



Jeremy Ward is a parent whose eldest daughter, Mena, lived with disability and required support to live in her own home, which she did successfully for over 10 years. Jeremy's older sister also lived with a significant disability all her life. He has many years experience in disability advocacy, in the law as it relates to people with disabilities, and in assisting families to plan for the future. *The Shouted Goodbye*, Jeremy's account of Mena's life, was published in 2015.

In this edited excerpt from his book, we see how Mena's parents, Jeremy and Margaret, supported her to live in her own home.

The Shouted Goodbye (excerpts)

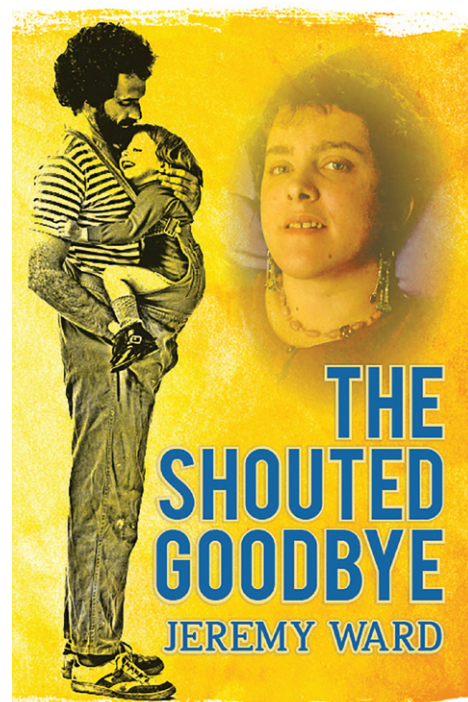
When Mena was fourteen, we had an opportunity to buy a small two-bedroom, low-set house near us in Corinda which, with simple modifications, we knew would work for her. We had ten years, or such was our plan. It turned out not to be Mena's plan. Not long after she left school she announced she was moving out of our family home on her nineteenth birthday. It might be that we contributed to her sense of urgency. After we bought the nearby house we often took Mena for walks to see it, or drove past on our way home from school, telling her that one day it would be hers to live in.

Mena moved into her new home on her nineteenth birthday. The move was successful, but far from ideal, and we decided to accept an offer from the department of housing for Mena to move into public housing. She moved into her department of housing cottage less than two years after her initial move from the family home. We had specifically bought the first house as a future home for Mena, yet it had been occupied by her for less than two years.

Margaret claims she began thinking about independent living for Mena when Mena was eighteen months old. Perhaps it was her architectural training and love of housing. I certainly don't remember those conversations. I was too consumed by the everyday reality of parenthood to be thinking that far ahead. But once we began serious planning, independent living for Mena was certainly a priority.

Mena required support twenty-four hours a day, seven days a week. Her level of disability required her to have someone with her at all times, including overnight. They did not need to be paid support workers, and certainly did not need formal training, but Mena's lack of capacity, both physical and cognitive, meant she was very vulnerable in a number of ways. Mena was a delight to spend time with, had a wicked sense of humour, was friendly and affable and always positive. She had highly attuned emotional intelligence. Yet the reality was that she could not roll over in bed, get out of bed, get into her wheelchair, bathe, toilet or dress

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herself, prepare food or undertake any tasks other than very basic ones, without support. She had a poor sense of danger and a lack of discernment when it came to strangers. In her house by herself, she would have no way of saving herself from a fire, especially if in bed.

Margaret and I never wanted Mena to be supported only by paid workers, even if we'd had sufficient government funding or private funds to make that possible. Our vision, that Mena would be a valued citizen in her community, could never be realised if she was surrounded only by paid people. Nor would she be safe in the long term if she had only paid workers in her life. Paid support workers come and go, the quality varies. That is not to say that they have no commitment or that they cannot become close friends. Many did in Mena's case, some remaining in her life long after they moved on from their paid role. But while working for Mena they were, first and foremost, in a paid role. They were not there primarily because of a deep, personal commitment.

Margaret and I saw the need to fill Mena's life with unpaid support as a welcome challenge, an exciting opportunity, an important safeguard, rather than an insurmountable obstacle. When it came to working out how to build the network of unpaid support, it was the coordinator of our local association who came up with the primary strategy.

The plan was to generate a guest list of approximately twenty-five people who would dine with Mena one evening a month. A meal would be prepared and each dinner guest would be with Mena alone for two hours dining with her and helping her with her meal. We talked to Mena's paid workers to clarify the dinner guest's role. We set out some rules: the dinner guest could do no wrong; Mena's workers were to treat guests as they would any guest invited to their own homes.

Margaret did all the work of setting up the roster. She made contact with each person by phone, discussed the idea and what was being asked of them and planned a schedule, initially for three months. She mailed each person a copy of the schedule, with their agreed dates highlighted. Guests could also see who else was on the list and when they were scheduled, in case they wanted to swap. Seeing who was involved allowed people to feel part of something creative, something exciting. Each Sunday evening, Margaret would phone those coming during the following week to remind them.

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The beauty of the roster arrangement was that it provided opportunities for people to maintain contact with Mena, such as paid workers who had moved to other jobs. The dinner roster also gave Mena a way of bringing people she wanted into her life, saying *I want you to come to dinner.*

About two years after Mena moved to her cottage, one of her support workers announced she was leaving to take another job. We were disappointed, but knew all Mena's workers would move on at some stage, particularly as many of them were students. She asked to become part of Mena's dinner roster and over the course of discussions about her leaving she revealed she was looking for somewhere to live. Margaret and I had been thinking for some time about Mena having a housemate. Our idea was to find someone who would agree to be with Mena for a number of nights a week in return for paying no rent. Ideally we would have liked Mena to have a housemate who shared her cottage on equal terms, but the reality of our funding situation, and the size of the cottage, did not really make that possible. But if a housemate was able to cover four nights a week, paid workers could cover two, and Margaret and I would cover one night. That would free up some funding for the daytime and make life easier for us. We also thought Mena would love it. We wanted her to have the experience of house sharing, just as most young people do in the years directly after moving out of the family home. Mena would learn about sharing the private space of others. We thought the young woman now leaving would be ideal in the role of housemate. She knew and liked Mena and they got on well. She knew the routine of Mena's house, with paid staff coming and going, and the dinner roster. She understood and respected our family values and the values we expected in Mena's house. We trusted her and knew she would keep a watch on things and come to us with any concerns.

We talked to Mena about the idea of someone living with her. We pointed out that her housemate would use the spare room, share the kitchen and bathroom, and be with her on some nights instead of a support worker, or better still, instead of one of us. We emphasised that it would not mean the house stopped being her house; she would just be sharing it with someone else. Mena was keen, ever open to something new, and her former support worker accepted our offer, agreeing to commit to four nights a week. She agreed to be home by nine on the four nights and to let us know if she was going to be late. She would not leave in the morning before Mena's worker arrived at seven. The spare room would be her private space and we asked that she be strict in policing that with Mena, so she would learn not to go in unless invited.

Mena and her housemate became very close through sharing the house. Her housemate sometimes joined in with dinner guests, most of whom she knew from her time as a support worker, but she did so without forgetting the importance of Mena being able to connect with her guests. To Mena's delight she kept her surfboard in her room and, if home on weekends, calmly closed her door to whatever else was happening when she needed some peace.

Sometimes, when we were scheduled to sleep over and there was no dinner guest, Mena's housemate would suggest that she and Mena have a 'girls night in' and offer to put Mena to bed and be there for her overnight. They were lovely, freely given times when she and Mena hung out like any other twenty-two year-olds. She would do Mena's nails and they would eat chips and watch movies together. Occasionally she would have to remind Mena that she was

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no longer her paid support worker, but her friend and housemate, whose only support role was to assist Mena to roll over in bed that night. When she moved on after nearly a year she remained firmly in Mena's life, becoming a regular dinner guest. She remains part of our extended family.

We learnt a lot from the house-sharing experience and were keen to replicate it. There was no obvious support worker that we could ask. Around that time, a small group of women around Mena's age had begun meeting with her to plan social outings. When we asked that group to think about how another housemate might be found, they suggested seeking young women from regional south-east Queensland who came to Brisbane to study. They drafted a flier and we sent them to all the local service clubs in towns within a two-hour radius of Brisbane, asking them to circulate it. Despite the brilliance we saw in the idea, we received no response.

With our brilliant strategy a failure, we went back to a more conventional approach and advertised on university accommodation sites. Almost immediately we received a response from a young Indian woman who was living with relatives while studying for a master's degree. She had no experience of supporting someone like Mena, which was a good start, and was keen to move from where she was living. When we met to talk about the proposal, she and Mena seemed to connect.

The young Indian woman was aged in her mid-twenties and had been living in Australia for some time. We knew she would need to study, and we understood that her family would want to know where she was living, but we hadn't reckoned on being subjected to scrutiny by an Indian mother. Emails passed back and forth. Would there be parties? Would there be boys in Mena's house? The family was from a four hundred year-old Indian Catholic community and her mother was not about to let her daughter be led astray. With her mother satisfied, Mena's new housemate moved in. As with the previous arrangement, we asked her to sign a simple agreement, setting out the same terms, conditions and expectations. Margaret told her about Mena, about the culture of the house, and that she would need to learn about Mena's routines and how to support her overnight, as well as accepting friends, workers and family members coming and going every day and, of course, know about the dinner roster. She readily accepted all those requirements, but had one request. She needed a pressure cooker. I had assumed all curries were cooked slowly over low heat and it had not occurred to me that whipping up a quick curry or dhal in a pressure cooker, after a long day at work or university was, for someone like Mena's new housemate, as commonplace as throwing a frozen meal into a microwave.

Over the next eighteen months the pressure cooker never had a day off. Mena's house filled with the aromas of southern India as she tried everything put in front of her. With such cultural differences it was remarkable how quickly the young woman fitted in to Mena's house. She became a loving friend and fierce advocate for Mena. She engaged with Mena's dinner guests and politely told support workers what she thought Mena needed. She came to staff meetings.

In the house she quickly learnt how to turn Mena during the night. She became used to people sleeping on the living room couch, including me. If that stretched her cultural boundaries, she never showed it.

Mena's two experiences of sharing her house were extremely positive. She learnt about living closely with someone who was not an immediate member of her family. She loved the experience of having young women in her house, who laughed and played and looked out for her. She enjoyed the freely given aspects of those periods in her life, the times when she and her housemates did girly things together, playing music, eating chips and watching movies.

Mena lived by herself, in her own home, for most of her adult life until she died in 2009, albeit with someone always present to provide support. Sometimes people say they do not want their family member with disability to live alone, offering it as a reason to opt for a group home or institutional living. But that is living with others who are not chosen by the person with disability and supported by people who work for a service, not the person. Mena did not live with someone in an intimate way, but she lived in a place of her own over which she had control. With the network of friends, dinner guests and other visitors, she was never actually alone and never lonely. As Margaret once put it in an article about our experience, by supporting Mena to live in her own home, we were giving her wings to fly.

Margaret and I often reflected that creating and sustaining a home for Mena – a home of her own – was the most important thing we could have done for her. She glowed with the love of her own home, where she felt in control, in her own space, safe and secure.