

## NOT WAITING ' CREATING

Carmel Lys

Paper presented at Personalised Lifestyle Assistance Project Conference, Melbourne 17-18  
August 2006

In the past I've been in the audience listening to other people speak, and often felt overwhelmed. By sharing my story today I don't want to do that to other parents. I just want to tell you a few things from behind the scenes that have helped Matt get to where he is today. It didn't just happen!!

This story is not only about Matt having his own home – this is about having his own life, of course eventually having your own home is a big part of that.

I love the way his life has gone – a photographer, artist, a drummer; didgeridoo player and member of a jazz band. Recently he started playing tennis again. He lives life to the fullest. I was always confident when I wasn't around any more that Matt's siblings would step in, and care for him; he would stay at their places and become part of their families. At that time I was confident that family was enough. However I realized that my other kids' lives were changing as their families got older. He would always share in their lives, but maybe he needed to have a life of his own as well. I realized if I could get Matt set up and put in place a lot of support with carers, family and a circle of friends, then Matthew's life wouldn't have to change a great deal when I could no longer do what I was doing for him. While it would have been easier to bury my head in the sand and keep going as we were. (after all life was okay) I knew that, while I was able to, I had to put a secure future in place for him. I have had seven others leave home but this is the hardest one to let go of. I can't tell you how much easier it would have been to do nothing. It didn't help when I listened to the stories of other families and heard what they were doing. I couldn't see how any of this would work for Matt. I kept waiting for someone to tell me what was the best way.

About this time, I learnt of the idea of the circle of friends. Perhaps this was what we needed in our lives now. When Mamre started the Building Informal Networks project I was keen to be part of it. Mamre had been part of our lives since Matthew was three so we had a long trusting relationship with them.

Also about the same time, a young support worker from another organization (not Mamre) let it slip, that he had heard a co-ordinator say "Be careful of Carmel – she knows what she wants"

This was the best motivation I could have had, because it made me realize that knowing what I wanted, was a negative in this organization. I thought No I don't but I'd better soon find out. All of this helped me start finding the best way for us.

So who is this Mattpac that Matthew mentioned? – They are a circle of friends and family who took up our invitation to be part of our lives. We have been meeting for three years, and they are a wonderfully supportive sounding board for our ideas, a voice of reason for my fears, and people we can call on for help. They help us with our planning and help us reach our goals. When we discuss our dreams for Matt we talk about less dependence; not necessarily independence – everyone in our family is dependent on each other – everyone supports each other, with babysitting, a shoulder to cry on or an instant party. With their support I've gained confidence that the best way is working out what's right for Matthew at the moment.

Matt attends every meeting and knows the Mattpac are very interested in his welfare. For example, recently he wanted to shave his head, but thought it would be a good idea to run it past the Mattpac first. Needless to say he got quite a bit of advice on the subject – mostly that it may not be a good look!! I like it when their point of view reflects mine !!!

However, when we started to talk about Matt moving out ... He communicated very strongly that he was scared about this idea – by his behavior, more than anything he said. His actions spoke louder than words and we had to listen to him. It was so serious that all talk of moving out had to stop.

At this point I might have thrown it in, but for the Mattpac – they reminded me that doing nothing would be worse – that we had to keep going and find another way and that they would support me.

A bit of time and some more creative thinking helped me realize I was fortunate to have the perfect situation – a high set house with an internal staircase and a double garage underneath. Without spending a fortune we were able to convert the majority of the area under the house into a very comfortable flat for him. We arranged doors and walls so that this was completely self contained. At the back of my mind was – this is probably where Matt would always live – its comfortable for him and me – its safe. So, with the Mattpacs support and my families help, Matt moved into his very own flat.

I was hoping Matt would learn how to look after himself in a safe and secure environment where I knew he would be happy and still have a lot of contact with me.

This went well and together with the Mattpac and Mamre's support, we got a weekly schedule up and going where people came in to help Matt cook and clean and share a meal. A couple of times

a week Matt ate with me or we went out for dinner on neutral ground! A support worker came in for a short time most mornings of the week to get him up and off.

However, living under the same roof, it was difficult for me to keep my distance. At a Mattpac meeting in April this year, my daughter said – Mum, even though Matt has moved downstairs into his own flat you are too involved with his decisions – you still know what he wears and when he goes to bed and everything hes doing. She admitted that she too is more worried about her son when he's home then she was ,when he was living on the other side of the world.

Ironically, the next day I got a phone call I wasn't ready for, Queensland Housing Dept rang to offer Matt a townhouse, five minutes down the road. This was totally unexpected as we thought he would be many more years on the waiting list. We'd only had the flat for eight months!!!! And of course the decision had to be made quickly. With great apprehension, and my daughter's words ringing in my ears, I called Margaret and a couple of my sons and Matt and I met them at the townhouse. Even though this place offered everything I could have wanted for Matt, I hesitated to ask him how he felt, so I let Margaret do that. Matts reaction was the biggest surprise of all. To everyone's astonishment it got two thumbs up and he started to plan about where his dog would sleep. Remember this was the young man who had protested so strongly only just over twelve months before at the very idea of not always living with Mum. In retrospect I realize how important those 8 months in the flat downstairs were.

When we got the thumbs up we ploughed in with what we had – and while we had no Adult Lifestyle Package of funding we had great resources – that large family and a well informed Mattpac who had been part of dreaming and planning with us for a couple of years ... and a little bit of funding from Mamre that would have previously been called respite.

At the moment, I sleep over at Matt's a few nights a week and a support worker sleeps there two nights each week; Matt has a night on his own and he comes to my place for the weekend. He is always happy to go back. His dog is having more trouble adjusting than Matt is. Members of the Mattpac come over and prepare and share a meal with him a few nights each week. He can get a frozen dinner for himself and he won't starve... but gourmet meals are a little way off yet. He's only been there about 3 months so things are still evolving.

Don't get the impression my life now is easy – far from it – I do more running around now than before and obviously I'm at Matts place a lot.

However, recently Matt was talking about what he was doing the next weekend. He mentioned coming home ... then he corrected himself and said 'to your place' – While that really hurt, I know it also means that he's developing a life of his own and I wont always need to be as involved as I am now.

We've jumped in; the water is deep; We are swimming not drowning. Some time soon we will have to stop for a while and tread water again – see how far we've come and where we're headed. We are looking out for rips and making sure we know where the lifesavers are. Fortunately we're not swimming alone. The horizon pulls us forward.