



# Key Directions for the Commonwealth Home Support Programme Discussion Paper

## Submission template

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**Completed submissions are to be sent by 30 June 2014 to:**

[CHSP@dss.gov.au](mailto:CHSP@dss.gov.au) (preferred method) OR

Home Support Policy Team, Level 6, Sirius Building  
Department of Social Services PO BOX 7576  
Canberra Business Centre, ACT 2610

**Submissions received after Monday 30 June 2014 may not be considered.**

Unless otherwise stated, the information and feedback you provide may be used for publishing purposes. Please state if you do not wish for your comments to be published

### Instructions for completing the Submission Template

- Download and save a copy of the template to your computer.
- You **do not** need to respond to all of the questions.
- Please keep your answers concise and relevant to the topic being addressed.
- Refer to the **Discussion Paper: Key Directions for the Commonwealth Home Support Programme (Hyperlink)** for context on the questions.

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If submitting on behalf of a company or organisation

**Name of organisation:** Motor Neurone Disease Australia

**Stakeholder category (e.g. service provider, client, peak body, academic):** Peak Body

**State/Territory:** National (office Gladesville, NSW)

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**Question 1:** Are there any other key directions that you consider should be pursued in the development of the Commonwealth Home Support Programme from July 2015?

The key direction to ***provide timely, basic home support services to frail older people and their carers*** should be expanded to encompass older people who acquire a disability not related to their age. Without this inclusion the aged care system will continue to focus on addressing needs related to ageing and not disability. Likewise the key direction for the CHSP to be underpinned by a wellness and reablement philosophy could prove problematic when assessing and providing services to people with a progressive disability.

In particular, focus must be placed on the engagement of specialist disability services by aged care providers to ensure that the needs created by disability acquired over the age of 65 are fully addressed. In particular, for people diagnosed with motor neurone disease, funded access to the rental and/or purchase of disability aids and equipment and respite need to be included.

**Question 2:** How should restorative care be implemented in the new programme?

It is important to ensure that the programme takes into account the needs of people with rapidly progressive neurological conditions where restorative care is not the priority. This group must have access to early intervention, allied health/therapy, ongoing expert assessment, complex case coordination, aids and equipment, respite care options and a range of services to meet their assessed needs.

Aids, equipment and home modifications are primary enablers and central to independence, choice and quality of life for people with MND. The provision of the right equipment in a timely manner is also vital in minimising support required, maximising cost effectiveness of programmes, supporting carers and service providers and supporting people to participate and remain engaged in their local communities.

The intention of the CHSP is to provide minor assistance for aids and equipment and the proposed annual limit of \$500 per person may be adequate for most frail aged people. However, people with a progressive disability over the age of 65 will need access to a well-funded program for the provision of a range of aids, equipment and assistive technology and the CHSP will need to be clear on how it will interact with any such program. What will be provided and how it will be funded by government is a major gap that must be addressed immediately in consultation with key stakeholders.

**Question 3:** Are these proposed client eligibility criteria appropriate? Should the eligibility criteria specify the level of functional limitation?

**The eligibility criteria ‘to have needs that do not exceed a basic support program’** – will result in people living with MND over the age of 65 falling through the cracks of service provision. Many people with high needs are currently receiving HACC services as they are unable to access a CACP or EACH package. Even with the increase to the range and number of packages available there will not be enough packages to support all people with high needs. The above criteria will result in many people with MND missing out on the care and support they need as their disease progresses as they will be unlikely to receive a package in a timely manner. They need some support, however inadequate, to help them to live at home. This statement is also inconsistent with the statement on page 29 that says that if assessed as eligible for a HCP but is waiting to receive that Package the client will be able to receive services under the CHSP. This needs to be written into the eligibility criteria.

People with rapidly progressive neurological conditions such as MND should be considered to have special needs requiring specific services, and should be accepted automatically for entitlement to access support.

**Question 4:** Are the circumstances for direct referral from screening to service provision appropriate?

Will assessment take into account the needs of people with rapidly progressive neurological conditions? Will assessors be trained to recognise the different needs of people who are frail aged and those living with a progressive disability? People diagnosed with a progressive disease such as MND may not be aware of their future needs so self-referral may not identify the person’s needs adequately. However, due to rapid progression it may be important for timely direct referral and there may not be time to wait for a face to face assessment although preferable.

It is essential that people with MND be supported through the assessment process by specialist staff with extensive knowledge of the disease, its impact and the needs it creates.

**Question 5:** Are there particular service types that it would be appropriate to access without face to face assessment?

Specialised allied health assessment to support independent living and the provision of aids and equipment to maintain independence, community access and safety of carers.

**Question 6:** Are there any other specific triggers that would mean an older person would require a face to face assessment?

Diagnosis with MND should trigger automatic entitlement to community aged care, with proof of diagnosis in the form of a letter from a diagnosing specialist or statement by a MND Association being accepted as evidence of diagnosis.

Complex care needs with rapid progression – progressive neurological conditions combined with risk for carers and paid care staff.

**Question 7:** Are there better ways to group outcomes?

The outcome group '**increased independence**' should include quality of life and not simply focus on improving or maintaining health and functioning which is not an achievable outcome for people with MND. Outputs need to include referral to aids/equipment/assistive technology program for access to equipment that exceeds the \$500 limit. Disease specific organisations such as the state MND associations can provide information and education and at present most also loan a range of equipment.

**Question 8:** Are there specific transition issues to consider?

With no access to case management/care coordination many people will miss out on services being coordinated across the various sectors. People with motor neurone disease are accessing support and services across a range of sectors, as do many other people, including health, HACC disability and aged care. Coordination is not achievable without ongoing case coordination/case management for complex needs groups. Currently case coordinators/case managers provide a service in working across sectors helping the person to navigate the system and supporting the sectors to work together for an individual. Coordination and management is essential for people who have complex care needs accessing the CHSP as many of these people will not be able to access timely home care packages.

The provision of, and access to, aids and equipment for people 65 and over should be an integral component of the aged care reforms. It appears that Service Group Five (Home Modifications, Home Maintenance, Goods & Equipment and Formal Linen Services) will be reporting on these issues, and we look forward to further information in the near future. It should be noted that anecdotal advice from existing aged care providers indicates that they do not believe there is sufficient funding within the proposed aged care packages to rent complex aids and equipment to address the needs of people with MND.

Access to a government funded aids and equipment program for people over 65 is essential to support the effective operation of CHSP. People currently access aids and equipment through state/territory equipment programs which are funded by the state/territory disability or health departments. In addition some MND associations receive disability or health funding to support their equipment loan service. It is very likely that much of this funding will be redirected to the NDIS for people with disability under 65. There is therefore the risk that these programs will no longer be able to adequately service people 65 and over.

We recommend that consultation be undertaken with peak bodies and service providers supporting people with rapidly progressive neurological conditions to ensure that they are not increasingly marginalised from necessary support initiatives.

**Question 9:** How are supports for carers (other than respite services) best offered? For example, should these be separate to or part of the Commonwealth Home Support Programme?

Need to be part of the CHSP so that carers are seen as an essential part of the program

**Question 10:** What capacity building resources are needed to assist with the sector's transition to the Commonwealth Home Support Programme?

Block funding for disease specific organisations to deliver specialist information, training and education and expert individualised and personalised support and services to support and enhance the CHSP.

Increased awareness and understanding of assistive technology (AT) will improve independence, participation and restoration, and is central to reducing long-term costs and residential aged care admissions. There is often a resistance to accept and utilise AT and equipment products despite the substantial benefits. Increased training of professionals and improved awareness of people over 65 about the benefits of adopting AT and equipment solutions would help to reduce these negative attitudes.

**Question 11:** How should the current Assistance with Care and Housing for the Aged Program be positioned into the future?

No comment

**Question 12:** Are there any other issues that need to be considered in transitioning functions from the current HACC Service Group Two to My Aged Care?

People diagnosed with MND must have access to early intervention and ongoing expert assessment. CHSP assessors will need to have an understanding of MND and its impacts. Experience in the NDIS launch sites has demonstrated the value of the MND association Regional Advisors being involved in the planning process and we therefore recommend that the person's regional advisor be included in the assessment process.

Block funding needs to be considered for specialist agencies to support people living with MND until they are able to access funded support via community aged care.

**Question 13:** Is there anything else you want to raise to help with the development of the Commonwealth Home Support Programme?

We are disappointed that the NACA recommendation of a single home care system was not incorporated as it creates a 2 tier system that will not be seamless and streamlined. It is important to note that neither program provides enough care for someone with a progressive neurological disease that leads to significant disability and people diagnosed with MND when 65 or over will be significantly disadvantaged compared to those on the NDIS. We are also concerned about cost of the program as people with complex conditions have many additional expenses and may have difficulty in paying. This is a great concern also with Home Care Packages.

The CHSP will fail if those needing more significant levels of AT and equipment do not have easy access to an effective government funded AT program for more substantial and higher cost items.

MND Associations are working with the NDIA to implement a basic bundle of care on entry to the scheme that includes complex care coordination (regional advisors), care management (case manager), home assessment, therapy, respite and \$5,500 p.a to access equipment as required on loan from the MND association. We would welcome the opportunity to discuss this model with the Department of Social Services.

## Aged Care and people diagnosed with MND

## POSITION STATEMENT

### **Background:**

The complex needs of people living with rapidly progressive neurological diseases, such as motor neurone disease (MND), cannot be met by existing or traditional aged care services or facilities.

The introduction of a national disability insurance scheme (NDIS) will transform the lives of people living with MND who are diagnosed when under the pension age and who will be funded to access reasonable and necessary supports to meet their individual needs.

COAG has proposed that the needs of people who acquire a disability after the pension age would be best met by the aged care system. The aged care system is designed to address needs related to ageing not disability and there are currently major gaps with respect to access, aids and equipment, choice and the range, level, and hours of services available.

The Australian Government is implementing a range of aged care reforms to give older people more choice, more control and better access to a wider range of aged care packages. The crucial issue is whether people with a disability over the pension age will be able to access reasonable and necessary supports to meet their individual needs following these reforms.

MND is not a disease related to ageing but approximately 50% of people are diagnosed when they are over the pension age. People diagnosed with MND need the same services and supports no matter what their age.

The reforms to aged care include enhanced access to four levels of home care packages covering basic home care support through to complex home care. However, the focus remains on addressing needs related to ageing and the highest, Level 4, that aims to support people with high-level care will only fund the same level of supports as the current EACH packages. Access to services addressing disability issues and hours of support available will remain limited and the gap between what is available under NDIS and Aged Care will widen.

Closing the gap, and preventing further discrimination following the introduction of NDIS, needs specialist disability services available and funded to address complex and changing needs. These services must include aids and equipment, flexible respite options, complex case coordination, allied health services and sufficient hours of support to assist people to remain at home if that is their wish.

People with rapidly progressive neurological disease have changing and complex care needs which very often cannot be met by aged care staff. In some cases people living with MND have been refused access to residential aged care due to the high level of care required.

Needs based support hinges on careful and appropriate assessment. Currently, Aged Care Assessment Teams are the gateway to aged care services but extensive anecdotal evidence indicates that they frequently refuse to assess older people with complex needs or, when they do, that they have difficulty in determining what level and types of support the individual needs.

Under current aged care assessment processes consideration of whether a person would benefit from a specialist disability service such as complex case coordination, flexible respite, aids and equipment, specialised therapy and communication aids rarely occurs.

## **MND Australia believes:**

- People diagnosed with MND must have access to early intervention, ongoing expert assessment, complex case coordination, aids and equipment and a range of services to meet their assessed needs irrespective of where they live, their age or which sector funds the service
- MND associations will play a vital role within the NDIS and aged care sectors to deliver specialist MND information, training and education and expert individualised and personalised support and services

## **MND Australia calls for:**

- 1. Improvements to the ageing-disability interface to ensure access to reasonable and necessary supports to meet the needs of people who acquire a disability when over the pension age. For example:**
  - a. Aged Care make provisions to provide the full range of services
    - i. Introduce a rapidly progressive neurological disease supplement similar to the dementia/behaviour/veterans supplement to supplement both home care and residential care to meet complex and changing needs
    - ii. Extend the provision of aids and equipment to ensure that older people diagnosed with MND can access the aids and equipment they need to maintain their independence and community access
  - b. If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top up funding through the NDIS to address needs not met by Aged Care
  - c. Clear assessment processes and protocols for the interface between the NDIS and the aged care system
- 2. Improvements to the health/allied health/palliative and aged care interface:**
  - a. Good interfaces with allied sectors, particularly health and palliative care, must be developed to ensure a coordinated inter and multidisciplinary approach to care
- 3. Timely availability of equipment and assistive technology:**
  - a. Aged Care sector to ensure equitable and cost effective access to aids, equipment and assistive technology for people at home and in residential aged care to support their independence and community access
- 4. The development of National Guidelines for the management of people with rapidly progressive neurological conditions:**
  - a. to assist with establishing and maintaining interfaces between different sectors, to minimise duplication and to ensure timely and responsive access to reasonable and necessary supports to meet identified needs

*On behalf of the MND Australia board and state MND Associations*

**Signed: David Ali (President)**

**Dated: 26 June 2014**