

Muscular Dystrophy Ireland

Pre-Budget Submission 2013

Summary

Muscular Dystrophy Ireland (MDI) is the national organisation providing information and support to people with muscular dystrophy and related neuromuscular conditions and their families. Neuromuscular conditions are a group of conditions characterised by the progressive weakening and wasting of the muscles, affecting adults and children. These complex conditions affect all aspects of a person's life and they require a range of supports including specialised neuromuscular clinics, genetic counselling, community services such as physiotherapy, access to aids and adaptations, adapted housing and transport, psychological support, respite, personal assistants and special needs assistants in schools. Some of these conditions are life limiting, requiring palliative care and bereavement support. However, with these supports, people with neuromuscular conditions can live an active life of their own choosing.

MDI understands the current budget limitations but in this submission, strongly advocates for current supports to be preserved for this group of people who require specialised disability support services which have historically suffered from a lack of investment.

Priorities

MDI is presenting three areas of focus for 2013:

- No cuts to personal assistant and home help services in 2013
- Improve waiting times to access essential aids and equipment
- Preservation of MDI's funding

PRIORITY 1

No cuts to personal assistant and home help services in 2013

People with neuromuscular conditions may require a Personal Assistant (PA) service in order to participate in education, employment or social activities and to live a life of their own choosing. However, it is becoming more difficult for people to access personal assistants and assisted living supports. MDI supports the independent living model and personal assistant ethos. At case conferences that staff have attended recently the HSE, even though they are funding a personal assistant service are focusing on covering personal care hours (personal care and hygiene) and not a true personal assistant service which is as follows; 'Personal Assistants (PA) enable people to live independently in the community. They may provide assistance with bathing, dressing, cooking or other personal or household tasks. They may also assist the person in going to and from work, or may aid them in working or studying or participating in social life. (Citizens Information Board 2012, "Entitlements for People with Disabilities")'

MDI is very concerned about this and the effect it is having on members. Members are being pressured to redistribute their existing hours to cover getting up, showering and going to bed.

There appears to be no funding for supporting people outside the basic care needs and this the organisation finds very worrying as it discriminates against the majority of MDI members living with neuromuscular conditions. In fact MDI was informed at a case conference that the criteria for allocating personal assistant hours are as follows;

1. Personal care hours only.
2. Emergency situations / discharge from hospital are being given priority.
3. If already receiving personal assistant hours, these hours must be reviewed and if possible redistributed to ensure efficient use of resources. Applications for additional personal assistant hours will not be assessed or approved until it has been shown that the person is using allocated hours as efficiently as possible as deemed by the HSE. This is causing issues for MDI as many of our members due to the muscle wasting condition need support throughout the day not just for getting up, meal times and going to bed. But the HSE is focusing on personal care hours only.

MDI would be very concerned that the Personal Assistant service which is invaluable to our members is being devalued and that people with physical and sensory disabilities in Ireland will in the long run suffer a great miscarriage of justice.

In the South & West Dublin, Kildare and Wicklow region, there are 4 people experiencing hardship due to lack of personal assistant hours. One member who is 48 years of age needs full time PA hours to live independently. He currently has a gap of 25 PA hours. A member of his family supports him where these gaps occur, however this is not sustainable. His family member is ageing and has their own health concerns. Recently when this family member took ill, the gaps remained unfilled. Fortunately MDI was able to provide emergency support to him but cuts to MDI's own budget limits our ability to support people like this in times of extreme need.

Another member has 8 assisted living hours. His needs have significantly changed over the last number of years, and his hours have not been increased despite there being a huge effort on the member's part and support by MDI to advocate for more hours. As a result this means that on the days he does not have assistance he cannot leave his home or access the door to let people in which is a serious health and safety issue.

A member who requires additional PA support due to changing family circumstances is currently short at least 24 PA hours and relies on his elderly mother to do two overnights a week in order to support him and his family with extra household duties. This places enormous pressure on his mother and the family. He now has gaps in the day when he has no PA. This means that he cannot access the kitchen to prepare a fresh meal. On occasion he has to go to bed to save up his hours.

Similar situations are being experienced throughout the country. As well as the 4 people mentioned above, 5 people in the South East, 9 in North Dublin, 9 in the West, 3 in the Midlands and 8 in the South need PA hours now. If they do not have this support, they and their families are placed under additional stress. At least one family have now required additional family support services in relation to counselling, specifically due to this stress. There are also health and safety issues as outlined above. Lack of PA services disenfranchises people with disabilities more by creating barriers to

employment and social activities, making them more isolated and continually reliant on state support.

Currently 8 people in the South East report that their Home Help hours have been reduced or are at risk of being reduced. 6 people in North Dublin, 19 in the West, 9 in the Midlands, 4 in the North West and 3 in the South either need the service or need an increase in their hours. One member in the South & West Dublin, Kildare and Wicklow region has applied for extra home help hours due to changing needs as a result of her condition. She has been refused hours and as a result has resorted in paying for her home help hours from a private agency which is affecting her financial situation and causing her and her family added stress.

Summary: A personal assistant provides invaluable support throughout the day not just supporting with personal care needs. A better understanding of the personal assistant service needs to be developed within the HSE to reflect this, to reduce the negative effect that the cuts are having on members and to become more aware of the cost saving benefits of supporting the person in the home as opposed to residential or emergency settings. 38 people need PA hours and 50 do not have sufficient home help hours. While people who need the service cannot access it, it would be unjustifiable to cut it further.

PRIORITY 2

Improve waiting times to access essential aids and equipment

Muscular dystrophy and related neuromuscular conditions lead to progressive weakening and wasting of the muscles. People require a range of equipment such as manual wheelchairs, powered wheelchairs, walking frames, orthoses etc. Members are reporting lengthy delays to access the equipment they need which is a serious issue for people with such a progressive condition. Two children in the North West were fitted for manual wheelchairs in April but still have not received them. One of these children has outgrown his current chair and is no longer able to use it. In the North East, one young man has waited for 10 months to have his wheelchair upgraded. Because of the long wait he has suffered anxiety and stress that resulted in him having to go to his GP. He became withdrawn and angry causing his family much stress and anxiety. In the same region, a mother has also been waiting 6 months for a wheelchair for her young son. These examples are representative of the 7 people in the South East, 11 in the West, 3 in the Midlands and 3 in the South who are waiting to receive essential equipment.

Delays not only cause anxiety and stress, but can lead to social isolation due to people not having the equipment to enable them to go to college or work or participate in the activities of daily life. It can also lead to discomfort and health issues for people who have outgrown their current wheelchair. There is also a risk that delays will lead to unnecessary costs to the state, if people are waiting for so long to receive equipment that their condition has already progressed and they need to be reassessed.

Summary: 28 individuals with muscular dystrophy are experiencing delays in accessing essential equipment.

PRIORITY 3

Preservation of MDI's funding

MDI provides a range of practical support services to people with neuromuscular conditions, their families, carers, health and education professionals. These include family support, youth support, information, respite, social outings and camps, accessible transport, support at muscular dystrophy clinics and access to a fully accessible apartment for short term stays. In recent years, MDI has experienced multiple cuts to its funding. This had led to the organisation streamlining administration and cutting spending on costs such as transport. However, it is unable to make any further budget cuts without impacting on direct supports to people with neuromuscular conditions and their families.

MDI's membership has been steadily increasing from 469 individuals with neuromuscular conditions in 2006 to 637 in 2012. MDI is currently involved in a study to develop a registry which will give much more accurate details of the number of adults in Ireland with neuromuscular conditions and it is anticipated that this study will lead to a further increase in MDI's membership throughout 2013. These individuals have rare conditions, caused by different genetic mutations which require specialised information and support. Many health professionals have never had a client with these conditions and so MDI becomes the main source of information to the individual and their family as well as to the health professional. A lack of information has been highlighted as an area to address in the development of Ireland's National Plan for Rare Diseases, which the Irish Government has committed to producing before the end of 2013. Despite this, MDI as the main source of information about neuromuscular conditions, is experiencing cuts which limit its ability to provide this essential service.

MDI's Family Support and Youth Workers provide direct support to adults and children in their local communities. This support is beneficial psychologically for people who are dealing with an often very severe diagnosis, but also practically, as social outings and activities are arranged to combat isolation, improve links with the person's own community and enhance the person's confidence so they are able to participate more in mainstream society. However, MDI does not have funding to provide the essential youth support service in all areas of the country and has also been prevented from replacing the family support worker position in the north east region. This can only lead to further isolation for an already isolated group of people.

Summary: MDI's budget should be preserved to allow it to maintain its essential supports to people with neuromuscular conditions and their families.

"MDI is a vital source for people with neuromuscular conditions. It provides a wealth of resources to families and individuals who experience the condition. Without the supports MDI provides, people with MD would find even greater difficulty in surmounting the obstacles towards making for themselves a fulfilling and worthwhile life. Their role in the lives of people with MD is an essential and fundamental necessity that cannot be taken for granted nor considered expendable."

- MDI member responding to the MDI Members' Audit 2010