

InVisible InCourage

Tuesday, July 7, 2020

Transcription provided by Stacie Valle for Virtual VRI

Kellie Pokrifka: Welcome back to InVisible InCourage. I am excited to be with Kate Nicholson!

Kate Nicholson: Thank you!

Kellie Pokrifka: Tell us about your career and medical life.

Kate Nicholson: My background is I work for it Dept. of Justice. Recently I have been advocating about the Reninghelst and needs of people in pain and people with addiction in the midst of the opioid crisis. I was a civil rights attorney before I had a disability.

I was working at my desk one day and my back started to burn. It felt like acid was burning my spine. I faceplanted on my desk. I couldn't stand without a walker for 15 years. I was mostly bedridden for most of my career. Spent about 3 years trying to fix the problem, it was caused by a surgical injury. They finally decided to prescribe me opioids and it allowed me to continue to function and have a decent career. Then I moved to Colorado and I was able to learn to walk again and was going down on the opioids but I went to a new doctor who wouldn't prescribe the meds anymore. A local physician had come under scrutiny for using opioids in 2015 and it had rippled through the community. I had already started tapering off them so I was lucky but it was hard on many.

Kellie Pokrifka: What was the emotional journey like through this?

Kate Nicholson: It was interesting. Those first 3 years I had hope

they would figure it out. I was diagnosed with all kinds of different things from negative tests results but what was the hardest was when they said "we're giving up, you have to live with this." That was the most difficult for me. And I eventually lost my marriage, wasn't able to have children, and things like that were very challenge.

Kellie Pokrifka: On your darkest days what gave you courage to get through the toughest days?

Kate Nicholson: The people I had around me. I had good role models. And I also think courage takes a village. I do a lot of talks about resilience and it really has to do with what is inside of us, but more about what comes to us from the outside. Do you have stable housing? Are you subjected to discrimination? What is your ability to heal? I have seen it described as a see-saw. You have where you begin with your base personality. I tend to be someone with a pretty happy disposition. I wasn't depressed or anxious. I didn't have a lot of trauma to start out. I was weighted toward the middle of the see-saw to start with. I am someone who had a happy disposition, good friends and family, I had graduated with a lot of privilege in education with a degree from Harvard law, and I a lot of a deck stacked in my favor.

Kellie Pokrifka: What was it like to go from being an attorney not like us to a person like us?

Kate Nicholson: I don't think that changed very much for me. I think for a while I lived with the cognitive dissonance that people do that we're all going to die. The week before this started I was doing my pitch about how we are all able bodied and it is important to have accessibility for others, and I didn't know I would be unable to walk the next week.

Kellie Pokrifka: I definitely had never considered I would wake up one day and my body would be terrible.

Kate Nicholson: I think for both of us, yours started when you were younger than mine, but neither of us expected this to start.

Kellie Pokrifka: So what rights are we fighting for right now?

Kate Nicholson: That is such a broad question. There are lots of things - with the opioid crisis many can't get to their meds. But as an example, there are other areas where there is a benefit in social security disability if you have a disability that isn't verifiable (like migraines) it is much harder to get access to your rights. It is not as likely to be recognized by those in the world around us and that can create a problem, you can be treated like you are faking or malingering.

Kellie Pokrifka: When you said a benefit vs. nondiscrimination - can you explain?

Kate Nicholson: One of the reasons they want objective proof comes from the 19th century and railroad accidents, but with proof they are just trying to level the playing field. You are asking for accommodations to allow you to continue to do work, but there is this feeling connected to handouts and there is a suspicion you are faking it to get something for free. I think that is why you see a difference for standards of proof.

The emotional experience is interesting I think with invisible disabilities. There is something I call the invisible lie. In our culture seeing is believing. For years we relied on eyewitness testimony for proof but now we know it is suspect and what we see isn't 100%. But most of us in life believe that what we saw is it. I think when someone looks at me they think nothing is wrong with me. Their experience of

the world tells them something is off, they haven't peeled through all the layers. That is challenging in the legal, healthcare and personal relationships. Often you end up isolated physically because of limitations. Not having a name for your condition. I had a lot of proof because my condition was so bad. It is an unusual conundrum.

Kellie Pokrifka: And the diagnosis process is so challenging because you can go years with no proof. It feels isolating, you start to question yourself.

Kate Nicholson: You know you are in pain, but if the doctors are pushing back it starts feeling not so clear. And I was misdiagnosed at first.

Kellie Pokrifka: And if the pain is variable you have a low pain day, and then you question if it is always that way.

Talk about the art in your recovery.

Kate Nicholson: Art is a big part of my life now. It was an unexpected gift of the pain. I was journaling through this process. Someone had given me some flowers and for some reason I started to draw them. And suddenly a new energy and type of focus opened up to me. It enriched my life. And I could draw pretty much anything. I slowed down enough to actually look at things. That's what it is for me, seeing things. So I started to collect it and be involved in the art world. There have been studies that show art reduces pain. There are places in Canada and the UK where doctors prescribe going and looking at art.

Kellie Pokrifka: And your nonprofit is?

Kate Nicholson: It is about supporting the emerging arts in the

region. We produce a journal and it is a lot of fun.

Kellie Pokrifka: Another thing I like to bring up is the idea of accommodations. They can be made and employers don't always know how to do it. What have you received that have benefited you?

Kate Nicholson: For me the main accommodation is what the entire society has received. COVID-19 has given everyone the social part. It is about including the world. The idea of accommodation is figuring out how to include everyone and for me that has been to be able to work from bed and home for periods of time using video. I was so well accommodated that they created a whole program for me. It is hard for many people because they are afraid to disclose their disability. But accommodations aren't that difficult. There are limitations if they are expensive but they generally aren't. Things like providing a sign language interpreter can be expensive for that one hour, but not compared to the cost of doing business on the whole.

Arming yourself with knowledge is a powerful tool. The DOJ has a great website and it lays out the technical aspects of the ADA. And there is a hotline for assistance too. It is available in plain language. And self advocacy is more effective initially than getting a lawyer. In my experience companies and schools, 30 years into the ADA now, understand the obligations of the law.

Kellie Pokrifka: You brought up the model of inclusion. What are other misconceptions that need to be cleared up?

Kate Nicholson: I think the main misconception is that people really do experience it. I think there is a tendency when someone has an Invisible Disability it is stigmatized. Like cancer, for example. It used to be thought cancer came from undealt with stress and emotions. That thought process is how we see Invisible Disabilities too. We

need to learn how to understand and accept how Invisible Disabilities are.

And things like how President Trump can't lift a glass of water. That doesn't make a difference in his ability to be president.

Kellie Pokrifka: Another thing you champion is making sure chronic pain patients aren't forgotten with opioids. How do we come to agreement that we are all victims of the system?

Kate Nicholson: Ryan Hampton was prescribed by a doctor and did become addicted, though that is not the common story. But I think that this infighting only hurts everyone involved. I think the reason that it happens is that there is bootstrapping of stigmas and now there is a stigma of addictions. It is being internalized. In some weird way the chronic pain patients were blamed for the opioid crisis and I think the only way to solve it is to recognize these are both illnesses that are coming from lack of recognition and lack of understanding.

The most evidence based treatment for opioid abuse disorder is taking another opioid.

Kellie Pokrifka: Thank you for that answer. Anything else you want to get out to the community?

Kate Nicholson: COVID-19? I think clearly COVID-19 has taken over everyone's attention. In the opioid crisis people are dying at a higher rate and that has disappeared. People with chronic pain are struggling to get their medication. The DEA changed some rules temporarily to allow prescribing by telemedicine. I do hope that with everyone experiencing a bit of this there is an energy for change that may happen.

Kellie Pokrifka: Anything else before we sign off?

Kate Nicholson: Not that I can think of!

Kellie Pokrifka: Thank you so much Kate. We are so glad to have had you. I have really appreciated having you talk to us today. We will see everyone on Thursday!

[End of show]