



This is Dylan Marcy's reflections after participating in the Got Transition Webinar "I Am More Than My Diagnosis!"- *The Impact of Personal Identity on Health Care Transitions for Young Adults with Special Health Care Needs*. As he prepared for the webinar, Dylan wrote this story, saying the webinar "naturally made me really contemplate my own personal identity, and what identity itself means." [Read more](#)

Dylan Marcy's reflection on his own personal identity- and what identity means.

The first question here is what is identity? To me, identity is a mix of personality traits, strengths, flaws, hobbies, perspectives and anything else that makes a person unique.

Naturally, a large part of my identity is my chronic "illness", Ellis van Creveld Syndrome. As far as the public is concerned, EvC Syndrome *is* what I am. I will never be tall, dark and handsome like the models that portray everyday Americans in the media. Then again, though, who is? I am told every day by others who see me that I am lesser because I'll never be that way, that I'm a dwarf before I'm a person. For a while, I believed them. It's hard to be really sure of who you are when people on the outside make sure you know you aren't good enough for them. After a while, you stop caring about who you are because you get the impression it isn't good enough for anyone else.

For a while, it was hard. I felt alone, with nobody to really be able to relate to. I was literally and metaphorically dwarfed by the people around me, the "normal" ones. I wanted nothing more than to be like them. This lasted up until midway through Junior year of high school. I wasn't sure of who I was, so I envied those who seemed to know who they were. I'm not sure what happened, but something changed.

I know for a fact that, had I not been best friends with the people I was, I wouldn't be essentially *me* today. I would be another drifting "wannabe". As I've gone through life (because, despite being only 19 years old, I've had to live and grow up faster than most of the people I know), I realized that many of those who I thought had it all together, the ones who were so full of confidence, were really more changing than the weather in Colorado. They shifted, conformed to the newest trend, newest popular music genre, newest *anything*. All that mattered was whether it was popular or not. Nothing wrong with that, sure, but they didn't seem to have any idea of *who* they were, just that they feared being left behind, so they adapted to their current environment, without ever really knowing why. It seemed to me (and I could be wrong) that they adapted not because their identity depended on it, but because up to that point, they hadn't *found* their identity yet, and had to try on the newest pair of clothing to see if it could be found there.

What changed for me was that I couldn't do it any more. I was different, and I knew it, and I didn't *want* to keep pretending I fit in. It's a tiring, exhausting process that drains not only physical energy, but deteriorates the mental, too. Telling yourself day in and day out that you needed to be someone else for your own good is a terrible way to live, and it takes its toll after a while.

Then, suddenly, I stopped pretending. I started being me, with all my strengths, and all my flaws. I lost some artificial friends, and that upset me for a while, but the friends I made, are friends I'll always have. I made three of my best friends because I stopped caring about what anyone

else thought of me, and started being myself. I got closer with my absolute best friend because I started being honest with him and myself about who I was, and he accepted that. I found someone who truly loved me because I was fully, absolutely me, all the time. I'm not perfect, but if I'm not perfect, at least I recognize my flaws.

Who, exactly, am I? There are a lot of things I could say. I'm a son, a brother, a friend, metal head, dwarf, etc., etc. For, although my dwarfism *doesn't* define me, it's led me to figure out who I am. And that is the greatest gift of all. I may not be my diagnosis, but my diagnosis is the catalyst that fueled the realization of who I am. So, despite the struggles I've had and the pain it's caused, the dwarfism is the one thing in life I'm most thankful for. It gave me a reason to be different, a reason to strike out and find out who I really am.

No longer will I "go with the flow", unless it happens to flow in a way that I'm already headed. I haven't done the norm since Junior year, and like a rock a river can't seem to budge, I'm too stubborn to go back, now that I know who and what I am. I'm me, and I'm comfortable with that.