

My story

Noah steps forward



● Noah Harrison

Noah was born in 2005, dystonia revealing itself immediately when his right foot turned in. In this article his mother, Roisin Harrison, speaks about the challenges of the first few years as the condition remained unrecognised.

"We were given some physiotherapy in the weeks following Noah's birth, but that was all that was offered. When Noah began crawling, we noticed he was pulling himself along with his arms so he wasn't putting any pressure on his legs and as he started standing, he'd draw his right leg upwards as though he didn't want to put any weight on it. If we tried to move his right foot into the correct position, he reacted as though it was sore.

I was really concerned by this point as it seemed as though his legs were always painful. He didn't like to be touched on the feet and gradually we noticed he was having the same reaction with his hands. By the time Noah was walking, he would trail his right leg and foot and as it spread to his left foot as well, he would walk as though he was sliding his feet along the ground. At 18 months, spasms were in the hand and lower back. At two years his face, eyes and mouth were affected.

I was pushing for more explanations at this point. The pain could affect Noah for up to three hours and when you dressed his bottom half, you could feel him tense up. Too much activity could bring on muscular spasms, he'd have excess salivation and his speech would be affected so he could be really hard to understand. Because he looked so normal, if you didn't know he had dystonia, he just looked like a toddler with really challenging behaviour. But I was sent away every time I went to the doctor. You trust your medics but when you know something's wrong and no one else will see it, you do begin to wonder if it's all in your mind.

After an MRI scan, a doctor mentioned dystonia. I'd never heard of it so didn't really know what we were dealing with. Noah was put on Baclofen and other medication. But the trouble was, we never had a solid yes or no as to what the problem was.

I was very unhappy about our lack of real diagnosis. I wanted to know whether it was dystonia or not – but no one seemed able to tell us. By now, Noah's feet had really turned in and his hands were tight and rigid. If he was tired or stressed his behaviour would peak and his body would twist. It was only when the physiotherapist who worked Noah got involved that we were referred to Dr Jean-Pierre Lin at the Evelina Children's Hospital, London.

Dr Lin diagnosed Noah with early childhood dystonia that responds to dopamine when Noah was 3 years 4 months and he's been on cinemet, baclofen and other medication since that visit. It had an instant result. He's stopped having such bad spasms and his quality of life has improved enormously.

Today, Noah has learnt how to manage his pain himself. He's at nursery and has one-to-one care because of his needs but he'll tell us what he can and can't do. Although he's walking further than he did, he still doesn't like to walk very far. He'll climb two stairs, stop for a rest and then carry on. I think it hurts when he puts weight on one leg at a time.

There's so little awareness of dystonia, it has been hard. There's been lots of tears and anger and our family has been under huge strain – it's shown in all of us – but having a diagnosis has meant we can move on. For much of the time, Noah's a happy boisterous boy of four who loves getting dirty as much as any child."

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