

Summer Retrospective... Yes, I Went There, I'm Looking Back



I try not to look back. However, this summer marks the 30th anniversary of the Americans with Disabilities (ADA) Act. So, I let myself peruse my memories a bit.

I didn't know I had MS until I had had it for decades. I was 40 when I was diagnosed with RRMS in 2014, and I have used a wheelchair ever since.

I could have been diagnosed before the ADA was signed into law. I am grateful I was not.

The ADA was signed into law 30 years ago in July 1990.

The first MS disease modifying therapy (DMT) was approved in 1993, before I was diagnosed.

I often thought that getting diagnosed earlier would have helped me. Maybe if I knew I had MS earlier, I could have been treated, and my myelin wouldn't have been eaten away so badly.

The first DMT I was prescribed in 2014 worked. I've been stable since my diagnosis and improved tremendously. Though, I have not regained the ability to walk solo and my bladder is neurogenic. For me, both have been very hard to treat.

Since I am indulging in this historical retrospective, I started thinking about what I was doing in the mid-90s. Going to college several states away, graduating from college, going to see lots of live music, interning, getting my first job, traveling a lot and moving... a lot.

I was ready to set the world on fire. I was fearless.

I travelled all over the country and to Europe by myself. If I were diagnosed then, I certainly would have paid more attention to how few mobility challenged travelers there were. Now, I get it.

I think now about how many things are not ADA compliant, 30 years later. The ADA is a broad civil rights law that has made a ton of great progress. However, there is still plenty of work to be done...

Before my diagnosis, I used to dine out at restaurants, flew on airplanes and stayed in hotels. I never realized how unfriendly those locations were to those with mobility impairment. It's a different story now.

Since I have been diagnosed, I have had many experiences with non-ADA compliant restaurants. A lot of businesses exploit loopholes to not incur the "expense" or "financial burden" of the ADA.

It makes dining out one more thing that is not spontaneous and requires me calling and asking many questions. Yes, I'm a control freak, but I find it necessary for my comfort and anyone who's with me.

One restaurant assured me they were accessible, and then they wheeled me through the kitchen like freight. Another high-end restaurant had to have someone from the kitchen wheel me in backwards over a step with no railing to get me into the restaurant. Nothing like making an entrance.

I had another new restaurant tell me that they didn't have "poles" in the bathroom. After telling the waiter that I was not a stripper, and I was looking for grab bars, I had to have a friend come in the bathroom with me. Very dignified.

Another restaurant made me wait at a high-top table for more than an hour in my wheelchair. So the table was way above my head. I never went back.

I am sure everyone has their own examples... which is why there is still so much more progress to be made with the ADA.

I can't even begin to write about how far airlines have to go. Think about it. I can't even get on a plane with my wheelchair.

I used to travel almost every week for work and for pleasure. I've gone on a plane two times in the past seven years. It was not a fun experience.

And hotels... they try, I feel, but often don't get the details right. Thresholds are too high in common areas, so I have banged and bloodied knuckles. And I never can get in and out of

the bed without me bringing a stool. Not safe. And not possible to bring a stool when not driving. And the bathrooms either get it right ... or don't. The mirror needs to be low enough that I can see into it. I also need a fully functioning shower, bench and shower hose/faucet that doesn't flood the bathroom so I can take a shower by myself. Some hotels get it right, and some don't. It's really hit or miss.

Unfortunately, I have found that chain restaurants that abide by the ADA rules are the best for me. I didn't frequent chain restaurants before my MS diagnosis. Now I do. Bonefish Grill is now one of my favorite restaurants.

I'm so thankful for the ADA and for everyone who fought to make it a law. But it will take all of us to continue to improve upon it.

Remember. We are not out of sight out of mind. Hold your elected officials accountable. Get involved. And **vote!**