

AOC 16/7/08

Submission No. 809
(Inq into better support for carers)

To The Committee Secretary
Standing Committee on Family, Community, Housing and Youth
email: fchy.reps@aph.gov.au

Re: Inquiry into better support for carers

I am a wife and mother to 2 teenage boys aged 17 & 15. I am the primary carer for our 17 year old son who has Duchenne muscular dystrophy (DMD). I am also the secretary of Parent Project Australia - a national voluntary non-profit, which aims to support families and professionals further our knowledge of Duchenne to add quality and quantity of life since Duchenne is life-limiting. This disease affects 1 in 3000 boys. It is a progressive muscle wasting disease that is 100% fatal. DMD is typically diagnosed in boys between the ages of 3 & 7. They generally lose the ability to walk between the ages of 8-12 years old. There is no way to stop the progression of DMD. To date there is no cure. To give you a better understanding of this disease & the care needs of my son, I liken his situation and mobility and care needs to that of a quadriplegic. He has no intellectual deficit.

The complex role as a carer of a DMD sufferer gradually becomes more difficult with the passage of time, due to the degenerative nature of this disease. It is exhausting and overwhelming at times. The fatigue experienced by most carers, along with the grief that we as parents /caregivers experience, makes our role even more challenging. The grief that we experience is ongoing due to the degenerative nature of this disease and the hopelessness we feel at our sons' plight.

Those carers who have responded with submissions need to be applauded. Most carers don't have the time or the energy to sit and think coherently. I think the catch-cry of most carers would be "I'm tired"- Tired of the lack of support; Tired of battling on our own; Tired of a government that doesn't care about the smaller issues, let alone the bigger issues; Tired physically, emotionally, mentally; Tired is a way of life. For many of us the caring role is not a role we willingly took on, or asked for. ...it was thrust upon us with no options included. Becoming a carer, whether by accident, incident or birth, is incidental. We take on this unpaid role with love and compassion, caring for our loved ones 24 hours a day, whilst fighting for funding, fighting for help, fighting for the rights of our loved ones, struggling to get equipment / services. Everything is a struggle. That's the problem. Most of us just get on with it and do it and hope we don't crash and burn in the meantime. We don't have time to crash and burn, we don't have that luxury. If we don't look after our loved one, who will?

Who is looking after the carers???

The role and contribution of carers in society and how this should be recognised:

The carer or carers in a family have many other roles. My husband is the sole income earner. Once my husband's paid shift at his place of employment is finished, he then comes home to assist me as carer to our eldest son. Our younger son attends school, then, once at home assists with normal household chores, but he does more than the average child, as he has the chores of 2 to do. As well as that he assists us in caring for his older brother. Our physically disabled son has very high care needs. He needs assistance with EVERY aspect of daily living. We are his arms and legs. From fully assisting with showering and toileting, to dressing and undressing, assisting with meals, drinks, brushing teeth, combing hair, to turning in bed, or scratching his nose. Our joint role as carers requires this and more: we are also his advocate, his defender, his nurse, his chauffeur, his valet. We carers save the government billions of dollars. How should this be recognised? EQUALITY. There should be no age limits on services for the disabled; the level of

funding should be equitable with the **level of care needs**, not age. In WA (I can only speak about the state in which I live as I do not know what is available/ not available in the other states) the respite /assistance for carers of young people who are disabled are limited. If my son was over 65 we would have access to many more hours of assisted care. There is the **EACH** Package: Extended Aged Care In the Home – this includes up to 20 hours per week of assisted care which includes personal care (eg. showering etc) social support, transportation and home help. So if you required most of that time allocated to personal care rather than social support or transport then that is an acceptable way to utilise the hours of care allocated to you. Then there is the **CACP**: Commonwealth Aged Care Package- same sort of conditions as the EACH, but you have 7 – 10 hours per week for personal care, social support, transportation and home help. There is also the **Working Carers Respite**- you can have up to 30 hours of care if the carer is working or studying to gain employment PROVIDING the person they care for is 65 years of age or older.

EACH, CACP and Working carers respite is inequitable. This is DISCRIMINATION. Definition: treating people differently through prejudice: unfair treatment of one person or group, usually because of prejudice about race, ethnicity, **AGE**, religion or gender.

Is the care that I give to my son any less valuable, less taxing, less physically, mentally and emotionally demanding because he is younger than 65? NO IT IS NOT. In many ways it is more taxing. It is not just me or my family who are affected by these inequitable guidelines. There are other carers of young people whose conditions have high care needs too: other types of muscular dystrophy and neuromuscular disorders, MS, Huntington's, quadriplegia, brain injury, and the list goes on.

These guidelines are discriminatory. It is not fair or just. It needs to be amended. Respite whether in home or out of home needs to be assessed on LEVEL OF CARE requirements, not age. In fact most funding, whether it be respite, equipment, support, centre link carers allowance, carers payment; needs to be assessed on level of care . These things will go a long way in recognising the invaluable role of the carer.

Carers Allowance needs to be reviewed, this is a paltry sum of money for those of us who don't work, but are unable to claim the carers Payment due to spouse's income being just over the threshold.

Funding from state to state is different. The amount funding that is available to me in WA, should be comparable in every state. I know, through talking to other carers in 3 other states, that they don't receive the funding for respite, support services, equipment etc that I get, and yet their sons have the same disease and have the same care needs. Why?

The barriers to social and economic participation for carers with particular focus on helping carers to find and / or retain employment:

As mentioned above **Working Carers Respite** guidelines need to be amended, so those of us, who care for younger members of the community, have the option of obtaining employment / further education, without having to leave our loved one home alone. This happens all too often. It is an unsafe practice and the government are failing in its duty of care to both our carers and our disabled community. Many of these disabled persons would have no way of evacuating a home and would be helpless in the event of a fire, break-in, etc. But many carers have no option in this economic climate. Either increase the funding for carers, or make funds available for respite. These respite funds should not have to be topped up by the carer either- it should be a standard set dollar rate per hour.

Non working carers can not afford to participate in many activities. Revise the guidelines for **Carers Allowance / Carer payment**.

The practical measures required to better support carers including key priorities for action:

Some paid direct care (patient care assistants) workers who work for agencies need more intense instruction before going out into the community. Although the care needs of many disabled/aged persons are not complex or demanding, there are those disabled/aged persons who have high care needs and high level of manual handling. These disabled/aged persons require some level of understanding and the direct care worker needs to have a good concept of good manual handling practices and a good personal care practices. Although the "high-quality" direct care workers outweigh the mediocre, there is still a problem there, and it does cause stress both to the unpaid carer/ parent and to the person with the disability. The most practical measure would be to increase the time and depth of the course and for the employers to be more selective of the persons they employ. The main question the employer needs to ask themselves is: "Would I want this person looking after the most intimate care needs of my mother, daughter, grandmother, sister, father etc"

In my opinion, the fast track system of training direct care workers needs to be eliminated/ revised – how can a professional level of care be inspired in course that requires 2 weeks of theory and 2 weeks of practical experience? There is no comparison; one course requires about 20 hours a week theory (approx 312hrs) for 16 weeks and then 2 weeks of work placement, the other as stated above 2 weeks theory (approx 70hrs) & 2 weeks prac (approx 70hrs).

We have experienced first hand the incompetent, inexperienced, the uncaring and at times apathetic manner of some direct care workers. Each agency must be more accountable for the persons in its employ. One comment we received indirectly when we did make a complaint about a carer that was sent to us was that basically "do we want a service or not?" Many carers, especially older people do not make complaints as they fear that they will be abandoned by the service provider or victimised.

We have heard many times that the agencies cannot find enough carers / direct care workers to meet their clients demands...the solution is not to put numerous people through a fast track course, – many of whom are not suited to a carers role - but to increase wages and or incentives. Many extremely good direct care workers leave their position and find employment elsewhere as there are other positions less demanding which pay more.

The amount of Patient Assisted Travel funding (available in WA) should be increased – petrol prices are continually increasing. After talking to other carers in other states, I am aware that some states do not seem have a scheme like this. A carer in Tasmania told me of the terrible financial burden they experience when they have to go to Melbourne to see specialists. Once again, this sort of funding should be available Australia wide.

There should be a data base of information that carers can access with all sorts of information related to carers, from what agencies are available in your area to provide care, respite, home help etc; which agencies can fund care, which agencies can apply for grants for you, where you can obtain funding for necessary items of equipment e.g. hoists, commodes/shower chairs, hospital beds, wheelchairs, wheelchair hoists for vans. If the person/agency in charge of your case is incompetent, apathetic or insensitive, then funding accessibility for the carer is greatly reduced. Government departments / agencies are reticent in "advertising" allowances / funding / facilities that are available to carers. The work ethic that is often present in agencies is one of presumption, "if they haven't asked for it they don't need it" or "it's up to the client to come to us

and ask for a service, we don't offer them a service that they may need". The problem is that the "client" is often unaware that there is a service or funding that may suit them, often it doesn't occur to them to ask.

In WA we have 2 schemes that are available to persons with a disability and Health Care Card Through the office of State Revenue. These schemes subsidise electricity accounts, and should be adopted Australia Wide.

Thermoregulatory Dysfunction Energy Scheme:
http://www.dtf.wa.gov.au/cms/osr_content.asp?id=1691

Life Support Equipment Electricity Subsidy:
http://www.dtf.wa.gov.au/cms/osr_content.asp?id=1280

Necessary items of care should be fully funded by the government Australia wide. The WA government has a Community Aid and Equipment Program (CAEP), which I am lead to believe, is one of the best in Australia. I personally have not yet had to pay for or find top up funding for any necessary piece of equipment my son has needed (The hospital bed was supplied through a charity organisation, not thru government funding) I am aware, however, that other parents in other states have had to pay for equipment or top it up. The necessary items would of course be different for each disease / disability. Things which I consider necessary are: electric wheelchair, commode / shower chair, hoist, wheelchair hoist for vans, hospital bed, pressure relief mattress, but the list could go on. The funding for these necessary items of care should be individualised. For example a basic electric wheelchair with standard seating costs approximately \$7000, but typically boys with DMD need specialised seating, which also needs to recline and tilt in space. This pushes the cost up to nearly \$12 000. So the ceiling level should be \$12 000 for this level of disability, because that added extras are not a luxury but a necessity and adds to quality of life. A basic commode / shower chair on wheels costs from \$800 to \$3000 for one which will tilt, recline & lay almost flat - which is necessary for some persons, so once again the ceiling should be \$3000 depending on the level of need. So in essence everything needs a ceiling level, but the ceiling level needs to be used in conjunction with the level of need as well.

Hospital beds (height adjustable bed) are not funded, however, because the unintelligent inconsiderate reasoning is that everyone needs a bed, and therefore it should not be funded. (Mattresses, on the other hand are funded.) A normal bed and mattress for a normal child who can sit up unaided and turn over unaided and get in and out of bed unaided can cost very little for a second hand bed to \$600+ for a very good ensemble, depending on what the parents deem necessary & / or their financial situation. But for a child / adult with a severe mobility disability a height adjustable bed is not a luxury, especially when carers need to lift / turn and care for their charges in bed. A height adjustable bed is a bed base that is manually or electrically operated. An adjustable bed is needed either for medical reasons, i.e. pressure relief, for ease of transfer, **for improved health and safety of the carer**, to allow for a change of position for comfort, i.e. when watching TV or eating. These are logical and valid reasons for having an adjustable bed, and therefore should be funded. For those who have severe mobility restrictions and require many night time / day time turning in bed the new "Turning Bed"- (<http://www.smartech.com.au/index.htm>) would be a "God-send", but the cost (\$10000+) makes this item an unreachable dream for many, whilst it would make a carers day to day life easier, and improve the quality life of a disabled person.

A wheelchair accessible van is not a luxury item. It should be stamp duty exempt. Sales tax on the sale of a new wheelchair accessible van / vehicle should also be removed. This could save up to \$10000 in a new van.

There are 2 ways I can think of to alleviate the burden of buying a wheelchair accessible vehicle. Firstly it could be 50 – 100% tax deductible. Many business items are tax deductible as they are necessary for the business to function – even a pen is tax deductible. The same should apply to the wheelchair accessible van. These vehicles are necessary for a family to function as a family when a loved one is wheelchair bound. In many cases, the family has had to spend over and above the amount they would normally have spent on a vehicle, had the loved ones disability not required such a vehicle for transportation. Another suggestion would be to subsidise the cost of the van. I don't necessarily mean the whole cost of the vehicle. There are criteria that need to be considered:

- How much would an average family normally spend on a vehicle? (maybe a conservative \$15K)
- What is the acceptable base cost of a wheelchair accessible vehicle – on an online carer's forum I have seen some exorbitant costs quoted for these vehicles. I believe one of the cheapest vans (Toyota commuter) available to buy new is about \$58K for a standard white automatic diesel. It has a higher roof so usually no modifications are needed on the vehicle, except for the installation of the hoist and the necessary modifications that go with it.
- The average cost of supply & installing a vehicle hoist is on approx \$11 -15K. So you have a \$58K vehicle fitted with a \$15K hoist = \$73K minus what you would normally have bought \$15K = a \$58K subsidy that should be available or tax relief to that value (this would be even less without the stamp duty and sales tax of around \$10K – so that would make the subsidy / tax relief \$48K). If you were to fancy a vehicle over and above the norm then it is up to the consumer to top up the cost. Of course there would have to be a different formula for the purchase of second-hand vehicles.

Receiving assistance for a wheelchair accessible vehicle will just put us on an equal footing with the rest of the community whose children can get in and out of a vehicle unaided and access whatever they want, whenever they want without hesitation.

I believe the Victorian government is proposing a scheme to assist the purchase of a Wheelchair accessible vehicle. Maybe the rest of Australia needs to look into this.

We carers work as an unpaid "business" for the government, saving them billions of dollars per year. A Wheelchair accessible van and any equipment needed to care for a loved one should be deemed "tools of the trade" – necessary items to run our business – so it should be tax deductible.

Taxi User Subsidy Scheme: In WA Most members are entitled to a 50% subsidy, up to a maximum of \$25 for each single trip. Members who use a wheelchair or scooter may be entitled to a 75% subsidy, up to a maximum of \$25 for each single trip. This should apply across Australia.

Post School Options (PSO): Throughout most of Primary School and all of secondary school my son has been allocated Education Assistant (EA) Time. Most of that allocation has been full time. Now we are coming to the end of his secondary education I am completely astounded to find there is very little support if he wants to better himself and go on to further education. I find it absolutely discriminatory and abhorrent that we are able to get funding for "secretarial / note taking" purposes, but can not get funding for him to have an "education assistant/ personal assistant" if he chooses to better himself

through further education. My son has no arm strength, but does have movement in his fingers so he can do some typing (not that fast) and a little writing. At school the EA will take over and scribe for him when he fatigues. She puts his laptop, books, writing material etc on his special desk as he needs it. She has to lift his arms up on to the desk. She also assists with drinking, eating, toileting, to scratch his nose, to shoo away flies, open doors the list goes on. WHO will do this for him if he goes on to TAFE? This is a human rights issue. Does not my son and so many like him have the right to seek further education in a safe and equitable manner like his able bodied peers? I have been made aware that other boys with DMD who are pursuing further education are only allocated 10 hours funding for assistance (this in effect sentences them to house arrest), whilst other disabilities with intellectual / behavioral issues are allocated the full 15 hours a week (15 hours a week may not be enough anyway). So, my son behaves and does not have an intellectual disability, but he is discriminated against in this instance too. The PSO forms that are used to assess those with an intellectual disability, are the same forms used to "score" young adults with physical disabilities, a completely unfair, inequitable way to assess them. If my son chooses to go on to further education, we should be allocated funding so that we can, ourselves, advertise for an assistant; someone that is receptive to his needs and will carry them out in a dignified manner whilst maintaining his independence. This issue is not about inclusion, it is about equal opportunity.

Accessibility: Wheelchair accessibility guidelines need to be reviewed. The minimum requirements should be to allow an adult electric wheelchair to pass through/ enter / turn around. These should be physically tested. 2 years ago my son did work experience for the local council and catalogued all disabled parking and disabled access toilets for display on the council website. Through the course of this, he and his EA visited all toilets and physically tested them to ensure they were fully accessible and documented the accessibility. One toilet they visited was being renovated to the "guidelines". Although he was able to enter into the cubicle; he was unable to close the inward opening door, due to the size of his electric wheelchair. Consequently they installed a siding door. The guidelines need to be reviewed so that the measurements allow for an electric wheelchair and carer to enter, and turn around and close the door. I have learned, as have many carers, by trial and error that the disabled sign on a door, does not necessarily mean that it is electric wheelchair accessible.

There are still many public places, shops, businesses, entertainment venues which are not wheelchair accessible. The guidelines for accessibility need to be upheld/ enforced.

Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring and effectively plan for the future.

If the Working Carers Respite was not age discriminatory then many carers of younger persons could access employment safe in the knowledge that their loved one is being cared for. With all respite, I think funding should be available so that the carer can choose whether to use an agency and their staff to perform those services or whether the carer interviews and retains the services of an individual who they think is suitable for their loved one.

If there was a data base of information as described previously it would increase the capacity of carers to make choices within their caring roles.

For me the transition into caring was a gradual one, due to the degenerative nature of my son's disease. I was a trained enrolled nurse, which stood me in good stead for my caring role that was to come. The most frustrating thing for newer carers is finding out things could have been funded after they were purchased, or finding out that funding or allowances are available and you only accidentally

happened to find out about them. A familiar phrase when carers are talking amongst themselves is "why didn't someone tell **me** about that" or "why wasn't I told". This is where a data base of information would be useful especially in this day and age where internet technology is available and accessed by many. Transition out of the caring role for parents of Duchenne boys will be extremely hard, as this disease is life limiting. Unless I die unexpectedly within the next 10 years, my son will surely leave this earth before me. I know that that sort of transition will be extremely difficult; I can not yet say what strategies would be useful. Effectively planning for the future; for many carers I imagine that this would indeed be troubling, especially when many carers will die before their loved ones and need to ensure that their loved ones care and concerns are looked after. That sort of planning for my son's future will hardly be necessary, however my personal financial future is bleak, as I no longer work and thus have very little personal superannuation- this would be true of many carers.

We unpaid carers are Australia's most precious resource. We care for our charges under trying circumstances and don't ask for special rewards. We just want to be treated equally and justly and have the necessary funding and equipment to do our job properly- a job, which, in paid circumstances and under Occupational Health and Safety guidelines would, in many circumstances require 2 persons, but many of us do the tasks on our own because we have no choice.

We carers will never be in the same position as non-carers. Carers have a totally different set of responsibilities and considerations to those who are non-carers. And our disabled loved ones will never be on equal footing as their able-bodied counterparts, because of the very nature of disabilities. But there are many things that can be done to make a carers life easier, and indeed the life of our charges.

In closing: The parent project group started in the US in the early 1990's, and the Australian organization (Parent Project Australia Inc) was formed about 5 years ago. 4 years ago I became a member, and 6 months ago became the secretary. For many years I had been frustrated at the lack of support and knowledge in the general community and lack of publicity for DMD. I used to sit and wonder how I could make a difference. Then I discovered (PPA). At last there was an avenue to put my energies into. By being a part of PPA, I hope that I can make a difference in our kid's lives. We have to fight for what we believe in and for our boys. We have to stand up against the inequality & indifference that is shown to DMD.

Compared to many other diseases, Duchenne muscular dystrophy is significantly underfunded. Duchenne has a low public profile, and so is a low priority for funding, research and treatment considerations. Unlike many high profile diseases, there are no celebrities / famous persons with this disease nor do they have children with this disease. Our 'boys' typically don't lobby on their own behalf, as by the time they are mature enough to do so, they don't have the energy to expend on anything other than staying alive. Many parents don't have the time and energy to lobby on their children's behalf either. The time that I spend advocating for Duchenne is time I take away from my family and my son, but this is a worthy cause and if we don't do it, who will? It is heartbreaking to see and hear of so many boys quietly surrendering to this disease, knowing this will be the plight of my son and MANY more to come. Even the simple task of getting a national registry up and running in Australia is proving seemingly impossible. With the advances in science and genetics, potential treatments for Duchenne are just on the horizon.

At the present time PPA have a petition requesting action in several areas of concern, the most important one being the formation of an Australian Registry. To do that, all boys suffering from dystrophinopathies (Duchenne and Becker Muscular Dystrophy) will need to have full genetic testing. Potential treatments for these diseases depend on where the problem is on the dystrophin gene. Once

the registry is formed, and each boy's genetic data is documented, it will be quicker and easier to locate those boys whose genetics match the potential novel treatment for clinical trials. We now have 5000 signatures in support.

What do we have to do to make the politicians sit up and take notice of our children's plight? How can we make them see that our cause is just as worthy as the next? Our kids, our families, the researchers & the scientists deserve better. We may be a minority, and we should not be subjected to feeling insignificant and unworthy of assistance.

Please don't hesitate to contact me if clarification is needed.



Mrs Pamela