

Invisible Disabilities

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Transcription provided by Stacie Valle for Virtual VRI

Kellie Pokrifka: Welcome back to Invisible InCourage. I am with Rene Morales today, living with Trigeminal Neuralgia. Tell us about your military service.

Rene Morales: I retired from the Coast Guard. And there I did a lot of championing of diversity. I was appointed to a committee, the Leadership and Diversity Council. We took on diversity and leadership issues at the lower levels and worked on those issues behind the scenes and made recommendations to the commandant for him to make decisions on how to resolve the issues.

Kellie Pokrifka: What do you do now?

Rene Morales: I am the Executive Assistant to the Deputy Director at the Washington State Department of Veterans Affairs.

Kellie Pokrifka: Tell us about your battle with Trigeminal Neuralgia.

Rene Morales: It started in 2018 and I was 50 and 2 days. The age onset for it is 50, so I got Trigeminal Neuralgia for my 50th birthday basically. It was not something I was happy to get. I struggle with anxiety also. When you have something like that and then you read about Trigeminal Neuralgia, the suicide disease, it is a hard pill to swallow. Because I am a retiree with the military I was going through an army medical center and my care at first was pretty good at getting the MRIs and the testing. But once I was referred to the neurology clinic they had a hard time dealing with me. They really don't see a lot of people with Trigeminal Neuralgia. The age it hits is 50 and they don't have a lot of people of that age. They didn't know what to do

with me.

At one point I was diagnosed with primary stabbing headache, and that is a symptom, not a disease. I had looked into CBD oil and if that was a possibility. The military won't champion that because it isn't allowed for active duty members. Out of frustration of not getting the care I wanted I signed up for insurance through work and now I am seeing civilian doctors and it is a different story.

Kellie Pokrifka: Interesting. There is so much stress and pressure with this disease and you have considered quitting your job, but you can't because of the insurance. Talk about that.

Rene Morales: I do have periods of remission. Sometimes a month or two, and these periods are wonderful. But then it comes back. The pain has steadily gotten worse each time it returns. It is where I don't know if I can do my job and if I can't do my job to the best of my ability I feel like I am failing them, and then someone else needs to do my job. I have struggled with this and spoken with them. I have very supportive bosses. It is the best place I could work. But my fear is if I stop working I will have to go back to military treatment and I just saw a neurologists last week and we talked about surgical options and I don't know how that would work through military care.

Kellie Pokrifka: Can you tell us about what Trigeminal Neuralgia is?

Rene Morales: Trigeminal Neuralgia is a chronic facial pain disorder. In the brain there is a trigeminal nerve that runs along the face. The trigeminal nerve in the brain contacts an artery and it creates electrical sparks. When I have episodes I am being electrocuted basically. Like touching 2 live wires. It is painful. My hands will clench. The episodes last anywhere from a couple seconds to maybe 20. Each time is different. Some have been like little shocks,

whereas the pain I feel now is more like an electrical burn. I am feeling it as I talk to you now, but its not "going off." It happens as I touch my head, eat, chew, swallow, brush my teeth, etc. I am on medication right now that slows the nerve down to help prevent the pain from happening. I have been on this medication at this dose for just a few days. The pain was so bad I had to go to the neurologists.

Kellie Pokrifka: How frequently do the attacks occur?

Rene Morales: Daily. If I am sleeping on my back and I roll over, my head hits the pillow and I am shocked and I wake up. No one should have to go through this. As I talking to you you wouldn't think there is anything wrong with me, then people see me have a seizure and they don't understand what is wrong with me. That's why when I was first diagnosed I retreated. It was hard for me to have my family see me in such pain and struggle.

Kellie Pokrifka: How did you deal with the pressure of being the lead of the family and looking vulnerable and fear of disappointing them?

Rene Morales: At first I retreated to my room. I didn't want people seeing me. I would be at work all day dealing with these shocks and I came home exhausted. I'd been talking and doing things all day and it was all in my head. They didn't pity me, but in my mind I thought I was being seen as weak and so I stayed in my room for months. It impacted my relationships and my interactions with my wife. I was so depressed -- in terms of eating I was eating mostly junk food and I put on 20 pounds. I still struggle coping with food and alcohol. I try my best to avoid the unhealthy ways to cope. I am trying to find healthier ways and stay positive. The reality is I could have been told I have stage 4 cancer and only months to live.

Kellie Pokrifka: What are your coping mechanisms?

Rene Morales: Meditation sets me up for the day. I struggle with it sometimes. I like to sleep in, and I don't get a lot of sleep, but I try to get up and meditate. Radical acceptance too. The reality is I don't like that I have Trigeminal Neuralgia, but accepting it doesn't mean I like it, but I have to accept it, cope with it, and deal with it. And it is hard. Some days I manage it, and there are days like this past week where I am in tears struggling and turning to friends and family to help me get through it. I am so tired of being in pain. It is a constant challenge.

Kellie Pokrifka: It means so much that you are talking about the pain you are in this week. People see these interviews and think "oh, they're good to go" and they have no idea what is really going on behind the scenes.

Rene Morales: I am just happy I am managing through it. It often affects my speech.

Kellie Pokrifka: What has been the hardest part of this journey?

Rene Morales: Battle of negative thinking. I struggle with that. People see me and they often think I am a Dalai lama with everything together but the reality is there are times it is hard to be positive. It is really easy though for me to give in to the pain and I have talked to other friends and talked about the inner coach telling me to get up and get through it. You have to find something to inspire you to get up and get going. I can't isolate myself in a room and disconnect from my family. That isn't fair to anyone. You have to find a way to block the thoughts and redirect them. To just say "this sucks, it hurts, but you will get through it."

Kellie Pokrifka: What have you learned about yourself dealing with

this constant pain?

Rene Morales: I have amazing family and friends. I have been married 26 years and the last 2 years dealing with this has been so much to put on my wife. We have been through 7 military moves but this has been the hardest challenge. It has been something that has kept us together. We always try and find ways to get through it. I have realized I am far stronger than I thought I was.

Kellie Pokrifka: And your wife is a therapist. I am sure her skill set helps in that way.

Rene Morales: It does but she can't be my therapist. That is something I really need to work on. It's actually getting a therapist. I have such a busy pace of life I just forget about it. You want to help and support others and you don't help yourself. That is something I really struggle with. I do need to find ways to take care of myself, exercise, eat and cope right.

Kellie Pokrifka: Do you have any other advice for other couples going through this, or other fathers going through chronic illness or pain?

Rene Morales: As a father you have this image that you have to be the rock. And you do, but also it is OK to be vulnerable. It is OK to not always be Superman. You can't always do the things you want to do. I found for me that I was trying to do that and not let this get to me and I do need days to just have time to myself to recover. I may want to be there for others but I need the time for myself. That is hard to do but important.

Kellie Pokrifka: So your disease goes completely into remission. What is the emotional struggle of going in and out of the pain?

Rene Morales: I have been fortunate. When it first started it began in February then went away in July, but back in January. And I have no way to explain why it happens. Maybe the nerve and the artery aren't in contact with each other? But for whatever reason it stops. To not be in pain all the time and to feel like yourself and to feel like you can do all the things you used to do, it is annoying to me. That was one of the hardest things about this disorder. I felt like I was no longer who I was. And I am more than that. Some people don't get the periods of remission and so I am fortunate for them. I celebrate them. I am not going to let this disease stop me, but then of course it comes back. That can be hard. You have a hope that you think you are cured and then it comes back and it can be depressing. But that is about attitude. You have to tell yourself it was just a period and you had a good ride, tough it up through the next one.

Kellie Pokrifka: The ups and downs would be mentally exhausting.

You also brought up the mourning of yourself. We don't talk about that topic enough with chronic illness. How did you make peace with that? Or how are you trying to?

Rene Morales: Through that radical acceptance. I was so depressed when first diagnosed and sunk into the stages of grief. As someone that loves to talk to people, I was getting shocked when I spoke and smiled so I was no longer being around people. Everything just stopped. I began to see myself as becoming someone I wasn't and I was going through the stages of grief. I was mad, angry, depressed, sad, denial. It all happened. But I had to stop feeling sorry for myself. But I had to stop that. I could either eat my way to 1000 pounds or find a way to get through it and find a new you. Find a person I could be with the disorder.

Kellie Pokrifka: What advice would you give someone that is just

beginning the diagnosis process or still trying to get the diagnosis?

Rene Morales: Educate yourself as much as you can on what you have. When I first got it all I read was "suicide disease" and I didn't read anymore. But then I realized that was one website, one opinion. Not to sugar coat things, but there are medications and surgery options and treatments. For now I am going with medications, and maybe I'll have brain surgery down the road, but you have to know what you are getting yourself into. So read and learn as much as you can about the treatments out there and maybe join a support group for people in pain.

Kellie Pokrifka: Great advice. It is such an isolating process for sure. So we always ask towards the end, on your toughest days what gives you the courage to make it through "that day?"

Rene Morales: My family. I want to inspire them and for them to inspire others. We all will face adversity and how we overcome it is up to us. It is a huge mental thing. I am not perfect. I will have days, or two, where I have a pity party. But then I will check out and get back on track. We aren't super human, we have days with weaknesses where we eat pizza for all 3 meals. But then we go back to being a better person for those we are around.

Kellie Pokrifka: You have such an incredible perspective. I wish I could have more of that in my life. Do you have any other messages to send to the invisible disabilities community?

Rene Morales: I recently joined the "unfixed" community and being a part of that had a huge impact on me. I am working with people who have Chrone's, Lou Gherig's, etc. Before I felt alone. It is so important though to realize that you aren't alone. There are others that have that same thing you have. Whether it is cancer or whatever it is, there are similar challenges and they all involve mental health.

Kellie Pokrifka: How did you get involved?

Rene Morales: I did a presentation on overcoming fear and I used the disorder as a backdrop. Someone in the audience knew the director and said I should apply. Through that I was interviewed and became a part of the film.

Kellie Pokrifka: Tell us about the fear speech.

Rene Morales: I had signed up to be a presenter, didn't know if I would be picked, but I was. I was given a 30 min. "Ted Talk" time frame and I spoke on fear. To learn as much as you can about what you are facing. It will no longer be an unknown if you have learned about what you have. How do you deal with fear? I talked about the stages of grief, struggling, etc. and how I came out the other side. I have no idea how these things happen. One day I am doing a presentation and 2 weeks later I am interviewed for a film and now I am doing this. I had no idea the courage to stand up would lead me to where I am today.

Kellie Pokrifka: Do you have links to that talk?

Rene Morales: No, unfortunately it wasn't recorded. But I want to thank you for this opportunity. Invisible disabilities is a wonderful organization and you are a beacon of light for others. I can't thank you enough for highlighting things that people are going through and helping others see they aren't alone.

Kellie Pokrifka: And thank you for showing how people can look so great while being in so much pain.

Rene Morales: Well, I am fortunate. I could easily have had an

episode. Chalk it up to new medication maybe. But either way, I would have shown vulnerability.

Kellie Pokrifka: Well thank you everyone for tuning in.

[End of show]