

How has the adversity impacted your life?

From an outsider's perspective, it may not look like my adversity has had an impact on me at all. If you don't know me then you don't notice the forced smile, the hidden limp in my walk on bad days, or the amount of energy that goes into acting like none of this exists. You see the happy girl, student class president, manager of the lacrosse and field hockey teams, and piano teacher. You see me laughing with my friends like nothing is wrong but what you don't know is that after school and work I will be absolutely exhausted. I'll walk straight up to my room get into bed and watch some Netflix before falling asleep. The truth is, my disability has impacted my life in so many ways that I can't even explain, I just don't like to let people know it. I manage for lacrosse and field hockey because I can no longer play the sports I once loved. I teach piano, but I can't play nearly as much as I used to. I'm 18 years old and I have, on more than one occasion, walked with a cane. I have a preference in hospital emergency rooms. My body hurts all the time and I can't eat gluten, dairy, or sugar. Every day is a struggle but everyday I get stronger. I work my hardest to act normal and I expend infinite amounts of energy on keeping up with that appearance. Ehlers Danlos syndrome has had an immeasurable impact on my life but I refuse to let it define who I am.

What did the adversity teach you about yourself or life?

My adversity has shown me just how lucky I am to be surrounded by the friends and family I have. Every day I read posts in my Ehlers Danlos support group from girls who's parents call them liars and who's friends think they're acting out for attention. They're bullied in school and their doctors believe what we have is a made up condition. And everyday I am thankful for the people I am surrounded by. I often like to pretend that I am not disabled. That I can do anything I want, even when my body cannot actually sustain such activities. I am learning the hard way what I can and cannot do because I am too stubborn to listen to the people who tell me when I need to stop. This stubbornness is a curse and a blessing; as I push the boundaries I learn I am able to do things I thought I couldn't. I also learn I'm not able to do things I thought I could. But even when I fall, literally and figuratively, my friends and family are always there to help me up. They've stuck by me through what I hope will be the hardest two years of my life. I've learned that the only real disability is a bad attitude and without my amazing friends and family I don't know where I'd be.

My adversity has also inspired me to branch out. I now understand better than ever what it's like to have a disability and, while mine is not as bad as others', I still sympathize with them in a way that was impossible before. I volunteered at buddy ball last year, before my diagnosis, and this year, after my diagnosis. Buddy ball is an event for three Sundays in the spring and fall where children with disabilities come together to play sports and other activities. It was an amazing experience both times I participated but this year it really stuck with me. This year, I understood the silent struggle each person experiences. I now know how hard it is to participate and smile when you're in constant pain and I know the fear of being judged or looked upon differently because of your disability. The strength and resilience of those kids at buddy ball inspired me. I realize that this has given me the opportunity to help others in a way I couldn't

before and I know that in some way I want to spend the rest of my life helping others who aren't as lucky as I have been.

What have you done to help others?

I volunteer through the National Honor Society for many different charities and organizations. I've participated in Lower Moreland's mini THON for all four years of high school. I volunteer with Alex's Lemonade Stand and I accompanied children with special needs at HVAA's Buddy Ball program. But the best help I give to others is my support. I support my friends through their struggles, and whether they want me there or not, I'm always there. The support I offer for my friends and family is something I pride myself in and since my diagnosis I have tried to branch out and support others with my condition. Through Facebook groups like Bendy Teens and EDS Teens I am connected with the few others who know exactly how I feel. It is a good feeling to know that there are people who understand my condition because they are living proof of how strong we can be. I'm privileged to be able to offer my support to those who don't have friends and family like mine and as I grow older I want to be able to offer more widespread help for those in need.