

Not waiting, creating; or in my case not being allowed to wait for every possible contingency to be covered.

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

The sight of this tall healthy happy young man here today can be deceptive. In fact Luke has faced many hurdles in his life. To begin this story of my journey with Luke, I'd like to give a brief background picture. Then I'll outline the history of Luke's circles of friends. These represent the more structured steps our family has taken over the years to ensure Luke's present and future well-being.

When Luke was young, it sometimes seemed that he needed to see every specialist and every therapist ever invented – ophthalmologist, stomal therapist, audiologist ... the list went on. As a result, Luke's early years were dominated by medical investigations and therapy appointments.

Through these daunting events we met many competent compassionate professionals who treated Luke with respect. Unfortunately there were also experiences with rude, condescending, ignorant professionals. (That could be a topic for another complete conference.) Now for us to see Luke healthy is like a miracle. We never take for granted Luke's ability to walk, his glowing health – and his wonderful enjoyment of life.

As well as facing health and developmental hurdles, Luke also encountered some social rudeness and intolerance – on public transport, at the shops, in the park.

On the other hand his educational path was at first promising. Luke attended the same state preschool as his sister and brothers.

Then I approached Catholic Education about enrolling Luke in the parish school his siblings attended. Instead of making a decision about Luke's schooling, they circumvented responsibility by appointing me to a committee to investigate the educational options families in our situation wanted for our children. I took this role very seriously. We read the latest literature, met religiously and produced a well researched report.

However, this report did not appear to make an impact. The local principal informed me Luke would not be accepted at the school because the teachers *didn't feel comfortable* about Luke attending.

From these (and other) experiences I could see that in some ways the medical, educational and social worlds were not ready for Luke. As this realization became clearer to me, my response was to become protective.

So now on to the circles and their significance.

To begin talking about Luke's circles of friends I must start with his extended family. My husband Denis is one of seven children and I am one of five – so we certainly had a head start.

Of course friends too have played an important role. For example initially I found it difficult to deal with the concept of respite. Then a friend compared it to a sleepover, which my other children regularly enjoyed, and it made sense. Thank goodness she did challenge my thinking because that was the beginning of our family's twenty-year relationship with Mamre.

Denis, my husband, organized the **first structured circle** of friends when Luke was about ten. This first circle was difficult for me. With four young children, I never felt ready for the meeting at home in the evenings, and I did not understand the concept nor the purpose of a circle.

Denis envisaged that this circle would discuss ways to plan Luke's future. He was hoping to develop a *process* we could follow so Luke would have ongoing security not solely reliant on family members. However, the circle members were more focused on immediate and interesting things to do with Luke. So this circle was really a mismatch of purpose and people, as well as not being the right time nor place for me personally.

To me it was a relief when it gradually faded away.

A few years later, as Luke was finishing school, Denis set up **a second circle**, this time with Luke involved in the circle. The focus of this circle was to develop a strategy to enable Luke to live away from home.

However, this circle was short-circuited when someone asked Luke where he would like to live in the future. This was before Luke began using FC. Luke emphatically signed HERE and said Mum and Pa – his response was clear: he wanted to stay living at home. I must confess that I felt relieved.

Logically, I knew that Luke could not live with us forever, but I felt overwhelmed by many concerns, such as:

- who would take the time to look into Luke's eyes and see whether he was in pain
- would everyone know Luke's version of Makaton signing
- how would we interview and choose staff
- how would we ensure continuity and security
- who would cut Luke's toenails?

While that circle also faded away, another initiative from this time has thrived and brought unexpected benefits to Luke. Denis organized for Luke

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to do **voluntary work** in the Disability Services Queensland office one morning each week. Through this shredding work Luke has made several close friends and many connections. Some of them have been members of his circles and quite a few spent time with him while he was house-sitting recently.

Then about three years ago, **Mamre** began playing a role in our circles. Mamre had started a new project called Building Informal Networks with Marg as coordinator, and part of her role was to facilitate circles.

At the same time, it was becoming clearer to my husband that Luke's future, like most people's, would not be funded by the government. Therefore, **the third circle** Denis created for Luke was again future focused and also included successful business people. From this group Denis realized that his dream of Luke living an unfunded but individual life was possible.

As Luke did not attend these meetings and I did not want to be part of this group dealing with the big picture, a **parallel circle** was set up - at the instigation of the same friend who had questioned my attitude to respite. Thus it was that a group of us met at a coffee shop once a month.

Our focus was "small picture" - to extend Luke's social life. We met after work, Luke had hot chips to keep him going until tea, we could have a wine or coffee, the chairs were comfortable and the meetings relaxed. Having Marg facilitating meant that there were minutes to refer to and that the next meeting date was organized before we left. It was low-key and enjoyable - for me it was the right time, right place and right people. Four significant outcomes came from this group:

The first key outcome occurred when my husband was invited to be in a short film to be shot near Windorah. This is a small town on the edge of Cooper Creek on the way to Birdsville. I had never been so far west, nor on a film set. When I told the café circle about this once in a lifetime opportunity, they insisted I should go too and that they would organize whatever support Luke needed for the ten days we would be away.

Before we set off out west, one of the ways I reassured myself about Luke's care was to describe in everyday language Luke's communication, personal care routine and preferences in food etc. That written information was available for everyone involved. This was the first time that Luke had stayed at home for more than one night without Denis or me being there. A few people came for dinner, Luke saw a movie with one friend, and only a very small amount of personal care was paid for (much less than had he gone to the respite house). He and his brother Patrick enjoyed it and survived. And so did we. (And since then Denis and I have also enjoyed a quick trip to New Zealand!)

The second exciting outcome from the café circle concerned Luke's communication. Luke's key worker from Mamre "planted the seed" by mentioning facilitated communication (FC) every meeting. I had read about FC fifteen years earlier, but had not followed it up. Sometimes I need to be given information several times before I actually "hear" it and grasp the significance.

So in late 2004, Luke was introduced to FC. Luke had always been perceptive, for example rubbing my back if I was tense, and we were aware that he understood much of what was going on around him - but we had no idea of the extent of his comprehension.

His inability to easily control his body movement means that his outward body language does not always mirror his depth of understanding. That could only be revealed once he started using FC.

Of course using FC does not take away the disability. Even though FC has opened Luke's world enormously, he still cannot just pick up the phone to chat to a friend. The easy communication enjoyed by many of us continues to elude Luke. And even if there could always be a facilitator with Luke, the necessity for communicating through a third person adds a level of formality that most of us do not experience in our friendships.

Also, initially, some friends seemed nervous about being with this "new" Luke. For all of us previous perceptions were challenged, and I think we became suddenly conscious - almost a feeling of being judged - of how we interacted with this newly revealed Luke.

However it was wonderful to see Luke's range of language, both figurative and literal, and his inner thoughts expressed through FC. Our circles and our lives would never be the same again!

The third outcome from the café circle has been the on-going development of Luke's social contacts. The first step was to write a letter to each of Luke's cousins, aunts and uncles, and to family friends and their young adult children. In it we outlined what our vision was for Luke's future and invited them to spend time with Luke. Many people took up this invitation. Through this group Luke's weekends became more interesting as he was not always stuck with mum and dad.

Occasionally we invited this entire group to our place for gatherings. For example, for Christmas 2004, the first year Luke was using FC, we invited everyone to join us for Christmas drinks and to bring their diaries to make a time with Luke. We made sure we had a calendar there and it was a fun and relaxed way to organize and keep track of the arrangements people made with Luke.

The **fourth significant outcome** of the café circle came when Luke went from simply being ‘involved’ to beginning to shape the circle and his life. In early 2005 Luke typed that he would like to have some men his own age in his circle. That made me realize – with a shock - that the café circle were all women and that the youngest was at least ten years older than Luke. In response to Luke’s wish to have male input, we changed the time and venue and specifically invited young men, including Luke’s brothers.

However, over time it became clear that there was a mismatch between who Luke would like to be there and who was available to meet on a regular basis. Instead, Luke organized his first men’s night, which everyone enjoyed. He is currently planning the next. In this way Luke increases the male contact in his life without expecting a regular monthly commitment.

Where is the circle now?

At the moment the circle is quite small although the network of friends and contacts is becoming larger. Our strategy is to conduct a planning day soon where the wider circle of friends can suggest ideas. We may try having a social convener for Luke.

Sometimes we need to remind ourselves that it is more important for Luke to have good people around him as he makes concrete plans to move out of home rather than for us to strive for the perfect circle.

May I detour to say how strange it is for me to be here today talking to you. Last year I was in the audience. At this and at other conferences over the years I have been inspired but I must confess that I have also been guilty of the ‘yes buts.’ Yes, that is a wonderful story, but our situation is different:

- *the person in that story can speak, or*
- *that person does not need support with personal care, etc*

Then there were other impediments, such as:

- *but those parents must have a lot of money, or for me the hardest to answer:*
- *but where do these parents get their energy?*

That is probably why seeds of ideas needed to be planted in me several times and then nurtured with excessive fertilizer. I have had to actually **experience** the support of the circles and Mamre. The best example I can give of this is the six weeks Luke spent away from home:

Luke’s brief comment, “all the planning paid off,” is a great understatement. Organizing twenty-four hour support takes a lot of patience, perseverance

and improvisation. An example of what just one week of the six-week stay looked like offers some insight into the level of planning needed.

Had I been responsible for this timetable, I think I would have felt overwhelmed. Probably I would not have been able to even begin organizing his stay. I would have foreseen too many problems and become paralyzed. For me, the arrangements would never have been watertight enough. Without Mamre's energy and enthusiasm and the contribution of the circle members I doubt the house-sitting would have happened.

Now I have more confidence that we can assist Luke to move to his own place and that this is indeed the correct next move for Luke.

More and more I am learning to see that my wanting to protect Luke from negative experiences is not only unrealistic but also unnecessary.

My job is to continue learning to de-parent.

Being part of a circle helps me do this, as other people have different ideas and viewpoints and historically are not as emotionally involved. As Luke's life, through Mamre and his circle of friends, becomes more independent of ours, de-parenting is becoming easier for me.

My job now is to let Luke live his own life. And he loves it!