

A Conversation with Amy Silverstein Author Of SICK GIRL

Q: You have lived 19 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: You and your boyfriend, Scott, were dating when your series of near-death episodes began. How did your relationship survive?

AS: I know it's hard to believe, but it never occurred to me that it would *not* survive. Scott was simply *there*, and he never for a moment gave me reason to wonder why. It was as if we were already committed by something more powerful than a boyfriend/girlfriend bond. Scott loved me. And for him, love can only be true and powerful and rock solid.

Q: Please tell us about your list of Intentions and why you created them.

AS: I have always been a writer; it has been my path to understanding myself. In my hospital room a week after transplant surgery, I felt such joy at being able to sit in a chair with no IV staring up at me from my wrist. But there was also fear. I had a dozen medicines to take—scary ones. I had heart biopsies lined up far into the future. I had a new heart, for crying out loud. I put pen to paper and wrote my list of Intentions to realize the hope, and lessen the fear, like: “I will take all my medicines every day, as directed, no matter how sick they make me, no matter their bad effects on my looks, no matter how much I might want to stop them;” “I will never let myself get fat, no matter what the Prednisone tries to do to me;” “I will return to law school, finish, and take the BAR exam;” and “I will exercise to keep this new heart strong, no matter how hard it is for me.” I still set Intentions for myself, new ones, even now. They keep me trying to be my transplant best. They give me something to shoot for, and I love goals.

Q: How was the choice to become a mother and motherhood itself most meaningful?

AS: The thought of being a mother was so incredible, so overwhelmingly wonderful that it made secondary the very real and constantly pressing concerns of my body. Another life quickly became more urgent than my own. The love involved was tremendous; Scott and I were able to make a triangle with our son, forming a family that made us feel more normal than we ever thought possible.

Q: For years, you hid your neck-to-navel transplant scar, your “flaw.” Then came the day when you were comfortable in a V-neck top. What changed?

AS: I cannot say that I became comfortable with my scar, rather, I came to an understanding that it was better not to hide it anymore. My son became a teenager and developed some acne on his back. Sitting poolside with him on a hot day, I noticed that he kept his shirt on. I realized that I, too, was wearing a shirt, and that it sure would be nice to take it off, no matter how my scar looked. It struck me then that I was a bad example for my son. I could tell him that he should accept his body and not hide away its imperfections, but I did not live by this principle. So, on that day, and from then on when I'm with my son, I wear my scar proudly and with a smile.

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: Approximately 94,000 Americans are currently awaiting organ transplants. From your perspective as a heart transplant survivor like no other, what is the most important part of the heart transplant issue that doctors, potential donors and recipients need to know?

AS: Heart transplantation is wonderful. Organ donation is a model for altruism, as it is literally a gift of life—to a stranger, no less. And the doctors, organ procurement specialists, nurses, and transplant organizations are part of an amazing transfer of life that seems to be as close to a miracle as any medical endeavor can be. Yet there is nothing miraculous about the post-transplant ills like lymphoma, diabetes, and irreparable artery disease that heart transplants inherit with their new organs. Post-transplant medicines deaden the immune system, the same system others depend on for their health. Heart transplant is not a cure; it substitutes one set of serious medical problems for another. It gives life to one who would surely die without a new heart, but how long and how disease-ridden this life?

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.

Q: The unrelenting threat of death is a given for you every day, yet you have never lived like a “sick girl.” What is your personal philosophy for living?

AS: I have come to embrace the concept of riding the wave of life. Nothing in anyone’s life remains constant, not our age, our happiness, or our health. When I get terribly sick, I try to remain calm and wait it out. Then I am able to appreciate moments of near wellness with true joy. I celebrate it quietly but so profoundly. I gave my book the title SICK GIRL not only because of the indelible mark left on me by the doctor who said it, but also because of the battle within me. I know I don’t appear to be a sick girl, but I am one. It is hard for anyone to believe that I might die soon: one month, six months, a year...they’re all possibilities. I work hard so that people don’t see me as a sick girl. No matter how ill I feel, I put my shoulders back and my chin up, and I go forward with whatever I set out to do. I am proud of my strength and my ability to do this. I am also aware that my efforts get me in trouble sometimes. I accept the struggle for what it is: a battle not to be a sick girl. In the long run, fighting the sick girl in me is a good thing, even if I can never really win that fight.

Q: Why do you think you’ve survived so unusually long as a heart transplant patient?

AS: I would like to think that I have some control over my longevity, that all the miles I run, sometimes with tears in my eyes because I feel so sick, the painful but necessary medical procedures, the careful eating, all the medicine day in and day out that actually poisons me, and all my diligence and will to do everything I can has lengthened my life years. But truthfully, many heart transplant patients work very hard to be well, and die anyway, hit with one or more of the typical and terrible heart transplant ills, like cancer, repeated organ rejections or fatally clogged arteries. Some of it is just plain luck. It can only help that my donor’s heart was a near perfect match for mine.

Perhaps most important for my survival has been the extraordinary love of my husband, Scott, who was my boyfriend when I was hospitalized with heart failure. He proposed marriage while I waited in the ICU for a donor heart. So there was love—a wonderful love—coursing through me when the surgeon put the transplant heart in my chest. Since that day, the love has only grown, between my husband and me; with our son, another gift of wonder, and with my parents and my steadfast friends. Even with my transplant cardiologist (my main doctor), there is a sort of love, a bond and a profound understanding, grounded in the respect that grows after sharing 19 years of hairpin turns and death defying acts. After he read SICK GIRL, these only deepened.