



David, Nicholas, Mary Lou Carter and her husband Trevor celebrating Nicholas' 18th birthday.

NO JOB FOR THE FAINT HEARTED

Mary Lou Carter knows better than most the heavy emotional toll that caring for someone with a severe disability has on their family. **Carolyn Collins** profiles an indomitable woman working to benefit other carers and families.

Mary Lou Carter's younger son, Nicholas, has a rare form of Angelman's Syndrome; he hardly slept for the first 15 years of his life. His destructive behaviour required the house to be turned into a fortress, making a normal family life impossible. From the age of six, her eldest son retreated behind the locked door of his room. Friends simply stopped calling.

Angelman Syndrome (AS) is a rare neuro-genetic disorder which was first described by English paediatrician Dr Harry

Angelman in 1965. Its features include severe intellectual disability, speech impediment, sleep disturbance, unstable jerky gait and seizures. While it is difficult to diagnose, it is estimated to occur in about one in 20,000 births.

Mary Lou first realised something was amiss when Nicholas was nine months old but doctors did not agree. Two years later, she saw a little girl with AS on the Phil Donahue Show and knew immediately that Nicholas shared the same disability.

"It was a bolt out of the blue," she recalled. "That's when I started investigating. I made contact with Angelman Syndrome Association and they said 'No, he's doing too much to have AS' but I knew that's what he had."

When Nicholas was five, Mary Lou heard of a German testing technique for AS and insisted he be tested. Six months later, the family was informed that Nicholas had a very rare variant of AS that affects just one in two million children.

Nicholas can't talk but communicates by gesturing, facial expressions and a range of noises. He doesn't have fine motor skills, was 14 before he was partially toilet trained and has very poor co-ordination and balance problems which Mary Lou believes is associated with his epilepsy, a common feature of AS.

The effect on the Carter family has been profound. Nicholas' inability to sleep over the years affected everyone's sleep patterns, and as he got older and more mobile, he became increasingly destructive.

"I couldn't have my books on a shelf; I had to pack them away for 10 years," Mary Lou recalled. "Every piece of paper had to be quarantined otherwise he'd tear it up and stick it up his nose."

Former friends avoided them because Nicholas would attack their small children. Looking back, Mary Lou says she never realised how very isolated she and her family were: "We were never really part of our community".

While Mary Lou was preoccupied dealing with Nicholas, her other son, David, was finding it increasingly difficult to cope. He couldn't have friends around and would lock himself in his room to escape his younger brother's behaviour.

"David was the perfect infant, it was as though he'd read the textbook in utero," Mary Lou recalled. But in Year 8, the pressure of his chaotic home life became too much and David had a breakdown.

"I put it down to the fact that we didn't approach the school and tell them what our family situation was and that they needed to keep an eye on David," she said. "No one understood what our lives were like."

Mary Lou believes David's creativity and love of music and poetry ultimately "saved" him. Now 24, he has completed a double degree in arts and law and is working with other young adults with disabilities.

In the meantime, the Carters struggled on alone, trying to find appropriate schooling for Nicholas, not realising there were even such things as 'respite services' for families like theirs until he turned seven.

"I turned up at school and the principal said to me, 'you look shocking' which of course I did. She said 'are you getting any respite?' and I said 'what's respite?'" Mary Lou said. "I'm not an unintelligent person but I'd never heard of it. I had a case manager but I didn't know what case managers were supposed to do."

At four, Nicholas was placed in a government special school attended by about 50 children ranging in age from four to 18 but some of the older children were violent and Nicholas copied their behaviour.

"He would punch me in the face and, because I wear glasses, my eyes would get cut. He'd also rag doll me," Mary Lou recalled.

Frustrated, Mary Lou sought out private options. A supported accommodation program which Nicholas attended four days a week, coming home on weekends, saw his behaviour finally start to settle down.

At 12, he started at Kingsdene which had an extended learning program where the school programs were carried through to the residence. Nicholas lived in a group home next to the school during the week and came home on the weekends. For the first time, he could walk to school like other kids and he made friends.

After witnessing the dramatic improvement in Nicholas' behaviour, Mary Lou was devastated when in 2003 the school was threatened with closure.

"I had never opened my mouth before," she said. "But when we got the letter (saying the school was likely to close), I banged the bench and said 'this cannot happen.'"

Mary Lou's efforts, along with others, ultimately saved the school but it brought her into conflict with other disability advocates who believed schools like Kingsdene were "institutionalising" children with severe disabilities.

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"The prevailing ideology was that the best place for a severely disabled child was with the family, supported by resources that meet the particular needs of the child," she said. "It is absolute rubbish... many families and many children have been sacrificed on the altar of these philosophies."

Now aged 18, Nicholas is still "boisterous", weighs 80kgs and is 5'11" tall, unusually large for AS. While his sleeping has settled down, as usually happens as AS children get older, he still requires very strict routines.

"He has this penchant for jumping the kitchen bench and we had to install a security grille across it. Every room has a lock on it. People talk about institutions – my home is an institution!" Mary Lou said.

But Mary Lou remains buoyant, refusing to be a victim and choosing, instead, to draw strength from her own experiences as she takes on state and federal governments in her political fight for rights and recognition of families like hers.

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“When it comes to disability, particularly severe disability and particularly when there are challenging behaviours, it’s the isolation that totally fragments the family and causes so much distress,” she said. “Unless you walk in the parents’ footsteps, you just don’t have any idea what they are going through.”

Mary Lou has emerged as one of Australia’s leading advocates for disability carers, and stood as a Senate candidate at the last election for Carers Alliance, the political party set up in 2007 to provide a voice to unpaid family carers and people with disabilities.

It’s a public role she never foresaw for herself. She was running her own legal support business in her early 20s and imagined she would be able to return to work when her children went to school.

Despite her personal challenges, including the question mark that hangs over Nicholas’s future once he finishes at Kingsdene, Mary Lou remains committed to her public campaign to change attitudes and to improve conditions for other carers.

She has also managed to maintain her sense of humour (or “black humour”, as she calls it), relating how a new puppy, not Nicholas, recently reduced a pair of her glasses to a mangled mess.

“I took the lot up to the local spectacle maker who’s looked after the needs of our family for years and he said ‘Oh my God!’ and I quickly replied, ‘No, it’s actually my dog!’ 🐶