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Submission No. 933
(Inq into better support for carers)

Tania - Carer

June 27th, 2008

Committee Secretary,
Standing Committee on Family, Community, Housing & Youth,
P.O. Box 6021,
House of Representatives,
Parliament House,
CANBERRA ACT 2600

Dear Secretary,

PARLIAMENTARY INQUIRY – CARERS

My name is Tania and I am a 34-year old full-time carer, who for the past 11 years, has had to rely on Government entitlements to enable me to care for my husband Warren and our three-year old son Josh.

I am also a Carer Ambassador for Carers Australia, Carer Representative for Carers New South Wales and a Board Member and Carer Ambassador for Sir Roden Cutler Charities in Sydney. I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

Eleven years ago when I was just 22, my life changed in an instant, when my fiancé Warren, was struck down with a life threatening brain tumour. From the moment that Warren fell sick I gave up my job and the life that I knew to be by Warren's side in the hope this would pull him through. After a total of 446 days in hospital, Warren was bedridden unable to do the simplest of tasks and doctors suggested that Warren should be sent to a nursing home at the age of 30 to waste away. It was at that stage that I decided to discharge Warren from hospital to take him home and become his full-time carer.

Becoming a carer at such a young age has not been easy. When others my own age were out partying and having fun, I was house bound devoting my life around the clock, 24 hours a day, to make sure that my loved one was well catered for.

Many people do not realise the important role that carers play in society and often take them for granted. Carers are truly the unsung heroes that save the Australian Government in excess of 30.5 billion dollars in unpaid care. My role as a carer allows me to provide assistance for my husband with every task in life that we often take for granted. I care for his needs 24 hours a day, from feeding, dressing, showering, toileting, rehabilitation and more. I perform this role on my own each day and receive 4 ½ hours of Homecare assistance one day a week and in addition to this, one full day per month for an outing to allow our family to go out together with assistance. My

role as a carer never ends, there is no time to be selfish, time off to be myself, no sick days, annual leave or holidays. It is a fulltime job around the clock and there are times when I get tired and wonder how I will cope.

The financial stresses caring places on a family are extreme and until you live in the shoes of a carer for a week, you will never begin to understand what they have to go through. Although I am grateful for the Government financial assistance our family receives on a Carer Payment and Carer Allowance, I totally believe this is not enough. My husband and I receive in total as a couple, an amount of \$459.70 per week (\$23,904 pa) to live on, plus the Carer Allowance of \$100.60 per fortnight. This amount only scrapes the surface to pay all our bills, not to mention the bills for his disability needs, his therapy and Homecare bills that are ongoing for the rest of his life. The amount we receive in carer entitlements is \$200.00 below the minimum federal wage and a pittance for the 24 hour a day role I play. Thank goodness I love my husband, because why would anyone want to become a carer and have to survive on such little financial support. Having both had to give up substantial incomes when Warren's life was struck down with his tumour, should we now be punished for a situation that is out of our control? Or should we be supported to live in society properly? What happens when we hit retirement age? As a young carer, I have no superannuation to fall back on? Government rewards low income workers with topping up their superannuation, if they contribute to it. So why does it not reward carers and the disabled by offering them a superannuation fund to fall back on in life too? While others in society will be retiring to large substantial nest eggs, carers will have nothing. Should we have to live below the line of poverty and rely on family just to survive and buy the necessities in life? What happens if you don't have family who are financially sufficient? Isn't it time that Australia looked after their own countries needs first and foremost and supported the neediest in our society, the carers and disabled, with the financial assistance they deserve?

For some carers it gets to the point where they can't go on caring. They are completely burnt out and their own health and wellbeing is diminished to the point that they can't care any more, because their own health has broken down, at which time government assistance is required for placement for their loved ones. Should it ever get to this stage? Shouldn't we prevent this from happening by offering support before it is too late?

In a recent study done by Deakin University in 2007 it was reported that Carers have been found to have the lowest collective wellbeing of any group yet discovered. Carers were found to be stressed, depressed, worried, and financially burdened by their role. Carers love what they do, and want to care for their loved ones in their own homes. Isn't it time that Government financially rewarded carers and provided flexible services to support their needs and take them off the poverty line once and for all. Carers have a big enough job to play looking after their loved ones, why are we placing more financial stresses on them too.

To me, my role as a carer is the most rewarding and fulfilling job I could ever imagine doing. I truly love what I do. But I sometimes feel that little support is given to ensure I can play the role I need to for my loved one.

Below are five (5) suggestions on how I believe Government can further support carers for the future. These five suggestions come from documentation I fully support that Carers Australia put forth in their election campaign documentation last year 'If you don't care, why should would'. I have added a few personal comments into these as well.

1. Integrated support for carers:-

Currently carer issues cross many government programs. No single Australian Government agency has responsibility for coordinating carer support policies. Each of these agencies has their own priorities that often take precedence over the interests of carers. There needs to be a co-ordinated approach to ensure policies work together to address the range of carer needs in a way that allows flexibility and options for individual carers and their families. And that is why Carers in Australia would like to see government establish an Office for Carers to coordinate carer policy across the Federal Government and to provide a national carer focus.

Recognition of the role and contribution of carers should be supported by appropriate legislation to protect their rights. That is why it would be great to see government in consultation with carers, integrate a national carer strategy that formally acknowledges the role and contribution of carers and provides choice for them.

2. Carer Financial Security

It is no secret that many carers and their families are doing it particularly tough financially. Why is it that carers are amongst the lowest income earners in Australia for the important role they play in society not only to their loved one, but in the amount of money they save government. On average, their gross personal income is more than 25% lower than non-carers. And out of this carers must manage to pay extra financial costs related to caring such as medication, equipment, transport, therapies, continence products, electricity and alternative care. A single carer who receives Carer Allowance and Carer Payment only receive \$311.80 per week. This is more than \$200 a week below the Federal Minimum Wage.

Because of their reduced workforce participation, many carers do no benefit from the existing compulsory superannuation guarantee scheme for employed Australians. Carers have little capacity to financially prepare for their retirement. With an ageing population and an already large number of carers rapidly approaching retirement, there is a strong need to financially prepare for their future.

So it is a must that Government review all Centrelink carer income supports and eligibility tools to provide carers with adequate support to improve their financial situations. The carer allowance needs to be doubled to help cover some of the additional costs of caring and the Carer Bonus (that has recently been in the headlines) needs to be made an annual indexed payment for all carers in Australia, not to mention a superannuation scheme equivalent to the Federal Minimum Wage.

Personally, I would like pensions to be categorised into three groups. An example would be High, Medium and Low. The pensions adjusted accordingly, depending on the caring role you play. Similar to what Veteran Affairs do. Why should the people

who provide 24-hour care to high care loved ones have to financially survive on the poverty line? Their job in caring for their loved one is stressful enough without having to inflict more suffering by not being able to pay the bills. You may be asking, how do we categorise, carers. Personally as a carer for a high maintenance loved one, I would be prepared to take Warren into a Centrelink office once a year for a face-to-face review to be assessed. Real carers have nothing to hide. We just need to be supported properly. Some carers look after loved ones with intellectual disabilities and who are in vegetative state. They deserve extra payment for this extraordinary role they play. Then you have carers on the lower end, who while still do a fabulous job, physically don't do as much as the high care carers. They help look after loved ones, but their loved one is still sufficient in feeding, toileting and dressing. The payments need to be fair for the roles that carers play and what extra financial assistance they need because of their severity of the disability.

3. Carer Workforce participation

With close to two million carers in the workforce age of (18-64) the overall participation rate and the proportion in full-time employment are considerably lower than for non-carers.

Losing carers from paid employment or limiting their ability to work is a loss for the carer, their family, their employer and the economy.

Carers who are able to find a balance between paid employment and their caring responsibility benefit both financially and in other less tangible ways. Many carers who are in paid employment find it to be a form of respite and a way to connect socially.

Carers need the workforce legislation to be extended to provide protection for carers from discrimination, the right to flexible work arrangements and adequate carer leave. Government need to fund adequate community care to allow carers to re-enter the workforce if they choose and to be reimbursed for 50% of community care up to \$10,000 per year to prevent carers being forced out of the workforce or to allow them to increase their working hours.

4. Carer Health & Wellbeing

Carers experience reduced physical, mental and emotional health once their caring commences. Over time the effects are intensified. The more hours spent caring the greater decline in a carers' health.

So this is why it is important for government to look after the carer's health and wellbeing. It would be great for the Federal Government to extend the Medical Benefits Schedule to include an annual health check for carers.

Increase Government funding of the National Respite for Carers Program and that program guidelines allow carers to participate in health maintenance activities, including carer counselling.

5. Education and Training

Consequently, many carers are unprepared when they first take on their caring role. Often the task can seem overwhelming and it is common for carers to become sick and injured. I personally think it should be compulsory for a carer who receives a government benefit of a Carer Allowance or Carer Payment to have completed a carer training day, to prepare them for the role they are about to play, educate them about what help is available to them, listen to their concerns and questions and make sure they are completely informed and kept up-to-date with the appropriate information they will required.

Many pitfalls in caring situations could have been prevented if there was appropriate education and training program as a preventative measure. It would give carers the coping and management skills to assist carers in their caring role, and to reduce their physical injury, while at the same time educating staff in the community to understand the impact of caring on carers and their families so they can provide services that meet carers' needs.

SO as a carer for a loved one with a disability requiring 24-hour assistance to survive, I believe these are the 5 important keys areas that can help support carers and further enrich their lives for the future. May all carers be entitled to the same rights, choices and opportunities as other Australians. The ability to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education. This belief is based not only on a sense of responsibility, but also on the understanding that what is good for carers is good for society.

When carers are properly supported, everyone benefits. So may Government make the topic of carers a priority and reach out to these ordinary people who are performing extraordinary roles, and take them off the poverty line and support them with recognition, financial security, opportunities for workplace participation & education and training.

I am proud to be a carer and I hope Government is proud of the role that I play in looking after my loved one. Carers need more support from government. It is time to give carers a voice and listen to their needs. May this inquiry change the way carers are treated and reward them with the services and financial rewards they deserve just to survive.

Yours sincerely,

A handwritten signature in cursive script that reads "Tania".

Tania

Primary Carer for husband Warren