Scott Dainty – Podcast 'extra' transcript

My epilepsy journey did start when I was two, or at least that's when I was diagnosed. I don't have too many memories of my childhood experiences with epilepsy. A lot of what I do remember started around high school, because that's when it was most severe in my life, going through a lot of hormonal changes and and body changes, and things definitely interfered with I guess my, my brain functioning and my seizures.

So, there were some weeks where I was having to go to the hospital two or three times a week. So yeah, that was a hard time in my life. Going further in school was never really on my radar until I basically graduated high school, because missing so many days, like up to 60 days a semester, I was, you know, barely passing. So, I didn't ever think I was going to go and do things, but after I had graduated, and took my time going through school. I ended up you know, getting a Bachelor's and a Master's and going on to be a naturopathic doctor, which I am now.

So, my seizures happen primarily in my sleep. They're triggered in a sleep state. So part of that has been kind of a blessing in disguise, because I've been able to maintain a driver's license and, and function fairly well throughout the day when I'm conscious. But, then if I do have breakout seizures triggered from a sleep state usually at night, and they become seizure like clusters and extend into the day that can, like, that's the reason why it would affect me during the day. I never lose consciousness for them. So although I'm, they're triggered in an unconscious state, I become conscious and experience them fully.

I love music. I've always loved music. It's been one thing that's kind of kept me sane throughout my life even in times where I was having a lot have seizures. And it was, a lot of my social groups throughout my life have been related to music and the type of music I've liked, at a certain time in my life, so it's definitely played a big role for me. And that's another reason why I was really I was really drawn to the Mozart study was, you know, if there's something as simple as listening to music, which I already love to do, then love to explore it.

So, in this study, we had to come into the clinic at different time points, and, they would hook our heads up to surface EEG to record our brain function, or our neurological function and activity. And so they did it, I think there were five different time points – a control one before you started the experimental Mozart piece in between doing the Mozart in a scrambled version of the Mozart, which literally just sounds like a symphony, practicing before the actual performance (laughs), and then a few months after we completed both trials. So, time-wise, it wasn't constrictive. And then daily, we would listen to either the Mozart piece or the scrambled piece, for three months at a time. And that

was only seven minutes. So it wasn't, wasn't restrictive and to see results coming out of that was really interesting.

What we saw was a decrease in seizure frequency, when I was listening to both the Mozart piece and the scrambled Mozart piece, compared to the first three months of a baseline period, and the last three months of listening to nothing. So, I found that really interesting and, and it could be, you know, from the actual piece and the engagement in your brain that is required for that - possibly even just the act of listening to something, and your brain kind of responding to that.

So, I can't remember exactly the number of nights per month that I would have seizures, but they were tracked on that kind of a basis. So, not necessarily, I had four seizures this night vs. two that night. It was more so how many nights a month was I having seizures. But I believe it went somewhere from eight to 10, down to three to five, somewhere in that range. Just thinking back on myself at that time. I felt pretty good hearing the results. It was definitely encouraging and a really neat thing to present to the world that something as simple as listening to a certain composition for seven minutes a day, and whatever further studies find coming out of this type of area, I find it really promising because it's such a simple intervention to offer to people.

What I've learned about myself (laughs) throughout this journey is a little tough to gauge because it's always been my life. I don't necessarily have a pre-epilepsy and post-epilepsy life like some adult onset epilepsy patients do. One thing that I've always felt or been encouraged to do is to really, kind of, keep going and keep pushing the limits of what people said I could or couldn't do. Some of that translated into education, going further in schooling. And some of that was hockey coaches that told me I was never gonna play higher because of my seizures. Then, I'd go on to play for a different team and beat their team next year (laughs). So, I think part of part of what I've learned is just to, you know, make your own destiny within the limits that I have. There's things that I know I will never be able to do because of the unpredictable nature of seizures, but, uh, there's a lot of things within my grasp. I think just learning to understand yourself more will help you develop and redirect your goals when you hit a wall in one direction.

I, I would love for everyone out there to, you know, to see their limitations not as an absolute border. But to challenge them and see how far you can go, and enjoy the things you love doing.