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Proem

Hi. Each of us can remember a moment, an event, or a time in our life when we realized the fragility of health. The first question I ask many of my guests, when did you realize health was fragile? Breaks the ice. It tells a brief story. And it shifts the brain from nervousness of a recorded conversation to something personal.

I recently attended Health Voices Conference sponsored by Janssen Johnson and Johnson Pharma. I. Janssen invited about 95 patient advocates for three days to network, learn, and party. What an opportunity. I brought my recording equipment and asked three questions. I asked,

- When did you first realize health was fragile?
- How do you recognize success in your advocacy?
- When you meet a newbie advocate, where do you point them for skills, resources, and research?

I spoke with 26 of the participants for about five minutes each resulting in over two hours of recording. I can't include all four topics in one episode. So, in this episode I'll share when people first realized health was fragile. I'll cover the others in subsequent episodes. For this episode, listening to the podcast audio will suffice, but seeing a snapshot of the speaker's beautiful faces might be nice. So read the transcript or watch the video on my YouTube channel. Thanks.

Podcast intro 01:46

Welcome to Health Hats, the Podcast. I'm Danny van Leeuwen, a two-legged, cisgender, old white man of privilege who knows a little bit about a lot of healthcare. And a lot of our very little, we will listen and learn about what it takes to adjust to life's realities in the awesome circus of healthcare. Let's make some sense of all of this.



Estela Mata 02:23

We take health for granted. And when you know that your life can be taken away, your health conditions can make an impact, I think is when you realize it.



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Sharnae 'Nae" Smith 02:42

Oh my gosh. I'm gonna tell you, it was like right when I got diagnosed with Lupus. Because I was living my best life. I was happy, I was young, I was free, Didn't have any worries, no stress, nothing. And then to get that diagnosis that I had Lupus, that's when my whole life changed. It's one minute I'm going on trips, living my best life with all my friends, and working a job, and now it's just oh, okay, so now I have to tend to me. You get diagnosed. It's, it must be more about you. I realized then like health is just fragile. I was taking advantage of it every single day. And so now I realize how important it was. I should have been taking care of me from the beginning.

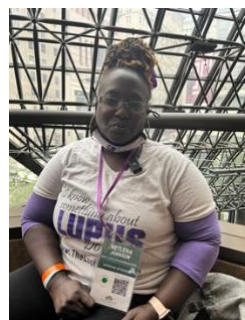


Jim Snedden 03:28

In 2005, I was handed a few too many issues. I got laid off from work. My daughter was raped, and I wound up getting psoriasis from that.

Christine Von Raesfeld 03:48

Oh, I think I have known that health was fragile my entire life. I will tell you, I have talked to people and I tell people that I don't remember a day in my life that I've ever had without pain or without ever some kind of issue. I would say my earliest memories were always pain and I experienced them even at like 3, 4, 5 years old. My first surgery was at five. I do tell people that being sick early in life and having this, has really given me a different sense of what life is. I live in Silicon Valley where most people are focused on money and all of that. I don't have that viewpoint. Money is nice, but I think really just having happiness and just knowing that you're okay. I meet a lot of people with money who are not happy. And even with my illnesses, I have a pretty amazing life.



Hetlena Johnson 04:42

I realized health was fragile when my health was threatened. Oh, okay. When my health was threatened, when. Being young you think that you can live forever and that everything is happening around you is nothing compared to you being you. And I wasn't jumping cars and things like that, but I was skateboarding, riding that bike grew around brothers and just living life like a thrill. Then all of a sudden you get hit with a chronic illness and it's whoa, stop. You cannot do the same thing that you were doing. That's when I realized, and my health was sensitive and that my life was fragile.



Jason Crum 05:22

I first realized my health was fragile during the pandemic. I was hospitalized and put into the nursing home because I had developed a poly neuropathy, poly peripheral neuropathy. I'm sorry. I also have HIV. As well as Monoclonal Gammopathy of a



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undetermined significance, which is a precursor to Multiple Myeloma. And I have chronic Hepatitis B. So I'm fragile.



Jason Jepson 05:57

I have schizophrenia and it was back when I was early in recovery and I was a danger to myself, my parents and they had to call the police on me. I wasn't arrested or anything like that, but they took me into custody. I was in handcuffed in the driveway. This is the bottom. But I knew I was going to finally get help and figure out what's going on inside my mind. Thank you.

Brooke Abbott 06:26

I probably was pretty little. I've had asthma in my whole life. I mostly advocate for inflammatory bowel disease, but I have been an asthma patient. I think I was diagnosed at one and a half, but I grew up during the AIDS epidemic. I had a lot of people in my life who were severely impacted by how it was mismanaged. And I understood very early how quickly your health can turn around. Knowing someone who was very healthy one week and then, unfortunately not alive in the next few weeks.



Phyllisa DeRoze 07:28

I realized health was fragile really when I was diagnosed with diabetes. But I was misdiagnosed. Oh. For eight years. Yeah. So, I would say I was 30 when I realized fragile health was fragile.

Bethany Yeiser 07:49

I think that I first realized that health was fragile when I was diagnosed with schizophrenia. I remember learning that it was a brain disorder that could affect anyone, and I learned that 1% of the population in every country, every race, every socioeconomic status, 1% of all of these people developed schizophrenia. It was no respecter of persons.



Ken Taylor 08:20

I'm a caregiver. So, I don't have a diagnosis and so it took me a little while, but my wife who I give care too. And she saw 43 doctors before she got a proper diagnosis. That's what really got me to realize how fragile things are. But that's what really triggered it for me, is watching her go through it. Naturally, when somebody has a catastrophic event take place, they don't have all the answers. Who does? So, you put most or all of your trust into the doctors and hope for the best. They're the experts. And we did that, and it took us down a few paths that we never would've chosen for ourselves had we known the outcome.



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Cindy Chmielewski 09:35

When did I first realize the health was fragile? I think I was fortunate that most of my life, I was healthy. My family was healthy, my children were healthy. So, I don't think until I myself was diagnosed with a cancer did I realize health was so fragile. I had friends who were going through hard times. But it wasn't really happening to me. So, I really, I felt bad for them. I don't know if that's good or bad, but I felt for them, but since it wasn't affecting my life, I just moved on, not realizing how health can impact your life for a long, long time.



Jesus Guillen 10:35

Such a simple, complicated question. First, I guess I was never the much type full of testosterone guy first. So, in some way I was always fragile. But the reality is that then like I mentioned before, my life has never a nine to five life and things happen to me for good or for bad. And sadly, and I'm not one of those guys, I can tell you I'm so glad I have my disease and that's why I'm here. I'm sorry. I just cannot say that. So there, being very honest, my health is getting. I think the moment that I started to feel really fragile the most was when I had cancer and I was so fragile that I felt my words because the nurse was even cleaning my shit, like they say. and I couldn't hardly move. I remember I was in bed one time and because I was not able to move for a long time. My back started to hurt a lot and I called the nurse, and I pressed the button and I said, something is really wrong. I'm in incredible, horrible pain. And the nurse came over and all he did was he just moved me to the side. because it was just because I've been not moving for a while. That's why I was hurting so much. But I want to get fast mentally also. That's when I got started to become more fragile because I suffer of anxiety and PTSD. And every time before going to bed, when the anxiety goes too high, that's when I feel the most fragile.



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Christopher Quimbar 12:31

I don't have any major health issues, but I have had family members, loved ones who are still here and some who are not here, who've dealt with major health issues. I've been a caretaker, so to speak, and I've had a partner pass away for mental health issues. I've had another partner who recently passed of HIV. And then my sister right now is, oh, my father also passed of cancer. Yeah. So it's certainly been in my life for as long as I can remember.



Stephanie Chuang 13:06

I first realized health was fragile when I was suddenly diagnosed at 31 with cancer. And at the time, and I hear this, I interview a lot of patients myself, and at the time I was a journalist, a TV news reporter and explained away all of what the first symptoms were fatigue. I'm exhausted because of my job. Bloating because I'm a woman. And it wasn't until there was a very foreign cough that was the catalyst to get me into the doctor same day. And from there, 24 hours later, I got the call that I had cancer.

Michelle Nadine Baker

The day I was diagnosed, which I'll never forget. Okay. Like many cancer patients and it was back in, in 2012. So, I have blood cancer leukemia called Chronic lymphocytic leukemia.

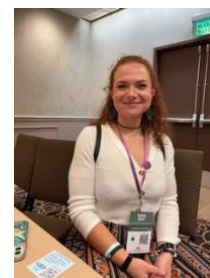


Jenna Greene

I first realized that health was fragile when I was in my late twenties and I was sideswiped by an ambulance and in a car accident. They were going to Dunkin Donuts, and they didn't see my little silver car. I'm not a bad driver, I just like to put that out there. They were not on alert. So that started some chronic back pain issues for me. A very lucky to be privileged growing up, rather healthy and active.

Kara Beck

Ooh I feel like I had a general sense of it for a long time. I grew up struggling with my weight. I grew up fighting that and was a test bunny in the medical field. Got a bunch of tests and I continued to struggle with it up until my adulthood and into my first pregnancy. and that's, I think, where I really realized that health was fragile because I had been facing the health issues my entire life, but I was in the hospital frequently with my pregnancy, and there were sometimes where my son's life was at stake because my health was not good. I had high blood pressure. I was induced two weeks early and he, both of us were struggling just because my health at the time was not where it should have been for a proper pregnancy. And it was that moment of fear for not just my life,



but for his, because I was like, I, I knew from growing up that I was not okay. But seeing it in a different perspective, it really woke me up.



Jasmin Pierre

That's a good question. Honestly, I feel like when I was 20 years old, because that was the first time I was diagnosed with depression. And I learned how broken the mental health system is, and that just woke up my eyes. Because until that point, I figured like the healthcare system had everything covered. Like they knew what they were doing with everything. But it's like with mental health, there's even things like healthcare professionals still don't understand. It's very misrepresented, just filled and it felt horrible being diagnosed at that time cuz I didn't really have a lot of resources or things to go off of. So, it's like I had to research and find out how am I going to navigate all of this?

Sue Rericha

Oh, probably really young. My grandfather had a lot of health issues, even though he was a few states away. I would hear stories from my mom. He had diabetes as well, and he also had cancer and some other conditions.



Alexis Newman

What comes to mind for me is when I was diagnosed when I was 18 months old with Type one diabetes. so I don't necessarily know, if I ever thought life was fragile, but I always knew that I just had to do extra things in order to stay well and be well. So like I had memories of like when my blood sugar would be very low and my parents running into the room shoving icing down my throat to help with my blood sugars to help them come up. So, I just have those memory. I don't know if I ever resonated about being fragile.

Ryan Williams

I first realized health was fragile when my grandmother seemingly went from zero to a hundred with Alzheimer's disease. She just, she went so bad so fast where it's just wow, health. Like you could get sick that fast and that really stuck.



Sam Seavey

Probably my mother passed away when I was 15. Passed away from breast cancer. And that was 1991. Oh, so I think that was my first experience with that kind of thing.



Andrew Shorr

In 1996, I was getting routine blood tests, and later that day I found out I was diagnosed with leukemia. I was 45 and I thought that was the end that I was dead, so I felt pretty fragile.



Howard Chang

I was diagnosed with psoriasis as a child. I lived with my grandparents who came over from Taiwan because they were sick. So I think very early on, my grandpa had two strokes and a heart attack. He was in a wheelchair. So I think I had a sense of the fragility of health through him. And then when I was diagnosed And had to start dealing with all these everything that comes with a chronic illness. I never could take my health for granted after that.

Reflection

Wow. Thanks for sharing. Some people reflected on hearing a diagnosis or misdiagnosis. Others reflected and abrupt change in function through illness or accident are the death of a loved one. Some feel sad and disappointed. Others hopeful and empowered, all crossed a threshold, a before and an after. All told a story. What's yours? Who do you tell?

Podcast outro

I host write, edit, engineer and produce Health Hats, the Podcast. Kayla Nelson provides website and social media consultation and creates video trailers. Joey van Leeuwen supplies musical support, especially for the podcast intro and out. I play bari sax on some episodes alone or with the Lechuga Fresca Latin Band.

I'm grateful to you who have the most critical roles as listeners, readers and watchers. See the show notes, previous podcasts, and other resources through my website, www.health-hats.com and my YouTube channel. Please subscribe and contribute. If you like it, share it. See you around the block.



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