

A.O.C. 27/6/08

**Submission No. 192**  
(Inq into better support for carers)

Secretary  
Inquiry into Better Support for Carers  
Standing Committee on Family, Community, Housing and Youth  
P O Box 6021  
House of Representatives  
Parliament House  
CANBERRA ACT 2600

Dear Secretary,

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 Carer's.

My role as a full time carer started in 1982 when I married my blind husband, Wade. One year later we gave birth to a son Jacob, who has cerebral palsy through birth trauma. We also have a son Nelson who is in Year 12 at Yeppoon State High. Nelson is an avid musician and sportsman, is School Music Captain and hopes to gain entry to the CQU Conservatorium of Music in 2009.

I was twenty two years old and became a carer for two people who have complex needs. In the last ten years Wade has developed epilepsy and suffers depression that at times leads to suicidal tendencies. Jacob is a vibrant young man who has had and still needs enormous amounts of energy put into him. However, I am now 47 years old and the toll of caring is so great that I often wonder how I am still alive. Wade has never had the ability or opportunity to be able to earn any sort of income so I have supplemented our income through various types of employment over the last two and a half decades.

During the last three- five years I have watched (like millions of others) the cost of living escalate. In that time we have seen the elusive dream of ever owning a house, just simply disappear. The costs of our weekly rent not only takes a bulk of our income but we are now placed in the highly vulnerable situation of never knowing if our rent will rise to a level that we are simply unable to afford. I cannot stress to you how much pressure the cost of living places upon me as the sole income earner. We are in desperate need of permanent and affordable housing.

As the sole income earner I find it difficult to accept the fact that on my paltry \$12 000 - 15 000 part time wage that I receive; I am not only forced to pay tax but the Wife Pension that I receive is slowly decreased in relation to my earnings. Essentially I lose part of the pension to go to work; add in fuel costs and costs to my health and the equation means that there is very little monetary incentive for me to work. Yet I know that work provides us as a family with much more than money and frankly I enjoy working. It sets a good role model for our family and it increases mental stimulation for all of us.

A good practical support system to people like me would be that we are not penalised by losing any of that pension unless we are earning over the average wage. I also want tax cuts - I am lucky to receive back 50% of taxes that I pay! I have put myself through university and am currently studying a Masters degree. Under the

Howard government I was not eligible for any government study support for my undergraduate degree and receive no government support for the Masters degree. For the last six years I have combined study, work and home responsibilities and received no government support while single parents who studied with me received study allowances. I am now continuing that cycle with this degree. Given that this country needs educated people one would assume that there should be some form of support for attaining higher levels of education.

I chose to marry my husband and I believe that as a family unit we greatly contribute to our community. We do not have a 'welfare mentality'. Wade is an active volunteer in our community and Jacob is encouraged to participate wherever he can. As mentioned, Nelson is a sportsman and musician and is involved with community events. We have brought both of our children up to have values of tolerance of difference, compassion and to have a sense of giving to humanity. Indeed there are times where I consider myself lucky to still be able to work. But I am tired. There is at times little light in my life. I do not have the option of using respite services as they are simply inappropriate to both Wade and Jacob. Once cannot simply 'put' people like Wade and Jacob into the usual respite service – it would be soul destroying for them. To access home support through Bluecare of Community Health means waiting lists and then inflexible support systems that more than often suit the organisational structure rather than the support user.

We do receive funding under a Family Support Funding arrangement through Disability Services Qld; interestingly enough we receive the minimal band of \$7000 per annum in flexible support. While this assists and we are grateful, it is ironic that I know of families where there is one disability and both parents have full earning capacity yet they receive higher bands of this same funding. It would help enormously to see this level of funding lifted for our family; but of course the funding programme is written with the aim of the younger person with the disability. Like most government programmes of support we seem to constantly be disadvantaged and don't fit the criteria yet our needs are high and complex. At times I feel totally ripped off and angry that I seem to be expected to continue with seemingly little support. We apparently just don't fit the 'box' of government support.

Put simply, my role as a carer saves government enormous amounts of money but my health pays the price. I do not see myself being able to continue to function the way I have for the last 20years; most of know that our abilities diminish with time to some degree but for a carer that diminishment is much more rapid.

To end this submission I would like to clarify five practical ways I could be better supported in my role as a carer.

- ✦ Tax cuts and offsets for carers
- ✦ Review 'allowable' carer earnings when on a pension so that we lose less of our pension
- ✦ Review government disability funding packages for flexibility for families like ours who do not fit the box

- ✦ Permanent and affordable housing
- ✦ Study allowance to encourage carers to pursue further education

I look forward to any response from your committee and would be happy to participate in discussions and conversations about any of the above concerns.

Julie