

## **INSIGHTS** Family reflections: Tomairangi's asthma journey

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My daughter, Tomairangi, was born in 2003 and diagnosed with asthma before she was 3 years, after several admissions to Gisborne Hospital. During her pre-school years and junior primary school years, her asthma was able to be managed in primary care. We had a great general practitioner (GP) during this time who was always quick to respond to Tomairangi's asthma with nebulisers, salbutamol and prednisone.



Tomairangi's asthma significantly worsened once she was around 9 years of age and her hospital admissions increased. By the time she was 10 years, she'd had 30 admissions to hospital. We had a great paediatrician who was the first one to explain to us exactly how asthma works and what's happening in her lungs when she has an attack. We became regulars in the children's ward at Gisborne Hospital.



In August 2013, she experienced a bout of pneumonia and when her paediatrician saw her again in October that year he was shocked at her appearance as she'd lost nearly 6 kg in that time. Lots of tests were completed (lymphoma, cystic fibrosis, tuberculosis) and she ended up with a diagnosis of bronchiectasis.



In February 2014, she suffered her first life-threatening asthma attack that landed her in high dependency unit (HDU) in Gisborne Hospital.

In May 2014, she suffered a massive asthma attack again in HDU in Gisborne Hospital that saw her experience two collapsed lungs, two respiratory arrests and 11 min of cardiopulmonary resuscitation. She was intubated and flown to Starship Children's Hospital

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paediatric intensive care unit where she spent 5 days in the unit and 3 weeks on the respiratory ward at Starship.

Because she'd gone so long without oxygen, she also suffered a hypoxic brain injury and had to spend the next 3 months at the Wilson Centre in Takapuna, which is the national child rehabilitation service. She must have been one of the few people to survive an asthma attack of that magnitude because everyone including nurses, physios and occupational therapists always asked how she got a brain injury from an asthma attack. We've never met anyone else who's gone through the same experience as her.

Her time at the Wilson Centre was really hard and really lonely as she had to learn how to walk, talk, dress herself and read and write again. To this day, there are still some lasting effects from that brain injury (e.g. cognitive fatigue, sensory overload).

From 2015 to 2016, Tomairangi's asthma continued to see her in hospital almost on a weekly basis. She did have her own care plan that quickly escalated when her asthma worsened (e.g. we didn't go to primary care, we would go straight to emergency department (ED) and she would automatically be admitted). She was on prednisone all the time and erythromycin, omeprazole, Seretide and her salbutamol. She also had to do twice daily chest physio for her bronchiectasis. She also had a portacath put in during this time and eventually we were trained and able to give her prophylactic antibiotics every 3 months for her bronchiectasis at home.

At this time, Tomairangi was 12–13 years old and the mental health side of chronic illness started to really have an impact on her wellbeing. She was sick of being sick, of missing school, of losing friends and just wanted to be 'normal'. She was extremely rebellious, refused to take her medications, threatened to run away and the whole situation was stressful on everyone including our other children. She was prescribed clonidine by the psychiatrist and this helped immensely. We were able to parent her again and her behaviour was much more manageable.

In 2017, after 18 months of poor asthma control and ongoing hospital admissions, she was approved for omalizumab injections and was the first person in our district to receive this medication. It's a lengthy approval process where she literally had to get worse to prove how much she needed this medicine. It's expensive medicine (about \$2K) per injection and she has three injections every 2 weeks. This medication was her game changer. It made her asthma more manageable. Her asthma attacks weren't anywhere near as serious and her hospital admissions decreased. Her quality of life improved.

In 2018, she was diagnosed with myalgic encephalomyelitis (ME; chronic fatigue syndrome) after going to bed one night and not being able to get out of bed for weeks after that. Out of all her illnesses, ME has been the one that has had the biggest impact on her life. She had to finish school and was pretty much housebound for the next 3 years. The only time she left the house was to get her fortnightly omalizumab injections.

In 2019, at the age of 16 years she suffered another lifethreatening asthma attack and ended up intubated and in Waikato Intensive Care. She had been sick all week and ignoring the signs of her asthma worsening. We had to force her to go to the hospital to get checked out and they admitted her right away. She was needing half hourly nebulisers and then in the space of 30 min she went downhill and ended up needing to be intubated.

That was an awakening for her. When she woke up in Waikato and saw how sick she was and how serious the situation was, it was like a light bulb moment. Being 16, she was now old enough to understand why she needed to take her medications and get help early.

While in Waikato they switched her preventor from Seretide to Vannair and that made the biggest difference again. Since then, she has not had any hospital admissions. She hasn't had to go to ED and her asthma is able to be managed in primary care. She takes her medication routinely every day, looks after herself and sees her GP at the first signs of illness.

In total, she has been admitted to hospital nearly 200 times. She has transitioned over to adult services and receives her omalizumab at the medical day unit at Gisborne Hospital. Her bronchiectasis has improved and she no longer needs the intravenous antibiotics. Vannair, Symbicort and omalizumab are the only medications that continue to work for her.

In terms of research, there are a few issues that we need more work on. The issue of equity is a big one. There needs to be equitable access to medications like omalizumab to vulnerable children (in New Zealand that means those from Māori, Pacific, low-income families). The cost of being in hospital is more than the cost of this medication. The quality of life that our daughter got from this medication was life changing. More tamariki (children) need to have the opportunity to access this medication.

Kids are generally compliant with medicine regimes until they hit their teenage years. More research is needed on how to support young people living with respiratory disease from a holistic viewpoint. Health professionals need training on how to engage with young people to help them understand and manage their illness early.

More research is also needed on the impact of chronic respiratory diseases like asthma on the whole family. The family are the main support for the child but who is supporting the family? There is limited support out there and the impact on the parents and other siblings is massive. We still live with a lot of that trauma today.

My message to researchers would be to keep going, as the more research we have, the better. Do more Kaupapa Māori Research (or indigenous health research), focus on equity, access, racism and bias and put the whānau (family) at the centre of this research.

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