



Amy Silverstein

Heart Girl

*Amy Silverstein: A Heart Transplant Patient
Survives the Medical System*

By Donna Caruso

Chances are, your shelves are filled with books by doctors detailing various medical conditions or telling you how to live a long, healthy life. But where are the books by patients telling you what it's like to survive the medical system when you're really sick? We complain that modern medicine isn't patient-centered, but what are we doing to change that?

Amy Silverstein's important new book, *Sick Girl*, is a brutally honest, angry, courageous and ultimately inspiring story of how a young woman's life was suddenly and dramatically changed forever by a heart transplant at the tender age of 25. The book is both an indictment of the sometimes tragic failures of our medical system, especially when it comes to critical cases like Silverstein's, and a recipe for its improvement, based on the author's many years of intensive experience.

The Truth About Heart Transplants

You may think you know what life is like for heart transplant patients—the seriousness of their condition, the problems they undergo following surgery, the pain, and the long convalescence.

But you also probably imagine that after a while, they adjust to their new hearts and go on to live pretty normal lives.

Silverstein totally shatters these misconceptions with her step-by-step narrative of everything she experienced from the time her initial symptoms were completely misdiagnosed by her well-respected New York family doctor to her present-day life, filled with love, happiness, constant pain, frequent visits to hospitals and doctors, and the ever-present knowledge that she could die at any moment. It's a tale hardly any of us have ever heard, one with the potential to shake up the medical establishment and make it take notice. In fact, that has already begun to happen.

You may think you don't want to read a book like this, with its painful narrative of a bright, healthy, happy young woman with everything to look forward to being thrown, without notice, into a brand new life of fear, sickness from immunosuppressants and other needed medication, and the everyday uncertainty of how long her life can possibly last, informed by doctors that 10 years is the best she can expect.

But your reluctance will quickly vanish as Silverstein's book entralls you, her writing skills



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taking you directly into her life, her mind, and her body, as you accompany her through the journey of her life-altering experience. The fact that 19 years later, Silverstein is not only alive, but an active wife, mother, and dedicated writer, is proof enough that a strong character, determination, will to live, intelligence to question her doctors and her treatment, and maybe a bit of luck, can sometimes have really great results. You will find yourself rooting for her, wanting her to live, keep growing and changing, and continue her fight to improve our often inadequate system of medical care.

Each year, Americans undergo about two thousand heart transplants, but thousands of others remain seriously ill and even die due to lack of donated hearts. With a five-year survival rate of 71.2% for males and 66.9% for females, patients like Silverstein are cautioned that the best they can expect is 10 years, after which they will either need a new transplant or will die from various medical complications, such as lymphoma, diabetes, or irreparable artery disease.

Sudden Symptoms and Life Changes Forever

In her book, Silverstein describes how, as a high-achieving 23-year-old law student who had just started dating a promising young man, she begins to experience a series of unusual symptoms, including shortness of breath, heart palpitations, fainting spells, and even temporary blindness. Her trusted family doctor diagnoses stress and low blood pressure, prescribing rest and more salt in her diet. When her symptoms continue, Silverstein dismisses them and doesn't inform her doctor. It is only in retrospect

that she realizes how close she came to sudden death as a result of this grave medical blunder.

A year later, diagnosed with a "grossly enlarged heart," Silverstein is referred to a cardiologist. The stock market crashes in October 1987, a time, as Silverstein writes, that also "marked the definitive beginning of my life as a sick person on the edge of dying. I would never again know any other kind of life."

Her attitude toward her sudden and life-threatening heart condition is characterized by her "bad behavior," a refusal to accept her situation and constant arguing with and rebelling against her doctors and their treatments. While her father trusts in the infallible wisdom of physicians, Silverstein constantly questions and defies them. "Passive acceptance was the key to success as a hospital patient," she explains. "Shut up and take it." But the defiance that at first seems to be self-defeating later appears to be part of her indomitable fighting spirit, probably one of the main reasons she is still alive and functioning as well as she is.

Terrified of dying so young, Silverstein's pre-transplant combative and unpleasant behavior alienates many of the staff. Undergoing a heart biopsy, which she describes as "torture that no person should have to endure, not even once" (she has since undergone more than 65 heart biopsies), the diagnosis is soon delivered: a damaged heart, probably from a virus (later discovered to be a rare genetic disorder), requiring medication and rest. When this, too, fails, Silverstein is eventually informed that she needs a new heart, but remains in denial, continuing with law school and pretending that nothing is wrong. Finally, her symptoms become overwhelming and she tells her

boyfriend Scott that she needs to go to the emergency room, where her life is barely saved.

Informed that she needs an immediate heart transplant, Silverstein cries out, "I won't do it," preferring the prospect of death. Only when her father falls to his knees at her bedside and pleads with her does Silverstein finally change her mind. She describes the moment, saying "I would always wonder: did I make a choice at all?"

The Transplant and After

Noting that the sickest and youngest usually get available hearts first, Silverstein receives her new heart after only a short wait: the heart of a 13-year-old girl, which later turns out to be an almost perfect match, with a recent, newly developed tissue test revealing unusual equality on nine out of 10 criteria. The transplant surgeon states, "We saved her just in time," but Silverstein is filled with fear after the transplant, with apparently no one recognizing the intense emotions, as well as physical agony, she is going through. An unexpected proposal from her faithful boyfriend Scott provides some comfort and joy, but still Silverstein seems ungrateful, writing, "...I felt my heart transplant had taken my life away...I wanted to be cured. I wanted to have my healthy, carefree life back as I knew it."

Not one to wallow in self-pity, Silverstein soon makes up her mind about how she will live, saying, "I decided I would be normal." But she soon discovers that her attempts to live a normal life cause "perpetual self-torment and frustration." To this day, Silverstein says she has to continually "wear a mask," hiding her constant pain and fear from everyone, even those closest to her, claiming that if she didn't do so,



now understand that everyone's life has ups and downs and you just have to go with the flow, like the flow of breath, and that is really helpful for me."

Amy Silverstein Today

Silverstein is an intelligent woman whose unusual life circumstances forced her to become an expert in how to be a successful patient. She has evolved from an innocent, inexperienced, angry young woman caught in an unfathomable situation that altered her life forever, to a well-informed, stable woman who uses her wisdom to get the best medical care for herself and help educate patients, the medical profession, and the public about how medicine can be improved.

A member of the board of the United Network of Organ Sharing (UNOS), Silverstein joined the 25 doctors on the board in 2007. When they discover she has lived with her transplanted heart for 19 years, "they don't hide their amazement," she comments. "My doctors don't know why I'm alive, but they just tell me to keep on going." In fact, heart transplant patients have lived as long as 25 years, but they are a rarity, and Silverstein is the longest-living healthy heart transplant patient at her New York hospital.

Why does Silverstein think she has survived so long and what can we learn from her? Here are some of her ideas, including items from the list of intentions she made for herself shortly after her transplant:

- Take medicines every day, as directed, no matter what the side effects
- Do not gain weight, regardless of prednisone's tendency to cause weight gain

she would have no friends. So she begins running, hiking, racing with the bulls in Pamplona alongside her friends, and telling everyone she feels fine, when most of the time, she's in physical torment.

"This is a burden I must carry and I believe it is mine alone to carry as much as possible," she explains in an exclusive interview with *Life Extension* magazine. "It's too big, it's too ugly, it's too present. I get up and walk across the room and I don't feel right. My heart says, 'What are you doing? Is this necessary?'"

The Struggle to Stay Alive

Silverstein keeps asking herself, "Why am I alive?" Is her survival due to her medical treatment, her husband's unwavering love and support, the joy of being a mother to her son, or just plain luck? Giving herself some credit, Silverstein notes, "I did it. I had learned what I was made of,"

as she marries Scott, who 19 years later, remains her devoted husband and father of the son they adopted after Silverstein was warned that the risks of pregnancy were far too great for her to survive.

Emotional difficulties lead her to therapists, who invariably fail to help. After all, how can they possibly understand or identify with a young heart transplant patient? What can they know about what it takes to endure every day of her life and how she must somehow accept that her former easy existence is gone forever? Far more effective is a Tibetan Buddhist meditation class, which helps her to calm down, live in the present, and accept life as it is.

"It has taught me the wisdom to ride the wave of life," explains Silverstein, "and not cling to 'I'm well at this moment, just let me hold on to it,' or 'I'm not well at this moment, I've got to get out of it.' I

- Exercise to keep the new heart strong, no matter how difficult
- Complete law school, take the bar exam, and then set new goals.

Silverstein explains that she loves goals and they are a big part of what keeps her going.

How Patients Can Improve Medical Care

When it comes to the medical profession, her advice to patients is:

- Doctors are only human and can make mistakes; they can also like you or dislike you, and this can affect your treatment and care
- Patients need to go for second and third opinions, especially when things don't feel right to them; always keep in touch with your intuition
- Be prepared when you visit a doctor; keep a notebook with information on any symptoms you experience and discuss them with the doctor; take notes when the doctor speaks to you, so you will have a record, just as the doctor has a record
- Find a capable internist who is connected with a good hospital; if you become ill, you will be carefully handed to the next physician.

Silverstein Looks Ahead

How does Silverstein take care of herself? "I'm very careful with my diet," she explains, "and have meat maybe three times a year, if I'm at a barbecue and there's nothing else to eat." She also exercises vigorously. "I push until I cannot take another step. I go way beyond

expectations in terms of my exercise, to the point of exhaustion," which she believes may be one reason her heart has remained so strong over the years. No doctor told her to do this, it just seemed right to her, part of her program to "be normal."

Silverstein plans to continue her writing career and her advocacy for better medical care, aspiring to lecture at Columbia, and hoping her book will be put on the required reading list at Columbia Medical School (which is now under consideration). She also hopes her book will improve the way doctors treat their patients, as it already has with the kinder approach her own doctor now takes with her.

"If you don't feel right about your doctor, if anything doesn't feel right, go to someone else," she advises. "You want somebody who is willing to embark on the journey of your health with you and if they're not, go find someone who is, someone who is as careful as you are about your health, someone you feel good about and can have a comfortable rapport with.

"Try to avoid the pitfalls and the things that happened to me," she adds. "Always remember that you are a very important part of your medical care, you know yourself better than anyone else does, any doctor, any psychiatrist. If you don't have a doctor that believes that, find a different one."

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If you have any questions on the scientific content of this article, please call a Life Extension Health Advisor at 1-800-226-2370.

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