

## Pierre's Story

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*Pierre wrote his own story.*

I was born in 1951 in McLaren Vale in the family home. I grew up living at home with my family of three sisters and a brother. The family moved to Willunga when I was four, where we lived with my grandmother and grandfather who was the local doctor.

My father used to take me to school at Ashford three times a week, until I started to go on the local bus to the city. I have very fond childhood memories of growing up in the Willunga area where I have lived all my life. I learned to walk with sticks when I was 11 years old.

A few years after my Dad died in 1985, Mum and I decided that I should have my independence. So we had a house built in Willunga especially for me using my own ideas to make it easy for me to get around in. My mother and I designed the house.

I loved living in my own home and managed pretty well living on my own, with a little help to do the shopping and cleaning and a few other bits. When I could do things for myself I was involved in community meetings, driving my electric car, and caring for and enjoying my dog.

In May 2004 I was forced to leave my home. After having several falls I needed to go to hospital and later needed surgery on my neck. I was not able to return to my beloved home. I eventually ended up in a nursing home where I thought I would finish my days.

Some of my feelings and experiences about moving into a nursing home included feeling scared because I didn't know what was happening. While living in the nursing home I had troubles being hurried with my toileting, with others queuing and waiting for me to finish—there was no privacy.

I used to talk with one or two people but mostly the nursing home had people who were old, and I didn't have anything in common with them. Bedtime was 7 pm and up again at 7 am by my choice.

I felt my life was hopeless because there was nothing to do. Mostly they tried to make life bearable for me. Many of the staff could not communicate with me because of difficulties with my speech and some didn't even try. I worried about how much physical ability I had lost, now that I needed someone to do everything for me.

What made my life a little bearable was a volunteer who came to play chess with me each Monday, and my friends from Willunga who popped in to see me whenever they could. During those visits we had fun, food and some serious conversations about where I might find a house.

When I was in the nursing home two of my Circle friends took me for a trip to Kangaroo Island—I didn't think this would be possible. I had lost so much of my independence since becoming more disabled in 2004.

The nursing home was where I lived with almost 100 other people, until my Circle friends helped me to move out in April 2006.

My friends were very worried about me in the nursing home and worked hard to find a way for me to get out. They decided to set up a Circles of Friends for me with the help of [Circles Initiative](#) at the [Community Living Project](#).

My Circle friends found lots of information about the Younger People in Nursing Homes government initiative. They spoke to Steve Alexander and I was lucky to be offered one of the first opportunities in South Australia for a person to be funded to leave a nursing home.

My Willunga friends who wanted me back in the community all came to the Singing Gallery one night to see how they could help. I have 8 Circle friends, mostly from the Southern Vales, who have agreed to be around for me and help to make sure my life keeps being good and that some of my dreams come true.

These people are the force that helped me get out of the nursing home and back living in my home town. We get together as a group every couple of months to talk, eat and have some fun, usually in the evening at my place—we've been doing this since October 2005.

I spend time with each person often doing something fun as we share similar interests. Most weeks Tony & Lyn spend a day with me and using my van with a hoist we can go all sorts of places regularly, and much more easily.

It seemed to take a very long time. My sister was not keen for me to leave the nursing home; she worried that I would lose the bed she had struggled to find for me, if moving out didn't work out.

Some of the things that worried and concerned me about getting out of the nursing home included being worried because I couldn't understand how I might ever be able to live outside the nursing home. I needed lots of help with personal care, eating etc. and I thought I needed nurses to do this for me.

I worried whether I could ever find a place to live that would be suitable, whether there would be funding support for me to leave and how long the paid support service might last. I also worried how I would spend my time during the day. In March 2006 I left the nursing home and moved into this lovely rammed earth house in Willunga.

When I left the nursing home I became eligible for my new electric wheel chair, which has controls specifically designed so that I can drive. The first day out of the nursing home in my new house, it was my birthday and my Circle friends had a welcome back to Willunga party for me.

I purchased my van in December 2006 so that I could more easily travel around with my friends, rather than them needing to lift me and my chair in and out of their cars. The rammed earth three bedroom house in Willunga which I rented had open plan with lots of space for me to move around in my electric chair.

In 2009 I needed to move to a different rented unit because the landlord wanted to sell the property. I now rent a two bedroom unit which has been made accessible for me at the other side of Willunga.

It's a short wheel up to the High street and to friends' homes. The unit is also much more affordable for me. My Circle friends have helped me to find a place to live that is suitable and accessible.

They take me to appointments like physiotherapy, doctors etc., play chess with me, go sailing or to shows and local theatre productions, visit me at my home and invite me to theirs and we celebrate special occasions together.

My friends also give me advice on all sorts of things as well as financial decisions and other important matters like buying a good car. We all get together as a group every couple of months for dinner and talk about things happening in my life. We also go wheeling around Willunga High Street and the district, and have meals out together.

I chose to have my funding and support provided through the Community Living Project because it's a southern-based service and they help me recruit my own workers and help me decide how I want to be supported.

I spend several hours each day on my own without staff and I am on my own overnight—I have an emergency call system in place. [Technical Aid to the Disabled](#) have helped to set up switching so that I can operate the call system and manage overnights on my own, operate my TV and use the phone. Two of my Circle friends are included on the list of people to call if I need help when my support staff are not there.

My personal support staff provide personal care, assistance with cooking and eating, take me to appointments (hairdresser, dentist, doctors, physio), respond to my call system if needed, and do my banking, shopping and household chores.

They also invent easier ways for me to do all sorts of things more independently. This support includes caring for my vehicle, pursuing interests, and planning and organising holidays.

My Coordinator helps me keep things running smoothly and with recruiting new workers. A team of four or five support workers are chosen by me and work with me alone. They assisted me to purchase a van with a hoist so I can get around more easily and friends can drive me around to do things together. I did go sailing again at Goolwa when I first moved back to Willunga but have recently stopped doing this.

I am now doing the things I never thought I'd be able to do such as getting an electric wheelchair (street suitable) with controls so I can drive myself. We can now wander around Willunga and catch up with friends and enjoy this beautiful area where my roots are.

I make my own decisions particularly about my finances, what I do and when I do it. Some things I now have control over in my life include choosing my own support workers, creating rosters for my support workers, where and how I live, what I do and when I do it, and my daily and weekly routines.

I make decisions about my finances and what I buy, whose advice I seek out and about what, what I eat and when I eat, my healthcare and doctor, who my friends are and what interests I pursue.

One of my sisters and her family live close by; the other sisters and brother live interstate. I got lots of help from my sister to move my possessions she was storing, into my new house. She is a member of my Circle of friends and I think is pleased that I have now taken back control over my own affairs and is pleased that my life is so much better than in the nursing home.

Like me, my sister sometimes still worries that maybe my support funding will not continue and some day, I will again need to go through all the worries and dilemmas of finding another nursing home bed to return to and again become dependent on someone for managing my affairs.

Some past and present interests include sustainable living, and wind and solar power, I am an anti-uranium supporter, I am also interested in Southern Vales developments, attending the Friends of the Willunga Basin Group, spending time with my friends, reminiscing about old times (especially my family's old cars the Nash and the Holden, driving my electric car, playing chess, sailing and travelling.

In recent years I have enjoyed some interesting holidays. These have included a road trip to Tuross Heads, New South Wales to visit my sisters and their families, a plane flight to Perth and driving down to the beautiful south-west of the state, a road trip to Mount Gambier to check out the Blue Lake and caves, and a trip to Queensland to present at a conference with my friend David.

I'm pretty dependent on others for everything these days, I have great difficulty with this, as well as not being in control of my body and the pain I have, but I'm certain I would not want to change back to my life when I was living in the nursing home.

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