

# Neurosciences & the Senses Health Network

## Motor Neurone Disease Services for Western Australia

Prepared by the  
Motor Neurone Disease Project Group  
Neurosciences & the Senses Health Network  
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Health Networks Branch

Working Together to Create a Healthy WA



Government of **Western Australia**  
Department of **Health**



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## ACKNOWLEDGEMENTS

This MND Model of Care was developed following a series of meetings and presentations between February 2007 and July 2007, summarising the current status of MND care in Western Australia, and the current standards of excellence for the care of motor neurone disease patients.

All MND subcommittee participants are involved in the care of patients with Motor Neurone Disease and include community representatives who have personal experience in caring for family members with the disease.

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## EXECUTIVE SUMMARY

Motor Neurone Disease (MND) is a devastating, incurable and *progressive* neurological disease that has a significant impact on the lives of patients, their families and the community. Fifty percent of patients die within 3 years of symptom onset. Rate of progress varies, and prognosis worsens with an increased age of onset, low forced vital capacity, short time between first symptom to presentation and bulbar onset <sup>(1)</sup>.

The management of MND has evolved over the last decade with a move towards coordinated multidisciplinary care that improves both the quality of life for patients and families and improves patient survival. Although incurable there are treatment and management options that can make a significant difference for patients and families with MND.

Coordinated multidisciplinary care for patients with MND is essential at all levels of health care. This includes community based care, the general practitioner, private neurologist and community aged care facilities, as well as the specialised MND clinic. A planned and well managed disease course based on the needs and wishes of the person with MND assist in improving quality of life. This can also prolong survival whilst being cost effective in reducing unplanned and possibly unnecessary hospitalisations.

With planning and support, the majority of the care of patients with MND from diagnosis through to death can be provided in the community setting or in secondary hospitals closer to home if complications such as pneumonia arise. Only more specialised care would require the tertiary hospitals.

This Model of Care reviews the multidisciplinary approach to the management of MND in Western Australia, and provides recommendations in line with the *Clinical Services Framework* and the *A Healthy Future for Western Australians: Report of the Health Reform Committee* (Reid Report). This Models of Care is developed to ensure people with MND get the right care, at the right time, by the right team and in the right place.

People with MND and their carers have been consulted about their needs and wishes for support in living well with this diagnosis. In essence they have identified the need for care that is better coordinated, well-informed and tailored to their specific (and often rapidly changing) situation



## RECOMMENDATIONS

- 1.** To recognise and endorse the leadership role of MND specialty clinics for MND care in the State, through:
  - i.** Clinical excellence.
  - ii.** Development of protocols.
  - iii.** Ongoing education.
- 2.** To endorse adequately resourced MND specialty clinics in the short term at Shenton Park campus (Royal Perth Hospital) and Fremantle Hospital and in the long term at Sir Charles Gairdner Hospital and the Fiona Stanley Hospital complex.
- 3.** To endorse Motor Neurone Disease care at a community level, through increased provision of MNDAWA Care Advisers and/or Nurse Co-ordinators to coordinate and manage care and support for patients and support for families from diagnosis through to after-death counselling.
- 4.** To endorse the need for allied health, neurological, palliative care, aged care physician and other specialty physician services at a non tertiary level, recognising the progressive and terminal nature of the Motor Neurone Disease.
- 5.** To endorse the provision of services and resources for patients with MND in rural and regional areas through better access to care, education and Telehealth services.
- 6.** To endorse the requirement for specific funding arrangements that provides aids, supplies and equipment related to the diagnosis and management of MND in the public and the private sectors in a timely and appropriate way.
- 7.** To endorse the requirement for both emergency and regular respite services for patients with MND and their carers in the public and the private sectors.





## VISION

The vision for Motor Neurone Disease (MND) care in Western Australia includes:

- MND patients and their families are provided with a coordinated multidisciplinary approach to the care for their disease; one that is integrated across the health system, recognising the specific needs of the MND patients and their carers.
- MND specific models of care are in place, utilising community, secondary and tertiary centres of expertise in the management of MND.
- There is adequate and timely access to MND specific education and information for health and community care providers throughout Western Australia.
- A state plan for MND is in place that embraces the current philosophies of health care within the State as outlined in the Clinical Services Framework and Reid Report, integrating with the care of other health conditions where appropriate.

## METHODOLOGY

The MND Project Group, a subgroup to the Neurosciences & the Senses Health Network, developed the basis of this document through a series of meetings held between February and July 2007. Additionally, the Project Group reviewed national and international guidelines and current literature. The detailed submissions that form the basis of this document are referenced and provided in full within the *Motor Neurone Disease Services for Western Australia - Support Document*.

This paper outlines the benefits of integrated MND services to deliver improved patient care, cost effective patient outcomes and averting adverse complications or hospitalisations.



## 1. MND BACKGROUND

MND has an approximate annual incidence of 1:40-50,000 per annum. The peak age of onset is usually between 40 and 70 years of age but patients may be affected at an age ranging from the second decade of life through to the elderly.

The MND Association of Western Australia manages approximately 145 clients at any time, which include people with MND and families that are being supported for up to six months after bereavement.

### 1.1 MND Definition

Most cases of MND are sporadic, with Familial MND accounting for around 5% of cases. Of the familial cases, approximately 20% have an identifiable mutation in the superoxide dismutase 1 gene (SOD1) on chromosome 21<sup>(2)</sup>.

Three main forms of MND are identified although patients usually progress towards Amyotrophic lateral sclerosis (ALS) over time.

#### ■ Amyotrophic Lateral Sclerosis (ALS)

ALS is the most common form and is characterised by muscle weakness, spasticity, hyperactive reflexes, emotional lability and subtle cognitive change.

#### ■ Progressive Muscular Atrophy (PMA)

PMA is characterised by muscular weakness and wasting, weight loss and fasciculation (without upper motor neurone findings). This is the least common form of MND, but is a common initial presentation.

#### ■ Progressive Bulbar Palsy (PBP)

MND may present with involvement of the bulbar muscles alone, as dysarthria and dysphagia.



## 1.2 MND Neurogenetics

The majority (95%) of MND is sporadic. However, in 5% of cases there is a family history of MND which indicates the presence of an autosomal dominant gene defect causing the disease. Of this 5%, one fifth (i.e. 20% of 5%) is due to a heterozygous mutation in the Superoxide Dismutase gene (SOD1). In the other four fifths, the disease causing gene/s is still unknown.

DNA is referred for SOD1 gene testing to the Neurogenetics Laboratory at RPH. Immediate gene testing is only done if the diagnosis is confirmed by a neurologist. For testing to be carried out, it is preferable that there is a family history of MND but the testing will be carried out in unusual circumstances such as a very young age of onset. The identification of a SOD1 mutation usually places other unaffected family members at risk. Genetic testing in this circumstance is termed “pre-symptomatic” and there is a well outlined protocol published through the Human Genetics Association of Australasia for this situation <sup>(3)</sup>.

The family member is initially seen to explain the genetics of the SOD1 gene and to perform neurological examination to ensure that there is no sign of MND. The person is then referred to the social workers and psychologists at the Neurosciences unit in Mt Claremont for counselling. If and when the person is judged sufficiently well informed and psychologically robust, genetic testing goes ahead. The results are given both by the doctor and the social worker involved and follow-up organised.

As a complicating factor, 5% of SOD1 gene mutation carriers don't manifest MND.

## 1.3 MND Data

**Table 1. National Public Hospital cost per separation by DRG (MND as principal diagnosis) and national ALOS.**

DRG	Description	National ALOS (days)	Cost per Seps (\$)
<b>B67A</b>	Degenerative Nervous System Disorders W Cat or Sev CC	15.2	10,512
<b>B67B</b>	Degenerative Nervous System Disorders Age >59 W/O Cat or Sev CC	7.0	4,355
<b>B67C</b>	Degenerative Nervous System Disorders Age <60 W/O Cat or Sev CC	3.7	1,996
<b>B60A</b>	Established Paraplegia/Quadriplegia W or W/O OR Procs W Catastrophic CC	25.1	24,918
<b>B60B</b>	Established Paraplegia/Quadriplegia W or W/O OR Procs W/O Catastrophic CC	9.2	7,494

Source: Australian Hospital Statistics 2004-05, Australian Institute of Health and Welfare (AIHW).



The DRGs listed in table 1 are those associated with the ICD-10-AM code G12.2 for Motor Neurone Disease. These data listed are the cost of each separation (a completed episode of care per patient) when care for that patient is provided in a tertiary hospital.

Additionally, the table shows the average length of stay (ALOS) per patient per episode of care. Some of the ALOS is quite extended, which can be detrimental to the patient on a holistic level. It is clear to see from these data that it would be in the patient's and hospital's interest to provide more MND care in a community setting. The recently completed project into Neurodegenerative disorders also supports the improved provision of community based MND care, including keeping MND patients out of hospital but the emphasis is on maintenance of personal dignity and quality of life which are thought by patients, their families and their health and care staff, to be best preserved in the home<sup>(4)</sup>.

**Table 2. Prevalence of MND in Western Australia per Area Health Service.**

Separation Year	Area Health Service				Total
	#NMAHS	#SMAHS	#WACHS	Non - WA	
<b>2001</b>	48	48	19	0	115
<b>2002</b>	64	52	29	1	146
<b>2003</b>	55	58	29	1	143
<b>2004</b>	51	44	24	0	119
<b>2005</b>	57	50	27	0	134
<b>2006*</b>	75	37	21	0	133
<b>Average</b>	<b>58</b>	<b>48</b>	<b>25</b>	<b>0.3</b>	<b>132</b>

Source: Epidemiology Branch, Analysis and Performance Reporting, DOH, WA Feb 2007

(# North Metropolitan Area Health Service, South Metropolitan Area Health Service, WA Country Health Service)

(\* 2006 data is preliminary as Sep-Dec 2006 is not complete.)

Table 2 outlines the number of MND patients per area health catchment per year. It is difficult to derive a trend from this data but overall there is an increasing trend of MND prevalence in WA. The disease is not necessarily occurring more frequently but rather with the population growth of WA more people are presenting with the condition. The net effect is that there is more pressure on the system to provide specialised care for these patients.



#### 1.4 Motor Neurone Disease Registry

There is an Australia wide MND registry (The Australian Motor Neurone Disease Registry, AMNDR) which now has 650 cases registered, to follow people with MND from diagnosis to death. This provides valuable demographic and clinical information regarding MND in Australia, as well as a valuable resource for use in clinical trials and research.

AMNDR has been developed by neurologists from around Australia to collect information on MND diagnosis, treatment, management and outcomes from all over Australia. The database will provide information about the disease; its progression and how doctors manage it, enabling doctors to compare treatment strategies and to establish 'Best Practice' guidelines for patient care<sup>(5)</sup>.



## 2. CLINICAL COURSE OF MND

The clinical course of MND can be considered in stages; the pre-diagnosis and diagnosis stage, the maintenance and progression stage, and a terminal care stage. Patients move through these stages at variable tempos, and need a well managed care plan to anticipate their needs, involving all members of the care team, the patient and family (MND Anecdotes & Evidence<sup>(6)</sup>).

The recently completed project into Neurodegenerative disorders has found that some people with neurodegenerative disorders (and/or their families) are in denial about their disorder and its life-limiting effects. This can prevent them from seeking help from health professionals, from the disorder-specific support agency or from home care service providers in the early, or even middle, stage of their disorder. They may be slow to seek help or to investigate the availability of, and access to, support or medical treatment. Providers are aware that, if this attitude persists, then a crisis situation may develop to the detriment of the wellbeing of the individual and their family. This may be exacerbated by the breakdown of family structures, which increases the strain on, and reduces the informal care available to, individuals.

Providers, particularly staff of disorder-specific support agencies (such as MNDA WA care advisors) may need to fast track access to services and other supports. Given provider experiences, this is not an easy task. There are usually long lead times in implementing home care support services in the home due to funding processes and availability of staff. Moreover, the supports are likely to be less effective than would have been the case if earlier interventions had been obtained.<sup>(4)</sup>

### 2.1 The Pre-Diagnosis and Diagnosis Stage

The diagnosis of MND is made by a Neurologist and can be difficult. The different presentations of the disease make this a stage of careful clinical evaluation and investigation and specialist neurological input is often required. The diagnosis of MND is frequently one of exclusion and a period of observation followed by repeat electrophysiological testing, which may be required before clinical certainty is achieved. This time of diagnostic uncertainty can be a time of significant stress for the patient and family, which may last from several months to a year or more.

In confirming the diagnosis, it is common to utilise a second opinion from a neurologist with expertise in the management of patients with MND, given the devastating nature of the diagnosis. An intentional delay in confirming the diagnosis is common, while waiting for clinical signs to evolve. During this time the patient requires close specialist support, regular follow-up and symptomatic management. Neurological input at clinical presentation is important as patients may otherwise undergo inappropriate interventions such as cervical or lumbar laminectomies or nerve operations.

The diagnosis of MND may be made in the public or private sector. The diagnosis needs to be conveyed in an appropriately sensitive and informative manner<sup>(7)</sup>. At



this initial stage, management may be by the neurologist with early involvement of the MND Care Adviser/Nurse Co-ordinator.

The diagnosing neurologist may not be comfortable with accepting long term management of the patient and may choose to refer the patient for multi-disciplinary review and management by a colleague, specialised MND clinic or aged care physician with an interest in MND management.

Fifty percent of patients die within 3 years of symptom onset. Rate of progress varies, and prognosis worsens with an increased age of onset, low forced vital capacity, short time between first symptom to presentation and bulbar onset<sup>(1)</sup>. Survival after diagnosis may be a matter of weeks, or with certain uncommon MND syndromes, many years.

The Pharmaceutical Benefits Scheme (PBS) approved drug Riluzole is currently the only pharmacological treatment available that might alter the course of the disease, prolonging survival by a matter of months in some cases.

The impact of MND on families is devastating with the burden of progressive disability, loss of income, an uncertain future and shortened life expectancy.

## **2.2 Maintenance and Progression Stage**

Once the diagnosis is established and disability is present, additional involvement of allied health supports and further medical input by respiratory physicians and gastroenterologists may be needed. Early involvement of palliative care physicians for assistance with symptomatic management and counselling is also needed.

It is common for patients diagnosed with MND in the private sector to move towards the public sector for care after diagnosis. This move is driven by the multidisciplinary needs of the patient, the heavy clinical management requirements and loss of financial means with loss of employment for the patient and often also for their carer.

MND is usually relentlessly progressive. In a typical case presenting with leg symptoms, where one leg will become progressively weaker followed by the other leg, the patient will require a wheelchair to assist them with mobility. At the same time as the legs are becoming weaker the arms become involved and the patient's dependency increases. Often at this stage the patient is starting to develop swallowing problems and symptoms related to weakness of respiratory muscles presenting as inadequate breathing.

The patient may experience complications related to their weakness. Weakness of the legs may cause falling, difficulty swallowing may cause choking or aspiration pneumonia and inadequate breathing may cause fatigue, headaches and poor concentration. Their quality of life is greatly affected by their increasing dependence (One MND Journey<sup>(6)</sup>).



The emphasis of management of MND is through symptomatic and supportive interventions. Supportive interventions need to be provided with some urgency due to the rapid progression and unpredictable clinical course of the disease. This progression necessitates a coordinated multidisciplinary approach to manage the patient. The advantage is that of a clinical care team experienced in the care of MND patients that can often anticipate the need for more specialised inputs, such as feeding gastrostomies mobility aids, pressure management and augmentative communication and ventilatory support. This patient centred approach requires close monitoring to anticipate the clinical changes and to plan for timely interventions.

Allied health input with physical therapy, occupational therapy, speech therapy, rehabilitation engineering, dietetic therapy, psychological therapy, and social worker advice are required to varying degrees throughout the disease course.

Early discussion and education regarding feeding options for the patient needs to occur. The introduction of feeding support can reduce complications such as pneumonia and avoid malnutrition. Approximately 20% of patients with MND elect to receive some form of feeding support such as a gastrostomy feeding tube. All patients who receive feeding support will require dietary intake advice (Gastroenterological Management of MND<sup>(6)</sup>).

Similarly, early respiratory support for some patients can improve quality of life (Managing Respiratory Inefficiency in MND<sup>(6)</sup>). In Western Australia approximately 20% of patients with MND received some form of non-invasive ventilatory support (non invasive positive pressure ventilation, NIPPV). Tracheostomy and invasive ventilatory support is rarely undertaken in MND management.

The case for non-invasive ventilation is well established. There have been several recent publications demonstrating increased survival, quality of life and cognitive function with use of non-invasive ventilatory assistance in MND (Effects of Non-Invasive Ventilation<sup>(6)</sup>). In a randomised controlled trial of non-invasive ventilatory assistance in MND, Bourke et al. demonstrated a median survival benefit of 205 days for patients with good bulbar function with maintained quality of life for most of the period of treatment. They were unable to show a survival benefit for those with poor bulbar function<sup>(8)</sup>. Of those suited for ventilatory assistance not all wish to receive it. In WA approximately 20% of all cases use this therapy in the latter stages of their illness. This is a relatively high uptake by international standards<sup>(9)</sup>.

Careful community based care and case management can prevent unnecessary admissions to tertiary hospitals or at least allow their diversion to secondary hospitals closer to home. Central to prevention of these admissions are lines of communication and contact between the patients and their MND teams, ideally through MND Care Advisers and MND nurse specialists (as part of a MND specialty clinic) and their general practitioners.

With good planning, most tertiary hospital admissions can often be avoided or length of stay reduced in duration for complex patients. Emergency admissions generally result in prolonged stays but with adequate discussions about management plans in the event of complications, the duration of these can also be reduced.





The main factor prolonging tertiary hospital length of stay is the lack of an exit strategy. A preferred option is to develop appropriate secondary hospital units, capable of effectively managing MND patients, and planning effective early discharge back into the community, for this to be effective case coordination and planning the time of admission to tertiary hospitals would be essential. . Additionally, the rapid and unpredictable progression of the disease often necessitates timely access to essential equipment to enable the patient to remain in their home environment.

The provision of electric wheelchairs with specialist controls needs to be timely and should be adjusted according to the patient's needs as the disease progresses. A range of such technology needs to be on hand at an adequately staffed specialist centre to enable fast response to changing need.

To begin to address this issue, the *Disability Services Sector Health Check*<sup>(10)</sup> recently recommended that alternative funding strategies for clients with fluctuating needs as a result of rapidly degenerating conditions such as MND be considered. The Disability Services Commission has allocated pilot program funding for 3 ½ years to provide timely and flexible response for this target group. The MS Society of WA has been funded to provide an intermediate intensity service that will be able to quickly provide expert, responsive and flexible services that will enable patients to remain living at home for as long as possible. This innovation is designed to work collaboratively with the treating teams and community based service providers to achieve better access and better patient outcomes. A one off grant for an equipment loan pool has also been provided to improve access to necessary equipment. This program is part of the MS Society's *Beyond MS* strategy and is targeted at MND and other patients who suffer from rapidly degenerating conditions.

Patient and family needs differ at various stages of the disease course. Each requires many disease interventions; with local studies showing that patients with MND meet an average of 82 different medical personnel during their disease course (Care Professionals: a Case Study of Private Patient with MND & MND Care Model<sup>(6)</sup>)

In the absence of an electronic record, patients are encouraged to keep a self managed file and to receive copies of all written correspondence in this file.

The MND care adviser/clinic nurse co-ordinator provides close monitoring and acts as a single point of contact to involve and coordinate the multiple services required. MND patients who are regularly reviewed and managed by an experienced MND clinician and an MND care adviser/nurse co-ordinator, rarely require emergency admission for their MND alone. Often it is a superimposed event such as a fall, a urinary or chest infection or an addition of a medication that adversely affects their condition.

Co-ordinated care with planning for all possible future contingencies and providing support for the carers avoids crises, hospitalisations and complications. The MNDAWA run a comprehensive carer support program. Palliative care physicians and psychologists should be involved early in the disease course, including establishing relationships and discussion of Advanced Care Directives before speech and or cognition is affected.



Unforeseen changes to the patient's home circumstances should be included in planning. The recently completed Neuro project <sup>(4)</sup> found that few patients and their families had considered what they would do if the primary carer was suddenly unable to provide the level of support needed to care for the patient at home. For example, this may occur if the carer is hospitalised suddenly for minor surgery. The project found that most carers of adults with MND felt that these care recipients could not manage to remain in their own home without their carer. There was limited capacity for other family members step in to provide care if the primary carer was temporarily unavailable. This again highlights the need for access to respite alternatives both in and out of home.

### **2.3 Terminal Care Stage**

The terminal care stage is a particularly intense time. Dignity is maintained in the patient by affording relief of symptoms and anxiety via the use of a sometimes complex medication regime. The patient will require 24-hour attention to hydration, hygiene, catheters, medication, possible ventilation as well as general nursing measures. The use of equipment such as hoists usually requires two people to manage the patient. The appropriate provision and maintenance of augmentative communication strategies is important to many patients in the palliative care stage of MND. The family also requires psychological support in this stage (MND Palliative Care & A Pathway for the Management of Pain in MND<sup>(6)</sup>).

Palliative care physicians are becoming involved early in clinical management, as appropriate, because of their expertise in symptom management. Palliative care facilities currently offer respite to patients with MND, but demand outweighs available resources. Increasing levels of community based palliative care is provided in the home with advancing disease and increasing intensity of care required.

Ideally, the preferred place of death has been discussed with the patient and family prior to the terminal stage. Patients can be supported at home, but if this is not desired or possible then optimally they would be cared for in a palliative care unit (hospice) or local hospital in the regional areas.

Before and after death there is a need for family counselling and support. The MND Care Advisers continue to support families for six months after death.



### 3. COORDINATION OF MND PATIENT CARE

#### 3.1 The Roles of the Clinic Nurse Co-ordinator and MND Care Adviser

The MND Care Advisers and Clinic Nurse co-ordinators “walk alongside” people with MND and their families as they deal with the disease, supporting them and actively linking them to the services that will add to their quality of life.

Nurse Co-ordinator roles predominantly:

- Co-ordinate clinic appointments between all the specialists and allied staff, to enable the MND clinic to function smoothly.
- Co-ordinate care plans between the speciality clinic and the local secondary hospital staff as well as GP’s, providing education for staff where required.
- Provide an initial point of contact and source of information for the patients and their relatives in the event of questions or problems.
- Refer patients to appropriate community based services.

The MND Care Advisers provide: (MND Care & Advice<sup>(6)</sup>)

- Support and information to families.
- Assessment and ongoing review of needs for families living with MND through regular contact.
- Coordination of care with treating clinicians and general practitioners.
- Referral to other medical and allied health services as required.
- Advocacy for patients and families to facilitate timely interventions and care.
- Carer Support Program. Includes monthly facilitated carer meetings (used for education and peer support), carer training sessions (e.g. manual handling and First Aid) plus twice yearly short breaks for up to nine carers each time.
- Equipment library. MND patients often urgently need equipment that is difficult to access elsewhere. The library includes large items such as wheelchairs, electric beds and lift chairs, hoists and commodes as well as small items such as adapted cutlery, transfer belts and urinals.
- Education of health professionals and service providers about MND. There is often a lack of knowledge about MND and its effects on families even within the health community. Care Advisers and Clinic Nurse co-ordinators seek to address this with presentations to health professionals, publications, seminars, visits to nursing homes and care agencies.
- Counselling and care of patients and families from diagnosis to after death.



## 4. WHAT ARE THE CURRENT SERVICE DEFICIENCIES?

### 4.1 Lack of Coordinated Services between Providers

The current care of MND patients in Western Australia is spread between private neurologists, aged care services at secondary hospitals (primarily Osborne Park Hospital), MND specialty clinics at Shenton Park campus (Royal Perth Hospital), and the Australian Neuromuscular Research Institute (ANRI) (Sir Charles Gairdner Hospital). Fremantle Hospital, Bunbury Hospital and some of the larger regional hospitals are also involved in MND patient care.

There is no coordinated system between hospitals and the placement of patients within the system is dependent on lines of referral and availability of care places. For example, some patients live in Mandurah but attend the Shenton Park MND specialty clinic, while other patients who live in rural areas may not have any specialty input (medical or nursing) following the initial diagnosis.

There is limited access to the Shenton Park MND specialty clinic due to limited resources, although the crisis has been eased in recent years by the appearance of clinics at the ANRI and aged care services at Osborne Park Hospital that are taking responsibility for some patients (Osborne Park Hospital<sup>(6)</sup>). However, under the Aged Care Assessment Teams (ACAT), social work is not well staffed for the complex and ongoing needs of MND patients.

Similarly there is a need for more staffing to provide psychosocial assessments and counselling services for the MND specialty clinics and the private sector.

These patients have urgent and high priority needs for which a monitoring approach is needed. Presently a reactive approach to care is taken rather than a proactive approach where social workers regularly contact family and patient to monitor and support existing arrangements. With further funding existing ACAT social workers could provide a care coordination role, within existing aged care infrastructure. With further resources in rehabilitation engineering clinics, the provision of assistive technology could be more proactive rather than current reactive systems which result in increased waiting times for services.

Private sector neurologists currently provide care to the majority of patients with MND, with some assistance from the MND care advisers. From a patient's point of view, limited availability of experienced allied health support in the private sector is a major concern.

When patients have a progressive disease, additional financial costs such as consultations, aids, home modifications, respiratory equipment and food supplements as well as loss of financial means adds to the pressure experienced by the patients and their families. This pressure results in the movement of patients back to the public sector.



In keeping with the Clinical Services Framework, additional community supports would allow patients to receive their care in the community and secondary hospital. This community support would reduce outpatient and particularly inpatient demands on the tertiary hospital system. Provision of Neurologist consultation services to secondary hospitals needs to be coordinated with other models of care. Coordinated Neurological and Aged Care specialist input together with Multidisciplinary teams lead by the MND specialty clinic is important to provide evidence based practice in secondary hospitals.

Pivotal to the success of the adopted Model of Care are the well-defined roles of a nurse coordinator and the MND Care adviser (case-manager) with clear exchange of information between all of those involved in the patients care.

#### **4.2 Limited MND Care Adviser Resources**

MND care advisers, with their limited resources, provide input to patients at the community level and attend MND specialty clinics to be part of the multidisciplinary clinic.

MND care advisers follow the patient throughout their disease course and are often the first point of contact. From that contact the patient may be redirected to their neurologist. Alternatively, after discussion between the MND care adviser and the neurologist, the patient may be referred to allied health services or other specialist medical services.

While the MNDAWA provides case management, it does not have sufficient resources for the number of people with MND. Case management and efficient co-ordination of care is essential, due to the progressive, complex and physically disabling nature of MND. Case management involves family meetings (with patient, doctors, nurses, allied health, family and carers attending), ideally in the patient's home as occurs in other Australian states. MNDAWA, as a point of first contact, needs increased resources including provision for after hour calls. This may coordinate with other disease groups. This would be an ideal model to set goals and plan appropriate coordinated ongoing care.

The Neurological Council of Western Australia neurological nurse specialists assist with the care of MND patients in the rural and regional area. There are a limited number of these specialist nurses spread across the State who support all types of neurological disorders, consequently restricting the extent of service to MND patients. The provision of a dedicated nurse co-ordinator to work alongside the MND Care Advisers would enable complete case management and co-ordination of care of all patients in WA with MND, both in city and rural areas.



### 4.3 Evidence from Consumers

Recent research projects with recommendations based on consultation with people diagnosed with MND and their carers<sup>(4, 11)</sup>, have all highlighted current gaps and a need for a shift in emphasis towards a more coordinated service to ensure better quality of life as they navigate life with often rapidly changing needs. Commonly identified needs were

- Ongoing support and assistance to navigate their local service provision network
- Coordinated care (suggesting a key worker model to facilitate communication.
- Access to aids and equipment in a timely manner
- Greater access to allied health professionals
- Timely and appropriate respite options
- Funding for high needs clients
- Education for service providers to understand the specific needs for people living with MND
- Access to after hours support.

**Table 3. .... Hours of MND Care advisers and number of MND patients.**

	<b>1997</b>	<b>2002</b>	<b>2007</b>
MND patients	-	110	116
Family support	-	10	25
TOTAL	114	120	141
Care Adviser hours	<b>20 hrs/week</b>	<b>35 hrs/week</b>	<b>51 hours/week</b>

Source: Motor Neurone Disease Association of Western Australia (Annual Report).

The scope of the care adviser role has evolved from a basic telephone service to one that engages the care advisers with allied health professionals and other organisations. Additionally, the care advisers support families in their homes, develop education programs and participate in Telehealth services. Case coordination is essential in the management of MND at the community and hospital level and the current available MND care adviser hours are grossly inadequate. The number of MND care advisers employed by the MNDAWA limits their level of involvement in MND patient care.



#### **4.4 Lack of Support for Respiratory Services**

The benefit of respiratory support for patients with MND is a recent evidence-based development<sup>(8)</sup>.

The need for respiratory services may be urgent and many patients have limited financial resources, which can prevent them from benefitting from this input. Implementing and managing non invasive ventilatory support requires the resources of an expert in this area. Currently the major centre providing this service is located at SCGH, which requires specific funding to maintain and expand its role.

Apart from operating outpatient clinics, respiratory services must have capacity to measure ventilatory function both during wakefulness and sleep, have inpatient beds for medical emergencies, offer domiciliary support through a visiting nurse and provide patient equipment such as ventilators, masks, humidifiers, suction devices, and cough assist devices. In time the SCGH service should be replicated at the southern tertiary site (FSH). These services should form elements of the multidisciplinary tertiary clinics envisaged in this paper.

#### **4.5 Difficulties in Equipment Allocation**

MND patients often need multiple pieces of home equipment with some urgency given to the progressive nature of their disorder (MND Equipment<sup>(6)</sup>). Application through traditional pathways such as the Community Aids and Equipment Program (CAEP) may be difficult, due to limited resources and time constraints. CAEP is a State funded, postcode based service with eligibility criteria that makes the equipment difficult to access quickly.

Those MND patients who are receiving Extended Aged Care at Home (EACH) or Community Aged Care Package (CACAP) Commonwealth funded packages are not eligible for CAEP, which is State funded. CAEP provides a large range of essential equipment that aged care services are unable to provide, such as specialised wheelchairs, hoists, structural home modifications and speech related communication equipment. People with MND, particularly the younger patients, frequently are not eligible for equipment under CAEP, EACH or Aged Care Services, though at times can receive support through these avenues. Additionally, people with MND in the early stages of the disease may still be working in some capacity which prevents them from being eligible for a pension or for CAEP. To avoid putting MND patients at unnecessary risk or stress, a MND specific program with a standardised approach to assessment and intervention is necessary, including maintenance.

There are some equipment items that can be difficult to access such as electrically adjustable beds and chairs that are not provided through CAEP or hospital systems. For these items patients rely on the MNDAWA or need to complete further applications to CAEP, which are often unsuccessful. Many patients resolve to buy their own at high cost.

Prescription of equipment by occupational therapists further adds to the inefficiencies of the system and may lead to inappropriate equipment being sought. For example,





people with MND can often benefit from the integration of technologies for mobility, communication and controlling their environment and these systems require assistive technology specialists for prescription and implementation. As timing is of the essence in maintaining the patient and carer independence and dignity, these difficulties consume time that is not available to the patient or their family.

The rapid progression of MND means that the patient and care/equipment needs change frequently. Ongoing review and early introduction of equipment helps with acceptance of the condition by the patient. This process has been found to be disruptive if there is no case management approach (i.e. if multiple people are involved).

There is a need for after hours, in home visiting emergency maintenance service for specialised equipment.

#### **4.6 Lack of Access to Allied Health Services at a Community Level**

While there is some Medicare funding for private neurological input to patient care, it is the difficulty of accessing allied health services (and therefore the multidisciplinary approach) that result in a drift of patients from the private sector to the public sector hospitals (Physiotherapy Management in MND<sup>(6)</sup>). The lack of home-visiting Speech Therapists has been an issue as clients are at times unable to come into the hospital for review of their swallow and communication levels (Framework for MND Future Planning<sup>(6)</sup>).

There is a need for recognition of the support for Allied Health Services for those who restrict themselves to the private sector to avoid the drift of patients. This may require the private Neurologist to access Allied Health Services (Occupational Therapy, Social Work, Physiotherapy, Speech Pathology, Psychology, Dietetics) through the secondary hospitals, MNDAWA or private sector therapists.

For patients attending the MND specialty clinics, there is a need to have access to additional Allied Health services through domiciliary Allied Health services (RITH and HomeLink). This service is already available for patients over the age of 65 years who are attending aged care facilities in secondary hospitals and needs to be available for those under 65.

The cost of Allied Health services and specialty equipment and supplies represents a major reason why patients move from private to public sector. Alternative methods of funding these services through organisations such as MNDAWA should be considered.

#### **4.7 Lack of Specialist Input to Patients in Rural and Regional Areas**

As with all chronic neurological diseases, the lack of neurological specialist care in rural and regional areas presents a management problem and a dilemma in equity of care. MND prevalence data show that one in four patients with MND is outside the metropolitan area, and unlikely to be receiving MND specialist input to their disease management.





#### **4.8 Lack of Flexibility in Prioritising for MND Care in Western Australia**

In addition to the distribution of patient's difficulties outlined in the earlier sections, MND patients also require a prioritisation in the public health system. They have an aggressive disease with an average survival after diagnosis of 2.5 years and probably of 12-18 months after they are referred to the clinic. Waiting up to 6-8 weeks for appropriate assessment within the clinic can lead to unnecessary hardships, temporary community interventions by the general practitioner and inappropriate admissions to tertiary hospitals. Prioritisation for patients with MND diagnosis is required.

#### **4.9 Lack of Flexibility in Eligibility Criteria for Existing Home-Based Programs**

With the often rapidly fluctuating needs of people with MND, the essence of intervention is that it be timely and periodic. A responsive domiciliary service is important for a range of health professionals to visit the homes of patients unable to easily access outpatient services and as part of the respite care options.

Some MND patients are approved for Community Aged Care Package (CACAP) assistance, which provide up to 5 hours of in-home services per week. Supplementary support is sought in the form of in-home respite care from the Commonwealth Carer Respite Centre. This type of care plan is tentative as some CACAP providers will cease services if continence issues arise and almost always when hoist transfers are needed.

Most MND patients depend on access to an Extended Aged Care at Home (EACH) package, which provides about 18 to 22 hours of assistance each week. Packages are flexible in content but generally include qualified nursing input, particularly in the design and ongoing management of the package. Although MND is an aggressive disease, MND patients are not prioritised for an EACH package, as this is specifically targeted at aged care clients. Patients do not have to meet specific age related eligibility criteria, however to be considered for an EACH package, the patient will need to be assessed by the ACAT<sup>(12)</sup>. This assessment is intended only after all other support options have been exhausted.

The MS Society of WA has recently been funded through the *Disability Services Sector Health Check*<sup>(10)</sup> to provide responsive and flexible services enabling patients to remain living at home for as long as possible. This program will be delivered as part of the society's *Beyond MS* strategy that is targeted at MND and other patients that suffer from rapidly degenerating conditions. The society works collaboratively with the MNDWA and other community based service providers to improve access.

People under 65 years need to be able to retain access to CAEP if other services are not available to them. This sector needs to be reviewed (DSC, Community, Funding of carers, home assistants) including the State/Federal divide.



The difficulty in accessing services for MND patients in a timely manner and the lack of access to the same care providers at each stage places extra undue stress on carers and family involved. A general lack of understanding of the disease precipitates the inflexibility of service providers.

#### **4.10 Lack of Respite Facilities for MND Patients**

There are few facilities available with suitably trained staff or adequate resources to provide respite for people with MND and this often leads to a crisis situation arising.

There is a need for the provision of increased respite services for MND patients, especially the young (< 60 years of age). Providing respite for a patient with MND often requires more nursing hours than other diseases, hence there are funding implications.

MND patients are currently admitted to a Nursing Home for residential respite care. Many facilities are unaware of and unable to manage the complex care needs of MND patients. In a Nursing home MND patients are surrounded by people usually over the age of 70, yet many MND patients can be in their 40's.

Respite care is usually needed for MND patients in a crisis situation and the only respite vacancies available at short notice are in the older more institutional style buildings with a twin, triple or quad share bedroom where many residents have a high instance of dementia. This is highly inappropriate and a specific unit/cluster home within a facility is a more desirable and humane alternative for MND patients for residential respite care.

Respite facilities are needed that can provide the specialised care of patients with MND. Such facilities should have staff that is trained in the care of and facilities appropriate to patients with MND, who may be relatively young, and who may have young families.

The lack of equitable access for MND patients to Palliative Care, compared with cancer patients, remains a major issue. The palliative care Network has developed a Model of care to address the gaps in this service provision.

Palliative care has traditionally been primarily provided to people with advanced cancer at the end of life. There is now international recognition of the need to extend the philosophy, the knowledge and the skills developed in this specialty to provide access to care for all people with a life limiting illness. The Palliative Care Network has developed a model of care to address the identified gaps in current service delivery, the inequity of access to palliative care services and in particular the groups of people who are not well served by the current models of palliative care<sup>(13)</sup>.



## 5. FUTURE MODEL OF CARE

The role of the MND specialty clinic is well recognised in the current medical literature <sup>(9, 14-18)</sup>. Large centres of MND care can be centres of excellence, with multidisciplinary input. Within Australia, these models exist in Victoria, New South Wales (Living with MND in NSW<sup>(6)</sup>) and Queensland.

The future model of MND care in Western Australia needs to take into account plans for the Western Australian health service, including the plans to decentralise care where appropriate and the need to provide neurological services to the secondary hospitals.

In terms of the numbers of patients cared for, some patients with MND will still be cared for in the community, through private neurologists and through aged care facilities at secondary hospitals that have an interest in the disorder, working closely with palliative care physicians and Multidisciplinary teams.

### 5.1 MND Specialty Clinics

Tertiary hospital clinical involvement needs to remain available for selected patients through the proposed MND specialty clinics and those patients who reside within the catchment of those area health services. The MND specialty clinics in the tertiary hospitals will have a leadership role for MND care in the state through the provision of support for local medical and allied health staff, educational resources and treatment guidelines.

The current unresourced model of care for MND in WA has less than 20% of patients being cared for at MND specialty clinics. With appropriate support, closer to 60% would benefit from the regular input of MND outreach specialty clinics through aged care or neurological facilities in the secondary hospitals in terms of their additional allied health needs and neurological expertise required.

To avoid inequities of care between the MND specialty clinics and care at other levels, adequate resourcing of allied health facilities at secondary hospitals is essential. Adequate resourcing of the MND specialty clinics in terms of Nurse Coordinators and Neurologists to allow a supervisory and leadership role for the care of MND is equally essential. Patients who are managed peripherally may in some cases need less regular or once-off contact with the specialty clinics so plans for future evaluations and care can be established, communicated to staff at the smaller hospitals and support provided as needed through outreach (Living with MND in WA<sup>(6)</sup>).



A select group of patients should be cared for in the MND specialty clinics. These include:

- Patients requiring respiratory support. The respiratory department at SCGH provides an outpatient service that enables patients who need respiratory support to continue receiving their care at the community level in some circumstances.
- Patients with unusual forms of MND, including young patients with sporadic and familial MND who often have greater needs (psychologist, social worker).
- Patients requiring expert second opinion at the time of diagnosis (and initial advice/ care plan) or during the course of the disease.
- Patients with diagnostic difficulties who require close clinical monitoring.
- Ongoing care for patients for whom the clinic is the closest care centre geographically.
- Patients requiring access to special procedures e.g. intrathecal baclofen pumps, botulinum toxin for hypersalivation or spasticity.
- Patients requiring specialised support for assistive technologies.

The non-clinical roles of the MND specialty clinics should include:

- A leadership role in the care of MND in Western Australia.
- Liaison with MNDWA and those involved with the management of patients with MND, promoting the early diagnosis and Multidisciplinary team needs.
- Fostering research developments and trials.
- Directing patient controlled records.
- Education and annual seminars to maintain current knowledge about MND developments and services available in WA.
- Epidemiological and demographic monitoring of MND within the state.
- Institution and monitoring of new treatments.
- Establishing and implementing protocols relating to the diagnosis and management of patients with MND, many of which have been established by leading Australian and UK MND working groups(7) (Pain Pathways(6)).
- To develop the working relationship and partnership approach between MND Clinics, Programs/Services and the MNDWA, MND Care Advisers and MND Nurse Coordinators.
- Contributing to the National Registry of people diagnosed with MND in Australia.
- Implementing regular meetings with the Clinic Director as well as Regional MNDWA Advisers and Clinic Co-ordinators.
- Encouraging and supporting the dissemination of information, learning and practice.
- Monitoring patient/carer satisfaction based on the Standards of Care as defined by National MND bodies.
- Encouraging and facilitating the dissemination of good practice nationally.



- Growing and developing the MND Special Interest Group. Bi-monthly e-Bulletins to encourage a network of peer support for health and community care providers nationally.
- Supporting the dissemination of advances in care, research and MND management through the Annual National MND Conference.
- Promoting a patient and carer-centred approach, proactivity and models of care endorsing the contribution of the MND Association and other community based providers.

## 5.2 Aged Care Services

The aged care services, which operate from the secondary hospitals, have significant existing infrastructure but limited capacity. Further training of aged care physicians with an interest and expertise in the management of MND would facilitate the care of patients within the community and secondary hospitals. Consultation advice from the MND specialty clinics at the tertiary hospitals and input from neurological consultation services at the secondary hospitals will facilitate the care of MND patients in the community and in the secondary hospitals. Funding issues need to be recognised for patients under the age of 65 years.

## 5.3 General Practitioner

Fostering the involvement of the General Practitioner in the care of MND patients is a priority. Medicare numbers for chronic disease case management for General Practitioners and Private Neurologists will facilitate this role, provided support structures in the form of MND care advisers and availability of allied health services (GP Role in MND<sup>(6)</sup>).

There are advantages to the patient and the health service in caring for the patient at the community level. Treating the patient in the community is in keeping with the recommendations of the *A Healthy Future for Western Australians* (Reid Report)<sup>(19)</sup>, which aims to reduce the dependency on tertiary hospitals through better use of secondary hospitals and by providing greater emphasis on primary and community care.

To receive care in the community is extremely beneficial to the patient as care is more conveniently accessible without the need for travel or additional expense of receiving care at the tertiary hospital level.

At all stages, the GP is included in communications. The care of the patient within the community involves the GP as one of the first points of call for acute superimposed medical issues, with management in outpatient or secondary hospital as appropriate.

## 5.4 Nurse Co-ordinator

Support of patients at the community level, while they are attending their private neurologist or aged care services within the secondary hospitals, will require enhanced co-ordination of care co-ordination. This could be provided by a nurse co-



ordinator with MND care adviser input, provision of allied health services and adequate resources (for example CAEP) to avoid crisis admissions.

The MND specialty clinic can monitor patients that are in their region but outside their direct care, using accepted clinical measures to monitor patient progress and facilitate provision of care to avoid crisis admissions. This requires the services of MND nurse coordinators to oversee care in the community as it relates to the MND specialty clinics and the tertiary hospitals.

The recently completed Neuro Project (Neuro Project Summary<sup>(6)</sup>) confirms that the heterogeneity of needs of people with MND and their families suggests that home care support should be individualised and the best way to do this is via case management.

Whilst the MND care adviser and the MND clinic nurse co-ordinator would communicate regularly about the patients in their care, the case management role would lie primarily with the MND care adviser. MND Nurse Coordinators would oversee the management of MND Care Advisers within the community, to anticipate and avoid unnecessary hospitalisations

The case manager would also need to liaise closely with home care support providers so that services in the home are in line with care plans and recommendations from health and allied health professionals

## **5.5 Secondary Hospitals**

Caring for MND patients at secondary hospitals is in keeping with the clinical services framework. The provision of neurology services to secondary hospitals of Perth will coordinate well with other chronic disease care plans, such as Parkinson's Disease, Dementia and other extra-pyramidal disorder care plans that are currently under development.

## **5.6 Rural & Remote Sector**

Care of patients with MND in rural and regional areas can be facilitated by developments in Telehealth, coordinating with country based physicians and general practitioners in regional areas and with general practitioners in more remote areas.

RPH has a Telehealth innovation grant to further develop Teleneurology services for Country outpatient and acute country consultations and will be the tertiary hospital (in the short to medium term) to provide this liaison service. In selected areas, the Neurological Council of WA regional nurses will be utilised to provide the same services as the MND care advisers in the Metropolitan area.

Direct, hands-on, clinical consultation in MND is required primarily at the stage of diagnosis. Following this, Telehealth consultation has the advantage of being able to involve care-givers, including allied health, rehabilitation technology and the rest of the multidisciplinary team, in the consultation process. On-site medical input may be provided by Aged Care medical visits to regional centres, as occurs with PD patients.



For specialised processes such as ventilation issues or feeding tubes, a triaged coordinated evaluation in the metropolitan area may be required.



## 6. INTEGRATION WITH OTHER SERVICES

### **Neurology Working Group report (February 2006):**

According to the Clinical Services Framework 2005 – 2015 (CSF)<sup>(20)</sup>, the secondary hospitals will have increasing neurological service needs that must be met by 2010 / 2011.

By 2010 all secondary hospitals (Joondalup, Swan Districts, Armadale and Rockingham Hospitals) will be Level 4 Neurology Service Hospitals (the CSF defines Level 4 services as “outpatient and inpatient care –resident general specialists plus visiting Type I subspecialists and some junior medical staff”).

Each secondary hospital will require an “outpatient neurologist”. Availability of a neurological consultation service would significantly reduce the channelling of patients from secondary hospital emergency departments to the tertiary hospitals for neurological assessments. The approach to this in general terms is described in the report from the Neurology Working Group Report<sup>(21)</sup>. The MND model of care is in keeping with those objectives, through decentralising MND care to the community and secondary hospitals, while maintaining leadership and expertise at the tertiary hospitals.

### **Parkinson's Disease extra pyramidal disorders Model of Care:**

The Parkinson's and extra pyramidal diseases model of care follows a similar decentralising model for patient care, with enhancement of Neurological services at secondary hospitals. The MND model of care will integrate well with this proposal.





## **GLOSSARY**

### **Average Length of Stay (ALOS)**

It refers to the number of days patients stay in medical institutions such as hospitals.

### **Diagnosis Related Group (DRG)**

A system to classify hospital cases into one of approximately 500 groups.

### **Separations (or Discharge)**

Separation is the term used for the completion process at the end of a patient's episode of care, be it a discharge home, death, transfer to another hospital or change of type of care.

### **Prevalence**

The current figure for a population and includes all cases.

### **Incidence**

Incidence is the number of new cases over a given period, usually a year.

### **ICD-10-AM**

International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian Modification



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## APPENDICES

### Appendix 1: The International Alliance of ALS/MND Associations Statement of Good Practice for the Management of ALS/ MND <sup>(22)</sup>

**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 e.g.: 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.



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