**Royal Commission**
**into Aged Care Quality and Safety**

**Statement of Debra Ann Barnes**

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| **Name:** | Debra Ann Barnes |
| **Date of birth:** | [redacted] |
| **Address:** | Known to the Royal Commission |
| **Date:** | 24 July 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. 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 based on my own knowledge, except where 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 were used, to the best of my recollection.

**Background**

4. My full name is Debra Ann Barnes. I am 65 years old. I previously worked in IT and HR. I am now retired.

5. My Mum, TP was born on [redacted] in Coburg, Victoria. Mum and Dad had four children, two sons and two daughters. Mum was a Physical Education teacher and lecturer in her early teaching days and later an infants' teacher and headmistress. Mum was one of five so we grew up with lots of aunts, uncles and cousins. Mum and Dad had eight grandchildren and eleven great grandchildren. For her 90th birthday, Mum celebrated with thirty-eight family members. Mum enjoyed her retirement and she and Dad travelled throughout Australia and overseas. Mum researched family history, learned to quilt and played cards regularly.

6. In 2002, Mum and Dad moved to an independent villa within the TR TR retirement complex which is located at [redacted]

**Entry into aged care**

7. In 2002 when Mum moved into the villa, she was generally in good health. She was managing Maturity Onset Type 2 Diabetes well with diet and daily medication. Mum and Dad lived independently and were able to cook and clean for themselves. They received some housekeeping assistance from DVA for a few years prior to 2017.

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8. On 20 December 2015 Mum fell in the Villa and broke her hip. After the fall, her mobility and cognitive ability declined. It was no longer possible for her to live at home with Dad. In January 2016, Mum had an ACAT assessment in hospital and we prepared to move her into full time care. The ACAT assessment identified that Mum was experiencing cognitive decline.

9. On 4 February 2016 Mum moved into the [redacted] the Unit within TR. Mum was very much still a part of the TR community while she was in the Unit. Mum's friends from the independent living area would come and visit her. Sometimes, my family or I would take Mum in a wheelchair back to the villa for family gatherings, lunch or morning tea with Dad and for Mum to check how Dad was going.

10. When it was time for Mum to enter high care the main factor that we considered as a family was accessibility for Dad. The Unit was walking distance for Dad to visit which was the key reason we were happy to have Mum at TR. At that stage, I didn't really know what to look for in terms of quality of care in the aged care setting.

**Advocating for Mum in care**

11. My sister and I became Mum's Enduring Power of Attorney after her ACAT assessment in January 2016. My sister had a full plate with her own health concerns so I handled most of Mum's needs. I made the time to be involved in the day to day running of Mum's care. I would say that I was the most annoyingly brilliant advocate daughter that I could be. I didn't mind coming across as a 'busy-body' if it meant that I could ask all of the questions that needed to be asked on Mum's behalf.

12. During Mum's stay in the Unit I texted or emailed my siblings to keep them updated. I shared everything from hairdressing appointments to changes in Mum's health. As I was present several times a week, I was able to observe the way TR staff handled Mum's needs and I often provided formal and informal feedback.

13. TR had a paper-based feedback system. There was folder of feedback slips available at the front entrance near the visitor sign in book, which you could complete and put in the feedback box. I also used the online web enquiries platform on a couple of occasions, however I never received a response from that medium. As far as I was aware, those were the only options for providing feedback in writing, unless you had a staff member's email address.

14. I regularly provided feedback via the feedback slips, both positive and areas for improvement. I estimate that I provided feedback on fifty to sixty occasions. In my experience, I only received acknowledgment of my feedback about 25% of the time and then mainly informal. I often had to find staff in the corridors if I wanted a response. I didn't like doing this as I was aware the staff were busy. However after being patient for a couple of weeks, I would then try and catch someone when I saw them.

15. On several occasions the facility ran out of feedback slips. I took to keeping a couple of feedback slips in my bag to get around the lack of slips.

16. On 19 January 2018, I contacted TR through the online enquiries form. We had experienced a recent bout of extreme heat in the area. When I was visiting Mum during that period, I could feel that the facility was unreasonably hot, and I could see that Mum and other residents looked uncomfortable. I was uncomfortable. The staff appeared uncomfortable. In my email to TR I noted that there had been an absence of feedback forms for the past week. I asked whether any of the senior leadership team had visited TR during the recent extreme heat period, whether they would be satisfied for their family members to live in those conditions and what plans they had in place to bring the facility up to a reasonable level of comfort. My query was never acknowledged by the facility and I never received a response.

**Mum's care plan**

17. From January 2018, I noticed that Mum was sleeping more and talking less.

18. On 5 March 2018 I spoke to [redacted], who had been Mum's GP for several years. We discussed the fact that medication changes had not improved Mum's recent drowsiness. I told Dr [redacted] that 'I don't want to rely on [redacted] for information on how we best support and look after Mum'. I also said that I want to understand better where Mum is at so we know what to expect from staff at TR and so we can all do the best for her. After this discussion with Dr [redacted] I requested a meeting with the key care staff to talk through Mum's care plan. The meeting was scheduled for 21 March 2018.

19. In early March I had several conversations with staff members about Mum's care plan being updated. The conversations were always in passing and I felt like I wasn't getting a clear answer. The Clinical Nurse Educator told me that there was a note in Mum's file that I was consulted on 6 February 2018 and that Mum's care plan had been updated. I explained that I had never seen a care plan let alone been consulted about updating it. The Clinical Nurse Educator told me that 'the problem is because you're here so often we don't get as formal.'

20. On 19 March 2018, I emailed the Clinical Manager, the Senior staff member and CEO of TR and advised that I thought there had been a communication breakdown. I wrote that I knew what information I had shared with the staff at the Unit but that I was not clear what information I should receive back, through which medium and how regularly. I told them that I needed information to be formally shared with me and not just conversations in passing in the corridors. I asked 'what else is being done or should be done to ensure we all look out for Mum as best as possible?' In response to my email the Clinical Manager advised that she would join the 21 March 2018 meeting to discuss my concerns.

21. On 21 March 2018 I attended a meeting with the Clinical Manager and another RN. I felt that it was bumpy in spots but was overall a productive meeting. My goal for the interaction was to focus the message on providing the best possible care and support for Mum. I was hopeful that communication was going to flow better between TR Mum and myself.

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**Missed hairdressing appointment**

22. In or around mid-April 2018, I realised that Mum had missed another of her regular hair-dressing appointments. Mum had always taken pride in her appearance and having her hair washed and styled at the hairdresser was an important factor in maintaining her quality of life. By this stage I had seen a draft of Mum's care plan at the meeting on 21 March. Mum had standing twice weekly hair dressing appointments recorded in her care plan.

23. I asked the RN responsible why Mum had not been taken to her appointment. The RN said that she didn't realise that this was in Mum's care plan and wasn't sure what had happened. After a short time, the RN came back to see me. She told me that the care worker who was scheduled to take Mum to her appointment was called away to another area and wasn't able to come back. After learning this I called the hairdresser directly. The hairdresser told me that when she realised that Mum had not arrived for her appointment she called **TR** and nobody answered the phone. The hairdresser said she also called again in two hours' time and again nobody answered the phone.

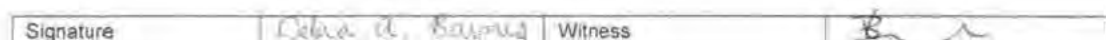
24. These appointments were important to my Mum and were recorded in her care plan. I felt really let down that **TR** staff were not communicating with each other to ensure that Mum was cared for in accordance with her plan. Also I witnessed the difference it made when Mum had her hair done. People would stop and comment on how lovely Mum looked and Mum would respond or smile. I submitted a feedback slip to share my concerns. The Clinical Nurse Educator called me later that night. We had an awkward conversation in which she aggressively asked me why I had put in written feedback when I could have spoken to her directly. I had been told time and time again that **TR** welcomed feedback, so I was overwhelmed by the Clinical Nurse Educator's response. I asked that we end the phone call because I felt extremely uncomfortable and I could not believe what I was hearing.

25. After this phone conversation I emailed the Clinical Manager and the **Senior staff member** ████ and requested that any future discussion about feedback or Mum's care not involve the Clinical Nurse Educator. Disappointingly, no-one even acknowledged that email or issue. I saw the Clinical Manager two weeks later in the corridor and asked her about it. She said to me 'it's all in hand, you don't need to worry about it'. I felt dismissed and disappointed.

**Mum's clinical care**

26. I felt that communication continued to be an issue with **TR** as time continued.

27. On 23 May 2018 I received a call from **TR** to inform me that Mum may need to go to hospital because she had perspired so heavily that her sheets were wet. I was shocked because I had been there that day and I had told the staff that if Mum was sick then of course they should send her to hospital. I waited with Mum before the ambulance took her to hospital. I consulted with the emergency doctor and RN, who told me that Mum had a UTI and high blood sugar reading. The RN explained to me that Mum's blood sugar would rise with an infection.



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28. From about January 2018, Mum had been speaking very little. When she was diagnosed with a UTI, it became clear to me that Mum had not been able to tell staff that she was uncomfortable which meant that they did not realise she had a UTI.

29. My key focus after the emergency room visit was to ensure TR had measures in place to prevent and identify any future infections. I sent several emails and spoke to different staff members about strategies that could be put in place to monitor and prevent further infections. The Clinical Manager offered an option of monitoring Mum's fluid intake to make sure Mum was drinking plenty of fluids. I told her that Mum needed prompting to drink at times.

30. On 2 June 2018 I visited Mum for the afternoon. I found that there was no cup of water available for her to drink and I had to get one myself. That happened regularly. If there was a water cup and a water jug on the bedside table, it was often out of Mum's reach when she was in bed. Mum's fluids were to be monitored over two days. The RN on duty on the Saturday after the monitoring period finished assured me that Mum had healthy numbers on her fluid intake sheet. When I followed up and questioned that further, the Clinical Nurse Educator told me that the fluid intake sheet only recorded what drinks Mum has been offered and that it didn't capture whether or not she drank them. I challenged the numbers as I had been with Mum from 10.30am to 3.30pm on the Wednesday and no-one had asked me what Mum had drunk or been offered.

31. On 4 June 2018, I spoke to the Clinical Nurse Educator in the afternoon about why nobody was making sure Mum was getting the fluid she needed. The Clinical Nurse Educator told me that they did not provide acute care and that it was up to Mum as to what she did or did not drink. I was feeling incredibly confused and frustrated because I simply couldn't understand how that would not be a part of the care they would offer Mum. At that point the Clinical Nurse Educator told me that I could be intimidating and that perhaps staff didn't feel comfortable approaching me with problems or information.

32. By that stage I had serious concerns about TR ability to care for Mum. I made enquiries at a new Residential Aged Care Facility closer to my home and arranged to have a tour. I found a geriatrician who was prepared to visit Mum at TR. The geriatrician advised that unless there was a major concern, we should keep Mum at the existing facility because she was familiar with her surroundings.

33. In or around July 2018 the Clinical Manager informed me that they needed to swab a pressure injury on Mum's buttocks to test whether there was an infection that required antibiotics. On 20 July 2018, I wrote to the Clinical Manager and asked for a meeting to discuss how long Mum had the pressure injury, what had been done and how I could track the treatment progress. At our meeting I was told that the injury had been identified in January 2018 and was being monitored. I had been aware of the pressure sore for a little while, but not from the beginning of 2018. It felt like I was not told anything or given updates unless I proactively asked for it.

34. On about 20 July 2018, my elder brother [redacted] and I requested that TR undertake an internal investigation into Mum's care. TR provided a report to us on 24 July 2018. The report recorded that staff were relying on word of mouth rather than

utilising the communication book. It also noted that there were annual care planning education sessions for nursing staff. TR advised that they planned to make these sessions mandatory every six months.

35. On 2 August 2018, my sister visited Mum and found her asleep at about 9am. Mum couldn't be roused and was taken to the Emergency Department. The doctors tried to assess Mum's blood sugar levels with a BGL machine. Her levels were too high for the machine to read. Doctors also found that Mum's stomach was distended due to urinary retention and a urinary tract infection. Mum passed away in the Palliative Care Unit at the hospital on 9 August 2018.

36. I was saddened and frustrated with the communication I had with TR in Mum's last 6 months of life. At several different stages I felt like my voice was not being heard and that I was powerless. I did not know who else I could talk to about my concerns. TR did not tell me about any external complaint services that I could access. As Mum's Power of Attorney and loving daughter I felt responsible for ensuring she was receiving the best care possible. I wanted to be kept informed and involved with decisions and any developments about Mum's care.

**Lodging a formal complaint**

37. After Mum passed, I was left with an overwhelming and absolutely certain feeling that she didn't get the care that she should have received. I spoke to a lawyer who had helped with Dad's estate and asked who I should turn to for help. The lawyer recommended contacting the Office of the Health Ombudsman.

38. In mid-September 2018, I contacted the Health Ombudsman to raise my concerns about Mum's care and subsequent death. Within a week or so, I was informed that they had referred my complaint to the Aged Care Complaints Commission (now known as the Aged Care Quality and Safety Commission (ACQSC)).

39. I was assigned a case officer at ACQSC who helped me understand the complaint review process. I was told that my complaint was being triaged and that they would return to me with an update as soon as possible. My case officer was very clear about ACQSC having processes that they need to go through to investigate complaints. She emphasised that there was no guarantee of an outcome. I provided all of the documents I had available, including files I had obtained through a Freedom of Information request from the hospital.

40. I contacted my case officer in September and October 2018. By November 2018 I had not received an update, so I sent an email to my previous contact at ACQSC asking if she would send on the correct person as I did not have their email address. ACQSC told me by phone that my complaint was still in the queue. The person that I spoke to acknowledged that they had said they were going to provide regular updates and apologised for the lack of communication.

41. I contacted ACQSC again in mid-January 2019, because I had still not received any updates. A case officer responded and said that my emails may have been lost in the

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system as they had been having technical issues since moving to the new Aged Care Quality and Safety Commission.

42. My complaint was then sent to the clinical assessment team at the ACQSC to evaluate Mum's care. I subsequently received a draft report from ACQSC and I was given an opportunity to provide feedback on the draft, which I did.

43. On 12 April 2019, ACQSC advised me by letter that a decision had been made to end the resolution process on the basis that TR had addressed the issues to the satisfaction of the Commissioner.

44. The ACQSC found that TR did not meet an expected level of clinical care when assessing and transferring Mum to hospital on 2 August 2018. The ACQSC also found that assessments conducted by TR were not comprehensive in that they did not adequately identify Mum's changed care needs.

45. The ACQSC found that TR had implemented a range of quality improvements including a dedicated assessment tool for acute change of status, a review of policies and procedures and provision of training to staff. These actions were found to have satisfactorily addressed TR failure to provide clinical care of a required standard to my Mum.

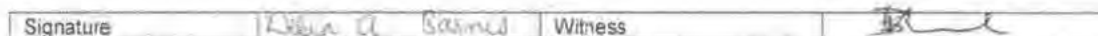
46. I do not understand how the complaint could have been resolved without there being an acknowledgment of what actually happened to Mum and who was accountable for it. The ACQSC report also did not identify that TR standard review and continuous improvement practices had failed to identify a number of areas for improvement.

47. My complaint was a non-standard input to a review and continuous improvement cycle. In my opinion, there should be standard inputs to the aged care provider's reviews and continuous improvement cycle, such as frequent reviews and education sessions with staff.

48. TR noted in their response to the ACQSC that they had implemented a range of new education and policy measures. I am concerned that if I had not complained, these improvements would not have been made. It felt like TR was reactive rather than proactive and that the ACQSC was satisfied with that approach.

49. I was not satisfied when I received the ACQSC final report. I felt like ACQSC had simply been through the steps of a process, rather than critically assessing the outcome to see if it was reasonable and fair.

50. On 14 May 2019, I sent an email to ACQSC requesting an internal review of the decision. In my request for a review I wrote that I thought some of the information provided by TR should be clarified, because I felt that the ACQSC review and TR response did not address all the matters that I had raised in my complaint.



51. On 11 June 2019, ACQSC advised by letter that they had reviewed the findings that were the subject of my review request and had decided not to investigate further.

Signed:

Date: 24 July 2019

Witness:

Date: 24/7/2019