

Invisible Disabilities

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Transcription provided by Stacie Valle for Virtual VRI

Kellie Pokrifka: Hi everyone! I am thrilled to announce Terry Holyoak.

Terry Holyoak: I was diagnosed in 2017 with an invisible disability and I realized how difficult that can be in the workplace.

Terry Holyoak: What is EOE? It is a esophageal immune disorder based on allergens in the air. It started back in 1993 for me and has been increasing. It will continue to effect more people over the years. It will look like allergies to different foods and some people will have more extreme reactions to it.

Kellie Pokrifka: Interesting. How does it effect your daily life?

Terry Holyoak: That can be intriguing. Some days I feel great. I can get up and move and work. I can do 50 miles on my quadricycle. Other days I can't get out of bed. EOE is when you eat something or consume something that you react to, you can basically choke. The body wants to think it is a parasite and it reacts violently. Because of the pain levels in the chest and throat you may be out of normalcy for several days. I can be out 3-5 days if I have a bad enough reaction.

Kellie Pokrifka: So this can hit if you can through the mall and the food court?

Terry Holyoak: Yes. Soy is a big trigger for me, as well as peanuts. And so if there is an oriental place in a food court the soy and the peanut oil can definitely hit me. I watch myself closer now and I know

the short cuts to get outside quickly if near a place like that. Even going to a restaurant can be difficult for me. I have to think about these things. People put butter on rice when they cook it and that can trigger me sometimes.

Kellie Pokrifka: That is such an everyday burden you have to carry.

Terry Holyoak: It is the wheat, the gluten, the soy, peanuts, dairy, and even things like yeast and things. Going out to be social could mean I get a glass of water.

Kellie Pokrifka: That is huge on you. People question why that is all you are getting and it can be embarrassing.

Terry Holyoak: The first few years I avoided most social interaction. I became one that went to work and went home. I didn't want to have an episode. It was embarrassing and emotional. I became a bit of a hermit. Now that I have a diagnosis and I have researched it I can be more open about it. I get some questions about it but most people know me now. People have seen my reactions and want to know how they can help. Doing the Heimlich is one of the worst things you can do. A Heimlich is typically done about midsternum. If that is where you are doing it, the choke feels like it is in your throat but it could be anywhere and you might be causing more damage where the choke actually is.

Kellie Pokrifka: What is the proper response?

Terry Holyoak: There is no one set standard. Everyone will be different. For me, the typical esophagus is the size of a quarter. But mine is 14 mm. Very small. Mine had a lot of tears and rips by the time I was diagnosed. The damage is so bad now that they won't do any more dilations on it. It has ripped twice when they have tried. I

don't even have to consume something to get a reaction. Airborne triggers are just as bad.

Kellie Pokrifka: What was the diagnosis process like for you?

Terry Holyoak: A lot of uncertainty and unknowing. Can I eat this or not? Trying to figure out what to eat on a liquid diet for 6 months just to get calories. I had surgery and they removed my teeth and restructured my jaw. I was lucky at the time to have the medical care. It can be very traumatic. One of my doctors actually looked at it and said there is a 1 in a million chance you might have this, but we will test for it. The gastroenterologist that looked into it doubted it, but tested anyway. It came back and they said anything over 15 ppm was considered having EOE and I was 1 part of 40. So 3 times the limit.

Kellie Pokrifka: So the longer you go without the diagnosis it pushes your condition further.

Terry Holyoak: I went 15 years without a diagnosis eating what I thought was safe but wasn't.

Kellie Pokrifka: So this effects personal and professional life both.

Terry Holyoak: Yes, the PhD is about how we can make it easier for people to disclose they have this disability. It isn't an easy process. You may never see the persons disability and if they don't disclose they may not know their options.

Kellie Pokrifka: Why wouldn't a person want to disclose?

Terry Holyoak: Stigmatism, distortions, not wanting to be singled out, etc. People start hearing things and they make assumptions.

They may think "we can't do this because of so and so." Or we can't eat this because of Patrick. My storyline is if it bothers me, I'll leave. But not everyone thinks that way. I can't just leave work every time someone wants to eat something. It got to where I was having an episode 2-3 times a week at times. I would be on the phone talking for 8 hours a day continuously with no voice, straining my voice and without accommodations it was hard.

Kellie Pokrifka: What is the best time to disclose? When applying, or later? In your opinion.

Terry Holyoak: That is a personal decision to make. It depends on how that person feels. In all the research I have done and what I have read there is no one specific model. The employer can't ask you if you have a disability but they can ask if you can perform the tasks of the job.

Kellie Pokrifka: So if the application asks "do you need to disclose a disability?"

Terry Holyoak: You have to be careful going through things like that. It is usually an optional aspect to answer. You can answer, many will say "I would like to discuss this." And we all know that there are places where that person that says that gets treated differently.

Kellie Pokrifka: Its scary to know how to answer that.

Terry Holyoak: I went to one interview and I didn't disclose it. Went to another interview where I was offered a position, disclosed it partially, and they didn't say I wasn't chosen at that point, but I was told it may not be the best fit for me. That was an emotional hit. I was honest and I got consequences for it. And I was out of work almost 18 months at one point. I didn't know what to say or not say.

Once I had a diagnosis it was easier to know what to do and say.

At an interview I was asked how many days it was OK to miss, and I said barring medical reasons, very few days. But I do have a medical disability but I know about my appointments 90 days in advance and I can work with you on those. So that was a good time to fit that in. If your Invisible Disabilities is very small, it may be something you can overlook. Mine was 2-3 episodes a week, my employer needed to know.

Kellie Pokrifka: Can we talk about accommodations? They are easy to know but not many know how to ask for them.

Terry Holyoak: They can range from being simple like closer to one side of the room, or away from the heavy traffic area. Different Invisible Disabilities can be very different. The EOE side can be better location. It could be closer to some facilities. If I have a reaction, how quickly can I get out the door? Where can I work through with my epi-pen, they are very loud. They walk you through the steps of using it. I have triggers and can notice when a reaction is coming. My voice changes, my pulse changes, my oxygen is changing. I know the reaction is changing. Anaphylactic is instant, no warning.

I was teaching a class and 4 hours into a situation I turned Smurf blue. The joke became that Oompa-Loompa orange and purple are OK, but Smurf blue is not OK. I have a medical card that says if I am conscious follow my directions. If I am passed out, of course I can't help much. For me I can usually sense things. Sometimes I have a tremor or a shake. I have had episodes begin but I have had them go away if I go outside and get fresh air.

There is no allergy test that is perfect for this. I had the test and reacted during the test. The left side of my face swelled up, I could barely talk, I looked like I had a stroke. It was anaphylactic shock.

Kellie Pokrifka: You also have a medical bracelet, right?

Terry Holyoak: Yes, I have a medical bracelet and on the flip side it refers to my wallet card with more information and that explains I have EOE. I also have a card on my desk that says "I'm not sleeping." If it looks like I am I need to be checked on. If you have a smart phone, many have apps that have a medical alert on them as well.

Kellie Pokrifka: Do you have a recommended app you like for that?

Terry Holyoak: Apple has Apple Health. There is a follow my health the bigger hospitals use. Android and Apple have the emergency connection to 911 where your health info pops up.

Kellie Pokrifka: To finish this off, you have had quite the journey over all these years. Through your toughest days, what has given you the courage to get through your toughest day?

Terry Holyoak: The first answer is family. Having them know and accept it. Having them available to lean on. The second answer is I have a puppy that recognizes my disorder and she recognizes my episodes. And third is my willingness to make sure other people learn. So many people don't know what is going on even after diagnosis. There isn't a lot of information on this or forums or information so I am trying to reach out. I have read stories about babies born with this condition and parents have no clue what is happening to them. But they have to have this special formula that is \$150/can that isn't covered by insurance.

Kellie Pokrifka: Advocacy is a way to take back things the disease has taken from you.

Terry Holyoak: I will agree with that. Also through cooking for charities I am bringing awareness. Ultimately I want to open a restaurant that pertains to allergy sensitivities but that cooks in a way you wouldn't know it. In the morning I would teach people how to cook and then in the afternoon and evening it would be feeding people the food that taste great even though it is healthier for them.

Kellie Pokrifka: That would be incredible. It would take the stress off so many people.

Terry Holyoak: I probably went almost a decade without going out to eat.

Kellie Pokrifka: No one should have to do that and live with that.

Terry Holyoak: It comes down to a very emotional thing. Until they know what is going on. I know which restaurants I can go to and some places will work with you and let you know what you can and can't eat. I reached out to a soft drink company and explained my condition and asked if this particular item was in their product and they said they would prefer I not consume their product. But now I know.

Kellie Pokrifka: You will have to let us know when you get your restaurant off the ground. And when you get your PhD complete.

Terry Holyoak: I should be finished within 6-12 months. As for the restaurant, lets get through the COVID-19 era first.

Kellie Pokrifka: Thank you for being here. We will see everyone on Tuesday!

[End of show]