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(Inq into better support for carers)

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To The Secretary of the Committee into the

# **Inquiry into Better Support for Carers**

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## Introduction

Carers make a major and important contribution to Australian society. They provide accommodation and care for people living with physical and mental disabilities and illnesses, at a fraction of what it would cost the Government. Sadly, due to the nature of their role, Carers are often left with feelings of frustration, anger, depression, isolation, degradation, guilt and hopelessness. They do not receive adequate training or professional guidance, be it medical or emotional, or appropriate financial assistance.

There is a severe shortage of services available to assist Carers, despite many organisations receiving Government funding for this purpose. Carers are not understood by their families, friends, medical professionals, or the community in general. They often have extremely difficult patients and major adversities to face each and every day.

I am the full-time Carer for my father, who suffers from a debilitating mental disease. This submission outlines my story, as well as my views about the role of Carers in our society, some of the key areas of difficulty Carers face and some suggestions for solving these problems.

## My story

At the commencement of 2005, as a 32 year-old single mother of an eight year-old boy, I was operating my own accounting business and looking towards a very bright future. Then, out of the blue one Friday night, I received a phone call informing me that my father was ill. He was behaving strangely and was very confused. Dad lived ten hours from me in a remote country town, but I organised for him to be taken to the local doctor on the Monday. The doctor immediately hospitalised Dad and had him flown out to a larger hospital on the Tuesday where he stayed for seven days. A week later I found myself driving my father to my home in Newcastle to commence being his full time Carer.

The care my father received in hospital was absolutely horrendous and nothing short of neglect. The original diagnosis was Emphysema, because in Dad's confused state he told the doctors that he was a heavy smoker. This had never been the case. The hospital staff completely ignored an extreme case of gout, lost him on one occasion when he decided he could leave 'the hotel' he believed he was staying in, and generally failed to provide my father with any reasonable level of care.

The only diagnosis I had at that stage was that Dad was suffering from 'Acute Confusion'. The hospital staff told me that I would not be able to cope with Dad at home and that I should institutionalise him immediately. Although I did not have a close relationship with my father – my parents divorced when I was only 2 years old - I was not prepared to expose him to any further lack of care. My understanding of Dad's 'care management plan' in a nursing home is that, due to him being labelled with 'aggressive tendencies', he would be sedated constantly until he died. I have never been able to consider this as an option. Besides, in the beginning, I truly believed that I could 'fix' my father and send him home again.

Dad's condition was not accurately diagnosed for another 19 months. During that time, I had no support in caring for my father and very little access to useful medical advice, or resources for Carers. In the end, after hours and hours searching on the Internet, I stumbled upon Korsakoff's disease.<sup>1</sup> My local GP confirmed the diagnosis a short time later. Dad's condition means that he has a memory span of around 20 minutes and is constantly confused by most aspects of daily life, causing him to become aggressive and fearful.

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<sup>1</sup> Korsakoff's Disease is a mental disorder characterised by severe memory loss, confusion, tremors and irregular eye movements, among other symptoms. Learning new information also becomes difficult and patients often confabulate (invent stories) to compensate. The condition is caused by thiamine deficiency.

In the beginning, every simple task was a huge battle. Just getting Dad out of bed was a massive effort. Showering was a two-hour ordeal, often ending in a yelling match. Then I had to get him to take his medication, which he believed was poison. During all this, I had to listen to major conspiracy theories and answer the same questions repeatedly, in twenty-minute intervals.

Basic tasks were too difficult for Dad. He couldn't make himself a cup of coffee or have a shower without assistance. If I didn't pull the bed covers back then he would sleep on top of the bed, as it was too confusing for him to pull them back. Dad's confabulation and anxiety were extremely difficult to bear. He would focus on one thing over and over "where's my jumper, I need my jumper..." and he might be wearing his jumper. For the first nine months, Dad believed that he was 'AWOL' from the army and he was at my house hiding from the Sergeant Major, he believed that he was to be court marshalled if they found him. Dad has never been in the army!

I would try to get him to see reason but that would only make the situation worse. So in the end I would just say "It's alright Dad, I spoke to the Sergeant Major and he said it was okay for you to be here". And then we would have phantom conversations about the Sergeant Major and his phantom army buddies.

Any small change in the house, like taking the lounge covers off to wash them, would upset Dad. He would become more disoriented and say, "This is not your house, I know what your house looks like and it's not this. Where have you taken me this time? You're just lying to me. Stop lying to me ..." Needless to say I don't wash the lounge covers very often!

I was eventually forced to close my business to take care of Dad. I tried to keep it open, but caring for Dad demanded so much of my time that it was just not a viable option. This was one of the hardest decisions I have ever had to make. As a result, our family was forced to live on Government financial assistance, placing us under serious financial hardship.

I had no one I could turn to for support. My only sibling came to visit my father in hospital but could not cope with the situation and left immediately. My brother now has contact with my father once or twice a year. My mother has contact with us about the same amount of time, although she does try to speak to me on the phone about once a month.

Initially, the community nurse would come to visit me and ring me, however she was promoted shortly after Dad came to live with us and her replacement provided me with nothing. I have seen or spoken to the replacement about three times in three years. The total sum of medical advice I have received is "the brain is a complex organ and we don't understand it ... if you are not coping then institutionalise your father". If I hear those statements one more time I think I will scream!!!

I have found help lines and services to be extremely unhelpful for advice and support. There are plenty of phone numbers out there. I call one phone number, they give me another phone number to ring. I ring that phone number and they give me another three phone numbers to ring. I ring those three phone numbers and they give me more, until I end up back at the same phone number that I started with. Having no diagnosis for the 19 months excluded me from accessing services because services are available only to particular conditions.

Even when I finally got a diagnosis and discovered that I fell under the Alzheimer's Support scheme, all the services I thought would suddenly become available to me, were not there anyway! I phoned the Alzheimer's help line once, when I felt that I couldn't cope any longer with Dad repeating the same question constantly. I was expecting some strategies to help me deal with my situation and Dad's behaviour, but the only advice I received was "just pop something sweet into his mouth and that will distract him". If this is the best advice available, then I am in real trouble!

All I seem to hear is: "Well, it all comes down to funding and at the moment the Federal government is saying that the State Government should handle this..." and around it goes. This is not useful or practical to a Carer at her wits end and in need of urgent help! A uniform system between State and Federal Governments is needed to streamline and simplify Carer services.

Then there is respite care. Dad tells me constantly that he wants to go home. I just deal with that. However, if I put him in respite care (that I have waited six months for) I have to sign an agreement that I will come and pick him up straight away if there are any problems. One of these problems is if the patient asks to go home. See my dilemma?

In addition to having Korsakoff's syndrome, Dad has had to have numerous operations and those hospital stays are an absolute nightmare. I remember one particular hospital stay, when I received a phone call from his doctor asking me to come into to the hospital as they were not able to cope with Dad. He had been there less than two hours!

The only piece of practical advice I have been given is, if I am really feeling so bad that I don't think I am coping, then I am to ring an ambulance and have them take Dad to the hospital and then refuse to pick him up. Apparently the hospital is not permitted to release patients, such as my father, without a Carer. But wouldn't that be a lovely situation for everyone involved. As if I don't suffer enough guilt on a daily basis as it is!

Home Care has been the only service that I have found helpful at all. Despite all their computer problems, staffing issues and OH&S protocol, they are fabulous. If it were not for Home Care, Dad would probably be in an institution. I did not get Home Care in for the first six months, because I still thought that I could fix him and send him home. Or at the very least, I could deal with Dad myself - I didn't need help! But I am so pleased that I did ask for help because there is no way that I could do this all on my own.

Another thing that has helped enormously is having pets at our home. Before Dad came, I had a gorgeous kelpie, a budgie and various breeds of fish. After Dad got here I decided that I wanted a little lamb. She is a wonderful distraction for me and Dad enjoys her as well. And then somehow we ended up with a Muskovy duck as well. The interesting aspect to these animals is that Dad cannot remember anything that has happened in the last ten to fifteen years, but he has never forgotten the animals names, nor the nicknames that he has given them. Dad often calls the dog over and says "come here, you're a good girl, you won't lie to me like everyone else does". The animals have been a wonderful support, for both of us. They have a great calming effect.

Dad's aggressive behaviour is the one of the hardest obstacles I face. My father has always had a violent nature, and now I have a violent person with brain damage! After the situation reached breaking point, my local GP prescribed mood-enhancing medication for Dad, which has made an amazing difference. I was very hesitant about using these drugs, but there are no side effects whatsoever and I wish I had received comprehensive information on their benefits and used them earlier.

After three and a half years, I have changed a great deal. I no longer think that it is my job to be orientating my father constantly. I have finally realised that no matter how many times he asks me "so what am I doing here?" he is never going to remember the answer. Now, if he doesn't get out of bed early, I am grateful! I no longer feel guilty when I explain to Dad that I do not have the time to answer his questions at that point, as I have something else that needs to be done, and that I will be back shortly. And I no longer feel guilty when he shouts out at me "well how am I suppose to get unconfused if you're not going to help me?" I have also learnt that I cannot fix Dad's condition. My job is to make him as comfortable as I can and try to be nice to him, even when he asks me that same question for the twentieth time, in as many minutes.

My son and my father are developing a relationship (in a strained sort of a way) and most evenings they play a game of cards together after dinner. I actively encourage Dad's old friends to contact him, but unfortunately most have stopped calling now. He has more friends here than he ever did at his old house. He gets two newspapers to read every day, there is always fruit and light beer in the fridge and he gets a good solid meal every night. He has his daughter and grandson around him most of the time and the menagerie of animals to entertain him. I don't think he could ask for more than that!

After three years as a Carer, I was able to see my way clear to re-open my accounting business from home, with the assistance of Home Care for 10 hours each week. I believe my business will make a profit in the near future and I will be less reliant on Government financial assistance. Because of my business, I feel I have a purpose and a sense of achievement at the end of each day. I am not devaluing the role of a Carer, but when you have to do the same thing over and over again, there is no sense of achievement, only a feeling of wasted time and energy.

I started [www.carershaven.org.au](http://www.carershaven.org.au) in December 2007, which has enabled me to feel connected to other Carers and accepted. I now realise that there are so many other people in the community going through the same feelings of frustration and anger as I am. And that it is okay for me to feel those feelings of frustration and anger. Whilst the site is only very young and the word has not spread yet, I have made some really good friends who do understand and are on the same wavelength as I am. I have something in common with other members of society after all! And I don't need to leave my house to do so. And it doesn't cost me anything to have these conversations and connections.

I believe I have worked through my feelings of anger, isolation and "why me?". And now I am currently trying to decrease my levels of frustration, which will take some time, I am sure. But I think I have established a fairly good life for all three of us.

Sadly, I had to get to this point the hard way, and alone, because of the lack of support services for Carers in my situation. While Dad is now comfortable and living a happier, healthier life than he has for years, my life has been turned upside down and our family has been placed under extreme financial and emotional stress.

## **The role of Carers and their contribution to society**

The role of a Carer is vast and varied and there is not a person who would willingly choose to undertake that role if there were other suitable options available. Firstly the role is 24 hours a day, seven days a week. Any breaks are few and far between and have to be organised well in advance, to usually fall apart at the last minute. The job description of Carer usually entails being a doctor, nurse, psychologist, pharmacist, cleaner, cook, taxi service, entertainment manager, personal assistant, bookkeeper and a total tower of strength, just to name a few. All duties are to be carried out without complaint, with a happy, helpful personality and often with patients that are going to fight you every step of the way with every particular aspect of your job. Carers usually have absolutely no training and little assistance to carry out this role.

The most significant contribution to society I make by being a Carer is that I save the Australian Government around \$280,000 per year by not institutionalising my father. I also enable my father to have a quality of life that he would not be afforded if he were living in an institution.

In addition to the every day difficulties of caring for patients with a wide variety of mental and physical problems, Carers in Australia are forced to navigate a bureaucratic and administrative maze, to access support services (which are few and far between) and the measly financial assistance available that is critical to their role. This belittles and undervalues the huge contribution that Carers make to society and makes a thankless job even more difficult.

The role and contribution by Carers should be recognised by placing value and importance on this role. The following sections set out some of the key problems Carers face, followed by some possible solutions.

## **The Challenges facing Carers**

Carers are faced with many challenges every day that reduce their quality of life and make caring for their patient even more difficult. These include:

- Dealing with the medical system
- Emotional and health issues
- Poverty
- Lack of services
- Problems accessing financial assistance.

These are detailed below.

### **The medical system**

#### **Lack of information and support from medical practitioners**

I have found it incredibly difficult to get good and consistent medical advice on my father's condition. There has been a lack of understanding of his illness – to the extent that I ultimately diagnosed it myself, as well as a lack of empathy and respect for the choice I have made to care for him. Whenever I ask a question or seek help on a subject, medical professionals either do not know the answer or suggest that I institutionalise him. This is incredibly frustrating. If the professionals don't know the answers, it would be more helpful if they could give the Carer some direction to research the subjects themselves.

To compound this problem, medical professionals often do not prepare for consultations by reading the patient's file beforehand. In my father's case, this results in a cycle of events where professionals do not understand my father's condition and he is treated in a way that confuses and upsets him. Ultimately he is refused medical treatment because he is too agitated and we are forced to reschedule the appointment and start again. The medical officer's involvement will end there, however, I am left to deal with a confused and aggressive person. This can be simply avoided by reading Dad's records before commencing treatment. It really isn't a lot to ask!

It is important that dealings with the medical profession are made as simple as possible for Carers, because just getting to an appointment is difficult enough, without having to deal with practitioners who are unprepared and do not treat the patient appropriately.

#### **Lack of respect for Carers' knowledge**

In most cases, Carers are members of the patient's family and spend many hours in the patient's company. Because of this, Carers have an excellent understanding of the patient's condition and behaviours. In contrast, health professionals often have a theoretical understanding of the condition at best, yet in my experience they often do not acknowledge the Carer's expertise.

Although Carers usually know more about the patient than the health professionals, this does not mean we don't need their help. We do not expect the professionals to know as much as we do, but we do not expect to be belittled or abandoned by them. It is critical that the specific case knowledge of Carers and the expertise and resources of the medical profession are used together to achieve the best possible outcomes for both patients and Carers.

## **Waiting times**

Waiting times for medical services are inexcusable. There have been many instances where I have taken my father for an appointment, only to wait for two or three hours! I understand that medical resources are underfunded, but as a Carer with no funding, no time and no support, I find it difficult to sympathise.

Continually being hours behind in appointments is bad management. Consultation periods need to be longer!

## **Humiliation of patients**

Although patients are often mentally or physically impaired, they should be afforded the same respect as any other patient visiting a health professional. In my experience, health professionals often have little regard for the patient's state of mind. They are there to treat a particular symptom. In one instance, a specialist tried to perform a prostate examination on my father – while I was in the room!

When most doctors work out that my father has some form of dementia they start talking to me as if Dad wasn't in the room. Doctors have said to me, with Dad sitting beside me, "Your father does not seem to have the ability to communicate normally, has inappropriate behaviour, and my professional advice is that you should institutionalise him". I try to explain "Doctor, he can still hear you, he is not deaf, there is nothing wrong with his hearing!" Patients also have emotions and this treatment is humiliating and degrading to them. To compound the problem, these feelings are often taken out on Carers. On more than one occasion I have been left extremely fearful for my safety, purely because of the treatment my father has received from health professionals.

Doctors would not contemplate having a denigrating conversation in front of a child they were treating. Why is it seen as appropriate for this to occur in earshot of handicapped or disabled adults?

## **Lack of care**

When my father was initially admitted to hospital, he was incorrectly diagnosed with emphysema, despite not having smoked for over 30 years. Medical staff said that this illness was his fault. They did not bother to seek his medical history to diagnose him correctly.

Because of his illness, my father is considered a waste of space and not worth the effort to correctly diagnose or treat properly. Dad was also extremely crippled due to degenerative knees. It took me months to find a surgeon who would see him. Finally I found a doctor that was so appalled with the state of my father's knees he agreed to do the operation. My father's brain doesn't work like it should, but he still feels pain. Why should he not be entitled to have his knees operated on just like every other member of this society?

Health professionals seem to see these patients as 'damaged' and therefore not worth the resources, time or effort they would afford to a healthy person.

## **Expectations on the Carer**

In a usual hospital stay, I am required to change Dad's sheets, remind the nurses that his medication is overdue, take him to the toilet and shower him. I also have to carry out his prescribed exercise and mobility schedules as no one else seems to ensure they are performed, and meet any other need my father has during that stay, aside from inserting needles. On one scheduled hospital visit, the ward organised a bed for me to sleep in so that I could continue the 24-hour care my father needed, as they were not able to cope with my father's condition.

On another hospital stay I had arrived at the hospital at 8 am that morning and left at 6 pm that night, only to receive a phone call from his doctor at 7 pm asking me to come back to the hospital straight away as they were not able to handle him. I informed the doctor that I was unable to come back that night as I had a 9 year-old son to take care of. I did make some suggestions to the doctor as to ways to better manage my father's condition. I



was abruptly told that he was not prepared to try any of those suggestions and that he would sedate my father until I was able to return to the hospital.

Please also consider that hospital stays are considered respite for the Carer.

## **Emotional Issues**

### **Isolation**

By the very nature of the caring role, Carers are isolated from the community. We are unable to leave the patient for any length of time, which means we cannot participate in social activities and generally lose all ties with the community. Carers find that when we do socialise, we are no longer on the same 'wavelength' as our peers, as our priorities and awareness has changed dramatically.

The caring role is all-consuming and sometimes we don't even have the time to watch the news, for weeks on end. This means that we are often not aware of current events around us. Carer's conversation topics are seen as depressing and not understood by the non-Carer. This inevitably leads to the Carer not raising the only subject they are privy to, therefore feeling totally isolated from any form of conversation because they cannot take part, or feel that we no longer have anything in common with our friends.

Poverty is another isolator for Carers. I have been invited to go to morning teas with school mums, however I could not afford the \$3.50 for a pot of tea. I would need at least a week's notice and to re-work my budget to be able to afford this luxury.

### **Degradation of the Carer's role**

Being a Carer has a stigma attached to it. I am a qualified accountant as well as being a full time Carer. The reaction is substantially different if I tell people that I am a Carer than if I tell them I am an accountant. I know that by caring for my father full-time, I am contributing to society and saving the Australian Government (and therefore taxpayers) a significant sum of money each year, although there is very little understanding or recognition of these facts by most non-Carers.

In addition, non-Carers have no idea of our daily struggles and can be quite judgemental. Strangers usually see the best side of our dependants. The patient can usually present very well for short amounts of time. This can cause people (including those in the health professions) to think that Carers are exaggerating their problems, or worse – rorting the system.

### **Guilt**

The guilt is overwhelming for Carers. I have guilt about how I speak to Dad when my frustration levels are high. I have guilt that I may not be providing the best care that I can because of ignorance on my part. I have guilt that I am neglecting other aspects of my life, such as my child's needs, because I am attending to the needs of my father. I have guilt because I am so frustrated and angry all the time, and I know I am not the best person to be around. I have guilt because I feel I have 'drawn the short straw' in life, made worse by the knowledge that there are numerous other people worse off than I am. I have guilt for wanting this caring role to be over, but knowing that involves the death of my father. So much guilt to live with all the time!

Carers need recognition that they are providing the best possible care for the patient that they can, and that usually the patient's alternatives are not very pleasant. Carers need reassurance that we are not trained doctors, nurses or health care workers and cannot be expected to have the knowledge that comes with that training. We need to be reminded that we are doing the very best that we can, given the circumstances. If there was greater support available for Carers, these issues may be alleviated to some extent.

## **Dealing with family and friends**

There are two types of family members, one that interferes and questions every decision you make, but doesn't want to 'get their hands dirty' or the one that runs away saying 'I can't handle this'. It is very rare to have supportive family members. My family were the 'runaways' and don't even bother to call my father for his birthday.

Generally speaking, Carers are usually caring for a family member, so are unable to vent to other family members about the caring role, due to family sensitivities. The patient often behaves differently with each family member, and some members may never see the full extent of their loved one's conditions. Families are emotional minefields at the best of times without adding a dependant relative to the mix.

## **Monotony, Redundancy and Depression**

The endless dreary routine of doing the same things over and over and over again! Knowing full well I am only going to have to do it all over again tomorrow and the day after and the day after that and there will be no improvement in my father's condition. My father is only 63 years old. This means that I could be doing this role until I am in my sixties myself. This has obvious implications for my life.

Carers generally take on the caring role because the alternatives are too horrendous to contemplate. It is a completely thankless role. As a mother, you generally have the joy in watching your child grow and develop into adulthood. As a Carer you usually get to watch your patient regress and deteriorate to the point of death.

As a Carer, I constantly have to ward off depression and anxiety over my situation. The constant arguing and fighting with my father to do the simplest of tasks, such as having a shower, knowing that this is not going to end anytime soon, is completely overwhelming. There is no foreseeable end in sight, no light at the end of the tunnel.

These factors all lead to high levels of stress, which the Carer lives with each and every day with nowhere to release it. I am constantly at my tolerance threshold and it takes something very small to push me over the edge. This is one of the reasons that so many Carers end up with health issues of their own. Other reasons why Carers end up with health issues are lack of time, money or the capacity to make themselves a priority. I have had a problem tooth, which often becomes abscessed, for three years now. Due to lack of time and money I have not had this tooth seen to.

## **Hopelessness and Grief**

The caring role is never ending. The only way this job ever finishes is with the death of the patient. If you are not actually working with the patient, then you are thinking about what you have to do next with the patient. I wake up some mornings not wanting to get out of bed, filled with despair at another day of caring for my father, knowing that I have no choice.

Grief is generally a large component for the Carer. Usually the patient is a spouse, child or parent and that relationship is fundamentally changed forever once the patient becomes dependant. The Carer has to cope with all the burdens involved in caring and the sudden loss of the relationship which they once had.

## **Frustration**

Frustration is the Carer's constant companion. You are frustrated because there are no services, no support, no understanding, no relief and no end. The frustration of constantly battling with the patient to do a simple daily task does not leave you before the next battle starts. My father has a maximum 20-minute memory span. So the questions that he asks now, I will have to answer in twenty minutes time. The more tired he gets, the smaller the memory span gets. My father can ask the same question before I have even finished answering the last time he asked it. Just knowing that the questions are coming is enough to make you want to jump off the nearest cliff.

## **Poverty**

The Carer's pension is \$280 per week. My mortgage is \$300 per week. Even as an accountant, I just cannot make those figures add up.

In addition there is the extra burden of medications and medical aides and accessories usually needed in the caring role. Items such as wheelchairs, walking frames, patient moving equipment, even incontinence aids, the list is endless. All Carers have extra hidden costs, which are not taken into account and are impossible to cover with the Carers Pension. For example, my father is not capable of taking a prescribed inhaler for a respiratory condition, which means we have to buy the medication in a tablet form at \$80 per month. Shouldn't this be subsidised because of my father's inability to use an inhaler?

To cover our basic costs of living, I was forced to borrow money against my home loan for three years straight. This ultimately made my mortgage repayments completely unmanageable, but I had no other choice. Usually Carers are thrown into the caring role without warning and if they have to give up work, then (unlike rental payments) there is no assistance available for mortgage repayments.

I save the Australian Government \$280,000 each year by taking care of my father and in return the Government pays me a paltry \$17,000 per year. It doesn't matter how you look at the situation, this amount of money cannot cover the financial costs involved in being a Carer.

In addition to the inadequacy of payments to individual Carers, the funding of government departments does not seem to be being spent where it is needed. I once phoned the Department of Aging and Disability and was told that there was no one in that entire Department able to assist me. I was informed that there were 900 employees working in that Department, instituted to oversee people like me, and no one was able to assist me. Flabbergasting!

A review of funding for this area is urgently needed – to ensure that it is adequate and that money is allocated to where it is needed.

## **Lack of Services**

I receive 10 hours of assistance from Home Care per week. I know that I am fortunate to receive this number of hours, and I am extremely grateful for this service. Without Home Care there is no possible way that I could continue this role as a Carer. Home Care is subsidised by the Government. I would not be able to afford this service if it wasn't subsidised.

However, there are so many rules and regulations, OH&S compliances and other protocols associated with this service. For a respite service, the Home Carer worker is not permitted to perform any task except 'babysit' the patient. For a personal care service, the worker is only permitted to toilet, shower and layout prepared food. For a domestic assistance service, the worker is permitted to clean only. It is against regulations for these three services to be intertwined. I just need help. I do not care what it is called. It would be of very helpful to me if I could have some one who is able to do a bit of all three services.

Pathology will come to my house to collect samples from my father. This is also of great assistance to me, as I don't have to fight my father to attend a waiting room for hours on end, for a test that he doesn't believe that he needs. It took me almost two years to find out about this service.

There are no other services available to me. In the beginning, I was told that there were no services available to me as I did not have a diagnosis and did not fall under any particular organisation. Dad was either too old or too young or didn't fit the criteria for this activity or that organisation. Finally when we did fit the criteria, there

weren't any real services anyway. It is extremely frustrating to believe that you are about to 'belong' somewhere only to find that there is nothing to 'belong' to.

After nineteen months, I finally identified Dad's condition myself. This meant we fell under the 'umbrella' for Alzheimer's. Feeling so elated that I finally had an organisation to turn to, I was left feeling cold when Alzheimer's Australia told me that there were no services available to help me anyway.

I was told bluntly that my father is the only person suffering from Korsakoff's Disease who is living in the community. I find this absolutely unbelievable, but short of putting an advertisement in the newspaper, there is no way that I can verify this. So I am left isolated.

The endless merry-go-round of telephone numbers is one of the most harrowing experiences of my life. Carers are all given a 'green' book containing a list of support places. I called one number, who told me they were unable to help me but would give me another phone number. I would ring that phone number and get told that they were unable to help me but to try these phone numbers. I eventually ended up at the same phone numbers that I started with. This type of experience is incredibly frustrating, leaving the Carer feeling more isolated and lost and abandoned than when they started. These feelings are compounded by the knowledge that precious funding is being spent on telephone operators that do not provide any assistance!

### **Access to financial assistance**

I spent the first two years in the caring role fighting with Centrelink. I understand that Centrelink has a job to do but each time I have dealt with Centrelink, they made me feel like a criminal trying to rort the system. As I have already noted in this submission, I save the Australian government \$280,000 per year by looking after my father, in return the Australian government pays me less than \$17,000 per year. I understand that some people rort the system, but who would choose to do this as a Carer?

Another issue relating to financial assistance for Carers is the 25-hour rule, which states that to receive the Carers pension, full time Carers may not work outside the home for more than 25 hours per week. It is important that Carers have interests, hobbies, or jobs outside our usual job of caring. If the Carer is able to manage the caring role and a paid job, it is important that we are able to do so and not be penalised. Usually the Carer is the best person to judge what the patient's needs are, and if they believe that they can work and fulfil the caring role, then they should be entitled to do so. Keep the pension means-tested, absolutely. But please allow us the flexibility to work outside the caring role and allow us to earn extra income, value and significance as part of the community.

Working outside the caring role will also enable us to be Carers longer as the 'burn-out' will not onset so quickly, and we will gain or retain other skills. The Government will end up saving money, as it will enable Carers to contribute towards household income, reducing their reliance on pensions and other Government assistance.

### **Respite Care**

While respite care is desperately needed to help Carers in their work, it is extremely difficult to access and there is a waiting list of at least six months. Carers usually only attempt to access respite when they are desperate. At this stage, the need for respite is urgent and this length of wait is unacceptable.

In addition to this, the conditions attached to receiving respite care are often prohibitive to the Carers that need it. For example, to access respite care for my father, I would be required to sign a form upon admission stating that if he asks to leave then I will return immediately and collect him. My father asks me many times a day to be able to go home. How long before he asks to leave a strange environment? This is not practical and not worth the strain and concern of attempting the respite, only to return within the first twenty minutes of leaving him.

My only option for out-of-home respite is to call an ambulance and refuse to collect my father from the hospital. Health Care professionals suggested this to me as a last resort. I have been close to calling that ambulance on numerous occasions, but this is not an acceptable care solution for me and would be a waste of resources for hospitals already under stress dealing with physically ill patients.

## **Possible solutions to the problems facing Carers**

### **Removing barriers to social and economic participation**

Carers are isolated from the community because they are required to be with the patient at home and find it very difficult to leave. Because the caring role is completely all-consuming, we find that we are no longer aware of what happens around us, which then isolates us more and makes us feel completely disconnected with society. Caring changes your perspective on the world and because we change and our priorities are dramatically different, often happening overnight, we feel that we don't have anything in common with our friends anymore.

One solution to this problem is to connect with other Carers. It doesn't matter what condition you are caring for, the levels of frustration, anger and hopelessness are going to be the very similar. Carers that do find other Carers can then socialise amongst themselves, creating a sense of belonging and acceptance.

I needed to feel connected and understood, so I started an on line forum, [www.carershaven.org.au](http://www.carershaven.org.au) which enables me to communicate with other Carers who understand what I am talking about, who don't berate me for 'downloading' about my father or the caring role. It also provides a forum for other Carers to do the same. I made a place where I felt accepted and connected. This is just one example of the types of resources Carers need.

Carers also desperately need access to real and useful professional advice, whereby the best help may just be someone to listen to you. Carers are fully aware that their situation is not going to improve, but sometimes we just need someone to hear our frustration and sympathise, if not empathise. Somewhere to download, be it online for some, or by telephone for others, or by face-to-face encounters.

Respite for Carers is also a critical part of the solution. This can allow the Carer some form of life outside the home, as well as having the patients needs met. Reducing the amount of time spent with the patient will increase the effectiveness of the Carer and also allow the Carer to regain some sense of themselves as members of society.

Carers need to find something for themselves. I built a house, which gave me a great sense of achievement to combat the hopelessness of being a Carer. It doesn't need to be that extreme. It could be something as simple as completing a jigsaw puzzle, or a patchwork quilt. The Carer also needs to have something to look forward to each week. It might be lunch with friends or a movie etc. Mine is a hot bath every Wednesday night and God help those that interrupt that plan.

A professional, free, regular telephone counselling service dedicated to Carers would help them to work through all the emotional issues involved in being a Carer and would probably speed up the process. Family meetings and perhaps mediation may be helpful in some situations also.

The economic barriers to being a Carer are obvious. However, as inadequate as the Carer's pension is, Carers rely on it and do not want to jeopardise this essential income. The restriction on paid working hours to 25 hours work per week (including travelling time) makes it impossible for Carers to find paid work. If the Carer can organise for the patient's needs to be met and work more than 25 hours per week, then why is this not possible? With the assistance of ten hours of Home Care per week I am able to run my own business from home and still ensure that my father has all the care he needs.

Being in the work force again has enabled me to break most of the social barriers I was facing when I was restricted to the caring role only. In addition, I anticipate that it will shortly help me break the economic barriers I face. Or at the very least, help meet my cost of living. This will also reduce my dependence on Government assistance.

Other practical solutions to the problems associated with poverty include:

- Allow for mortgage assistance, as for rental assistance.
- Allow GPs and community nurses to evaluate what medical aides are required for each patient and have them request this equipment and services directly from the government which the means-tested Carer isn't required to completely pay for out of their \$280 per week.
- GPs could also be given the power to fill in ACAT forms (Aged Care Assessment Teams) therefore reducing the two-year waiting list for accessing these forms.
- Review the funding and role of the Department of Disability and Aging. In my experience, this large department does not provide any useful services for Carers. The cost of running this department could provide tangible relief such as medical aides, mortgage assistance, grocery money for Carers and their dependents.

## **Practical measures to support Carers**

The key practical measure to support Carers would be a free telephone counselling service. While telephone counselling currently exists, it is limited to 6 calls per Carer and then you are left on your own. This service needs to be ongoing and available for any Carer to access, regardless of the condition they are caring for.

Another measure would be on-line support, perhaps in the form of an on-line forum. This would allow the Carer to communicate with other Carers in the convenience of their own house and in their own time. [www.carershaven.org.au](http://www.carershaven.org.au) is a good example.

A single national phone line whereby the Carer makes one phone call and the services that are available to that particular condition contact the Carer. Or the Carer is told from the onset that "there are no services available to help with that condition, but here is the Carers free telephone counselling line". No more months of the merry-go-round phone numbers to finally realise that there are no services to help.

Consolidate all the small support groups that receive piece meal funding and government organisations into one very efficient and streamlined 'one-stop shop' that can provide real help for Carers. There are 900 people working in the Department of Aging and Disability and not one person there could help me. Carers Australia, Alzheimer's Australia etc has been absolutely no help to me in the three and a half years I have been a Carer.

Consolidate all the different forms and administrative hoops that Carers need to go through. Have the GP fill in the forms for ACAT – after all they are completely aware of the patient's condition. Have the GP fill in the forms Centrelink require. I understand that a lawyer has to draw up the Power of Attorney and Enduring Guardianship forms, but make Carers aware of the need for these documents and make them easier to obtain, through a letter from the GP.

Provide family counselling or mediation, because families are usually divided on what is the best care for the patient and this can be quite a minefield to manoeuvre without outside help.

Provide subsidies for medical equipment and medication needed by the patient. The patient's doctor could verify these needs.

Another very simple idea that would help reduce the isolation Carers feel, is to create local registers, kept at local libraries, hospitals, or similar places, where Carers can record their age, the patient's age and their disability so Carers can access other people in similar situations. This would obviously be done voluntarily. This would cost next to nothing to facilitate. An exercise book is all that each library/hospital would need to provide.

To help improve problems with the medical profession, professional health care worker should be required to do work experience in a full time caring role as part of their training, to experience the day-to-day trials and tribulations of the Carer and the patient.

### **Strategies to assist Carers to access opportunities and choices**

Usually the Carer is thrown into the caring role unexpectedly and suddenly. There is no warning, no adjustment process. Carers need time to adjust and cope with the new challenges they face with being a Carer. This took me two and a half years before I began to see that there was a chance that I could have a life as well as be a full time Carer. It takes longer for others. This process may have been sped up for me if I was able to sit down and discuss my situation with someone who had some experience on the subject and could provide reassurance and counselling on opportunities available to me outside the caring role, as well as choices to help me care for my father. Perhaps this could be achieved by telephone counselling, which would also assist with many other issues that Carers face.

Once the Carer has moved through the initial shock, they need to work out a management strategy. This is very different for every individual. But this process could also be assisted through telephone counselling. To work out a management Strategy, the Carer will need to know exactly what services are available to them and the patient in order to be able to make informed decisions. A National telephone line which identifies all the services available to the Carer in one simple phone call would be extremely helpful to make decisions.

The most effective facility enabling me to make the transition into and out of the Caring role is Home Care. Without this in-home service, I would not be able to make any transition out of the caring role. I have no one other than Home Care that can assist me with Dad. I have ten hours of Home Care per week. With this knowledge I am able to plan my life around this help. I can stretch the two-hour Home Care visit to four hours by leaving Dad the hour before and not returning until the hour after. I am extremely fortunate to receive ten hours of Home Care per week. Not everyone is able to receive this amount of time. Perhaps more Home Care hours for Carers should be contemplated.

The Home Care Service has a number of flow-on effects for my situation. Because of Home Care, I am able to operate my bookkeeping and accounts business from Home. The mundane, redundant and repetitive jobs associated with the caring role are easier to cope with because I have a sense of achievement, purpose and fulfilment through my business. I can now cope with the idea of being a full time Carer for a great many years. This was not the case before re-opening my business.

I anticipate reducing my reliance on government financial assistance in the near future due to my business operating at a profit in the foreseeable future. So not only will I be saving the Australian Government \$280,000 by caring for my father, I will also be decreasing the \$17,000 I receive in assistance.

I now feel re-connected with the community and can manage 'normal' conversations that don't involve the drudgery and hardships of being a Carer. I am somewhat more aware of the society in which I live due to my reconnection. And my clients are extremely happy that I am able to assist them with their issues relating to their accounts and bookkeeping. This is all due to ten hours assistance from Home Care.

## **Pre-emptive financing**

The Australian population is ageing and increasing. Medical advances are managing to keep our loved ones alive for longer periods of time, albeit with impairments, disabilities and other physical and mental deteriorations. This means that there will be an increased need for medical aides, such as wheelchairs, mobility assistors, incontinent aides etc. It would be wise to budget for these future needs with an introduction of a National Medical Aid Scheme, or something similar, along the lines of Medicare.

To illustrate such a scheme: If there are 4 million tax payers, who pay \$25 per year into this National Medical Aid Scheme, this would produce \$100 million per year which would be available to assist in the purchase of medical aides when they are required. This National Medical Aid Scheme would not require a major department to 'oversee' the operation. The local GP could put the request for aid into one of the 900 existing staff in the Department of Ageing and Disability. The GP would be verified and the request would be granted according to priority.

Perhaps a National Insurance policy could be an option to cover our costs should we find ourselves forced into the caring role? However, I would not have willingly participated in such a scheme as I would have been adamant that I would not find myself in the caring role.

## **Conclusion**

Carers provide an important service to Australia and yet do not currently receive the financial, medical or emotional support they need to effectively carry out this role.

Carers desperately need practical support services, better funding and better medical care. Above all else, Carers needs to feel connected and understood. We need to have a sense of purpose, value and a sense of achievement. We need hope and a belief that we will be able to obtain a manageable situation. All of this is achievable with the right support.

Thank you for taking the time to read my lengthy submission. I hope some of my information and personal experiences are helpful to your inquiry. Please feel free to contact me if you require further information.