

Mission Moments

Made Possible By YOU!

Edition 25, March 2018

Erin Explains Life with an Invisible Disability

In celebration of Indiana Disability Awareness Month, we asked Tangram Life Coaching client, Erin, to share her experiences with living with an invisible disability. A transcript of that interview, edited for length and clarity, is this month's Mission Moment.

Can you describe your disability?

I have severe narcolepsy. It is an overwhelming, constant tiredness that is uncontrollable. It will ebb and flow in its severity, but it's like I constantly need more sleep than anyone could get in a day.

Can you describe the impact your disability has had on your life?

Out of college, I was a paralegal and I was thinking about going to law school and I realized I couldn't do a 9-5 job anymore. Well, I lost my job—I got fired from it because I couldn't do the job. I was missing work and I wasn't staying awake at my desk. I was unemployed for like 5 years because I didn't think I could ever hold a job normally again, and it was so depressing. I was extremely depressed during that time and I had to move back in with my parents. I miss out on social events with my friends, I can only do part-time work, which is really frustrating because I want to be at work all the time. My doctor once told me that I could only expect to have 80-90%, or maybe less than that, 70-80% of a normal person's life in terms of feeling fully present all the time, and I feel that. I miss out on 20-30% of what a normal person should be able to do in their life.

You work with a Tangram Life Coach. How has that helped?

After going through Vocational Rehabilitation and getting a job and finally living with roommates in a house, my head was barely above water. Basic things like going to the grocery I struggled with. It (Tangram Life Coaching) has made me a much higher functioning human being. It seems so little, but she (Stephanie, Erin's life coach) has helped me make huge impacts—like going to the grocery store regularly, staying on things and helping me address things that I would have resisted before and that were keeping me from being as thriving as I can be. So, she has just taken my life to the next level and far beyond what I thought I could have been or would have been five years ago. And I still don't think that I have reached that potential for what I can be, which is a beautiful thought considering I felt so limited before that. My potential ahead of me excites me and I know that Stephanie is going to help me figure that out and look in the areas where I haven't thought to look myself. Yeah—it's exciting.

Tell me about the type of work you do.

I work at Vintage Vogue, which is a Goodwill store, but it's a boutique version of a Goodwill. I hadn't initially thought about going into retail because I have a college degree and there are other things I wanted to do. But I just freaking love my job! I love everything about it. Five years ago, too, I didn't think I could hold commitments to meet with anyone, much



less have the responsibility to have a job. I was able to follow through on that and now I am a Team Lead who is early to every single shift.

How long have you been at Vintage Vogue?

It'll be four years in June. I'm really impressed with myself!

How long have you been with Tangram Life Coaching?

It has been maybe a little over a year. Tangram has helped me so much. I got approved for disability! I'd been appealing my denials and it had been a really long process. We used the legal services (Indiana Medical Legal Partnership, which Tangram is a member of). I don't know what I would have done without them. But it's gone from needing to do things like grocery shopping and paying bills to her (Stephanie) going to the Social Security Office because I need to get stuff done there. It's changed a lot, but I love the flexibility of what she can provide for me and my needs. She figured out my prescription situation, which I was crying about at CVS monthly. It was terrible! I passed out there and they had to call the ambulance once because I find the whole thing so stressful. She figured it out for me—I use Young at Heart now, which is delivery. That changed my life so much! She set that up for me and that right there was just a huge life improvement. It's been about a year, but a lot has happened in that year. My mom and I love that we have someone to go to because for me and my mom it was really stressful for us individually, and also as a family—relationship-wise. My mom, I think, would lose sleep over it and she feels at peace knowing there is someone out there helping to advocate for me. She calls it Team Erin. Stephanie is a big part of Team Erin.

March is Disability Awareness Month in Indiana. What do you wish people knew about living with a disability, and particularly an invisible disability?

Oh man.

Or what is one misconception people have about disabilities that you wish you could correct?

It's such an emotional topic for me. The thing that frustrates me or is hard to convey is how much I want to be where everyone else is. I have a physical limitation that they don't have a cure for. When I have to change my shift or miss family events, it's not because I don't want to do it, it's because I can't do it and it's really hard unless you've experienced something along those lines. You can't articulate it to someone, they have to get it, and it's frustrating to me. It sucks to feel like you are letting people down all the time. It's not a matter of picking and choosing when I want to live. It's me being tired, and there is a stigma or a social connotation between that and laziness. I'm a hard worker, I have a good work ethic. I don't think people would necessarily argue that that's the problem. When I was a paralegal, I know when I left there they were thinking I was lazy. And that's so frustrating. You just want people to understand. It's hard enough to be there enough as it is and then to worry that people—

Maybe have an opinion of you that is incorrect?

Yeah! People's opinions really shouldn't matter, but then when it does directly affect my relationships with them—that's the thing. Not that I've lost friends because of it, but there are people that I keep in a certain group, like they just don't get it, and therefore they don't get me.

I think you kind of spoke to this subject earlier when you said it was validating that you received disability.

Yeah! Because that's the thing I struggle with a lot. I've gotten a lot better at just knowing this is what it is. If I was sitting down in an office, I would fall asleep, even on my best day I don't know if I'd stay awake. So for the government to say, 'We agree that you can't work a normal 40 hour week,' really helped me. I think it put me at some peace, like "Ok, your limitations are your limitations," and it validated that.

You read a lot about how people with invisible disabilities feel like—just what you said—people have this perception that if it isn't visible, it must not be a real disability—just get over it, pull yourself

together...

Pull yourself together is the thing! Also, the thing is, even though it is an invisible disability, it still does come out in other ways. There are times when my motor skills are so delayed. It's why I like people to know I have narcolepsy so they can understand the reasons why my handwriting today is so very poor when I write tags for the clothing—because I'm so very tired and holding a pen is more difficult than any other day.

You have said that you love to talk about and bring awareness to your disability.

Oh my gosh, yeah!

Why are you so passionate about this?

Yeah, why am I so passionate? Maybe just the fact that I know the struggle is real. I'm proud of how far I've gotten and where I'm at and what I'm able to do despite it (my disability). And the fact that there are people out there who struggle with their hidden disabilities and aren't in as good a place as I am. I want them to know that I get it to some degree and that you can make more of yourself. Knowledge is power to me, so if more people know about it, that can only benefit everyone else. I think it's also cathartic for me, in a way, to talk about it. I'm owning it.

You said that you have come further than you ever imagined, so what are your ultimate goals for your life?

I would love to just be fully independent and not have to have my parents support me in any way. Stephanie has helped me hugely with my financial dependence on my parents. I'm so glad that it's freed them up too. I would love to feel independent and able to just be more like people my age. I guess the less I think about my narcolepsy day-to-day, the more I feel like I'm being successful. Ultimately, I want to feel like it is less. It's part of who I am, but doesn't define me anymore. I think I'm getting there more and more. And that's the thing—I just realized I have continued to push past any obstacles that have come up. I am excited about the fact that I don't really know what's ahead of me. I think there is potential for anything. For me, it's about being in a place where I can live my life and do the things that I want to be able to do and also feel like I'm contributing to the world as well. I guess not to need Tangram would be a great goal. To be in a place where I felt I was self-sufficient enough.

[Your support helps Tangram provide vital, individualized services so that people with all types of disabilities can live their best lives. Make a donation in honor of Indiana Disability Awareness Month today!](#)

