Submission No. 952
(Inq into better support for carers)

Rec 27/7/08

30 June 2008

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to present a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

Introduction

Carers are a diverse group of people including: Grandparents, parents, sons, daughters, grandchildren, spouses and siblings. They care for a diverse group of people, including: Grandparents, parents, sons, daughters, grandchildren, spouses and siblings. All requiring a variety of medical, educational, personal, emotional and physical supports and needs.

Some Carers are new to the role and others may have had many years experience. Some have support networks and others work alone. Some care for one person and others more than one. Some have previous employment experience and others have not, and there are some who maintain employment alongside caring duties and responsibilities.

Carers are as diverse as those being cared for, yet, interwoven amongst the diversity are common concerns and challenges. I hope this submission highlights common issues and provides an insight into the roles and responsibilities of Carers, which may be considered by the Committee for inclusion in the current Government inquiry to better meeting Carers needs.

Background

In acknowledging the diversity of Carers, I believe it is necessary to clarify my current role as a Carer and the challenges that I face in my situation.

I resigned from employment at 41, to care for my mother (who had a stroke at 60 years), my Grandmother of 84 and my 10 year old son. I now have 3 years experience as a Carer.

In 2006 my mother's health issues worsened and she relocated to an Aged Care Residential Facility. She visits us every 4-6 weeks for a few days to spend time with the family; creating communication boards and attending GP or specialist appointments. At times I am required to attend the Facility to assist her with issues that need to be addressed, such as ensuring her meals meet diabetic requirements, arranging a phone in her room or internet connections.

- I am not recognised by Centrelink for this additional care, which I believed would become the responsibility of the facility, as she was a permanent resident. However, I now realise there are many staffing issues surrounding this issue.

My Grandmother's medical conditions include: Aged, Macular Degeneration (Vision Loss), and Hearing Loss, Osteoporosis, Osteoarthritis, and Rheumatoid Arthritis, Hernia, Anxiety and Hypertension. She uses a walker and wheelchair for mobility and needs assistance with daily tasks.

Personal care services (showers) are booked daily in addition to 1 ½ hour companion care per week and 1 ½ hour domestic services per fortnight. This enables me to access 4 ½ hours respite regularly per fortnight, which is when I am able to leave the house knowing my Grandmother in not alone. In addition my grandmother attends a residential facility for two weeks every 3-4 months per year, enabling me to spend time with my son while she has time with her daughter.

Becoming a Carer

Concerns, challenges, suggestions

Following are a range of issues that I have found to be or currently find challenging, including possible suggestions for consideration.

Medical

- The first issue to face was Mum's stroke. What was her condition? What were her medical needs now and in the future? What was the impact on her cognitively, physically and emotionally? Would she be independent? Is she mobile? What are her nutritional needs? What are the side effects of the medications she is taking, which exceeded 17 per day at that time? Will she be able to communicate?

  Staff at the hospital did provide advice on the medical condition/s and what to possibly expect and a list of her medications and medical needs – while I hastily wrote down names and numbers and a list of things I needed to remember to

contact or organise. Funnily enough in my haste not much of it made sense when I read it. At this point I was fairly overwhelmed and overloaded with information.

When Mum was discharged was when I needed the most support, information, encouragement and the physical energy to be effective. I did not know who to call first and which agencies were phoning me back about what.

- *Perhaps at this point a Case Manager could be assigned to assist the Carer with a 'checklist' of prioritized items for consideration combining a list of services for the most appropriate assistance. Wouldn't it be lovely if one person could come and ask me a list of questions to then return with a complete list of who would be here, when and for what including all their contact details?*

- *Of course the person being cared for would also need a Case Manager, however, it MUST be recognised that they require a separate Case Managers. Both clients are entitled to be recognised as individuals who are receiving professional impartial advice representing their own interests in order to protect their rights as people.*

  For example if my Grandmother had concerns regarding her care, who represents her? In addition the concern could be as simple as getting meals 10 minutes earlier to neglect or abuse, which she many be unwilling to raise with me or my Case manager. Yet with her own Case Manager she may open up about these and other issues. From the other perspective I may be unwilling to raise issues with her as simple as why is she always late for meals to as harsh as her hitting me. Of course these situations DO NOT occur between us and are extreme examples provided only for impact of the necessity of two different Case Managers as representatives for two different people's needs.

- *Two case managers could work as a team, representing both clients, professionally, impartially, confidentially, ethically and supportively, and perhaps at times act as mediators for simple miscommunications or frustrations with service provider issues that impact on each person differently.*

- *Two case managers could simultaneously time their appointments so the spin off could be a little bit of respite.*

Accommodation

It was obvious that the family home would not be suitable due to lack of mobility. The house entrance and exit had unmanageable stairs. The hall ways were too narrow for a wheelchair and the bathroom would need renovation. To relocate for Mum was going to be a difficult emotional experience; it was where she felt safe. I

know myself when I am unwell I want to be in my own home, with my own things and this was going to be something that never crossed our minds until later. We were too stressed and confused and it was the following list that kept churning through our heads.

- Where could Mum live?

- Her home was not large enough.

- We could organise a ramp at the front and rear, but that doesn't fix the 'can't get the wheel chair down the hallway' problem.

- Mum could move to my rental property? Her furniture would need to be put in storage and I would need landlord approval.

- Rent a property that suited her? Where? Cost?

- Who can look after her during the day? At this point Mum was in a position where she needed someone with her. She was scared and needed help. She would ring my office no less than 4 times a day regarding something minor. Due to her stroke, her memory had been impaired and she did not realise she was doing this.

- What can the family do? My brother he had a 4 year old daughter with mild Autism and a 3 yr old active son and he himself had recently completed a course of chemotherapy and radiation for Hodgkin's Lymphoma. We sat and discussed it to try and come up with any plan possible; it seemed the only thing left to do.

- Aged care facilities would be expensive. The facilities were at that time entitled to 85% of the person's pension. That would leave mum about $90 a fortnight to pay for her medications, telephone line, and special creams for her pain relief, travel costs etc. Leaving no savings opportunities.

  While investigating accommodation options we could only think of two. An Aged Care Facility or relocate (rent/buy) accommodation that would be appropriate for Mum, my Grandmother, my son and myself.

- She had *just turned 60*, two weeks before the stroke.

- Influenced by the above points we relocated myself, Mum, my son and our 4 pets to one home which we could modify to suit our needs. My Grandmother, who my mother had been caring for was in a Nursing Facility and she joined us 4 months later. While making it a very busy house, it was lovely to have 4 generations in one home.

- What accommodation would suit Mum's current and future needs if she wanted to remain independent?

- *Perhaps a village type of residency where people can live in their own independent and equipped unit/home. The residential site could provide onsite laundry and dining facilities, an activity centre, hydrotherapy and physiotherapy areas, transport to shops, personal carers, and medical services and staff when required.*

- *Younger clients could then have more choice. To live independently while using onsite services as a community member as such, or they could be a resident on-site. Residencies could be purchased or rented enabling lower income clients' rental ability while locating to adequate housing, which was catering for their needs and may be entitled to some government rental assistance.*

- If we found accommodation would it suit all our needs and our budgets and which services are we willing to sacrifice?

- When we found accommodation, how will she manage, personal care, meals, medications, and her daily needs when she is alone?

Finding a Carer

- What are the options out there? What do they cost? What do we qualify for? How long does it take for the assessment, the approval, and the start up? We did have an issue with personal security of having a number of strangers in the home and not knowing their qualifications or their experience with the situation they are working in. For example, do they know how to communicate with a Deaf/Blind person? Someone who has sensitive skin conditions and needs dressings changed daily? Are they able to administer medications?

- After one month of investigating this option it was obvious that a live-in Carer would exceed any budget we could manage. A live-in Carer would certainly expect a salary above the Carers pension, which did not include any work related entitlements such as: sick leave, recreation leave, superannuation, compensation etc. Carer support in the community could not guarantee a consistent staff member as there is a high turn around in this industry. Influenced by these financial constraints and the limited facility options the responsibility fell on a family member.

- I resigned from my part-time office and part-time CIT Teaching positions and maintained subcontract employment as an Auslan Interpreter. It seemed reasonable that on-call work of an interpreter may be more manageable than employment with fixed times. However, on-call requests for interpreting services and the required employment and professional development and training clashed

with my Mother and Grandmother's medical appointments, meals and medication times. I was committed to providing reliable employment services in my field, however attending professional development and training alongside Caring duties encouraged my resignation from the interpreting industry after 25 years service and became a full-time Carer.

Since this time the Interpreting industry has undergone major changes to the professional developments and training standards and requirements in order to maintain one's qualifications and a professionally reliable standard of service to Deaf people. For example in order to maintain my Professional Interpreter qualification status I must attend professional development and training. The National Accreditation Authority for Translators and Interpreters (NAATI), have currently undergone an overview of Auslan Interpreters and a variety of Professional Development and Training Options have been recommended. These can be reviewed on their website.

After viewing the variety of possible training and development options from a very broad list and then comparing it alongside my Carer responsibilities I identified the following would be required for me to maintain my qualification as a Professional Interpreter. Attend at least 2 conferences, 3-4 workshops and *a minimum of 40 employed assignments each year (an average of one per week) for a three year period.* Whilst NAATI was recommending this as a minimal expectation it was something that Employers were considering in future employment. For me to maintain my professional employable status I would be required to travel interstate, (300km + return trip) to attain the minimal training requirements. At my level of accreditation there are currently no skill development training courses available to me in Canberra. There are only 2 professionally accredited interpreters, of who I am aware of, in the Canberra region including myself. I could also consider some training via Macquarie University online components and attending block sessions, yet it was a little out of my financial capacity.

As a full time Carer it is not possible to travel interstate to attend weekend or weekly training workshops or conferences, nor be reliable for regular or on-call employment. Therefore I did not at that particular time believe I would be able to continue, or possibly return to this industry and certainly not at the level I had worked 25 years to achieve. I resigned from Interpreting and became a full time Carer and mother.

- *Perhaps a dedicated case manager could be assigned to Carers and those being cared for to assist with individual case plans to address the Carers experience and the current/future employment opportunities and how to possibly achieve these. This person may also be the one to advocate or liaise with employers regarding skill maintenance as impartial representatives of the Carers confidential situation.*

- *There may be a need for future employment services to have specialist services with experience, training to be considerate of particular issues Carers may face at that time.*
- *Perhaps a list of service providers including supports, services including costs which could be utilized to address the potential unemployment issues now and in the future.*

It is most important to be mindful that at this point the Carer is possibly emotionally involved while working through some of life's major challenges, such as: moving house, unemployment, accessing (known/unknown) services, grieving, major changes to family life, major reduction to income opportunities and an uncertain future.

Unemployment

- The next challenge was leaving work and applying for the Carers pension which at that time I was advised would reduce my income by 65%. To be perfectly honest, that was probably the only thing that I remember hearing, obviously as it is first on this list. However, once I had heard this it became difficult to take in much more.

  Thank goodness we were provided with a lovely officer in our local area and as it was a small office we managed to attend a number of appointments with the same person. This was very helpful for my Mother who can easily become very confused and irate with changes to staff especially when she is discussing her personal issues.

- While attending a Centrelink appointment I was presented with a number of application forms which I was required to complete and provide the appropriate identification documents and financial documents for all persons named on the application.

  This process was overwhelming, time consuming, not easy to track down and frustrating for me, my family and I am sure the officer who was working with us. A person with a stroke can continually ask the same questions over and over because they may have short term memory issues or pain management issues causing them confusion which makes the appointments quite long, personal and particularly difficult when dealing with more than one officer regarding my application.

  Prior to my Mother having her stroke, she had previously been the Carer for my Grandmother (her mother) and Centrelink had files for both of them and their current situations. When I was completing the application I was unable to locate

my Grandmothers UK Birth Certificate or an entry certificate. It had been misplaced in our relocation. These papers were on her current Centrelink open, or recently closed, case file, however the current procedure does not allow us to access them and we would need originals or official copies for which we could apply for.
Obtaining these certificates caused additional costs to obtain them, internet searches, delays in lodging a completed application and a delay receiving benefits. I understand that my identification is required as a new applicant, however, identifying the other applicants who are holders of identification cards produced by the organisation who is requesting duplicates of previously provided identification documentation, well, I just cannot get my head around it.

- *When a senior does not hold a drivers license they have no photo identification and the Centrelink card which links into their case file is not considered appropriate identification. Therefore, can a provision be made to consider:*

  1. *An automatic identity card for seniors who are required to hand in their driving license. This can provide them with appropriate photo identification of equivalent authority and acknowledgment as senior contributors to the community.*

  2. *The Centrelink card could include a photo identification – therefore making it a more legitimate identification card which links directly with the persons case file/s.*

  3. *Perhaps a dedicated case manager could be assigned to Carers and those being cared for to assist with individual case plans to address these issues.*

- *While learning which allowances I qualified for, it was obvious that a 65% reduction in income would not cover any currently accumulated debts, I was not debt free at the time of my mother's stroke. (The debts would certainly not reduce by 65% per fortnight.) Consequently I was required to use all of my savings and incur many more debts. The following table outlines income and expenditure for Carers and I believe highlights the standard of living that Carers have available to them.*

<u>Financial constraints and considerations</u>

- The following table lists common expenses to maintain a home and a vehicle for people in rental and non rental accommodation. It also compares these expenses with current entitlements and provides and an estimated hourly pay figure for each situation. There are a number of items listed that are necessities and some may be considered privileges. However, I would like to draw your attention that

estimates are minimal for example only $80 per fortnight has been allocated for food and no funds allocated for entertainment.

Items have been noted with the symbol (*) indicate items which increase with not only CPI but the regular costs of living that are forever increasing.

The first component of the table identifies expenses which have been calculated at fortnightly, monthly and annually. These are then followed by a list of income (allowances) and then the calculation of savings or debts incurred.

Included is an estimate of the expected hourly rate of pay per Carer. Hourly rates are based on 24 hours per day and 12 hours per day for seven days per week of duties.

It is worth noting that financial constraints can limit the level of care in particular the number of social events that can be budgeted for. A holiday would be difficult to consider for example.

I hope the following table indicates the constraints and creative budgeting techniques Carers have possibly developed to maintain their tasks.

Expenses	Living in own dwelling				Living in Rental property		
	Fortnightly	Monthly	Annually		Fortnightly	Monthly	Annually
Food *	80.00	173.33	2080.00		80.00	173.33	2080.00
Rent *	0.00	0.00	0.00		500.00	1083.33	13000.00
GP and Medications *	25.00	54.17	650.00		25.00	54.17	650.00
Gas *	50.00	108.33	1300.00		50.00	108.33	1300.00
Electricity *	50.00	108.33	1300.00		50.00	108.33	1300.00
Phone *	30.00	65.00	780.00		30.00	65.00	780.00
Mobile *	15.00	32.50	390.00		15.00	32.50	390.00
Internet *	35.00	75.83	910.00		35.00	75.83	910.00
Pay TV *	17.00	36.83	442.00		17.00	36.83	442.00
Petrol *	80.00	173.33	2080.00		80.00	173.33	2080.00
Car registration *	16.92	36.67	440.00		16.92	36.67	440.00
Car Insurance *	17.31	37.50	450.00		17.31	37.50	450.00
Car Service *	30.77	66.67	800.00		30.77	66.67	800.00
Car Maintenance *	15.38	33.33	400.00		15.38	33.33	400.00
Home & Contents Insurance *	23.08	50.00	600.00		23.08	50.00	600.00
Equipment eg heat packs, blankets	23.08	50.00	600.00		23.08	50.00	600.00
Rates (Water/Sewerage) *	38.46	83.33	1000.00		38.46	83.33	1000.00
Trash Pack	12.69	27.50	330.00		12.69	27.50	330.00
Gardener	0.00	0.00	0.00		15.00	32.50	390.00
Internet Shopping – if unable to leave home.	15.00	32.50	390.00		15.00	32.50	390.00
Dental	5.77	12.50	150.00		5.77	12.50	150.00
Optical	3.85	8.33	100.00		3.85	8.33	100.00

Expenses	Living in own dwelling				Living in Rental property		
Clothing	15.38	33.33	400.00		15.38	33.33	400.00
Shoes	3.85	8.33	100.00		3.85	8.33	100.00
Personal care e.g. Haircut	3.85	8.33	100.00		3.85	8.33	100.00
Exercise - gym, yoga	0.00	0.00	0.00		0.00	0.00	0.00
Therapeutic - pool *	40.00	86.67	1040.00		40.00	86.67	1040.00
Pest Control *	7.69	16.67	200.00		7.69	16.67	200.00
Tax Agent	3.85	8.33	100.00		3.85	8.33	100.00
Personal Loans/Credit Cards	25.00	54.17	650.00		25.00	54.17	650.00
Companion Pet and Vet Costs							
Recreation							
Social Activities		THERE ARE NO REMAINING FUNDS					
Education		AVAILABLE TO CONTRIBUTE					
Entertainment		TO THESE					
Memberships		NECESSITIES					
Superannuation							
Life Insurance							
Medical Benefits							
Income Protection Insurance							
Total of current expenses	**683.92**	**1481.83**	**17782.00**		**1198.92**	**2597.67**	**31172.00**

Income	Living in own dwelling				Living in Rental property		
	Fortnightly	Monthly	Annually		Fortnightly	Monthly	Annually
Carers Payment (single)	552.60	1197.30	14367.60		552.60	1197.30	14367.60
Carers Allowance	100.60	217.97	2615.60		100.60	217.97	2615.60
Telephone Allowance	3.38	7.32	87.88		3.38	7.32	87.88
Rental Assistance (average)	0.00	0.00	0.00		110.00	238.33	2860.00
Total of current income	**656.58**	**1422.59**	**17071.08**		**766.58**	**1660.92**	**19931.08**
Balance Remaining	**-27.34**	**-59.24**	**-710.92**		**-432.34**	**-936.74**	**-11240.92**

Hourly rates of pay for Carers			
24 hours per day	1.95		2.28
12 hours per day	3.91		4.56

Relocating

- When relocating we needed accommodation which could house my mother, grandmother, son, myself, our three dogs, a cat and was accessible for wheelchairs to all rooms with adequate bathroom facilities where we could add required equipment and care was given safely and effectively.

- During this move my son had to relocate to a different school which is a separate issue but one that contributed to and identifies that Caring responsibilities extend beyond the person they care for.

  This was probably one of the most physically and emotionally demanding tasks for all of us. Relocating, breaking my lease on my own rental property, changing our addresses, finding accommodation close to hospital facilities and also finding a new GP and Pharmacist, organizing Webster packs for the medications and finding a school for my son, while maintaining daily caring tasks.

- Breaking the lease on my rental property meant that I was financially responsible for rent payments until a new tenant could be found to take over the lease.

- The cost for removalists to relocate 2 homes into one at this time was not as successful as it could have been and was very expensive. For example, many companies advertise that they will pack goods as well as removing them. However, if the person in the house is disabled and has short term memory issues it is very easy for them to be taken advantage of as was the case with my mother. Unfortunately I was finishing my last week of work when my mother had arranged for a removalist to come and pack her things "to save me the trouble". When we arrived at the new home to unpack the goods there were a number of broken items (which they told us were already broken) and even some sentimental or expensive items missing. When I contacted the company they said they dealt directly with my mother who by this point could not recall any of the conversations that had taken place with the company or the name of the lady who had been packing the items. She was sure she had arranged insurance for the move, while they assured me this was not done. My options were to report it to the ombudsman and after 3 complaints they could investigate the company involved, or if I was inclined to do so I could take it further and start court proceedings. We did nothing but complain about the company and have developed a buyer beware attitude that is: when a person is disadvantaged it appears there is the double disadvantage of being an opportunity for being taken advantage of. A disappointing experience.

  - *Perhaps there is an opportunity for a Case manager to recommend appropriate removalist companies who have experience and understanding of people in these situations who are relocating.*

  - *Perhaps there is an opportunity for the Government to employ or to contract these reputable companies which provide the Carer and the Cared for some protection surrounding relocating homes, in particular where medical conditions are involved. It can't always be rushed and*

the priorities of the person being cared for may conflict with the removalists causing a great need for patience and understanding.

Medications

The administration of medications can be done personally or via a pharmacy who provides Webster Packs. These packs provide the medications in the doses at the required times of day. With Mum taking over 17 per day and my Grandmother taking regular daily medications and additional weekly medications, it was obvious that a Webster Pack would be more convenient.

- Finding a Pharmacist who was capable of providing Webster Packs was a frustrating challenge. For example I was assured that the chemist and the GP would liaise directly regarding scripts and my concern would be regular medical appointments and collecting the Webster packs.

  One important point regarding the chemist and GP liaison is that some medications are distributed in packs of 20 or 25. If for example the patient requires 30 tablets for one fortnight they would require a repeat script. If there is no communication between the pharmacist and GP then the Webster packs are incomplete and the patient is required to make an appointment with the GP for an additional script. Please note: that the patient may be without medication during this period. If the medication is authority based for approval repeat scripts may not be possible, contributing to increased GP appointments to obtain scripts.

- I have had personal experiences with one pharmacy when I went to collect the Webster pack on the Friday was told they had run out of scripts and it was incomplete and then asked me to pay for the incomplete Webster packs. When I complained I was advised that I could make an appointment with the doctor on the following Monday (it was a long weekend) or phone the doctor's receptionist and request a script for collection, unfortunately they were closed. I would need to collect and deliver the script as a fax was inappropriate. The current of an over the counter script has increased to $15 to collect. The medication would cost $5 if in receipt of health benefits or up to $185 if not. When raising the issues of the lack of medication contributing to my mothers health conditions which included; a heart condition, diabetes, stroke and chronic pain, I was assured by the pharmacist that if I thought it was required, I could take her to Emergency Department at the local hospital – with no consideration that I care for two disabled people and a son and somehow this was now my problem to rectify without support.

- Fortunately, 8 months later, I located another Pharmacy and would like to highlight that they have been our lifesavers in regards to this matter. Always able to advise me when scripts are running low at least 2 weeks before requiring them, consulting directly with the GP where necessary, they have been incredibly patient and provided advice on other services or medical centres that they have had success with.

- I would like to formerly acknowledge the Ngunnawal Pharmacy for their continued professional and caring support which has been exceptional.

    - *The administrative process to obtain scripts extends GP appointments to long consultations or double consultations. This increases the cost of the appointment to $80, while minimising medical attention time. If there is a process where the pharmacy and doctor communicate directly regarding script requirements then the appointments would not need to be double consultations, reducing our expected financial outlay and providing attentive medical attention rather than administrative attention.*

    - *Not all GP's provide bulk billing options to holders of health care cards. Therefore after paying for the appointment we need to attend Medicare to claim our refund. This is not always the same day as sometimes a visit to the GP is quite tiring for the person being cared for and they do not wish to drive to another location.*

    - *Over the counter scripts cost $15 and only $5 to fill, if the person holds a health care card. The $15 payment is not claimable via Medicare. Can this be reviewed either by Medicare or by Doctors treating people being cared for?*

    - *Perhaps the 'Case Manager' could provide a list of reputable pharmacies or medical services which cater for the particular needs of the person being cared for. For example a specialist GP who may perhaps have more up-to-date information about current services and entitlements for clients with particular needs or perhaps prefers to deal with a particular pharmacy.*

    - *Revising the packaging options of medications may elevate the difficulties surrounding repeat scripts or authorizations. As noted above if medications are packed in 25's when 30 are required for the fortnight, then a repeat script is necessary.*

- *An outline of side effects of medications would be beneficial. Such as do they increase or decrease appetite, involve mood changes or memory loss or impair mobility. This could be assistive to know when outings and medications can be best used or clash.*
- *Perhaps a specialist Carer or GP, to monitor the Carer and oversee their particular needs are being met. For example their individual ages, health maintenance, nutritional and age groups. .*

Equipment

The new home required safety equipment including; rails, ramps, non-slip material on the wet surface areas, wheelchairs, walkers, heat-packs, creams and the most important transport.

- Firstly, what do we qualify for? How much does it all cost? Which service provider do we approach? How do we get on to the system? Are we utilizing the right services? What paperwork is required to access these services? How long will it take to establish? How can we improvise? How long will we improvise?

- When we had a wheelchair, it didn't fit in the car. My current Ford Festiva was not capable of holding; a wheelchair, walker, two disabled people and heaven forbid any shopping they may wish to get on the way. So we could either modify my vehicle with roof racks and tow bars or update the vehicle – all additional expenses. We traded my car and purchased a new one to cater for our equipment needs. The expense of a new vehicle, transfer costs, registration and insurance expenses where above budget, unexpected and difficult to manage. Without the outlay we would be trapped in the house or limited to public transport facilities.
    - *Where do you go to update your vehicle?*
    - *What costs are involved?*
    - *Are their financial supports available for these situations?*
    - *Perhaps a Case Manager could assist with these issues?*

Transport

- At one time my Mother had arranged for a taxi to collect her from the Residential facility and transport her home for a regular visit. This was booked through the

recommended service for transporting disabled persons. Unfortunately we had not been advised that there is a voucher system for people using these services. Without a voucher my mother would be required to pay either $20 to the company or $11 directly to the driver. My mother asked what that was for and was advised by the driver that it was because he had to assist her in and out of the taxi. The driver was required to lower and raise the ramp (an electrical device), my mother would wheel herself into the allocated area and the driver would check she had secured her safety belt. Consequently my mother did not have the additional money and could not afford to visit our family for that allocated visit.

When I telephoned to clarify this I was advised that she should have a voucher book. When I said we did not have one they said it would be issued today and therefore be no more difficulty.

However, I wanted clarification on the Vouchers. I was advised that the vouchers are given to the drivers who then forward them to the company and are reimbursed/paid a 'handling allowance' for each voucher to recognise the additional service they provide transporting disabled people.

- *Perhaps the Case Manager could advise people requiring transport that there is a voucher system?*
- *How many vouchers are given per driver? Some drivers ask for more than one and we have been asked for up to 3 vouchers for a one-way trip.*
- *The term 'handling fee' infers that the people being transported are in fact 'freight'. I personally find this offensive and am curious as to how the people being transported would feel to know that this term is being used to describe their transport needs, or in fact, the Human Rights Commission.*
- *The voucher system may be a method of providing the taxi drivers with acknowledgment of any additional services however this is a condition of employment. I would expect it to appear as an allowance provided in their salary conditions not the responsibility of the disabled person to coordinate the paper work for employment related allowances.*
- *This issue was infuriating as it had a huge emotional impact on my Mum. Not only couldn't she visit but she felt like a piece of freight.*

Respite

Carers are entitled to a Health Care Card, Carers allowances and entitlements and a total of 63 days per year respite before Carers payments are reduced accordingly.

- The day the person in care goes to respite services (e.g. 2 weeks) that particular day is included in the 63 days of respite because the person in care does not sleep in my home for that evening. I would like to highlight that residential care facilities do not allow admission to the facility before 2pm. The day the person goes to respite they need to be cared for until 2pm, including personal care, packing their bags, providing meals and transporting them to the facility. If I am not the acknowledged Carer in this instance who is?

    - *In the above example where the Carer transports the person to respite but is not as Centrelink policy stands the carer of the person. Could this be reconsidered so the Carer does not lose this day of care or acknowledgement?*

- Coordinating respite is something that one would think of as an opportunity to look forward to and a break in responsibilities. To do so for a two week period requires the following:

    1. Contact the Carers facility to book respite and hope that the dates and requested facility is available. Note it is not always possible to book respite at the same facility for more than one person at a time. Therefore the Carer of two or more people may not access simultaneous respite at the same time or facility giving the Carer little opportunity for respite.

    2. Ensuring an ACAT assessment is up to date. It is currently necessary to book assessments up to 8 weeks ahead of time to ensure they are done. The ACAT assessment determines whether the person is low or high care and which facility they qualify for, for respite services.

    3. Attend a GP appointment and ensure there are enough scripts for medications to last the period of respite and for their return. Also enabling the chemist time to package the medications.

    4. Book a double appointment with the GP for the persons return, as their medications' will have run out and scripts will be required urgently. They also usually return with a minor ailment.

5. Take the scripts to the pharmacy and have all medications prepared into a Webster Pack completed with a signing sheet for the Residential facility. Residential facilities are unable to administer any medications which are not included in the Webster pack or do not have signing sheets. For example:

    a. If I forget to get a signing sheet I have to return to the chemist and then take it to the facility – only originals are accepted.

    b. If the incoming resident is taking cough medicine or any additional breakthrough pain relief such as Panadol. They need to be in the Webster pack as staff will not administer them. My concern is how can my Deaf/blind grandmother manage to administer medications she cannot see?

6. Her GP is requested to provide a letter to the residential facility confirming if they will attend the facility, on-call, if my Grandmother requires medical attention. If it is not possible for her own GP to attend, then the doctor of the residence may see her when they visit. If the Residential doctor makes changes to medications I am not included in the discussions to do so and I am advised when I collect my Grandmother, usually by her. Therefore we need to see her doctor immediately. Any medications she has already purchased cannot be reimbursed.

7. While the person is in the residential facility they may need to attend hospital for some treatment. In this instance the facility usually contacts a family member – the Carer – to ask them to transport them to the hospital due to staffing issues. This is occurring during the Carer's respite period. The alternative is to transport the person by ambulance; however they would again be travelling alone due to facility staffing issues. If I transport the person while on respite can I ask for Centrelink to reimburse me that time/day?

8. If the personal care or domestic care services are being accessed it is imperative that I contact them in advance and advise them that there will be a break in the service requirements. Consequently upon my Grandmothers return any previous times and staff we had for personal care are now no longer available at our regular times as they have been reallocated to other clients. I realise this is an issue that I need to raise with the service providers but as yet have not managed to find a solution other than to consider avoiding respite which defeats the purpose and I become a frustrated and frustrating customer and carer.

9. During the first week of respite there are admin follow ups such as: reminding service providers that the person is in respite and when they will return. There have been many times that staff arrived to provide showers when my Grandmother is away. I then ensure that her room is cleaned and refreshed for her return and her washing and ironing is complete.

10. Then there is a small window of a few days that I call 'Carer catch up time'. By that I mean I am not listening out for my Grandmother, or getting up to get medications, thinking about meal preparations and worrying if she is comfortable and then giving myself time to spend with my son.

11. The second week is spent reminding agencies that my Grandmother is returning. It is usually at this point that I find out that our regular staff members have been reallocated to other clients and will not be able to be moved back to us. (We have been using their services for over 2 years and still do not qualify for a permanent staffing or booking arrangements). At one point we had no less than 7 different staff from the same provider to provide showers. This causes great distress and confusion to my Grandmother as she does not know the staff, they are not used to her routine and her regular times are changed and therefore her routine.

12. Respite is usually coordinated while my son is on school holidays, in the hope that I can spend quality time with him as a mother. Although it does make 'respite' sound anything but.

Carer health

There have been a number of incidents where I have required medical attention myself and due to Caring responsibilities have not been able to attend immediate medical attention. Two examples are listed below.

a) While assisting my Grandmother I fell and split my elbow open, requiring stitches. However at the time of the fall, 2.40pm, I had to collect my son from school, calm my Grandmother, provide her with her medication at 4pm then drive myself to the hospital, in the hope they could stitch me up in time for me to drive myself home, tend to my Grandmothers medications, cook dinner and then tend to my own recovery.

b) I had a cyst rupture inside my thigh, which required surgery, hospitalisation and IV antibiotics. This occurred on the Thursday, my Grandmothers medications are collected on Fridays and I had little time to find any emergency support. I bargained with the Doctor that after the cyst was lanced that I would tend to it and if necessary agreed to go to hospital for IV antibiotics. Consequently, I didn't go to the hospital but saw the Doctor again on the following Monday, Tuesday and Wednesday of the following week and am currently on the surgical waiting list with the hospital for a formal procedure that I hope will be a day procedure or in-line with respite.

¤ *There are no sick leave entitlements for Carers.*

Concerns

The concerns I have for the future include:

- As the person I care for ages, their support needs increase. Will I have the stamina and funds to maintain this task?
- How do I maintain a Grandmother and Granddaughter relationship?
- Am I expecting too much from the person I care for? E.g. making them sit out of bed for longer than they want to or should.
- What are my legal responsibilities and how do I discuss this with the person I care for?
- Is there an independent person who can raise legal issues so the Carer doesn't appear to be a Gold-digger?
- What employment options will be available for me if and when I get to that point?
- I have isolated myself from friends/peers etc, and now have difficulty fitting in.
- How do I maintain a relationship with my son?
- When my Caring duties cease, how long before my entitlements cease? During or after the funeral?
- The opportunity to holiday in a special resort with my family where I am not the Carer but a family member. Where each carer is allocated someone to take over for them so they can feel like a family member rather than the

nominated Carer and participate alongside the person and relax with them. Someone to push the wheelchair so I can walk along side them – that is a little 'Lottery Dream' Holidays together as a family (sometimes even Xmas) can be misinterpreted as caring time rather than family time.

- As previously stated, some Carers were employed prior to undertaking the duties of Carers. At the time of employment they may have been contributing to a superannuation fund which requires annual administrative fees to remain active. Since becoming Carers they may have been unable to maintain these fees and subsequently lost those superannuation entitlements. (For example, I could not afford to contribute to one of my superannuation funds and have lost $4,000 + of my future independence.) There are also the Carers who may have never been employed or financially able to contribute to superannuation funds and they will also be financially disadvantaged in their later years.

  - *Someone to discuss these issues or remind Carers to take care of these issues would be helpful*
  - *Superannuation support, or security or an especially established fund may reduce some stressors Carers may have about their futures.*

<u>Suggestions for consideration</u>

1. A case manager to discuss options and perhaps act as an advocate for the Carer. Sometimes we are thrown into the role and other times perhaps born into it. However, one common theme is that it is the Service Providers who know about which services are available and accessible. The advocate can act as a contact point especially when the Carer is having difficulty with service providers and can be easily misinterpreted as aggressive rather than burnt-out.

   Of course the person being cared for would require a separate Case manager. It is important that they have different case managers in order to maintain professionalism and impartiality. Some examples being: the Carers requirements can sometimes clash with the person they care for, a terrible consideration is if the Carer or the person being cared for is being neglected or abused or just to have independent mediators to assist with simple communication breakdowns that easily develop into major issues.

2. The Government establishes and oversees a superannuation fund or superannuation fund or safety net for Carers to assist with the establishment or maintenance of any current superannuation funds. Ensuring Carers do not lose any current superannuation contributions, are able to plan towards retirement and are acknowledged as employees of the government.

3. An independent/impartial person to broach the legal subjects of wills, power of attorney, funeral arrangements and future care options if something happens to their current Carer. This may help reduce the stress of the Carer raising difficult subjects with the person they care for and for these issues to be clarified without emotion to the person being cared for.

4. Bereavement leave, of perhaps 3 months (the equivalent of Long Service Leave) with payment for when the Carers cease their duties. This would enable the Carer to; re-establish themselves, personally and financially, review their health issues and options. It may be at this time that they need to have continued support to ensure they tap into the correct services. For example there may be a need for Employment Agencies to provide specialised services for Carers who have been performing these duties for extended periods they may also have particular health issues to address.

5. Review the Carers payment to enable Carers to maintain an adequate lifestyle. The financial table above identifies a regular fortnightly loss of income which becomes future accumulated debt, with little ability to maintain any social activities throughout Caring responsibilities.

6. The production of a Hints and Tips booklet on strategies for motivation, exercises via home-based activities. It can be difficult to motivate someone when they think of activities as exercise.

7. Information on how to care for the variety of people being cared for. E.g. The needs of seniors (male/female), children, parents, siblings etc which can outline supportive services for particular conditions.

8. A welcoming kit which includes:

   - A checklist for important things to consider
   - A list of service providers, what they do, contact details and expected costs
   - A flow chart on arranging respite or a more convenient process
   - A list of chemists that provide Webster packs (reputable only)
   - A list of support groups

- A list of lawyers/counsellors that specialize in this field
- A list of carers rights responsibilities and legal obligations
- A list of doctors that work well with the person you care for, for example the aged, stroke, young people with disabilities, nutritional requirements and necessities
- A list of hairdressers that visit homes
- A list of jokes for when the days are hard
- The best places for accommodation/holidays. Family holidays are not really possible when the Carer is on duty. The dream of a holiday resort that provided each family with a professional carer so the family can holiday as a family would be my Lotto dream.
- The best places to purchase equipment
- A list of alternative medical facilities, physiotherapy, podiatry, nutritional, hydrotherapy etc.

9. Improved wheelchair paths

10. Shopping bags that fit onto wheelchairs to enable Carers to take the person shopping. The Current shopping bags cannot be slung over the handles of the chair as they rub on the wheels and break. I have been recommended the use of a backpack however the straps dig into my Grandmothers back.

11. Covered disabled parking. Have you ever tried to get an elderly person out of a wheelchair, into a char, pack the wheelchair and any shopping into a vehicle while it is raining? It is impractical to only go out on a clear day. On this issue I have noticed that there are two disabled car parking spaces alongside 5 spaces allocated for prams at the shopping centre we previously frequented. Ironically the some parents can get quite agitated if I try to use 'their' allocated spaces.

12. A list of shops that wheelchairs can access. There have been a number of times where my Grandmother has been left sitting outside a clothing store while I run in and get permission from the manager to take clothes outside the store to show her.

13. Reputable and cost effective removal companies to assist with relocating.

14. Review the cost of 'over the counter' scripts

15. Review the procedure of being charged for double appointments due to mobility or administrative matters

16. A residency option for younger people

17. Automatic identification cards for seniors

18. Review the Centrelink paperwork process

19. Review the 63 days of allowable respite and why the sleeping arrangements are the deciding factor of Carer recognition

20. Prepare a similar document relating to the needs of people being cared for.

21. A survey of what future Australians expect these services to provide would be an interesting research project.

Summary

I am excited at the opportunity to provide you with this submission whilst also being overwhelmed by the amount of information I have tried to provide to you. The most difficult part of preparing this document has been that I cannot focus on it for a concentrated period of time and it has been prepared between my constant and daily interruptions. My concern is that due to haste and interruptions I may have overlooked something *and* that this document represents only *my* perspective. I hope it does identify some of the difficulties that may be common and remain that it has been written as unemotional and positive as possible.

I would like to acknowledge that there are a number of current services and providers out there and they have been understanding and patient. Especially when I am aware that what may appear to be a simple change to their timetable, can throw my day out and they may receive an unexpected, possibly irate, response. I realise it is very much also out of their hands and they are doing their best.

Again, I would appreciate that this document is recognised that it represents my situation. I have no idea of the complete opposite or any other combination of Carers and I would not attempt to do so. This is a document that will change over time; perhaps by the time you read it there will have been other considerations for inclusion. It only reflects *my* perspective of *my* responsibilities and a completely different document would be required for the people who 'employ' our services, the people being cared for.

I would therefore, like to reiterate that if a Case manager is considered for Carers then it is imperative to acknowledge TWO Case managers are required. One for each of the individuals involved.

Thank you for taking my views into consideration as part of the Committee's inquiry. I look forward to reviewing any recommendations you make to improve the life for Carers in Australia.

Yours sincerely

Deborah

Cc