

Amy Silverstein Discusses Her Experience with Two Heart Transplants

Jennifer Cohen and Amy Silverstein

Jennifer Cohen 0:04

Welcome back to Voices in Bioethics. I'm Jennifer Cohen and it's my great pleasure to welcome Amy Silverstein to the podcast. Amy, thank you so much for joining us today.

Amy Silverstein 0:15

Thank you for having me, Jennifer.

Jennifer Cohen 0:17

Amy Silverstein is an attorney and author of two books the first entitled *Sick Girl* published in 2007 by Grove Press, and the second entitled *My Glory Was I Had Such Friends* published in 2017 by Harper Wave. Both of these books detail the two heart transplants she underwent the first as a 25-year-old law student and the second 26 years later. Subsequent to her heart transplants, Amy has practiced corporate law served on the board of the United Network of Oregon Sharing, shared her expertise with others through speaking nationwide on women's health issues and patient advocacy. In addition to her two memoirs, Amy has written articles for academic medical journals, as well as for the popular press, including *Self*, *Prevention* and *Glamour* magazines, and she shared her story on CBS News, ABC News, the Hallmark Channel, her story is set to become a series on Apple TV starring Jennifer Garner with Amy executive producing, and we're thrilled that she's brought her to the podcast today. Amy, your first book, *Sick Girl* is a beautifully written extremely reflective look back on your experience as a very young, fit, smart, high achieving woman in her early 20s with wonderful friends, a devoted boyfriend loving parents just starting out in the world, when you're suddenly confronted with this life threatening heart failure diagnosis that as the title suggests, prompts people to put you in a different category a quote unquote, "*Sick Girl*".

Amy Silverstein 1:50

Right.

Jennifer Cohen 1:50

Can you talk about some of these labels that you were confronting as a young person, *Sick Girl*, heart failure, and

how you reacted to them in these early days of the diagnosis?

Amy Silverstein 2.01

Yes, well, the first time I was called a sick girl was actually by a doctor and it happened just this way. I did get suddenly very ill. I was in my second year of law school at NYU, and all of a sudden couldn't keep up with my friends as they were walking, and I felt that I was sort of drowning in something in my throat. I went to my family doctor, and you know, pretty quickly was diagnosed with heart failure. They did a heart biopsy and told me that I had had a virus of some kind, maybe Coxsackie and had done some damage to my heart, but that it was going to be okay in six months. But about four or five months later, I was at my husband's graduation from his law school, and suddenly had an emergency situation where he drove me to the hospital. And when I arrived, they took me right and cut my clothes off and defibrillated me because I was having ventricular fibrillation, which nearly killed me. I called my doctor in New York and said, you know what's happening, you know, oh, I was supposed to be better. And he said, well, Amy, you're a very sick girl. That was the first time that I heard it. I hadn't thought of myself that way. I thought that I was a woman who had some sort of virus and viruses get better. So, I was labeled that by a doctor. I think what I've been doing in 34 years since then, is trying not to define myself that way. And before I get back and hear your next follow up, I just want to say that the rest of the people around me in my life, my parents, my friends, my colleagues, they do not see me as a sick girl. And you would think that that would make me feel good. But that also makes me feel upset because the truth is living with a heart transplant is a life of perpetual illness, it is. Immunosuppression is just another disease state. So I'm sort of caught in the middle, you know, and no one could win. And I understand that whether you think of me as a sick girl or not, I'm not very pleased with the way you see me.

Jennifer Cohen 4.02

Yeah, I think your book so beautifully navigates that paradox you just described, that illness has this power to bifurcate one's sense of oneself, that there's a sense that there's a real Amy sort of underneath the illness that you're going through and you're gonna fight that bifurcated feeling. But at the same time, it's maybe not a winnable fight, in the end, you're both those things. Is that a fair way of

Amy Silverstein 4.27

It is you know, it's interesting, Jennifer, I think about that sometimes. Am I my heart transplant? I know a lot of people who have illnesses, and they say I am not my XYZ disease, but I am my heart transplant. I am. There isn't, there isn't an hour in the day where I'm not dealing with something that has to do with my heart transplant especially during COVID time but it's all consuming, you know, having a transplant and so I can't forget it, I can't put it aside. So, the bifurcation is something that I find very frustrating because it just comes around to remind me that first and foremost, if I'm not a heart transplant, first and foremost, I will die. If I don't take my medicines, you know, I can forget about it, that's the end of me. So, you know, I've tried really to sort of accept that, you know, I am if you want to call me a sick girl, actually. And then I am also Amy, in that sick girl body, you know, sort of take away the body from, I guess, the spirit of me. It's an ongoing sort of quest, I guess.

Jennifer Cohen 5.33

Yes, yeah. It reminded me of Susan Sontag's essay *Illness as Metaphor*, the wonderful first line that everyone who's born holds dual citizenship in the kingdom of the well, and in the kingdom of the sick, and that we're somehow navigating both these worlds. There are so many themes in your book and I want to tease out as many as possible during our time together. But a major theme, in *Sick Girl*, especially is around information sharing and you come at this topic from many different angles. There's the clinical information sharing, and then the information sharing and your personal relationships, when to divulge, when to withhold details about your illness or your feelings about your health. So it's not too upset people around you, or even to calm yourself down. And information sharing about that sort of this dry neutral phrase, but in the way you talk about it, and I think in the way most people experience, it's something actually very profound, the decision to share one's sufferings and anxieties, and there's a giving away of maybe something that might be protective, when one shares how one really feels. And I think one of the ways you capture that is one of the chapters I love so much in the book about your wedding. And I'm going to jump around a little in our discussion, which is sort of the way the first book is structured. But one year post transplant, you're getting married, and it's this wonderful, joyous day, and you're getting dressed in an ante room, and you catch sight of yourself in the mirror with your veil, and your gown and your jewelry and you have a moment of not recognizing the person in the mirror. And you have a moment of thinking, am I sharing this room as another bride? Almost comical moment. Can you discuss that moment? And the thoughts in your mind and sort of the way you use that in the book as a metaphor, especially the veil, of when to disclose when to not disclose your feelings?

Amy Silverstein 7.30

Right, yeah. I haven't thought about that scene in a while. It's been 33 years since I have. But, yes, I do remember that moment, I suppose any bride who has a veil over her face and looks in the mirror, it could be anybody. It's very strange thing to look at yourself and not see yourself. So, you could be anyone. But yes, I do use the metaphor of the veil, of the mask that we wear when we have illness and we have that dual citizenship that Susan Sontag wrote about so wonderfully. I think that might even be to me the theme of the book, the masks that we wear, because I've look normal. Not all transplant patients do. But you wouldn't know that I have a transplant to look at me. So, you know, how much do you share? If you look normally, I've often thought if I were toting around an oxygen tank, or had a sign on my head that says, I don't feel well, that it might be easier. And yet again, with the bifurcation, I'm trying desperately for people not to know that. So this sharing of my sufferings has been at my wedding and since then something that I sort of struggled with, because I find that no one can really understand. No one can really understand what I feel what I live, it's so very abnormal. And you can say, well talk to another transplant patient, they understand, but they don't, because they're not me with a transplant. So, I live very much alone in the things that I feel and struggle with. And I have found that, for the most part, really expressing my sufferings does not do well for me. People come back with things that are really not helpful, you know, like, well "be optimistic", "look on the bright side", you know, "but you look so good". And even with physicians, you know, when you go to a doctor's appointment, you walk in, and the first thing your transplant or other doctor says to you is "you look great". What are you going to say to that? Yeah, but I feel awful. No, you're going to keep it down because a tone has just been set. And the tone is set by doctors and everyone in my life to, you know, look on the bright side, and really not share what you're really feeling, no one wants to hear about your aches and pains, right? I mean, at any age, it's just not something and when you start that at 25, they certainly don't want to hear about it.

Jennifer Cohen 9.47

Let's look at this theme of information sharing from the clinical angle, as you just mentioned, we'll pivot to that some of the issues you faced. There's so much discussion in bioethics about the ethics of information sharing the extent to which information should be shared with the patient in order for the patient to have quote, unquote, "informed consent", right. And your book is such a brave foray into the role of fear, and how that works to affect the way someone is reacting to information, the way it impacts a person's ability to think clearly. And again, I'm going back to sick girl where you were much younger, and you talk about one of the first interactions you have with a doctor where they're talking about heart failure. And I'm gonna quote what you wrote here because it's so honest and so accurate, I think how many patients feel "this consultation had become unmanageably scary, deflating my capacity to think clearly and remain calm. The newly bold, keenly critical patient in me began to slip away. In its place came the dreadful sense that I was being forced to take on the concerns and worries of a much, much older person, I began to backpedal. Moving away from everything I promised myself about being a smarter, more insistent patient, this time, my accumulated years began to fall away from me one by one, until I landed in the safe haven of a 10-year-old girl and a bratty one at that." Can you describe that incident, and then you go on to say that that sort of followed you because again, with the labels, something was put in your chart, about the way you reacted, enter the larger role of fear and whether through the decades of being a transplant patient that has changed for you. Has fear become less of a factor? If you've found ways to deal with it more effectively?

Amy Silverstein 11.44

Yeah, I'd like to tell you that I've become better at dealing with fear, I think what I become better at is saying, "well, you know, I'm 58, if I die, I've had a good life, you know, my son is older, I've lived longer than I should have with a transplant." So, I'm more accepting of death, I guess. But when I was young, the fear was more acute, but fear in itself has not lessened at all, and I haven't come up with a way to deal with it, that's any better. And I can't say that I want to be because if there is one thing that I'm sure of, it's that I am so happy that I am a human being and that I have cognition and that I can have emotions, and that I can feel them fully and react to them in a way that is appropriate in the scheme of life. When they tell you you're dying, I'm not a rock, we're humans, we were given, you know, emotional states. I mean, when you're 25, and you're dying, you know, you're upset, you're frantic with grief and fear. And when they tell you that at 30, and when you go through all of the things that I've been through, you know, to break away from this for one second, I had a friend of mine recently who had a traumatic event, and she's going to try some EMDR and she said to me, you know, maybe that'd be good for you, you've had so many traumas. And I privately went back and sort of started listing the traumatic things. And I'm not talking about, oh, I had a heart biopsy, I'm talking bigger things like, oh, I flatlined on a table, you know, with doctors all around me, things like that. And so, I counted them up and when I got to 43, I stopped, okay, because it just became too depressing. And I said to myself, how can I ever deal with post trauma because there is no post, there is no post when you live with a transplanted organ, it's perpetual. So, fear is part of my life, I accept it, I even embrace it, because it is real feeling and it's okay with me to feel it. The bratty part of it, I can't say that I become a brat. Still, I understand why I did I try not to, but sometimes I just, I can't be a mature person, I just want to wail a little bit. And I forgive myself those times, when I can't rise to the occasion, they're rare and I write about them, and I get some criticism for them from some readers. But I know I'm doing the best that I can. Again, it's a level of acceptance. It's not that I can put fear in a little box and I've got this and there it is, you know, and it's just

something's not going to get me down, it will get me down because the things that I deal with are immense. They are unimaginable. Now, I just want to say as a side issue, are their worst things, certainly there are there are a lot of people suffering out there with all sorts of terrible things. But I'm only focusing here on my own.

Jennifer Cohen 14.32

The acceptance is fascinating. I think if the expectation is to banish fear, as you say, that's always going to be a disappointment. And it's not possible and as you say, it's not human. So I think that that pivot you've made is, it sounds crucial to your ability to move forward to embrace fear.

Amy Silverstein 14.55

Yes, it is. It's pretty central in my life, and I think asking too much myself to rise above it every time and I think that the day that I just say, oh ho hum, you know another transplant cancer, okay, you know, that's all right with me, then I'm not me anymore. Then you really have that bifurcation in a terrible way.

Jennifer Cohen 15.15

Right. Another theme in your writing and in your life has been becoming what the medical world calls an informed patient. You wrote smart savvy patients are not born, they're made. Which I took to be a reference to Simone de Beauvoir's wonderful first line to the Second Sex women are not born, they're made. What were your strategies for becoming a smart, savvy patient?

Amy Silverstein 15.38

Learning the hard way, that was my strategy. It was forced. I mean, you don't realize that you have to be smart and savvy until you are on the other side of something where gee, I wish I were smart and savvy. Recently, I was asked by a transplant organization to answer some questions, one of which was, if you could tell yourself one thing, you know, go back to your old self just post-transplant, what would it be? And to me, it would basically be to realize that my survival would be so dependent on me being on top of every detail of my care in the years following my transplant. And to understand that no one not even a transplant physician is going to pay as close attention to my care as I am. And this means never ever handing myself over to a transplant team. Check everything, question everything, voice concerns, express reasonable intuition, and always, always be an active participant, if not the most active participant in your care. For instance, I'll give you one for instance, heart biopsies are part of routine transplant care to check for rejection. Cack in the 80s and 90s, those were early heart transplant days where heart transplant was just becoming routinely successful-ish. We were having a lot of heart biopsies back then, I've had 93 heart biopsies, none of which have given any actionable result. So, they are an invasive exam where you're awake, they go in through your neck and pull-out pieces of your heart and it's really unpleasant to say the least. You're not sedated, nothing like that. So with all of those heart biopsies that I just took willingly, because my doctor said biopsy time, biopsy time, I went for them, I went for them, I went for them. I didn't know that they could be harmful, but they are harmful, because every time they're done, your tricuspid valve becomes abraded. And at some point, in my first 26 transplant years, my tricuspid leaflets broke apart, necessitating an open-heart

tricuspid valve surgery on my transplanted heart, which is not done and it's really not good for the heart, or the patient for that matter, and it came directly from too many heart biopsies. So, I learned from that when a doctor says time for a heart biopsy say why? What is this really going to do? What are you going to do? If you find something? Why do you think you need to do this? Is this just protocol and plus parenthesis, they're about 60,000 a pop, or at least they were last time I checked for a heart biopsy, they are a money-making kind of procedure. So back to your original question, how did I learn to be a smart patient? By the hard way. You know, looking back and I wish I would have questioned it?

Jennifer Cohen 18.24

Do you think it's an incumbent on the clinical team to tell patients that?

Amy Silverstein 18.29

I think it's ideally the clinical team knows that and is looking out for the patient and sort of tallying it up too. You've had you know, 82 of these, maybe that's enough, and maybe we're gonna get a little too close to the tricuspid valve. Now, that's what I really think I don't think most patients want to know that your tricuspid valve can be abraded. I don't think most patients want to know that every time you have a heart biopsy, you're receiving enough fluoroscopy to the chest, that it's going to cause cancer eventually, which I've also dealt with. I think that if there's a very careful clinician watching, they will start to balance the utility versus risk of giving these invasive tests.

Jennifer Cohen 19.08

And did you ever hear from a clinician what you said at the beginning of the answer that it was going to be your role to be more informed? The most informed you possibly could to learn everything you possibly could. Do you think, did a clinician ever tell you to take that posture or?

Amy Silverstein 19.24

Yeah, that's a really good question, Jennifer. I've never heard that from any doctor in any part of my life ever. I mean, have you?

Jennifer Cohen 19.32

No, no.

Amy Silverstein 19.33

No, no, that's one of the things I speak about a lot and get out there and try and scare patients a little bit. Nobody's watching you as much as you, you know, nobody's taking care of your child like you are. Nobody's you know,

nobody cares as much as you do. But I think it would be good advice. I would think that there might be some issues with that. It's sort of saying don't trust me, trust you. I mean, that's, yeah, I don't know.

Jennifer Cohen 19.57

What were you told prior to the first transplant? I know you wrote that most of your family felt that once the transplant had taken place, this would be the end of your illness. Were you told what to expect as a transplant recipient?

Amy Silverstein 20.13

Yeah, I was told nothing. I was told nothing. Just that if I was lucky, lucky, lucky, lucky, I might eke out 10 years, that's all. And yes, again, back in 1988, right, they were sort of going by the seat of their pants. They were giving me all sorts of medicines that are not given now, they just really didn't know very much. But the survey that I referred to before, by the transplant organization asking me questions, I got to see some of the responses from other transplant recipients. And many of them were saying that they wish that their transplant centers would have told them what it would be like, the medicines they would have to take. The life compromise that comes with transplant was not talked about. Even now.

Jennifer Cohen 21.02

Wow. you've alluded to it a bit already. But can you describe some of the ongoing health challenges you've had?

Amy Silverstein 21.10

Sure. So let me preface this by saying I'm lucky. There are many, many patients worse off than me. Everyone I know who has received a heart transplant within 10 or 15 years of me is long, long gone dead many years. So, I'm very fortunate, also fortunate to have good health insurance and great support of friends and family. So that's terrific. But transplant comes with immunosuppression and immunosuppression causes infections. In the first 26 years of my transplant, I took over 100 courses of antibiotics, I counted, I keep a tally 100 courses of antibiotics. So, the infections are, or were, and I'll get to that later why it's different, constant, and really debilitating when you go from antibiotic to antibiotic. I've also had two cancers in the chest area. Of course, no one ever knows why they have cancer, but it has been told to me by cancer specialists that they look odd, they behave odd. And they are undoubtedly tied to immunosuppression and all of that fluoroscopy to the chest as well. So, I've had to deal with that. As I've told you, I had the open-heart tricuspid valve surgery on my transplanted heart, I also had with my first transplant a lot of arrhythmias. To get a little technical for a minute back in 88, they did a biatrial anastomosis, meaning that they left a piece of my original atrium and attached it to the new atrium of the donor heart. When you have two atria, they are both getting signals and those get very confused, leading to arrhythmia. And I had to deal with that, which was very disturbing to me. They now do it by Caverly, where the vena cava is the way of attachment and it's much better. But I didn't deal with that for many years.

Jennifer Cohen 23.03

You've written about in a recent article that we'll get to, you've written about something you call the gratitude problem for transplant recipients. Can you discuss what you mean by that?

Amy Silverstein 23.14

Yeah. So, when you have a transplant, there is an immediate expectation that you talk about nothing but your gratitude. You can't be anything but grateful because, after all, there was a donor who died. Of course, you didn't cause that death, but you are the beneficiary of that death. And so, it's expected that gratitude should be the prevalent emotion and certainly the only one that you talk about. And this puts a lot of pressure on transplant patients not to speak up and say it's hard. I've been hospitalized three times this year post transplant and such. It silences you, yeah. And what happens is when patients feel that they can't speak up, the world you know, the doctors, that your friends and family and this goes out to the general perception in the media and in society that transplant is a piece of cake. You know, look at it on TV ever see it on ER, it's like the person that gets a transplant, it's like an appendectomy, off they go, they look great, and it is not that way at all. So, there's an expectation out there that you need to live up to that you're doing great and you're nothing but grateful. Now I have written in Sick Girl that I was grateful, and I was grateful and sad that I was given up 10 year life expectancy at 25. Sad that the medicines that they gave me grew hair on my chest and back, which doesn't look so great in a wedding dress. Sad that I am with my young friends, they all feel great, and I feel so sick from my medicines that I'm carrying a vomit bag in my purse, which I still carry by the way and might need to use it. This a lot of pressure on transplant patients but there is another there was corollary of this that I find most upsetting. Robin, you know, in these 34 transplant years that I have had, there has been very little improvement, advancement in transplant. Can you believe the one-year survival rate for heart transplants has gotten much better, it's something like 97% at most transplant centers. But the long-term survival is still about 10 years, 10 to 12 years, has not improved. The funding and energy toward transplant research to help patients live longer is not there, and I think this is for two reasons. One, is because you know, Medicare, Medicaid payments for hospitals are based on a quote, "success rate" of keeping the patient alive for one year. Now, that's a slam dunk, as I said about 97% can do that. After that, doesn't matter if you can keep them alive two years, or 10. It doesn't matter. So, the money is in the first year and that's where the attention is to keep patients alive that long. And secondly, I think it's the gratitude problem that is a problem here. You know, if patients aren't clamoring for more, if they're not saying this isn't acceptable, no donor wants their loved one's heart to live on for one year, and no patient wants to live for one year. If they're not clamoring for more research and funding and energy, they're not going to get it. And with this very quiet, very grateful population, why should you know the NIH, or the FDA pay attention to transplant with a sense of urgency?

Jennifer Cohen 26.38

Okay, let's turn to I want to bring your second book My Glory Was I Had Such Friends into the conversation. First, can you explain the title and how you structured this second memoir?

Amy Silverstein 26.49

It's from a Yeats, quote, think where a man's glory most begins and ends and say my glory was I had such friends. He was referring to his war buddies, his fellow soldiers. I think very much of what my friends and I did during my

wait for my second transplant as a, you know, sort of a band of brothers. I think it was a band of sisters what we did.

Jennifer Cohen 27.13

Can you walk us through what led up to your second transplant? And why you were at a different transplant center than the one where you received your first transplant and all the follow up care?

Amy Silverstein 27.24

Yes, so about 26 years into my transplant, all of a sudden, I couldn't run anymore. And then I started having pain down my arms, even though they said that transplanted hearts can't feel pain because they are not attached your nervous system. Well, you know, newsflash, those nerves grow back because I was having cardiac pain. I had some testing, and it was revealed that I had vasculopathy extensive small artery disease, and what they call restrictive disease, which is very typical of heart transplants, that usually happens at year eight, year 10, but I was getting at year 26 and it meant the end of my heart. The question was, could I get a second transplant? The problem was that I had accumulated a lot of antibodies that made it very difficult to find a match. There are antibodies and there are dangerous antibodies, I had the dangerous ones. And my doctor in New York told me that if I stayed in New York, I would die because they did not have the treatments for the extensive antibodies that I had. He said my only chance was to go out to Cedars Sinai in California, join an NIH study with a special antibody drug complement inhibitor and try to get a transplant. It was a slim chance; I was dying fast and my antibodies were so high that I was 84% of the population would not match with me. That's how high my antibodies were. So off to Cedars Sinai went.

Jennifer Cohen 28.49

And that's been an advance this new matching system based on antibodies, whereas it beginning it was sort of blood type and size

Amy Silverstein 28.57

It definitely has; however, patients aren't living any longer.

Jennifer Cohen 29.01

Oh, interesting.

Amy Silverstein 29.02

Back in my day in 88, they matched based on blood type, and that was it. And there have been advancements in treatments for antibody mediated rejection so that they can bridge a person better to get another transplant.

Jennifer Cohen 29.16

I see, okay, so I'd like to bring in this theme of autonomy, which again, is so central to bioethics. The idea that an individual patient is making a decision about their health care or to put it in sort of a negative formation that a doctor or a family member is enforcing a decision on a patient. And both of your books are fascinating looks at the complex way decisions were made about your health care and the first book, the people in your life are primarily your husband, Scott, and your parents. And you talk about in *Sick Girl* when the idea of a heart transplant is first brought up and you have an immediate reaction of no, your father bursts into tears and really collapses saying you can't leave and you say yes, and then you write, I would always wonder, did I make a choice at all. And the second book, it's an exploration in nine chapters of nine women who, you know, upended their immediate life in order to rotate out and be with you at Cedars Sinai as you waited on the transplant list. Can you discuss the ways your family and your friends in particular, for the second transplant influenced your decision making?

Amy Silverstein 30.32

Well, and also my doctors influenced my decision making. I've never seen it. And in a way, I hope I never see it. But I've never seen it in medicine, or in my family, or my social circle of anybody saying, you know, that's okay, Amy, you can die. It's just you can never say die, never say die, that is always going to be a problem in my decision making, because I feel differently than they do. Again, even when I was at Cedars Sinai waiting for the heart, dying, I looked good. You know, I would get dressed every day, and someone would come in to take me for an x ray and say, "okay, who's the patient?" and it's very hard when you're looking at somebody that looks okay, to say it's okay to die. And, you know, with my friends and family, they see me as so very alive and vibrant, I just have to keep going. And that's easy for them to say, because they're not living with the complications and daily illness that I lived with you after my first transplant. I am a rare person I've never heard anyone else say it although I think probably many people harbor this, this thought is that I think it is okay to choose death. Not in every circumstance, but in my circumstance. I think that if at any point, I don't want to do something and I say, that's enough, I think I've earned the right to say that and no one in my life agrees with me. And that was a hard thing out there in California, because with each successive friend who came, I was trying to convince them of that. And they saw me dying and they saw the horror and the heart pain and what I was going through, and they were right there sleeping by my side in a cot every night on a cot and they got as close as they could. And I thought we could have a conversation and they would say, you know what, Amy, I support you, but they couldn't, and they didn't to the end, to the end. So, you know, another point of acceptance, I understand that I'm going to be alone in this view, and that the choices that I or the choice that I may make someday will not be understood by those around me. But I will make that choice someday because I do have limits. And I think that in terms of making choices, health choices, I think healthy people or reasonably healthy people, many of them think that they don't have a limit. They haven't gotten near it. I've gotten to mine. I know what it's like. You might mention, Jennifer that at some point I said to my doctor at Cedars, I can't do this anymore. I was all night long with excruciating cardiac pain, it was just too much, and I said I can't and he said give me 30 days, give me 30 days and if you don't get a heart in those 30 days, you can turn off your pacemaker, they had given me a pacemaker at Cedars. Now if I turned off my pacemaker, I would die. And that could be my choice. Now, I don't know if we reach those 30 days if you would have allowed it or thought I was insane and not allowed it or whatever. But in my mind, I was taking him at his word, and I got the heart six days before that 30 day limit. But I think about it sometimes and I would have made that choice, I would have turned off the pacemaker and it would have been okay with me. And that's something no one is ever going to, a choice no one will ever allow. Although I will take it if I need to.

Jennifer Cohen 33.54

It's escaping me now which friend you discussed it with but in the second book, you talk about your consideration of medical aid in dying as an option.

Amy Silverstein 34.05

Right.

Jennifer Cohen 34.05

And the friend acknowledges that's an option that's on the table, not one that the friend liked. And how good it felt to have the friend just acknowledge that that was almost the first time that someone hadn't immediately said, well, no, you know, rejected that out of hand.

Amy Silverstein 34.19

I think I've gotten them to the point of being able to discuss it without shutting me down. But it's almost like how you move a child along and I really don't like it, you know, in terms of yes, good, okay, well, we'll have a lollipop, you know, but first we're going to do this and this and this and you're not gonna give them a lollipop because they'll be busy with something else. I don't think they take it to heart; I don't think they take me seriously. A theme I thought about writing about in a book, although I'm not putting it in my next book, but I constantly think about it, is the idea that there are some things, medical or not, there is some things that we all know to be true in our heart of hearts. There's something you know, and maybe the people around you don't, and they might not. But you know that one thing to be true. And I know to be true that at some point, what I'm going to need to do is going to be too horrific that I've just reached my limit in terms of what I can carry medically. And whether anybody knows that or not, that was not something I knew at 25 at 58, I do. You know, we're sort of talking on this side of it, but the whole other side is that I'm so grateful. Today, actually, as we interview is my eighth anniversary of my Cedars transplant, May 9. And I had a kettlebell workout this morning, and after I sat on the ground and looked out at the beautiful trees, and I am filled with gratitude. When I walk up the stairs in my house to the top level, where my bedroom is, I pause at that landing every time for a little second and I smile to myself, because I know what it's like not to be able to walk up those stairs, or to walk up and have my heart go out of control and think I might have to dial 911. So, with all of this sad stuff I'm talking about, there's enormous gratitude too, but the gratitude does not erase the challenges that I live with. And the fact that I've been through so much that, you know, like, people say, it's okay for people to say, I've been to war, you know, three times, I can't go back to war. And we sort of understand that. But if I say I can't go back to work nope, nope, nope, you're going back to war. Right, so I think that's a great analogy.

Jennifer Cohen 36.27

Wow, oh that's so beautiful that today's the anniversary and oh that's wonderful. Let's briefly talk about the two

very different experiences you had post-transplant at two different centers. Can you talk about the variability in follow up treatment protocols you experienced; it surprised me to read about how different they were two different centers. And then you could talk about the centrality of a transplant center for ongoing care how important that is.

Amy Silverstein 36.57

You know, I was at a transplant center in New York, and I thought that was the best one, right? You don't know, can't I was young, you don't know that maybe it isn't. I was matched up with a physician who I really didn't match well with. And the program, it always seemed a mess to me. I felt like I was driving the bus have my own carrier. You get blood taken, it wasn't the days where you could look up your blood results online. No one would get back to me it was too late, it was just, it was a complete mess. No one had their hands on the steering wheel and witness the tricuspid valve, but many other things and it just made it so much harder. I was constantly sick, way, way too much medicine, too much immunosuppression because when I went out to Cedars Sinai, they looked at my blood in a more sophisticated way and said, oh, you're taking way too much medicine, you're way too immunosuppressed. That's why I had all the infections and cancers and whatnot, at the earlier centers. So, I didn't realize when I was at that New York Center that it was really quite a mess. It was only in retrospect, when I got to Cedars, and I didn't want to go to Cedars I didn't want to leave. It's like not wanting to you know, leave your abuser until you get to this other place. You can't look back and say what? So, it was basically a mess. Other patients there felt that it was, but we sort of thought, well, that's transplant. And then I arrived at Cedars and I really had my dukes up. You know, I was like, what are you saying? What are you doing? Who's doing that? Who's that? Because I expected the same kind of thing. And I watched myself sort of take off my boxing gloves slowly but surely, my doctor there every time he walked into my hospital room, he gave me a handshake, I realized I'd never shaken the hand of my doctor in New York and 26 years. Now we hug you know, so the way Cedars Sinai works. They're just so kind and so well organized. I think that kind of organization starts at the top, and they all feel whether it's the nurse or the person who works at the reception desk, everyone, they feel like they have the plum job. They're very well respected and contributive to care and everyone you know, hums together. I really am hesitant to use the word but it's perfect, it's perfect. And now not that I take my hands off the wheel, but I'm not gripping it. And they also have a genuine respect my doctor does for my input and my intellect and he says it like, "well you know your body Amy" or "I trust you on this Amy" or "what do you think about it, Amy?" At my other center and 26 years, my doctor never knew who I was. So it's very important that your transplant center fit you well, that your doctor fits you well, and that you can feel secure in it. Not this iffy feeling like oh my goodness, what's going on here? Because there is so much contact with your transplant center from blood work and the ongoing exams and things are always coming up. So when I wrote Sick Girl I wrote in that book that I pretty much was having a very hard time and at times felt like I couldn't go on. And I wrote at the beginning of My Glory Was I Had Such Friends that when they told me I needed a second transplant, I was really on the verge of saying no. And now I say, if I needed a third transplant, where do I sign, I'm in now, I don't think I'll need one anytime soon, I don't know if they would even give me one, but I'm in because I have such a different experience. I want to add one more thing is that I'm involved with a lot of different transplant recipients on various committees and organizations. And I hear that from all of them that there's so much variety center to center, and it's just that way, so where you land or where you put yourself is very important.

Jennifer Cohen 40.48

Okay, let's turn to some of the specific policy work that you've been involved. And you recently published an article in *Transplant Infectious Disease Journal* on Antimicrobial Stewardship Programs. What are those and how have they changed antibiotic use in hospitals?

Amy Silverstein 41.05

Well, I don't know that much about them because I, you know, I wrote my own opinion. But I did lead a major paper for the *American Journal of Transplantation* that was all about the importance of having these stewardship programs, transplant specific. Which means a group of infectious disease doctors, specific to transplant, who are attached to the team, who everything is run by, when a transplant patient needs an antimicrobial. You know, taking something as simple as a Diflucan pill, which is for a yeast infection, can interact significantly and push the transplant calcineurin inhibitors, which all transplant patients take, pretty much, to a toxic level immediately. So, it's very important that there be very careful attention to anything that a transplant patient takes. antifungal, antibiotic, antiviral. And of course, antibiotics need to be very carefully attended to also because transplant patients take way too many of them and they become ineffective, and then you have resistant microbes and that becomes a real problem. So, these stewardship programs are essential. Some hospitals don't even have stewardship, you know, groups for the whole hospital never mind transplant. So, I am pushing for and wrote about how important these programs are and they asked me to write about, they gave me a name, The Good, the Bad and the Ugly in Antibiotics and the Transplant Patient. So, I wrote about my history and that lands in a very virulent *C. difficile* infection that I got when I was in the hospital after that tricuspid valve surgery. You see how it all comes together? It almost killed me, you know, vancomycin, vancomycin didn't work, didn't work, didn't work. I had a fecal transplant years before they were doing them. I had done stealthily by a very intrepid gastroenterologist and saved my life. So, *C. difficile* was a real problem in the transplant population. I'm all for the stewardship programs. I hope that it gains traction, I think it will.

Jennifer Cohen 43.07

It's such an important subject and you describe perfectly this kind of better safe than sorry, skittishness around transplant patients that results in this over prescription of anti-microbials. And again, tying into your point about information knowledge, self-advocacy, it's so important, especially when you get outside of the transplant center population of clinicians, of gynecologist or dentist to understand the effects of anti-microbials on yourself as an recipient. You come up with a very practical suggestion of transplant recipients being given a chart that talks about facts and warnings about antibiotics, antivirals, antifungals and patients can then share that with other medical providers. Have you gotten a response to that suggestion, which seems eminently reasonable?

Amy Silverstein 43.56

Well, the article hasn't been published quite yet. But I hope that they will take it to heart patients can share this give it to their doctors, because the truth is the primary care physicians are really the ones who are giving those ear infection antibiotics and giving them flucan pills. It's not, you don't go back to your transplant center for that. So, it's really important that they know, so hand that to them, or at least patients should be aware that when it comes to any drug you get, you have to check and they don't know that, they don't.

Jennifer Cohen 44.26

Yeah, and primary care physicians will not coordinate with the transplant center and your experience.

Amy Silverstein 44.31

They don't really know that they need to until you tell them. So, you know, I'm just bringing it down to the patient. You know, it has to be woven into their post-transplant, care and knowledge. I mean, they're given booklets about how they have to look for signs of infection and so on. This should be right in there. It should be part of their basic education.

Jennifer Cohen 44.54

Finally, Amy, let's end with the future of transplant care. The first heart transplant was done in 1967, 55 years ago. The introduction of CNIs, calcium neuron inhibitors to fight rejection post-transplant, that happened in the early 80s. So, the operation and the drugs have been around now for decades. As you've mentioned, the long-term survival rates haven't moved that much. What type of research would you like to see go into heart transplantation?

Amy Silverstein 45.22

Yeah, I love that question. I would really love, and they're working on it, but not fast enough and not with enough funding to see an alternative to calcium neuron inhibitors. If you ask any doctor who was honest in transplant, they will tell you that CNIs have had their day. They have really bad side effects, which I didn't touch on, I'm very lucky to have avoided many of them such as high blood pressure, dyslipidemia, kidney failure, all of these other problems that come to many, most transplant patients. So, I would like to see an alternative to that, that can keep the organ going even longer. What I am most interested in and most hopeful for, are sort of things that are out of the box like nanoparticle technology, for instance, which they're using in cancers. What about the idea that you can, and the reality that you can, direct a medicine through nanoparticles to go directly to the organ, immunosuppressing the effect of the body's immunity in the organ itself, rather than shutting down the whole immune system. Things that are more targeted, I would love to see more targeted medications to be more effective, and less toxic to the body. One thing I do want to stress here at the end is, in the meantime, while they're trying to come up with better drugs and longer life, I think what is really important and perhaps overlooked is the quality of transplant life. If we're here for 10 years, let's make it a good 10 years, let's not give us more heart biopsies than we need. Let's not give us more medication than we're going to need. The fact that I was taking all that medicine when I came out to Cedars Sinai and they said, "well, you're taking way too much medicine." I felt so sick from that medicine and yet I was still dying. It wasn't working. So, pay attention to how those years are lived. Really pay careful attention to what you can do to improve patients' day to day lives. And that could be reducing their medicine judiciously and also being kind, you know, offer a bottle of water when they come to clinic if they're waiting there for 45 minutes. These are limited life years. Let's be honest about that and let's try and improve them.

Jennifer Cohen 47.39

Amy Silverstein, thank you for sharing your story and for working so hard on behalf of heart transplant patients and best of luck in the future.

Amy Silverstein 47.47

Thanks so much, Jennifer. It's a pleasure.