

I am writing as I am very concerned about the state of Aged care in Australia. I have tried to put across the journey that I have been through and I would request that you read this letter in its entirety so that you may understand what I (and countless other carers) have been/or are going through.

My main issues of concern are:

- The state of home care – mainly the changes in funding but also the quality of this service
- Obtaining a place in a Nursing Home
- The prohibitive cost to a resident in a Nursing Home
- The attitude of staff at Department of Human Resources
- A NSW doctor being unable to attend a resident in an ACT Nursing Home
- Finding a doctor who will attend a Nursing Home resident
- The ratio of staff to high care residents in a Nursing Home
- The quality of care to high care residents in a Nursing Home
- Lack of a full time registered nurse in a Nursing Home
- Being unable to get a placement in a Hospice
- Lack of care for a resident on Palliative care in a Nursing Home
- Lack of attendance by the doctor until nearly 11 hours after death

My story is that in late 2014 my husband [REDACTED] who was then 70 years old and who had previously been healthy and active started to suffer from a condition known as Progressive Supranuclear Palsy (PSP)¹. This is a rare neurological offshoot of Parkinsons but with a much faster deterioration than Parkinsons. The early symptoms were loss of coordination and frequent falls. I kept a record of his falls for twelve months and he had seventy-five falls during that time. Luckily he rarely hurt himself beyond a few bruises and scrapes but he did have two hospitalisations for injuries during this time – one for a week and one for sixteen days. This was a great concern as his condition progressed as he could not be left unattended for long.

As he was 180 cm tall and 90kg there was no way that I could lift him on my own when he fell and he was unable to get up himself. As our children were not always available to come and assist because his falls were mainly in the middle of the night when he tried to get up on his own, I would call the ambulance service for assistance. I am full of praise and very grateful for their usually prompt attendance as I could not have managed on my own. They would always check him for any injuries which was very reassuring.

I cared for him while still working for the [REDACTED] for as long as I could. As his needs increased, I reduced my work hours in an effort to give him the best care possible. I purchased a Vital Call pendant which he wore and if he fell when on his own he could press the button and it would ring my mobile phone. I would then leave work and return home as quickly as I could. As his needs increased, I found it increasingly difficult as he became more and more dependant for all of his daily needs.

As his condition progressed I would get him up in the morning, assist him with the toilet, I would get him on a shower chair and shower him, dress him, shave him, clean his teeth, do his hair and nails,

¹ <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Progressive-Supranuclear-Palsy-Fact-Sheet>

feed him and most of all loved him. It became increasingly difficult to transport him to his frequent medical appointments as I could not get him in and out of the car by myself. Our local GP was a great support during this time and occasionally made house calls and I was also given some training in other aspects of his treatment. He was on Warfarin (blood thinner) and required frequent blood tests. To make it easier for me, our GP loaned me a testing machine and I could then do these blood tests at home and phone in the results. I would do all this in the morning before going to work late mornings.

During this time, I had very little assistance and as his needs increased, I purchased the necessary equipment and invented ways of coping with what had to be done. My son and son-in-law helped with home modifications and handrails to make the home safer. It was not until one of his hospital stays that I was informed that I could get some home help and have carers come to assist with his care. While he was in hospital they were not geared up to care for someone so dependent but I was able to stay in the room with him overnight and tend to his frequent needs. I also showered and fed him while he was in hospital. While the staff were very good they were not able to do all of his care. While in hospital I took ill myself with Vertigo and could not get up. I had to go to casualty as I was not a patient and they could not do anything for me in the ward. Casualty told me I was suffering from exhaustion and would not discharge him until I had gone home and had a good rest.

The staff at the hospital advised me that I could get carers come to assist with his care at home. He had an assessment done and he was classed as High Care. I engaged [REDACTED] to provide a carer while I was at work which then gave me a great peace of mind to know that he was not alone. I still needed to work financially and to have a much needed break from the stress of caring for him. My workplace was very supportive and understanding of my needs and without their assistance, I could not have coped as well as I did. On quite a few occasions, I would receive a call at work that he needed assistance and I would just leave and return home and nothing was ever said. To have a supportive work place meant a great deal to not have to worry about that as well.

I was not very satisfied with the level of care from [REDACTED] I paid \$68 a week for their services. I was working longer hours at the time and I used more hours than was allocated for a High care client. [REDACTED] informed me that they were able to access unused hours from other clients to cover what I needed. This cost was very affordable as it was subsidised. My main concerns with the home care were:

- The carers were frequently late or did not come at all. This then made me late for work or I would not be able to go at all.
- I would send a weekly email regarding the hours I needed a carer but this seemed to be ignored. If he had an appointment, I informed of the change of hours but a carer still came and I would get a phone call enquiring where we were as no one was home. On one occasion when he was in hospital, it took them three days before they understood that we did not need a carer until further notice. This was a waste of time for these carers.
- Some of the carers were quite elderly themselves. Three of the carers who came were over 70 years of age which was highly unsuitable for a client who was as dependent as he was. One carer suffered from a condition herself (oedema of the legs) and her legs were "oozing". I came home to find that as her legs were weeping and her shoes were wet from this liquid, that everywhere she had walked in the house left stains and wet patches on the carpet. Apart from the high risk of infection to my husband, it was very gross and unsightly. I complained to [REDACTED] and they arranged to have the carpet cleaned but this did not remove the stains caused. They agreed to replace the carpet which was a major chore for me as I had to get quotes (when did I have time?) and pack up everything in these rooms

and store it when the carpet was replaced. They then informed me that I would have to pay the \$800 excess but I felt that I would not have replaced the carpet as it was previously in good condition. After much complaining they did cover this cost.

- Some of the carers were not physically strong enough to assist him. One carer, although she was very good, was only 4ft 6in and 50kg herself and could not move him or assist him with walking or adjusting him in his chair. I would return home and find him slumped in a chair.
- I did not get a choice as to which carers would come. When I complained I was told that they had trouble getting adequate suitable staff.
- The carers were only allowed to be there for two hours at a time and then another carer was scheduled to come. This was always a great concern as to whether they had arrived on time and he was not left on his own. This created problems as with so many different carers coming they were not all familiar with his needs. I did leave a typed information sheet on the table but this seemed to be ignored.
- I found a lot of the carers did not really care and just turned up and watched TV. I was informed that they would help me with household chores but this was done in a very slap happy way. I had purchased an electric lift chair for my husband and one day came home to find that the carer had turned his chair off and was in another room reading a book. This meant that he could not get up.
- The carers were not all trained in the ability to pick up on if their client was in pain. On one occasion Herman had had an early morning fall and had injured his knee. Throughout the day his knee had swollen to literally the size of a soccer ball and he was in considerable pain although he did not complain. It was only the third carer for the day who came and knew immediately that he was in pain. The other two had been walking him to the bathroom and hadn't noticed anything amiss with him. This third carer rang me and I came home immediately. We called an ambulance and he was taken to hospital where he stayed for sixteen days. He had severe bleeding in the joint and after a couple of days his leg was black from ankle to groin.
- One carer had a spider phobia and would not come inside the house when she saw a small spider on a wall. I had to remove the spider before she would come in. What would have happened if I was not still at home and she saw a spider inside?

I was in a constant state of worrying about the care he was receiving from these carers. Just as his needs were increasing the Government brought in changes to home care to "make it fairer" but I definitely did not find this the case. The options available to me were to have a carer come 5 days a week for ½ hour to assist with showering him in the mornings and to have a carer come for 5 hours a day for 2 days a week (10 hours a week). This would cost in excess of \$400 a week as now I was required to pay the carer's travel time and also an hourly rate. Previously these costs were included. These changes also meant that I would not be able to access unused hours from other clients as the package was now directed to me. I was also told that it would be my choice to have 2 carers at a time come if needed but then I would have had to pay for 2 carers as well as their travel time. This was not my choice, it was a necessity. The cost was also very prohibitive to have a carer accompany us for any medical appointments so mostly I would just manage on my own. This caused me financial stress as I was not earning this amount even with the meagre amount I received from the Department of Human Resources for the Carers payment and the part Carers pension. As his needs increased it was safer to have 2 people to dress him as he could not stand very well but without a carer I would manage on my own (just). Our children helped where they could but they also worked or had small children.

In June 2015 I had a breakdown myself and collapsed in a crying heap. I was exhausted and could not cope with it anymore. He had got to the point where he could not walk or even stand unaided and I could no longer safely move him. I actually dropped him on a couple of occasions and I came to the realisation that for his safety he would have to go into a Nursing Home. This was my husband of 42 years and I loved him dearly but I just couldn't continue on this way. He never complained and just accepted what was dealt to him and he worried constantly about me.

I was fortunate that I found a placement for him quickly as I had had his name down at several Nursing Homes for quite some time. My daughter and I had looked at homes and put his name down at several but when the need became urgent I had to plead to get him a placement quickly. In June 2015 he moved into [REDACTED] in [REDACTED] ACT. We lived in Queanbeyan NSW but the options to get a placement for a nearby NSW home were very limited. I actually received a call from one of the other homes 9 months after his death that they had a vacancy.

A lot needs to be done about the state of Nursing homes and my main issues are:

- Our local GP who we had a very good relationship with was not allowed to attend him in a Nursing Home in the ACT as he was a NSW doctor and we had to find a new doctor. This took quite some doing as most of the local GPs would not attend Nursing Homes. He had a succession of doctors that didn't really care or took the time to know his history and I had constant hassles with his medication even though they had his medical records and our GP was available to consult on any issues. I had been very involved in his medications for quite some time and was very familiar with his reactions to changes in doses and was constantly arguing with the doctors and staff about how it should be handled – particularly the warfarin. Quite often they omitted to give him one of his medications and if I was not there to ensure that he was given all of them he would have missed them.
- There was a SEVERE shortage of staff in the home. [REDACTED] had forty-two residents and I was told the ratio of staff to patients is 1 staff to 7-10 residents. At most I found there was only 4 staff members on at any time. At least 1 staff member was required to be in the Dementia wing at all times. This only left 3 staff available at any time for all of the other residents. The staff were mostly very good but were very overworked. There were occasionally volunteer staff during the day but even they were overworked and didn't stay long.
- I found that there was a very high turnover of staff as they were very overworked. This did not give the staff a chance to get to know [REDACTED] or his needs.
- [REDACTED] was assessed by the physio as needing 3 staff to assist him with moving, dressing etc. so he frequently had to wait long periods for any assistance. He was in a wing with 8 residents, 7 of who were in wheelchairs all needing a high level of care. I frequently witnessed all of these residents waiting long periods for assistance. The carers would come, turn off of the buzzer and return when they were able.
- There was no full time registered nurse on duty. There was a nurse from 8a.m. until 6p.m. but through the night the nurse was only on call.
- Mealtimes were particularly bad as he had to wait until there was a staff member available to feed him and he was usually left until last. He still had a good appetite and I would make every effort to be there for meals so that I could feed him myself. Other residents told me this was good as he would then get his meal all at once and not a little bit at a time over a long time. On one occasion at mealtime I witnessed an elderly man spill a full glass of cold water on himself but there was no staff available to tend to him and he was left wet and cold for nearly an hour until there was. I occasionally fed this man also.

- He was only showered on average every 2-3 days. I find this appalling as he would get sweaty and I think this is a basic right to have a daily shower. I was told they did not have the staff to shower all residents more often.
- On frequent occasions I witnessed the care staff working in the kitchen or laundry when these staff members had not turned up. This took valuable care staff away from their very important duties. Also the care staff were not replaced during these occasions.
- Staff who were absent were not always replaced with other staff or agency staff.
- Through the night there was only 2 staff members on duty for the whole facility and this included the Dementia Wing. As [REDACTED] was assessed as needing 3 staff to assist, they just had to cope on their own if he needed assistance at night.
- There was a significant shortage of suitable equipment available for his use. His condition deteriorated very quickly and he needed more suitable chairs and bedding which were not readily available. After finding him frequently falling out of the wheelchair and complaining did they get him assessed for a day bed that could be wheeled around. Even then they measured him and ordered a new bed which took a couple of months to arrive. In the meantime, they took a day bed from another resident who was then put in a different chair. When this bed/chair finally arrived, it was found to be too small for him and he had to continue to use the previous one. When he entered the home I took his electric lift chair in for him but this was soon unsuitable for his needs. I was asked if another resident could use this chair as they had a shortage of this type of chair. This resident used our chair until [REDACTED] passed away and then I took it back (my mother now uses it). This poor man then had no suitable chair and remained in his bed.
- They only had 1 suitable lifting machine available. On one occasion, this machine broke down and [REDACTED] was left in his bed for 4 days while it was repaired. He was given a bed bath and had his meals in bed.
- The same happened with the shower chair as he could no longer sit safely in the normal shower chair. They ordered a more suitable one for him and another resident to use but this took over 2 months to arrive. It came 2 days before he passed away and he only got to have 1 shower with it. He was given bed baths which were not really adequate for most of the time. I found that he got severe cradle cap as they were not washing his hair properly.
- He had had a catheter fitted in his abdomen prior to going into the Nursing Home which had made it easier at home but most of the staff were not familiar with this or its care and I frequently had to remind the staff to clean it as it would often get very "gooey" or "crusty". Also they did not ensure that the tubing was safely tucked inside his trousers. All of this was a real concern as it was a high infection risk.
- After a short while he was not put on the toilet regularly and they would put a pad on him. I came in one morning and found him dirty. I informed the staff he needed changing but was told they would tend to him soon. "Soon" turned out to be more than an hour even after several reminders. I would have changed him myself but had been told that I was not allowed to. On another occasion close to mealtime he needed changing and I was told as it was close to mealtime there was no one available to do it. He was then taken to the dining room and had to have his lunch with a dirty pad on (where is the dignity in that?). Mealtimes were worse as one carer was full time on the medication round at this time and could not be disturbed from this important job. This only left 2 staff members to attend to him and as he needed 3 he just had to wait.
- At bedtime the staff were very busy getting all of the residents settled and in bed. I found that he was frequently left until last to be put to bed as there would then be more staff then

to assist him. He was often asleep and had to then be changed and lifted into bed. I constantly reminded them to clean his teeth, and dress him properly – a simple thing like pulling his shirt down and not have it bunched up on his back which increased the risk of bedsores. It was a constant battle to get them to clean/change his catheter bag and also to empty it.

- I was not permitted to be in the room with him for any medical procedure like blood tests or changing his catheter although I had been present for every procedure he had had before he entered the Nursing Home.
- Our GP had advised us that it was safer for him to have a shave with an electric razor because he was on Warfarin. I took in his electric razor but found that the staff still shaved him with a blade – even after being asked repeatedly to use the electric one. Most did not know how to use the electric one or how to clean it when they did.
- I had to increase my work hours in order to pay for his care at this home but I would go there before work which usually upset me as he was frequently still in bed in mid-morning because there was no staff available to get him up earlier. I would come there straight from work so that I could feed him and stayed until he was put to bed. I would come the whole weekend as I found there seemed to be less staff on then.
- I was not provided with any meals and there was not even any tea/coffee making facilities for use and I found that I was not eating properly myself. I did not have time to prepare myself meals and just grabbed a meal when I could.
- He could not communicate very well as the palsy affected his vocal chords and he was usually just left in the day bed which they “parked” in the dining room where staff could see him. The moment I arrived he would whisper “coffee, coffee” and I would go and get him one from the kitchen staff and then help him with it. I found he was not checked often enough and one day found that he had been given coffee and cake but as he could not manage it by himself it was just left to go cold on the table beside him. On another occasion he had been given him a drink in a sippy-cup without assistance. When I arrived I found the cup empty and him completely wet – even the blanket covering him and had to inform staff that he needed changing.

When I would arrive, I am sure that the staff saw me coming and would run away as I was usually on the buzzer immediately wanting attention for him but this was my husband and I wanted him to be looked after properly. He could not talk very well but could whisper and if you took the time he could be understood.

I found the cost of his care in the home very prohibitive. There is a daily accommodation fee which I was told was 85% of the aged pension and the cost (bond) of his room was \$470,000 which I found to be average in Canberra. I did not have this amount available – we did own our home and had purchased an investment home unit a few years prior. I informed our tenant that the unit would need to be sold in order to help pay for his care but he had not been paying the rent properly for some time and then stopped paying rent. It was a private rental agreement and I really did not have the time to chase him.

After an assessment with the Department of Human Resources where they assess your assets, I was informed that we would be required to pay at least \$200,000. If you cannot pay the \$200,000 or the \$470,000 up front, you are required to pay interest and the amount I was required to pay was \$1,810 per fortnight. I managed to sell some shares that we owned to put towards this cost but still needed the bulk of this amount. I was not earning this amount and needless to say, my bankcard was very soon maxed out as it was very important that he get care. Any amount that is paid towards

this cost is returned when the person leaves the home but interest is not. I was in the dilemma of working longer hours to pay for his care and not seeing and assisting him as much as I would have liked and honestly I was not really fit to work any longer hours at that time. Human Resources assessed the amount of rent we were supposed to receive as part of our assets even though our tenant was not paying rent. This added extra financial stress to everything else.

Slowly as his palsy worsened he needed his liquids thickened to a jelly in order to drink and would often choke badly on it. After a while he would also choke on food and his meals were required to be blended. Even still he would choke on it and quite a few times he got aspiration pneumonia and needed hospitalisation. He was barely over one episode and would get it again. During his last hospital stay the doctors informed us that he was not responding to the treatment and his condition was worsening rapidly and that he would not survive long. After discussion with our children and the doctors, we made the worst decision that anyone ever has to make and that was to withhold treatment as we were told that his condition would not improve. He was then put on Palliative care.

Then came the next horrible chapter. As it was deemed he had a "bed in the system" at [REDACTED] he could not get a placement at the Hospice where he would have received more specialised care in his last few days and he would have to go back to [REDACTED] to die. At this stage it was not possible for him to return home. A senior staff member at [REDACTED] advised me not to send him back as they were not geared up for palliative care (unofficially of course) but I had no choice and after a few days in hospital he was sent back there even though there was no full time nurse to assist.

I soon learned that the home was not suitable for a resident on palliative care. I took more leave from work to be with him and for more than a week I stayed by his bed only going out occasionally to get myself a meal. I even slept there a few nights in a chair. Although the staff were very sympathetic they were chronically short staffed and could not assist with most of his care in the end and I was left to do it. If I was not there, there would not have been anyone to be with him or check on him regularly enough.

He had a morphine driver fitted but this soon proved to be inadequate and he required regular top ups to keep him comfortable. Only the registered nurse could do this but as there wasn't a nurse there at night, he did not get any then. I lost my brother a few years ago to cancer and also a good friend. Both of these men died at home and their wives were able to give them morphine as often as it was needed at home but at the Nursing Home only the registered nurse was permitted to administer it and not even the care staff. He often had coughing episodes and although there was a suction machine at the Home they would not use it to suction excess mucous because I was told if he choked that I could sue them.

He clearly needed a top up of drugs throughout the night and It was arranged with the palliative doctor that the nurse would come in at 11p.m. on what turned out to be his last night to give him a top up but this nurse just gave him the injection and then he left even though [REDACTED] was clearly in a bad way. There was only 2 staff on that night – one a young man (he was probably only in his mid-20s) and a very young girl. They were very good to us through the night but they had all of the other residents to care for. I asked for the nurse to come again but he would not return so I requested they call the palliative doctor but the number that the nurse had provided the care staff was incorrect and they could not contact them. I knew [REDACTED] was in a bad way as he was struggling to breathe and thrashing about but all I could do was be there and for the next 4 hours, I just sat with him talking to him and wiping him down until he finally passed away at 4.30a.m. on 28 January 2016. I really feel that he died in a most horrible way with no dignity and without any medical assistance in his final hours. I put in a complaint about this nurse and he was subsequently dismissed and I was

told he would never work in the system again. I am not sorry about this as [REDACTED] should have had a doctor or at least the nurse attend him that night.

When the next staff shift arrived, the doctor was called to pronounce and I was told that they were required to take his body within 10 hours. Even after several calls to this doctor, he did not come until after 2p.m. The funeral director had been there for a couple of hours but they could not take him without the doctor's signature. I was left alone with my poor husband's body in his bed in his room for most of the day just waiting and was told to keep the air conditioner on.

I was then told that I would have to clean out his room or they would continue to charge for his room. The staff and a lot of the other residents were very compassionate and came in to see me but I felt very alone. Our children were not in Canberra at the time. One lives at [REDACTED] with his family, one is in the [REDACTED] and was overseas at the time and one lives in [REDACTED]. She had been here for quite a while but she had had to return home. They had all been in to say their goodbyes while he was still in Hospital.

This was my husband of 42 years and I loved him dearly. I cared for him for as long as I could myself out of love and I would not have had it any other way. He never complained about his illness and accepted what was dealt to him but he did not deserve it. This illness is quite rare and nobody can explain why he happened to get it. I really feel that he deserved to have had better treatment at the end with at least a nurse available to administer the necessary drugs to keep him more comfortable.

My biggest concerns through this whole ordeal were the lack of support from the Government with aged care and the chronic shortage of staff at Nursing homes. Carers in the home provide a very valuable service and need a lot more assistance themselves. Carers ACT did offer me a 3 day break at Jindabyne with about 90 other carers in March 2015 and it was obvious that I am far from alone with the burden of caring for a loved one. A lot of people go through a long, torturous ordeal caring for a loved one without adequate care and assistance for themselves. Carers ACT arranged for a brief respite in another home for my husband so that I could attend and also travel to [REDACTED] to see my elderly mother who is also not well. On my return, I found the staff shortage also to be the same at this home and I really feel that he had not been getting the level of care that he needed. At this time he could still walk with a walking frame and assistance but I was told they did not have the staff or time to walk with him and it was easier to put him in a wheelchair to move him. His mobility deteriorated quickly after that.

Even though [REDACTED] passed away in [REDACTED], I am still coming to terms with life without him. I managed to sell our home in [REDACTED] and even sold the unit in its present condition (at a much reduced price). I have moved to [REDACTED] and now live in a dual living set up with my daughter, her husband and their daughter. This works very well as I have their support and my little granddaughter nearby. My mother is also close by and is starting to need more support so it is good that I am closer. My workplace arranged for me to work remotely in the [REDACTED] office for which I am really grateful as it meant that I could keep the job that I know. I still only work 3 days a week as I am still recovering from this ordeal. I had the support of family and some very good friends but I do really feel that a lot more could be done to help carers and to keep people in their own homes longer without a huge financial burden. It has taken a long time for me to recover enough to write this but I will come out of this ordeal OK. I am sure that a lot of carers do not fare as well as I did. I will always miss him but I know that I did all that I could possibly do for him while he was still at home.

Thank you for reading this and I hope that it might help with improvements to the way assistance is given to carers in their homes and the state of Home Care and also the conditions in Nursing homes. Nursing Homes may be OK for residents who are still mobile and able to communicate but if you need high care, you do not receive adequate care and a lot needs to be done to improve this. You just become another number in an endless production line without any dignity. Without family to assist in Nursing Homes, a lot of residents are left in a really neglected state mainly due to a severe shortage of staff.

THIS IS NOT AN ISOLATED CASE!!!

Thank you for your time.

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

