

LIVING WITH THE GREEN GOBLIN

Dementia is a frightening disease whenever it occurs, but it is especially difficult when the affected person is only in their 40s. **MARIE WILLIAMS**, winner of the 2013 Finch Memoir Prize for her book **Green Vanilla Tea**, tells the story of her husband, Dominic, his journey with dementia, and how her family dealt with the Green Goblin, as they called the illness.

I remember the evening my son Nic came through to me in my bedroom holding the dog-eared manuscript of *Green Vanilla Tea* in his folded arms. He leaned against the doorframe, favouring one leg as his dad would have done, and stood there for a few seconds saying nothing. I remember noticing how much space he took up in the doorway. My little Nic; no longer the boy he was when this story all began but a strapping 19-year-old. He was the age I was when I met my husband, Dominic. I thought he might ask what was for dinner – some things never change – as he and his brother Michael are perpetually hungry and continue to eat more than I believe is humanly possible. But he said, ‘Thanks Mum – I think this is the most powerful gift I could ever give to share with my life partner one day.’ I leaned back in my bed and thought, *Wow, we did it; my job is done.*

The manuscript Nic held in his arms is a story I wrote that follows our family journey through the illness and death of my husband, Dominic. The road to diagnosis was long and confusing, and all the while the illness – the Green Goblin – slowly robbed him of body



Marie Williams

and mind. It is a story of love and life in a world where so much was amiss, written as an offering of hope to my two teenage sons.

My writing started out as a spontaneous response to grief. Amid the demands of caring for Dominic and parenting my sons, writing gave me time to pause.

It held still the paradox, where life was both empty and full, together and falling apart and the simplest things were the most extraordinary. I wrote of love and loss, courage and vulnerability, and finding hope in inexplicable times.

After Dominic died, I collated my musings together for the boys – a way to give shape to a story that lay beyond the reach of language. So much of what they experienced felt invisible, slippery and without words. They asked me to write about it, to try to capture it somehow and give the story form. I had no intention to publish; it was enough that my writing provided a wonderful launching pad for my rich conversations with my sons.


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The human experience is intricate – as joyous as it is painful – and we explored it all. Whether chopping vegetables or driving to the supermarket, we talked through every evolving chapter, giving the story voice, and their reflections are woven throughout the pages of the book, which they will be able to share with their life partners one day.

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Never did we imagine this family story would be acknowledged with an award. I've been asked, 'How has the Finch Memoir Prize changed your life?' I had to think about it. In some ways nothing much has changed. In other ways, it has changed absolutely everything. All at the same time. I still go about my daily life as I always have: walking the dog, paying the bills, folding crinkled laundry, ironing, hanging out with my sons. But when I think back to the origins of this book, I am so grateful for what this award has made possible. So much is different now. It is a profound affirmation of a story that at one time had no words, and it has given us the opportunity to set this story free to do its own work in the world. What an amazing outcome!

This creative act of family storytelling is now a memoir and a story about love. It's a tale of a strange place – the real world – in which green goblins and hope find a way to live together. 

Green Vanilla Tea by Marie Williams is published by Finch Publishing, rrp \$24.99, e-book \$9.99.

Green Vanilla Tea

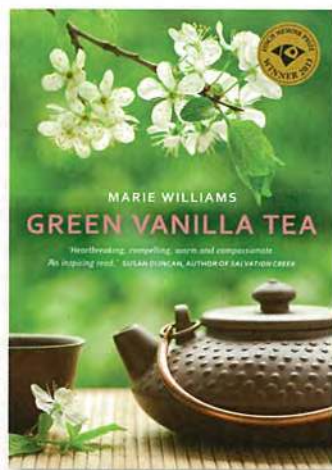
by Marie Williams

Dom had never had any musical training. He never played an instrument or sang in a choir. But music seemed to enchant him, and it opened up another doorway for all of us once he fell into the clutches of the Green Goblin. When Dom had been at home with us, we put all of Queen's songs onto the boys' computers. That way, when Dominic paced into their rooms with repetitive and annoying questions, they could redirect his attention to Freddie Mercury and sing together. Dominic's incessant pacing and tedious questions required the patience of Job. Daniel once described it as 'Chinese torture'. He worried it would wear down our nerves and wondered how we managed. Sometimes, we didn't. But the music helped.

Like the day when Dominic bopped stiffly, on his pacing route, to 'We Will Rock You'. Michael turned up the volume so that Dom could hear it wherever his pacing took him. Freddie's voice belted out of his room. As the next track came on, Dominic returned to Michael's room and asked him to play the track again. He asked for it to be played over and over, and from his frozen face, where muscles no longer responded, he merged with the rhythm, and his usually empty eyes sparkled with light. Freddie got us on a good day. The four of us spontaneously started singing, stamping our feet and clapping. Stamp, stamp, clap. Stamp, stamp, clap. Stamp, stamp, clap. Stamp, stamp, clap.

We were having fun, the kind of spontaneous fun that we remembered from our lives before dementia. The chorus got extra volume out of us.

After about the tenth replay, Michael's mobile rang.



'Hey, mate!' Jack yelled into the phone. 'Turn the bloody music down - what are you doing playing the same song over and over? It's driving me nuts!'

Mike laughed and cranked the music up louder.

'Dude! We're having a rock concert with Dad.'

'Oh. Cool!'

The song rang through our heads for days. I even heard [family friend] Felicity humming it as we worked on

the quilt. Jack had filled them in, she said, and they had joined in that day, rocking with us from their house. Stamp, stamp, clap. Stamp, stamp, clap.

Other than the song 'Angels', Robbie Williams became a passing phase. Queen and Josh Groban remained firm favourites, although Dominic didn't seem to need the volume as loud anymore. While time in the nursing home rolled over for him with no sequence or carry-over from one moment to the next, there was something about music that gave us another way to be together. I will always carry close to my heart the image of Michael singing to Dominic at McCorely, the high-care facility. Michael has a beautiful singing voice but doesn't show it off; very few people have heard it. I watched him many times, sitting on Dominic's bed, singing gently as the music in his voice called out to his dad. Dominic joined in with no inhibitions. Fixing his gaze on his son, he would follow Michael's words as they moved their hands in time, conducting an invisible orchestra in tune with the beat of their hearts.

Music enlarged Dominic's existence. The more he lost the abilities of abstraction and language, the more his sensory response to music seemed to grow. He would close his eyes and inhale the sounds, responding to music in ways that left me convinced I had seen the shiver in his soul. 