

Kerry's Story

Kerry wrote her own story.

Twenty years on and Multiple Sclerosis (MS) is no longer the foreign invader of my body that it used to be. Nowadays it sits beside me in an awkward liaison. We are competitors of old, I have learned through trial and error ways of managing the illness alongside living my life. It has been a long slow dance; two steps forward, three steps back. I am at the same time both victorious and bested.

When I think about the hurdles, challenges and chaos that surrounded me in those early days I wonder how I ever found a pathway through the turmoil. But here I sit, the worst has happened and yet I still live with a reasonable quality of life. Looking back, it seems as if the fear of deteriorating abilities was worse than when it actually occurred.

I live in Adelaide with my partner and two cats. I have lived alongside MS for 20 years. I have a part-time job in the disability sector as a research officer. Mine is no extraordinary story. I think I have done what many people do; that is, go after the desire to live a good life.

When I knew that my health was threatened by chronic disease I experienced this as a fracturing of my sense of self and identity. I no longer had access to many of the pieces of my life that had made me who I was. Most importantly I felt less than I was prior to MS. I felt out of step with life and could not seem to get back 'in the groove'. I could not make plans or put my mind to a future.

Life keeps on happening whether you are in the groove or not. Pretty soon it was uncomfortable to sit with so much chaos. I was aware that a decision was before me. On one hand I could sit in turmoil being miserable and saying "why me?" That option did not appeal to my ego, to my desire to live a good life.

The other option was to go out and find out what was possible.

I remember that I deliberately posed a series of questions to myself. So what would I have done had I not been diagnosed with chronic disease? What things was I interested in and how would I pursue them now that I lived with a chronic disease? Who was I now that I could not run and jump? How could I maintain a sense of dignity and integrity while living with MS? What would be important for me to continue from my life prior to MS? How would I stay interesting as a person?

I did not know it at the time, but this was me attempting to rebuild my shattered identity as a person. Looking back, this was an incredibly important process in finding out what was possible while living with MS and redefining my sense of self and identity. The decisions I made back then mapped out a pathway and assisted me to set some short-term goals.

Reflecting back, I think goals have been an important part of adapting to life alongside chronic illness. In the early days when I felt useless, setting goals enabled me to experience small successes and feel better about what was possible for me. For example, in those early days of bewilderment I enrolled to do a short-term course on managing life with chronic illness. I remember it feeling like an overwhelming hurdle to get to the first class, but once I met other people in similar situations I found it to be more supportive than anything else I had tried. I met people who are still my friends today and some of whom have been my greatest teachers in learning to adapt to living with multiple sclerosis.

I conclude that learning to live with chronic illness is a process of trial and error to see what works best for you and your symptoms. It is incredibly helpful to be in touch with other people who have lived with that condition or illness longer than you have. In those early days I hung on to the pearls of wisdom that spilled from their lips about how they had managed symptoms and how they had overcome hurdles. I found these people were a lot more helpful than doctors who could do little for me apart from offering me drugs that I did not want to try and labelling me a “silly girl” because of it.

Without doubt, the most useful thing for me was to return to a work role once I was able. I had experienced being at a loose end at home with a mind filled with horror stories about how the disease would play out. Getting back to work put structure back into my day. Striving toward work-related goals distracted me from the chaos of MS and gave me the sense of purpose that was so important to me prior to MS. Relationships with colleagues added richness to my life and made me feel a sense of ‘normal’ again. Most importantly, my achievements at work fed into my sense of self and identity, which made me feel good about myself. MS was no longer defining me as a person. There were other interesting aspects to my life that would become the basis of conversation in social situations. I conclude that a continued work role alongside progressing MS has enabled me to feel as if I live an ordinary, valued life. I feel in sync with other people who work.

Somebody once said to me: “You don't stop doing things just because you've got MS, you just do it differently.” I think that might have been one of the most important things anyone said to me. My desire to live the good life led me to continue doing the things that I enjoyed and that provided me with a good quality of life. I remember thinking about what things I wanted to keep doing and what I would need to do to keep doing them.

There were many things that just needed some logistical planning, e.g. going to a restaurant would require phoning beforehand to establish accessibility status and the availability of accessible toilets. I had loved horse riding prior to being diagnosed with MS and so I joined [Riding for the Disabled](#) for a while and loved the contact with the horse. I continued to study what interested me and continued to develop a career

identity. If there is something new you want to develop in terms of knowledge or a profession you owe it to yourself to pursue that. Living a valued life is about having knowledge and skills that you can contribute to the community.

Unless illness or disability creates very poor health and experience of life there is no reason to stop doing the things that you are interested in. Experiences such as attending conferences, workshops, and tackling challenges all nourish my sense of self. I realise that it might not be the same for everyone. We're all different and what 'floats our boat' will be different. Each person has to find out what is right for them and go after it!

Don't be put off by knock-backs; dust yourself off, get back up and try again. While living in Melbourne I applied for 50 jobs before I was employed as the manager of a service in a hospital. Every time we get rejected we feel like giving up, but a belief in ourselves as people who can—and want to—contribute is the reason to keep on persevering. We deserve the opportunities that other people enjoy; we owe it to ourselves to keep on keeping on.

So if there are things you have a passion for or are interested in, put energy into those pursuits. Find out what music excites you and why, listen to it and develop your collection. Know what brings you peace and surround yourself with such things. Be clear about what energy you want to be near and surround yourself with people that exude that energy. Be aware of your rights as a person living with disability and have 'fire in your belly' about standing up for them. Claim the same rights as other people living in the community enjoy.

Most importantly, believe in yourself, that you have plenty to contribute to others and be prepared to do that in your everyday life. Lastly, make sure you laugh a lot!

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