

The Cycle: Growing Up with Turner Syndrome

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Alyssa Dennis is an example of how a random genetic disorder can complicate life but how personal outlook can result in a positive outcome. She has always known she had Turner Syndrome. She noted two challenges in childhood. She had great difficulty with her growth hormone shots which she resisted, something she now wishes she hadn't done as she could be taller now. School also proved to be a challenge. She had difficulties understanding concepts that were being taught and had trouble studying. Math was her hardest subject and she always had a math tutor. She had an IEP until 8th grade when her mother felt she didn't need one anymore.

Because of a good support system, she was able to thrive. She was fortunate to have a mother and grandmother who are always there for her as well as a group of friends who she still keeps in contact with regularly. In school she hung out with five people who were very understanding and supportive of her. She became more outgoing and open about her Turner Syndrome by high school. It was comforting that no one seemed to care that she had it though.

As a result of her Turner Syndrome, she remembers having difficulties fitting in. She remarked, "I always felt like an outcast among other kids. I always had doctors' appointments and health issues and they didn't understand that." However, she also learned that she could live a normal life. She said, "It is difficult to live with Turner Syndrome and you are different, but you are special. Yes, it might take an extra step or two but you can still live a normal life and achieve anything you want to." Social issues certainly do impact the lives of many girls and young women with Turner Syndrome. A 2011 article in *Developmental Disabilities Research Reviews*, a publication by the National Institutes of Health, by David Hong, Jamie Scaletta Kent, and Shelli Kesler cited numerous studies where girls with Turner Syndrome have an increased self-report as compared to their peers of anxiety, depression, low self-esteem, and

impaired social competence. The article also said, “Social cognitive deficits can result in social isolation, peer neglect and/or rejection, reduced number of meaningful relationships, difficulties understanding the emotions of others as well as one’s own emotions, and deficits in recognizing another’s point of view among others.”

Her difficulty “fitting in” resonates with the concept of disability culture. The basic idea of disability culture is that people with disabilities realized that they shared a unique history based on common perceptions of disability. Steven Brown of the Institute on Disability Culture wrote, “People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives, our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. We are who we are: people with disabilities.”

Even so, Alyssa has moved onto adulthood valiantly. In regards to her medical history, she has found a great endocrinologist, Dr. Eapen, and continues with estrogen replacement therapy in order to maintain feminization, protect bone density, and avoid endometrial issues. Her primary care physician, Dr. Carson, knew all about Turner Syndrome so she didn’t have to go into a long explanation about what the condition was.

She will be graduating with a nursing degree from Reading Area Community College in Kutztown, Pennsylvania, in June after completing a summer course. It was a long process getting there because of her learning issues but with help from her professors and tutors she will be able to obtain her degree in June after completing a summer course.

As she moves into the future, Alyssa struggles with the fact that a lot of her family and friends have babies and she knows that it will be difficult for her to have children. She said, “I just think that when I am ready I will have the child I was always meant to have and that you are never given anything you can’t handle. There is a reason for everything.”



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