



Royal Commission
into Aged Care Quality and Safety



Statement of Nicole Louise Dunn

Name: Nicole Louise Dunn
Date of birth: [REDACTED] 1983
Address: [REDACTED] VIC 3015
Date: 19th 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 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 Nicole Louise Dunn. I am currently 36 years old. I live in Melbourne, Victoria.
5. In April 2015, at age 32 I began caring for my grandmother, Roma Dunn who was 83 years old at the time. I cared for her until she died on 6th April 2017.
6. Family was the pride and joy for my grandmother Roma. She was a loving and dedicated wife to her husband Peter of 48 years, mother to son Andrew and daughter Karen, grandmother and a friend to all. My grandmother could only be described as fiercely independent and was chopping wood with an axe during the week in which she was diagnosed with terminal pancreatic cancer. My grandmother enjoyed the peacefulness of her home at Mount Macedon and was active in her local community; through volunteering for the local historical society, attending hydrotherapy and social gatherings with friends. Ironically, my grandmother was always the carer for everyone else.
7. I have attached to this statement a photograph of grandmother and I [RCD.9999.0122.0002]. The photograph was taken in the front yard of the family home in January 2017, three months before my grandmother passed away. It was not until I saw this photograph that I could see the family resemblance, and in particular our smiles.

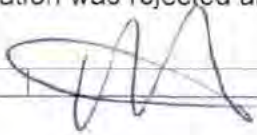

Signature		Witness		19/7/19
-----------	---	---------	--	---------

STATEMENT OF NICOLE LOUISE DUNN CONTINUED

8. In 2015, I received a call from my aunty who had gone with my grandmother to an appointment with her general practitioner. My aunty told me that the doctor was concerned about how jaundiced my grandmother appeared and recommended that she go to the emergency department of a hospital.
9. At that time, I was working in the emergency department of a Melbourne hospital. I told my aunty to bring my grandmother into the hospital as it was reasonably quiet. When my grandmother arrived, I saw that she was completely jaundiced. My colleagues did some scans and when the results returned they took me aside and told me that they had found a mass on her pancreas.
10. It was pancreatic cancer with a prognosis of one year. It was not curable and could only be managed with palliative chemotherapy. The diagnosis was unexpected and came as quite a shock to my family and I. My grandmother had gone from being completely independent to having a prognosis of 1 year to live.
11. Prior to the diagnosis, my grandmother was very active and independent. She was doing everything for herself including managing the family home in Melbourne and her retirement home in semi-rural Mount Macedon.

Becoming a carer

12. When my grandmother was diagnosed with cancer I was living by myself in an apartment in Melbourne. I was working full time, had a lot of independence, a busy social life and was heavily involved in playing AFL and netball.
13. It was clear to our family that my grandmother needed someone to care for her. The other family members were not in a position to provide this care so I decided I would move in with my grandmother and become her carer.
14. My professional background is in physiotherapy and I had further retrained to be an emergency department care coordinator, so I knew the aged care system well. In my job at the emergency department of a hospital, I would often coordinate aged care services for people and this had given me a lot of relevant knowledge for the care of my grandmother.
15. I moved in with my grandmother and continued to work full time. Initially, things were fine. My grandmother was quite stable and we weren't needing much help from the aged care system.
16. I organised an occupational therapist to assess the home and we made some modifications such as rails on the stairs and in the shower. My grandmother's general practitioner set up a care plan. This was all privately funded to avoid lengthy wait times knowing my grandmother had a terminal illness and her time at home would be limited.
17. At the time, I was working 40 hours per week and there was a lot of time when my grandmother would be home alone. She was getting quite frail and I was concerned about her having a fall when I was at work. I was aware that there was funding available from the local council for a personal alarm so applied on behalf of my grandmother. Initially, my application was rejected and I was told my grandmother wasn't eligible as I

Signature		Witness		19/7/19
-----------	---	---------	--	---------

STATEMENT OF NICOLE LOUISE DUNN CONTINUED

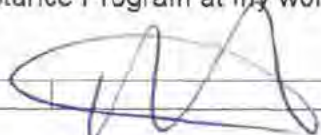

was living with her. The council eventually agreed to fund the personal alarm but it took a lot of advocacy, time and effort on my part.

Increasing home supports

18. After approximately 10 months, my grandmother was starting to become more frail and forgetful. She was having trouble managing her medications even though they were in a Webster pack, required prompts to eat meals and had sustained a couple of falls.
19. One of the biggest challenges was all the appointments. There were just so many of them. My grandmother had regular appointments with her general practitioner, her oncologist and she was starting weekly chemotherapy. The chemotherapy required an appointment for a blood test, then a separate appointment for the treatment. Either my aunty who also worked or myself would attend these appointments with my grandmother. It was a lot of work to coordinate the appointments and organise the time off work.
20. I started to organise an increase in supports at home. I completed a self-referral to My Aged Care to get an Aged Care Assessment Team (ACAT) assessment completed. One of the challenges with My Aged Care is that they required verbal consent from the person receiving the care every time you called. I had to hand the phone over to my grandmother for her consent every time I had to call.
21. There was a significant amount of double up with these services too. I would have someone from My Aged Care call me to ask a range of questions then later someone from Aged Care Assessment Services (ACAS) call and ask all the same questions. These calls would be during business hours when I was at work. I would ask to be emailed, however services continued to call all the time. I don't think that these services realise how much time carers spend arranging, coordinating and talking to service providers. Every moment of time that was spent repeating information to service providers was time taken away from being with my grandmother which was precious and limited.
22. When the ACAT assessment was completed, my grandmother was approved for respite and residential aged care. My grandmother was also eligible for a home care package but we turned it down because I knew that she would probably have passed away before it was available and my grandmother didn't really need a care manager due to my background in healthcare.
23. We applied for many of the services before they were needed as I knew through my work there could be lengthy wait times until a service was available. In my experience, people will often apply for a service when it is needed and are then advised it will be several months for the service to be available.

Supports for carers

24. When my grandmother was first diagnosed with pancreatic cancer, I experienced anticipatory grief as I knew what was ahead of us. I accessed counselling through the Employee Assistance Program at my workplace reasonably soon after my

Signature		Witness		19/7/19
-----------	---	---------	--	---------

STATEMENT OF NICOLE LOUISE DUNN CONTINUED

- grandmother's diagnosis. This was useful and I was lucky to work somewhere that has this program, although there was a restriction on the number of sessions the employer could provide.
25. Aside from the Employee Assistance Program, there were no workplace supports available to assist in my caring role. I was reliant on standard personal and carer's leave. It is also worth noting that in many Australian workplaces carer's leave can only be used when caring for an immediate family member. Because of this, if a carer was providing care for a friend, cousin, uncle, aunty or neighbour they would not be eligible for carer's leave.
 26. I was familiar with Carers Victoria through my work so called to access information on the services they might be able to offer. I knew that I needed some in-home respite support so I could have a break as a carer and have support from a professional. There was a waiting list of about two or three months for a carer support worker. I applied for this service and we eventually received the support. In-home respite was essential for my mental wellbeing and to recharge as a carer. We paid a private service for additional respite and cleaning assistance.
 27. Carers Victoria also supported us when my grandmother eventually transitioned from home to an aged care facility.
 28. As my caring responsibilities increased it became obvious to me that I could not maintain full time work. I had always been a reliable employee and I felt really stretched. I had a conversation with my manager and we decided that I would go down to 4 days per week. I had a mortgage to pay and I couldn't afford to work any less than that. At the same time, I was trying to do the best for my grandmother and I didn't want to let anyone down.
 29. I applied for a carers supplement payment via Centrelink and this was denied as my grandmother was considered 'too good' at her current level of functioning, which was how the payment was assessed. The application involved a tick box type assessment that was based on specific indicators. The assessment did not take into account my grandmother's prognosis. Despite my grandmother being deemed 'too good' by Centrelink for myself to receive a carer's supplement, within one year she was placed in a residential aged care facility and required 24 hour care. My grandmother passed away approximately 6 months after entering a residential aged care facility.

Transition into an aged care facility

30. In September 2016, my grandmother was booked in for two weeks of respite at a residential aged care facility in Melbourne. In the month leading up to that respite my grandmother's health deteriorated significantly. She had three falls, two episodes of double dosing on her medications, her memory was deteriorating and she had an episode of delirium while in hospital. It became clear to me that my grandmother would have to stay in the facility on a permanent basis and we had the respite converted to permanent care.

Signature		Witness		19/7/19
-----------	---	---------	--	---------

STATEMENT OF NICOLE LOUISE DUNN CONTINUED

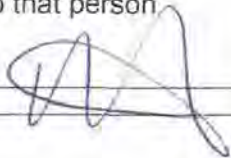
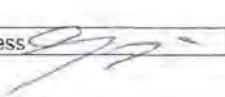
31. My grandmother was very well cared for during her time at the facility. She participated in many of the home's activities, enjoyed her private room, made friends with the staff and enjoyed the meals. In particular she found the support of the pastoral care worker to be of much benefit during a difficult time.

Impact of caring

32. My social life pretty much stopped when I was caring for my grandmother. I hardly saw my friends during this time as my caring responsibilities always came first. I was able to maintain my involvement in netball and football because I would take my grandmother along. Sport was a good outlet for myself as a carer.
33. I placed the health and well being of my grandmother ahead of my own. I would delay going to a general practitioner and other primary health services unless it was urgent. During my time as a carer I experienced an asthma attack, was extremely unwell and required treatment in an emergency department. Despite being unwell and in emergency my main concern focused around arranging someone to be with my grandmother if I was not there.
34. The balance between maintaining employment responsibilities and carer responsibilities was difficult. I reduced work hours and needed to constantly take calls from service providers whilst at work. This did have an impact financially and I was also concerned about the impact it would have for promotional opportunities in future.

Concluding comments

35. I feel there needs to be some provision for individuals newly diagnosed with a terminal illness to receive rapid access to services, allied health and equipment through the aged care system. Our family were in the fortunate position of being able to privately fund home care services and allied health so there was no wait.
36. For individuals waiting for government funded services and equipment with a newly diagnosed terminal illness, such supports may not commence in time with an individual potentially in an aged care facility by the time such supports become available.
37. Putting one's work on hold to care for someone can have a big financial impact. This is particularly true for women who are often the ones who have time off work to take on these caring roles. This is compounded by any time taken off to care for children.
38. There is not a lot of recognition and understanding in the community of the pressures that one comes under when caring for an older person. By comparison, there is a lot more understanding, empathy and support available when caring for children. There can often be a misconception that an older person can care for themselves, however due to health and medical reasons this may not be the case.
39. To improve the support for carers I would recommend the following:
- a. Expansion of the definition of a carer particularly in relation to carer's leave. A carer should be defined by the assistance that is provided to someone, irrespective of their relationship to that person.

Signature		Witness		19/7/19
-----------	---	---------	--	---------

STATEMENT OF NICOLE LOUISE DUNN CONTINUED

- b. Employers need to have policies in place that cover all employees who act as carers.
- c. The availability of flexible working arrangements. For example, the option to work from home.
- d. Additional leave during periods of crisis. For example, when someone you are caring for moves into an aged care facility.
- e. Expansion of the Employee Assistance Program.
- f. Expansion of carer support services. For example, Carers Victoria and further opportunities for government funded in-home respite.
- g. Increased financial support to carers via Carer Payments and Carer Supplements through Centrelink. Applications need to further take into account the prognosis of an individual and not just their current functional ability.

Concluding comments

40. In closing, I have often been described by people in the community and service providers as being 'not the typical carer'. I am not sure if this is attributed to being 32 years of age when I became the primary carer for my grandmother, or if it was that I was caring for a grandparent rather than a parent, or for reasons that I am unsure of. What I do know is that there is no 'typical carer'. Modern carers now face the challenges of balancing caring responsibilities with the responsibilities of employment, financial pressures, smaller family support networks and maintaining their own health and wellbeing.
41. Older people often wish to remain at home which is where they spend most of their life. For older people who have a carer, it is typically the carer rather than formal services that provides the bulk of support for the person to remain at home. Carers are the absolute backbone in supporting an older person at home and without adequate support being provided to carers the system will fail.
42. Being a carer was something I never planned for nor expected, although I wouldn't have had it any other way. The importance of this is that anyone may find themselves being a carer for a loved one, it affects us all.

Signed: _____

Date: _____

Witness: _____

Date: _____

Signature

Witness

Page 6 of 6