

Relationships and community: The essence of life

Anna and Keith Coventry are parents of two boys; Henry aged 19 and Will aged 16. Will lives with a disability and as he enters the later years of schooling they are determined to ensure that he continues to have a good life in which he contributes and is valued for his contribution. In this article Anna and Keith speak about the ways in which they have sought to build relationships and make connections for Will.

Last year our son Will participated in his school swimming carnival. At school pick up that afternoon the Principal came to me as he wanted to let me know how well Will had participated – he swam the 25 metres freestyle, breast stroke and backstroke – unbelievable! Then a big, burly year twelve boy from Will's house said to me, "Hey Miss, Will did really well today". The following week I was at the school gate, when a new Mum at the school told me she had attended the swimming carnival. She recalled that when Will swam the whole school became involved and chanted his name, supporting him – she cried.

Our son Will attends an inner city co-educational catholic school. Will shares a passion for sport, as does his older brother Henry. He has a wicked sense of humour and is a gentle and loving young man. Swimming, horse riding, spending time at the beach and at his Grandparents' property in the country are some of Will's other interests. His favourite subjects at school are Outdoor Education and Catering. Will is blessed to be a member of a large supportive extended family network.

In his infant years Will was quite ill and his severe myoclonic epilepsy was not well controlled resulting in numerous hospital admissions. During this time, our focus was on surviving from day to day. It seemed like life stood still for some time, as we sought to unravel what was happening with our Will.

Around the age of five or six years Will's seizures were better controlled and he was more medically stable. He began to attend the nearest local special school, nineteen kilometres from our home. After a while, we started to question Will's school placement and ask ourselves why he was not attending our local school, where Henry had attended and where we were known. Our friends had children at the local school and we increasingly realised these children were engaging with Will and inclusive of him in social situations. We believed he needed to be present in our local community so that he could make friendships and connections.

Will commenced part time at our local school in year three. This was to be a split placement between the local school and the special school and continued as such for the rest of Will's primary school years. During Will's time at our local school we would take every opportunity to inform his class and the school about his rich and full life – a family trip to Uluru in the camper trailer, and attending rugby matches and cricket tests at the 'Gabba. When they asked for family photos for the power point at assembly we always made sure we sent a photo in.

Someone once said I was constantly 'putting Will out there.' Not really, we hoped this was informing the community that Will's life was like all other school children. He had the same interests and dreams as everyone else, just difficulty in expressing them.

Will had a group of four mates with whom he would play and socialise. When we were out and about, children were always coming up to say “hello” to Will. It was here in our local school that we first experienced the power of belonging and the support of other families. We also experienced our greatest challenges regarding inclusive education at this time. However, it was the support from other families that made us realise this was all possible and inspired us to continue to pursue our dreams for Will, especially with his secondary education.

For Will’s secondary education we looked at local schools but our final choice was an inner city location. We sought a school that embraced diversity and a community where Will and we could belong, contribute and continue to make connections. This school was close to Henry’s and under the auspice of the same education organisation. Will commenced here five days a week in year eight. Like all students beginning at a new high school, Will had to begin building new friendships and finding his place in the school community.

When Will showed an interest in a sport or activity we would look for ways in which he could be involved. The school has a great reputation for basketball and Will developed an interest in this. In year eight or nine he would train with the junior team and he and Keith would go along to support the senior team at their matches. As a result of being present at these matches Will was given the role of water boy. He also developed a close bond with one of the coaches who is now a significant person in Will’s life.

Will has recently begun rock climbing at Rocksports as part of his outdoor education subject. As a result of this, he has become a member of the school climbing group which he attends every Thursday after school. By participating in these activities Will is building relationships and connections with people who share a common interest. Will participates in all aspects of school life – swimming carnival, cross country, cultural night and he is currently the roll monitor for his home room. Last year Will was ill and had an extended stay in hospital. During this time the school had a visitation roster whereby twice a week a staff member and three or four students would visit Will, play UNO and spend time with him. This was amazing support.

In addition to friendships and support at school, as a family we have always sought to make connections in our community - the local shops, newsagent, butcher etc. We have been very conscious of making these connections for Will and of sharing his story through our interactions, as he has difficulty telling it himself. We focus on Will’s interests, achievements, hopes and dreams. As people have grown to know Will, they understand how he communicates and they look out for him. It was at our local IGA that Will first shopped independently. We have a local coffee shop that we frequently visit where Will enjoys a coffee, especially a flat white. Over the past few years they have come to know Will and are aware that he’s presently undertaking a hospitality course. Henry and I were having brunch there the other day when the staff asked about Will and his hospitality course. In addition to being a connection for Will, it’s great for Henry to see Will being valued. This is an informal connection but significant; it’s through these sorts of interactions that we create natural supports in our community. It may lead to a part time job one day – who knows!

Now as Will reaches the final years of school, we are preparing for life after school. This is quite daunting and at times we have been overwhelmed by the enormity of preparing and planning for this next step. It was whilst attending forums and conferences we first heard about ‘Circles of

Support', a formalised group of people who come together regularly to support a person with a disability.

Keith, Henry and I talked about this as a possibility for Will. We would have discussions about the purpose of the Circle, who we would invite to be a member, who was significant in Will's life and who we felt would be willing to contribute. We wanted to create a more formal support network around Will to assist us in planning for his future, especially his final two years of school. We believed the Circle would assist us with this and also help to ensure we had ongoing support for the future as there will come a time when we are no longer able to provide this.

We had our first Circle meeting eighteen months ago. We were nervous about creating Will's Circle. It took courage to formally invite people into our family life and share with them the challenges we face. Everyone invited wanted to be part of it and were delighted to be asked. The circle consists of his immediate family and his Godmother, two uncles, a cousin and two friends. All of these people were actively involved in Will's life previously but the circle has deepened that involvement and their commitment to Will. Each member brings their own skills and gifts to offer the circle.

One of the very first meetings involved us sharing very personal family information about Will – this was difficult at first. However, if they were to assist with planning for Will's future they needed to know more information about Will's abilities, his passions and interests but also where he needed support. They needed to know a typical day in the life of Will. The focus of our meetings has been organising work experience and making connections within the workforce. As mentioned Will has an interest in horse-riding and the outdoors. One of the circle members has a business contact in the racing industry. He was able to organise work experience for Will at the stables at Eagle Farm racecourse. We have a vision and we creatively brainstorm about pursuing our hopes and dreams for Will. Having the group's assistance with thinking, planning and particularly sharing their local contacts is such a practical support for Will and for us.

After our first meeting we felt a sense of relief and also empowerment, by having these people committed to sharing the journey with us. They challenge us, push the boundaries and keep us on track. The circle meets about every three or four months – some meetings we have more to discuss than others but it's a formal way of staying connected and communicating about Will's life. Will loves the meetings and we are trying very hard to have him actively participating. Being a member of the circle has enriched everyone's lives in a way they didn't expect. They want to be a part of Will's life and to make it happen. We find they go out to their own networks and look for opportunities for Will. The members are actively seeking ways to be engaged with Will well beyond what they did previously.

In addition to family and now the circle, Will has numerous friendships and connections in his life that vary in closeness. We have worked at creating and maintaining these friendships and connections for Will. It has not always been easy.

What spurs us on is that we can see that these relationships give meaning to his life; it is through these relationships that Will feels valued, has meaningful things to do and contributes to his community. We believe that a network of people around him will be essential in ensuring that Will lives a safe and fulfilling life.