



The
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Society™

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A Patient Perspective

Annie Barlow

The EDS Global Learning Conference 2019 Nashville

Video <https://youtu.be/llggvfD2swY>

[00:00:00]

[00:00:06] **Annie Barlow:**

Hi! Welcome. I've never spoke in front of such a huge audience, so, if you could all strip down to your underwear, that would be really great for me.

[Laughter]

[00:00:17]

Just kidding...just kidding. I was born on November 22, 1983, to Wanda and Jim Barlow, in Centralia, Washington. Early childhood was great, lots of laughs, lots of camping, lots of good memories. The early 90s took a turn, however, and dad started having major complications. After a couple of surgeries, we were put in touch with Dr. Byers, for dad, my older brother Spencer, and myself were all diagnosed with vascular Ehlers-Danlos syndrome. On December 12, 1994, dad was stolen from us, of the, by the monster that is vascular Ehlers-Danlos syndrome. His aorta ruptured. He was 49.

[00:01:09] Since, our family has changed, but the love is still there. Spencer's had some complications like a bowel rupture Christmas Eve 2011. But that was since been reversed and he's doing very well. I've had migraines, a slow heart rate, I've had migraines, a slow heart rate, but in 2007, I was diagnosed with two internal carotid aneurysms but in 2007, I was diagnosed with two internal carotid aneurysms. I wanted to have some fun then, because that's what life is all about. I wanted to have some fun then, because that's what life is all about. Went to the UK and got deported.

[Laughter]

[00:01:50] They thought I was there for free medical care. Not the case. In 2009, I went to Barcelona for three months and crossed something off my bucket list. Skydiving! Whereupon arriv –

[Applause]

[00:02:07] Thanks. Where upon arrival back home, at an appointment with my neurologist, she told me: "I have common sense. I need to start using it." Well, I – in my opinion – I did use the common sense. When was the next time I was going to have that opportunity? And I leapt at the chance, no pun intended. Between 2009 and 2016, things were good. I went to Burning Man and a bunch of other adventures with the ones I love the most.

[00:02:43] August 21, 2016 changed my life. I went to the hospital complaining of side pain thinking it was a kidney infection. So, I wasn't very concerned and neither was the staff. In fact, it wasn't until I did a – I peed in a cup, they thought something was wrong. I had a CT scan. Turns out my renal artery had dissected. I was put in a closet where they kept all the extra linens and the hot towels because they didn't think it was that big of a deal until after I had the scan...And things started moving very quickly. I was transported to a bigger hospital where they could care for me, and once I got into the hospital, it was a domino effect. Things just started rupturing and dissecting. I can't even remember the order or how many actually happened. But it was pretty painful, and my mom was told, expect the worst. We can't really do much. I was in ICU. I was miserable. I cried to my mother every day: "Kill me now. This is not what I want."

[00:03:54] On August 29th, I coded. I flat-lined. Luckily, my mom who was an RN, and in the audience today, she was there and yelled, "Code Blue!" If it wasn't for her, I don't think I'd be standing on this stage today.

[Applause]

[00:04:16]

I woke up with the tube down my throat and tons of tubes and wires all around me, beeping, making so much noise...but they were keeping me alive. Some of the ruptures and dissections included my superior mesenteric artery and a carotid cavernous sinus fistula...which no one caught until I was out of the hospital for about a week or so. My eye was dilated. My eye was droopy. I was dizzy, I had double vision, and I had what sounded like a washing machine inside my head. Since my mom was a nurse at an eye clinic, she knew this wasn't good, and had her connections figure something out. We got diagnosed with a, a fistula. I was put in touch with Dr. Daniel Holland at Harborview. He had only had one experience with somebody with vascular Ehlers-Danlos and a fistula. In my opinion, he was the best doctor in the area to do what we had to do to fix what was going on. Dr. Dan decided to do an intravenous route instead of an arterial route just because of all the dissections and ruptures that I have in my abdomen and pelvis. So, they started at my right groin, took some – two coiled, platinum coils and traced them all the way up to my left eye. That took seven hours. We were told it was going to take two. The coils relieve the pressure of the nerve and the aneurysm of my carotid artery. It was successful. And you know it was successful when I woke up and the washing machine cycle had finished, and Dr. Dan was fist-bumping the nurses. It was time to heal because I was, because I kicked the monster to the curb.

[00:06:10]

Healing was tough. Headaches all the time. Exan—anxiety and pain every day. All the time still. But this girl, Lula Mae, and this guy, makes my days brighter and better, and makes me what I want to live for. I was a nanny before all this, but decided for the safety of the children that I worked for, that I should quit and pursue happiness, and adventures and love, whatever that may be.

[00:06:39]

In November 2017, I was given options to try and fix the eight or so aneurysms in my abdomen and pelvis. One included a car—cow artery. But none of these options were a hundred percent certain, and we didn't know what my quality of life would be like afterwards. So, I chose not to. One of the doctors in the room said a prognosis of six to eighteen months. It was 18 months in May and I'm still here.

[Applause]

[00:07:18]

I'm getting married in October.

[Applause]

[00:07:22]

Thank you. October 25th, actually, it's my dad's birthday. We're getting married at the park where he actually maintained and passed away. But I know that he'll be there, and I know that he would love Jason as much as I do. Because of everything, I have decided to live every day to my fullest. Even if I can't get out of bed, sometimes I'm still – sometimes I'm – excuse me. I'm still a joker that loves to goof around and have fun. I've had to adapt to this new normal at times, and it has sucked. So badly I just wanted to give up, but then I realize how lucky I am. I died. My heart stopped. But I'm here and I'm still going. I have some limitations, but I also break those sometimes...because what's life without fun and adventure, and breaking the rules? I've also had to adapt to losing people in my circle. Some people don't get it. I look fine on the outside, but on the inside, my aorta and my arteries look like some crazy root growing off the Tree of Life. It's heartbreaking that some can't understand and it makes me love those close to me even more. A mantra I've been saying since I got out of the hospital: "Live fully. Laugh loudly. And love fiercely." I try to do this every single day. It may seem easy to say it, but it's kind of hard to live it. Thank you, so much, for allowing me to tell my story. You can put your clothes back on now.

[Applause]

[00:09:12]

And thank you to, Lara, and the organizers, speakers, volunteers, and everyone else involved in this conference. It's been amazing. Thank you so much.

[Applause]