

Steppin' Out

*Two years ago **Kate Alcorn** moved from the family home to a home of her own – just a few minutes' walk from her work and in the community she grew up in. To help with this, Kate and her mother Carolyn started 'Kate's Crew' - a group of family and friends who meet regularly to help Kate plan for her future, organise her life and live the life she wants to live.*

In this article, together with founding circle member Glenys Bull, Kate and Carolyn reflect on what it has taken to bring a group of people together to help start realising Kate's vision and how this can be safeguarded in to the future.

"Oh no!" Kate exclaims, when asked if she would like to move back in with her mum. "I used to live with my mum all my life. My relationship with mum is different now - I think I've grown up".

For the past two years she has lived in a town house in the community where she went to school and has worked for the last fifteen years. She shares her unit with people she finds with her mother Carolyn, and together they enjoy the ups and downs of share house living. Carolyn was clear about where she wanted Kate to live. "Our family vision is for Kate to live in her own place and form an independent life in her community to the degree that she is able. As with any young person moving to independent living, there is much to learn and adjustments and allowances that have to be made. It is an ongoing journey for us all, and Kate has continued to surprise us with how well she has done".

This has certainly presented challenges for both Carolyn and Kate. As Kate says, "My housemates sometime never clean. Some people never learn how to use a dishwasher. It's not fair on me. They have to do their share". Fortunately Kate has her support circle, 'Kate's Crew' to assist at these times. However it was not always like this and this goes to the heart of why *Kate's Crew* was started.

As Carolyn explained "It all came to a head when Kate asked me one day, "What's going to happen to me when you die?" Having lost her father in 1996, she understood fully about life and death and had come to the point of realizing that I may not always be there for her. Up until that point I hadn't thought seriously about this possibility or its consequences for Kate. I suppose I had assumed that family would look after her and more particularly, the family we had asked to be our children's guardians when they were younger. As my thoughts became more focussed, I realized that should something happen to me, this would not only mean a move to Melbourne where they now live, but also the loss of her job. She would be far from her colleagues at work and her church family and friends. What a huge loss on top of losing her mother! It became very clear to me that this was not the life that I wanted or dreamed of for Kate."

After attending a workshop with a local planning agency, Carolyn and Emily (Kate's older sister) were introduced to the idea of support circles. Following this workshop, Carolyn, Kate and some close friends and family subsequently went to another planning workshop which took these ideas further. As Carolyn reflects, "we were challenged to think creatively and plan without a lot of reliance on government help. We were asked to visualise the ideal life we would wish Kate to have and then start thinking how we could make it happen. Our perspective was broadened as we were presented with new ideas, strategies and possibilities. Kate was also taken through a process to help her develop and clarify her own vision for the future. What is amazing is that both visions were very similar:

Our Family Vision for Kate:

That Kate live a safe, full and fulfilling life as a valued member of her community.

Kate's Vision:

To be around a group of people that I live with in my own apartment

Managing my life,

Being responsible and independent

With time to myself.

"Although the idea of starting a support circle for Kate was very daunting for me, in reality it happened quite quickly. A lot of people say they have difficulty getting people to become a part of their circle but we never had that trouble. Kate was so excited about the idea that she was inviting people before I had a chance to catch my breath ... and they all said yes." Kate explains "People I've known for years have to be in the circle". "Yes", agrees Carolyn. "It's a mix of family and friends".

This circle of support meets every two months and has been running now for over five years and they gather on a Sunday afternoon at Carolyn's house. "We have the meeting first and Kate shares what's happened in her world since the last meeting and then brings up anything she wants to discuss". "I just say it" says Kate, "what I want to do with my life" and together with Kate, *Kate's Crew* work out how they can help make this happen. The meetings finish with two of Kate's favourite things – food and time with friends.

"It's been a stable group of about 10 of us" says Glenys, a friend of Carolyn's and a founding member of *Kate's Crew*. "Over the last five years we've come to know each other quite well and are all committed to Kate. We're on the same page - with common values and standards." Despite the circle forming quite quickly, it has not been without its challenges, as Carolyn reveals. "When *Kate's Crew* first started, Kate felt like everyone was organising her life and she sometimes found it quite overwhelming. As time has gone on, she's come to understand that no matter what is said during the discussion, she has the final say with big decisions. Kate needs time to process what has been said and wasn't always ready to make a response. Whereas now, she's much quicker to say, "No I don't want to do that", or "I like that". As Kate describes, "my first time planning my future was so hard for me. I have Down Syndrome and my speech is not wonderful. People always have opinions and I felt like I had to do what I was told to do." As Glenys was quick to point out, this is less of an issue these days. "She's quite forthcoming about what she wants. She is quietly determined". Kate agrees. "I don't want them to make decisions for me, I want to make my own decisions".

All the members of *Kate's Crew* bring a mix of skills, interests and opportunities. "We go around the circle and talk about each member's gifts. For example, Martin is very practical, so he puts ads in the paper, fixes things at Kate's unit and things like that. We rely on Peter for his computer skills. My brother and sister in law live at the Sunshine Coast [and living so far away] there's lots of things they can't do, but we value their input and Chris (Peter's wife) shares in facilitating the meetings. This facilitation role is an important one. They are responsible for keeping the conversation going and making sure Kate's vision is at the centre of all decision making. Others help out with taking minutes, interviewing prospective housemates and being part of sub committees to solve in-depth problems.

As Carolyn explains, "For the first couple of years I had both visions printed out on the table to keep us focussed. Because we've been meeting for so long now I don't feel it's quite as necessary."

Glenys went on to elaborate. "Most of the early goals and desires that Kate had, and that we talked about, was to be part of THIS community, - the community she can access. There are plenty of things on all over Brisbane, but engaging in her own local community provides a safety net where she is known and people look out for Kate. It's not just a matter of activities to fill in time, it's a matter of getting to know people and being part of a relational community". And it doesn't end there. "Whilst 'the big goal' of living independently has been reached, it is still ongoing and there is always lots of the nitty gritty to work out. Maintaining and growing in independence does take a long time. It takes a long time for any young person to develop responsible independence. So for Kate, it is an ongoing thing. Most of what we've focused on this year is the nitty-gritty".

A typical example of keeping things going is finding suitable housemates. There are particular things required of a housemate for Kate's safety (amongst other things) and every time someone moves out, it's on again. "Carolyn had an idea of inviting some new people in, as a one off" said Glenys. "It's a good idea to get new blood and fresh ideas. Having a circle that is so close, sometimes we can become stale and need to see things from a fresh perspective." As well as providing some fresh ideas, it will also give Kate's Crew a chance to hear from people Kate's age about how they find their own housemates.

Whilst there are challenges from time to time, Carolyn is adamant that it is worth it. "It is hard work, but by the same token you don't want to hand decisions over to just anybody. I want the people in Kate's life to know her well enough to be able to help her achieve her goals. Because of my work commitments, Glenys and Carmel have quite often interviewed housemates and this is a great help."

"I think there's a tendency to think that once you start a circle, it's going to be all rosy, but it is hard work." Glenys points out, "Things don't work out for *anybody* all the time. You've really got to have that vision and want it and hang on to it and be prepared for the hard work that will go with that."

It is still early days but Kate is enjoying the independence of living in her own home. Her unit is within walking distance from her work, which is just as well as she starts work at 6.00am. For almost fifteen years Kate has worked at the local Coles supermarket and is a valued employee. When asked what her favourite thing is about living in her own home, Kate replies, "Relaxing. I got my new lounge suite now" - a lounge suite she paid for with money she earned through extra paid work she did on top of her work at Coles.

With her independence has come confidence and with this, further independence. "Sometimes I prepare my own meal, bring stuff and post it, get to bed on time and go to work on time". When asked about how her life has changed since *Kate's Crew* started the answer was clear, "My life has gotten real good!"

Carolyn reflects, "It would be a different situation if my husband was still living. I'm sure we would have eventually considered starting a support group, but as a sole parent I need people to bounce ideas from. *Kate's Crew* fulfils that for me. I have found that unless you have walked the road, most people don't really understand the day to day pressures, challenges and decisions that need to be made. The members of *Kate's Crew* are committed to Kate and understanding her needs and dreams. They also provide the encouragement I need and the valuable perspective of those who are that little bit removed. I will do anything to achieve a good life for Kate".

"I think Kate is determined to have a good life" Glenys agrees. "She definitely has her own voice." "Oh yeah!" says Kate. "I gotta get all the housework sorted out first".