

The story of Mary and Jan

In which a humble woman meets a passionate woman and they build a life changing relationship.

'So many shitty things in her life and she never complained.'

Imagine living in solitary confinement in a dirty horrible little flat, without food, lacking medication for your chronic physical and mental health, with a phone that you never use, a shower you never take, a stove you never turn on, a fridge that never has any food in it, and completely alone except for some locals who come and bludge your cigarettes and some children who taunt you. Your pleasures are a few cigarettes a day, a cat and the television.

Surely you think, 'this is someone who does not have services, family or funds.' Sadly, you would be wrong.

When Jan met Mary, a woman in her 50's, she was cut off from every good thing that we expect people to enjoy in our community. Jan thought she was meeting someone who was lonely and would like a semi-regular outing for coffee and a chat. She thought she was meeting someone who used public transport and got out and about. What Jan discovered was that Mary, whilst conversationally adept and literate, was unable to take basic care of herself and was completely neglected. She was underweight because she did not get enough food, she was filthy and unkempt, her old clothes covered with cigarette burns, she had not attended a medical clinic for 18 months or a dentist for over 10 years. Everyday she was having epileptic seizures and falling and hurting herself. She was afraid to leave the house and repelled the few people who ventured to her door. Although her parents had died she had a brother and a nephew who never visited, staying away in resentment that she had been left any money by their parents.

The full extent of Mary's vulnerability emerged one day when she proudly showed off some shoes brought in a recent shopping trip with her 2 hours per fortnight support worker. The shoes were the wrong fit and when Mary removed them her toes were revealed to be gangrenous with long horn like nails gouging her decaying flesh. No wonder she limped. The doctor, who had written letters but never followed up on Mary, was so distressed by this level of neglect (and most likely guilty for her own negligence) activated the services system to respond to Mary. Jan says: 'services fell out of the sky', but Mary had to pay for them as the services squabbled over responsibility.

It was here that Jan discovered the scale of connection to bought services that took no responsibility for Mary at all. She had a large sum of inherited money held by the Public Trustee who meted out small amounts for cigarettes and supposedly paid for food and clothes on a voucher system and a cleaner who did nothing because she 'had a bad back'! The Guardianship Board charged with responsibility for medical and other life decisions had not monitored her health needs for years. The Housing Association (who had 'referred' Mary to citizen advocacy) had not arranged for

protection of amenity or basic repairs. The disability support service did nothing to improve Mary's quality of life. Further investigation revealed that 2 large state service providers had determined she did not meet their selection criteria so she had fallen into a gap. Eventually Jan saw Mary's 'official' file that had been opened when she lived in institutional care from 12 years old following the death of her mother. Her 'case' had not received any attention for almost 30 years.

Some time later when Jan asked Mary why she did not complain about the pain in her body, Mary looked at her blankly. Jan concludes that Mary thought that pain was just her life.

Getting the services system to take responsibility was a real strain, but it worked.

All this was revealed within about 4 months of the Citizen Advocacy program matching Mary and Jan. Jan reports that it took another year for the services to start cooperating and looking after Mary. During that time Jan wrestled everyone to get a response, to be accountable, to intervene in a way that would open up Mary's life, protect her health and her cleanliness. There was always room for improvement but over time Mary was assisted to eat well and she put on weight. She was clean, the chiropodist boasted that she had the second best feet (apparently the chiropodist's feet were perfect!), repairs were carried out on the house, the cleaner cleaned, and Mary's health was checked and monitored. Despite Jan's best attempts money was never made available for Mary to go on a holiday or to get some smaller pleasures such as Foxtel connection. Much more could have been done to bring her joy. However, the support service started to work very well with Mary. One worker from the support service became a firm ally in her life, a 'rock' who took Mary home on public holidays and to spend relaxed time with Mary.

Between them Jan and the worker were able to identify when things were going wrong for Mary. Mary still did not speak up for herself at all, but at times she would present another Mary who was angry and swear most inventively. Mary and 'The Other' would wrestle for space in the conversation and The Other would sometimes triumph, presenting with accusation and hostility. Jan and the support worker slowly came to recognise that this mental state indicated active stress and anxiety in Mary's life, sometimes triggered by concern for the cat, at other times apprehension about medical appointments. Over the 4 years that Jan was connected to Mary she saw The Other appear less frequently and with less intensity and insertion.

It was hard having this relationship but I was always glad when I persisted.

If Jan's contacts with the various services were not always satisfying, as her common sense, decent questions to the service providers provoked shame about being exposed as so neglectful, and they reacted with various justifications, barriers and excuses, her relationship with Mary was not always easy either.

Mary had spent so much time by herself with a deteriorating mental and physical state she found it hard to be hospitable. At high points of stress, The Other, her alternative voice, directed Jan to leave, at other times she was afraid. In the first year of their relationship Jan escorted Mary to many medical appointments that often

required uncomfortable and intrusive tests. It was as though Mary associated Jan with this discomfort and pain. The persistent Jan identifies a turning point when Mary, who could write beautifully, started to make notes as a reminder to discuss an idea or something on TV. She not only expected that Jan would appear but she started to look forward to it and to plan for visits. She also started using her phone (for the first time ever) to ring Jan to tell her things and make arrangements. Jan was still never sure what reception she might receive if Mary or 'The Other' were most in evidence, but over time they learned how to enjoy being together, especially if they went out together.

Mary's lasting pleasure in life was smoking cigarettes. She was often subjected to controls about it (along with the neglect of other needs) – with cigarettes limited, not being allowed to smoke when workers were in house, and compelled to hide the evidence. All her spare (and sometimes not spare) funds were devoted to the purchase of cigarettes and she grew to distrust everyone who didn't smoke because they would try to stop her. Jan recognised this early on and never tried to stop her, she revealed that she had been a smoker too and one day might just come around for a cigarette herself! This was a key to building trust and the little conspiracies that build intimacy.

Perhaps the most poignant conversation that Jan recalls relates to a pact they made about post-death plans. Mary initiated a conversation in which they revealed their funeral plans. Mary, who did not like fire, expressed a strong desire for burial and Jan agreed that if Mary died when Jan was still alive she would let the family know.

When Mary died four years into their relationship, the formal services did not alert Jan, they said they did not have her phone number. Mary's brother's resolve to go with the cheaper option of cremation was acted upon and they refused to comply with Mary's wishes.

So, even in death, Jan had to advocate for the simple recognition of Mary as a person whose wishes and memory must be respected. Jan did however manage to convince Mary's nephew to accede to her desire to speak at the funeral. She explained that she was the only person in Mary's life who was not paid to be there and that they had grown very close. His initial reaction was along the lines of 'why would you bother? She was a nothing person.' After hearing Jan's words his reaction was different, his early childhood impressions held in place by the distance that his father had kept transformed, and he said 'I had no idea'.

Jan was devastated by Mary's death but at her funeral was able to talk about her with deep appreciation, to acknowledge her love for her cat and her cigarettes. To retell how she would always introduce a conversation with an enthusiastic Guess What! Jan said 'she had such a zest for life that I have never seen in someone with so little. She would make the smallest thing exciting. It was exciting for her, she could pass it on, and it was contagious. She was a lovely woman who never complained. And that's pretty much it.'

What does the story of Mary and Jan tell us about Citizen Advocacy?

So far this account has focussed on the way that Jan discovered what was really (not) happening in Mary's life and set about changing things for the better. It has looked at how a close relationship grew between the two women as Mary learned to trust and to enjoy the company of another. We have seen how Jan learned the necessity to look into the real life conditions not just think everything is OK because the person does not complain. This was an awakening about unmet fundamental need and the extent of vulnerability in Mary's life. Shocked by her discovery that in this day and age and within our communities of plenty individuals can live like isolated, overlooked paupers, Jan's gentle passion was translated into the value of persistence.

She quietly reveals that she had to 'do' many things for Mary, like attend the doctor, argue with all the service providers, buy coffees when they were out, arrange for repairs to the fence, advocate for her needs to be the focus of all those paid to support her, ensure accountability from all the services and so on. Throughout this whole period she persisted with visits even when Mary was not welcoming, constantly looking for signs that the trust was building.

When asked to reflect on Citizen Advocacy Jan says that its value lies in number of vital areas. First, the program makes a deliberate match. Jan is a woman with a strong sense of responsibility to her family and generally to the community. She has a wide life experience and an easy, amused manner. She knows what it is to live with physical pain and restriction. Jan was open to having a relationship with someone like Mary but it deepens as she begins to see the reality of Mary's life. She understands why this is primarily an advocacy relationship that is kept free from conflicts of interest. Jan is very clear that because she was not paid to be there she was set free to do what was required, there was no point when she could say, it is not my role to care about this.

Jan also stresses the value of the assumption that the community is good. Her discovery that this work is carried out by ordinary, decent people who can see that things are not right and are prepared to do something about it is 'wonderful'. Her fellow advocates are not discharging a religious commitment or being do-gooders but are simply motivated to be community members looking after other community members. For Jan, to be part of this movement is this is both humbling and uplifting.