Best Practice Guidelines for Member Associations

Introduction:
MND Associations in Australia were formed during the 1980s 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 2010 the MND Australia network comprises six state Associations, representing all states and territories, and the MND Association of New Zealand as an associate member. MND Australia and its members work together to advance, promote and influence local, national and international efforts to achieve the vision of a ***World Free From MND.***

Over the last 20 years the state associations have grown and developed significantly. The Board of Directors of MND Australia recognises that the development of services for people living with MND and their families in each state has been, and will continue to be, dependent on the resources, capacity and priorities of each independent state association. However MND Australia believes that all members are now in a position to provide at least a baseline level of level of service that reflects international, national and state best practice to improve outcomes for all people living with MND and their families in Australia.

These guidelines endorse the Family Support Model (Appendix 1) and the International Alliance Statement of Good Practice for the Management of ALS/MND (Appendix 2). These guidelines are intended as a resource to the State Associations to guide the development of appropriate services, systems, processes and procedures within a national framework. These guidelines outline the baseline level of family support service related to the National Family Support Model that each state association should provide in order to achieve best practice. The aim is to support and promote equitable access to services for people living with MND nationally within appropriate governance structures.

Family Support Services

Background:
In August 2008 the Executive Management Group (EMG), which comprises of the senior employee of each State Association and MND Australia, adopted the National Family Support Model to help guide the development of family support services.

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. The focus is to ensure that no person with MND has a high level of unmet needs through the provision of four main family support services:

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

To achieve national best practice MND Associations should be providing each of these four family support services at least to the baseline level as provided in these guidelines.

1. Information:

Printed information about MND is a fundamental service. 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.

Telephone and email requests for printed information and information on membership may be the first contact a person recently diagnosed with MND or their partner or family member has with the MND Associations. It is important that these requests are dealt with as promptly and as professionally as possible to promote ongoing contact and support.

To achieve best practice the following is the baseline level of service related to information provision:

- That all national resources are available on request
- That during each association's office hour's telephone and email enquiries are handed onto the appropriate staff member as soon as practically possible.
- That introductory verbal information to people diagnosed with MND, or a family member, is provided by an employee staff member of the Association who is trained and supported in the provision of information.
- That initial information posted to new members includes, as a minimum:
    - A membership/registration form, MND Some Facts, MND More Facts and a list of other information available
- That a letter and the booklet "Motor Neurone Disease – A problem solving approach" are sent to all new members' General Practitioners, with the members' permission, and other health services being accessed by the person.

2. Regional/Care Advisors

As outlined in the National Family Support Model, the Regional/Care Advisor role is to provide ongoing professional support, information, education, referrals and advocacy for people living with MND. Their role is not to duplicate services already available through State Government departments or other non government organisations.

Some MND Associations employ Regional/Care Advisors responsible for supporting people in a defined geographical area. Empirical data suggest that each regional/care advisor should support no more than 60 people per 0.6 FTE or equivalent

To achieve best practice the following is the baseline level of service related to Regional/Care Advisor support:

That Regional/Care Advisors with appropriate tertiary qualifications related to allied health, nursing, welfare, disability etc are employed to:

- support people living with MND and their families by providing personalised information, appropriate counselling, and service needs identification whilst ensuring that people with MND retain control

- identify emerging needs for disability aids and equipment and organise appropriate referrals for professional assessment and prescription
- act as a conduit to services available
- achieve timely referral to appropriate services based on need
- advocate on behalf of the person to achieve timely access to services
- provide timely information and education sessions to health professionals and service providers

3. Aids and equipment

The often rapid rate of progression of MND and the increasing disability it creates means that 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 in a timely manner.

To achieve best practice the following is the baseline level of service related to aids and equipment:

That an appropriately qualified staff member is employed or identified to:

- manage and maintain the disability aids and equipment held by the Association, including waiting lists, rentals and acquisition in order to achieve timely provision of aids and equipment for people with MND
- provide information and support to health professionals responsible for the assessment of clients and prescription of aids and equipment
- implement systems so that aids and equipment are suitable and safe for use, and have appropriate standards and processes for cleaning and regular maintenance
- manage the equipment loan pool/library within their state OH&S/worksafe guidelines/laws and have in place appropriate documentation systems, insurance, policies and procedures
- manage and oversee other staff or volunteers employed to assist with the equipment service .

4. Volunteers

Volunteers founded and managed MND Associations in Australia. As professionals have been employed volunteers have remained the backbone of the Associations providing myriad support roles. The roles of volunteers vary within each state Association and may include helping with administration and fundraising or running support groups, providing phone support and/or visiting people with MND in their homes to enhance and support the role of the Regional/Care Advisor.

To achieve best practice the following is the baseline level of service related to volunteers

That an appropriate trained and skilled person is identified or employed to manage the volunteers so that all volunteers:

- undertake an orientation program
- understand their roles and responsibilities

- have appropriate volunteer identification
- receive ongoing mentoring and support
- are taught to understand their own limitations and where appropriate support can be sought from within and without the Associations resources
- understand the roles and responsibilities of the professional family support staff
- are protected by relevant insurance

The engagement of volunteers should comply with community standards such as those recommended by Volunteering Australia. The MND NSW Volunteer Visitor Manual is available to all state associations to assist with the development of an orientation program, roles and responsibilities and volunteer policies and procedures.

Conclusion:

As outlined in the introduction the aim of these guidelines is to support and promote equitable access to services for people living with MND nationally within appropriate governance structures. MND Associations are governed by elected Boards of Directors (however titled) who have the responsibility to ensure that MND Associations are controlled and operate to benefit people living with MND. MND Australia understands that governance is an individual association responsibility and that there will be differences related to State Legislation and each associations Constitution or Rules. MND Australia expects that all members will meet their own core legal responsibilities such as their State Governing Legislation and Constitution or Rules.

These guidelines also aim to assist members to be responsive to their MND community needs and expectations. These baseline levels of service can be used to guide input and feedback from members to improve and enhance services. This will assist all association's to provide a high level of service, based on identified needs, that is accessible by everybody who wants or needs it in their State.

Primarily these guidelines aim to support and promote a commitment from MND Australia and its members to engage, communicate and collaborate at a national level to improve outcomes for people living with MND and their families throughout Australia.

APPENDIX 1

National Family Support Model

Background:

About MND Associations:

MND Associations in Australia were formed during the 1980s 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 1990s. 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’*.

MND Associations provide family support to around 1000 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 of Human Services (Vic) – Disability
  - Dept of Health (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 DVDs

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 if 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.

APPENDIX 2

THE INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS STATEMENT OF GOOD PRACTICE FOR THE MANAGEMENT OF ALS/ MND

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 eg: 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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