**Reflecting on “A Tangle of Dreams”**

What an honour it was to attend and listen to Marchant and his mum, Susan, talk about their experiences of living with dystonia, and what has inspired them to rethink the idea of a wheelchair. Prior to the conference, I was asked to select a talk to attend and then write a reflective piece. The bio for Marchant’s talk entitled ‘A Tangle of Dreams’, immediately grabbed my attention. He writes, “It is imperative to move; with movement I know I am alive. Without movement my life is stuck - a river dammed”. This is such a powerful analogy for movement disorder and emphasises the complexity of managing dystonia. Providing support is important, like a dam whose function it is to stabilise water. But providing support, and ultimately restricting movement, increases dystonia. In Marchant’s words, he feels like “a storm of spasms locked in a chair”.

Throughout the talk we were able to hear from both Marchant and his mother, Sue, who explained their journey towards making the standing wheelchair that has formed an essential part of Marchant’s life. Marchant’s own words were narrated over some beautifully illustrated graphics. Together, they powerfully highlighted the impact his spasms have on his pain and ability to use equipment. Marchant spoke about how he had “broken many chairs, and many chairs have broken me - torn my skin, bent my bones, warped my muscles. Chairs have defined what I do”. Sue talked about the importance of standing for people like Marchant. The benefits of this being not only physical, but also psychological and social - allowing him to be able to stand when he chooses and to engage in everyday life. Marchant can go into a café, order a coffee at the counter, then sit down and enjoy it. He can be seen.

For an individual with complex disabilities, I believe the ability to continue to stand throughout adulthood is reliant on access to, and the correct use of, the right equipment. Regular therapy input also plays a key role. As a physiotherapist who works with adults with disabilities, I have only a handful of clients who have access to and use a standing frame. Many lost this ability as they transitioned to adult services. Provision of standing frames is limited to a small selection of standers that are often not suitable for the complex physical presentations that we see. Funding for equipment is a separate, complex issue and service provision varies greatly from county to county. After the presentation, I had a conversation with Sue about this and she advised that the standing frames that were available for Marchant growing up were not suitable for his needs and he had very limited options as a result. For this reason, Iann Barron, Marchant’s father, with the help of Remap Engineer Dave Richards, designed a ‘sit to walk’ device for Marchant. This was built specifically around his needs and what he functionally wanted/needed to do.

Before I wrote this article, I decided to see what else I could find out about Marchant. I visited his website (marchantbarronwords.org) where I read a selection of his poetry and learnt about his poetry installations that have been showcased across four sites in the UK, beautifully displayed in the trees. I saw photos of him sailing, photos with his dog, Ted, who was also present at the talk, and I read about Marchant’s studies in Creative Writing at Bath Spa University where he graduated with first class honours. Marchant is an inspiring individual and he is surrounded by a phenomenal group of individuals, both family and friends, who all share the same passion and desire in supporting Marchant to be himself.

There were so many things to take away from this talk, but I think the key message is we must listen more as practitioners. There is so much fantastic equipment out there now, as well as innovative engineering that has the potential for some incredible life changing products, like Marchant’s standing wheelchair. We all need to keep listening to the people using this equipment, as well as advocate more when it comes to getting access to the correct equipment for the individual. Complex movement disorders require joined up thinking and it is essential that we really know the person using the equipment. We need to continue to think outside the box, and as Marchant has done, challenge engineers to rethink the idea of a wheelchair.

Sue quoted Jimi Hendrix in her presentation, “knowledge speaks, wisdom listens”. It is essential that we share our knowledge but more importantly, we need to start truly listening. In Marchant’s own beautiful words: “by listening, we can free minds and bodies”.

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