

I would like to preface my submission with a few general comments: (Inq into better support for carers)

Please be advised that I do not want my name published.

MC 2/8/08

This is my personal story about a hidden life that I lead as a carer. It is a hidden life because most of it occurs behind closed doors. Nobody, apart from my husband and children -----not my extended family or even my closest friends and definitely not my neighbours -----know what I do and how hard I work.

My story is not all gloom and doom and for every bad experience I have had I have also had a very good experience. However, it's just that for this submission I think the committee need to hear some real facts, about real situations involving carers, that for the most part, have gone unheard. Perhaps on another day you might be interested in what I have found to be helpful, and in some instances, uplifting.

I am the primary carer for my 20 year old daughter, Erin, who suffers from Rett Syndrome. Her assessment by DADAHC (June 2006) placed her in the Very High Support Needs group for the Community Participation Program. Erin is much loved and at the present moment, she is well.

Looking back over the years, the hardest thing I have had to cope with has been sheer physical exhaustion ----the broken sleeps, the bending and assisting with toileting, showering, dressing, feeding, cleaning up after toileting accidents and food spills, the medical appointments and the constant assessments.

There has been an emotional cost to my to my role as a carer. In 2003 we had to sell our family home because the layout of the house, the number of steps and slope of the land made it impossible for me to care for Erin. We purchased land and built a house on one level with a bathroom that could accommodate my daughter. I am unable to put into words the stress of making the decision to sell the family home of 21 years and the impact on my three other children. The bottom line was I was physically unable to cope in my old house, and after exploring all options, the decision was made to relocate.

My husband I are in our fifties and as I grow physically weaker and unable to keep up the physical side of my caring role, my husband is taking over the more physical tasks. My daughter requires a wheelchair for community access and as she weighs 50kg and the chair weighs 15kg, my small frame is unable to push the chair for any

great distance or length of time. I now look at my husband and wonder how long will he last? We cannot grow old or get sick, or God forbid, take a day off because our home has become a workplace. The natural process of having children and watching them grow up and become independent does not take place and this sets up a lot of internal stress and pressure within families.

Economically the costs are high. My husband must work to provide enough superannuation for all of us! How much harder my husband has to work to provide financial security for our family because my role as a carer precludes me from working full time. The cost of nappies (even with Government assistance) and other incidentals adds to the household budget. My CASS and PADP allowances last about 6 months.

So how can carers be helped? Carers as a group need to be acknowledged as a group of people at risk. We are at risk of marriage break ups, siblings leaving home early, physical and mental health problems, disengaging from community life, being unemployed etc. **So rescue us!** The community at large needs to be educated about the needs of carers and **carers need to be educated to look after themselves.**

It is so difficult to engage in community life. The community needs to get accessible. Do you know how a person in a wheelchair gets into the Sydney Town Hall?via the goods lift at the back entrance. My family attended a function there in 2006. We were given instructions with the purchase of our tickets for the person in a wheelchair, and one carer only, to go to the lift entrance and ring the operator of the lift on his mobile, to gain entry. You guessed it, the operators mobile was not on!and there are many more examples to give of how access into my community is difficult.

Waiting lists for services are an on going frustration. I received a letter in 2007 from an organisation called Life Links saying I had applied for a service in June 2004 ----- and did I still need the service! I had been on the waiting list for a DADAHC case worker since August 2004 and I received a case worker in June 2006. Erin has been on the waiting list for a recreational service at Springwood, since February, 2006, but at the assessment I was told there were about ten people in front of her and I would have to wait for people to leave the area, or go into group homes. I received a letter from Springwood Recreational Services about 6 months ago telling me I am still on the list but they cannot help me yet. However, there have been some services I have had to wait for and they have been worth the wait---- I hope your committee finds out about these!

What about respite packages? Do you know that some packages come with strings attached? When I received a small left over package from the Hawksbury Nepean Respite Service in May 2006, the package was not to be used between 9am and 5pm Monday to Friday, and the client could only be cared for out of the home no more than 20% of the time. As a carer I am not feeble minded and do not wish to be told when and how I can use my respite package. If you give us respite then let us use it as we want! I hope your committee consults with carers on the type of respite they need.

Throughout all of the above I have managed to hold down a part time job and how I do it is another story-----suffice to say at a considerable economic cost to myself. Why do I try and hang onto my job?-----because it is a mental health issue and I am a happier and healthier person for doing it. Can I keep it up? I don't think so if I am not successful in getting a respite package from year to year **but because I work part time the people who assess me say I'm not in crisis and therefore don't need the respite as much as somebody else. CATCH 22. My response is I will be in crisis if I don't work! Waiting to see if you are successful in getting a package each year is very stressful. Why don't you give all carers who apply for a respite package, \$2,000 -----so they can go to a wedding or have one weekend away. If people don't use the respite hours there is no penalty but the money goes back into the pool for the next year so there will be a little more to go around. People who need more ongoing respite apply in the normal way to have their \$2000 package increased.**

The cost of respite is prohibitive. I had a \$5000 respite package for the year 2007-2008. My husband is a Vietnam Veteran and I applied for respite so that I could watch him march in the ANZAC Day March in Sydney. I live outside of the Sydney Metro area and so there was a lot of travelling time. We decided to stay in Sydney over night so that my husband could meet up with other veterans. The cost was approximately \$1,400 from my package-----unbelievable isn't!!!!!!! I was told that ANZAC Day was a public holiday!!!!!!!!!!

There should be tight control over the training given to staff who work as carers. We need qualified people to work in the area and to provide quality services. Wages should reflect the important work they do.

My ability to cope as a carer is dependant on the services I am able to access. Will I be able to continue doing what I am doing for the next ten years? I don't think so. For the next five years? Maybe, if I have services to support me. My gut feeling is that if I can continue to engage in community life-----and that for me is to work-----I have a chance to remain happy and healthy and that has spin offs for my family and the wider community. I urge you to consult directly with carers and peak bodies. Thank you for reading this submission.