

## Matthew's story ~ A home of my own

### My adventure into independent living

by Matthew Slater

I think I'll start my story when I was about 18, I was probably still at school doing year 12 (VCAL) then. This is when I first told my parents that I wanted to move out. It was in the car, I was surprised Mum didn't have a heart attack and cause an accident!

I'm now 22, and permanently living in my own private rental place (have been for about 18 months I think). It might have taken a while, but it was well worth it. Even to this day, sometimes I still pinch myself that I'm where I am today. This is largely thanks to Deb Rouget and the gang at PLA, and my parents who I'm very grateful to.

I go down the street and do most of my own shopping. One day, I'm thinking I might make a documentary on how I do it. I just generally LOVE the independence.

As I said before, I'm very grateful and appreciative to EVERYONE involved.



Matthew Slater, 22, loving his new-found independence, January 2010

## Releasing my fears ~ Matt's journey and his deepest wish to 'move on'

by Cathy Slater

I'm the Mum of a young man, Matthew (now 22) who has cerebral palsy. He is a very bright and independent young man. Matt has always been a joy, having a wicked and witty sense of humour and a particularly admirable philosophical view of his world and his situation.

Matt has high support needs. Although he doesn't have an intellectual disability he is VERY physically dependant on others to meet his needs. Whilst he can use a motorised wheelchair and the computer (with specialised provision), he is dependant on someone for everything from eating, dressing, going to the toilet and even turning in the night. Matt also has difficulty with verbal speech, although those that know him are able to engage in normal conversation with him (albeit requiring the occasional additional efforts or augmentation).

From a mum's perspective it would, however, be fair to say, supporting Matt to meet his needs has been a lot of work! Meeting Matt's physical needs has meant that we have had to relinquish many things in life that most take for granted. We have had no room for spontaneity, our ability to work has been reduced and every day comes with its own organisational obstacles. We have lived with very high levels of stress, not only from the responsibility and continuity of meeting Matt's needs but also the unseen implications (the physical demands of our involvement; fighting for rights,

funding etc....down to the daily frustrations of hitting your shin 'yet again' on the damn standing frame or turning yourself into a knot getting the chair strapped into the car!!!) but also from the very real and daunting angst about his future.

Matthew attended mainstream school right through to VCAL and later went on to do Cert. 2 and 4 in Multimedia. I must say we have always been fortunate with the support he has got educationally. I put this down, in part, to our strong but gentle and positive approach with the 'system' and of course Matt's endearing personality!

At 18 ½, Matt said to us "I think its about time we thought about me moving out into a place of my own". WHAT ! How in the world are we going to do this!!!!

I have always had a very strong 'won't be beaten' attitude but this was seriously going to put me to the test! My first obstacle was myself of course! "No-one can look after Matt like I can; I know every little need without being told; he's hard to understand. What will happen if he can't make himself understood?" Matt's response to this was "Mum, I'll be alright. What will be, will be. I want to do this".

I had to work hard to not allow my fears to get in the way. This was Matt's journey and his deepest wish to 'move on'. I had to support it, give it all I could and of course, if by some miracle it worked there was the solution to my fears for his

future, beyond us being able to care for him.

For two years I made phone calls, came up with plans and hit lots of dead ends. One idea was to set up a cluster of individual units so as the 'support' could be shared, thus reducing care costs to 'affordable' limits. (A group home situation was never even contemplated). I felt I actually got to the point where I was close to having the infrastructure paid for and the Support needs a 'possibility' through discussions with different organisations. I was up too exploring who'd be interested in residing in such a setup (to further support my proposal to these organisations) when I hit my next 'hurdle'. I found people were of course 'particular' about who they were prepared to live with (including myself to some degree) and a whole new level of difficulty became evident. Matthew said to me also at this point, if this form of housing was the best we could achieve, he'd be OK with it. But he really didn't want to be defined by his disability by living in a cluster housing arrangement with other people who have a disability and he would really rather just be 'out on his own'.

It was around this time that the most advantageous connection happened. I met Deb Rouget, Facilitator of Personalised Lifestyle Assistance (PLA). Along with attending a series of particularly inspiring workshops that PLA organised, Deb enthusiastically engaged in private meetings with Matt and myself, to help us identify his vision and support needs. She then assisted us in putting together a plan and proposal to enable Matt to live in his own place that we then presented to the Department of Human Services (DHS).

One lesson that sticks with me mostly from the PLA workshops I attended was the innate right of ALL individuals to pursue a life of independence – their own life. That although we all use services for our 'survival', some may require more than others, it's still possible for people with disabilities to have the same opportunities and develop their independence if the "right" services and supports are in place.

The second most important lesson is that you can neither anticipate EVERY need nor wait until every 't' is crossed and every 'i' is dotted to initiate this sort of undertaking. It simply would never happen! There are always too many variables and too many unknowns. This is the way life is! Even though the Disability Act states that there is a responsibility of the government to support people in their independence, bottom line is, at some point we need to make 'some' plans, and jump in! See what 'needs' unfold, see what works, what doesn't work but jump in at the deep end and MAKE IT WORK! Allow it to evolve and accommodate the needs as they arise.

Following our meetings with Deb and our first endeavours at drawing up a plan, I started asking around at Estate Agents for rental houses/units that might be practical for

someone in a wheel chair. Our initial thoughts were around Matt sharing a place with someone who, for either free rent or reduced rent, would provide the overnight support. Obviously this would reduce our funding needs. The 'House Mate' would be in a position to go off to their regular work during the day whilst carers would be employed at the necessary times throughout the day.

After about five months we had a phone call from an agent regarding an appropriate unit. We went and had a look, with a resounding 'I'll take it' from Matt. He was subsequently 'signed up'! At first Ian (Matt's dad), myself and Matt spent a few days there each week (the rest of the week at home). We employed Matt's usual (though only 'occasional') carers to come and assist at Matt's home in our absence whilst we were at work. And so began him having his own home! We put our initial 'Proposal' to DHS. We were requesting funding of a 3 month trial of Matthew being supported to live in his own home 5 days a week. DHS accepted, and IT WORKED!! Carers were handpicked by Matt and ourselves and sourced through Country Care (a flawless and wonderful service). Matthew went from strength to strength. Making his own arrangements and enthusiastically rising to his new challenges. He loved his independence so much he 'ditched' the idea of sharing with someone!

It worked so well, another proposal was put to DHS for continued funding beyond the 3 month trail. It could readily be seen to be working and Matthew made no bones about this being the lifestyle he wanted. It was a nervous time but, after all, the government has its responsibilities and abandoning him now would have been 'crushing'!

DHS supported the proposal. Matthew can now stay at his own place seven days per week due to creatively and flexibly using paid supports and drawing on family supports when needed.

Over time we have organised his ability to 'remote control' most aspects of his home so he can access all he needs to. He can come and go from his home independently and make phone calls using Voice Over Internet Services.

Matt loves his new life. He is as independent as he can feasibly be. He often surprises us with new achievements like doing his own shopping, buying us a gift, making his own arrangements and getting about down the street on his own like any other person.

We are so proud of him. It takes a good degree of bravery and determination for someone so vulnerable. However, I must say, it takes a lot of 'bravery' on the part of us parents too!!

The difference to our lives as "carers" is amazing. But not a pinch on the satisfaction that Matt now enjoys. We're all 'winners'!