



## A long road to an independent lifestyle

Meet Graeme. Graeme is 49 years old, has a great wit and a wry smile. He is a huge footy fan and barracks for Melbourne. He lives on his own in a purpose-built unit next door to his mother Ann and father Bill in a Melbourne suburb.

Graeme is very attentive toward his parents and willingly steps in to a caring role if one of them is ill. He has a younger brother and a sister and is close to both of them too. He is very sociable and enjoys chatting to his neighbours.

Graeme's life today is very different from the negative scenario that was put to Ann and Bill when their son was born, and they were offered a 'lovely institution just down the road' for him. They were angry when informed that they 'wouldn't get anything out of him' and determined to support Graeme to have a full life. And that determination clearly runs in the family – Graeme learned to read when he was 15 years old because he was frustrated at not being able to read about his footy team in the newspaper. These days he reads the paper from cover to cover daily.

The family travelled to London on a number of occasions, and on one trip when Graeme was 18 years old, Ann spent time researching accommodation

options for adults with disabilities. One night after a day spent visiting these, Graeme asked: "Mum, what's gonna happen to me when you die?"

From that moment, Ann and Bill decided they had to assist Graeme to work towards a life with more independence and self reliance. Over many years they, and other carers in Graeme's life, have coached and supported him to look after himself and live independently. And in 2003, when Graeme was 39 years old, he moved into his own unit. The building has been planned to enable Graeme to look after himself with minimal help, including easy access and low maintenance both indoors and outside.

Ann and Bill had an intercom installed so they could communicate with Graeme. Although their initial intention was to also put in a video surveillance system, the intercom proved to be enough on its own. In the beginning, Bill stayed overnight with Graeme until he was used to the new situation and felt comfortable. These

days Graeme only occasionally buzzes them at night if he hears something he's unsure of. There is a note next to his intercom reminding him about how to answer the door.

Graeme's house is spotless. He has council cleaners but he also does the dusting weekly with a carer. He does all his own washing and ironing and will not let anyone help hang washing on the line "... cos they don't do it properly!" Graeme likes to have a routine – his mother thinks he's a little obsessive about it – and this helps him to run his own life. Another important thing is that Graeme lives within easy walking distance of everything he needs (shops, restaurants, parks, neighbourhood house, men's shed, movies, train, bus) and this has helped him to be independent and as a bonus *healthy!*

Graeme used to work at Waverley Industries and Birra-tek (now Paramount Industries) but has retired because he has slowed down and because he now has scoliosis of the spine and arthritis. Ann comments: "In some ways, at 49 he is more like a 69 year old, but he shows no signs of dementia."

Graeme's time is now his own and he has a busy weekly routine, supported by his individualised service package (ISP) funding. He walks to many places but he doesn't catch public transport because he falls asleep when travelling. (His mother blames herself for this, as she used to put him in the car and drive around when he was little to get him off to sleep.)

On Monday mornings Graeme walks to the Monash Men's Shed which is only 200 metres from his home. He is very much liked and supported there by the other men. In the afternoon he attends the Community House 500 metres from his home where he does tapestry.

Tuesdays start with swimming at Monash Aquatic Centre, for which Graeme is accompanied by a carer, David. In the afternoons another carer comes to take Graeme shopping, and they then go home and cook a main meal together – and a cake which will last a few days!

On Wednesdays Graeme attends a literacy and numeracy class for people with disabilities at the local Neighbourhood Community House.

Thursdays includes a woodwork class and night out at a Social Club where they do things like 'Tonight live', bowling, pizza nights, BBQ's and shows.

On Fridays Graeme goes to a computer group where he often researches and plans activities for his Sunday outing. He also enjoys writing emails to people – including regular correspondence with Jim Steins who once sent Graeme a great book about the history of the Melbourne Footy Club.

Every second Sunday Graeme has a day out with a carer. This is often a trip into the city to take in a show or a movie.

And the answer to Graeme's question about his future? Ann and Bill are still working hard to ensure security for him. They are still looking ahead and, anticipating that Graeme will need full-time care at some point in the future, they are currently looking into aged care facilities. They are also taking a keen interest in the development of the National Disability Insurance Scheme and the implications it may have for Graeme.

### **We asked Ann and Bill what advice they would offer to other families about the journey to independence they have taken with Graeme.**

- ✓ Get information and plan carefully – you need time to do this
- ✓ You need contingency plans....remember to often ask yourself "What if ...?"
- ✓ Involve your son or daughter in the community – look for opportunities locally
- ✓ Always strive to make your son or daughter more independent
- ✓ Expect socially acceptable behaviour from your son or daughter and expect him/her to be accepted within the community
- ✓ Be patient! Slowly but surely you will see progress
- ✓ Repetition, repetition and repetition ... and more repetition
- ✓ Never give up!

**Graeme, Ann and Bill were interviewed by Sue Blandford, Down Syndrome Victoria Family Support Manager. Jean Cotchin took the photographs.**