Joe Doliczny

My story

Now looking forward...

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The first signs of Joe Doliczny's generalised dystonia began before Christmas 2003, when he was twelve. As Joe, who lives in Chippenham, Wiltshire now explains, it started with constantly jerking spasms in his right arm before eventually progressing into his neck, most of his upper body and to his other arm, until even sitting down became a difficult task.

This worsening condition had a huge impact on my confidence and education – as the spasms became so obvious, it was clear that people were noticing and I had a hard time at school. Also as I was right handed, I found it impossible to write. This was clearly a problem, so I taught myself to write with my left hand which meant I could still attend school.

A year of tests and treatments later, involving a range of drugs, botulinum toxin injections and MRI brain scans, led to me originally being misdiagnosed with Niemman Pic Type C, which is a terminal degenerative brain disease.

This pushed me into a state of depression as my spasms became worse. I stopped attending school and spent the majority of my time confined to my room. Although the relief that I did not have the terminal disease was indescribable, I became frustrated that there was still no explanation as to why I was unable to control my body.

The day finally came in June 2005 when I was diagnosed with dystonia and I spent a long time with the doctor who explained the illness to me. I was told that I would have to undergo an operation called deep brain stimulation.

It would be a lie to say that, on the day of my main surgery, I did not feel incredibly nervous when going into the operating room but the actual operation was apparently straightforward, even though I now have a battery pack in my chest that is powered through leads into my brain. Coming out of the operating room and later waking up to see the Bristol Club Football team at the end of my bed was confusing to say the least but I also felt a new sense of hope as I believed I could finally follow the road to recovery.

Sadly, it was not as I hoped. Far from being the equivalent to flicking a light switch and going back to my previous self, the device in my brain had to be tuned in to send the right signals to my body. As everyone's brain is different it became a matter of hit and miss as to what settings would improve my dystonia. This continued through another painful year of disappointing trips to the hospital to fiddle with my device which also included a dangerous reaction to certain drugs leading to the High Dependency Unit because my brain experienced too much trauma.

As a result of my dystonia, I did not want to return to school until my spasms were totally under control. I think the major problem was that there is a very low awareness level to what dystonia actually is, or how it affects people and this has a psychological impact on people with dystonia. It had a massive impact on me as my dystonia developed so suddenly, therefore it is very hard to explain when this change occurs after so many years of being without the illness.

At the end of 2006, once the device had been tuned to the correct settings, my spasms stopped and no longer appear to exist. It was the most miraculous change I had ever experienced as my body returned to the same state before the dystonia had begun. I returned to school and my friends and have now just finished my A levels at college and obtained a B and two C's. Six years ago I would not have believed that my dystonia could be controlled completely but after the support of my family, especially from my mum, my friends and the hospital, I overcame dystonia and am now looking at universities and hoping to pass my driving test."