

Dean's Story

Dean wrote his own story.

I'm 43 years of age and live at home with my 75 and 77 year-old parents. I have a brother Brett and a sister Tanya; both are married and between them I have four nieces and a nephew. I value family and have a close relationship with all my nieces and my nephew, and I am Godfather to my oldest niece.

On occasions I take the older two nieces (aged 15 and 17) out for lunch and a movie. The younger kids (aged 5, 8 and 10) enjoy playing games, including me chasing them in my chair around the backyard. Before my accident I was a fourth year plumbing apprentice and enjoyed sports—I played golf, football and cricket.

In 1987 (aged 20) I had a water skiing accident and suffered a spinal cord injury that left me a C5/6 quadriplegic. I am passionate about improving the lives of people with a disability. I have spoken at conferences and Rotary clubs about my experiences.

I was not eligible for compensation from my accident and after seven months in the Austin Hospital, I had one of two options: go to a nursing home where care would be provided, or return home with my parents where they provide me with all my care.

With a job possibility with my old employer, I returned home with my parents providing all my care. In April 1988 (approximately 13 months after my accident) I returned to work in an administrative position. My parents would assist in getting me up and my father would drive me to work. He would then work his job before picking me up afterwards.

After working for a while I was able to buy my own van and have it fitted with a hoist so I could be driven around by others. This was a big change, as I was able to use friends and relatives to pick me up from work. It also opened my social life as friends could now transport me around without me relying on my father's assistance. It also freed my father up and took the pressure off being the only person to assist with transport.

In 1994 I received a Home First package of 20 hours from the Department of Human Services—I was now able to employ and roster attendant care. This enabled me to have support workers get me up each morning and take me to work, and on weekends they could take me to the football games or assist with shopping. I could also roster some evening shifts and so the burden on my parents was greatly reduced.

Unfortunately there were restrictions; service providers generally only offer support between 6 am and 11 pm. As a young person, it meant I would have to leave social functions early or I had to pay a premium for a small shift after 11pm. This was not

an inclusive life. Luckily, with the support of my family I was able to enjoy an extended social life and on nights when I would be out Dad would either pick me up or he'd assist me to bed when I got home. There were still occasions where I would cut my social life back as I was conscious that my parents were waiting for me to come home to assist.

In 1993 I joined the committee of the Bentleigh Football Club and would attend meetings, games and social functions, and I would assist at matches with writing down player's names that had kicked goals and the quarter by quarter scores. This information would be passed onto the Secretary who would then inform the league and local newspaper. Support staff would drop me off at games, and family and friends would pick me up afterwards. In 1998 I became Secretary of the football club—a position I held for seven years. I have been on the committee since 1993 and currently hold the position of Public Officer/Historian. I deal with all matters relating to the club's incorporation and I keep records of games players have played, results of games and goals kicked by players.

Through football I've made good friends and for a few years I would have a friend pick me up from home (he'd drive my van). We'd meet others at the club and a group of us would travel to games together. I have won The President's Award, Best Clubman, been made a Life Member and inducted into the Hall of Fame—all things I'm very proud of.

In 2003 I attended a forum run by [Personalised Lifestyle Assistance](#) (PLA) where Michael Kendrick spoke about how individuals could influence their own care. From this forum I joined a small working party and we realised that what was required was a more flexible and responsive service model of support which was developed around each individual's lifestyle.

It also recognised that the often cumbersome models of support developed by existing service providers both *over-supported* by providing too many hours of support (for example 2 hours when 30 minutes would be enough), and also *under-supported* people as their supports were provided at the wrong times and in inflexible models that brought about constraints in people's lifestyles.

We found more and more people were required to build their lives around a range of inflexible supports. Through discussion, the working group recognised that a flexible model, providing individuals with a small amount of targeted support during the night, would enable many service users to stay in their own homes and communities while reducing the strain on families and avoid costly congregate settings that tend to isolate people from their communities.

Using the service model of the [Queensland Mobile Attendant Care Service](#) (MACS) as a base, the working party, together with Deb Rouget from PLA, developed a

model of service to suit people in Victoria. The intent of this model is to create a flexible night-time service for people with disabilities living in their own homes in the Southern region of Melbourne.

Nightlife aims to not only be an emergency overnight service, but a service that liberates and makes an 'ordinary' life possible for people with disabilities. It seeks to enable people to live as independently as possible in their own homes and enjoy an inclusive lifestyle. The type of support people receive from Nightlife will vary and is uniquely tailored to each person's needs.

The Department of Human Services recognised the need for such a flexible responsive night service and agreed to fund the project in the bayside suburbs of Melbourne to enable people living with a disability to have a better quality of life. [Nightlife Disability Services](#) was formed and is hosted by [Melba Support Services Inc.](#)

Nightlife is a consumer driven organisation—developed by people who have disabilities *for* people with disabilities to ensure that supports are provided in the context of people's lifestyles rather than being the defining factor in people's lives. Nightlife now assist with some evening shifts, this now gives me great flexibility knowing that I can go out and enjoy myself and when I get home I will have support to go to bed.

It has also given my family peace of mind. Knowing that I no longer have to rely on my parents for assistance, my parents now go away on holidays with the knowledge that if I need help through the night that Nightlife is only a call away.

In 2005 I was invited by the Department of Human Services to be a consultant for a project they were considering hosting. The program was called *Direct Payments*, and is designed to enable people with a disability to have greater independence, choice, control and flexibility over the disability funded supports and services they require.

People with a disability currently receive support from the Department of Human Services who give funding to an agency on their behalf. Direct payments allow funding to be given *directly* to people with a disability (or their responsible family member, legal guardian or administrator). The person with a disability is able to choose, arrange and purchase the supports they require to meet the goals they have identified in their individual plan.

The project actively involves people with disabilities in the development and implementation of new policy. The participants in this project took part in a series of workshops where ideas and options for direct payments were discussed in preparation for participation in the trial of direct payments (Part 2 of the project). Part 1 of the Direct Payments Project provided an opportunity for people to discuss and

explore the different options for how funding will be paid to them during Part 2—the trial of direct payments.

The trial of direct payments (Part 2) started in June 2006 for a period of 6 months. Over the trial period there was a series of meetings to support people to use direct payments. Feedback from people with a disability, family members, guardians and administrators regarding how the system was working and how it could be improved was an important part of the trial. Direct payments work best for people with a disability who want to take more control over the supports and services they require.

After starting direct payments I decided that if I was to coordinate the rostering of staff, complete timesheets and keep track of hours used—and then provide this information to my service provider—I should not be paying the full unit cost. I had discussions with my service provider but they did not understand and were not willing to change their current practices. I contacted another service provider who was willing to sit down and discuss my proposal; after a meeting a set of guidelines were drawn up on what the service provider was responsible for and what I as the service user was responsible for. It also outlined the fee they would charge to facilitate what was required.

The agreement was signed and I was able to now advertise for my own staff, interview them, and, through the new service provider, employ the staff. I now am responsible for recruiting, rostering (including filling vacant shifts), and completing and emailing all timesheets. This now means that I have been able to stretch my funding further. Instead of a service provider sending staff without me having any say in recruiting, I now can choose the staff that suit *me*. I have reduced overheads and I have more hours of support. It has also assisted me in being able to assist around the home with things like house cleaning.

In 2010 I received a Certificate of Commendation in recognition of outstanding achievements and abilities from Rotary Southern Districts.

The Future.

I hope to watch my nieces and nephew grow and to share in their joys. I remain passionate about improving the lives of people with a disability. I will continue to serve on the Committee of Management of Nightlife. I hope to eventually be in a position to have my own place and live independently.

For more information about Nightlife Disability Services (in Victoria only) visit the website at www.nightlife.org.au, or email enquiries@nightlife.org.au. You can also call (03) 9532 5455 or fax (03) 9532 5055.

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