally get proper medical treatment, I would have died, even if that medical treatment was nothing extraordinary.

The final truth is this: I didn't die.

But in an alternate universe, where the laws of atomic energy differed as slightly as a misplaced electron, I might have been as extinct as the dinosaurs, as silent as fossil fuel.

The spectrum of my perception spread out like a large ravine, the edges of absolute truth steep and slippery. When it came to the state of my health, even within my own mind, I

was always wondering if I was under or over-reacting about what happened. Even now, I still make mistakes. I don't always know what to do.

If I had received proper medical care in a timely manner, none of this would have happened, or it wouldn't have happened like it did, or at least I wouldn't feel so damned guilty about it all the time. If I have one piece of advice for anyone who is sick, it is this: don't wait. Find a way to see a doctor regardless of your insurance, or your means to pay for it, or your busy schedule. And make them listen.

Go now. Don't wait.

On those first days of being home following my nephrectomy, the surgical removal of my kidney, I would fall asleep thinking, *How could I have let this happen?* But I did let it happen. I couldn't change the fact that. It didn't matter if I had learned my lesson, or if I promised to be a better woman, or if I figured out what I had done wrong. My kidney was gone, and it wasn't coming back.

I would someday find out that there are worse things to lose.

I used to run my finger along my incision when it was still fresh, and deep, and precarious, ten inches long, punctuated by staple holes, and held closed by hemostatic agents, coagulants used to seal it, like modern-day cauterization. I reacted badly to those agents, and my side burned like it was on fire. Even years later, possibly forever, I would still wake up sore, aware that I was no longer complete.

I hurt myself.

When my mind and hands became too idle, I would think too much, and in those moments of over thinking, it felt no different than if I had cut myself, like a mental patient, which I was. I had gone crazy from pain, from illness, and from the despair that came with it. Though, clinically what I was feeling was not mental illness, but what my therapist would later call grief.

It was grief for my whole self, not my just my physically whole self, but the innocence that had come with it. Don't the healthy always take life for granted? Don't they believe themselves to be invincible? Don't they need this delusion in order to focus on the banality of everyday life? Who can worry about things like the dry cleaning when they know that someday they will die? And we will all someday die.

But we still need to pick up the dry cleaning. And we find a way to carry out those mundane tasks, even when the myth of safety has been replaced by the truth of our vulnerability. It is the ultimate existential experience, returning to the other side of illness. We continue to move forward, knowing what we know, and we grieve for the loss of innocence that comes with serious illness, but we still move forward; we still pick-up our dry cleaning and we go to work, and we pay our bills. And it feels like insanity.

There is a black hole running through the center of my universe. It seems like I should have known that. Now I do, and I can't give back that knowledge.

My therapist assured me this grief was normal, healthy, and productive. I still think my recovery was one of mental health as well as physical, and in order to recover from that grief, which made me question my identity, I had to ask all the questions I didn't want to ask, even though most of them didn't have answers.

To ask those questions in any meaningful way, I had to write, because at the core of myself, I am a writer, and writing is what I do. I had to learn how to rewrite the mythologies of not only my illness, but of how I perceived my life.

My truth had been replaced by the perceptions of others who thought I was a hypochondriac, or a narcotics addict, or on the other side of things, people who worried about me in ways that I didn't know how to worry about myself.

While I was hospitalized, the burden of my health became someone else's problem. I didn't question much while I was there. I slept a lot. I tried to let others do their jobs.

Eventually, like most patients, my vocabulary became replaced by the clinical language of my medical records, which told different stories depending on the status of my diagnosis, which was always changing. I was a hypochondriac, a pain medication addict, eventually a renal patient with potential kidney failure, and finally my diagnosis was focused on the one thing they knew for sure, a staghorn kidney stone the size of a golf ball had gone rogue.

To tell a memoir about my illness, I would have to open Pandora's Box. I would have to take a risk, and I wasn't sure it was a good idea.

What would my curiosity set free and who would it hurt?

To tell the story of my own illness, I would have to include the illnesses of those patients who informed my experience. And to do this ethically I would have to lie. I would have to re-arrange key facts that might have revealed their actual identities. I would have to create compilations of several patients into a single symbolic one to serve as their representative. In essence, I would have to adhere to the spirit of my experiences of working with the ill, but I would have to deviate from the journalistic absolutes of those individuals. While the integrity of their stories were some of the building blocks of my own, their privacy was something that under no circumstance could be invaded. I would have to learn how to navigate through altered versions of the truth and what truth means.

I couldn't write this in a bubble free from my family and friends. I couldn't write this without implicating others or myself. For all the hundreds of mistakes made by the healthcare system, I had made thousands of others. I had fucked up in more ways than I could count.

Eight years before my hospitalization, my father kept working when he was dying. He even kept working when he needed to urinate into a bucket because the bathroom was too difficult to navigate to at night. I brought him a plastic urinal because my mother didn't know where to buy one. I still feel guilty for not knowing sooner.

He was 48 years old.

Did I learn how to speak to my doctors (or more precisely how not speak to my doctors) from my dad? Why did I keep working as a tech, the skilled manual labor of nursing, when I was sicker than my patients? Why didn't I know how to get the proper help?

This is a book of infinite questions, few of which have answers. Most came with more questions until I found they too had no answers. In fact, this is more like a book of rhetorical questions, the kind of questions that make a statement without the expectation of resolution.

I can't complain, only question. I don't expect answers.

With each diagnosis, my perception dutifully fell in line with its authority. When I was told there was nothing wrong so many times, I really wanted to believe it. I came from a long line of hypochondriacs, which didn't help my brain much. For years, I wondered if I really was imagining it, like one of my relatives imagined he had the Ebola virus whenever he got a bloody nose.

I was told that my symptoms were psychosomatic; a trick of my mind, which only wanted narcotics. For a while I even wanted to believe I was addicted to pain pills, because that was preferable to the reality I was going to die. What did that mean about me, that I might have been addicted to prescription drugs, when I had been so hard on my father for being an

alcoholic? How much did being the child of an alcoholic have to do with my own medical condition?

I still don't know exactly what happened and if I am not the one to ask, then who is?

Maybe no one knows. Isn't that the point?

—That I was too alone, that no one was there with the safety net when my mind began to melt, when the edges of myself began to buckle, and I lost track of the truth?

How can a person who doesn't know the truth write a book?

Don't the doctors know the truth? Isn't that how physical illness works? When a person does not know how to heal herself, she seeks the help of a professional who defines the ill person's reality and makes it better.

But what about all those people who are sick and never get help, those who live between the truth and a lie? And what about all those people who never get a diagnosis, do they not exist? And by "they," do I mean: That their illness does not exist? Or that they as people do not exist? Now limbos might have names like chronic fatigue syndrome, and fibromyalgia, but some of them will never have names.

Most cultures see the importance of naming not only people, but objects as well. Whoever owns the names owns the power. In some cultures, a baby's name is kept secret to keep it safe. In the Navajo culture, formal names are only used in ceremonies. The Sioux Indians have as many as six first names that could change in a lifetime. In Judaism a naming ceremony, helps insure that a new child is given a meaningful name, and often because their Hebrew name is sacred, they are also given a secular name for the Gentile world.

I learned this in my cultural anthropology studies: whenever a culture is assimilated into another culture, the dominant culture will rename people. They will rename towns and even mountains and whoever owns the names owns the power. Isn't that what political correctness is all about? Allowing a group of people to choose their name allows them to transcend their oppression. If a person knows who they are and can choose how they are named by others; then that person has power over his or her own life.

But an ill person depends on her practitioner to tell her who she is. She relies on doctors to know how to behave, how to react, and what to do. Who are we, when we become ill? Who owns the truth in our stories about illness?

Is it the ER doctor who three years before my nephrectomy assured me that my re-occurring kidney infections were "due to not wiping your ass properly?" I still remember that day's new definition of me, and the doctor and her hideous socks—the way they bunched up beneath her Birkenstocks and sagged off her calves, crumpling below her unshaved knees. She asked my mother to show me how to "wipe my butt," and my mom wrinkled her nose. To address the unexplained weight loss the doctor handed my mother a pamphlet with some title like *So Your Teenager has an Eating Disorder*, but I was nearly thirty, and I loved to eat. I didn't have an eating disorder.

My mother took the pamphlets and threw them directly into the trash.

Go Mom!

But wasn't that the first time I saw my mother defy an authority figure? Didn't I grow-up with her not questioning, with her being afraid, not for me or for her, but for what people of authority could do to us? Didn't I grow up believing that what I needed didn't matter? Didn't she teach me how to be afraid of doctors, and social workers, and teachers who asked too many questions?

I never knew the names for what was happening to me, and I want to now, and I want you to know to know how to find names for your own experiences, even if we have to create those names from nothing more than dirt and clay. I want people to know what it is like, not to be in charge of their own destiny. I want people to know how it feels to always wait. I want people to find ways not to wait, to move on from illness, and to be free, until it really is time to let go. How many people don't know how to ask the right questions until there are no longer any answers?

I had grown up in chaos and poverty. I didn't learn to have the sense of entitlement that middle-class people did, even when it came to my own health. This is no excuse for my complacency; I know. By the time, I became sick, I had not quite transitioned into middle-class, but I could usually pay my bills. I rebelled by leading an organized life, by having a job, by driving a fuel-efficient Toyota, and by eating lots of leafy greens.

I didn't think about my father who—when I was a child—told me to quit acting like the little girl. I put my anger about this to sleep when he died. I stopped being mad, but the influence of his words still lined the membranes of every cell in my body. Didn't I still believe that above all else it was my duty not to complain, to not look weak? Didn't he teach me that being a little girl in a man's world was the most dangerous thing to be?

This was no excuse for not directing my own care better. I don't mean to ask forgiveness. I only wish to give a reader who doesn't understand, something to hold onto, a reason.

I was so drenched in morphine that day when the doctor, with her hideous socks, examined me that I don't remember my mother taking me home. If my mother's memory of that day didn't line up so exactly with my own, I would have thought I was imagining it. How many doctors did I see alone? And how many of them had been just ridiculous, because I didn't know how to talk to them? How were the pain pills, which made me tearful, sensitive, and unreasonable, breaking down my ability to make proper decisions about my care?

I cried because a bird died.

I cried because of global warming.

I cried because the Chicxulub Crater killed all the dinosaurs.

Like many patients, I became the secondary voice in my own stories. These are the roots of experimentation in illness memoirs. We tell stories, with passive sentences, because we do not do the acting, we are acted upon, like objects, like sick bodies. Out of necessity the medical community controls the narrative of our illnesses. We are taken out of our lives, which we surrender to strangers. The disease contaminates the foundation of the self. We are prisoners in the very bodies that we depend on. And that betrayal distorts everything.

When I first started working at the rehab hospital, my insurance was provided by a research study. A year later, when I thought about getting insurance through the for-profit hospital system where I worked, I was being tested for HIV, and for the third time I received a Chlamydia and gonorrhea test, to rule out a workplace injury. I worried about what my medical records said about me. I worried about my employment, and because of this fear, I chose a private insurance company. It was unreliable, and I was never consistently insured.

This is what fear does. This is how illness changes not only how others perceive you, but also how you perceive yourself. This is how able-bodied people have to worry about their illness destroying their lives. This is how the fear of being defined by my illness led me to make bad decisions.

There is no excuse for this. Because I was afraid, I didn't have reliable insurance. I made a mistake, one of many, that contributed to the failure of maintaining proper preventative care. Yanking out my decaying organs was a waste of state money and resources. Some people would say I should not have received this care. Some people say I had no right. Some people would have preferred I died. I hope some people never have to go through what I did, just to understand how easily it could happen to them.

Even when I had insurance, a good doctor, and thorough tests, nothing was found. I was referred to a psychiatrist who gave me a prescription for anti-depressants, which I threw in the trash. It was something a mental patient would do, but I wasn't depressed. I was exhausted.

I couldn't mix anti-depression medications with narcotics, and I needed to take Oxycodone to keep working. My prescriptions ran out, and out of desperation I ordered Tramadol online from India. I kept working through the pain, even when it was not sensible, because I didn't know what else to do.

My common sense was compromised. When I think back on it now, I can see how stupid it was. I took care of patients when I couldn't even take care of myself, but I still don't know what I could have done differently.

I hate that people suffer unnecessarily because their illnesses don't fit into a specific container that can contain them. I hate that they feel like they don't exist. I don't have anything to offer them but the solidarity of my own experiences told as genuinely as I am capable of.

In the story of *Pandora's Box*, hope was what was left when everything else had escaped. Maybe that is what we have to offer each other, by looking at the stories of others. Maybe even though I don't have the answers my questions, I can still ask them. Maybe I can only open Pandora's Box, and hope that I am doing the right thing by asking the questions I do not wish to ask.

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