

Catherine Murray and her son Jonathan at a Disability Enterprise art show in 2008. Jonathan's painting is behind them. Three weeks after this photo was taken, Jonathan died from an obstructed bowel.



LOSING POSSUM MAGIC

BY DENNY ROSEY

Catherine Murray, diminutive, slight and softly spoken, doesn't look the kind of woman who would take on Kevin Rudd. But last year she confronted the Prime Minister at a Community Cabinet Meeting in Penrith NSW:

"You and I are the same age Mr Rudd. We have children the same age. But that's where the similarities end. I have a profoundly disabled son. Who will care for Jonathon when I die? Where will he be sent? Cradle to grave care is a big ask Mr Rudd. And I really, *really* dislike having to beg," she said quietly.

Much the same has been said to this, and other Prime Ministers before, but rarely as powerfully and Rudd listened; a month or so later so did thousands of people watching the ABC's Four Corners program *In Our Shoes* about Australia's army of parent-carers. Catherine Murray summed up the

fear at the heart of their anger: "Mothers are dying without the confidence that their child who may be in their 30s or 40s will be provided for – and in this day and age it's a disgrace."

Catherine knew that her son's health was precarious; his body had twisted 150 degrees, he had massive seizures and recently he'd begun vomiting. Despite this Jonathon was still smiling and playful, and she believed she would be caring for him till the end of her days, not his. But weeks after the Four Corners program aired, her beloved 25 year-old son died. Her "heart and soul" Catherine says, went too.

Jonathon's death did not give rise to the biting grief that can affect whole communities when a healthy child or young adult dies, but Catherine hadn't anticipated that it would: she'd had twenty-five years exposure to seeing her son and

others like him devalued. "I got the sense from many people that I must be relieved. They don't understand that when you have a child with profound disabilities, you have to fight for them and the more you fight, the more you love them. And you have to fight *constantly*. I loved Jonathon with all my heart."

It was late one night when Catherine and I spoke. We'd heard several splendid speeches on disability and eaten our way through three courses. Slides of two little boys who desperately needed speech and physical therapy came on the screen. The parallels to Jonathon were obvious.

"Jonathon means gift from God, and he was born on the 11th of November - Remembrance Day. He was a much wanted, much loved baby. He was just beautiful! Soon after the birth I sensed the doctors were alarmed whenever they examined him. But the only thing my paediatrician said when I asked was, 'some babies are like that'.

"I was moved down the hall: I'll never know if this was to stop my tears upsetting other mothers or something less meaningful but that wouldn't happen today. Nurses who had been so lovely and friendly before the birth avoided my room and could not look me in the eye. We were transferred to the Royal Alexandra Hospital for Children at Camperdown. I will never forget the terror and isolation of not knowing what was wrong with our son.

"Like all newborn babies, Jonathon cried and one of the senior nurses, whom I'd seen comforting other babies, came over and said, 'he'll have to stop doing that'. Even at three weeks of age my son with a disability was being judged as unworthy of comfort, while a sickly child was. The lack of tact I'm sure was born of ignorance, not malice

"The cat scans showed that his brain was very close to normal, perhaps some spaces that were larger than they should have been but nothing conclusive and the chromosome study was normal. I was never told that he had cerebral palsy: I gathered this slowly, a painful osmosis. At that stage Jonathon was a baby first and foremost who just happened to have an underlying disability which doctors referred to as 'global delay'. That was the only description I was given.

"We moved to the Blue Mountains to be close to Greystanes Children's Home. I would never have been able to part with Jonathon but I needed the security, the safety net of knowing there was help close to hand if and when I needed it.

"The irony was that I managed throughout his childhood and it was only when I really needed help and reassurance that I was alarmed to realize that it was not readily available. My 47-year-old husband had had a major stroke and all of a sudden I felt very mortal.

"This is when I became politically aware. Disabled children are so vulnerable, so needy and you have to fight for their dignity.

"Jonathon had magnificent eyes and we used to call him Possum Magic. He was quite healthy for most of his life and he loved to eat. I love cooking so it was a great partnership! He adored everything I cooked except Brussels sprouts. His favourite meal was my spinach and ricotta lasagne. Jonathon was unable to speak, but he gesticulated 'Bellissimo' with his eyes and left arm. When he was 20, he had a little taste of wine – I think he enjoyed our reaction more than the wine. We savoured this tiny morsel of normality.

"He'd learned to crawl and sit and stand and then it was all taken away when he hit puberty. He doubled in size in nine months and his body couldn't cope; his spine curved 150 degrees, his body contracted and his leg began to bend. He was quite a bit taller than me but I walked him every single day until he was 17 and then his legs gave way.

"During his latter years I worried about his future. My goal was to care for him to the best of my ability for as long as I could. As I couldn't give him health, the very least I could do was to give him love and security. And I needed to be reassured that much needed respite was safe and appropriate to the needs of a profoundly disabled, medically frail young man. I never considered aged care or multi-function (one size fits all) respite appropriate for profoundly disabled young people.

"In the last three weeks of his life Jonathon began to vomit. I wasn't overly concerned at first. Then his stomach became very distended and he was admitted to hospital with a bowel obstruction and tachycardia.

"I wish I had been quietly told that he might die and that they would do everything to make him comfortable. No one asked if my husband was about – I had sent him away as nothing had been said or hinted at to alarm me.

"I only discovered that Jonathon was dying when I was standing in the hallway and overheard the doctor talking on the phone: '25 years old, yes he is dying'. The sound of Jonathon in distress will haunt me forever. My son was a 25 year old baby when he died – he couldn't talk, he couldn't even turn over. I work very hard to remind myself of Jonathon playing 'peek a boo' and trying to smile at me.

"Last year I heard Jane Goodall talking about primates and how like humans they are in their emotions and their love. She said that when a primate loses their child, they go up to the mountains and stare out at the wilderness. If a primate can feel anguish and loss and not understand the depth of that loss, how are we humans supposed to write off such loss?

"In time I might be able to say that I did the best I could for as long as I could, but at the moment that's beyond me. If I'm going to move on I have to feel I've made a difference – that I've done something."

You have Catherine. 🐨