

# Acts of Love

## Vivienne Thomson

As a mature woman facing her future without her husband, without many of her friends or family nearby, Flossie felt somewhat stranded. She'd managed to get along living alone over the last two years since her husband died of cancer but it wasn't how she'd envisaged her life. She always thought she would go first and her husband had planned to live into his 100s but it wasn't to be. Now she felt at sea without him there as her rudder and reference point. She felt a bit down thinking about the prospect of what lay ahead. The roof needed fixing, the fridge was on the blink and she'd soon need a new sofa because it was now too low and difficult to get out of.

She was sick of cooking and had lost all enthusiasm for creating nutritional and interesting meals for one. She felt justified having an egg in the cup as she had cooked over 20,000 meals in her life so far – that was enough. She couldn't see anything appetising in the fridge other than a package of snapper which she quickly pan fried and ate with a lettuce leaf. She put the jug on the stove to boil, made herself a cup of tea and went to bed.

The next day her closest friend Barbara dropped by to see her. The door was locked. Barbara couldn't let herself in. After a long time knocking Flossie eventually opened the door. She looked dreadful, dishevelled and aged. She'd been up most of the night being sick. Seeing the need, Barbara pushed her way in immediately taking charge. She went to the kitchen to make Flossie a hot drink and found the kitchen in a mess. Dirty dishes piled up in the sink, the plastic jug sitting on the stove blackened from smoke and melted onto the element. Sensing something was amiss Barbara asked Flossie what she'd had for dinner and found the empty wrapping from the fish – it was one month past its use by date. She looked in the fridge which was empty except for some wilted vegetables, stale milk and a musty mouldy smell.

Unaware of the mayhem in the kitchen Flossie walked around the living room agitated, saying she'd got a lovely letter from a friend that she wanted to reply to but couldn't find it anywhere. Barbara looked at where Flossie normally left her mail and held up an

envelope. “You mean this one?” Flossie was dumbfounded. “Where was that, I’ve been looking everywhere for it.” Being a similar colour to the timber shelf the manilla envelope blended in. Next to the letter was a pile of bills. A worrying thought stirred in Barbara. She decided she would call in on her way home to see a neighbour Paul, a central person in Flossie’s network.

Paul was a big bear of a man, gentle, generous and happy. He enveloped Barbara in a hug and offered her coffee and a big chunk of home-made orange cake.

Barbara: *Have you seen Flossie recently?*

Paul: *I've been meaning to ring you. I saw her yesterday driving home from the shops. She was all over the place. She backed out of the parking space, bounced over the curb and barely stopped at the intersection. Then she pulled out right in front of another car that had to swerve out of her way. They drove off tooting angrily at her but she carried on seemingly oblivious. I know she's never been the greatest driver and her car does have a few dings but she's a menace on the road and shouldn't be driving. I think I'll suggest I take her car for a service. It's got a few things that need doing that I could look at. That would keep her off the road for a bit.*

Barbara: *Oh boy, I've just come from her place and I must say I am worried. I think she's given herself food poisoning from eating fish that's off and she's put the electric jug on the stove to heat it up so it's all melted – she could easily have started a fire. I'm wondering if it's safe for her to be alone.*

That afternoon Barbara rang Flossie’s doctor for advice. He said he had the power to revoke her licence but would need to see Flossie to make an assessment. They made an appointment for the next day. Barbara returned to Flossie’s place to stay the night and prepare for what might come.

In the morning Flossie had got herself dressed and appeared for breakfast. Barbara looked at Flossie. She was wearing her nightie with a nice bright blue top that had food stains all down the front, shoes and socks and no trousers. It was a shock to register that Flossie had not managed the basic task of getting dressed and confirmed Barbara’s fears about Flossie’s state of health. Barbara

took this in her stride and quickly redirected Flossie saying it was cold outside and suggested they go and find something more suitable for the weather. Flossie went along with the redirection and accepted Barbara's guidance getting changed into a new outfit.

Over breakfast Barbara talked about what Flossie might need to talk with the doctor about. Immediately Flossie launched into a tirade about the doctor being a quack, that he was not trustworthy and that he had a team of people around him to back him up. None of this made sense to Barbara so she changed the subject to avoid escalating any difficulty getting to the doctor.

She said she'd been to see Paul. Flossie cut her off saying he wasn't to be trusted either and that he was in cahoots with the doctor, he had stolen her car and she had been lucky to escape after he'd held her hostage for three weeks. Barbara knew then that Flossie was not in her right mind. She listened without challenging, contradicting or correcting and prepared herself for a more extensive consultation with the doctor.

When their husbands had died Flossie and Barbara had had some heart to heart conversations and with the consent of their children had set themselves up to have enduring power of attorney (EPOA) for one another for both health and welfare as well as property and finance. They both owned their own houses and had investments so they let each other know where their important documents were and how much they valued being able to live out their lives in their own homes. They'd discussed what they wanted for their end of life care including a 'do not resuscitate' request, noted that they wanted to be organ donors, then laughing heartily at which particular organs might actually benefit someone or might even lead to a remarkable scientific breakthrough, they updated their wills. Although difficult conversations to have, it felt good to have all these matters sorted and it had brought them even closer to each other.

Barbara was now relieved that the EPOA was set in place as it was obvious she would have to ask the doctor to activate her as attorney for Flossie and find someone else to have EPOA for herself.

Flossie was reluctant to go to the doctor but couldn't or wouldn't fight her friend. In the waiting room Flossie asked repeatedly what they were doing there and why she needed to go to the doctor. Barbara did not explain or give too much information. Her main intent was to reassure Flossie about the need to get the all clear from the food poisoning and a clean bill of health. She wanted Flossie to

feel secure and that what was happening was in her best interest.

In the doctor's consulting room Flossie pouted and complained and was generally uncooperative. Despite this the doctor managed to conduct some sort of cognitive test and sent Flossie out to get a urine sample which might indicate a urinary tract infection that could be the cause of some of the difficulties Flossie was experiencing. Having Flossie out of the room gave the doctor and Barbara an opportunity to speak in private. He made it clear that Flossie was exhibiting signs of vascular dementia and spelled out what the stages were, what symptoms to look for, what to expect and plans that needed to be put in place. He said in most situations behavioural changes were noticed only after many years so it was likely that Flossie had already had dementia for some time. He also gave the statistic that life expectancy from that point was three to ten years.

Barbara cast her mind back over the past 10 years. Could she recall symptoms that might have indicated anything? Had she missed things she should have picked up on earlier? She could identify occasions when Flossie had forgotten things but nothing really significant or more than anyone else. But she had been in denial. She had minimised the things she had noticed. She didn't want to think of her friend in any way diminished from her intelligent, lively, engaged self but the truth was that Flossie had been confused, had been forgetful and couldn't do some basic tasks. Flossie had been coping and so had she. Facing up to the facts required guts. Barbara knew she had what it took to face into whatever was ahead.

The doctor gave Barbara resources and contacts for her to follow up. He said he would email a health practitioner's certificate assessing that Flossie was mentally incapable to make decisions. He also drafted a letter revoking her licence.

Within the space of twenty minutes Barbara's (and Flossie's) life had been set on a different course. Barbara had to pull herself together before facing Flossie who was sitting vacantly waiting to be taken home.

Barbara contacted Flossie's family to let them know the situation. Of course they were dismayed and concerned but also very supportive. They were a hundred percent behind Barbara and whatever she felt was necessary to do. They would do anything to help. They agreed that Flossie's car should be sold.

Barbara arranged for Paul to take the car to an auction yard. This

was a significant milestone in Flossie's loss of independence. Flossie's confabulation about Paul and the car came as a bit of a blessing as it meant Flossie's paranoia was focused on Paul rather than Barbara. Barbara had heard that people with dementia could quickly and easily turn against the people closest to them and that was something she wanted to avoid if possible. The car was sold. Flossie continued periodically to say she couldn't find her car keys and gradually she forgot about Paul.

Considering the options that would ensure Flossie's quality of life, Barbara explored a local retirement village. She clarified it was not an option as given previous discussions they'd had about retirement villages Flossie would experience it at best as a prison sentence and most likely result in her premature death. Personalised home care was expensive and difficult to organise so also not a viable option. There was a facility in Bali that met all requirements – good staff, all health issues covered, reasonable cost, beautiful setting but the geographical dislocation also not an option as much for Flossie as well as her family and friends. Barbara was left with a final resort – she could move in and become Flossie's primary carer.

Barbara was methodical, rationally weighing up the pros and cons. They were both widowed, were living alone in big houses, they liked each other, they had many shared interests, they liked the same music. The arrangement could be good for them both. Barbara considered the best and worst case scenarios and the reality of what she would be taking on. She was cognisant of the legal, financial and health responsibilities she was committing to and thoughtful about the impact on her. After talking with her own and Flossie's family Barbara concluded that the best option for everyone was that she would move into Flossie's place. Flossie was a bit surprised when Barbara offered to move in with her but she liked the idea and so it came to pass.

It was an easy transition for them both and after settling into everyday life Barbara took stock of her priorities as Flossie's primary caretaker. With the help of the local needs assessor, GP and health provider she established a routine that they could manage: Personal alarm in place; a clock which Flossie loved that displayed the time, date, day, medication; breakfast 8:30am; twice a week personal cares with carers from a health provider which included showering, dressing, making her bed at 9:30am; morning tea; lunch; afternoon tea; dinner; preparing for bed. The days passed with walks, picnics, playing duets with Flossie on the piano accompanying Barbara on the flute, reading, hobbies. Life was relatively simple and everyone

was happy. Several months passed with this workable routine.

Then one day throwing the bread out to the birds Flossie suffered a heart attack. She didn't register at the time but returned to her room and lay down. The first Barbara knew was finding Flossie lying on her bed uncomprehending and unable to move due to an excruciating pain on her side. Barbara called the ambulance. Five hours later it arrived. Flossie would need to be hospitalised for an assessment.

The nurse couldn't find Flossie's veins. After multiple attempts, the bruises swelling on Flossie's arms, hands and feet, the phlebotomist was called. After an ECG, a series of x-rays, a CT scan, an MRI it was another 12 hours before Flossie was finally admitted as a patient. Yes, she had definitely had a heart attack but the doctors also suspected fractured vertebrae or possibly gallstones. Exhausted, Flossie was admitted to the orthopaedic ward. Barbara asked if she could stay what remained of the night and was directed to an unused family room next to Flossie's ward. She fashioned herself a bed using some chairs, pillows, sheets and blanket. This would be her room for the next five nights. At 7:30am the cohort of specialists arrived with their clipboards and questions. Barbara was ready for them, Flossie wasn't. The orthopaedic doctor was first in. He introduced himself and proceeded to gather information he needed.

Doctor: *Does this hurt?*

Flossie: *Ow.*

Doctor: *What about here?*

Flossie: *Yes.*

Doctor: *...and here?*

Flossie: *Not as much.*

Doctor: *Have you ever had a fall?*

Flossie: *No.*

Doctor: Is there a history of osteoporosis in your family?

Flossie: *No.*

Doctor: *What medication are you taking?*

Flossie: *Nothing.*

Some of those answers were true.

He went on to say: *You don't have anything we can help you with so you really shouldn't be in this ward.*

Barbara (and Flossie) were a bit on edge with the orthopaedic doctor. His only focus was on her bones and the workings of various body parts disregarding the fact that all were part of an actual person with thoughts and feelings. Barbara observed that his preoccupation with the anatomical, left no room for anything personal in his bedside manner. She had a private thought that there wasn't much hope that the troupe of trainees hanging off his every word would ever learn the significance of the doctor/patient relationship in the healing process.

The barrage of questions continued with the Needs Assessment that followed – a set of questions designed to determine a person's cognition and memory.

Nurse: *I'm going to say four things and see if you can remember them when I ask you later: train, watch, ball, horse.*"

Flossie hated being questioned probably knowing that she would never be able to remember. She would play the game but not have any idea that some of her answers would count against her in these tests.

Nurse: *Can you see how many mammals you can name?*

Flossie: *Cat, dog, cow, kapibara...*

The assessors two young women one from the Philippines and one from Sri Lanka, both with just enough English to get a job, gave each other a knowing look. Barbara caught the non-verbal exchange and realised the assessors didn't have a clue that a kapibara was in fact a mammal and not a figment of Flossie's imagination. She put them straight.

Nurse: *What's your daughter's phone number?*

Flossie: 3.

Again Barbara knew this would not look good on the assessment. She informed the assessors that all frequently used numbers on Flossie's phone were on speed dial so Flossie's answer was in fact correct.

Nurse: *What time is it on a clock when the big hand is on nine and the little hand on three?"*

Even knowing that a symptom of dementia was a loss of the concept of time, Barbara couldn't hold back her comment about "who uses an analogue clock these days?" Acknowledging the assessors disapproval of her input, she left Flossie and the assessors to their work.

Nurse: *Who's the Prime Minister? What's your address?...*

A month later Flossie was discharged with no diagnosis and a prescription for oxynorm, betaloc, aspirin, colecalciferol, paracetamol, omeprazole and laxatives to counteract the effects of the other medications.

Barbara felt her own loss at being able to influence the practitioners in the health system who were focused almost entirely on the physical dimension of their patient. By extension, Barbara felt her friend's experience. While most of the time she was happy, Flossie would often look to Barbara for validation. Flossie knew there was something not quite right but could not grasp it. She would cry not knowing what she was crying about but upset by the experience and her knowing incomprehension. Barbara verbalised this and the experience of distress. Flossie thanked Barbara saying she felt calmer hearing that. On one of these occasions she observed, "You are made differently to me. Are you from a different planet?" That made Barbara cry as she felt the alienating effects of the disease. She wanted to do whatever she could to alleviate the effects of it. Not a fan of drugs herself, Barbara wanted to see if Flossie could convey whether she thought it might be worth seeing if anti-depressants might help. She let Barbara know that she trusted her and whatever she thought best. A low dose of escitalopram was added to help with Flossie's depression.

For Flossie, swallowing large pills was a problem, as was the taste of the liquid version of the pills, and the accumulative effects of the drugs on her digestive system. Barbara established a routine of cutting and organising tablets. After advocating for Flossie's quality of life and with the support of Flossie's GP she also managed to reduce and eliminate the need for some of the prescriptions.

The new routine included additional carers. Barbara had signed up with a health provider and after rejecting a number of people who did not demonstrate they could be trusted with the care of her frail

friend, she found several carers who did and was lucky enough to establish regular shifts with them. One of them in particular was the perfect fit – she had a sense of humour, was gentle and thorough, was efficient at making the bed and ensuring Flossie's room, clothing and toileting supplies were well organised. This carer had previously been a physiotherapist and her experience enabled her to do a number of things that assisted Flossie. On her arrival, the first thing the carer would do was smile and engage with Flossie. She would sit right in close, give Flossie a big hug and show interest in her. She was always positive and for the time she was in her presence genuinely engaged.

Flossie and the carer looked forward to spending time together. The carer brought her cat to visit which Flossie loved. It reminded her of an earlier time in her life when she'd had two cats who had been a comfort to her.

The carer was in awe of what Flossie had done in her life and, as she came from a different culture, looked forward to learning what she could. Flossie came alive with the attention and was thrilled to be able to educate her carer or share things that would delight her. Over a period of time it was clear that both the carer and Flossie loved each other. As their intimacy developed Flossie was often confused and she wasn't sure whether the carer was in fact her lover. The carer was skilled and professionally appropriate and never took advantage of this. They spent time admiring the flowers and butterflies, singing songs, sharing personal stories, taking turns to say something to make the other giggle and they would laugh out loud as they walked together around the garden. The sight and sound of this was music to Barbara's ears. One evening Flossie said, "I think I'm the happiest I've ever been."

Over the next few years people commented to Barbara about how patient she was and reminded her that being with someone with dementia was often referred to as "The Long Goodbye". Barbara however did not share these views. Instead she recognised in herself that if she felt like she was having to be patient or that she had become impatient, she was relating more to her own interests or agenda than Flossie's. From the moment she agreed to be Flossie's EPOA and had it activated, Barbara made a commitment to be alongside her friend.

As for the long goodbye, Barbara did note the gradual decline in Flossie's health and the continuation of losses and the consequential impairment and dependency for Flossie, but she didn't relate to

Flossie as someone who was disappearing – she was her closest friend and when she was with her, she was entirely present and focused on being with her. Barbara remembered a line from the play *Witi's Wāhine* that had inspired her, “Her mind had gone for a walk and she had followed.” Barbara had chosen to accompany Flossie on her walk.

Thinking about what she knew of dementia and its common symptoms reminded Barbara of the stages of child development except this was in reverse. She knew that each person displayed different symptoms and progressed through stages at different rates but things she had noted were that:

- ◆ Flossie now found it hard to play the piano as every time she looked at her fingers as she played the notes she lost her place in the music.
- ◆ Flossie’s use of nouns disappeared first to the point where Barbara was no longer sure whether Flossie even remembered her name. In most interactions as Flossie increasingly communicated in partial sentences, Barbara would search for connections trying to second guess or interpret what she was talking about.
- ◆ Flossie was not able to keep up with discussion or quick changes of topic resulting in her withdrawal and loss of interest in socialising. Except for her daily contact with her daughter that she looked forward to, phone calls were almost impossible with the dislocation of a voice and no visual reference for her to make sense of the conversation.
- ◆ Flossie couldn’t distinguish between fantasy and reality or separate her own from others’ experience. Barbara often had to explain that what was on television wasn’t actually happening and she became more careful about what she shared of her own experiences as Flossie would often identify as Barbara and assumed Barbara’s experiences as her own.
- ◆ Flossie would become overwhelmed and needed guidance and structure or limited choices. Instead of asking Flossie what she would like to do, Barbara would give her a couple of options to choose from e.g. “Would you like to go on a picnic or visit an Op Shop today?”

- ◆ Flossie tended to be more self-absorbed and decreasingly aware of or sensitive to others. She would sometimes say and do things that were uncharacteristically and unintentionally brutally blunt or offensive.
- ◆ As her physical ability and motivation declined Flossie gradually stopped doing things. She no longer read or engaged in her hobbies and would sit passively either looking into the middle distance or nodding off. In an attempt to stimulate Flossie Barbara dreamed up simple and playful activities they could do together. One of these was painting which Flossie had never done before and needed a lot of cajoling to get started. Being new to painting herself, Barbara was very upbeat and encouraging. They covered the dining table with a large cloth, arranged the paints, paint brushes and other tools Barbara had made out of straws and earbuds and donned oversized men's shirts to cover their clothes. They decided to paint a field of sunflowers. Barbara squeezed the paint onto the canvas showing Flossie how to make the brush strokes and build up the picture. It was clear it was difficult for her to co-ordinate ideas, imagination, physical hand movements to produce a picture on a blank canvas and it was messy. The result however was very pleasing and in the end Flossie accepted it as her work and appreciated the compliments it generated.
- ◆ Flossie experienced increasing bouts of incontinence which was a major embarrassment for her and created a fear of being caught short. She no longer wanted to go out or be too far away from where she knew there was a toilet.
- ◆ Flossie had increasing hallucinations and experiences of being disoriented. There were times, particularly with the changes in daylight when Flossie would think she was in another room or time or place. At night she would ask for help to find her bedroom upstairs when she had only ever lived in a single level house and this current one had been her home for more than 30 years. Depending on Flossie's mood Barbara might say to her, "I'll take you to the stairs." and she would help her. As Flossie walked along the flat corridor she felt as if she was going uphill. By the time they reached her bedroom Flossie would say. "Here we are."



Flossie's painting of sunflowers

and as she got into bed commented, “I thought I was in another place”. Barbara asked her did she know where this other place was. Flossie asked, “Did this place used to be a school?” “No, what makes you ask that?” “Because there are so many rooms and different people sleeping in them.” It was taxing for Flossie to try and find her way through these realities and she was content to climb into bed feeling warm and safe. Barbara’s interpretation was that Flossie was relating to a memory of her old school which was a two storey building where there were boarders but that wasn’t the point; she was pleased that Flossie wasn’t agitated and was happy to get into her bed.

As Flossie became more incoherent and dependent Barbara recognised that she needed to be increasingly attentive, noticing and anticipating Flossie’s needs, motivations and desires.

Ultimately Flossie drifted into unconsciousness. At that point she was moved to a health facility. Barbara organised a roster for friends and family and Flossie’s beloved carer to spend time with Flossie. When she was with her Barbara would hold Flossie’s hand having a one way conversation with her, reminding her of their shared experiences, playing her favourite pieces of music, letting her know about the weather and what was blossoming in the garden. She made sure she was physically comfortable, she brushed her hair and kissed her good night. Two weeks later Flossie died in the early hours of the morning when the cold crept in.

After this Barbara needed time to adjust, to re-orient herself, to shift her focus back to the living. When she reflected on her experiences of being Flossie’s carer she felt thankful and satisfied. She knew she had made a difference in Flossie’s life. She had done everything she could to fulfil her responsibilities as her primary carer. She felt the difference Flossie had made in her life. Because of Flossie’s dementia Barbara had been stretched to constantly remain in the here and now, to relate to her friend’s experience and the immediacy of her emergent expression and needs. She also had to remain conscious of their social context, their intimate friendship, and her responsibility for Flossie’s well-being. Barbara felt she had grown from the experience and had learned a lot from being alongside Flossie over these years. Entering Flossie’s world had felt like a privilege. Barbara concluded that as a result both of their lives had been enriched.

## Author's notes

I don't profess to know a lot about dementia from a medical perspective but I have had experiences with a number of people who have been close to me who have been diagnosed with one form or another of it. The people and account of events in this story are fictitious however the content is based on actual events and experiences in my life. I would like to thank Alison, Betty, Bobbie, Brigid, Charlie, Dale, Jane, Judith, Marilyn, Mary, Sister Katherine, Peter, Trevor, Walter, Warwick whose dementia enabled me to have some extraordinary experiences in my relationship with them.

I have had a long term interest and involvement in the field of aged care. As our population ages the incidence of dementia increases. In New Zealand aged care is one of the lowest paid areas of work and typically staffed by immigrants. The allocation of financial and other resources falls short of what is required. Typically the workload of carers is excessive, the job demanding, often involves a lot of travel, and the hours of work and conditions unattractive. As a sociodramatist I wonder what might be required to address the inevitable problems ahead in this area of work as the proportion of older people in our population grows. For many of us facing into the last phase of our lives, the questions relating to how our own health and well-being will be sustained become more immediate. I have written this story as a celebration of the work and people who are committed to creating satisfying and meaningful relationships with older people and their vulnerabilities.

I would like to thank the people whose friendship and services I have relied on – Chihoko, Dahlia, Geraldine, Isabel, Julia, Lindsey, Lyn, Maninder, Margaret, Michael, Terry, Yashoda. Their capacity for kindness, interest and love was a source of inspiration that not only assisted the people with dementia but also myself in relationship with them. And my special appreciation to my sister Annie who has been the best double I could have had.

For me this story and my experiences are tangible, living examples of Moreno's spatial-proximity hypothesis ..."that the nearer two individuals are to each other in space, the more do they owe to each other their immediate attention and acceptance, their first love." (Moreno, p.xx) and the principles that guide us in our applications of psychodrama.

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Vivienne Thomson Sociodramatist and Trainer Educator Practitioner. I am a third generation New Zealander with a close knit family that I value for all its delights and challenges. I live on Waiheke Island off the east coast of Auckland where I am enjoying rejuvenating my garden. I have been involved in psychodrama for over forty years about the same length of time I have worked as a consultant engaged in organisation development. One project relevant to this article was providing training for the legal services of Age Concern NZ to prevent elder abuse and neglect and developing a resource for the preparation and establishment of enduring power of attorney.