



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

Statement of Joan Barbara Rosenthal

Name: Joan Barbara Rosenthal

Date of birth: [REDACTED] 1940

Address: [REDACTED]

Date: 23.07.2019

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 Joan Barbara Rosenthal. I am 79 years old.
5. I live in Sydney, NSW with my spouse, Ian Hamilton. Ian is 87 years old. I am Ian's carer. Neither of us has relatives in NSW or anywhere else who could participate in caring for Ian. We have no children.
6. I am retired but with a small home business in academic editing. I have a background in linguistics, speech pathology, university teaching, and editing.
7. Ian is a retired doctor. He and I have been together for 36 years. He worked mainly in the fields of public health and occupational health and safety. His favorite activities before his accident were photography, enjoying classical music, socialising in coffee shops, watching cricket. He kept up with national and international current affairs and was interested in people in the public eye.
8. I attach a photograph of Ian and myself to this statement [RCD.9999.0128.0001].
9. In August 2015, Ian had a fall and sustained fractures in his spinal vertebrae C1 and C2. After four months of hospitalisation and rehabilitation he was discharged, having been judged eligible by ACAT for a level 4 Home Care package and/or Residential care (marked 'This approval does not lapse'). He had a transfer-to-home package for 12 weeks and then a level 2 Home Care Package. Fortunately, since about November 2016 he has had a level 4 Home Care Package.

Signature

*Joan Rosenthal*

Witness

*LEONNY C. PALMINO*

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10. As a result of Ian's spinal injury, he now has daily neuropathic pain, lowered sensation and poor balance. His night sleep is invariably disturbed by pain and restlessness. This means that I or somebody else needs to be with him most of the time. His hands have poor sensation; he no longer drives. To get around the house, he uses a walker or he holds onto furniture. When I need to go out, I set him up with a VitalCall, which is a personal alarm device. If Ian had a fall or felt ill or had some other emergency when I was not around he would use the VitalCall to summon help such as an ambulance. He has never had to use it thus far.
11. Since Ian's fall his activities have been much curtailed by continued pain and health sequelae, as well as by aging. Although he tries to do as much as possible he has become saddened and frustrated by his limitations.

**Ian's needs**

12. Like some men, Ian has few friends and he relies on me for company. I am his best friend. As he is very talkative I get to do a lot of listening, which can become frustrating to me – and frustrating to him if I tune out.
13. Ian also relies on me for physical support and to help him navigate his way around the house and beyond. For example, if he forgets his walker I assist when he wants to move from one part of the house to the other, or I fetch when he needs something from another room. I also assist when he needs to use the toilet. Sometimes, I feel like I am Ian's servant.
14. Before Ian had the fall, our life was very different. Now, I feel a sense of grief and loss at the situation that we are in. The hardest part for me is managing my anger and the sense of loss at the situation. Ian also has feelings of loss and he has anger as well. We have talked about it. We are each grieving for what we have lost. We have lost part of our lives. There is nothing we can do but put up with it. It's sad.

**Impact of caring**

15. My caring role has had a significant impact on my life. My commitment to caring for Ian has meant that I cannot leave the house as much as I used to and I have had to drop a lot of my social activities. Before I began caring for Ian, I would go on bird watching trips with a group, visit the opera with friends, play Scrabble at a club, and I would travel a lot more. Although Ian and I did many things together, we did also have some separate interests and friends. These things are now more difficult to arrange, sometimes impossible. On the other hand, whereas we often had lunch separately before his accident, we now go out for lunch together 5 days a week (the other 2 days are with paid carers for Ian).
16. Previously, I would also travel to play scrabble around Australia and internationally. I was an Australian representative in three World Championships for scrabble, in New York, London and Melbourne. Now, I find it's not feasible to attend games at my local scrabble club or with friends. Also I would often go on group bird-watching outings and even overseas trips, sometimes with Ian but sometimes independently.

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17. The changes to my social life have been a blow, but I have been very lucky to have several really good friends who have helped me in various ways. I have one friend who sometimes stays with Ian when I need to go out, and has even stayed the night when I was away. I maintain my connections with friends by regular weekly or fortnightly activities like bird watching and walking together. I have been so lucky with my dear friends and I'm enormously grateful to them.

**Home Care Package**

18. In December 2015, Ian was discharged from hospital. Although we had been looking forward to Ian coming home, we were both in shock when it happened. It was quite a bit of an adjustment. The most difficult adjustment was that Ian would not sleep through the night and needed frequent help with toileting.
19. Following his discharge from hospital, Ian had a transfer-to-home package for 12 weeks. That introduction to the care that was available was really good. The package was quite intensive. It included professionals coming to the house and looking at what physical changes we needed made to the house like installing rails in the bathroom and a railing up the outside stairs (we have 25 steps from the street to the house). The package also involved physiotherapy and having people attend at the house to shower and dress Ian.
20. Once the 12 week care package finished, even though Ian had been listed as eligible for a level 4 package, there were none available. It wasn't that services didn't provide packages, it was that none were available. We basically had to wait until someone died. We had to sit on various care organisations' lists and hope that we would get any package, really. We felt quite lucky when Ian received a level 2 Home Care Package with [REDACTED]
21. Around October 2016, Ian was allocated a level 4 Home Care package. The package covers a carer to shower and dress him 6 days a week and to take him out 2 mornings a week. It also covers occasional expenses such as dental treatment and a one-off clean-up of the outside of our house and the overgrown garden.
22. Because of our joint income (mainly mine) we must contribute a considerable amount for Ian's level 4 package. This reduces its monetary value to us. For example, for a typical month, January 2019, Ian received \$4270 monthly government funding which was however reduced by the monthly \$927 'income tested fee', and on top of that must pay the monthly \$837 'consumer contribution'. His provider is [REDACTED]
23. We also find that as a package recipient he can be charged more for external services. For instance, a Sydney bus company provides transport for older people for purposes such as GP visits and shopping. When Ian became an aged care package recipient the cost of such transport was more than doubled.
24. The people that have been provided to us as carers and assistants have been really great. Until last month, we had a single person assisting with Ian's morning personal care. Consistency is valuable but sometimes I do think it would be better for a variety of people to help Ian. Having different people coming in and out is now quite stimulating for

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him. Different carers can assist with different things. Some can do things that others can't. So I think it's better for Ian to have different people.

25. I do realise that in Australia we have an excellent home care system. Even though we have to pay a lot due to our financial situation, it is great that the government provides services. It is given with one hand and they take back a lot with the other, but it is a great system. I talk to people from other countries and they are amazed at the level of support we can get subsidised.

#### Extra Services

26. To supplement Ian's aged care package services we pay privately for additional services. To supplement what the level 4 package can provide, we have paid privately for a second half-day outing per week, extra day care for occasional needs, and for overnight carers 4 nights a week. We couldn't have any more than that because of the cost and Ian is somewhat resistant to having people in the house overnight. He is grumpy when they arrive, grateful during the night when they help him, and friends with them by the morning.
27. The overnight care we have been able to arrange privately is less expensive than equivalent care that would be available from regulated aged care providers and it is a godsend because it allows me at least 4 good nights' sleep per week.
28. All in all, the costs to both of us for Ian's care represent a substantial financial outgoing, but they enable him to be at home and live a more 'normal' life than he would in residential care where he would be classified as a 'high care' inmate.

#### Respite

29. So much for background. The main reason I want to make a statement to the Royal Commission is to highlight our difficulty in obtaining temporary respite care in an aged care establishment.
30. It is difficult to plan ahead for respite. In theory, Ian's package provides each of us 63 days of respite per year. However, this is extremely difficult to arrange. And I should add that we are willing to pay well for temporary high level care in a well-equipped and well-staffed establishment. Naturally, we would like Ian's stay to be a pleasant experience for him as well.
31. In May 2019, I had a break for a holiday tour of 11 days within Australia. It took me about 2 months to arrange respite. I contacted several establishments, but all the aged care establishments I contacted did not take bookings until at the most 2 weeks before the date needed, and their ability to accept Ian depended on the availability of a respite bed. They did not provide a facility to pre-book before that window of 2 weeks. This I heard was the usual practice among aged care establishments. In fact with some, the booking window was only 1 week before the required time.
32. Searching for respite accommodation was very stressful. I was tired, very tired. At the time, my level of functioning was affected and I felt I was not providing Ian with the amount of support and companionship that I used to. He needed a break as much as I

Signature	<i>Joan Rosenthal</i>	Witness	<i>L. E. P. Allen</i>
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did. It was nerve-racking because, being required to pay for my tour 2 months before the departure date, I stood to lose money if I couldn't find a respite place for him. I was worried that my friend who would be my travelling companion might have to holiday alone. I knew that the break that was planned would be highly beneficial to both Ian and me.

33. We have had this problem previously and very fortunately found a respite place each time, but the availability seems to be tightening up. The aged care establishments that I approached seemed to have other priorities, such as selling permanent accommodation or servicing people with lower care needs. This is a systemic problem.
34. Eventually, we found a respite place at [REDACTED]. We found it by using the Aged Care Decisions website which I happened to find online. This, and the helpful personnel involved, was most helpful to me in finding respite possibilities for Ian in our area.
35. The Aged Care Decisions website allows you to put the disabled person's name down for respite for a certain period and will get back to you with a list of places in your vicinity, which you can contact and follow up yourself. Even though there was no final assurance of a respite place until a week before the date it was required, I could still make positive contact with several establishments of my choice, not all of which I had known about, and visit them. Such an organisation would have been an invaluable support to me in my earlier years of seeking respite.
36. Ian has been to several respite facilities across Sydney, NSW. The services range from small and homely to large and institutional. Ian has been unhappy in all of them for one reason or another. He hasn't enjoyed respite.
37. In April 2019, I had a lovely holiday but Ian had a less than wonderful time at [REDACTED]. For example, he was left in the same dirty clothes over the weekend, was virtually uncontactable (with no signal or Wi-Fi connection in his room) and he was not allowed to leave the building and walk independently in the grounds at the weekend using his walker, although that had been permitted during the week. On the weekend, Ian spent Saturday and Sunday stuck inside the building instead of being outside where he would have surely found a lot more pleasure.

**Concluding remarks**

38. I would like to see greater availability of respite accommodation in quality aged-care establishments that have sufficient qualified staffing both day and night. I would like to be able to consult an online register of aged care establishments that have available

Signature	<i>Joan Rosenthal</i>	Witness	<i>L.C. PALOMINO</i>
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respite accommodation at least three months ahead of the present time, and to be able to book such accommodation.

Signed: Joan Rosenthal  
Date: 23-07-2019  
Witness: LEONNY C. PALOMINO  
Date: 23-07-2019

Signature	<u>Joan Rosenthal</u>	Witness	<u>L.C. PALOMINO</u>
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