

AOC 2117108

Submission No. 959  
(Inq into better support for carers)

3/7/08.

Secretary,  
Inquiry into Better  
Support for Carers  
Standing Committee on  
Family, Community, Housing & Youth  
PO Box 6021.  
House of Representatives  
Parliament House  
Commonwealth, ACT 2600,

Dear Secretary,

I wish to make a submission to the House of Representatives  
Standing Committee on Family, Community, Housing & Youth Inquiry  
into Better support for carers

My role as a carer (son carer) is that I care for my husband  
my husband has had a disability since the age of 15 months old  
he has cerebral palsy caused by spinal meningitis, combined  
with neurological disorders. Combined with Epilepsy although  
he hasn't had an epileptic fit in ~~23~~ 23 yrs "Praise the Lord" for that,  
he does suffer from Cluster Headaches & Anxiety Attacks  
he also has a shunt down the right side of the Brain  
& is Paralyzed down the right side of his body. Although  
while he walks around & does most things himself  
he does need care & attention he also has a crippled right  
hand.

When he is going through Cluster headache syndromes there are  
times when he needs to be hospitalised these cycles can go on

were between 6-12 weeks plus a 3 month recovery which can be sheer hell not only for him but for me as well and its during this some when I need help in the home - can't get it. His health in the past 10 yrs has deteriorated & I worry about his & my future as we have no financial backup & support. (with the Cuts Cuts & headwinds they come in a 2yr cycle) & one of side effects is known particularly at this time is "suicide" & I keep very close eye on him at this time there is no cure. As I stated before I get ~~hard~~ no help.

I contribute to society by looking after my husband at home & care for him 24hrs a day. He is not at the stage were he needs a nursing home and nor does he want to go into one. I have promised him & that I would do my best to look after for as long as I can. I do have failing health as a result of all the cares that I have looked after my husband. My health issues are: - Diabetes Type 2, Iron Deficiency Anemia, High Blood Pressure, Sleep Apnea & Restless legs syndrome.

Plus due to changes in Centre link last year 2007, I re-entered the work force after 23 yrs away from work. I never thought I would see myself return to work. But they got to a stage were I had too become financially like every body else we were struggling to the point we had no money left over after Bills were paid out. Something I needed to do for my self & as away for finding my own identity as a person & provide for our future. I came to realise that we have no financial support for our future. I also needed my self confidence

back. I underwent studies before re-entering & believe you me going back to work at my age 49½ is damn scary & particularly; with the health issues that I have I shouldn't be working. I cannot work long hours like I use to I have tired & ended up in hospital on couple of occasions. Currently at this stage I don't know how much longer I can keep working. I am currently working as a in Nursing which had been my back ground before I was married. The Studies I did were Cert III in Aged Care, Disability Cert III & Community Services, Mental Health Cert IV.

I would like to see Carers receive more recognition in the community & by community leaders. I also feel that Doctors & professional people need to recognize & respect carers for the work they do. I would like to see more funding given to carers to help meet their need & better access to services in the community. I would like also to see carers receive cheaper 'cab fees' & even possible having a cab voucher which at this point in time we are not able to access, my husband has one but I can't use it.

I would also like to see People on Disabilities be given the B Bonuses like everybody else has been given over the last few years they have missed out every year at Budget time. My husband also missed out on the Utilities rise because he is on Disability Pension he also cannot get Seniors Card even though he is 54 yrs of age.

My role as a carer has effected my life in every aspect of my life, Particulary my health as stress takes its toll I get no stress relief. As I stated earlier my health is also deteriorated in last 10 yrs. I'm needing to by a sleep apnea machine but do not have the funds to by one & it also looks like my husband will need one too.

As I stated earlier I don't know how much longer I can keep working. My doctor has already told me to start slowing down I cannot do any more than 10 hrs per night. It also has an effect on my work performance I have days were I just don't function at work as well as I should be.

I would like to be more involved in things in the community but, my work, My duty of care to my husband & chud commitment is enough for me. Currently I feel like I'm going through Burn out. & don't know how long I can keep working.

I worry about our future as we are in mid life & in the next phase of our life.

I have found it hard with cost of living going up all the time, not being able to afford our nor home we have never had over even here. we live in private rental & although I feel we are fortunate as I have a cousin who has given us this place to live in & she has kept the rent at reasonable place although I'm expecting rent to go up this year

We have been on Housing Waiting list for years now they cannot give us a time period of how much longer we have but told at least another 11 yrs.

We find Groceries very expensive & I now cost my husband & I \$250 a fortnight in food. Electricity is also very expensive & struggle at times to Pay Bills. There is never enough money left over for treats and selves to go out for dinner or to buy a nice outfit or even replace a washing machine. As the bigger items we have trouble replacing.

One of my major complaints with Government is State Legislation when it comes to people working & they on paid pension while I'm working that's fine, but what I don't agree with is they also take money out of Tony's pay which is disability pension. Take it out of my me but not my husband's. The Pension is all he has ever known & I have to work hard to make ends meet & meet his needs as well that's not fair to him he's always been independant this takes away there independant.

The Barriers I have had to face being a carer, People not believing you or the person you are caring for. Doctors don't respect carers nor acknowledge carers. Some Employers don't give carers time of day or show respect to carers. But I've been fortunate because my Boss takes time to listen. And Cared for me when I collapsed at work & landed in hospital they were seeing me to see how I was & checking up on me.

People in community friends family often don't understand our needs or show concern or respect. I've had some awful things said to me over the year neighbours in particular can be ~~abuse~~ abusive. Ambio's also can make it frustrating when they don't believe you in what's happening at the time I've had to report Ambio's for refusing to take my husband to hospital, when he as needed to be taken particularly when going through a cluster headache attack.

Practical Needs more access to Services for carers  
More help when going through crisis  
Increases in Pensions  
wouldn't go astray

Thank you for taking time to read my submission

Yours Sincerely

Mup

RS