

Mena is 28 and has lived in her own place now for nine years. A home of Mena's own was part of the family's plan for her from a very young age.

Mena's mother Margaret places great emphasis on formulating a vision for a person's life, planning as early as possible and taking control of how this will happen: "Don't make the assumption that government or services will 'lead the way'. They won't. Families need to lead. You need to place yourself in control. I call it 'family business'. Once you've handed responsibility over, you spend the rest of your life trying to get it back. You work just as hard, but in a negative kind of way, against the constraints placed on you, instead of taking and keeping positive control. There are dozens of opportunities, all the time. Not being ready to take them up can be the result of waiting for others to take the lead."

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A planning group, a 'circle of support', was created for Mena when she was as young as about 10 years old. This group of family and friends has been critical over the years in "the process of developing the vision" for Mena's life and planning the practical steps to achieve this vision. Way before Mena left school, the circle had thought about preparations for life beyond.

Knowing Mena would eventually want her own home, her family started looking around near them for an accessible house. When she was about 13, they bought a small 2 bedroom house nearby. Margaret laughs that one of her main conditions for the house was that she wanted "to be able to run to the house in the middle of the night in my nightie" if necessary. This house was let on open rental market until it might be needed as part of the plan for Mena's life. Margaret notes that even though this initially put the family into some financial stress it meant that Mena had some options for later. Likewise, as soon as Mena turned 18, even though there were no immediate plans for her to move out (the original idea was that she might not do that until around 25), her name was put on the public housing list. The waiting lists are long and these actions were like "taking out an insurance policy" for Mena.

Families should try to "be ahead of the game".

About three years prior to Mena leaving school the circle started to think about planning for work. Margaret knew there were no available post-school services that would meet the vision of Mena's life: "One idea was to find Mena employment by making it ourselves; to start her in her own business." About 18 months prior to Mena leaving school, Margaret left work to research what this business might be. "I had to make the space to think this through". The decision was made to set up work for Mena by creating a family enterprise in card-making.

A paper press and materials were bought and the family became stallholders at the weekly Brisbane Markets. This involved morning work during the week creating and packaging the cards and all day Saturday and Sunday at the markets selling them. This family enterprise represented about ten

hours' work per week for Mena. She was, in fact, as Margaret notes, "the first one to leave school with a job", because the planning for this had gone on well beforehand.

Mena did not leave school with funding adequate to meet her support needs. There was an allocation of \$18,000 'Moving Ahead' money. This was paid to a service and Margaret notes one of the things Mena's circle had done earlier was to look around and find a small service that would be "supportive of the family's vision". Establishing a partnership with a supportive service was an important step.

At around this point, Mena showed clearly that she was driving this vision of where her life was heading by deciding, after a conversation with someone at her church, that she wanted to move into her own place by her 19th birthday. Margaret notes, "sometimes the people you're planning for will run with the vision ahead of you".

So suddenly this modest amount of "Moving Ahead" money was nicknamed by the circle "Moving Out" money and the priority became Mena's own home. Because of the early planning for an eventual home this new priority was a possibility. When Mena first moved out it was into the house bought long ago for that purpose. Her rent was subsidised by the family.

Margaret describes a kind of "patchwork quilt" of little bits and pieces of funding and support built up over time around Mena. Initially the family covered the gaps in Mena's support. Other little "bits and pieces" of money were sought out, "an hour and a half a week from community options, some HACC money and so on" Margaret recalls. The card-making job saw Mena working from the family home in the mornings, and initially Margaret would extend her stay and provide support until about 4pm.

"A patchwork quilt": little "bits and pieces" of money and support.

One creative strategy that both added to Mena's support and brought people into her life was a "dinner roster". 28 different people gave a commitment to spend two hours, once a month, having dinner at Mena's. This had the effect of gradually building a network of people in Mena's life. The dinner roster has operated now for nine years. People have come and gone from it. Mena no longer needs the roster to make up gaps in support, but she enjoys the varied group of people she sees on a regular basis. Margaret observes, "It's a safe way to invite people into Mena's life."

One person even anonymously donated money to the service to fund a sleepover a week for Mena.

By the time Mena finally did get a public housing unit, her original house had served its purpose, and was eventually sold. The funds will contribute to a trust fund for Mena's future.". **Some people respond to Mena's situation, saying to Margaret, "You're so lucky Mena has her house" or "You're lucky you could take time off to plan this", but Margaret's response is that "The lucky don't sleep in. What appears 'lucky' to others is the result of very intentional steps, thinking through what will be needed and planning thoroughly."** She continues, "We see our other kids lope along through life and opportunities come along, they fall into a degree or fall into a relationship, but for people with a disability there's a much greater cost in failure, fewer opportunities and the safeguards are not always there. **Nothing good happens without planning.**"

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Margaret also notes that "lives are journeys". We can't just focus on an outcome, like 'getting a job' and that's that. People's needs, desires and priorities change all the time.

One circle of "bright young women Mena's age" was specially formed to address three issues Mena had raised herself: a holiday, a job in the public service and a flatmate; all were dealt with in three months. From the card-making business Mena moved on to other work, to small jobs in the public service, and at a community art gallery; all paid work, on productivity based wages, with Mena working at her full capacity. Lately, as her health has deteriorated, she has moved onto a full funding package. The circle once planned for school, a job, a home. People have come and gone but the circle has remained. Now it thinks about the long term, about support for Mena without her parents, and also about adapting for the new circumstances of her health and safeguarding her lifestyle as much as possible.

Margaret sees in Mena's situation a lesson about the power of a vision. She believes without the family taking matters into their control, guided by a vision, Mena would never have got funding and would never be in her own home. What acting on this vision had meant for Mena is that she has been able to fulfil her dreams, build her own life, to have a job, to have her own home, her own social life.

She has never had any intention of ever coming back home!

Margaret encourages families to plan as early as possible, but also notes, **"It's never too early; it's never too late."**