



Royal Commission
into Aged Care Quality and Safety

Statement of Elaine Maree Gregory

Name: Elaine Maree Gregory
Date of birth: [REDACTED] 1960
Address: Known to the Royal Commission
Date: 25/7/2019

1. This statement made by me accurately sets out the evidence that I am prepared to give to the Royal Commission into Aged Care Quality and Safety (Royal Commission). This statement is true and correct to the best of my knowledge and belief.
2. The views I express in this statement are my own knowledge, except when they are based on information I have received. Where I rely on information, I believe that information to be true.
3. Where direct speech is referred to in this statement, it is provided in words, or words to the effect of those, which to the best of my recollection, were used at the time.

Background

4. My name is Elaine Maree Gregory. I am 59 years old. I live in Mildura, Victoria.
5. My 97 year old Mum, Erna Mead currently lives in residential care at Princes Court Homes in Mildura. Mum went into care in May 2016. Prior to this, I was her full-time carer.
6. In 1945, after the war, Mum and my Dad, Bob Mead met at a local dance. Dad was a war veteran. He had spent 5 years in the Solomon Islands. In 1912, my Dad's family bought the family farm in Walpeup. My brothers still run the farm now. Walpeup is about 130kms from Mildura. I was always close with my Dad.
7. I attach a photograph of Mum and Dad to this statement (EGG 0001.0001.0002). The photo was taken in December 2005. Dad was dying of leukaemia at the time. It was his last Christmas.
8. In June 2004, my Dad was diagnosed with lymphoma. In October 2004, Mum and Dad decided to move to Mildura from the farm to be closer to medical services.
9. Mum and Dad lived in Mildura for 12 months together before Dad died in 2006.
10. Mum has always been hard working. Mum had her own garden and was hands on with things at the farm. She was involved in the community with things like Church

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Guild, Red Cross or arranging community get-togethers. Mum even hand-raised an injured kangaroo. Mum always took care of us.

11. After Dad passed away, I wanted to make sure someone was always with Mum. For the first 6 weeks after he passed away, one of my daughters would sleep at my Mum's house during the week. On the weekends, my other daughter would sleep there. When I first became Mum's carer, I feel like the role was thrown on me. Mum and Dad always looked after each other but when Dad died, Mum was lost. There wasn't anyone to help her. I have siblings but they were running the family farm, lived away or weren't involved. Mum lived next door to me so I just took on that role. I had four children living at home at the time. They were all teenagers but I just had to make it work. There was a couple of times I nearly cracked with all the pressure, but I knew if I wasn't going to care for my Mum, then no one was.

Day to day role as a carer

12. As a carer you don't think you are doing a lot, but it's often the small things that build up. Each morning, I would go next door and check on Mum. I would do things like fix the lightbulbs, do the shopping, take her to appointments, do her administration work and make phone calls on her behalf. It took me a while to realise that it's a full-time role. Mum liked going out during the day but a trip out could take up your whole day.
13. Sometimes I get help from Sunassist to get Mum to appointments or to take her on outings. Sunassist is a great volunteer program that helps to take care of older people here in Mildura. However, when I first started helping as Mum's carer, you could only use Sunassist once a week.

Impact of caring role

14. Caring for Mum impacted my ability to work. When I started caring for Mum, I was no longer able to work with my husband at our mowing and paving business. I couldn't go to jobs because I had to take Mum to appointments or do other things. It got worse as Mum's health deteriorated.
15. Being a carer is pretty tiring at times. I didn't realise the stress or the anger I felt. I would find myself thinking "Oh my god I can't even do anything for myself for five minutes". It was constant. I was always busy and felt on the edge. I couldn't just pop down to the farm for a visit. I always had to have my phone on me in case I would get a call. Someone always had to be there for Mum. If it wasn't me, then there was no one.
16. It was frustrating because a sibling lived an hour away but didn't help. They didn't think they needed to do anything.
17. I still do the running around now even though Mum is in full-time residential care. It takes a toll on you. Even though Mum is in full-time care, I still have to do a lot of things that the home don't do for her. I might be there a couple of days in a row, mending or washing her good clothes, buying groceries or things to have in her room, taking her shopping. I am lucky because my brother handles the financial side of things.

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Elaine Gregory

Witness

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Navigating the aged care system

18. When I first started caring for my Mum, I felt like there was no pathway I could follow. I felt like I was thrown in the deep end and had to work everything out for myself. I didn't know anything about what services were available to her, let alone for me.
19. Figuring out all the paperwork took time. Nothing was easy. The organisations don't communicate with one another. I would ring up Veterans Affairs but they would tell me to call Centrelink. Centrelink would tell me to call Medicare. It was never ending. The system would be much easier if it was a straight line centralised service. Services should be proactive in helping to complete the paperwork.
20. Unless you make the phone calls and chase things up then things don't happen. Mum would go to the GP monthly, but the GP wouldn't give us any advice or guidance. Simple advice like "why don't you try a support group" or "access this or that service" would have made such a difference. I felt like I was going in blind. I just wish GP's would give you more advice. Having to work everything out myself was difficult.
21. ACAT would come and do an assessment but they wouldn't sit there and tell me what was happening with Mum. Mum made sure the house was clean and she would say she was fine when the assessors visited. They didn't see that I was the one doing everything for her. They don't ask how you're going or if being a carer was taking a toll on you.
22. About twelve months ago, my mother-in-law was put into a home. It was easier for my sister in law because I guided her and told her what to do next. Having guidance and support is incredibly valuable.

Support Network

23. The worst thing with the aged care system is that you're constantly reaching out for support or guidance without anyone asking if you need a hand. It wears you down.
24. I had been caring for Mum for about 12 months when I decided to look up the number for a carers support group. I knew I needed to get myself some help. I had started feeling like I wanted my Mum to pass away so I could take the pressure off and have my life back. I knew that wasn't the right way to look at things so I reached out for help.
25. I got in touch with a carers support group. I can't recall if the group was run by Carers Victoria or Bendigo Health. At the time, I was helping Mum with everything by myself. I started going to the support group meetings because I just needed support. This taught me how to take care of myself and to consider the impact being a carer was having on me. I was going to the meetings quite a lot. I was one of the younger ones. I ended up stopping because everyone talked about caring for a partner. I felt I wasn't getting anything out of it.
26. My daughter worked in Aboriginal Health Services and was able to help me get Mum assessed. She told me Mum needed to be on a package. I was lucky because she was able to give me advice and hints.

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27. The Mildura Carers Hub (the hub) opened in Mildura in December 2017. The hub provides peer support and advice on accessing services. It has an educational role for carers in the community. It would have been really helpful if the hub were around when I was caring for Mum. It would have just given me someone to talk to. I always feel like I can pop in and have a cuppa and just chat to someone, it's a place I can vent.
28. The hub has lost some of its funding. It's now only open one day a week. If you miss that one day then you have to wait a week just to talk to someone. It makes a big difference to a lot of us.
29. In 2018, I started attending the hub's carers support group. Initially, there was only ten of us but we have now expanded to over twenty regular attendees. Our support group meets once a month. Some of us also catch up for a weekly coffee. A variety of people attend. People that have lost partners, parents with autistic children, husbands or wives that are carers, everyone is welcome. It's nice to be able to talk to people experiencing similar things as you.

Respite

30. Respite was a gradual process for Mum. It was tricky because there aren't a lot of respite beds available in Mildura. Mum was a DVA gold card so Veteran's helped me book respite three or four months ahead. At Princes Court, I was only ever able to get two weeks at a time, that's all they seemed to offer back then.
31. The issue was with short term respite. If I said I needed a bed tomorrow, then I wouldn't be able to get in that quick. I would have to go somewhere else. In 2014, my husband Jeff had a quadruple bypass. Mum had to go out to the farm because there was no way we were going to be able to get her into respite.

Putting Mum into residential care

32. In May 2016, I had to put Mum into residential care at Princes Court Homes. By that time, Mum's eye sight had started to deteriorate. Mum would be turning on the wrong hot plates, or setting the fire alarm off, she also started to have falls. I felt Mum was unsafe at home.
33. I found it overwhelming that I only had one week to put Mum into full-time care. Mum was on a waiting list, but the nursing home rang me and said "You have a week to organise everything or the bed will be given to someone else". One week is all I got to organise everything. I was lucky Mum had been in respite so I had already labelled her clothes and done most of her paperwork, but it was still an emotional time.
34. Mum loves it now. I am at peace knowing she is in the right place and taken care of. But the guilt of putting her into care was hard. I felt guilty because I wasn't looking after her. Making the decision to put Mum into care was hard. I felt like there was no one to talk to. There wasn't a counsellor or anyone to ask how I was feeling. I felt terrible.
35. Mum is cared for really well at Princes Court. I really like it there. My husband and I help with organising morning teas, carpet bowls, bingo or taking the residents on day trips. The facility has a family friendly atmosphere.

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Recommendations

36. If I could think of one thing the Royal Commission should focus on, it would be for there to be a bit more communication. Even doctors in a way, I know it's a lot for them, but there is so much they could be telling you, or helping you with. I was inexperienced as a carer so I had no idea what I was doing.

Signed: Elaine M. Gregory

Date: 25.7.2019

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