

Faith Journey: An Interview with Tonya Arndt

Tonya Arndt is a disability advocate living in Trenton, Missouri (Grundy County). She is a speaker and lobbyist (traveling to Washington D.C.) with the National Spinal Cord Injury Association.

L- Can you tell us about yourself? For example, what are three important things we should know about you?

T- Growing up I moved around a lot. I lived in numerous, different states and part of that was going to a lot of different denominational churches within the Christian Faith. So, something that I think is very unique about my childhood, that I really love, is that the moving around gave me this strong desire to just know people. It made me have a lot of respect and just a desire to get to know people -- people that were different than me.

And along with that, I think it made me realize that we're all different, everybody has things that are unique about them, but as humans we're all pretty equal in that we all just want to be accepted and loved and feel like we belong. So that's something that I think has had a lot of impact on me, throughout my life, and I don't know that I would've had that if I hadn't moved around so much.

When I was about to go into high school, I actually moved here to Missouri to live with my dad, and it would've been just a couple weeks short of my senior year, I had a wreck and it gave me a spinal cord injury. I'm a quadriplegic, and as cliché as it sounds, the three most important things for me are my Faith, my family, and my friends. Those are the three things that I know will get me through anything. I had other issues, other challenges, other obstacles in my life before my paralysis that I got through and during those times, it always came to those three things.

So, a couple of weeks before my senior year I got in that wreck. I think I was 17, and I really thought "this is the year I'm going to gain even more independence"

and eventually, graduate, and go on to maybe the military or health care field. Looking back, independence was always huge for me. I was always very independent from a very young age, and instead, with that injury, I found myself more dependent on anybody than since, probably, I was a toddler. And I had actually said to a friend of mine just a few weeks before my wreck, the two of us were having a conversation about "things we could handle or overcome." And the main thing that came out of my mouth was that I could never handle being in a wheelchair for a long period of time, and it was because of that fear of being dependent on other people.

I was active in the church, with my Faith, and people would have described me as a Christian (and I was), but because I had my injury it forced me to realize: God has that control. And He always had it. I think I had been very self-reliant, up unto that point. Anyways, that was a big turning point for me.

Of course, immediately after my wreck, I was like.... "okay, I wanna live, I wanna go on," and thankfully I was able to turn to my Faith and totally relied on that, and I didn't really experience a lot of the anger and that kind of emotion that I hear some people have-- because I think I had that Faith and because I had other challenges in my life before that that I had overcome with my Faith, my family, and my friends. That was something I was very thankful for.

L-How did you become involved in self-advocacy and advocacy for others?

T-As you're probably well aware, maintaining your independence as a person with a disability can be extremely difficult. So that's where a lot of my experience with self-advocacy comes in. It is really focused on just how I can maintain as much independence as I can.

At my level of injury, I have to have a personal care attendant. It's something that I accept. And I'm very thankful that I've been able to have some great ones.

But it's something that I've also had to fight every year with the state of Missouri to maintain,

because I get that assistance through Medicaid. And so every year they try to tell me that they're gonna drop me because my income's too high and so every year I have to go in and say, "oh no, that's not it!"

So through that process, I started to think of others, and I thought—"it is frustrating," "it's very overwhelming," and the idea of anybody being forced into a nursing home, when they can live independently in their own home, even with assistance, like I have, is just completely heartbreaking to me.

So that's when I really started thinking, and I was praying on that a lot, reflecting on that.

I also realized that if I see somebody being bullied in front of me, I'm going to stick up for that person.

Anyway, I was kind of praying about it, and I'd just been struggling about what to do when I was approached by the Greater Kansas City Spinal Cord Injury Association to represent the Missouri chapter out in Washington DC at United Spinal Roll on Capitol Hill.

They have one every year. To be honest with you, at first I thought, "I'm not qualified—I'm just a small-town girl!" A lot of these people I had seen attending this were very successful and were in very high-level positions. I was really kind of struggling with that....and so I said to myself, "you know what, Tonya, this is how you show your love for other people, because this is not just about you."

I've figured out and built a relationship with my local people here at the Department of Health and Senior Services. They know every year probably we're going to have to fight, and get it approved and everything, so I know I can't be the only one that's facing that battle. I'm stubborn and hard-headed and I fought for years to try to find a program out there that would let me work and still receive that assistance that I have to have, 'cause so many times I was told

"you can't do it" and

"you can't make more than this little amount of money."

(That isn't enough to support anybody). And so I was able to figure out these different things,

but it's hard and it's scary for people and so, as far as going to Washington, if you can get something done on the national level so it's not caught on the state level-- then that would be amazing.

Also, it just so happened that the year I went out there, one of the bills that we got to talk to the senators and representatives about, stated that if insurance would cover the expense of a person residing in a nursing home that they also had to cover care in the most integrated way as possible in the community, such as in their own home.

So I got to share my story with the different senators that we met and their staff members. For me, that was one of the most rewarding things that I've done so far.

L- When was that?

T-It was in 2017, and I'd love to get back out there. I haven't been able to do it the last couple of years.

L- Can you remember one moment from that trip that stands out to you?

T- I don't know that I can say that there's just one. But I think, with each of the different staff members that we met with, it was probably that moment after I shared what I faced every year. I could see them processing that, and then they would say, "that doesn't make any sense: from a financial standpoint, from a quality of life standpoint, that shouldn't be a battle that anyone has to face."

That moment of recognition that they had was probably the thing that stood out most to me.

L- How does your Faith intersect with your advocacy?

T- I think it's just about my love for other people, and not wanting them to have to face the battles that I have had to...