

My story

Sticking the pieces together



Julian Parker, aged 11, was diagnosed with myoclonus dystonia at the age of three. We talk to his mother Joanne about how it has affected him. Julian and his family live on the Isle of Wight.

“Julian had very jerky movements when he was a tiny baby. It wasn’t really obvious as many babies move in a kind of jerky way but when we pointed it out to the health visitor, she told us not to worry and that he’d grow out of it. He didn’t and when he was three,

● Julian Parker

after seeing a number of specialists, he was diagnosed with myoclonus dystonia. What is odd is that there are two genes usually responsible for the condition and Julian’s test results came back as normal. That said, anxiety is also associated with the condition and Julian can be an anxious person.

The jerky movements mostly affect his trunk, neck and arms and they get worse when he’s under stress or if he’s really trying to do something. He finds fine motor skills like writing very difficult and it’s hard for him to hold an open cup without spilling the contents. Doing things like cleaning his teeth and cutting his nails and hair can also be difficult. In a typical Julian way, he loves construction toys and Airfix which can be a nightmare for him but he usually finds a way around the problems. When he was little, he found it difficult to put Lego pieces together but he got round it by sticking them together with blu-tack!

Julian’s been in mainstream school since reception. We had a lot of difficulty getting support for him and I had to really fight for a statement but he has one and for the moment he’s supported.

He looks reasonably ‘normal’ and a lot of adults don’t notice anything different about him, but the children do. His difficulty with writing makes it hard for him, but he’s content going into school. I’ve taught him to touch-type and he uses a laptop but I think because he takes part so willingly, a lot of teachers forget he has needs. There are 200 pupils in his school at present, so it’s small, but that will change when he goes to high school in 2011.

Julian’s a very determined boy but he’s not confident and he can be very anxious. He can be very fussy about hygiene and he has a real fear of heights and high ceilings. I took him to the theatre in London and he was genuinely scared witless because we were sitting high up in the theatre in the circle.

There’s so little information about myoclonic dystonia and it has been very difficult. There doesn’t seem to be anyone quite like Julian. He is very much isolated in his own condition. That said, Julian’s generally a very happy boy (I think he enjoys being a bit different) and we’re grateful that he isn’t actually ill and his condition hasn’t got any worse.”

To obtain a leaflet about myoclonus dystonia, or if you have any other questions about dystonia, please visit our website www.dystonia.org.uk or call our helpline: 0845 458 6322



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