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Secretary of the House Standing Committee on Family, Community, Housing and Youth  
House of Representatives  
PO Box 6021  
Parliament House  
Canberra ACT 2600

#### Inquiry into Better Support for Carers

Please find a submission to the Inquiry into Better Support for Carers from the Muscular Dystrophy Association Inc (MDA) attached.

In essence, it is our view that the role of carers, while being absolutely critical to the survival and development of people with Muscular Dystrophy, has been largely undervalued and under resourced in our community.

Clearly we advocate that an increased range of flexible supports and financial assistance is essential if we truly wish to provide the level of care to people with a disability, mental illness, chronic condition, terminal illness or who are frail, that we would wish to receive were we in the same position.

This would need to include Government funding and assistance to provide direct relief and services as well as to ensure the development and maintenance of volunteer supports in the community.

Please feel free to contact me should you have any queries.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Paul Creedon', with a horizontal line underneath.

Paul Creedon  
Chief Executive Officer

## Inquiry into Better Support for Carers

### The Muscular Dystrophy Association Inc:

The Muscular Dystrophy Association Inc (MDA) provides services and support to people who have Muscular Dystrophy or any of the more than 60 neuromuscular disorders, and their families/carers with the aim of improving or maintaining their independence in the community.

The service operates across SA and provides some services into the NT, and provides assistance to approximately 650 individuals per annum, plus their family and carers.

Services include information, hydrotherapy, speech therapy, physiotherapy, short term, day activities, accommodation, camps, carer's retreats, counselling and general casework activities.

### Introduction:

There is little doubt that many carers carry a significant burden in maintaining their loved ones in the community. This burden is made up of financial, physical and emotional costs which will frequently be so significant as to diminish their ability to provide the level of care that the community would likely believe someone should get.

While some supports, such as respite, do exist these are generally so limited and inflexible that their value to carers is limited at best and useless at worst.

However, the only option other than to continuing to provide support is to leave the person they care for to the state to accommodate. This is clearly an unacceptable option for the vast majority of carers, and could never be serviced by Government in any case.

An increased range of flexible supports and financial assistance is essential if we truly wish to provide the level of care to people who have a disability, mental illness, chronic condition, terminal illness or who are frail, that we would wish to receive were we in the same position.

This would need to include Government funding and assistance to provide direct relief and services as well as to ensure the development and maintenance of volunteer supports in the community.

### Overview of the issues:

Note: It is likely that much of what is said in the initial section of this paper will be reflected in other submissions. They are also issues which have been widely discussed and debated and should therefore be relatively well understood. As such, issues will be highlighted here rather than investigated in great depth. Further valuable information concerning impact and statistics can be obtained from organisations such as Carers Australia.

For the purposes of this paper a carer is defined as someone who provides *"unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail"*, as per the Carers Australia definition.

It would be safe to say that few people in our community strive for a relationship, whether with a life partner, child, parent, or friend, which involves them being a 'carer' or 'recipient of care'. Yet this is the reality for perhaps as many as ½ million Australians.

'Caring', by its nature, changes the reality of any relationship, both positively and negatively to some degree. Certainly it can deepen the sense of commitment to a relationship, but for many people this comes at enormous financial, physical and emotional cost.

Relationships in which one person is required to provide ongoing care for another, are fraught with multiple and overlapping issues, such as:

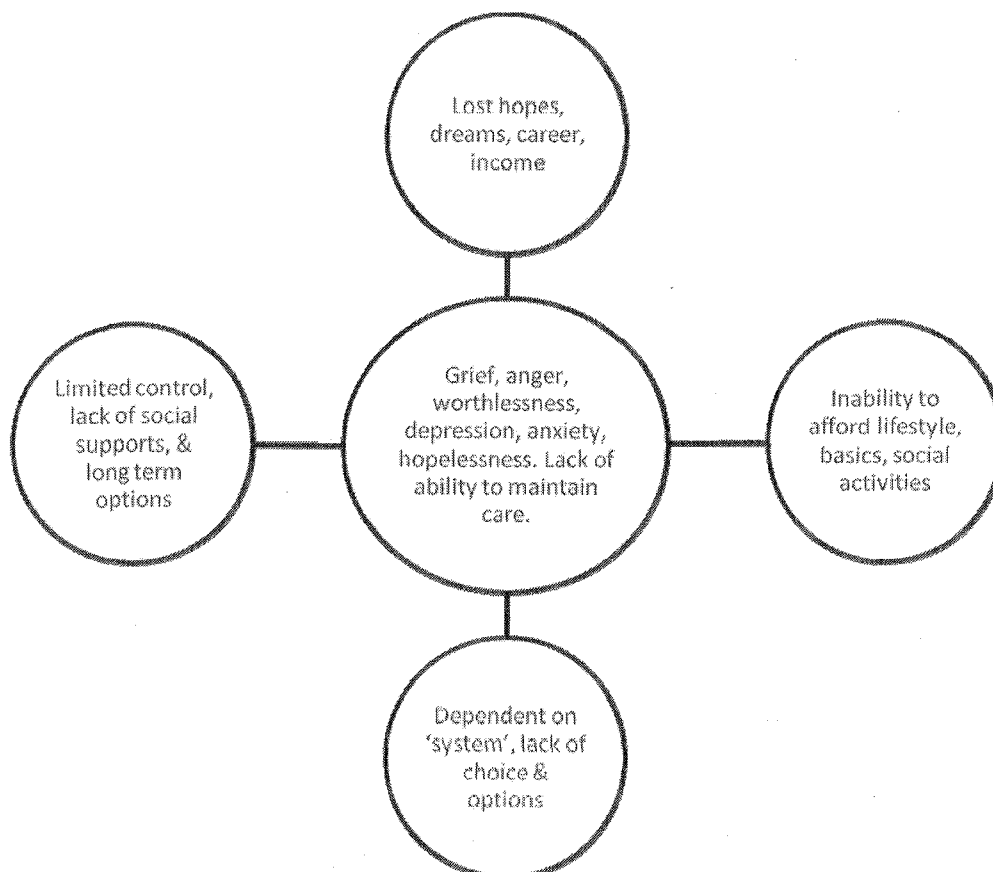
Financial	Physical	Emotional
Increased cost in most areas of life, e.g. motor vehicles, housing, holidays, medical treatment, medications, etc	Fatigue and ill health of the carer, exhaustion, age, etc	Competing feelings of obligation and guilt.
Purchase of equipment	Restricted ability to balance friends, other relationships, work, hobbies, etc such that these things usually diminish or disappear.	Ongoing grief at 'lost' opportunities and hopes.
Purchase of supports	Increased stress from ongoing organization and monitoring of life. Organising appointments, carers, equipment, planning an outing, etc, etc	Lost mutuality of the relationship between parties, and increased co-dependency.
Loss of earning capacity and potential	The difficulty in trying to do everyday things such as go on holidays, go shopping, being unwell, etc.	The loss of relationships with others such as other children, friends etc.
Inability to work 'full time' hours	The presence of strangers in the home – carers and other service providers.	The inability to support other family members such as grandchildren.
Loss of savings		Issues of dependence and co-dependence.
Inability to afford appropriate accommodation, purchase housing, purchase modified vehicles, etc		The difficulty of having to relinquish care
		Changing family roles, offspring toileting parents, mothers toileting adolescent boys (or fathers toileting girls),
		Grief, depression, anxiety, isolation, hopelessness, anger, etc.

To compound the difficulties people face, when these issues are recognised they are often only recognised in isolation, as individual issues. That is, the carer is experiencing grief, so the solution is perhaps counselling, or the family can't afford an accessible vehicle, so the solution is perhaps access cabs. This ignores how these issues interact.

The issues are underestimated if they are seen in isolation, they in fact can interact and overlap to such a degree that they can have an enormously dramatic impact upon the carer's ability to provide the care they and the community would want. The diagram below gives one example of what this may look like.

This diagram is not presented as the case for all carers, but it is quite likely that most carers will experience the emotions of grief, depression, etc which will affect their ability to provide care, and

this will come from a multitude of issues which all need to be recognised and addressed. It is also likely that most carers will experience the outer circles on a consistent basis.



It is also important to remember that in terms of caring grief is not a linear process, rather it is cyclic. In other words, rather than going through the commonly understood grief process of denial, anger/guilt, bargaining, sadness/despair and acceptance carers can often go in circles or certainly revisit certain stages as challenges present. For example they may go through this process, to some degree, every time the condition worsens (in the case of a deteriorating condition) or every time they are confronted with a new barrier.

#### Discussion:

Carers of people with Muscular Dystrophy/neuromuscular disorders reflect the cross section of the Australian community. They are women and men, sometimes children, sometimes aged, sometimes employed, often not, of no particular cultural grouping, from all communities and all cities, suburbs and regional centres.

Likewise, the issues presented above are just as relevant from a Muscular Dystrophy/neuromuscular disorders perspective as they are for other groups included in the definition of 'carer'.

With this in mind, the Muscular Dystrophy Association Inc would like to make the following comments to the Standing Committee.

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

There is little doubt that without the enormous contribution of carers, disability and aged services would collapse. Certainly their commitment to their loved ones reduces enormously the cost to the tax payer in terms of accommodation, day care, medical

treatment, home care, etc. But clearly this comes at enormous personal cost to the carer and her or his family and network.

Carers, in general, wish to continue this role but many find it difficult to maintain the caring effort continuously over what is likely to be many years. Many then struggle to meet the financial burden of caring as well as the impact of lost income and the inability to obtain adequate 'time off' from the caring role. Certainly many carers would find their task easier, if:

- There was easier, fuller and free (or more generously means tested) access to equipment and resources for the person they care for, that makes their job easier, e.g. wheel chairs, continence pads, transport, etc.
- They had access to the financial resources necessary to pay for the services they require, over and above other members of the community, e.g. health, transport, pharmaceutical, etc.
- There was a higher level of 'respite' available for them, particularly if this provides meaningful activity for the person they care for. This might include traditional respite centres, but it could also include day activities, breaks during the day for personal activities, etc.
- The level and frequency of alternative care available to the person they care for was adequate to actually allow them to work and earn an income.
- Flexibility/relief from the volunteering/study expectations of some Government benefits, unless a reflective level and frequency of alternative care was available.

2. The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment.

Each situation is of course different and people who share the caring role (e.g. parents, or siblings) may find it easier to participate in the labour market. Likewise, carers of children at school or of people with relatively low level care needs might also find it easier to participate in work, study and the community. We would expect that most often these groups would participate at a higher level than those on limited incomes, fewer backups, 24 hour responsibility or with high care needs.

This is not to say that people in the first category do not have significant needs, they do. But it is to say, in general terms that the second group are more likely to have more difficulties in terms of accessing the community, employment, study, friendship networks, and personal relationships, etc.

The barriers are usually plain and self evident, as listed in the earlier chart. The solutions may however be less evident and will certainly include the points in the previous section as well as:

- The ability to access emergency respite/alternative care where work or other commitments and caring commitments conflict.
- The ability to access long term, planned respite/alternative care around regular commitments such as work, holidays, etc.
- The belief that the respite services they can access will be reliable and able to provide a rewarding environment for the person they care for.

3. The practical measures required to better support carers, including key priorities for action.

The following points, reflected in the comments above, are not presented as 'recipes' to cure all ills. Rather they are programs that would need to be created to provide support at a practical level to carers as and when they need it.

Priority	Supports
1	Easier, fuller and free (or more generously means tested) access to equipment and resources for the person they care for, that makes their job easier, e.g. wheel chairs, continence pads, transport, etc.
1	Access to adequate financial resources necessary to pay for the services they require, over and above other members of the community, e.g. health, transport, pharmaceutical, etc.
1	Higher level of 'respite' available, particularly if this provides meaningful activity for the person they care for. This might include traditional respite centres, but it could also include day activities, breaks during the day for personal activities, etc.
1	Level and frequency of alternative care available to the person they care for being adequate to actually allow them to work and earn an income.
2	Flexibility/relief from the volunteering/study expectations of some Government benefits, unless a reflective level and frequency of alternative care is made available.
1	Ability to access emergency respite/alternative care where work or other commitments and caring commitments conflict.
2	Ability to access long term, planned respite/alternative care around regular commitments such as work, holidays, etc.
2	Ability to form a belief that the respite services they can access will be reliable and able to provide a rewarding environment for the person they care for.

4. 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.

The issues which prevent carers accessing employment are essentially the same as those that prevent access to the wider community, and especially for transitioning in and out of the caring role.

That is if you are a carer, especially of someone with high needs, then you can't walk away from the caring role even for a short period of time with support services being present to take that responsibility.

Certainly not all of these supports need to be funded to be effective, but most carers would confirm that family, friend and volunteer supports tend to be unreliable, and to dissipate over time. As such significant work to develop and maintain these voluntary networks is necessary, and largely absent in our current disability services structure.

#### Summary and Key Points:

As this paper and I am sure the vast majority of papers to the Inquiry indicate, carers carry a significant burden in maintaining their loved ones in the community. This burden is made up of an overlapping series of financial, physical and emotional costs, and these costs will frequently be so dramatic that they diminish the level of care that is actually available.

It is true that some supports, such as respite, do exist. But as I am sure the Inquiry has and will hear these are generally so limited and inflexible that their value to carers is limited at best and

useless at worst. This has certainly been the message that service providers have heard repeated over many years.

There are however almost no real alternatives for carers. Even should a carer wish to leave the caring role there are no supports or services that can pick this up long-term and very few that can pick it up short-term. Clearly, no government would wish carers to abandon this role, nor could the community afford to replicate it if carers did.

An increased range of flexible supports and financial assistance is essential if we truly wish to provide the level of care to people who have a disability, mental illness, chronic condition, terminal illness or who are frail, that we would wish to receive were we in the same position. Some of these are listed in this paper.

This would need to include Government funding and assistance to provide direct relief and services as well as to ensure the development and maintenance of volunteer supports in the community.

Paul Creedon  
CEO  
Muscular Dystrophy Association Inc