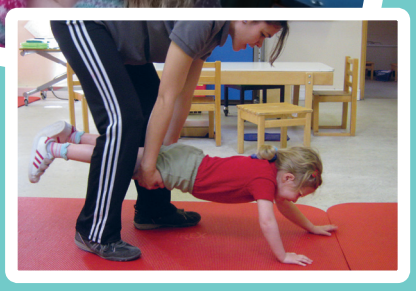
A NICE Story

Laila's Story

From Laila's Mum



Laila has Dravet Syndrome, a rare form of severe, uncontrollable and life-limiting epilepsy. She is now six years old, and has had life-threatening seizures since she was three months old. She must always be within 15 minutes of a hospital and has spent many terrifying episodes in the resuscitation room at Birmingham Children's Hospital. Her seizures are managed, to an extent, by a complex combination of medicines, but the side effects of these and the condition itself makes speech, learning and basic physical activities, like walking difficult.

Although the first two years were frightening and very difficult to come to terms with, for me, the more heartbreaking time was when Laila's development started to slow visibly. When she was two years old her friends were learning to run, jump, dance and chatter but Laila was struggling to walk and talk at all. What people saw was what she couldn't do. I was also constantly making comparisons and struggling to accept what was happening to Laila. I know now that I was in a sense of denial. I was holding on to the hope that actually Laila wasn't going to be affected by her condition, that somehow she would pull through and lead a full and independent life, that she wasn't going to be disabled. Meanwhile the threat of seizures was a daily fear. Laila's future seemed very uncertain.

A few months before Laila's third birthday we arrived at NICE – Centre for Movement Disorders and from that day my outlook changed. I was able to accept that yes, she did need help and with NICE's support, accepting that reality no longer felt frightening and I felt less alone and more empowered. Laila and I started at NICE together, once a week in the parent and child class where I was shown exercises and techniques to best help her. After a year she then moved into the pre-school class – a weekly morning session, with four classmates her own age. She had to work hard but at a pace she could keep up with, whereas large groups in her mainstream pre-school were making it harder for her to focus. A particular joy for her at that time was getting to be the best sometimes, with constant encouragement from her friends! Now she has moved into the Red Boots School Group rated "Outstanding" by Ofsted in 2016. The Conductors have incredible energy. They are strict but inspiring, and the once weekly day here is stimulating and fun, covering balance, stamina, speech, concentration and life skills such as eating – all whilst following the National Curriculum.

In the past few years, Laila's Dad and I have separated. The pressure of having a child with severe and complex needs can put irreparable strain on family life and relationships. Sometimes it brings people together, but in many cases, sadly, it takes them to breaking point. I would never have dreamt when I became pregnant, that I'd be the single parent of a disabled child. But with NICE on Laila's side, life feels full of hope.

"Laila has so many challenges in her life, but I watch her make progress all the time and know how much of this is due to the three years of consistent and focused help she has had at NICE and will continue to have. Life with a disabled child can be isolating, overwhelming and frightening. But Laila is full of joy and she takes on the challenges life has thrown at her with a love of life and thanks to NICE, she is gaining the skills to live it to her full potential."

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