



## National MND Support Service Model

### *Background*

Motor neurone disease (MND) Associations in Australia were formed during the early 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 MND Associations nationally.

MND Australia, its research arm, MND Research Australia, and members, the State MND Associations, form the only national network focused on improving the lives of all Australians living with motor neurone disease (MND) and advancing research to end MND. For over 35 years this national network has helped increase understanding of the disease and advocated for improvements in its treatment and care to ensure people living with MND have the best quality-of-life possible.

One of the major roles of MND Australia is to promote and support 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, reviews of services provided by ALS/MND Associations internationally and research literature consistently confirm that the key needs of people living with MND, their carers and families 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
- Coordinated care
- Service providers who understand the specific needs of people with MND
- Support to deal with grief and loss.

A review of the National Family Support Model was undertaken in February 2015 by representatives from MND Australia and each of the state MND Associations. This group recommended that the name of the service be changed to the MND Support Service to more broadly reflect the 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 may be delivered through the provision of five key service areas:

1. Information and education
2. MND Advisors
3. NDIS Coordination of Supports
4. Occupational Therapy services
5. Assistive Technology

The State Associations have developed their MND Support Services in line with the needs of their members and in response to local priorities. The role of state based services is to connect the person with MND (and their families and carers) to services, supports and funding systems to enable them to access timely, ongoing and appropriate care. Most importantly, MND Support Services act 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. MND Associations also work to ensure that local health, disability, aged, palliative care and community providers understand the specific needs of people living with MND and their families through the provision of information, education, training and support.

MND Associations have a commitment to support people living with MND wherever they choose to live. Community expectation is that all Australian's are supported to continue to live in their own home. There are, however, times when this is not possible, or the person themselves chooses an alternative residential environment.

In a recent study exploring the experiences of people living with MND and their carers in Western Australia, 90% of respondents reported that the MND Association support service was of significantly high value to them both as a practical and an emotional support mechanism. 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. The introduction of the National Disability Insurance Scheme (NDIS) has led to further changes to the support services provided by MND Associations.

## **1. Information:**

Information about MND is a fundamental service. High quality, trusted information resources are vital for people diagnosed with MND, carers, 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 or friend, is usually through an approach for information via telephone or email. The National MND info line service provides people impacted by MND access to an MND Association staff member who can provide introductory information on MND and the

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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.



services and supports available in that person's state or territory. A referral to the relevant MND Advisor is also provided to establish ongoing support. An information package may then be posted or emailed 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 is identified. A number of education and information programs are provided by the MND Associations using multiple delivery formats. These programs aim to:

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

Additionally, tailored information via the National MND info line and face to face, or virtual, training sessions for health, aged, palliative, disability and community care professionals is provided, as a means of building the capacity of all service sectors to provide the best possible care. Research updates, conferences and information sessions support the MND Community in its entirety, supporting contemporary approaches and ensuring best practices. This ambition is supported through the [MND Care](#) website which offers easy to access, up to date information for health and community care professionals and providers.

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

## **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 role of the Advisor is to understand the person with MND and their family holistically and to work with them to develop capacity and understanding of the health, disability, aged and community systems from which they will draw their support. Such meetings are often frequent and intense in the early part of the relationship. The MND Advisor remains with the person and their family as they move through support systems and as their MND and needs change and progress.

MND Advisors are professionals with qualifications and experience in health, nursing, allied health, disability or similar. The MND Advisor role is focused around:

- initial support and information provision to the person diagnosed with MND, their family and carer
- collaboration with the person with MND and their support network to identify needs, develop a care plan and identify appropriate service pathways
- facilitation of access to supports, advocating for timely and responsive services and provision of ongoing support of the individual and their carer
- support and training for the service providers and advocates
- monitoring and reassessing as needs change due to progression of the disease, and facilitating review of supports as required
- assisting with timely provision of assistive technology to meet changing and progressing needs.

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

In some states NDIS Coordination of Support may be provided either as part of the MND Advisor role or as a separate role, depending on the State. Coordinators of Support assist NDIS participants to understand, make choices and implement their NDIS plan. They work collaboratively with NDIS participants to assist them to use their support funding flexibly to meet their needs within the rules of the NDIS. As described in the 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
- support the decision making process to identify 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. Occupational Therapy Services**

Access to a responsive and MND knowledgeable Occupational Therapist is vital to people with MND to enable them to maximise independence and maintain quality of life. As such, some State MND Associations now employ Occupational Therapists as part of their support service team.

In some states MND Associations Occupational Therapists can provide a number of supports including (but not limited to):-

- NDIS Access requests
- Functional (ADL) Assessments
- Prescription of AT
- Identification of funding sources for AT
- Home assessments and home modifications
- Carer Support/education

Occupational therapists work with people living with MND and their families to provide advice, support and guidance related to assistive technology, community access and home modifications as their needs change.



The Occupational Therapist may assist with gaining access to the NDIS or My Aged Care liaising with the appropriate authorities to assist with this process. The Occupational Therapist works with other health professionals involved in the care of the person living with MND to ensure a coordinated, multidisciplinary and holistic approach to each person's unique situation.

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

AT is vital to people living with MND in maintaining quality of life and independence. AT includes such things as everyday living aids, mobility aids, respiratory supports, communication devices or other items that a person may need to live a fully inclusive and independent life. 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 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 remains 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 MND Associations move in and out of the lives of people with MND, their carers and 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 from diagnosis through to end of life and to support the family carers through to bereavement.