What is motor neurone disease?

Motor neurone disease (MND) is the name given to a group of diseases in which the nerve cells - neurones - controlling the muscles that enable us to move around, speak, breathe and swallow, fail to work normally.

Motor function is controlled by upper motor neurones in the brain that descend from the brain to the spinal cord where they connect with the lower motor neurones. The lower motor neurones exit the spinal cord and directly activate muscles. As nerves degenerate, muscles gradually weaken and waste. The patterns of weakness vary from person to person.

MND has a low incidence (2:100,000) and prevalence (7:100,000). In NSW, there are about 450 people living with MND.

Most people with MND want to remain at home where their primary carer is often a family member, partner or close friend. While some people with MND are cared for in a nursing home, hospital or hospice, supporting the family at home can often be a primary focus of professionals in their practice.

Motor Neurone Disease Association of NSW

The Motor Neurone Disease Association of NSW (MND NSW) provides and promotes the best possible support for people living with MND, their families and carers; advances research and raises awareness of MND. The Association has a culture of building relationships and developing working partnerships with palliative and acute health care services, MND clinics and services, aged care assessment teams and community care providers.

MND Special Interest Group (SIG)

An e-network is a vital resource for health and community care professionals and facilitates the sharing of knowledge, experiences and information.

The MND Special Interest Group is an informal network of health and community care professionals interested in the care of people with MND. The aims of the group are to:

- promote best practice multidisciplinary care for all people living with MND
- enable the dissemination of MND specific information to health and community professionals
- encourage the sharing of expertise in MND

The key focus areas of the group are:
- communication, swallowing and nutrition
- independent living
- psychosocial and supportive care

"The e-bulletin format allows the information to be available when relevant to my work. It does mean that I am more up-to-date."

"It is great to hear about MND care developments at the workshops and conferences. The articles I get with the e-bulletins are usually ones I haven't seen before."

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e-bulletin and workshops

Members of the MND SIG receive a bi-monthly e-bulletin containing the latest MND news, research, information, links, abstracts and full text articles.

MND SIG workshops are usually conducted bi-annually in Sydney. They provide a forum to update, expand and gain new knowledge about motor neurone disease. They also provide an opportunity for health and community care professionals to meet with others involved in the care of people with MND.

Joining the MND SIG

Membership of MND SIG is free and open to all health and community care professionals with an interest in motor neurone disease including:

- case managers and case workers
- community workers
- counsellors
- dietitians
- general practitioners
- home care service coordinators and staff
- medical specialists
- nurses
- occupational therapists
- palliative care teams
- physiotherapists
- psychologists
- residential care staff
- social workers
- speech pathologists
- spiritual counsellors
- others

Complete the form overleaf to join.
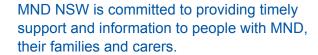
MND Special Interest Group Registration Form

Title .... First name ……………………………………

Last name ……………………………………………………

Organisation ...…………………………………………………

Mail address (w) ………………………………………………

……………………………………………………………………

………………………………… Postcode ………………

Phone (w) ………………………………………………………

Email (w) ………………………………………………………

……………………………………………………………………

Discipline.………………………………………………………

Signed …………………………… Date …………………

☐ I give permission for my name and contact
   details to be provided to other SIG members.

☐ I have received a SIG Starter Pack.

☐ Please send me a SIG Starter Pack relevant to
   my discipline (NSW and ACT only).

I can assist with:

☐ Contribution of articles or current topics
☐ Review of articles or current topics

Return form to:
Motor Neurone Disease Association of New South Wales Inc
Locked Bag 5005, Gladesville NSW 1675
Fax 02 9816 2077
sig@mndnsw.asn.au

Motor Neurone Disease Association of New South Wales Inc.

Mission
To provide and promote
the best possible support
for people living with motor
neurone disease, their
families and carers, to
advance research and to
raise awareness.

MND NSW is committed to providing timely
support and information to people with MND,
their families and carers.

MND NSW welcomes your feedback to
assist in the improvement of services.

If you would like to be removed from a Special
Interest Group or update your details contact
MND NSW.

**Motor Neurone Disease Association
of New South Wales Inc**

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