



## MND Support Service Model

### **Background**

#### **About MND Associations:**

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 MND and their families. MND Australia was established in 1991 to represent the State and Territory Motor Neurone Disease (MND) Associations nationally. The MND Australia network comprises six state Associations, representing all states and territories. The MND Research Institute of Australia (MNDRIA) is the research arm of MND Australia. The MND Australia members work together to advance, promote and influence local and national efforts to achieve the vision of a **World without MND**.

One of the major roles of MND Australia is to promote and support international best practice and evidence based care and support for people living with MND and their families throughout Australia.

#### **Evidence:**

The initial National Family Support Model was developed during the late 1990's based on surveys conducted in Victoria and NSW. Subsequent Australian surveys, review of services provided by ALS/MND Associations internationally and research literature have confirmed the value and relevance of this model to people living with MND and their families and has guided further development.

Australian surveys and research literature consistently confirm that the key needs of people living with MND are:

- Information provided by experts in the field
- Access to appropriate assistive technology in a timely manner
- Ongoing support and assistance to navigate and access local services as a need arises
- Coordinated care
- Service providers who understand the specific needs of people living with MND
- Support to deal with grief and loss.

[The International Alliance Statement of Good Practice for the Management of ALS/MND](#) provides MND Associations with practice guidelines to enhance effective management of the diagnosis and care of people living with MND. This paper supports the focus of the family support model and confirms that good practice must include timely and MND specific:

- Information
- Support
- Response to needs and
- Coordinated care and advice

A review of the National Family Support Model was undertaken in February 2015 by representatives from MND Australia and MND NSW, Victoria, Queensland, Western Australia and South Australia. This group recommended that the name of the service should be changed to the MND Support Service to more broadly reflect the current role of this service.



## **MND Support Service**

The MND Support Service is focused on ensuring that no person living with MND is living with a high level of unmet needs. The service aims to achieve this outcome using two complementary strategies:

1. The delivery of key services by MND Associations
2. Supporting other service sectors by providing information and education about MND and its impact

These strategies are delivered through the provision of four key service areas

1. Information
2. MND Advisors
3. Coordination of Support
4. Assistive Technology

The State Associations have developed their MND Support Services to be the interface between the person with MND (and their families and carers) and the service sector.

People with MND most frequently prefer to continue living at home within their community, however there are occasions when they need to seek alternative accommodation, including residential care. MND Associations have a commitment to support people living with MND wherever they choose to live. The focus is to ensure that the generic service systems of health, disability, palliative and aged care are able to provide a timely response to meet the complex and changing needs of people living with MND.

This interface effectively assists cross sector coordination and acts to smooth the way for people who may have little or no experience of health, disability or aged care services. In effect, the MND support service acts as a navigator for people living with MND interacting with a complex service system. MND Associations work to ensure that local health, disability, aged and community providers understand the specific needs of people living with MND and their families through the provision of information, education, training and support.

In a recent study to explore the experiences of people living with MND and their carers in Western Australia 90% of respondents reported the MND association support service being of high value to them both practically and emotionally. They particularly valued the personal contact, the time dedicated to the visit and the focus on the needs of the family carers<sup>1</sup>.

Each Association works to provide the core services outlined in this model. However, the services outlined are not exhaustive and there are some variations in service provision between State Associations.

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<sup>1</sup> Samar M. Aoun BSc (Hons) MPH PhDa , Anne Hogden BA (Hons) BSpPath PhDb and Lay K. Kho MBBS, *“Until there is a cure, there is care”: A person-centered approach to supporting the wellbeing of people with Motor Neurone Disease and their family carers* European Journal for Person Centered Healthcare, 2018, Vol 6, Issue 2.



## 1. Information:

Information about MND is a fundamental service. High quality, trusted information resources are vital for people diagnosed with MND, family members, friends, general practitioners, allied health and all service providers involved in the care and support of a person with MND. MND Australia produces a range of resources available online nationally and through the State Associations. State associations also produce resources relevant to their state.

First contact with a person diagnosed with MND or a partner/family member is usually through an approach for information. This contact is often as a result of a referral to the association from a health professional or specialist MND Clinic or via MND association websites.

Introductory verbal information is provided by an MND Association staff member and a referral to the relevant MND Advisor made. An information package may then be posted out to the individual and, with their permission, a letter and MND specific information is sent to their general practitioner.

Different types and levels of information are required as the person's disease progresses. The MND Advisor plays a pivotal role in monitoring needs and providing information as requested or as a need arises.

A number of education and information programs are provided by the MND Associations. These programs aim to:

- assist people with MND adjust to living with the disease
- assist carers in their caring role
- support family and friends from diagnosis through to bereavement

Tailored training for health, aged, palliative, disability and community care professionals is provided, supporting all service sectors to provide the best possible care. Research updates, conferences and information sessions support all involved in MND to remain up to date. In addition evidence and best practice MND information is available online for health and community care professionals on the [MNDcare website](#).

Information and advice regarding accessing pathways of support available through My Aged Care (MAC) and National Disability Insurance Scheme (NDIS) is also provided.

## 2. MND Advisors

MND Advisors work with people living with MND to ensure a person-centred, goal orientated approach to address the identified needs of the individual. The MND Advisor provides an interface between the individual and their family/carers and the service sector and supports the individual to develop an understanding of the community support system and the interaction between it and the generic services of health, disability, aged and palliative care. A face to face meeting is arranged wherever possible based on the wishes of the individual and their circumstances.



The role and services of the Association are outlined, immediate needs identified and referral options discussed and actioned. Contact is maintained throughout the disease trajectory based on a person's wishes.

The MND Advisor role is focused around six main activities as follows:

**a. Initial support and information provision to the person diagnosed with MND, their family and carer.**

The outcomes to be achieved are to:

- establish understanding of the disease and its impact
- establish a base of understanding on which to build ongoing care and support
- offer support, and a person to discuss issues with
- facilitate referral to specialist support in grief and loss, family counselling and bereavement as required
- inform the person with MND and/or family about the range of support and services that are available within the community to address current or future needs
- support family decision making
- establish contact with or link the individual with the specialist MND multidisciplinary clinic or service in their area if applicable

**b. Support to identify needs, development of a care plan and identification of appropriate service pathways.**

The outcomes to be achieved are to:

- support the person with MND and their family to identify existing needs as well as to plan for current and future needs
- provide support to assist the person to navigate the appropriate pathway
- facilitate effective access to MAC and NDIS
- support the person through service assessment, planning processes and eligibility on the individual
- work in partnership with the person's specialist MND Clinic or service coordinator to support a coordinated, multidisciplinary approach to health care

**c. Facilitate access to supports, advocate for timely responsive services and provide ongoing support of the individual and their carer.**

The outcomes to be achieved are to:

- support the person living with MND to enable self-directed care and reduce associated stressors
- provide effective advocacy on behalf of the person living with MND, based on identified needs and expected progression of the disease
- facilitate efficient use of community resources through ongoing support of the individual and family while accessing the service
- where applicable, attend the MND Clinic/service meetings as part of the multidisciplinary team

**d. Support and training for the service provider, advocacy, maintenance of contact and delivery of MND and person/issue specific training and support.**

The outcomes to be achieved are to:

- facilitate effective, coordinated and timely service provision through training of the provider on MND and its impact

- provide peer support for the provider, with a common contact point for expert advice on MND and person specific issues impacting on service delivery
- achieve heightened confidence and capacity of service providers to meet identified needs
- increase local knowledge of, and skills with, the disease supported by specialist agency knowledge and information
- improve service delivery by advocating for and supporting a responsive, coordinated approach
- increase the persons confidence that providers understand MND and its impact

**e. Monitor and reassess as needs change due to progression of the disease, and facilitate review of supports as required.**

The outcomes to be achieved include to:

- facilitate and provide ongoing review of needs and supports
- identify appropriate services, including eligibility and availability, as needs change
- monitor and update care plan
- provide effective ongoing advocacy in relation to existing needs and arising/emerging needs, with appropriate early assessment and referral
- provide emotional support and a listening ear to the individual and their family from diagnosis through to bereavement

**f. Assist with timely access to assistive technology to meet changing and progressing needs**

The outcomes to be achieved are to:

- assist people to access affordable assistive technology in a timely manner
- support health professionals undertaking assistive technology assessments
- participate in the planning process to ensure inclusion of reasonable and necessary assistive technologies in an individual's plan and to facilitate early access.

### **3. Coordination of Support for NDIS participants**

In some states Coordination of Support may be provided either as part of the MND Advisor role or as a separate role. Coordinators of Support assist NDIS participants to implement their NDIS plan. They work creatively and resourcefully with participants to suggest how they may utilise their support budgets to achieve their goals. As described in NDIS publication *Support Coordination: Information for providers* this is likely to include supporting the participant to:

- assess a number of mainstream, community, informal and provider options
- choose preferred options or providers
- negotiate services to be provided and their prices, develop service agreements and create service bookings with preferred providers
- negotiate services and prices as part of any quotable supports
- arrange any assessments required to determine the nature and type of funding required (e.g. assessment to determine the type of complex home modifications required)
- decide the budget for each support type and advise any relevant plan manager of the breakdown of funds
- liaise with any plan manager to establish the appropriate claim categories and attribute the correct amount of funds



- link to mainstream or community services (i.e. housing, education, transport, health)
- strengthen and enhance their capacity to coordinate supports, self direct and manage supports and participate in the community, including providing participants with assistance to:
  - resolve problems or issues that arise
  - understand their responsibilities under service agreements
  - change or end a service agreement
- assist the participant get ready for their plan review

#### **4. Assistive Technology (AT)**

AT is vital to people living with MND in maintaining quality of life and independence. Due to the often rapid rate of progression and increasing disability, people living with MND need early and timely access to a wide range of AT items. Providing or facilitating access to AT has been an integral part of State MND association services since their formation.

Where AT is not available from a State MND Association, MND Associations play a vital role in assisting people to access AT, augmentative assisted communication (AAC) and respiratory support services from the relevant State based service in a timely manner. They provide information and support to assist the person with MND to plan ahead for their AT, AAC and respiratory support needs, facilitate referrals for assessment and advocate for a timely response. However in many cases the waiting period, costs and response to need remain untenable.

In response to long waiting periods from AT supply services, MND Associations have developed AT loan/hire services. The number and types of AT available from the State MND Association varies. Some State MND Associations are able to provide a wide variety of AT in a very responsive manner, others may only be able to provide a limited range and others may provide top up funding. However, all target and work to address the needs created by MND.

In some states, MND associations are NDIS service providers for AT and hire equipment to people with an NDIS plan.

#### **Conclusion**

This model of MND support aims to support people living with MND to make informed decisions about living with MND so as to achieve the best possible quality of life and dignity in living and dying. These services empower people living with MND to adopt a proactive approach to disease management whilst respecting the needs and wishes of the individual and their carers.

The Associations move in and out of the lives of people with MND, and their service providers, as their personal needs demand. Given the relatively short life expectancy of people diagnosed with MND (27 months from time of diagnosis), coordination of services and the monitoring and reassessment of needs is an essential element in ensuring that they are able to appropriately access quality services when they need them. The aim is to assist people to live as well as possible with MND.

UNTIL THERE IS A CURE THERE IS CARE