

Invisible Disabilities Live with Kimberly Warner

Thursday, June 11, 2020

Transcription provided by Stacie Valle for Virtual VRI

Kellie Pokrifka: Hi everyone! Welcome back! I am Kellie and today I am excited to introduce Kimberly Warner! Tell us about your health story.

Kimberly Warner: I live with MDDS. That is short for a complicated term that is French and it took a long time for me to figure out what I had. It is a rare neurological disorder. It started as episodic 5 years ago. The ground started swelling underneath me, like I was in a bouncy castle, and then it would pass. Then it would be gone for 2-3 weeks and I would have another episode. This continued for 4 months and they would last for 30 seconds. It was strong enough I pulled the car over as I driving to work. It was nothing like I had ever experienced before. Then it disappeared. Around the fourth episode it was daily in the afternoon so I contacted my doctor. I would be walking and it was like the sidewalk dropped out from under my feet. My anxiety was through the roof. My nervous system wasn't accustomed to it. Now I am experiencing it, but it has been 5 years and I am used to it. There are shocking moments of it and my heart will race but mostly I have learned to adapt to the experience.

It is consistent and it doesn't go away. I think it was May 7, 2015 and it never goes away when I am sleeping, or lying down, or anything. Only when I am driving and in passive motion. If anyone has this, you know it is MDDS if you are sitting in the car driving and it goes away. Totally gone. Then at a stop sign it comes back full force. I am famous now for my rolling stops. I don't want to stop the car.

Kellie Pokrifka: Tell us about Unfixed.

Kimberly Warner: Unfixed is a result of me around year 4 after lots of doctors visits and experiments and chasing a cure and refusing to accept this for the rest of my life, and realizing that searching for an answer was making me feel worse with stress and anxiety. Getting hope from a new doctor and no real results. So I got to the point of thinking about what would this be like to live with this forever, that seed had been planted around year 3, and I stopped going to doctors, my money ran out, I had to, and I had to learn how to do this. In doing that I found people that were already on this path and my husband and I were discussing what this might look like. And I put a flyer out to my naturopath, my university here in Portland, and I thought there have to be people with chronic illnesses that might be willing to talk to me. Within 2-3 months I had had deep, rich conversations with people all over the country, and a few in Europe. And now after 8 months I still keep finding extraordinary lives that still aren't fixed but until them we are finding our voices and saying "these are things we can do to live a good life still." This film really grew out of that and it is the stories of 20 peoples lives who are in various stages of learning to thrive with what they have.

We have Dylan with Lou Gherig's disease that can't speak and uses a device to help with that. We have Rachelle, also with MDDS, Todd lives here in Portland and has early onset Parkinsons and was working to qualify for the Tokyo Olympics and now he is still training daily to qualify for them in 2021. That just scratches the surface.

Kellie Pokrifka: Tell me some findings you have. How are people learning to thrive?

Kimberly Warner: The biggest one - starting with myself the piece that has worked for me is there is a quote by River Phoenix "run to the rescue with love and peace will follow" and I probably say that in my

head a dozen times a day, and that is in relationship to the part of me always resisting. This physical resistance to what my brain is experiencing. Its like talking to a child that is nagging and pulling on your pants leg. You don't kick that child, you say I love you, and "why are you here?" Dylan has a similar approach. He studied Akido for 5 years before developing ALS and he talks about finding ways he can communicate with the world now. In Akido when the attacker comes at you you don't push back, you allow them to come to you, and you use the energy they come at you with you discover something new. He allows ALS to be that discovery for him to be a new adventure in his life. He adapts with his communication device. Instead of focusing on he can't move anymore, or communicate, he compares himself to a tree. A tree doesn't move, but it nurtures life. When inspiration comes to him he can write letters to friends, and write his blog, and share inspiration with the world. Adaptation is huge. We have to learn to adapt with what we now have.

One of the other things that struck me was we have Brian Langins and he has Chrons disease, and his pain is extraordinary. He is really allowing this experience of pain for him be an opportunity to serve others. It is like his lifeline knowing if I can sit across from someone and offer just a little empathy or advice to someone, that makes my experience worth it. He says, "God doesn't waste training." I could just go on and on. There are so many cool people. The key is really adaptation. Everyone has had adversity. We aren't perfect at it. We have really, really bad days. Like a piece of coal getting force from the earth making diamonds. I think as long as we are willing to be kind to ourselves, those diamonds will emerge.

Kellie Pokrifka: How can we access these stories?

Kimberly Warner: If you go to YouTube and type in "unfixed community" you will see these stories. We also have done some coping

techniques related to COVID-19. And a lot said their life hasn't changed much, they have been in isolation for 10 years. They have been getting a lot of training. We know what it is like to be disappointed, to have our dreams or plans canceled, to wake up one day and life is different than it used to be. Everyone with chronic illness knows what that is like. We are experts on dealing with a pandemic.

Kellie Pokrifka: One thing I love most is how you celebrate small victories. We aren't all going to climb mountains or win the Olympics. Tell us about that.

Kimberly Warner: That is huge. It is part of the name, "Unfixed." I grew up in a self-help family. I felt there always had to be an answer or a cure. So when this happened to me I put on my fix-it hat and just kept going. I felt so abandoned. "Why can't I find a cure?" I would go on social media, or read a book, or whatever and feel everyone could find a cure and when I couldn't find one year after year I felt isolated and alone and unworthy. Did I have a bad past life? I tried everything to make it go away and no one was listening. So I needed to find the small victories in not being cured and there is where so much more love was fostered. It makes for a great Hollywood arc when you can climb a mountain after your limbs are removed, but for so many of us that isn't the story and we need to hear those stories too.

Kellie Pokrifka: What gives you hope in humanity?

Kimberly Warner: These people. Observing and listening to their stories. The people that aren't getting what they want. They are pushed against adversity daily and they are still finding empathy and their isolation becomes community and they turn their isolation into kindness. This month we are doing talks with caregivers or their neighbors and friends and loved ones that have shown up for them. It is remarkable to hear the story from the loved one that says "I am

here for you and will love you until the day you die." We got one today from a woman with a terminal form of lung cancer and she was sitting with her wife in Vermont and she said "I'm with you until the day you die." and I'm thinking "how will we edit this down, everything she is saying is so important! And this woman says "I expected to be poor later in life, but I never expected to be poor and happy." But she is. She sends me pictures from her life and everything is just beautiful around here and its amazing how her life is.

Kellie Pokrifka: How can you find these small victories on the days you feel terrible. On your darkest days, what gives you the courage to wake up and get through another day?

Kimberly Warner: For me, giving myself grace. I am a bit of a perfectionist. If I feel terrible I need to know that it is OK to feel that way and not be OK. To allow for me to be districted on those days. I don't have to save the world, I need to be distracted from this neurological sensation. Maybe it means I need to watch The Office for 2 hours with my glasses on and be distracted. Or maybe I need to do needle felting. It drops the periphery of the sensation around me and sometimes I need to spend days doing that.

And there is this acronym TLO and it stands for Trust Let go Open. And I use that SO MUCH.

For me, Trust. I wake up, feel terrible, and I just have to Trust. I'm not going to die. I'm not going to fall over.

Let go means to let go of the idea that I need to do or be anyone other than I am in that moment. I let my shoulders relax.

Open. Open to the experience. Let the bobbing happen. We are going for a boat ride today. The seas are rough, but pushing against it

makes it worse. I allow myself to be curious about what is happening.

Kellie Pokrifka: I love that you bring up the productivity. This is important in our modern culture, but we have days we just can't do anything but we still deserve care and love.

Kimberly Warner: Absolutely. We are making a movie that isn't really what a lot of people want to hear. They want to know that Dylan will be cured at the end. They want Dylan and Jacqueline cured. But in reality that isn't always the case. There are thousands of stories out there that aren't always going to end pretty. I spent 2-3 years in complete isolation and not engaging with the world other than doctors and feeling like a failure. All my dreams of being a filmmaker and feeling confident were just gone. Even my husband had to go through grieving that loss of me being independent. He had to hold my hand so I could walk across the street.

Kellie Pokrifka: Tell us more about the isolation piece. How have you learned to work through that.

Kimberly Warner: We live very isolated and I have learned to embrace it. I know too much stimulation makes my symptoms go up. If I am on a job and there is a big wrap party - I need to chill in my hotel room. I have a granny lifestyle. Maybe it's easier because I am a bit of an introvert anyway. We have a gentleman named Renee with a disease that creates a shock like pain in his head and he can't do ANYTHING during his episodes without increasing his pain - he'll speak with you in July - and he is an extrovert and I talked to him about adaptation and I talked to him about maybe writing as something to do in his isolation.

I sent him this poem from a French philosopher that says, "my dear in the midst of hate I found there was within me the feel of love. In the

midst of chaos, an invisible calm" and it goes on. And I think he is discovering that in the darkness it sucks, but there are these little seeds that will emerge eventually.

Kellie Pokrifka: It is so nice to hear someone say that even if you don't have a fairytale ending, your stories are still worth listening and sharing.

Kimberly Warner: I hope so. I want to talk to us and validate our stories, and I want the rest of the world to go, "yeah!" All of us are unfixed. There is something for everyone in this film. And right now in a pandemic it is obvious. We are all in this together that is very human. We are getting to experience the uncertainty that it means to be alive.

Kellie Pokrifka: This is been so incredible. Do you have any last words or messages?

Kimberly Warner: Just reiterating that every one of your stories are invaluable and important. Every single one of you are teachers. If you could just record yourself -- it is an act of kindness to tell your story and the more we hear them, the more the world can recognize that it is a very real and true way of being alive. We have contradictions because we can be in pain and gratitude at the same time.

Kellie Pokrifka: Thank you so much for being here with us. Thank you all for tuning in. See you next time.

Kimberly Warner: Thank you! Bye!

[End of show]