Supporting people living with MND

mnd Victoria
Motor Neurone Disease (MND):

• is a rapidly progressive neurological disease
• causes the nerves controlling voluntary muscles to gradually fail, causing weakness, wasting and paralysis
• varies from person to person - initial symptoms, rate and pattern of progression and survival from time of diagnosis are different in every occurrence
• has no remission or known cure
• causes death usually within 2-5 years
Who are we?

• A state-wide community based organisation with over 800 members, 125 volunteers and 22 staff

• We were formed in 1981 by a small group of volunteers - people living with MND, family members and others, to promote and provide the best possible support and care for people living with MND

• Our key focus is to help people to live better for longer by providing support, information and equipment services

• We have over 30 years experience working in partnership with clinicians, health professionals, community agencies, palliative care organisations and funding bodies to support people living with MND to get the services they need to live better for longer

• We are advocates raising awareness of MND within the community and the service system
People with MND

“...someone who knows what you’re going through.” MND Victoria Client

MND is an uncommon disease and often people may not have heard of the condition prior to being diagnosed. With over 30 years experience MND Victoria has developed expert knowledge on how to best live with the condition.

MND Victoria can assist you to access health and support services to enable you to live as independently as possible.

Family and Friends

“We knew so little of MND and still don’t know what’s ahead of us. Having MND Victoria there supporting us in so many different ways is very valuable. We’d feel lost without them.” Carer

When someone is given a diagnosis of MND it impacts on all those around them, including their family and friends.

Supporting someone with MND is best done as part of a team effort. MND Victoria can help coordinate this support team.

Health Professionals

“I could not have achieved what I have achieved in this role without the support and training supplied and the generosity of staff with their time and knowledge.”

Health Professional

Working with someone with MND poses unique challenges. MND Victoria can provide you with access to the right information and support.

MND Victoria’s Equipment service is available to people with MND on referral from an appropriate allied health professional.
What services do we provide?

Support Services
MND Victoria provides a range of services across the state to support people living with MND, their family, carers and health professionals. These services are provided at no cost to the person with MND.

MND Advisors
Equipment
Information
Groups
Volunteers
MND Advisors are experienced professionals who advise on care management and link people living with MND with health and community services. They:

• provide personalised information and advice to people living with MND, their family, friends and health professionals
• help people understand the disease and its complexities
• conduct an assessment of needs
• maintain regular contact with people living with MND through home visits, telephone and emails
• work in a defined geographic area with expert knowledge of community resources
• facilitate access to health and community services and supports
• advocate on behalf of people living with MND for provision of services and funding
• facilitate MND Victoria support groups, information sessions and forums
MND is a rapidly progressive disease and equipment needs are often urgent, ever changing and short-term. MND Victoria has a range of disability aids and equipment available for loan and rental.

These include:

- bathing and toileting aids, mobile commode chairs
- electric beds and mattresses, hoists and slings
- power lift armchairs, surround chair tables manual and power wheelchairs, portable ramps

Equipment assists people to remain independent, safe, living at home and accessing their community for as long as possible.

Equipment may be borrowed from MND Victoria for as long as required at no cost to the person with MND.
MND Victoria disseminates information via telephone, internet, mail, social media, group sessions and forums ensuring that information is easily accessible regardless of location or ability. MND Victoria provides information on:

- the disease process
- managing the disease
- support services
- treatment
- research
- grief and loss
- other requested topics

Information is current, accurate and tailored to the needs of the requesting person; be they a person with MND, a family carer, friend, health professional, student or a member of the general public.
MND Victoria offers a range of group programs delivered by volunteers and staff to support people with MND and their carers.

Programs take on a variety of forms and offer participants the opportunity to:

- meet and share experiences with others in a similar situation
- give and receive strategies and tips
- join in facilitated discussion
- learn about living well with MND
- receive support for loss and grief

The length and format of groups varies based on the needs of the group participants.
Volunteers play an integral role in supporting people living with MND. The following MND Victoria services are provided by volunteers:

- hand and foot massage
- life stories
- friendly visiting
- group facilitation
- telephone support

Volunteers continue to underpin all MND Victoria activities through:

- administrative support
- fundraising
- awareness raising
To apply for Support Services you can:

• submit a Client Application form found on our website www.mnd.asn.au
  or

• contact MND Victoria by phone on (03) 9830 2122 or 1800 806 632 or by email at info@mnd.asn.au
  or

• Request that MND Victoria be listed to provide services on your National Disability Insurance Scheme (NDIS) plan.

Is there a cost for Support Services?

Client membership and Support Services are provided at no cost to the person with MND, their carers or their family.

For further information

If you have a question about MND or would like to enquire about any of the services or activities that MND Victoria runs please contact us on:

T: (03) 9830 2122 or 1800 806 632 (freecall)
MND Victoria provides and promotes the best possible care and support for people living with MND

Contact Us

Phone: (03) 9830 2122
Free call: 1800 806 632 (freecall)
Fax: (03) 9830 2228
Email: info@mnd.asn.au
Webpage: www.mnd.asn.au

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Office hours: 9am-5pm Monday to Friday

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