



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, and;
- Service providers who understand the specific needs of people living with MND

[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

As of 30 June 2015 MND Associations were providing support to 1360 people living with MND in Australia plus their carers, friends, family members and the health, aged, disability and community care professionals involved in their care.

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 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 three key services:

1. Information
2. MND (Regional) Advisors
3. Assistive Technology

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

People with MND prefer to continue living at home within their community, however there are occasions when they seek alternative residences, 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 have little or no experience of health and community services. In effect, the MND support service acts as a navigator for people living with MND interacting with the 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.

Each Association works to provide the core services outlined in this model. However, the services outlined are not exhaustive and there will be some variations in the level and types of services offered by State Associations.

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 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 a result of a referral to the association from a health professional or specialist MND Clinic or via MND association websites.



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

Information may be provided in a variety of formats throughout the disease trajectory. The MND Advisor plays a pivotal role in monitoring needs and providing information as requested or as a need arises, and putting that information into the context of the person's disease and circumstances.

A number of education and information programs are provided by 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 to support all service sectors to provide the best possible care and support. 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](#). This website includes MND Aware training modules which provide health and community care professionals with a basic understanding of MND and its impact on an individual's life.

2. MND (Regional) 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. The aim is to support 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:

1) 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 so that the person with MND and their family do not feel that they are unsupported
- 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

2) **Support to identify needs, development of a care plan and identification of appropriate service providers.**

The outcomes to be achieved are to;

- support the person with MND and their family to identify existing needs and plan for current and future needs
- provide support to assist the person to navigate the service sector
- facilitate effective use of available generic and specialist services
- minimise the impact of service assessment, planning processes and eligibility on the individual
- work in partnership with the persons specialist MND Clinic or service coordinator to support a coordinated, multidisciplinary approach to care

3) **Facilitate referral processes, advocacy for timely responsive services, 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

4) **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.

5) **Monitor and reassess as needs change due to progression of the disease, identify new services and facilitate referrals as required.**

The outcomes to be achieved include to:

- facilitate and provide ongoing review of needs and service responses
- 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

6) 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 aids and equipment/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. 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. 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 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.

Conclusion

This model of MND support is world's best practice. It aims to support people living with MND to make informed decisions about living with MND so as to achieve 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 Association moves 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.