

Secretary,
Better Care for our Carers,
Parliament House,
CANBERRA. ACT 2600.

Dear Sir / Madam,

Re. Better Support for Carers.

1. The role and contribution of carers in society and how this should be recognised;

I am caring for my Granddaughter Jasmine aged 15 years who has been in a Wheelchair for the past 13 years and my Wife Shirley who for the last 4 years also in a Wheelchair.

Jasmine is as High Dependant Child by the South Australian Education Department whilst at school. Shirley and Jasmine have been assessed as complex high care clients by Domiciliary Care Services for showering and toileting through OH&S rules, but I do have to manage to care for Shirley and Jasmine by myself every day.

If I was not able to care for Shirley and Jasmine the Government would be up for the cost of employing 2 people 24 hours per day 7 days per week 52 weeks in the year for a total of 17,472 hours at \$35-00 per hour costing around \$611,520-00 per year.

The present cost to the Government is 1066 hours at around \$35-00 per hour costing around \$37,310-00 per year plus my carers Allowance \$11952-20 per year total \$49262-20 saving the Governments a total of \$562,257-80.

But if I were not caring for Shirley and Jasmine then the Government would have to pay me Single rate age pension of around \$14131-00 per year.

Better Financial assistance in an increase of at least 50% in the Carer pension.

Be able to claim GST, Excise off Fuel, Registration, Insurance, Tyres and the Servicing of the vehicle by means of may be the bat statement type of form which Business currently use.

Financial Assistance for Families that are Caring for a Disabled Person (as above) when having to change a Vehicle to suit circumstances, including Wheelchair Lifter, Restraints, and Seating.

2. The barriers to social and economic participation for Carers, with particular focus on helping carers to find and / or retain employment.

The distance Shirley and Jasmine have to travel to get to Renmark if I did not have the vehicle would make it near impossible for them to have outings.

The conditions and access from the vehicle onto footpaths such as Disabled parking, suitable ramps to the footpaths, suitable footpaths for wheelchairs that are not like country corrugated roads, access to all shops from the footpaths, by means of ramps, suitable ramps from the footpath to cross the roads to the footpath on the other side of the road.

The building code should be addressed in the need to better access in Disabled Toilets with hand rails on both sides of the toilet. This would assist those that have hemiplegic or a disability on 1 side of their body which are not all on the same side, it is very difficult for these people to use a toilet seat sitting side saddle on the toilet seat, reach the side rail with the good hand to help stabilize themselves whilst on the toilet and then to get the toilet paper plus then to get back into their wheelchair.

We have to travel to Women's & Children's Hospital in Adelaide three or four time each year for the Jasmine's treatment and assessments. We get \$53.00 from the State Government by way of (patient assisted transport scheme) for each trip which is a 5 hour trip each way, unloading the 2 wheelchairs for 2 toilet stops on the way to the W C H it is a 260 kilometers trip each way. If this was claimed on tax at 68cents per kilometer it would be \$176-00 reimbursement.

We do have much difficulties in getting parking at the Hospital, getting Accommodation that has got disable Toilet and Showering facilities as we can have upto 6 appointments over a 1 week period for Jasmine at the Women's & Children's Hospital.

When we want to use public transport to go to Adelaide we have to give the Bus firm at least one weeks notice to have a bus that can handle wheelchairs and the same on our return home. This is in most times a big Question mark depending if we have stay down longer for Jasmine's treatment, the waiting around to catch a taxi for transport to and from our accommodation is very unreliable and frustrating.

No one is interested in employing me (due to my complex caring role) because I would have to stop what ever that I may be employed for should a problem arise with either Shirley or Jasmine.

I need to carry a mobile phone with me 24 hours per day, 7 days per week, 52 weeks of the year, even when I have respite in case of an Emergency. This happens numerous times per year. The STRESS of being a Carer is great. Even though Jasmine goes to the Riverland Special School in Berri this is 25 kilometres from our home and a 50km round trip in an Emergency.

Jasmine has had an incident at school as of the treatment given by the Ambulance Officer. Jasmine was latter transferred to the W.C.H. with a Retrieval team because of the Ambulance Officers Treatment. It was 26hrs before she was able to fully understand that we were there with her, which was a very Stressful time for us too. It was 2 days before she was released from Hospital and we were able to come home.

I have been in a Caring role for the past 48 years, 27 years as a Voluntary St John Ambulance Brigade Officer, 20 of these years as the Officer in charge of the Renmark Combined Division. When I retired from St John I was still heavily involved in Caring for the Disabled, Aged People, Sick and Injured People including my Parents one of whom was wheelchair bound.

Jasmine came into our care when she came out of the W C Hospital in February 1994 after spending the previous 8 months and 16 operations and being there fulltime was very Stressful due to her condition and the worry if she was going to get through it all.

3. The practical measures required to better support carers, including key priorities for action; and

Not being able to find out what State or Federal Funding is available without asking a lot of question, making a lot of phone calls. Going through a lot of Government Red Tape and being absolutely frustrated. It appears that this is what the Governments Departments want, so that we give up by putting it in the to hard basket, I do persist but a lot of people are to STRESSED OUT to persist but for me it is like putting a RED flag in front of a Mad Bull which assists in me being more determine in getting what I may want and upping my STRESS LEVELS.

Better Financial assistance in an increase of at least 50% in the Carer pension.

Be able to claim GST, Excise off Fuel, Registration, Insurance, Tyres and the Servicing of the vehicle by means of may be the bass statement type form which Business currently use.

Financial Assistance for Families Caring for a disabled person (as above) when having to change a Vehicle to suit circumstances, including Wheelchair Lifter, Restraints, and Seating.

I needed to change our vehicle in 2007, to another Van so that I can now carry both Wheelchairs in it.

The change over and fitting out of the new vehicle cost me around \$64000 after selling the previous vehicle I did the fitting out of the vehicle which had to pass the Department of Transport S.A inspection.

The state Government Assisted with Stamp Duty off the vehicle and registration, BUT THE FEDERAL GOVERNMENT refused any assistance when I had asked for GST exemption before buying this new vehicle.

I was told that I did not have special circumstances to warrant any assistance from the Federal Government Ha Ha.

The City Council, Municipality and Local Councils should be made to have ramps from streets to footpaths, access to all Public Buildings and Shops (ramps) more Disabled Parking Areas and with ramps to the footpath that do comply to the Disability acts.

The conditions and access from the vehicle onto footpaths such as Disabled parking, suitable ramps to the footpaths, suitable footpaths for wheelchairs that are not like country corrugated roads, access to all shops from the footpaths, by means of ramps, suitable ramps from the footpath to cross the roads to the footpath on the other side of the road.

The building code should be altered to give better access in Disabled Toilets with hand rails on both sides of the toilet. This would assist those that have hemiplegic or a disability on 1 side of their body which are not all on the same side, it is very difficult for these people to use a toilet seat sitting side saddle on the toilet seat, reach the side rail with the good hand to help stabilize themselves whilst on the toilet and then to get the toilet paper plus then to get back into their wheelchair.

Have the City Council, Municipality and Local Councils forced by the end of June 2009 to have all of the above in their area's fixed regardless of cost as they have been doing the above since the act came in (to that's good enough it does not effect us).

Not being able to get a local Doctors Appointment in less that 2 months period of waiting.

Strict Policing of Illegal parking in Disabled Permit Parking Areas with a suitable ramp to the footpath where applicable with a suitable penalty to deter infringement.

More sign posting to disabled toilets and facilities.

No suitable public transport for the disabled people or transport for wheelchair people other than an ordinary taxi in country areas.

The Renmark Paringa Council in South Australia are slowly doing a little work to assist people with Disabilities and Carers as far as ramps and footpaths but they do not realize the amount of Energy, Worry and Stress that they cause to us that are involved in the Caring Role.

The Renmark Paringa Council put a footpath / walkways along the River Murray in the town. This footpath / walkways is leaning towards the river and the ramps that are so steep that it takes 2 people to push a manual wheelchair up and it was much harder going down these ramps. All these footpaths / walkways and ramps have been done since 1993.

4. Strategies to assist Carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

Since Jasmine has come into our care we have spent in excess of \$130,000 on her care, including changing vehicles to suit her needs. Buying of equipment that have arisen when we could not get any funding for it, my down hill condition started when a local Doctor started treating me for Extreme Post Traumatic Stress Disorder and putting me on indefinite Stress leave which resulted in the selling of our family 200 acre fruit and vegetable property because of my health. My health level did deteriorate more and in 1998 I had a Heart Attack which required a stent being inserted into the vessel that caused the attack, later that year I had my Gallbladder removed. In year 2000 I was diagnosed with Prostrate cancer and had to be away in Adelaide for 3 months having Radiotherapy Treatment. This left Shirley to handle Jasmine and shortly after my treatment was finished, my wife was diagnosed as having Parkinson illness and Diabetes and now on insulin. They have tried controlling it with medication, but with no luck. She has now been taken off all her Parkinson medication and now requires help 95% of the time as she is confined to a wheelchair full time.

The only Respite time that I get to myself is on a Wednesday each week for 4 hours after I have Transported Shirley to the Daycare Centre, Thursday nights, I go and do indoor Air rifle or Airpistol shooting for 2 hours and each Sundays 2 hours on the Live Shooting Range. This helps relieve my Stress level but I still

carry my Mobile Phone which has to be in a reception area which limits where I can go all the time.

In March I had 3 days Respite and May 2008 I had 14 day Respite which gave me time to rejuvenate and go fishing but this does not often happen, I am now feeling washed out and have to have 2 or 3 sleeps each day.

On the 10th of June 2008 I was asked to attend a meeting at the Domiciliary Care Office in Renmark to Discuss Shirley and Jasmine's future Care and Respite care plan. They have suggested putting Shirley in Residential Care at a cost to me of \$425-00 per fortnight and Jasmine in the Crop House whilst I have some more Respite. But after a night to talk and think about it Shirley and myself are not happy about this type of arrangement we will require them to be together at night and weekends. If this was to go ahead I will have to refuse because of the Stress this would course me knowing that they are not happy with this type of arrangement

The respite residence will have to be made more accessibility for showering and toileting which will mean enlarging both of these rooms not just for my 2 people but to assist all clients that use it so the OH&S is satisfactory for all concerned and extra rooms be made available so that more clients can be accommodated at one time.

Until these alterations are done it looks rather grim for me to have anymore than a few hours per week of Respite.

If I was to get out of my caring duties I would be able to travel around Australia doing the things that I like most (shooting and fishing).

The help that I require is explained in the above Questions.

Please feel very free to contact me if you would like any more information.

Yours truly,

M
18/06/2008

23/06/2008