



PAUL'S STORY

My name is Paul, I'm 44 years old and I have Duchenne Muscular Dystrophy. I live in an adapted house with my parents on the Wirral. My diagnosis was at the age of five and this took place at Birkenhead Children's Hospital, through a Dr Segar. To be truthful I don't remember a great deal about it as I was so young but I was always determined to be as independent as possible.

Initially I attended St Saviours, which is a mainstream primary school. I attended there until the age of nine. I really enjoyed my early school years but things became more difficult as time went on because I had to negotiate getting up and down stairs. Mostly I managed this myself but our school caretaker often gave me a hand. I was always grateful to him because he wasn't really supposed to help but it enabled me to attend mainstream school which was important to me. Unfortunately, the school wasn't too keen to help me continue there, and it was built on split levels. When I started school in the 1980's, most of them did not have disabled access or adaptations in place.

From then I spent the next few years, up until the age of 15 in two special schools, Clatterbridge and Meadowside. It was there that I started using a power wheelchair as I had lost the ability to walk but I used a manual at home. When I was around 10, I started to need the power wheelchair full-time. I wasn't really happy at special school, not only because I lost touch with people I knew, but also the lessons were not appropriate for my age. I felt held back by this because I wanted to go to college and university.

I knew of a lad who had MD, who moved into mainstream education, because it was one of the first schools the council were putting lifts into. This helped pave the way for me to do the same. Changing schools had a profound impact to my life because I was finally in mainstream education. Unfortunately, I had to go back a year when I started mainstream to get me up to speed with everyone else. It was well worth it though because I gained enough qualifications to go on to 6th Form college, where I did extra GCSE's and A Levels. I had received physiotherapy regularly in special school but when I moved to mainstream it was a bit hit and miss.

Following 6th Form I went to Staffordshire University, where I gained a HND in Business Studies. I then went on to the 2nd year of a degree in Business Studies. Unfortunately I was not able to continue with the course due to depression. I had hoped to return to university the following year, but this was not possible. University was fantastic and I made some great friends. I managed to do this independently as the University was fully accessible. I didn't really need any extra help in my lectures as I was still able to write at this point. I enjoyed my time there and gained a lot of confidence and experience from this

so my time wasn't completely wasted. I had started to look for jobs, without success. I was at home for a few months after this wondering what to do next.

It was while I had a hospital appointment at Oswestry, where I met Ruth Lambert, a Physiotherapist at the NMC who enquired about what I was up to at that time and invited me to visit. I was aware of the NMC as I had been to see a lady called Kate Fox who was one of the founders of the Neuromuscular Centre, several years earlier. I was still recovering from depression, so wasn't completely comfortable - The truth was I still had low confidence, and had always wanted to mix with able bodied people, and not as I saw it being 'stuck with' disabled people. Many years on, I am perfectly happy with being at the NMC.

Being invited to the NMC was a good opportunity, especially as it was the first time in many years I received regular physiotherapy. It also helped me to feel useful, and being with people regularly helped overcome my depression. It took me awhile to get to know everybody and to get used to the way NMC runs but I soon got into the swing of things.

When I was about 26 I began experiencing breathing difficulties and was referred to Aintree Hospital where I was then put on Bi-Pap machine which I use at night. This made a great difference to my well-being because I stopped being short of breath at night, felt a lot less tired and had more energy to do the things I enjoy doing. I have attended The Neuromuscular Centre for 22 years and have worked on reception, fundraising and attended many events promoting the centre and the work that I am part of. I have also tried my hand at graphic design. After completing 2 years of study my desire is to continue to study design and eventually work in the design department.

I enjoy watching movies, going to quizzes, playing scrabble, visiting new places, hanging out with friends and many other things. As you can see life has been very busy for me and I enjoy all the things that I do. I have also got several nieces and nephews that I spend time with which is great. I've also travelled abroad on family holidays and had some great experiences. I make the most of life and enjoy spending time with friends and family. I believe it's really important to make the best of everything and do the things that you can do!