30th. May 2011

Neville E. Maxwell

The Productivity Commission
GPO Box 1428
Canberra City 2601 Fax (02) 6240-3377 Attention; Roberta

Dear Commissioner,

Disability Carer Support Enquiry

There has been frequent mention in the press and media over the past weeks about the state of mental health treatment in this nation. I have seen no reference to the plight and needs of carers who look after seriously disabled people with Acquired Brain Injury and in doing so lighten the load on institutions and service providers. I ask why have carers' needs not been addressed?

My wife Judy suffered a cardiac arrest in November 1992 which left her in a coma. After several weeks I was advised she would be a 'vegetable' in a wheelchair. I should go out and find a new woman and start a new life. Judy had supported me as I climbed the corporate tree and I was determined to give her my best support to achieve any recovery. I was most fortunate to meet Dr. Edward Freeman, consultant to the National Brain Injury Foundation and under his guidance we made useful progress. When I brought Judy home she was incontinent, could not walk, could not talk and had a naso-gastric tube for feeding. She was described as having an 'Acquired Brain Injury' hypoxic brain damage and this was also described as 'serious and permanent'. I was told that to try and care for her at home would be extremely stressful and this could in fact lead to my collapse in which case there would be two of us in high need care. They were so right. To provide care 24/7 for a person with serious brain injury is extremely stressful. It is onerous and exhausting. Judy, as she improved, had to be constantly watched to ensure she did not inadvertently put herself at risk. Even as she improved she could not reliably retain instructions or information and part of the nature of her injury is that she can no longer recognize faces.

I was also advised on several occasions that she would most likely make any recovery for up to six months and then 'plateau', resulting in no further recovery. Doctors advised that it was virtually impossible to predict the probability and timeline for any recovery and basically 'time would tell'.

I was asked if I would place her on a brain injury research project at Royal Prince Alfred Hospital as I was told little is known about recovery from cardiac arrest, as most victims do not survive many days.

This was agreed to and she was monitored over the next few years. I am told her recovery to date is 'unprecedented' 'miraculous' She can walk, talk, eat unaided although food has to be prepared and cut up. She cannot dress or undress herself or perform tasks such as turn on TV. However she can hold a conversation, her memory is patchy and she can not reliably remember instructions. Before this incident, she was very active, very intelligent, very engaging company. She taught Interior Design for over 20 years and taught horseriding.

My value to the community is not as a Carer but as an engineer and company manager, earning a good income, paying tax and employing others to pass on my engineering knowledge and experience. In the 1960's I was a contracts engineer on major industrial projects in NSW and Tasmania, handling projects worth over two million pounds. I have set up 'start up' companies for a multinational, designed and patented equipment that was used in the construction of the Cahill Expressway in Sydney and the Gladesville Bridge, at the time the largest single span prestressed concrete bridge in the world. Have been employed as design engineer and manager for a major multinational manufacturer. And other challenges. I enjoyed my work but found I had no choice when it came to care for Judy. There were no alternatives.

Financially it was most difficult. There are many extra costs incurred when providing high need care and a significant loss of freedom. There is much additional laundry, extra costs for detergent and electricity for the washer and the drier. Extra electricity costs for heating in the winter, cooling in the summer and higher use of television. Additional costs for special foods and medicines and incontinence pads. One becomes a 'prisoner' in the rooms, particularly when feeding through a naso-gastric tube which took well over an hour. Should Judy's tube come out only a few inches, the food would go into her lungs instead of her stomach, and she would drown. You are afraid to leave the room to even go to the toilet.

We were renting a property at Terrey Hills where we had horses and a pair of dogs when Judy collapsed. With the guidance of Dr. Freeman we found that daily contact with the animals was very beneficial and stimulating for Judy. From my perspective as a Carer your world shrinks, you become a 'prisoner' of the disability. You cannot go out unless you have relief carer and to 'buy' only 8 hours of respite will cost your entire weeks Carer Payment, (your weeks income) The needs of a person with brain injury are immediate, you cannot ask them to wait, if they don't understand what you mean. This constancy is absolutely exhausting.

We became so financially compromised that even to buy the daily newspaper became a considered decision. With the assistance of the Belrose branch of St.Vincent de Paul who set out to use our predicament as an example of a problem that needed to be addressed, respite care was provided and I tried to return to work but we found the cost of substitute respite care was exorbitant and consumed my income.

1996 Judy's mother was diagnosed as suffering from Alzheimers and was assessed as qualifying for admission to a nursing home. Judy and her mother had been very close and I decided to try caring for Phyllis as well. This worked quite well but the demands on me increased and my own health was suffering somewhat. I was very frustrated by the lack of appropiate assistance and on the advice of my local Federal Member of Parliament joined the NSW Carers Association. I was elected to the management committee and subsequently elected Vice President. I found this association had focused on aged care, not disability care and it also seemed to be very constrained as the manager pointed out to me by the threat of losing funding if comment critical of the government was made.

In 1995 it was acknowledged that 1.5 million carers were saving the Federal Government some $8 billion per annum. In 2006 it was acknowledged Carers saved the Federal Government over $32 billion ! Not all caring is the same and my position is that I first proposed in 1998, that the demands of the Disability be assessed and graded and the Carer be paid a commensurate wage.

In 1998 Choice magazine investigated the plight of Carers and recommended that Carers be paid a wage.

The true cost of providing 'Rest of Life' care to people with severe brain injury has been well established by the courts and insurance companies over the past fifteen years when sums in the order of $6 to $10 million dollars are awarded. There many extra costs incurred when providing high level care and generally carers like myself experience increasing financial hardship. This has been commonly known for over 15 years but is getting much worse. In 1997 National Carers Association President Mrs. Avril Fink OAM wrote in the 'Australian Carer', "Poverty so dire as to be quite shocking were it not so common". In 1999 President of the Carers Taskforce Australia Inc. Mr. Roy Wyatt wrote " Carers are not suitably financially recompensed. In fact to become a carer is to plunge into poverty".

Not all caring is the same. Some carers are needed to provide only a few hours per week while others at the extreme end, replace 3 shifts of staff in a nursing home yet there is absolutely no recognition of this established fact and no recompense. This is beyond disgraceful. I describe the assistance given to some carers is often "a grossly inadequate, unco-ordinated, chaotic shambles". As an engineer in industry we are trained and deployed to identify problems, propose appropriate solutions and implement them in a timely and cost effective manner. Over nearly 20 years first hand experience I have seen no such iniative from successive governments when it comes to recognizing the needs of 'rest of life' carers and addressing them. There has been unbelievable incompetence and waste in other areas which is blithely passed over, yet carers like myself, who collectively, save over $32 billion per annum are treated with indifference or contempt. Further, a great insult, we are treated as 'welfare'.

It is practical that any financial assistance is paid by Centrelink. However, this does not make me 'welfare'. Bearing in mind that I work hours no union would permit a paid employee to work, there must be acknowledgement of this fact. I should have been provided proper support. To fail to give me the support needed, is to deny the disabled person the care they deserve. Further, as has been proven, my own health suffers. As a result of this high need caring I have been deprived of the opportunity to socialize, the opportunity to provide for my own 'retirement' and the freedom to come and go. I have seen very clearly the future and it is frightening.

In 2006, November 22nd. it was reported in the "Sydney Morning Herald" that "the cost of a low care nursing home bed has soared 11% in a year to an average $141,654.00". That is $2,724.00 per week. Providing the care I have since 1992 plus 3 years of 'nursing home care' for Judy's mother I have saved the Government/taxpayer over $2.7 million and get treated as 'welfare' and denied even essential basic assistance. The 'System' was, and is, prepared to spend $3,000 per week to look after Judy, yet I am worth only $53.00 per week? It cannot do as good a job as I have done. What is going on here?

A carer, such as myself, looking after a person requiring nursing home level of care is therefore providing a 'One Bed Nursing Home' but I receive only $53.00 per week! Less than 32 cents an hour. No Workcover, no holiday pay, no superannuation, no sick leave and if I need time out I have find a substitute care and pay them. Commercial enterprises charge in the vicinity of $30.00 per hour. I would spend my entire Carer Payment buying 8 hours of respite. It is long overdue this was rectified.

The Prime Minister has been reported as saying 'those who work the hardest will be helped, not those who complain the loudest'. I record that no one works harder than primary carers of the profoundly disabled, particularly those with brain injury and request that I and others like me be given appropriate assistance. "One Size Fits All" is most inappropriate. Some carers need respite and medical assistance, some need more money, some need a mix. We save over $30 billion per annum and some of our saving for the Federal Government can be allocated to us. Caring for a person with serious brain injury is a demanding 'job'. No government has the right to grossly exploit people as we have been in past years.

If you ask the service providers what carers need they will say 'services of course, and we can provide them (at a cost) However, "services" do not pay the bills! And carers have extra bills as a direct and connected result of our caring work.

We are in fact 'service providers' and must be regarded as such. Anyone who doubts this is a tough and onerous job, I challenge to walk in my shoes for only a full week of 24 hours a day. You will have broken sleep, you cannot just go out, and if out and enjoying yourself you cannot extend your time unless you somehow get a relief carer. You will find you have to be alert all the time in case your cared for puts themselves at risk. You will have to attend to their needs before you can consider your own. Your are constantly worried as to how you can afford the essentials, let alone any repairs or small luxuries

It is not a question of 'sympathy' or 'compassion' This is a commercial reality. On the one hand the government will pay strangers, without hesitation. On the other it effectively 'steals' my time. And deprives me of the basic right to even prepare for my own old age. I have not had a even a week off in 17 years. Because we were renting when Judy collapsed we could not get in a position to buy our own home. I have been given the runaround by NSW Housing. Because of my full time caring role I have not been able earn other income and as a result have no superannuation. I and many other carers nationwide have, for the past sixteen years, brought this unacceptable situation to the attention of ministers, members of parliament Federal and State as well as senior bureaucrats. Nothing has improved. Matters have got worse. There is no point in saying carers can have 63 days off each year, or even 52 days, if this is not available, suitable, or affordable.

So far as Judy is concerned the 'system' could not facilitate the recovery that she has experienced to date, it could not provide the tailored stimulation and rehabilitation that has helped so much. After she was discharged from hospital we received a few months rehab at home from the Commonwealth service and that was all. There has been no ongoing physiotherapy. We do not have brain injury clinics similar to those in the USA. We do have younger people with Acquired Brain Injury kept in nursing homes with the aged. No rehab, no constant stimulation, no hope. Cost? No problem.

Carers in most urgent need of financial assistance can be defined as those in receipt of the Carer Payment which is means tested and therefore they are assessed as needing support and also the Carer Allowance which used to be assessed on that fact that the person in care qualified for immediate admission to a nursing home. There are, I am advised, some 30,000 nationwide. This group can also be also refined and reduced to those who are renting. While the Federal Government allocates funding to the States to assist such people, in fact the assistance is often so minimal as to be useless and the requirements to qualify are repetitive and onerous. I am well used to the 'smiling refusal' offered by well paid public servants. There are many people who make a fine living out of my misfortune and they say there is no money for me and other carers who are actually doing this job. I am in fact a 'service provider' and should be treated as such, not as a bludger. I save the federal Government /taxpayer some $3,000 per week. For the Federal Treasurer to talk of tax cuts and parental payments is inappropriate, what about us carers?

Carers can be divided into three categories;

1 Those who come home from a hospital with a disabled child needing care for the rest of it's life. Often the partner leaves and the woman is left to struggle on. No partner, no job, no assets. This persons needs financial assistance in addition to other requirements.

2 Those whose family member suffers a traumatic accident leaving them requiring rest of life care. These people, particularly, if they are renting and were working need financial assistance in addition to any other specific needs.

3 Those who are aged and suffer from age related illnesses most probably have all their material needs including their home and most likely will need services and respite rather than financial aid. I have met many carers of aged disabled who would be offended at the thought of paying then. They are financially secure and do not need money. There are other carers in category 1 or 2 above who desperately do need more money and they should get it.

There is a proliferation of departments and ministries and, as a result, any assistance can be difficult to access. There is a Minister for Health, Minister for Community Services, Minister for Ageing, Minister for Mental Health, and then State Ministers including Minister for Housing and so on repeated. There is a proliferation of public service employees with full benefits yet there is no money for me, actually doing the job. True knowledge comes from experience, everything else is just 'information'. There are too many people in decision making positions who obviously have absolutely no real idea or understanding of this task. The treatment I have received over the past nineteen years has been, on occasion, frankly disgusting. It is not acceptable that carers like myself who save the Government so much should be reduced to grinding poverty.

The Carer Payment ~~is the~~ was the same as the Age Pension, the Disability Pension, the Unemployment Pension yet although those recipients only had to be, that be Aged etc, the Carer has to work for it, and in fact has to work 148 hours per week. Under the conditions I was only allowed 20 hours per week off for work or study. By default then on duty for 148 hours per week. Interestingly an unemployed person might have to work for the dole but they might only have to work 20 hours a week for the same money a Carer has to work 148 hours. The unemployed person does not save the taxpayer but costs the taxpayer whereas a Carer of a high need patient saves the Government some $3,000 per week.

And, each and every week I receive the Carer Allowance of $53 I save the taxpayer some $3,000

Neville E. Maxwell.

My request is;

Instruct Government Departments to assist Carers rather than obstruct and dismiss my needs

Allocate to me what is needed for Judy's welfare and what nursing homes are funded.

Minimum wage for financially disadvantaged carers who are saving the need for a nursing home bed.

Legislation to define my role and protect me from discrimination. "A Carers Act" Federal legislation.

6th. April 2011 Neville E. Maxwell

Copy to Productivity Commission 24 .5 .2011

Hon Julia Gillard, Prime Minister
236 Synnot Street
Werribee Vic 3030

Dear Prime Minister,

Re Unacceptable Treatment of Carer of Profoundly Disabled Person

I am writing to record my protest in the strongest terms at the treatment accorded me in response to my previous complaint. Upon discharge from Royal North Shore hospital I was advised that I must take great care to facilitate a good recovery from surgery. Since 1992 I have been providing 24 hour care to my wife Judy who suffered a cardiac arrest, was in a coma and subsequently made a modest recovery. She has serious, permanent 'Acquired Brain Injury'. Prior to this she was very active, intelligent, great company.

Staff at the hospital assured me they had arranged with ADSSI to provide the appropiate care when I returned home. However this did not happen as promised and when I contacted ADSSI I was told there was no service available to me. This failure caused me great inconvenience and anxiety. I wrote to then Prime Minister Rudd expressing my concerns and much later received a letter from Ms Tracy Mackey, Assistant Secretary at the Department of Health and Ageing. I found her response to be dismissive and patronising, not addressing the issue and worse, not proposing any remedy to assist other carers who may find themselves in similar circumstances in the future.

I wrote a letter to you, addressed to your office in Parliament at Canberra. This letter received a reply from the same Ms Tracy Mackey, once again avoiding the issues I raised and fobbing me off with irrelevant information about other services that may assist. Too late! The urgent need was at the time!

To say that I am very angry is great understatement. I have been caring for nearly 20 years. I have been financially devastated as a result and life for us is very grim. I have been Vice President or President of carer groups since 1996. and am fully aware of 'services' that may be available. That is not the point. There was a need for action and that action was not provided for me at the time it was needed.

There is a duplication of 'information services' and there are many who make a fine living out of my misfortune. The growth of service providers is astounding. However, 'services' do not pay the bills and caring brings with it many extra bills. I am in fact a 'service provider' myself and I provide a "One Bed Nursing Home" but I am denied the basics that the commercial homes receive as a matter of course.

Each and every week I receive the Carer Allowance of some $53.00 I am saving the Federal Government the cost of a nursing home bed. Reported in 2006 as costing the Federal Government $2,724.00 per week. I have saved the Federal Government over $2 million dollars since 1992 and along with countless other carers find we, and our needs, are treated with contempt.

Interestingly I copied this correspondence to Hon Nicola Roxon, Health Minister and Hon Jenny Macklin Minister for Community Services. To date I have not received a reply. Over the years the Howard Government was in power I always received replies promptly from ministers and members of parliament.

I was invited to a meeting with Hon Wayne Swan prior to the 2007 election and I described to him many of the serious problems carers face. He was receptive and I had hopes when Labor came to power some of the carers most pressing needs would be addressed. Not so, even 4 years later. I first wrote to Hon Jenny Macklin in 1998 and hoped there would be an understanding of carers needs. Needs, not just wants. I met Kim Beazley and had discussions with him on the same matters. He sent advisers from Canberra to Sydney for lengthy discussions. Once again, no action.

Forget 'Workchoices' I know for a fact that many carers voted Rudd Labor in 2007 and after being ignored they advised me they did not vote for Labor in 2010. I do not believe political advisers understand or even know, the level of frustration and anger too many carers feel. There are over 2.5 million carers with some 2.5 million cared for, some 5 million voters! Reported that carers saved the Federal Government $32 billion per annum, more than the Defence budget, yet we are ignored, or worse, treated as 'welfare'.

In the meantime, legions of well paid public service employees and 'service providers' make a fine living out of my misfortune. Yet there is no money or appropiate assistance for me. This has gone on for over 18 years in my personal experience and matters are getting worse year by year. I know of countless carers reporting the same problems. These public servants, with this attitude and failure to improve our lot cost you votes.

Notice that on page 2 of Ms Mackey's letter to me she attempts to justifies the Carer Allowance at it's pitiful level of $53 00 per week for 168 hours of care.. She also ignores the gross harm caused by a 'One Size fits All' approach. If the Department of Health and Ageing is not in a position to issue directions to ADSSI, who is? Who sets policy for this department? Clearly the staff do not take carers' needs seriously.

Judy has serious permanent brain damage. This is a Mental Health issue. Workers from Homecare or Community Options have repeatedly told me over the years they are not allowed to spend more than four hours at a time caring for her as it is too stressful. Among your policy makers and public servants, who cares for my health? Mental Health issues are not just related to young people.

Long overdue that I received support. Since 1992 I have saved the Federal Government over $2 million in nursing home costs. I have saved the need for staff and infrastructure which are both in short supply. In return my needs have been ignored and we are suffering severe hardship as a result. To have my 'needs' after surgery dismissed, effectively laughed at, is not acceptable. This failure jeopardised my recovery and has had a serious negative effect on Judy. True knowledge comes from experience, everything else is just 'information' and it is clear that too many senior public servants have absolutely no idea about carers' needs.

I would like to know if you approve of the replies I have received from Ms Tracy Mackey. Do these represent your position? Is this in fact Federal Labor policy? I look forward to your response.

Yours sincerely,

Neville E. Maxwell

Attachments; Letters to; Hon J. Gillard, Hon K Rudd,
Letters from; Ms. Tracy Mackey & 'Intensive Care'
News article. Jones