



National Family Support 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. In 2008 the MND Australia network comprises of six state Associations, representing all states and territories, and the MND Research Institute of Australia (MNDRIA). The MND Australia members work together to advance, promote and influence local and national efforts to achieve the vision of a **World Free From the Impact of MND**.

Evidence:

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. Over the last 10 to 15 years MND Associations in Australia have developed a model of family support based on initial surveys conducted in Victoria and NSW and the MND UK service model. Family support services have grown and developed and the Australian model continues to be supported by surveys conducted by State Associations in Australia, International ALS/MND Association service models and service development, the International Alliance Statement of Good Practice for the Management of ALS/MND and international research.

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

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

The results of these surveys and engagement with MND UK helped to establish the MND Australia Family Support Model during the late 1990's. Subsequent Australian surveys, and 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 guided further development.

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 confirms that good practice must include timely and MND specific:



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

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

As of 30 June 2008 MND Associations were providing family support to 998 people living with MND in Australia plus their carers, friends, family members and the service providers involved in their care.

Family Support Model

The MND Association response to the needs created by MND is focussed on a simple strategy to address the key needs identified by people living with MND:

- Information
- Ongoing support
- Assistance to navigate their local service provision network
- Aids and equipment
- Volunteers

Through addressing these needs MND Associations support the generic disability, aged, allied, palliative and other service sectors to do what they do best. The focus is to ensure that no person with MND has a high level of unmet needs.

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

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

supported by management, fundraising and administration.

The Associations have developed its Family Support Service to be the interface between the person with MND (and their families and carers) and the service provider sector. People with MND have expressed their commitment to continue living within their community, and seek facility-based care outside their community rarely and when absolutely necessary. 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 meet the needs of people living with MND, including in particular, the need for a timely response to rapidly changing needs.

This interface effectively assists in the transition of people with MND to, from and through the service sector. It acts to smooth the way for people who have little or no experience of community services. In effect, MND family support acts as a navigator for people living with MND interacting with the complex service system. In facilitating transition to and through the service sector, MND Associations ensure that training and support raises skills and knowledge within the local community and local service providers.

Recurrent funding from State Governments to support the development of the family support services is currently being received as follows:

- MND Victoria:
 - Dept Human Services (Vic) – Disability
 - Dept Human Services (Vic) – Pall Care
- MND NSW/ACT
 - NSW Department of Health
- MND WA

1. Information:

Information about MND is a fundamental service and good quality resources are vital for people diagnosed with MND, family members, friends, GP's, allied health and all service providers involved in the care and support of a person with MND. MND Australia has a range of resources available nationally and the State Associations continue to review and develop further State based resources.

First contact with a person diagnosed with MND or a partner/family member is usually through an approach, via the telephone, for information and a request to be registered as a member. Introductory verbal information is provided by a professional MND family support worker and a referral to the relevant Regional/care Advisor, if available, made. An information package may then be posted out to the new member and, with their permission, a letter and information is sent to their GP and neurologist.

Information may be provided from Family Support in a variety of formats throughout the disease trajectory including:

- Written information as required or requested
- Telephone information support
- MND association websites
- Videos and DVD's

A number of education and information modules are available for use by the various State MND Associations, and provided as capacity allows. These modules aim to help people living with MND to adjust to living with the disease, to assist carers in their caring role and to support service sectors to provide the best possible care. The modules include:

- Information Evenings for people recently diagnosed, their family and friends



- Care for carers programs
- Living Well programs
- Learn now/Live well
- Telelink programs
- Carer Retreats
- Ask the Expert sessions
- In-service education for health and the service sectors involved
- Special Interest Groups
- Living On
- Past Carers groups

2. Regional/Care Advisors

Once the person is registered, a case file is opened, and they are referred to the relevant Regional/Care Advisor to make a time for a home visit. A home visit is undertaken and all information provided is put into context for the individual and their circumstances. The role and services of the Association are outlined, with a focus on what they don't do. Immediate needs are identified and referral options discussed and actioned.

Regular review is undertaken, often in person, but sometimes by telephone. Referral is undertaken to a wide range of services and service types and relevant information provided.

The Regional/Care Advisor role is focussed around six main activities as follows:

I. Initial counselling and information provision to the person diagnosed, their family and carer.

The outcomes to be achieved are:

- establish understanding of the disease and its impact
- establish a base of understanding on which to build ongoing care and support
- referral to specialist support in grief and loss, family counselling etc
- identify the range of support and services that are available within the community to address current or future needs
- support family decision making

These actions support the transition of an individual and a family from not having any interaction (usually) with the community support system to recognition of the types of services that may be required in the future, and their availability. There is emphasis on the support provided by the Association and the Regional/Care Advisor to individuals and service providers to ensure that the best possible care and support is available. The availability of support to access and negotiate the community sector is significant to reduce the level of stress and increase their capacity to deal with MND and its impact.

II. Needs assessment and identification of service and support needs, counselling about service provision and benefits, development of a service plan and identification of appropriate providers.

The outcomes to be achieved are;



- accurate identification of existing service needs
- identify the impact the service will have for the person, including opportunities, effect on family, needs to be met and acceptance of the service
- effective use of available generic and specialist services
- prevent service hunting
- minimise impact of service assessment processes and eligibility on the client

These outcomes ensure that appropriate services are both identified and considered as elements in meeting the needs of the person. Facilitating the transition from non service user to service user promotes more effective use of services, less stress in the person and the family while effectively assessing and measuring needs, and making appropriate service referrals and access.

III. Negotiation and referral to providers, following establishment of service eligibility and advocacy, initial and ongoing support of the individual and their carer.

The outcomes to be achieved are:

- Reduced stress and pressure while assessing service eligibility
- Effective advocacy on behalf of the person, based on identified needs and known progression of the disease
- Efficient use of community resources through ongoing support of the individual and family while accessing the service

These outcomes promote effective and targeted use of local and community resources, and reduce the service shopping opportunities that can result when coordinated advocacy and referral do not occur. Effective and efficient use of community resources is achieved through effective referral of eligible clients.

IV. Support and training for the service provider, both in issue specific and MND general issues, maintenance of contact and delivery of MND and client/issue specific training and support.

The outcomes to be achieved are:

- Effective service provision through training of the provider on MND and its impact
- Peer support for the provider, with a common contact point for expert advice on MND, MND and service delivery issues, and client specific issues impacting on service delivery
- Heightened confidence and capacity of service provider to meet identified needs
- Local knowledge of and skills with the disease supported by specialist agency knowledge and information
- Improved service delivery by making the service MND responsive.
- Person with MND confident that the provider knows and understands MND and its impact.

These outcomes ensure that providers are best positioned to deliver the services they are funded to deliver, and that training and support are available from a specialist agency to meet emerging needs. In particular, issue specific and client specific support regarding a matter that directly impacts on the ability of the service to deliver is often required. Available contact with the Association during office hours ensures that support is available, and that adequate information about the specific individual and their level of progression is available to underpin



support. Capacity to organise a site visit or programmed training is an essential element in appropriately supporting local providers.

V. Monitor service delivery and continuing relevance of the service to needs within the framework of disease progression.

The outcomes to be achieved are:

- effective service delivery
- service delivery to meet existing identified needs
- service delivery maintains relevance to disease progression

These outcomes ensure that the service investment remains relevant to the person and that the service is focussed on meeting existing needs. It is essential that the service being delivered does not lose relevance - if it does, the service is wasted, as it is no longer appropriate to meet the needs of the individual.

VI. Monitor and reassess people, as needs change due to progression of the disease, identify new services and undertake referrals.

The outcomes to be achieved include:

- ongoing review of needs and service responses
- identification of appropriate services, including eligibility and availability
- monitoring and updating of service plan
- effective ongoing advocacy in relation to existing needs and arising/emerging needs, with appropriate early assessment and referral

These outcomes ensure that as the person is moving through the progression of MND, timely and effective referral is made to services that can address new and emerging needs in a timely manner. This minimises waiting lists and ensures that progression of the disease is not complicated by reduced or no access to services to meet needs.

3. Aids and equipment:

Due to the often rapid rate of progression and increasing disability people living with MND need timely access to a wide range of aids and equipment. Equipment has been an integral part of the family support service since the formation of MND Associations as generic government equipment services were unable to meet the needs of people living with MND due to the long waiting periods. MND Association family support play a vital role in assisting people to access aids and equipment from their State based equipment services in a timely manner. They provide information and support to assist the person with MND to plan ahead for their equipment needs, facilitate referrals for assessment and advocate for a timely response. However in many cases the waiting period and response to need remains untenable. All MND Associations therefore maintain an equipment loan pool to help address unmet need. In NSW and Victoria the MND Association equipment loan service is very well resourced and increasingly recognised and appropriately funded by the respective State Governments.



4. Volunteers:

Volunteers initially founded and managed the MND Associations. As professional staff have been employed volunteers have remained the backbone of the Associations providing myriad support roles. Family support volunteers are involved in running support groups, providing phone support and, where capacity allows, visiting people with MND in their homes to enhance and support the role of the Regional/Care Advisor.

The provision of these family support services 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), 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.

Conclusion

This model of family support is world's best practice. It focuses on supporting people living with MND in their own community or residence of choice. The model assists the transition of people to, from and through the service sector by providing the six main Regional/Care Advisor activities outlined above in addition to the provision of information, aids and equipment and volunteers. MND Associations are committed to the generic service system meeting the majority of needs of people living with MND, and sourcing needed services from the health, disability and aged care sectors. The Association moves in and out of people's lives with MND, while operating continuously in the background to ensure that the emerging needs of people with the disease and service providers are adequately identified assessed and addressed.