

PROFESSIONAL PRACTICE

Reflection

One family's stroke experience

Eilish Rose Jukes was a healthy 3 1/2 year old. She

contracted chicken pox mid April 2005 and recovered unremarkably, although her attention span and behaviour were out of character afterward.

On 1 June 2005, Eilish was watching her father shave when she fell to the left. He sat her up and when he asked her to wipe the shaving cream off her hands, he noticed she took the towel in one hand and only wiped that hand, completely forgetting the other hand. She stood with a lopsided mouth and her arm hung by her side. She couldn't walk or talk, the words sounded like nonsense. We called an ambulance. About 4 minutes later she began to talk and walk again, and by the time the ambulance arrived she was back to normal. The ambulance transferred her to the local hospital and our GP examined her and found no residual symptoms, weakness or paralysis.

Eilish was transferred to the Royal Children's Hospital (RCH) in Melbourne and, although she had no neurological symptoms or signs on arrival, she experienced another similar episode 5 hours later, which again resolved completely. Chicken pox was identified as a possible but unlikely cause – varicella vasculitis is very rare.

A number of tests were taken: MRI, EEG, ECG, echocardiography and bloods. Lumbar puncture was not considered necessary as there was no evidence of active infection and it had been 7 weeks since the chicken pox. Eilish was diagnosed with hemiplegic migraine and went home on 75 mg/day of aspirin.

Five days later she had another episode. The presentation was the same, but this time she almost lost consciousness. She was taken by ambulance to the local hospital, and the following day we took her back to the RCH.

Another series of investigations followed. This time a lumbar puncture was performed; proof of postvaricella vasculitis. Prednisolone and clexane were commenced. On 10 June she had another episode, and again regained full function. Clexane was ceased and unfractionated heparin commenced. Test options were discussed. An angiogram was the test of choice. We were told there was a risk of her having a stroke from ceasing treatment or from the procedure itself. Maybe we misunderstood the statistics, or maybe we just needed to know!

The angiogram was performed on 17 June 2007. While waiting in the pre-op area, Eilish began to cry and say her head hurt. She then began to vomit bile. She had never once complained of a sore head and had never vomited

or dry retched before an anaesthetic. I suspect that this is when the stroke began. She took many hours to recover from the anaesthetic. At 3 am Eilish poked me to give me her bottle and I saw the left side of her mouth droop. That was when I knew she had had a stroke. A MRI confirmed the diagnosis of right internal capsule stroke and cortical stroke; secondary diagnosis – postvaricella vasculitis.

Eilish was commenced on warfarin. Rehabilitation began 11 days later with physiotherapy, occupational therapy (OT), and speech assessments. This was a very difficult time for all of us – the disruption to family life, Eilish's age, the behaviours that had emerged as a result of being institutionalised for 3 months – an eternity for a family. And our anxiety did not lessen as the episodes continued – much milder but nevertheless still present.

We were all set to go home when Eilish had another major episode and was re-admitted. She was recommenced on heparin, steroids and antiviral therapy. The episodes became less frequent and we were finally discharged home, this time for good. However, things remained difficult. We continued to attend appointments for orthotics, speech therapy, OT, physiotherapy, blood tests, neurology and psychiatry. Therapy was always a difficult area and continues to be, if she remotely thinks it 'therapy'.

Eilish has moderately severe left hemiparesis with significant spasticity in the left leg for which she wears an orthotic. We tried botox. This did not go well. She needed to stop warfarin and take clexane for the procedure and needed general anaesthetic. Her hand has proved to be troublesome and is a real challenge. She wears a splint to keep her wrist straight in an attempt to assist with using the hand more. She doesn't use it much, because the concentration it takes is too great, and the tone kicks in.

Eilish continues to have mild episodes, despite medications. We are currently waiting an ambulatory EEG to establish whether the ongoing episodes are vascular or electrical, as it is possible she has now developed partial focal seizures as a result of damage from the stroke.

Eilish received her first award at school 2 weeks ago. Her award was for 'loving school and trying hard'. What more could we ask for? She is happy, and the most amazing little girl, loved by all... especially her family. I am Eilish Rose's mum, Jackie Jukes, and this is our family's journey.



Jackie Jukes

Jackie Jukes lives in rural Victoria. Her daughter Eilish suffered a stroke at age 3 years. Jackie has been involved in establishing a childhood stroke support network: www. strokidz.com