

**A Conversation with Amy Silverstein
Author of SICK GIRL**

Q: Your memoir sparked debate on patient-related issues, such as the role of gratitude in illness, the omnipotence of doctors, and the pressure felt by the chronically ill always to smile and harbor unwavering optimism. What do you make of the varied responses to *SICK GIRL*?

AS: After reading letter after letter, it became clear that many reactions stemmed from my honest self portrait and unsparing look at my heart transplant life, a depiction that was brutally candid at times. This kind of openness, I came to realize through reader mail, was unprecedented—and, mostly, welcome.

I have received voluminous communications from chronically or terminally ill people who tell me that it is the compelled silence, the forced mask of empty optimism, that makes their tough journeys unbearable. They want to know: Why can't we all just call a spade a spade—say, darn it, it's hard, it's sad, it's unfair, it's painful—and then go on with life, gratitude for each moment, and with joys where they might be found? Some people feel pressure to be ever cheery and full of confidence and gratitude for another day, and so, feel badly about themselves because they cannot summon up such glee and steely optimism. They feel guilty. Weak. Negative. All this merely for being "real" about their situations. They thank me for writing a book that opens up the possibility of being true to their feelings, and maybe to summon the courage to voice them once in a while.

And such voicing does take courage. Some readers have expressed strong opposition to my honesty and have told me, flat out, that I should keep quiet. They prefer that I—and perhaps other chronically ill folks like me—keep my reality hidden. Their criticism focused on what they believed to be a lack of gratitude on my part. As they saw it, it is not possible to be grateful and also state forcefully how hard and challenging it is to live with a heart transplant. Some transplant advocacy groups expressed concern that by voicing my struggles with illness post transplant, I might deter people from becoming organ donors.

I understand and appreciate these sentiments. Still, I believed strongly that it is absolutely possible to be hugely grateful and also feel worn out by the challenges of daily, unyielding illness and seriously compromised health. The journey I describe in *SICK GIRL* shows a young woman who was tiny steps from death and was saved by a miraculously donated heart; clearly, organ donation saved my life. And I have made my post transplant life into a worthwhile one—full of love, purpose, giving, contributing, and enjoying. Anyone considering organ donation can see that. The fact that my life also has illness and hardship is simply a reality that accompanies the fantastic circumstance that I am alive because of a wondrously donated heart.

While the positive responses have far outweighed the others, I am glad that there is spirited debate and an opening up of many issues that had not been voiced before the publishing of *SICK GIRL*.

Q: You have lived 20 years since receiving a heart transplant at age 24—as you say, a "crazy kind of amazing" medical miracle. What made this the right time for you to write *SICK GIRL*?

AS: In my 17th post-transplant year, I experienced a pivotal event—a terrible brush with a threat of post-transplant lymphoma. Faced with the possibility of living as a heart transplant patient and a cancer patient, I simply broke apart. Even after I found out that the lump removed from under

my arm was benign, I was unable to bounce back to my usual can-do will-do self. Reeling from post-surgery complications, I was also disappointed in my doctor. It was one of the worst times in my life as a transplant patient, but something wonderful came out of it. Seeing that I was unraveled by years of illness and then a lymphoma scare, my doctor grabbed for straws, anything that could make my life more livable. We talked for the first time ever about things like meaning in life, and he came up with an idea that would launch me into writing my first book. So, as is true for other self-discoveries and new beginnings, I had to hit rock bottom to get myself to where I wanted to be. And now I am a published writer on her way to a second book. Amazing.

Q: Remembering yourself as a high-achieving 24-year-old, how was it possible for you initially to overlook your symptoms of shortness of breath, temporary blindness, and blackouts?

AS: I did not overlook them. No, they tugged at me every day, and I did pay attention, I just failed to interpret them in the right way. I was young, had been perfectly healthy and didn't know anyone, friends or family, who had ever been ill. I had no tools with which to construe my symptoms, and my family doctor had told me I was just a nervous law student with low blood pressure. Why would I doubt a smart, top-notch New York City physician with a great smile and an impressive white coat? Serious illness just wasn't a possibility that was going to occur to me.

Q: What about gratitude? You are, after all, alive and would have died without the transplant. And yet there is still anger, sadness, and struggle. Shouldn't gratitude carry the day?

AS: I believe it is wrong and harmful to categorize chronically ill people as being either entirely grateful or entirely ungrateful, or being terrific troopers or awful complainers. The truth is, most people fall somewhere in the middle. I know I do.

And I know from the outpouring of mail that many chronically ill people see themselves somewhere in the middle as well. They have a whole range of feelings about living sick, everything from gratitude to despair, and yet they feel societal pressure to keep their talk strictly positive. This only makes the burden of illness harder for them to carry.

I am tremendously grateful for being alive, for this wonderful donor organ, and for the support of my doctors, family, and friends all these post-transplant years. My goodness, I am so fortunate for having been saved by transplant and for surviving it for so long.

But what I am not grateful for is having had my health taken away from me when I was just 24 years old, and for living every day since then with transplant-related illnesses and struggles that challenge me at every turn. Nor am I thankful that I live every day with the threat of imminent death by my side. Still, I do feel so much gratitude. There is nothing more spectacular than opening my eyes into a new day—even if that day is a difficult and sick one.

Beyond my personal medical story, I would think that most any person who lives with day to day suffering and illness lives with a combination of gratitude and struggle. To have a difficult time abiding endless illness does not erase gratitude. In fact, someone who perseveres in spite of illness, and who goes on day after day facing each medical challenge in the best way he or she can—that is a person who is grateful for life. But being grateful does not mean the daily battle is easy or that you are happy about it, or even okay with it.

Q: You've written an extremely honest book—even to the point that shows you in an unfavorable light in places. Was this your intent?

AS: I was determined to write with complete honesty, even though I know that society frowns upon honesty when it comes to talking about living with chronic illness. People only want to hear about the grateful parts. And I am so grateful.

But what has been missing from the dialogue—and what I tried to introduce in my book—is the concept of a person feeling and voicing both gratitude and the frustration and loss that can accompany chronic illness. Being open about the entire picture does not take anything away from gratitude or appreciation for life; it just tells it like it is.

Q: Do you think your book will affect organ donation?

AS: I believe that anyone who reads my book will understand very clearly that I was tiny steps away from death when I was just 25, and my life was saved NOT by a smart doctor or a great medicine or an implanted device, but by a wondrously donated heart that came from a family that showed incredible altruism in their time of loss and gave the gift of life.

The plain fact that I live post transplant with serious medical challenges does not take away the lifesaving reality of organ donation.

Q: What role does love play in your story?

AS: I think that first and foremost, above all, SICK GIRL is a love story. I live an extraordinary love story that still amazes me to this day. You know, I was only 24 when I wound up in the ICU waiting for a donor heart to save my life. And my boyfriend at the time, Scott, he stayed by my side for the 8 weeks I waited for a new heart. We had been dating only 6 months. He was just 25 years old. He certainly could have cut and run, and no one would have blamed him. But instead, he proposed marriage to me, right there at my hospital bedside, with all the tubes and wires and oxygen apparatus reminding him of how sick I was. Incredible.

The doctor told Scott that if I was LUCKY, I would probably live about ten years after the surgery—which meant that Scott almost surely would be a widower in his thirties. But still, he wanted to marry me—no matter what.

This act showed me the truest kind of love I had ever known. On that day, and continuing to this day, I try my hardest to be worthy of this exceptional love. And so when the going gets tough, and the transplant illnesses pile up and hit hard, I pull myself up and do my very best—always trying to live up to the wonderfulness of this love that sustains me and inspires me.

Q: How have your relationships with friends, family, and doctors changed after writing SICK GIRL?

AS: The relationships are more real and open—and this can only be good. I no longer feel that the people in my life misunderstand what I live each day in my body. And this too is a positive change.

No one likes to feel misunderstood in their day to day existence. We all want to feel appreciated for the things we do in a day—especially for the things that are difficult and take extra effort, but that go unnoticed by those around us. For instance, a stay-at-home mom does so many things for the house and the kids in a day, but many of them are not plain to see. And someone who works in an office also does things that are difficult and vital, but that are not appreciated openly.

Sick people feel the same thing—we want others to understand that we jump hurdles and rise above medical challenges each day, even though we appear fine and unburdened, like it's all an easy ride for us. But, on the other hand, we don't want to be pitied and we don't want to be thought of as being a complainer. So, we just accept the fact that we are going to be misunderstood to some extent. It is an unfortunate circumstance.

I still grapple with this issue—even after writing *SICK GIRL*. I am still trying to strike the right balance between sharing the reality my medical challenges and keeping things to myself. But the book has brought about a higher level of understanding among my friends, family, and doctors. And while this doesn't take away the illness, it does make me feel a lot better.

Q: What can doctor's learn from your book?

AS: I have heard from many doctors who have read *SICK GIRL* and they all seem to take away something different from it. But one common theme is that the book serves as a reminder to doctors about how vital it is to see the human being behind the illness and not to make knee-jerk assessments based on appearances. Appearances can be dangerous.

This is seen *SICK GIRL* when I tell about when I first approached my family doctor complaining of vague cardiac symptoms. I was in law school at the time, 23 years old, busy, active, seemingly healthy, and my doctor took one look at me, saw that I appeared fine on the outside, told me I was a nervous law student, and sent me home. The fact was, my heart was failing—but my doctor did not see past my healthy appearance.

Only good can come from reminding doctors to be thoughtful, careful, and thorough, and keep in mind that when it comes to illness, there is so much more than meets the eye.

Q: You discuss the price you paid for "dumbing" yourself down. What five things would you tell a best friend about becoming a smart, savvy patient?

AS: More important than the price I paid were the lessons I learned:

1. Remember that doctors put their pants on one leg at a time. They might like or dislike you, and it can affect your care (doctors are not immune to snap judgments made on the basis of superficial things). They might be flat out wrong, so don't be afraid to trust your judgment and go for a second or third opinion.

2. Keep your own records. Take notes while your doctor talks. This is not meant to be confrontational; it shows that you are paying close attention, and you take your doctor and your care seriously. It is also a valuable record. If I feel something odd or new, I can look back and see if this is something I have had before, what my doctor might have said about it, and whether it went away without incident. Keep yourself honest and smart about your own body!

3. If you have a bad feeling about your doctor, any bad feeling, move on. Unless your insurance plan or a unique medical condition allows you only one option, never feel bad saying, "So long!" and asking for your medical records to go. Doctors are people; you are allowed to dislike them.

4. Tell your doctor everything, even things that you think have nothing to do with your illness. When I was vomiting blood, I thought it was a stomach problem, when in fact it was the result of a failing heart that had caused other organs to fail. Scan your body in your mind; think about all the places that hurt, the bumps and lumps, the bloating, the changes. Do you feel "like yourself" or not? It's okay to say, "This might have nothing to do with my sore neck, but I have been having headaches at night..." Trust your instincts. You know your own body best.

5. Your doctor's care will only be as valuable as the information you provide (all of it). You are true and equal partners with your doctor. Make sure your prescription is correct. Check new medications for interactions with others you're taking; don't expect your doctor to remember anything about you. You remember it for him. Together, you can ensure good medical care.

Q: What is wrong with being an "easy" patient?

AS: An "easy patient"—someone who is passive and who would rather not bother her doctor with her own ideas, concerns, or grievances about her medical care—is a recipe for disaster. Winning the patient popularity contest will not get you the best medical care. A patient can be kind, considerate of her doctor's time and patience, and she can be a pleasant presence in the office, while asking the tough questions. Easy is not the goal. Smart is.

Q: Is there a temptation for doctors to tell their patients white lies, even a temptation for patients to tell themselves the same?

AS: I don't think a doctor should ever lie to a patient, even a white lie. Given my medical journey, I am always on the lookout for even the slightest softening of reality by my doctors. I have learned to notice the subtleties of language. When my doctor says, "I think you should be fine on this new medication," I focus on the think and should red flags. If the new medicine lands me in the emergency room (which has happened), would it be fair to say that my doctor told me a white lie? No, it was more like a bad guess. As for patients telling themselves happy little lies, there is a fine line between optimism and kidding oneself. Now, I err on the side of strict candor and clarity. I keep records of my symptoms, with dates and careful descriptions, to keep me honest with myself. I want to believe I am well. I want to think my symptoms are due to nerves, something I ate, or a lack of sleep. But I will not allow myself that, not ever again.

Q: What should we, your readers, know about organ donation?

AS: Organ donation saves lives. I would have died at 25 were it not for the gift of a donor organ. Thousands and thousands of people would be gone were it not for the same gift. So I ask you, please, to sit with your family and discuss your wishes about being an organ donor. Sign up at your state's organ donor registry, if you are inclined. Organ donation is truly a gift of life.

Now, in my book, I am very honest about the chronic post-transplant illnesses I have and how I struggle with them—sometimes with grace and sometimes not. But the bottom line is this: I

HAVE LIFE. It is a life with illness, yes, but it is LIFE just the same—and I have life for one reason and one reason only: the gift of a donor heart.

So make your organ donor wishes known to your families. Keep in mind the lifesaving truth of organ donation. Spread the word.

Q: Ultimately you learn that you suffered from a rare genetic heart disorder. What was it?

AS: The name of the disease is Arrhythmogenic Right Ventricular Dysplasia (ARVD), a heart disease in which the myocardium (heart muscle tissue) on the right ventricle wall is replaced over time by fibro-fatty material, causing major dysfunction of the heart. Accounting for 17% of all sudden cardiac deaths in young people, ARVD is usually inherited and there is no standard genetic screening test yet. First symptoms generally occur in early adolescence, are most often exercise related, and may include palpitations. The disease can cause sudden death. In its early stages, an EKG may show some abnormality, but this finding may be considered normal in women and children. If a family history exists, offspring should begin cardiac testing in their teenage years. Tests might include an EKG, echocardiogram, a Holter monitor (continually monitors the heart's rhythms), stress test, and MRI of the heart. None of these are painful or risky. My sister, who developed some heart symptoms in her 20s, has some degree of ARVD, but it is very mild, unlike mine.