



LIVING OUR LIVES

Hi – my name is Sanjay and I have something called Limb Girdle muscular dystrophy, which affects my arms, legs and shoulders.

I work full time for AstraZeneca and want to talk about employment and share my experiences with you. I graduated with a first class honours degree in Chemical Engineering from University College London and it was in my final year that investigations started into why I was struggling to climb the stairs.

Meanwhile, I was busy applying for graduate jobs in engineering. I went for interview with a company and was offered the job subject to the medical. I failed their medical because of my blood test results and the offer was withdrawn. Luckily I was also offered a good job with ICI up in Teesside. But I was away from my entire support network – family and friends – and was still processing what was going on in my body and what it meant for me now and in the future. I was supposed to be settling down, buying a house, looking for a wife – the usual tick list. It was a very difficult time for me trying to deal with all this by myself. I was quite moody, feeling down and not really sure what I was supposed to do. There was no real support offered along with the initial diagnosis and I felt very alone.

After 11 months, a few positions opened up at AstraZeneca in Macclesfield. So I went for it. I was selected for interview and was very worried when I turned up on the day. Should I tell them investigations were ongoing, that I had a neuromuscular condition that was undiagnosed currently and that I have no idea what lies ahead and may end up in a wheelchair? Will they reject me if I do? If they do, what if I never get a job? What's going to happen to me? What should I do?

I decided to tell the truth at my interview because it was the right thing to do, and I was ready to face the consequences. Much to my surprise, I was told that I'd got the job. I was told I wasn't being employed for my body, but for my mind, and that any changes in my body would be taken care of as and when they needed to be. That was 18 years ago and true to their word, AstraZeneca have adapted as I've changed.

I've had a variety of roles over the 18 years that have been stimulating, challenging and very rewarding. In my first couple of roles I was based on a manufacturing facility making sterile products. I loved that job – I remember saying to people even if I wasn't paid, I'd still go in and do the work. That's what it meant to me. At this point I was OK on my feet but after a few years I needed a walking stick for support as I had occasional falls.



How was I supported by AstraZeneca at this time? I couldn't go into the facility as I couldn't get gowned up (it required me to stand on one leg). But I was given plenty of other tasks to do and could go into the facility during maintenance shut downs every 6 months.

In case I fell (which unfortunately I did), I was given a lone worker alarm so I could call for help, or if I was not able to call (if I bumped my head for example), it would go straight through to security who would come to find me.

To keep me mobile and manage my condition, I was allowed to go weekly for physio treatment to the Neuromuscular Centre. That kept me on my feet for much longer and gave me (still does) lots of support.



I then moved into planning and logistics. Here I was allowed my car on site so I could park nearer the office. Extra handrails were installed to make it easier and safer to get to the office when I was walking with a stick. All the while I've had an annual risk assessment looking at how I was doing, and what we needed to do to be one step ahead of the game.

During this role I was set up to work from home. I'd had a couple of falls that meant I couldn't walk until my bumps and bruises healed but I could at least log on and work from home so the team weren't overloaded. Also when it was icy outside I didn't need to go in. That arrangement still applies today. The picture is what came up on google for 'working from home' – honestly, that's not what I do!



And then to Stability where I'm now a Stability Quality Assurance Manager. During this role is when I finally accepted that I needed a wheelchair. A very tough time but when I told my manager, he was relieved as I'd been falling more frequently and he didn't know how to talk to me about it. I then changed my mind as I didn't want to 'give in' to the condition but my manager told me that he had a duty and responsibility to keep me safe at work. If I didn't get the chair then I may not be able to continue working for AstraZeneca for safety reasons. That was a shock to me but I totally understood. So that's when the chair arrived.

Interestingly, I hadn't noted the impact on my colleagues. Sue, who I shared an office with, had seen me fall in the office a few times. She later told me she'd also worry every time I went to the loo in case I had a fall. When I got my chair, she told me she stopped worrying but felt quite redundant as I could get my own water, get my own printouts and whizz about the place safely.

My way of helping others accept the chair (and probably myself too) was to give it a name. Charlie Chair. It lightened the whole transition for both me and those around me. I realised how important it is to think of the impact on work colleagues – it's as big a change for them as it is for me – they worry because they care. I wonder if this is something taken into account normally – the emotional side of other people seeing someone in a chair?

Working for a great company, having varied roles and being given opportunities to learn, develop and challenge myself... what has that meant for me? My attitude is that there's nothing I can't do – it may take more planning and I'll need some help, but that's all.

I've learnt that life is precious. We never know what tomorrow will bring or even whether we'll be here tomorrow or not.

I realised I have a choice. You heard me talk about the difficult times when I was away from home. And the difficult times coming to terms with being in a wheelchair. I had a go being miserable and feeling sorry for myself – I didn't like it much to be honest! So I chose not to do that any longer and to make the most of each day.

I've been involved with the charity RESULTS for 20 years. RESULTS is about tackling hunger and poverty but through advocacy and educating our key decision makers. I've been to Washington DC 3 times to lobby the World Bank about international development and poverty related issues.

And last year, with the help of the talented team at NMC design and Print, my poetry book was completed

All the while I was doing the above, I was working for AstraZeneca. The confidence and my attitude to life has come about from having a fulfilling job, working for a company that really does care for me. And that in turn inspires me to want to do more.

The most interesting revelation of all hit me recently - I don't see myself as disabled. I was with a friend and when I pulled up in a disabled parking bay, she said 'why are you parking here' – followed by 'oh yeah, I forgot!'

Some people say 'oh you're wheelchair bound' – until you've experienced life struggling to walk, struggling to get in and out of the car, struggling to get up from chairs and sofas, being tired from walking, then you can't know the FREEDOM that a wheelchair brings.

So you can see from this session how I live with MD, how I lead a full, productive and passionate life, and how employment is such a core part of it for me.

Thanks for reading!