Ellen’s Story

Ellen wrote her story

As a young teenager I was diagnosed with an auto-immune disease. It came on very suddenly and I went from being outgoing, confident and highly social to spending the majority of my time at home in bed. This happened almost overnight. The nature of my disability is invisible which creates some unique challenges. Nobody can look inside me to see that I have this disease. There are some physical cues but they are very subtle and won't be picked up by anybody who doesn't know me well.

When I became ill at 14, my friends thought I disappeared seemingly without reason. Suddenly I was absent from school more days than I attended, I wasn't participating in social events like sleepovers or trips to the movies. I tried my best to explain what it was like for me but the fact I "didn't look sick" made it difficult for my peers to fully comprehend. They didn’t understand why I couldn't just keep up with them, they would forget I couldn't walk very fast or far before needing a break, or that I had to go to bed early.

The variability of my illness also confused my peers; why could I do certain tasks one day but not on another? I gave up constantly reminding them. I felt embarrassed about being sick. I wouldn't talk about it and spent all my energy trying to hide it instead. Nobody else I knew was sick; sitting in the specialist waiting room I was surrounded by older people. It was rare for me to see anyone younger than their 50s.

I felt alienated and alone. Sometimes comments my friends made about my illness would amplify these feelings. I recall a friend telling me they were jealous I was on the disability support pension; they wished they could get money for sitting around doing nothing. I was crushed and didn't bother explaining how badly I wished I had the health to take on a part-time job, how much I just wanted to be normal! I didn't have the vocabulary to explain to them how ignorant and hurtful such comments were.

It wasn't just my peers who had trouble understanding I was sick. The adults in my life could be just as guilty of making thoughtless assumptions based on how I looked, even when they had been apprised of my illness. Teachers operating on the "but you don't look sick" principle would accuse me of wagging school or ”taking advantage” of my illness.

I had trouble concentrating on my school work and missed whole chunks of the curriculum. Nobody thought to say "hey, let's modify this curriculum for you, let's adjust the way we assess your learning". When my teachers noticed how withdrawn I was at school one of the counselors thought it would be helpful to buddy me up with an older student, essentially creating a mentor relationship for me. Unfortunately the mentor I was paired with was not someone who lived with chronic illness or had knowledge of any kind of disability. I experienced the same road blocks with them as I did with my peers, my teachers and other adults in my life.

There was a fundamental lack of understanding between myself and others who have not lived through a chronic disabling illness.

I was introduced to Julia Farr Youth in a newsletter advertisement when I was volunteering with another organisation, Interchange. JFY were searching for new members. I had been looking to get involved with more volunteering and was intrigued by the ad. Not being 100 per cent sure what my role would be if I were to be accepted, or what exactly JFY did, I filled out an application form and went along to an interview. I was under the impression that the group was a forum for young people with disabilities to discuss issues that are important. I was right, but it is also so much more! It is a place where we are supported to take action and make a real difference in the lives of young people living with disability through Julia Farr Youth Mentoring. As someone with a passion for social justice I knew I had to be involved with these amazing people and contribute in any way I could to the work they were doing.

The aim of JFY Mentoring is to pair a mentee with a mentor who has gone through similar experiences and hardships, and has a deep understanding of what the mentee is struggling with. Mentors don't just empathise; we understand, we really know, we've been there. There is a wealth of shared experience to mine and that starting point lays the foundations for a meaningful relationship between mentee and mentor.

A mentor isn't expected to come in and revolutionise a mentee’s life (although that is certainly a possibility). Oftentimes it's about the smaller things: meeting someone just like you; seeing they have gone through similar struggles and come out the other side ok, and; are living their life the way they want. Being a mentor is about sharing things with a mentee, demonstrating what is possible and that there are ways to achieve your goals. I didn't realise, for example, that universities are quite flexible when it comes to disability, that they are willing to modify requirements and work around your limitations.

At 14, I simply could not imagine myself succeeding at university the way I currently am. I would never have thought I could manage to survive living out of home, all on my own, the way I currently am. I desperately wanted to travel abroad, but if someone had told me that I would actually manage that, and go without my mother, who was my carer, I would have shook my head.

If I could go back to when I was younger, going through the struggles of the transition phase that is adolescence on top of the problems a chronic illness brings, I would explain to myself that things do in fact get better, that some problems don't last forever and that I would be able to achieve these goals. It would have made my life easier to have someone like myself to look up to, to see someone else dealing with the everyday realities of disability and getting on with it.

One of the ways I found to deal with my illness was seeking out others like me online. I joined online communities and discussion groups centered on illness and disability. The elation and relief I felt at finding other people like myself was palpable. It was like the weight I carried on my shoulders suddenly wasn't just mine anymore; others were carrying it with me and that made it lighter.

There were people I could engage in gallows humor with, share tips with, complain to and know they truly understood rather than just feeling sorry for me. A doctor can know all there is to know about a medication or a disease symptom, but speaking to someone who has been through it, who can tell you how they personally dealt with it, to say "hey it's not so bad, I got through this, this is how, you can too!" is invaluable. It also helped me to know other people were sick too, that is was OK for me to be sick and not something shameful to be hidden, that is was something I could have control over.

An aspect of my illness was the experience of disempowerment. Control was taken from me in a few ways: I didn't have control of what was happening within my body, the disease took over; I also didn't have any control of what was happening to my body, how my disease was dealt with. At 14 I was put on a plethora of medications without a whole lot of explanation from doctors. It was my job to comply with instructions and take the pills. Oftentimes I felt like a walking illness, rather than a person, it consumed my identity. All the doctors seemed to care about was my test results or symptoms.

This somewhat dehumanising dynamic between doctor and patient was described by French academic Michel Foucault as “the medical gaze”; I became the subject of this medical gaze and was seen by doctors as the sum of my illness, rather than a person and an active agent. Now that I am older I have learned to take a more active role in my treatment, to speak up with my doctors and demand to be involved in decision making. I can say "hey I really don't like how this medication is making me feel" or "I do not wish to do this" and they have to listen to me, because we are dealing with my body and the choices belong to me.

I didn't know that could was possible, and a huge part of my developing those skills and developing the confidence to exercise my autonomy was my exposure to others with chronic illnesses, and their input. If I had not read about other people doing such things, having that behaviour and mindset modeled to me, I would never have considered it a possibility. I can only imagine how much more enriching it would have been for myself as a teen to actually interact with people like myself in real life, to be able to sit down face-to-face and speak about things, just to have someone "like me" in my life.

When I think about my situation as a young teen, and the needs I had, I can see how fantastic mentoring could have been for me. I want to give that to someone else! I muddled through my teen years and got through ok, but to be able to shine a light for someone else and make things just that bit easier, for others to learn from the mistakes and experiences that I have had, would be fantastic.

At the very least I have certainly accrued a lot of helpful tips for living. My experience of living with a chronic illness has taught me a lot, and I have grown in ways I would not have without it. This experience is what qualifies me as a mentor.

Nothing special, I'm not a super-hero or an aspirational figure; I haven't built hospitals or started a fortune 500 company. I am just regular me, living my life the best way I know how and negotiating the challenges that come my way. That's all that's needed.

Being a mentor isn't just about giving. The very fact you are helping someone like yourself can be quite transformative and healing. It is almost like you are going back to that younger more vulnerable version of yourself and finally meeting those unmet needs that you had.

It is something very special when you have a meaningful connection with a mentee, to realise how you look in their eyes and to know that you can potentially help them out, and to know they want to be around you and learn from you. There are also plenty of things a mentee can teach a mentor. I have learnt a lot from people I have ostensibly been mentoring.

The experience of being a mentor has made me stronger, it has increased my confidence and helped push me to realise things I was unsure about. This mentor program isn't just meeting the needs of potential mentees in the community; it is also meeting the needs of mentors. It is an opportunity for people to be recognised for what they are doing and to develop leadership skills within them. For someone to say to me: "Hey, you are doing really well! I think you can be a role-model, I think you have the capacity to help" nourishes my wellbeing, and encourages my potential.

The fact that this mentoring program is "for us by us" recognises and encourages the autonomy of young people like myself living with a disability. We are in control; we know what is best and what can work because we have lived it. We are the experts on our lives.