MND

MOTOR NEURONE DISEASE
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30 July 2004

The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
CANBERRA ACT 2600

RE: Inquiry into Aged Care

The Motor Neurone Disease Association of Victoria wishes to make the following submission to the Senate Committee's Inquiry into Aged Care.

If you require any further information please contact me on 03 9830 2122 or 1800 80 6632.

Yours faithfully

Rodney Harris

Rodney Harris
Chief Executive Officer

SUBMISSION TO THE

SENATE COMMUNITY AFFAIRS REFERENCE COMMITTEE

INQUIRY INTO AGED CARE

BY THE

MOTOR NEURONE DISEASE
ASSOCIATION OF VICTORIA

ON BEHALF OF

PEOPLE LIVING WITH
MOTOR NEURONE DISEASE

Introduction

MND affects people across a range of ages. This results in people requiring a broad range of support delivered by a similar range of organisations. Organisations providing support include those funded through Disability Services (State Government, primarily) and Aged Care (Commonwealth, State and local government).

People with MND access residential aged care services because their care needs exceed the ability of their carers or other funded services to meet in their existing accommodation. Some people who do not have family carers have no option other than to seek supported accommodation.

As many residential aged care services are also available for younger people with disabilities, such services are accessed by people with disabilities across all ages. It is clear, however, that these services are accessed by people with MND on the basis of need. However, service types and delivery options are based on age, and in many cases bear little relationship to the needs of the individual.

People with MND access aged care services via the same access pathways as people over the age of 65 – assessment via the Aged Care Assessment Service, and referral to appropriate residential aged care services.

Generally, residential aged care services have the skills to meet the needs of people with MND, but do not have the time, resources, knowledge or commitment to support them in a manner which reflects their support needs.

Background to MND and the MND Association of Victoria

In summary:

- MND is a progressive degenerative neurological disease that causes rapidly increasing levels of disability, and death
- Average life expectancy in Victoria from diagnosis is about 27 months
- Average age of onset is 59 years, however, the age range of onset is 40 to 70 years
- The rapid progression of MND creates high levels of disability and consequent needs for support — feeding, communication, movement, transferring, toileting, day activities etc. MND has a comprehensive impact on all aspects of living.
- While people of working age can remain at work after diagnosis, this is usually for a very short time, often only weeks of a few months.
- The key feature of the disease is the speed of progression, which poses huge problems of adjustment for people who have MND, an escalating burden on carers and families, and a challenge to those who are involved in providing the highly variable and complex care.
- Over 90% of people with the disease are supported by a spouse or carer in the home (Sach, 1995)
- Carer stress is a significant cause of hospitalisation, facility-based care/respite and movement to residential aged care facilities

- ❑ People living with MND are not traditional service users, and have rarely had involvement with the disability or community services sector.
- ❑ Research by Sach (1995, 1997) indicates that people living with MND **will not access services** unless they have confidence in the provider's knowledge of MND and its impact.

Service Needs

Service needs arising from MND include:

- counselling and support at and following diagnosis
- accurate information
- respite for carers and ongoing support in day activities for client
- accommodation services when people cannot remain at home
- support from volunteers when appropriate
- equipment and activities to maintain independence, including communication
- a focus for supported access to services
- coordinated support from a team of professionals
- early intervention which often reduces overall service needs
- need urgent response - waiting lists are not appropriate

In addressing service needs, people with MND need recognition that while they have a progressive disability, they have no cognitive deficit, and are aware of themselves and their surroundings at all times.

In terms of accommodation services, they need support that recognises the lost ability to communicate, or to use call button systems. The environment and management must be able to cope with PEG feeding and ventilation.

And despite severity of the disability, people with MND require interaction and communication with people.

Association Services

The Association delivers four main services, supported by administration and fundraising.

The services are:
- Equipment Loan
- Case planning and Assessment (Regional Advisors)
- Volunteers
- Information

The Association has registered and is supporting 98% of the projected cases of Motor Neurone Disease in Victoria. This market penetration has given the Association a clear understanding of the impact of aged care services on people diagnosed with MND and their families.

The Motor Neurone Disease Association of Victoria was established in 1981 and is a community-based organisation run by an elected State Council.

Membership of the Association is currently over 900, comprising patients, carers, former carers and interested people. The Association, as at 30 June 2004, was supporting 236 people with the diagnosis of MND. They receive a variety of services provided by the Association, including Family Support, information, equipment and volunteers. In 2003/2004 346 people received support from the Association.

The Association moves in and out of the lives of people with MND as their needs demand. Given the relatively short life expectancy of people diagnosed with MND (29 months from time of diagnosis), the monitoring and reassessment of needs is an essential element in ensuring that they are able to appropriately access quality services when they need them. Our aim is to assist people to live as well as possible while living with MND. Transition management and facilitation is an effective mechanism to achieve this.

This transition process, or the role of being an interface between people with the disease and the service sector, is fundamental to effective service delivery for people with progressive degenerative diseases, and particularly MND.

Case Studies

CASE STUDY 1

Joe W is aged 78 and has motor neurone disease. He has a carer who is frail and aged, and physically unable to support him safely at home. Joe lives in a residential aged care facility.

Joe is unable to use the facility call button as he has lost the use of his arms, but can use two fingers to communicate. He has lost speech, and communicates via an electronic device.

For three evenings, at meal times, Joe was delivered his evening meal by a staff member who was a relieving casual. The meal was placed on his side table. An hour later, the staff member returned and took his meal away untouched, commenting that he “mustn’t be hungry”.

At a visit by his carer, Joe indicated that he was not receiving his meal at night. The issue was raised with staff, and the issue identified – Joe couldn’t use his arms to move the meal tray to where he could eat it, and could not use his arms and hands to feed himself. He needed time of staff to feed him. This was known to all staff, but not communicated to relieving staff.

CASE STUDY 2

Mary is aged 54 and is a resident in a residential aged care facility.

Mary requires a pressure management device on her bed to prevent the occurrence of bed sores, to address chronic hypersensitivity and discomfort, to optimise comfort levels, and to enhance quality of life.

The residential facility is required to provide pressure management devices, and supplies a “ripple foam mattress” which is inappropriate for people with MND, and who require a variable air pressure ripple mattress. The air pressure mattress provides alternating and variable pressure support which optimises comfort, reduces pressure areas and which significantly reduces the requirement for turning of the person and repositioning.

The residential aged care facility will not purchase the appropriate pressure care device and the state Aids and Equipment program will not fund people living in residential aged care which is funded by the commonwealth.

Mary also requires socialisation and activities outside the nursing home. As her fellow residents are mainly people with dementia, there is no ongoing program that assists Mary to maintain social interaction and contact, and intellectual stimulation.

CASE STUDY 3

Simon W is aged 65 and lives in a residential aged care facility. He has motor neurone disease and has a tracheotomy and invasive ventilation to support his breathing. He is unable to walk, but can operate his electric wheelchair with his remaining strength in one hand.

He was attacked by a fellow resident who was suffering from dementia, and who attempted to pull-out his breathing tube. Simon could not defend himself because of lack of use of his arms but was able to call for assistance with the call bell system.

Simon is keen to get out and about, and his electric wheelchair, provided by the MND Association prior to his admission, is fitted to support his ventilator. However, staff do not have the time to transfer him and his ventilator to the wheelchair, and support his attempts to get out and about.

Residential Aged Care

In relation to residential aged care, we would like to highlight the following issues:

Staff Training – our experience is that staff are trained in respect to managing frail aged and aged people with dementia, but do not have the skills, training or experience to appropriately support, in a caring environment, people living with MND.

The high turnover of staff, combined with significant use of temporary or agency employees, often means that staff on duty are not aware of the issues to be addressed with a person with MND. Some examples:

- a person with no use of their arms or ability to speak is delivered meals, but because they cannot feed themselves, the meals are taken away uneaten, and the person is unable to communicate that they need to be fed. The information regarding feeding and communication is available in the patient file.
- a person is given a call button to press to attract attention of staff, but due to significant loss of strength in their arms and hands, cannot reach the button, let alone press the button to attract attention when needing assistance to use

> the toilet. The end result is a soiled bed, and a person whose dignity and self-esteem is severely damaged. The impact is compounded when inappropriate remarks are made by staff within the person's hearing, on the assumption that they have dementia and don't understand, or thinking that because they can't speak, they can't hear.

Staff who work in an aged care facility where people with MND are living need to be made aware of the nature and impact of the disease, and services planned and modified to ensure that good quality care is combined with understanding of the disease and its impact, appropriate communication, opportunity to participate in activities and recognition of their needs.

Dementia focussed services – increasingly, residential aged care facilities have become focussed on dementia care. This is a natural progression from the Government's focus on assisting people to remain at home for as long as possible with other aged care support services. However, people with advanced MND who access aged care facilities do not suffer from dementia, are aware of their surroundings, can hear and understand all that is going on around them, but are trapped in an increasingly unable body. They need the "nursing" component of the aged care facility because of their disability and the inability to receive sufficient support to remain at home.

People must be treated with respect, recognising that they are not suffering from dementia, but from a physical disability.

Risks for people with MND – people with MND living in residential aged care facilities are increasing facing the risk of assault or disruption to life support equipment by other residents. Some people with MND require ventilatory support, while many have PEG feeding tubes. This, combined with severe physical disability, can place them at risk of assault or interference with their medical equipment by people who are physically able but suffering from dementia. In one reported instance, a person with dementia had to be restrained from disconnecting ventilation equipment from a person with MND who was unable to protect or defend themselves due to their disability. Other reports have been received of people with dementia abusing and attacking people with MND in their beds. These events highlight the existing risks of having people with severe physical disability but mentally able living in an environment where other residents are physically able but suffering from dementia.

Residential services must be made available for people with high level physical needs and who cannot be supported to live in the community to protect them from inappropriate behaviours.

Aids and Equipment – while residential aged care facilities are required to provide appropriate aids and equipment, most residential services do not have the funds available to provide equipment that is necessary for people living with MND. This is complicated by the State Government aids and equipment program (A&EP) specifically excluding people living in residential aged care facilities.

The outcome of this exclusion is inappropriate pressure care provisions, non supply of electric wheelchairs to facilitate access to the community, unavailability electric riser chairs to facilitate comfortable seating in communal activities or areas, non supply of appropriate pressure care devices, and non provision of electric adjustable beds to facilitate repositioning and comfort for the person, and workplace safety for the staff.

Residential aged care facilities are required to make available a range of disability equipment to support residents. However, facilities generally acquire the minimum equipment, or equipment that meets a very basic standard. For example, the acquisition of ripple foam mattresses as “pressure care” is an inappropriate mechanism to provide pressure care for most people, and MND people in particular.

Clarity of the requirement of operators of residential aged care facilities to provide aids and equipment, along with agreement between State and Commonwealth government regarding the provision of equipment in residential aged care facilities, is essential to ensure quality of life and opportunity for people with MND, and safety for staff.

<u>Communication</u> – residential aged care facilities are required to have call facilities to enable residents to call for attention. However, the emergency call systems are generally structured around a push button system. People with MND requiring residential aged care support have generally lost the capacity to use their hands and are unable to use a call bell system using the traditional push button switch.

Inability to call for assistance is potentially dangerous and creates a high risk for people living with MND.

Residential aged care facilities must be required to have an emergency call system which is able to be adapted for use by **all** residents, recognising their abilities and disabilities.

<u>Time</u> – significance of needs created by MND is reflected in the time required to assist or support someone with the disease. This is particularly true of those who live in residential aged care facilities. Time is required for positioning and repositioning to reduce pressure areas or to optimise comfort or reduce discomfort, time for communication, feeding, transferring from bed to chair and return etc.

Yet the time to do these things is not available in residential aged care facilities.

People with MND with high support needs could be adequately supported in aged care residential facilities if the facilities were adequately resourced to deliver this service. Additional components of funding should be available to these facilities when they have a person with MND to ensure that time can be made available to facilitate proper care and support.

Younger People in Nursing Homes

Residential aged care facilities are not appropriate service models to provide high level support and care your younger people.

As stated above, residential aged care facilities appear to have a primary focus on dementia and care for aged people with dementia. Younger people with disabilities require high-level care, but also require social interaction, conversation and activities which might include work or volunteering.

Some key issues to be addressed are:

Adequacy of Support – some younger people with MND need the level of care and support that can currently only be provided in a residential aged care facility. However, this support is only made available in a dementia or aged care framework which does not recognise the needs of a younger person with a disability.

Inadequate funding is available to provide anything more than basic care, which does not address the aspirations of younger people with MND. They want to be able to maintain and develop community interests and activity, participate in community and social activities, and receive support that respects them as a person with high physical needs. This support does not take account of their existing family and social relationships, nor address their disability. They do not have dementia, and are fully aware of their surroundings. They need to be active players in their care.

Support at this level must provided in a setting which does not focus on age, but on the care needs of the individual. It must recognise and respect their disability, and deliver services that allow them to optimise their quality of life and fulfil their ambitions.

Need for disability focussed support – people with MND need a service that focuses on their disability, and is not based on age. Services need to understand the disability and provide support and services which address disability and complement ability.

Funding needs to be available that allows disability focussed care and support in an environment which includes people with similar needs, desires and aspirations. The service should address disability issues, and create an environment which supports and enhances quality of life, creates opportunities for action and interaction, and which promotes interaction with the community.

Service Options – the existing aged care residential facilities to not provide options that provide appropriate support for people with MND or significant disabilities. Current services provide accommodation and basic support and protection for those who are at risk. However they do not provide appropriate levels of access to allied health, including occupational therapy, physical therapy, and speech therapy/pathology.

Where younger people with disabilities and people living with MND require “nursing home” levels of support, services should be made available in an environment that delivers services based on the needs created by their disability, not their age, and not services based on an age group needs other than theirs. Services must be focussed on addressing the needs created by the disability, not on the delivery of a generic service model. Services need to be individualised and focussed, with packages of support being used to optimise outcomes.

Aged Care Packages – The Community Care Aged Package (CCAP), and the amount of support each package can purchase, is insufficient to support an older person with MND to remain at home with their carer.

If the person with MND was under the age of 65, the State Government Disability Program "Home First" can purchase up to 34 hours of support to enable the person to remain at home.

Home and Community Care

Home and Community Care programs currently target the elderly and people living with disabilities.

Experience with HACC indicates that there are insufficient hours of support available to achieve a meaningful change in the level of support received by people with MND. Most HACC outlets are or have reduced the available hours to two per week, providing inadequate support and a significant gap between HACC and CCAPs. Significant delays exist in assessment, particularly when people are over 65 but under 70.

Assessment delays compound the impact of lack of support. In one Melbourne area, the ACAS team has a waiting list of 8 weeks and is managing that list by not doing assessments for any person under the age of 70, and not doing assessments of people with disabilities who may wish to access residential aged care facilities or care services that require an ACAS assessment.

When assessment is managed in tis way, there is a significant component of unmeasured unmet need. If unmet need is not measured, it is impossible to identify resource needs and service gaps. This results in policy makers not being informed of the true needs within the community.

Key issues are:

Adequacy of support – the current levels of resourcing of HACC services are inadequate for existing demand. As places in residential aged care facilities become more difficult to access, there is increasing pressure downwards on the other support mechanisms available in the community. CAPPs become limited and each packaged reduced in quantum to spread the available resources further. This results in a bandaid approach with inadequate resources being available in a package to provide proper support and meet assessed needs. As the CCAPs become squeezed, HACC becomes further squeezed. Some local government areas approve one hour of support per week – this is tokenism at best, and does little to address the assessed needs of clients.

This is then compounded by restrictions on assessment.

Resources allocated to HACC must be reviewed. Needs of people eligible to access HAC must be assessed and policy decisions made regarding funding priorities.

Token funding should be abandoned and replaced with an effective funding strategy that ensures that unmet need is identified and addressed.

Limitations of assessment – as noted above, access to HACC services and to aged care services is being limited by control of the assessment process. In particular, one ACAS team is refusing to undertake assessments of people under the age of 70.

As ACAS assessment is the gateway to accessing some HACC and aged care services, restricting access to assessment controls demand. The result is that some older people and people living with disabilities are unable to be assessed and their needs placed in the queue for services.

Arbitrary restrictions on assessment must be abandoned and positively discouraged. Assessment is the only tool available to identify unmet needs and create priorities for action.

CONCLUSION

Services for people with disabilities must be provided based on needs, and not on the basis of age.

It is clear that some people under the age of 65 require levels of support that are currently only provided in residential aged care facilities, including 24 hour care, meals and activities. It is also clear that some people over the age of 65 need services that are currently provided through disability services but only for people under the age of 65. This barrier or division of responsibility, currently in place between Commonwealth and State funded services, must be removed.

Services must be available for people to address their unmet needs, not on the basis of age.

Where services are provided, they must be holistic and effectively address the needs of people. In residential aged care facilities, service providers must supply age and disability appropriate services. Support must reflect disability and the needs it creates. We must move away from a generic service model, and move to a model of service which has basic components which all people require and different components that only some people require.

People with MND have a short life expectancy, and deserve the opportunity to access the broad range of services that the community has available. Those services need to address the needs created by MND, maintain quality of life, and support intellectual and social stimulation and community participation.