



National Health and Hospitals Reform Commission

Submission Cover Sheet

Please complete and submit this cover sheet with your submission to:

By email: talkhealth@nhrc.org.au

By mail to: PO Box 685 Woden ACT 2606

A. Details of the person or organisation that prepared this submission

Date of submission: **May 31, 2008**

Who prepared this submission?

Individual Organisation

For individuals:

Name of individual: _____

Street address: _____

Mailing address (if different from above): _____

Phone (daytime): _____

Fax: _____

Email: _____

For organisations:

Type of organisation. (Please tick all that apply)

Consumer group

Government agency

Private company

Professional body

Other non government organization

Other (Please specify) _____

Geographic focus of organisation. (Please tick all that apply)

Nationwide

Statewide (Please specify State/Territory) _____

Metropolitan

Rural / regional

Remote

Please specify the particular sector focus of your organisation (if applicable).
_People living with motor neurone disease their families and carers and the health and community care providers involved in their care.

Purpose/s of organisation. (Please tick all that apply)

Research

Education

Service provision

Advocacy

Other (Please specify) _____

Name of representative: - **Mrs Carol Birks** _____

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Please note that in making a submission you agree that it may be made public.

B. Response to draft principles

- This submission specifically comments on the draft principles developed by the Commission to shape Australia's future health system. (Please tick if this applies)**

C. Response to key themes

This submission specifically responds to the following key themes taken from the Commission's Terms of Reference. (Please tick all that apply)

- A greater focus on prevention to the health system
- Improving frontline care to promote healthy lifestyles and prevent and intervene early in chronic illness
- Improving Indigenous health outcomes

- Integrating and coordinating care across all aspects of the health sector, particularly between primary care and hospital services around key measurable outputs for health**
 - Improving the provision of health services in rural areas**
 - Integrating acute services and aged care services, and improve the transition between hospital and aged care
 - Reducing inefficiencies generated by cost-shifting, blame-shifting and buck-passing**
 - Providing a well qualified and sustainable health workforce**
 - Maintaining the principles of universality of Medicare and the Pharmaceutical Benefits Scheme, and public hospital care
 - Maximising a productive relationship between public and private sectors
 - Providing a more seamless experience across public and private services
 - Providing advice on the framework for the next Australian Health Care Agreements (AHCAs), including robust performance benchmarks
 - Addressing the escalating costs of new health technologies
 - Increasing access to services**
 - Addressing the growing burden of chronic disease**
 - Providing for an ageing population
 - Managing the escalating costs of new health technologies
 - Addressing overlap and duplication including in regulation between the Commonwealth and states

 - Other (Please specify) _____
-

Submission two page summary:

MND Associations in Australia were formed during the 1980's to meet the varying and complex support, equipment and information needs of people living with motor neurone disease (MND) and their families. MND Australia was established in 1991 as a national peak body for motor neurone disease (MND). In 2008 the MND Australia network comprises of six Associations, representing all states and territories, and the MND Research Institute of Australia (MNDRIA). The State MND Associations provide family support services to people living with MND in their State.

MND Australia members work together to advance, promote and influence local and national efforts to achieve the vision of a ***World Free from the Impact of MND.***

MND is a rapidly progressive degenerative neurological disease that causes increasing and complex levels of disability leading to death usually within five years of diagnosis. Currently around 1300 Australians are affected by MND and thousands more; family, friends and carers live daily with its effects. Each day at least one Australian dies of this cruel disease and a new person is diagnosed. Although MND was first described nearly 150 years ago there is still no known cause, no known cure and no effective treatment. Average life expectancy from diagnosis is about 27 months (Sach 1995). Average age of onset is 59 years (a very productive time of life); however, the age range of onset is 20 to 80 years.

The social impact of MND is amplified by its complex nature, the speed of its progression and the spiraling series of losses, which poses:

- huge problems of adjustment for people who have MND;
- an escalating burden on carers and families; and
- a challenge to health professionals involved in meeting the variable and complex care needs, particularly in regional, rural and remote areas of Australia.

The rapid progression of MND results in increasing support needs and reliance on a range of aids and equipment to maintain quality of life and social inclusion. Support needs can include assistance with: feeding, communication, breathing, movement, transferring, toileting and all daily activities. The range of aids and equipment required during the disease trajectory usually includes walking frames, manual wheelchairs, shower commode chairs, electric wheelchairs, lifting devices, hi-low electric beds and non invasive positive pressure ventilation (NIPPV) machines and masks. Equipment must be available as soon as the need arises and at minimal cost to the consumer. Home modifications are often required to support the equipment needed in the home. MND has a comprehensive impact on all aspects of living and care must be based on the needs of the individual and their family. Whilst in some areas of Australia people with MND have access to world best practice care the majority currently experience huge unmet need.

Caring for a loved one with MND can have a devastating long-term emotional and financial impact on families. An adequate and consistent level of support from health and community services can help minimise the traumatic effect of living with MND and maintain carer health and well being, workplace participation and social inclusion. Carer specific education, family counselling and financial assistance are all issues that require increased focus in health care planning. Relevant and flexible respite options are imperative to assist family carers to maintain their caring role and employment.

The rapid response necessary to manage changing and complex need presents a challenge to health and community care professionals and to the health system as a whole. Access to evidence based quality MND information and education for health and community care providers is vital to assist them to provide best practice care. In particular rural and remote single practitioners have specific and urgent need for information to assist them to provide the range of support usually provided by a multidisciplinary team.

Care provision for people with MND crosses traditional departmental boundaries including; health, disability, chronic disease and palliative care and involves a combination of state and federal funding bodies. People with rapidly progressive neurological disease struggle to navigate this complex system and are consequently one of the most 'under provided for' diagnostic groups within the current health system. The principles set out by the National Health and Hospitals Reform Commission state that "the health system must respond to those with special needs".

MND is a very individual disease with varying sites of onset, symptoms and rates of progression and care providers must work in partnership with clients and their families to deliver appropriate and tailored services to meet individual need. People with MND face many physical and emotional losses; however, their cognitive ability is usually unimpaired. They should be helped to maintain autonomy and empowered to make informed decisions about their care through reliable information and advice.

The support needs of people with MND and their families resonate with many of the design principles set out by the Commission. MND Associations, MND practitioners, governments and researchers in various States have developed models of care, based on the needs of client groups that are beginning to lead to better outcomes for people living with MND and their family. Increasingly surveys, research and evidence based reviews specific to MND are providing evidence to support the benefits of these models of care in helping people to live better with MND. In addition, MND Associations through their experience over the last 20 years in engaging with people with MND and their families, MND practitioners, researchers and the International community, have identified many useful and constructive ideas for promoting the way forward for MND care and management.

This submission highlights that the MND population in Australia is an ideal demographic to pilot models of care and to gauge the responsiveness of the health care system to rapidly progressive complex conditions. The submission also highlights that in the States where State Governments have provided seed and recurrent funding to MND Associations to develop services (Victoria, NSW and Western Australia) best practice models of care have been established and innovative models are currently being piloted by a range of people. These people are committed to working with the MND Associations to establish and develop best practice MND care in their State highlighting the value for money of a relatively small investment from State Governments. These models of care and ideas for the way forward related to the design principles will be outlined in this submission.

NHHRC Submission

MND Association Family Support Model

Over the last 10 to 15 years MND Associations in Australia have developed a model of family support based on initial surveys conducted in Victoria and NSW and the MND UK service model.

Evidence to support the Model:

Family support services have grown and developed and the value of the Australian model continues to be supported by surveys conducted by State Associations in Australia, International ALS/MND Association service models and service development, the International Alliance Statement of Good Practice for the Management of ALS/MND (see Appendix 1) and international research.

In Australia the Sach Reports conducted by MND Victoria 1995 and 2003 and the MND NSW Needs Assessment, 1997, established that people living with MND want:

- Information
- Access to aids and equipment in a timely manner
- Ongoing support and assistance to navigate their local service provision network
- Coordinated care, and;
- For service providers to understand the specific needs of people living with MND

Increasingly international research is providing evidence based practice for the MND Association family support model. Namely, Miller R.G. Rosenberg D.F. et al. "*Practice Parameter: The care of the patient with amyotrophic lateral sclerosis (an evidence-based review): Report of the Quality Standards Subcommittee of the American Academy of Neurology*", Neurology 1999;52;1311, http://www.efns.org/files/guidelines_29.pdf confirms that people living with MND and their families need – '*printed information about the disease and the support available at diagnosis and MND specific information that is timed appropriately for decision making and delivered well in advance of major management crossroads*'.

Where capacity allows, MND Associations, provide four main family support services to meet the identified needs:

1. Information
2. Regional/Care Advisors
3. Aids and Equipment and
4. Volunteers

This model of family support is world's best practice. It focuses on supporting people living with MND in their own community or residence of choice. The model enables Regional/Care Advisors to assist the transition of people with MND to, from and through the service sector by providing, information, education, ongoing support and timely referrals. They also facilitate access to aids and equipment and support from volunteers. The Associations move in and out of people's lives with MND, while operating continuously in the background to ensure that the emerging needs of people with the disease and service providers are adequately identified assessed and addressed. MND NSW provides services to people with



MND in the ACT and NT and MND Victoria works in partnership with MND Tasmania supporting the development of a family support service in Tasmania.

Relation to the design principles:

This model is **people and family centered** – it is based on the identified needs of people living with MND and is responsive to individual differences. The key component of the Regional/Care advisor role is to assist people to navigate the system, to provide evidence based information, support and advice to assist people with MND to make informed choices and to live as well as possible. This model promotes the provision of care and support from the person's local community services. This is achieved through the provision of information and education for local health and community care providers who may have little experience of MND. This model provides equipment in a timely manner and at no cost to the consumer from MND Associations, or provides assistance to people to help them access equipment from the government equipment loan services. The provision of equipment helps people with MND and their carer to maintain independence and social inclusion and to live as well as possible. It facilitates continued care within the home and optimal quality of life.

This model promotes **equity**. All MND services, including aids and equipment, are provided at no cost to the consumer. Access and care based on need are actively promoted although currently not always achieved. The provision of tailored information and education for people with MND and their families and carers promotes **shared responsibility** helping people to manage the complex nature of MND and to make informed decisions about their future care and interventions.

Although MND cannot be prevented this model, through the provision of targeted support, information and education and timely equipment provision, **strengthens prevention and wellness** for the carers of people living with MND. It also provides flexible and timely information and education for health professionals, including in some States access to Special Interest Groups, therefore **providing for future generations**.

Current barriers:

The amount of support provided by MND Associations varies considerably with those States receiving recurrent state government funding i.e NSW, Victoria and Western Australia providing a much higher level of family support than South Australia, Queensland and Tasmania who are not supported by State Government. At present family support services in these States cannot respond effectively to increasing demand and need. Equity of access to services from MND Associations therefore remains a barrier and all MND associations should be funded to a level that builds their capacity to provide an equitable level of service. State government support in NSW, Victoria and WA remains around 20 -30 % of income.

Timely, access to specialised aids and equipment is essential to maintain independence, comfort, quality of life and on-going care within the home. The more established MND Associations, NSW and Victoria, can supply most of their client's equipment needs. Equipment can sometimes be accessed through state and federally funded programs (eg HACC, palliative care and PADP). However, equipment provision programs can vary within and between states and the application process is usually too slow to be of benefit to people whose level of disability can change quickly. Consequently, people with MND often have to purchase their own equipment. This can contribute to a profound financial impact on families and there should be national consistency, reliability and equity in the funding and provision of specialised equipment.

The Way Forward:

1. Demonstrate **responsible spending on health** through the provision of ongoing State Government funding for MND Association family support services in every State to enable all State Associations to provide this best practice family support model
 - a. This model demonstrates **value for money** as it leads to:
 - i. Increased income from donations and fundraising
 - ii. Reduction in crisis admissions to hospitals
 - iii. Improved continuity of care
 - iv. Efficient and timely equipment loan services
 - v. Well supported carers able to maintain their own health
 - vi. Well educated and supported health and community care providers providing coordinated best practice MND care
2. Acknowledge the MND Association aids and equipment service as a **model of best practice and value for money** and fund appropriately
 - a. This service has just been reviewed nationally and a report will be produced in the near future
 - b. Equipment service reviews in NSW and Victoria by external consultants promote alternative models of equipment distribution, such as the MND Association's library models
 - c. NSW and Victorian Governments have recognised the value for money of the MND Association equipment services in these States and have funded them accordingly
3. Establish a national approach to funding equipment loan services that is responsive to the needs of the individual and includes respiratory support – NIPPV machines and masks

MND Multidisciplinary Models of care

Evidence based best practice care to meet complex and changing need requires seamless, continuous and integrated service delivery from a number of health and community care providers across state, federal, and the non-government sectors. Care providers include medical, nursing, allied health, community care, palliative care and MND Associations.

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. The care provision system is difficult to navigate and variable in the resources available 'on the ground' in different geographical areas.

A few major metropolitan areas are well serviced with specialised multidisciplinary MND clinics and models of care. MND NSW has been providing seed funding to three clinics and a Palliative Care Service in Sydney for a number of years to ensure their viability. Clinics link with localised community health and support services, palliative care teams and the state based MND Associations. Unfortunately, specialised MND Clinics are tenuous and dependent solely on the good will of the medical and allied health personnel involved.

In NSW and Victoria some regional multidisciplinary teams meet regularly to ensure coordination of care for people living with MND. MND Associations are integral to the establishment of these models of care.

Evidence:

Miller et al advocate early diagnosis from neurologists expert in MND and regular review as does the International Alliance Statement of Good Practice for the Management of ALS/MND (see Appendix 1). Increasingly in some capital cities in Australia people with MND are able to access Neurologist led MND Clinics which are able to provide expert, early diagnosis and ongoing review. Miller's review cites a number of papers that provide evidence that multidisciplinary clinics or models of care improves care and may extend survival. MND specific clinics or models of care ensure effective communication and coordination.

MND multidisciplinary clinics provide respiratory monitoring and the timely provision of non invasive positive pressure ventilation which the evidence based review confirms has a positive effect on survival and quality of life.

Leigh et al. The management of motor neurone disease , *J Neurol Neurosurg Psychiatry*.2003; 74: iv32-iv47 states that:

Coordinated multidisciplinary care is the cornerstone of management and evidence supporting this approach, and for symptomatic treatment, is growing.¹⁻³ Hospital based, community rehabilitation teams and palliative care teams can work effectively together, shifting emphasis and changing roles as the needs of the individuals affected by MND evolve. In the UK, MND care centres and regional networks of multidisciplinary teams are being established. Similar networks of MND centres exist in many other European countries and in North America

Relation to the design principles:

This model addresses many of the design principles shaping care around the health needs of the individual and providing a 'one stop shop' for medical and allied health care. Decisions about future care can be made in a supported environment with relevant professional information available. Medical interventions to help people live as well as possible for as long as possible such as enteral feeding and non invasive positive pressure ventilation can be instigated as soon as the need arises. Crisis is avoided and unnecessary admissions to acute care hospitals minimised. This model promotes partnerships with other providers and best practice care into the future.

Current barriers:

MND Clinics currently in operation, apart from Calvary Health Care Bethlehem in Victoria, are not supported financially by the hospital in which they operate. The existence of these clinics relies solely on the goodwill and commitment of the specialists and allied health providers involved. Patient numbers have increased dramatically and the current clinics are unable to keep up with demand and their future operation is tenuous.

Formally structured MND Clinics are not tenable outside the major metropolitan areas and other models of care need to be developed to meet the needs of people with MND in all areas of Australia to promote equity and accessibility. The Victorian MND Clinic Project is supported by the Victorian Department of Human Services and led by Dr Susan Mathers from Calvary Health Care Bethlehem. This project is investigating the outcomes desired for people living with MND and how those outcomes can be achieved in a variety of geographical areas where resourcing and skill base varies.



Most regional and remote areas have limited and inconsistent capacity to adequately manage MND clients. This situation could be addressed by developing their access to MND specific information through the use of information and communication technology.

The way forward:

1. Formalise MND Specific Clinics and care programs within the healthcare system through targeted funding
2. Review the results of the Model of Care project currently being conducted in Victoria and translate to practice nationally if applicable
3. Use information and communication technology to promote coordinated multidisciplinary care in rural and remote areas
 - a. Provide funding for MND Australia to develop online resources to assist regional, rural and remote health and service providers and single practitioners to provide multidisciplinary care in their community
 - b. Support MND clinics and experts to tele-consult with patients and practitioners outside major metropolitan areas

Palliative Models of Care:

MND is a terminal illness with an average life expectancy of 27 months. Palliative Care is therefore relevant from diagnosis onwards to provide expert symptom management and vital emotional and psychosocial support for the person with MND and their families. Discussions around end of life care can be instigated as soon as the person with MND indicates and their wishes discussed. Quality end of life care for people with MND is imperative.

Many palliative care services embrace this need and provide care and support for people with MND from diagnosis onwards. A number have instigated MND specific models of care and regular case conferencing. Respite care is provided in many hospice or palliative care facilities, which is more appropriate for most people with MND than a residential aged care facility. However, many do not have the capacity to provide optimal services for people with MND or are constrained by time limits for the provision of palliative care being imposed as a means of rationing services.

In some areas palliative care teams have established MND specific models of care to ensure a seamless approach to care from diagnosis through to bereavement. Regular case coordination meetings with all service providers involved in the care of people with MND and the MND Association Regional Advisor help to minimise duplication and promote palliative care led integrated multidisciplinary care.

The MND NSW Volunteer Visitor Pilot Program, initially funded through the Australian Government Department of Health and Ageing, developed an education manual and program for palliative care volunteers to provide information on the specific and complex needs of people with MND. This program supports volunteers to provide best practice support for people with MND and their families. This model is currently being extended to Queensland through a project supported by the Australian Government Department of Health and Ageing Local Palliative Care Grant round 4.

Evidence:

Again Miller et al in the evidence based review cites a number of papers that provide evidence for the need for palliative care for people with MND. The good practice points provided recommend a palliative approach from diagnosis, early discussions around end of life decisions and advanced care planning and optimal end of life symptom management.

The Motor Neurone Disease Pathway Project - The Department of Human Services (DHS) in Victoria funded a six month project to establish a pathway using the best available evidence to identify criteria that trigger a referral to specialist palliative care for a person with Motor Neurone Disease (MND). The report published in April (see link below) recommends that a document should be developed and piloted to provide health professionals with the range of needs and providers for people with MND to assist them to access palliative care and community services. It recommends that a key worker model be developed for people with MND when referred to palliative care and that a comprehensive education program be developed for palliative care staff involved in caring for people with MND. The report recognizes the need for guidelines and supplementary funding for people with MND with high care needs. It recognizes the need for timely and appropriate respite and after hours support. In the recent State Budget, funding was provided to implement the key worker model 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 \(PDF File 505kb\)](#)

Relation to the design principles:

A palliative approach from diagnosis through to bereavement addresses many of the design principles again shaping care around the health needs of the individual and providing optimal emotional and psychosocial support. Decisions about future care can be made in a supported environment with relevant professional information available.

Current barriers:

Some palliative care services focus on end of life and not on quality of life which is the key component of the WHO definition of palliative care.

Capacity and culture of some palliative care services precludes involvement with MND clients. Barriers to entry include ineligibility, scarce resources and lack of understanding of MND. Many palliative care services do not have the resources or capacity to take on MND clients due to the complexity of need and impact on their resources.

MND Associations have been unable to extend the Volunteer Visitor program due to lack of capacity and funding.

The way forward:

1. Palliative care services to promote a quality of life vision for their services
2. All State Governments to commit funding to extend the recommendations of the Victorian MND Pathway Project nationally
 - a. Key worker model
 - b. MND information and education for palliative care staff
 - c. Timely and appropriate respite
 - d. Top up funding to address high needs
 - e. After hours support



3. Support all practitioners to provide quality end of life care
4. Promote a palliative approach for people living with MND from diagnosis through to bereavement
5. Extend the Local Palliative Care grant initiative to encourage and support all State Associations to run Volunteer Visitor Education and other established programs

MND Research and current projects:

Research is integral to realising our vision of a world free from the impact of MND. Scientific research provides the hope that the causes, effective treatments and ultimately a cure for MND will soon be found. Scientific research must be adequately supported and funded in Australia and the design principle - **a culture of reflective improvement and innovation** - supports the commitment to a continuum of basic science. Clinical and health services research must also be a priority until an effective treatment or cure is discovered. Access to best practice care and support is the only option for people with MND to help them live better for longer.

The size of the MND population and the complex nature of the disease provide excellent opportunities to pilot projects and innovations. The MND community is very willing to be involved in research and is open to sharing practices and ideas and developing partnerships. MND Associations have demonstrated ongoing innovation and continue to seek quality feedback from its members to drive development and guide practice.

There are currently a number of projects and funding models being conducted in some States and the commitment of the State Governments involved in funding and supporting these innovations and projects is gratefully acknowledged.

In NSW:

MND NSW has established a consortium with MSL (Multiple Sclerosis Limited) and the Muscular Dystrophy Association of NSW. This consortium has been successful in obtaining funding from NSW Health to provide flexible and innovative respite options for people with these progressive neurological conditions to support the carers to maintain their caring role.

Community Options NSW has received funding from DADHC to provide extra services to people with MND when their needs become more complex. COPS works in partnership with MNDNSW to identify people with MND who need extra services and to ensure a timely and coordinated response.

A study, funded by the MND Research Institute of Australia (MNDRIA) is currently being conducted by a research team at the University of Sydney: **Letter on Future Care: Development of an Individualised disease specific future care plan for MND**. This study promotes quality end of life care and an individualised approach to advanced care planning. Once completed the guidelines will be available to MND practitioners in NSW and opportunities for amending the guidelines to be translated nationally could be explored.

In Victoria:

In the recent State Budget, funding was provided to implement some of the recommendations of The Motor Neurone Disease Pathway Project report outlined above. Funding will be provided to develop the key worker model and to provide top-up funding for palliative care services supporting people living with MND.



The Victorian MND Clinic Project outlined previously will provide guidance for the development of a range of models that best meet the needs of people with MND no matter where they live.

In Western Australia:

An investigation into the support needs of people with MND, funded by Lottery West, is currently being conducted by Dr Margaret Giles and Silver Chain. MND WA has been actively involved in the project. The final report is due for completion mid year and could provide vital information to assist with care planning and resource allocation.

Curtin University in collaboration with MND Victoria, South Australia and Western Australia is currently developing an education manual for palliative care practitioners.

The WA government disability department (DSC) has recently directed specific funding for progressive neurological diseases to provide equipment and extra services based on needs.

The Neurosciences and the Senses Health Network has developed the Motor Neurone Disease Services in Western Australia model of care. The proposed draft model is currently undergoing consultation and review. The finalised Model will provide a state-wide policy resource for Motor Neurone Disease. The draft model sets out a strategic and coordinated approach to Motor Neurone Disease services and builds on the strengths of existing services while addressing the gaps. The draft model of care has been developed by a group of key stakeholders across the acute and community health care sectors

In Queensland:

MND Australia has received funding through the Australian Department of Health and Ageing Palliative Care Grants round 4 to conduct the Confident Caring Pilot Project. This project is in partnership with MND Queensland and NSW. The project will provide education programs and sessions for people recently diagnosed, their family and friends, carers of people with MND, health and community care providers and palliative care volunteers in Brisbane and surrounding areas to support home based care. Existing MNDNSW education modules and information will be adapted for Queensland and these will be an ongoing resource for MND Q. This is a 12 month project and will finish in May 2009. Its continuation will depend on whether funding from State Government is forthcoming.

MND Australia:

One of the major roles of MND Australia is to promote equitable care and support nationally. MND Australia works collaboratively with the state MND Associations to identify gaps and to establish national projects and priorities. MND Australia in collaboration with the State MND Associations has identified an urgent need for two national projects. There is a need to conduct a national audit to provide quality feedback regarding the support needs of people living with MND in Australia. The results of this audit would help to develop National Standards of Care and to implement national Care Pathways specific to Australia to support the myriad health professionals and service providers involved in the care of people living with MND to provide a seamless approach and continuity of care.

Secondly MND Australia has identified the need for regional, rural and remote practitioners to have easily accessible, timely, relevant, quality and evidence based information about MND care and management. For many practitioners being faced with caring for a person with MND may be a once in a lifetime experience and readily available information is vital at this time.

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Many practitioners in rural and remote areas are sole practitioners expected to provide a full range of multidisciplinary care and support. Web based interactive resources would help to address this immediate and intense need.

Funding is needed to implement these identified projects and is currently being pursued.

MNDRIA:

MNDRIA is solely supported by the MND State Associations and donations. In 2008 it is providing \$480,000 for research in Australia www.mndresearch.asn.au MNDRIA supports biomedical researchers to try and unravel the mysteries of MND and also supports healthcare researchers to find ways to help people with MND to live better for longer. MNDRIA has a goal of providing \$1,000,000 for research per annum and also to ensure that every dollar donated for research is used for research. Funding to support the administration of MNDRIA is therefore being actively sought.

The way forward:

Action research must become a reality and it is therefore imperative that pilot projects which demonstrate better outcomes are appropriately funded to be translated nationally. State based projects are invaluable in developing and demonstrating better outcomes for people with MND and their families. They do not, however, promote equity and do not ultimately address the design principles recommended by the NHHRC.

Many of the excellent projects outlined above could be translated nationally to promote equitable access to effective, people and family -centered and value for money models of care.

MND research at all levels must continue to develop and to be appropriately funded and supported. People living with MND are desperate for answers and clues as to the causes of MND. MND researchers in Australia work collaboratively with their counterparts overseas and the recent announcement relating to the TDP-43 gene mutation is a prime example of international collaboration. The International ALS/MND Symposium held annually demonstrates the worldwide interest in MND research, care and management. Attendance grows each year with scientists, researchers, neurologists, specialists, nurses, allied health and palliative care practitioners coming together to share their research, models of care and practice. MND Australia has been nominated as the host in 2011 and the Symposium will be held in Sydney in November/December that year. This will be integral to **providing for future generations** providing an opportunity to learn about international best practice care and management and how to support people with MND into the future. Opportunities to showcase Australian research and promote collaborations will also be provided.

In Conclusion:

The principles set out by the Commission to help shape Australia's health system have the potential to improve outcomes for people with rapidly progressive neurological disease. Statistics show that the number of people living with MND is gradually increasing thus highlighting the importance of long term planning.

The number of MND specific models of care outlined in this submission to meet the individual and complex needs of people living with MND and their families demonstrates the NHHRC Submission

intense health care needs of this client group and the drive and commitment of the MND community in this country. Equity however remains an issue and many people living with MND in Australia do not have access to best practice care and struggle daily with the complexity of the health and community care system. Ideas to improve health outcomes for people living with MND and their families, and to provide for future generations through the education and training of the health workforce, have also been outlined. Translating these evidence based ideas and models of care nationally has the potential to ensure world best practice care for people with MND now and into the future. To achieve these outcomes NHHRC needs to specifically recommend the following:

- For all State Governments to provide recurrent funding to MND Associations to support the MND Australia Family Support Model of Care
- That MND Multidisciplinary Clinics and models of care be formalised and funded within the healthcare system
- A national approach to the provision of equipment including NIPPV
- Promotion and support for a palliative approach for people with MND from diagnosis
 - Key worker concept
 - MND Education and information
 - Timely and appropriate respite
 - Top up funding
 - After hours support
- Funding to support the MND Australia national projects
- Funding for MND research and the administration of MNDRIA

This reform process presents a very real opportunity to adopt a national approach to health care, to stop the blame game and to move forward to ensure better health outcomes nationally. MND Australia welcomes the opportunity to contribute to healthcare reform from the perspective of those whose complex needs provide a unique challenge to the efficacy of any healthcare system. MND Australia hopes that members of the MND community will be invited to participate in the National Consultation Program which has just commenced to provide further input and personal experience of living with MND.

APPENDIX 1

THE INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS STATEMENT OF GOOD PRACTICE FOR THE MANAGEMENT OF MND

Statement of Good Practice:

Support and care management for people living with ALS/MND is underpinned by five basic principles:

- Management of the disease determined by the needs and wishes of the person living with ALS/MND, treating the person with ALS/MND with care, respect and dignity
- Timely response to identified needs
- Access to a coordinated and integrated care plan
- Regular monitoring and review of the person's condition, and appropriateness of the care plan
- Information about the person's medical condition held in confidence

The International Alliance of ALS/MND Associations recommends the following good practice that will result in effective management of the diagnosis and care of people living with ALS/MND.

Before Diagnosis...

Early recognition of symptoms and access to a physician competent to diagnose complex neurological diseases

At Diagnosis...

Diagnosis given by a physician who is informed about ALS/MND, in a sensitive way appropriate to the person with ALS/MND and, in an appropriate setting with family and/or friend(s) present

Information provided in verbal and written forms about the disease, including its impact, sources of help and support, and referral to the ALS/MND Association as appropriate to the needs of the individual

Information sent to the patient's principal health practitioner about the disease, management implications, and the ALS/MND Association

The opportunity to return to the diagnosing physician for further information, care and follow up

After Diagnosis...

Access to:

- information and support services
- planning and coordination of support and care

These include:

- advice about personal care and equipment, clinical interventions, treatments and therapies, palliative care
- support for caregivers and families eg: respite care, bereavement support
- health and financial benefits
- research and clinical trials
- access to support from the ALS/MND Association

In summary, it is essential that people living with ALS/MND are enabled to make informed decisions about living with ALS/MND so as to achieve quality of life, and dignity in living and dying. Adopting a proactive approach to disease management, and respecting the needs and wishes of the individual and their caregivers is imperative

International Alliance of ALS/MND Associations

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NHHRC Submission

