

Katharine's Story

Katharine wrote her own story.

I was born in 1973 the oldest of three children. My parents built their home in the Adelaide Hills. I was born with Myoclonus Dystonia Syndrome and Autism Spectrum Disorder. The myoclonus was obvious from a very early age and as I grew I had difficulties in school with socialisation and anxiety.

I wasn't diagnosed with Autism Spectrum Disorder until later in life when it became apparent to the psychiatric community that people who had language skills and higher intellect could also have Autism. I also have a brother with Autism Spectrum Disorder, Myoclonus Dystonia and learning disabilities.

I went to several schools as a child leaving my first because I was too anxious to cope and because my parents decided that all three children would benefit from a different style of education. I attended the Waldorf School in Mount Barker which seemed to suit my learning style.

However in my teenage years I moved to the country with my mother and attended the local high school. This was not necessarily the best move for me as they really were not equipped to deal with different learning styles and emotionally and socially unique children.

After finishing school I moved to the city and decided to repeat my year 12 studies. This did not go as planned as I found living independently and coping socially very difficult and by the end of that year I was very unwell with anxiety and depression.

Here is where I entered the mental health system and unfortunately they didn't have any really definitive answer as to what my issues were. After some time in recovery I participated in many schemes designed to get people ready for work or to study such as the Landcare Environment Action Programme, women's self-defence, various TAFE certificates and a diploma course in visual art.

Finally, through the [Commonwealth Rehabilitation Service](#) I gained an arts administration traineeship at the age of 26—this was my first full-time job.

This traineeship allowed me to learn a lot about the social side of the workplace. As a theatre trained person my employer took it upon herself to use drama skills and other techniques to teach me how to act in the workplace and how to understand workplace culture.

After this traineeship I wasn't offered any further employment so I decided to look for other work, and although I found some casual work, I still found it very hard to get a job.

When I was 28 I decided to apply to go to university as I still hadn't found a career as such. I ended up being accepted into the Bachelor of Applied Science in Disability Studies.

In this area I really found my niche and began to realise that I had an aptitude for study and for understanding disability theory. It was also during these years that my conditions were clarified with proper diagnosis.

Myoclonus Dystonia Syndrome is a very rare syndrome and it affects six members of my family and the understanding of it has grown as we have grown older, so now we have a lot more information about the syndrome and how it affects people, physically and psychologically.

As previously noted, Autism Spectrum Disorder, specifically Asperger's Syndrome, was not heard of in the 70s, so it was with the expertise of my university professor that I was directed to a diagnosis while I was studying.

In 2003 I graduated from university and took a job in the disability sector. I worked for the same organisation until 2011. During 2011 I became unwell and decided that the type of work that I was doing was too stressful and contributed to my declining health.

I had previously enrolled in a Master of Disability Studies and have decided that in 2012 I will complete this study. During my study it has been important to work with the Disability Liaison Officer and my lecturers to plan appropriate accommodations, set goals and complete my study.

During my life and career I have always been drawn to activism and leadership. In the 1990s I was involved in activism around youth issues and global financial and environmental issues, attending protests and becoming involved in lobby groups.

This passion for activism stretches across many areas of my life. I am a disability activist, a gay rights activist, and am particularly interested in the rights of women. In 2008 and again in 2010, I was fortunate enough to travel to the USA to attend the Women's Institute on Leadership and Disability. Each time I was the only Australian delegate to be chosen.

This experience changed my life and instilled in me many of the leadership qualities I have today, and I also got to meet many women with disabilities from around the world, particularly those from developing countries and I keep in touch with them to this day.

These activities have given me the skills to serve on many boards and committees. I currently serve on the [Minister's Disability Advisory Council of SA](#) and am a director of the [Australian Federation of Disability Organisations](#) where I look after the International Portfolio and am the Treasurer. I am also involved with [Women with Disabilities SA \(WWDSA\)](#) and the [Autistic Self Advocacy Network of Australia](#).

Family is extremely important to me and I am lucky to have two sets of parents who are very supportive, and two living grandparents who are also very supportive. I have two young brothers, two stepsisters, a niece and three nephews. Being an aunt, especially to my biological niece and nephew, is one of the most important things in my life.

I live with my partner in a house we are buying together. We have been in a relationship for nine years. A lot of people would say it is doubly difficult to live with disability and be gay, however this is just the way I am.

Our relationship has lots of give and take and my partner is very, very supportive of me and quite patient. She has supported me with many things including encouraging me to get my driving license two years ago at the age of 36. When I was unwell last year she took time off work and in the end even changed jobs to a less stressful job so that she could support me in my recovery.

A lot of people would look at my life and say I don't have any trouble living independently. I would say my world has opened up significantly since I got my driving license, and I'm glad that I had patient people to help me get there.

On a daily basis there are just little things that help me get by. For example I'm dictating this to the computer using a Bluetooth headset and software called [Dragon Dictate](#) which I find very useful, as my hands cannot keep up with my brain.

We have changed all the crockery in my house to non-breakable so I can keep doing the dishes without breaking things because I often drop things. I like order but I have problems with organisation, so I'm good at lining things up but I am not necessarily good with organising paperwork or paying bills or dealing with schedules.

I find this area overwhelming and need a lot of prompting, which I get from my partner, and things have changed a lot since online banking and direct debits have become a way of paying things.

The other thing I have to do is manage my energy levels, as living with a movement disorder—although relatively mild—can be extremely tiring because your body does a lot of extra work.

My mind seems to do a lot of extra work too. So when I'm overworked I need reminders to slow down and be kind to myself. Like any couple, we have to work hard at our relationship and my conditions are part of the mix that sometimes make the work harder but the effort is worth it for the meaningful relationship we have.

Sometimes I think people with disabilities suffer from a 'superhero syndrome' in which we try to be the best at everything we do as if to make up for things we can't do or things we are told we can't do.

This is the kind of underlying work or water treading that people with disabilities do to maintain an independent lifestyle. Some of it is the same as what other people do to live and some of it is different, but it is all human endeavour.

What is vitally important is the support of your family and the support of the community and a circle of friends who understand and celebrate diversity, and support you to develop loving and trusting relationships. I am blessed to have some special friends in my life who stand by me and challenge me to be the best me I can be.

Mentoring and mindfulness are two really important things to me in the work I do with other people around life-enriching skills. It is important to have mentors to receive guidance from and to look up to. Mindfulness skills are something that can help you live in the present moment, experience life to the fullest, and deal with past traumas and the uncertainty of the future.

Life only happens in the moment!

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