

Submission No. 857

(Inq into better support for carers)

From: Patricia
Sent: Friday, 4 July 2008 8:37 PM
To: Committee, FCHY (REPS)
Subject: Better support for carers.

Dear Secretary

I am a mother of a profoundly disabled son who is 22yrs old. My son has been disabled since birth suffering from cerebral palsy, developmental delay, severe epilepsy, cortical blindness and scoliosis. My marriage was over by the time my child was six due to his fathers inability to cope and accept our sons prognosis leaving me as sole provider of 2 sons, 12 and 6yrs. Since the age of 14yrs my child has been fed via a peg in his stomach as his ability to swallow became compromised as his upper body began to twist at puberty. Over the last 5yrs my son has been hospitalised about 40 times with pneumonia and is under the local palliative care team.

Over the last 22yrs the amount of support for the disabled and their carer has decreased dramatically. The ability to access caseworkers, physiotherapists, speech pathologists etc has become so bogged down in red tape as to be almost impossible and is set up to so confuse any carer trying to get longed for help that they eventually give up. I have just heard that our local DADHC office has just gained yet another layer of bureaucracy taking away more funds from front line services. That is a joke. How many past enquiries have done any good or had any recommended measures implemented.

So many carers are struggling emotionally and financialy from the strain of being solely responsible 24/7 for another persons needs. HOUSING IS A BIG PRIORITY. Many carers like myself have mortgages that they are finding harder to pay as there is no assistance for the carer unless they are renting. WHY?

I worked until my son was 18yrs old and became to ill for me to stay employed. My carers pension of \$547 per fortnight is not enough to exist on. \$310 goes straight to the bank for the house leaving the grand total of \$237 per fortnight for food, petrol, electricity, gas, water, clothes etc. My only other income is my \$100 carer payment which gets taken for my monthly deductions of house and contents insurance, life insurance and extras insurance for teeth, glasses etc. I hope you are getting a realistic picture of the stress of lack of money causes carers. Without a home for my son he would have to go into care. Renting is not an option as you cannot modify bathrooms in rented accomodation.

A MORE REALISTIC CARER PENSION BASED ON DEGREE OF CARE NEEDED, as some carers are still able to work in paid employment to accumulate superanuation if the person they care for is mildly disabled as opposed to profound. Carers unable to accumulate superanuation because of their inability to work should have some sort of government safety net for their old age.

REGULAR SAFE RESPITE CARE. SOMEWHERE THAT IS SUITED TO THE TYPE OF DISABILITY.

Seperate respite houses for profound medically frail clients so that they are safe from harm by other more aggressive types of clients. LONG SERVICE LEAVE 4 weeks continuous respite after 20yrs would allow for a holiday if you could afford it.

AKNOWLEDGEMENT BY THE POWERS THAT BE OF THE MILLIONS OF
DOLLARS CARERS SAVE
THE GOVERNMENT EACH YEAR BY KEEPING THE CARED FOR PERSON IN THEIR OWN
HOME.

I haven't even touched on the isolation,lonliness and total loss of self a person feels after years of
struggle
begging and grovelling to government departments for services that should be a right not a
priviledge.
The worry when you are ill and have no one else to call to fill in your carers role so you can go to
bed or
rest.In 2008 we have a government department DADHC dedicated to the wellbeing of the frail aged
or
disabled (HA HA) that when you ring for emergency respite for an operation for example you are
told to take
the person you care for to hospital with you as they have nowhere for them to go till you get well.

I wish to be reconised in our society for being a loving caring person of worth.I wish for
aknowledgement
for putting my own hopes and dreams aside to tend to someone elses wellbeing ahead of my own.
I wish to be able to live a comfortable life without fear of losing everything I have worked for
because the
carers pension keeps me living in poverty now that I can no longer work.I would like to have
facilities in
the community available for short or long term care if and when it is needed.I want help with
equipment,
nappies day programs etc without the new rules of user pays contributions.PAY WITH WHAT?

PLEASE AT LAST SOMEONE LISTEN AND ACTUALLY DO SOMETHING TO HELP MAKE
OUR
JOB EASIER NOT EVEN HARDER THAN IT ALREADY IS.I FINALY UNDERSTAND AFTER
22YEARS
WHY SOME CARERS THROW IN THE TOWEL AND WALK AWAY.YOU GET SICK OF
BEING TREATED
WITH CONTEMPT BY THE PEOPLE WE ELECTED INTO POWER WHO ARE SUPPOSED
TO WORK
ON OUR BEHALF AND FORGET AS SOON AS THEY ARE PUT INTO POSITIONS OF
POWER.

Yours sincerely
Patricia