Australian Government

National Health and Hospitals Reform Commission

Response to Interim Report

A Healthier Future for All Australians

Submitted via email

To:

talkhealth@nhhrc.org.au

On:
Monday 16 March

By:
Carol Birks
National executive Director
MND Australia
PO Box 785, Gladesville, NSW, 1675

Dr Christine Bennett
Chair
National Health and Hospitals reform Commission
PO Box 685
Woden
ACT 2606

Dear Dr Bennett,

MND Australia welcomes the opportunity to respond to the Interim report of the National Health and Hospitals Reform Commission and congratulates the commission on their work to date.

We are pleased that chronic and complex disease, disability, palliative care, rural and remote and aged care, all of which are relevant to people with MND, have been integrated into a future model for health care in Australia. We support the need to enhance integration of services, collaborations, networks and the use of telehealth to improve outcomes and quality of care. The recognition of the need to develop a national approach to advanced care planning is also welcomed.

We have addressed in this response concerns related to primary health care centres and how they would integrate multidisciplinary services to ensure a comprehensive and coordinated approach to care for MND. We have also highlighted the needs of carers and the integral role of community care services including respite and case management in supporting people with chronic and complex disease and their families.

MND Australia would welcome the opportunity to provide further information or to participate in any public hearings.

Carol Birks
National Executive Director
MND Australia

0408416932

carolb@mndaust.asn.au
www.mndaust.asn.au

Motor Neurone Disease Australia Inc.

Building 4, Gladesville Hospital Gladesville NSW 2111
PO Box 785, Gladesville NSW 1675
Phone: +61 (0)2 9816 5322 Fax: +61 (0) 2 9816 2077
info@mndaust.asn.au www.mndaust.asn.au

ABN 52 650 269 176

mnd Australia

Response to Reform Directions

Reform Area 1
Building good health and wellbeing into our communities and our lives

MND Australia agrees with most of the reform directions outlined in this reform area with some provisos and recommendations. Private health insurance must be relevant for people with chronic and complex disorders, including progressive neurological disease, and for those people nearing the end of their lives to ensure choice and access for all. This should include access to a wider range of support services that have a health and support focus, including respite care.

We strongly agree that universal entitlement needs to be overlaid with targeting of health services for disadvantaged groups. Disadvantaged groups include people living with chronic and complex disorders and in particular those with rapidly progressive neurological disease, and their carers. In addition health services must be provided based on the needs of the individual and their family who should be central to care planning and management of their condition. Quality of life care rather than disease prevention and health promotion is the focus for health services provided to these groups and it is therefore important that outcomes don't get confused with outputs, and that appropriate monitoring and evaluation mechanisms are put in place.

National leadership must ensure that goals related to health promotion and prevention take into account diseases that cannot be prevented, such as MND, and include chronic and complex conditions. Health promoting palliative care, with a focus on quality of life care and maintaining carer health and well being, must be included as health promotion and prevention goals.

MND Australia agrees with the concept of supporting strategies that help people take greater personal responsibility for improving their health through policies that 'make healthy choices easy choices'. However, not everyone has capacity to take responsibility for their own health and again there are many conditions that are not impacted by any healthy choices. Access to information about specific diseases, case management, community care, allied health and disease specific support and education programs assist people living with chronic and complex conditions and their carers to take greater responsibility for their health, prevent crisis intervention and support people to make choices regarding location of care.

We strongly agree that access to evidence based consumer friendly information that supports people to make decisions and choices about their health and community care is vital. Non government groups play a vital role in developing and providing this information and this should be acknowledged and funded appropriately. Research funding to provide the evidence is also vital where evidence is scarce.

Recommendations:

- Private health rebates should include access to a wider range of support services that have a health and support focus, including:
    - respite care
    - specialised equipment
        - non invasive ventilation and communication aids
    - palliative care services
- Target health services for people living with chronic, complex and life limiting disorders and their carers – explore **top up** funding models available in some states for people with MND.
- Link the provision of accessible information on the health of local communities to a commitment to improve urban planning, public transport and accessibility for disabled people

- Focus more on maintaining the good health and well being of carers and families of people with chronic, complex and life limiting illness and include reforms to support:
    - Employers to provide flexible work practices for family carers
    - Access to meaningful and timely community care
    - Access to flexible respite options
    - Access to case management or a key worker
- Include health promoting palliative care as a health promotion and prevention goal
- Include health literacy on death and dying in the National Curriculum
- Support and fund non government groups to develop, provide and keep up to date a range of information resources and to provide ongoing education and support to their client group to promote well being, decision making and quality of life
- Promote research funding to provide and promote evidence-based care

Reform Area 2
Creating strong primary health care services for everyone

MND Australia agrees in principle that to better integrate and strengthen primary health care the Commonwealth should assume responsibility for all primary health care policy and funding. MND Australia, however, recommends that the Commonwealth is very clear about the role and function of the proposed Comprehensive Primary Health Care Centres and the definition of primary care. We recommend that Primary Health Care Centres should be able to provide a collaborative coordinated inter/multidisciplinary approach to care. The full range of allied health and nursing services should be available within the centre or strong and appropriate links made with existing services in the community. Allied health includes; occupational therapist, physiotherapist, dietician, speech pathologist, social workers and psychologists. Basic funding levels and grossly inadequate workforce issues would need to be addressed before Primary Health Care Centres could sufficiently resourced and incentive funding introduced.

We agree with the option for people with chronic and complex conditions of enrolling with a single primary health care service to improve care and with the proposed funding models. We do have concerns however with regard to care for people who choose not to enrol in these services. Case management must be included as part of this reform direction for people with chronic and complex conditions. Disease specific information and education would also need to be included to ensure appropriate knowledge within the team. There would also be the need to provide infrastructure to support consultations with centres of excellence re disease specific management (eg MND Clinics) using telehealth or similar technology.

MND Australia strongly agrees with the commission’s reform direction to support improving the way in which primary health care professionals and specialists manage the care of people with chronic and complex conditions through shared care arrangements in a community setting. We agree that primary health care professionals are vital in the ongoing management and care of people with chronic and complex conditions, but we reiterate that primary health care must focus on coordinated multidisciplinary care. Shared care arrangements should also include links to disease specific services such as MND Clinics, MND models of care outlined in our original submission and the MND Associations using telehealth or other communication mechanisms. Community care services and respite care are also integral to shared care arrangements in the community setting for people with chronic and complex conditions.

MND Australia agrees with the establishment of Divisions of Primary Health Care, evolving from or replacing the existing Divisions of General Practice. These divisions would need to include allied health and nursing professionals with appropriate links to disease specific professionals as outlined above and also community care.

Facilitating access to care where doctors are scarce, particularly, remote and rural areas is a vital reform direction for the health of our community as a whole. Establishing a network of neurological nurse practitioners, able to access Medicare rebates as suggested, and able to

link with disease specific clinics and associations using telehealth would enhance care for people with progressive neurological disease.

MND Australia strongly agrees with the development of a person-controlled electronic personal health record. MND is not a common disease and many health professionals will never have confronted the disease before so it is imperative that as much information as possible regarding care and management to date is easily available to them particularly in an emergency situation.

Recommendations:

- Structure and workings of the Team in Primary Health care Centres needs further clarification
- Primary Health Care Centres should be able to provide a collaborative coordinated inter/multidisciplinary approach to care and include allied health and nursing
- Community care services and respite care must be included in shared care arrangements
- Case management for people with chronic and complex conditions
- Disease specific information and education
- Shared care arrangements should also include links to disease specific services
- The electronic health record should include access by allied health and community services providers to ensure that a complete record is maintained and available.

Reform Area 4
Ensuring timely access and safe care in hospitals

MND Australia agrees with the proposed development and adoption of National Access Guarantees for planned procedures and National Access Targets for emergency care. People with MND need access to timely and expert diagnosis and management interventions.

MND Australia is concerned about the efficacy of proposed reforms to funding based on incentives and targets and suggests that a better approach would be to fund the system as a whole more comprehensively. We do however agree that financial incentives to reward good performance in outcomes and timeliness of care could improve access to diagnosis and improve the way the diagnosis is given. In addition incentives for timely provision of discharge information including details of any follow-up care required could be of benefit.

MND Australia strongly supports the proposal that all hospitals review provision of ambulatory services (outpatients) to ensure they are designed around patients' needs and, where possible, located in community settings. Once again we emphasize needs based care in the community and increased communication between services.

We agree with reform directions to improve quality, data on quality and safety which we would anticipate would improve outcomes for people with MND in respect to fast tracking the diagnostic process for people with rapidly progressive disease. Evidence confirms that fast tracking the diagnostic process helps to reduce emotional distress and ensures early implementation of treatment options (19th international Symposium on ALS/MND, 2008).

We agree that to improve accountability public and private hospitals should be required to report publicly on performance against a national set of indicators which measure access, efficiency and quality of care provided. It is also important that they be required to report on outcomes of care including timeliness and communication with other services.

MND Australia suggests that the reform direction related to using a patient's Medicare card number to understand better people's use of health services and outcomes across different care settings will not capture gaps in services.

MND Australia strongly agrees with a nationally led, systemic approach to encouraging, supporting and harnessing clinical leadership within hospitals and broader health settings and across professional disciplines. MND Australia has identified the acute need for national care pathways for MND to ensure optimal care for people living with MND in Australia. MND multidisciplinary clinics or centres of excellence should be available in every capital city with telehealth facilities to provide consultancy to primary health care centres throughout the country.

Recommendations:

- Waiting times for elective admissions to hospital for diagnostic tests, insertion of gastrostomy and respiratory assessment should be minimal and measured in weeks/days.
- Discharge information must include discharge planning and the organisation of community services and necessary equipment prior to discharge.
- Consider disease specific national care pathways
- Resources are needed to assist quality improvement work and care must be taken to minimize increasing demands on staff that interface with patients
- Formalise MND multidisciplinary clinics or centres of excellence within the health care system
- Support Telehealth infrastructure
- Implement national Care Pathways to define roles and communication between Clinics, Outpatients and Primary Health Care Centres.

Reform Area 5
Restoring people to better health and independent living

There is no cure for MND and no effective treatment and therefore maintaining quality of life and independent living is a priority for people living with motor neurone disease.

MND Australia strongly agrees with the reform direction to increase the visibility of, and access to, sub-acute services through more directly linking funding to the delivery and growth of sub-acute services. Sub acute services should be one of the top priorities for health care reform. Workforce issues including disease specific education, funded case management and equipment provision require particular attention.

MND Australia is again cautious regarding the proposed funding of sub-acute services, with a mix of activity-based funding and incentive payments related to improving outcomes for patients. We suggest that adequate activity based funding including targeted funding for quality activities needs to be implemented before incentive payments are introduced. For people with MND incentive payments related to access and timeliness of sub acute services could lead to improved outcomes. MND Australia agrees that clear targets to increase provision of sub-acute services be introduced by June 2010. The demand for sub acute services, especially for disease groups such as MND would need to be established in the first instance. We strongly agree that investment in sub-acute services infrastructure be one of the top priorities for the Health and Hospitals Infrastructure Fund.

MND Australia strongly agrees that we need to ensure that we have the right workforce available and trained to deliver the growing demand for sub-acute services including in the community.

MND Australia strongly agrees with the vital role of equipment, aids and other devices, in helping people to improve health functioning and to live as independently as possible in the community. We strongly support access to such equipment in maintaining independence and quality of life as opposed to supporting a restorative journey.

Recommendations:

mnd Australia

- Sub acute services for people with chronic and complex conditions to include timely assessments and ongoing review from a multidisciplinary team that includes all allied health disciplines
- Affordable and timely access to assistive technology and non invasive ventilation
- Adequate base line funding for sub acute services
- Include data on nurses and community service providers
- Affordable and timely access equipment to maintain independence and quality of life
- Include early intervention and supported self management for people with complex chronic disease including progressive neurological disease and for people with disabilities

Reform Area 6
Increasing choice in aged care

MND Australia supports funding directly linked to people rather than places, and to those who are most likely to need care. Addressing unmet needs is of paramount importance for this target group and any reform must focus on care based on the needs of the individual. MND Australia is cautious, however, regarding accommodation bonds or alternative approaches as options for people entering high care.

MND Australia agrees with the proposal requiring aged care providers to make standardised information on service quality and quality of life publicly available to enable older people and their families to compare aged care providers. MND Australia advocates flexible care based on need and would agree with consolidating aged care under the Commonwealth if this concept is embedded into the changes.

MND Australia strongly agrees with the need for developing and introducing streamlined, consistent assessment for eligibility for care across all aged care programs providing the Commonwealth can ensure that people with disabilities over the age of 65 access levels of support the same as those under 65. MND Australia also strongly agrees with the need for a more flexible range of care subsidies for people receiving community care packages, determined in a way that is compatible with care subsidies for residential care.

MND Australia is concerned that the proposal for people who can contribute to the costs of their own care should contribute the same for care in the community as they would for residential care could lead to major problems with separating out the capital issues. We believe that the contribution should be very reasonable and capped at a certain level per person as the amount of service increases. People with chronic and complex disease (which may progress) who have made good provision for their future could potentially lose much of their financial base – while those who are on a pension etc can receive services at no cost.

MND Australia strongly agrees that older people supported to receive care in the community should be given the option to determine how their allocated resources are used and that they should be given greater scope to choose for themselves between using their care subsidy for community or for residential care. Any effective individualized funding approach, however, must incorporate case management and service navigation. Case management would need to extend beyond the brokered services.

We agree that all aged care providers (community and residential) should be required to have staff trained in supporting care recipients to complete advanced care plans for those care recipients who wish to do so. MND Australia strongly agrees that funding be provided for use by residential aged care providers to strike arrangements with primary care providers and geriatricians to provide visiting sessional and on-call medical care to residents of aged care homes. MND Australia strongly agrees with increased use of electronic clinical records in aged care homes as outlined subject to patient consent and improved outcomes.

mnd Australia

Recommendations:

- Include alternative arrangements for younger people with disability and complex needs requiring residential care
- Adequate protection for low income/assets holders be a key component of any reforms related to accommodation bonds
- Flexible care based on need
- A rapid response for assessment for people with progressive diseases not related to ageing and rapid response to services once eligibility has been established. This is not the case at the moment
- Care packages need to be consistent with care packages available for people under 65 and should be transferable so that people with disability who are ageing are able to continue using the same services
- Care packages must include flexible respite options
- Access to funded case management services for people with chronic, complex and life limiting diseases such as MND
- Improve funding levels to residential care facilities who have residents with high and complex needs to support adequate staffing levels and improved skill base + essential equipment to assist with care & independence
- Funding to provide sessional care must be extended to all allied health professionals and other health supports.

Reform Area 7
Caring for people at the end of life

MND is a terminal illness with no effective treatment and a life expectancy of only 27 months (Sach 2003), palliative care is therefore an appropriate approach to care management from diagnosis onwards. People living with MND need coordinated multidisciplinary care provided by health professionals who understand MND and its impact on the family.

MND Australia agrees in building the capacity and competence of primary health care services to provide generalist multidisciplinary palliative care support for their dying patients. Greater educational support and improved collaboration and networking with specialist palliative care service providers is imperative immediately.

The Motor Neurone Disease Pathway Project, funded by The Department of Human Services (DHS), Victoria led to the Victorian government providing funding to implement MND key workers, MND specific education and to support top-up funding for palliative care services supporting people living with MND. Motor Neurone Disease and palliative care - Interim report on the MND Pathway Project - April 2008 (PDF File 505kb). This project highlighted the need for disease specific education and top up funding for palliative care providers to assist them to provide optimal care to people with MND. This model could also be applied to support primary health care teams.

MND Australia supports strengthening access to specialist palliative care services for all relevant patients across a range of settings, with a special emphasis on people living in residential aged care facilities. We also agree with the proposal that additional investment in specialist palliative care services be directed to support more availability of these services to people at home in the community. People with MND are often denied access to specialist palliative care services until the last few weeks of life when communication is compromised.

MND Australia strongly supports a national approach to Advanced Care planning however we are concerned with the proposal to fund one model, the Respecting Patient Choices program, across all residential aged care services. We are concerned that patient choice is compromised by funding one model and that this program does not respect the right of a patient not to make a choice. MND Australia also strongly agrees with supporting greater awareness and education among health professionals of the common law right of people to make decisions on their medical treatment, including the right to decline treatment.

mnd Australia

Recommendations;

- Ensure educational support for primary health care and improved collaboration and networking with specialist palliative care service providers
- The national palliative care program has helped to promote palliative care nationally and to build knowledge and services related to MND ongoing continuation of this program is recommended
- Care needs to be taken when referring to end of life care interchangeably with palliative care – there have been many instances reported that this has translated to care for the last few weeks of life for people with MND
- Caring for people at the end of life should be based on quality of life care for all people with life limiting/terminal conditions.

Reform Area 8
Closing the health gap for Aboriginal and Torres Strait Islander people

MND Australia strongly agrees that the Commonwealth Department of Health and Ageing take a lead in the inter-sectoral collaboration that will be required at the national level to redress the impacts of the social determinants of health to close the gap for Aboriginal and Torres Strait Islander peoples. MND Australia recognizes the need to provide MND specific information and support to Aboriginal and Torres Strait Islander health services and education providers.

Reform Area 9
Delivering better health outcomes for remote and rural Communities

In our original submission we highlighted that access to services for people with MND throughout Australia remains inconsistent and inequitable with many patients slipping through 'cracks' in the service provision network, especially in rural and regional Australia.

MND Australia strongly agrees with flexible funding arrangements to reconfigure health service delivery to achieve the best outcomes for the community. We strongly support the development of networks of care which include community care services, allied health, specialist services, palliative care and disease specific support organisations.

MND Australia strongly supports a national patient travel and accommodation assistance scheme that is funded at a level that takes better account of the out-of-pocket costs of patients and their families and facilitates timely treatment and care.

MND Australia supports reform to support undergraduate and postgraduate places across all disciplines being allocated to remote and rural regional centres.

Recommendations;

- People with MND living in rural and remote communities need locally designed and flexible models of care with appropriate support and education from MND Clinics and MND associations
- Funding to expand specialist outreach services from MND Clinics, using telehealth, and regular outreach visits from MND association family support staff
- Support for multidisciplinary team meetings and case conferencing to enhance care planning for people with chronic and complex conditions in remote and rural communities
- MND Associations can support timely referrals and provide information and education to improve quality of MND care
- Development of disease specific pathways to assist with appropriate and timely diagnosis and referrals.

mnd Australia

Reform Area 10.
Supporting people living with mental illness

The prevalence of frontotemporal dementia (FTD) in the MND population is estimated to be between 30 - 50%. A diagnosis of MND has a profound emotional and psychological impact on the person diagnoses and their family access to professional counseling and support is imperative. MND Australia strongly agrees that governments must collaborate to develop a strategy for ensuring that older Australians, including those residing in aged care facilities, have adequate access to specialty mental health and dementia care services. However we recommend that younger people in residential care or people with younger onset dementia should be included in this reform direction.

MND Australia strongly agrees with a sustained national community awareness campaign to increase mental health literacy and reduce the stigma attached to mental illness. We would recommend that dementia and cognitive change is included in community awareness campaigns. We also agree that there must be more effective mechanisms for consumer and carer participation and feedback to shape programs and service delivery related to mental illness and dementia.

Recommendations

- Early diagnosis of frontotemporal dementia and access to expert neuropsychological assessment and support
- Access to appropriate information on frontotemporal dementia
- Younger people in residential care or people with younger onset dementia have access to specialty mental health and dementia care services
- Consider the mental health needs of people with disabilities and the emotional impact of rapidly increasing levels of complex need
- Access to counseling and ongoing support for people diagnosed with life changing diseases and their families to maintain mental health and well being

Reform Area 11.
Improving oral health and access to dental care

MND Australia strongly supports free access to dental health care for people living with chronic and complex conditions. Dental health care needs to be available to people with disabilities, unable to attend a dental surgery, in hospital, residential facilities and in their home.

Reform Area 12.
Strengthening the governance of health and health care

MND Australia agrees with the need for a consistent and national approach with regard to leadership for patient safety and quality (including service accreditation), health promotion and prevention, professional registration, workforce planning and education, performance reporting, private hospital regulation, and technology assessment.

We agree that the Commonwealth should take responsibility for policy and funding of all primary health care.

Recommendations:

- Any option for reform of governance needs to ensure clear accountability and transparency and a commitment to the provision of care based on needs
- The system must be less complex and the incidence of people falling through the gaps in service provision minimized.

Reform Area 13.
Raising and spending money for health services

MND Australia agrees that major reforms are needed to improve the outcomes from health spending and to contain the upward pressure on health care costs; and agree that evidence-based investment in strengthened primary health care services and health promotion and prevention to keep people healthy will help to contain future growth in spending.

MND Australia strongly supports safety net arrangements that are more integrated, cover a broader range of health costs and are family-centred to protect families and individuals from unaffordable high out-of-pocket costs of health care. MND Australia also supports payments for care of people over a course of care or period of time. This should include funding for primary health care, including allied health, and community care services. We agree that funding should be available to cover the full range of health care activities including clinical education.

We strongly agree that funding arrangements may need to be adjusted to take account of different costs and delivery models in different locations and to encourage service provision in under-serviced locations and populations. MND Australia agrees that additional capital investment will be required on a transitional basis to facilitate the reform directions.

Recommendations:

- There needs to be a cap on out of pocket expenses particularly for people with chronic and complex conditions
- Safety net arrangements would need to include equipment and aids such as communication devices and non invasive ventilation
- Special attention would need to be given to payments to reward good performance in outcomes and timeliness of care for people with chronic, complex and life threatening diseases
- Consider extending funding arrangements to also take into account the impact on the health care system of different diseases
- Review top up funding models available in Victoria for palliative care and MND and in NSW for case management

Reform Area 14
Working for us: a sustainable health workforce for the future

MND Australia is committed to supporting the health workforce to improve care outcomes for people with MND. We strongly agree that improving workplace culture, management and leadership skills at all levels of the system would facilitate support for the health workforce in Australia.

MND Associations have implemented a family support model of care that includes disease specific and evidence based information, education and support for all health professionals to improve their knowledge of MND and its impacts on the family to support their ongoing commitment to delivering care to people living with MND.

MND Australia strongly agrees with facilitating access to care where doctors are scarce. We agree that Medicare rebates should apply to some diagnostic services and specialist medical services ordered or referred by nurse practitioners and other registered health professionals according to defined scopes of practice determined by health professional registration bodies.

MND Australia agrees with the reform direction related to a new education framework for all education and training of health professionals. We agree also with the reform directions related to the establishment of a National Clinical Education and Training Agency and with national registration to benefit the delivery of health care across Australia.

MND Australia agrees with the implementation of a comprehensive national strategy to recruit, retain and train Aboriginal and Torres Strait Islander health professionals and that a higher proportion of new health professional educational undergraduate and postgraduate places across all disciplines be allocated to remote and rural regional centres.

Recommendations:

- MND Clinical pathways would help to support and guide disease specific education
- Engage with MND associations to promote partnership approaches and the grass roots needs of clients to health professionals.
- Support the establishment and running of special interest groups for health professionals working with specific diagnostic groups similar to the MND special interest groups run by MND NSW
- Neurological nurse post graduate courses with funded positions available in regional, rural and remote communities to enhance care and support for people with progressive neurological disease
- Facilitate linking up Centres of Excellence with Primary Health Care teams via Telehealth - as mentors and peer support

Reform Area 15.
Fostering continuous learning in our health care system

MND Australia strongly agrees that the Commonwealth Government should increase the priority of health services research to facilitate the uptake of research findings into practice and that infrastructure funding (indirect costs) follow direct grants whether in universities, independent research institutes, or health service settings. MND Australia also strongly agrees that the National Health and Medical Research Council should consult widely with consumers, clinicians and health professionals to set priorities for collaborative research centres and supportive grants.

MND Australia agrees with reform directions related to enhancing the spread of innovation across public and private health services and supports promoting research collaborations and a national health care quality innovation awards program. MND Australia also agrees with reform directions aimed at improving safety and quality nationally.

MND Australia strongly agrees with a national approach to the synthesis and subsequent dissemination of clinical evidence/research which can be accessed via an electronic portal and adapted locally to expedite the use of evidence, knowledge and guidelines in clinical practice. MND Australia also agrees that all hospitals, residential aged care services and Comprehensive Primary Health Care Centres should be required to produce an annual public report on their quality improvement and research activities, including reporting on actions arising from investigation of adverse events.

Recommendations:

- Include non government organisations in consultations to set priorities for research
- Liaise with peak bodies such as MND Australia to promote health care research to provide evidence for the care management of people with MND and to enhance the quality of life of people with MND and their families
- Include mechanisms to support and fund implementation of reforms related to improving safety and quality and monitor impact on direct patient care.
- Develop and implement national care pathways to facilitate this reform.