

Meeting the health needs of people with motor neurone disease



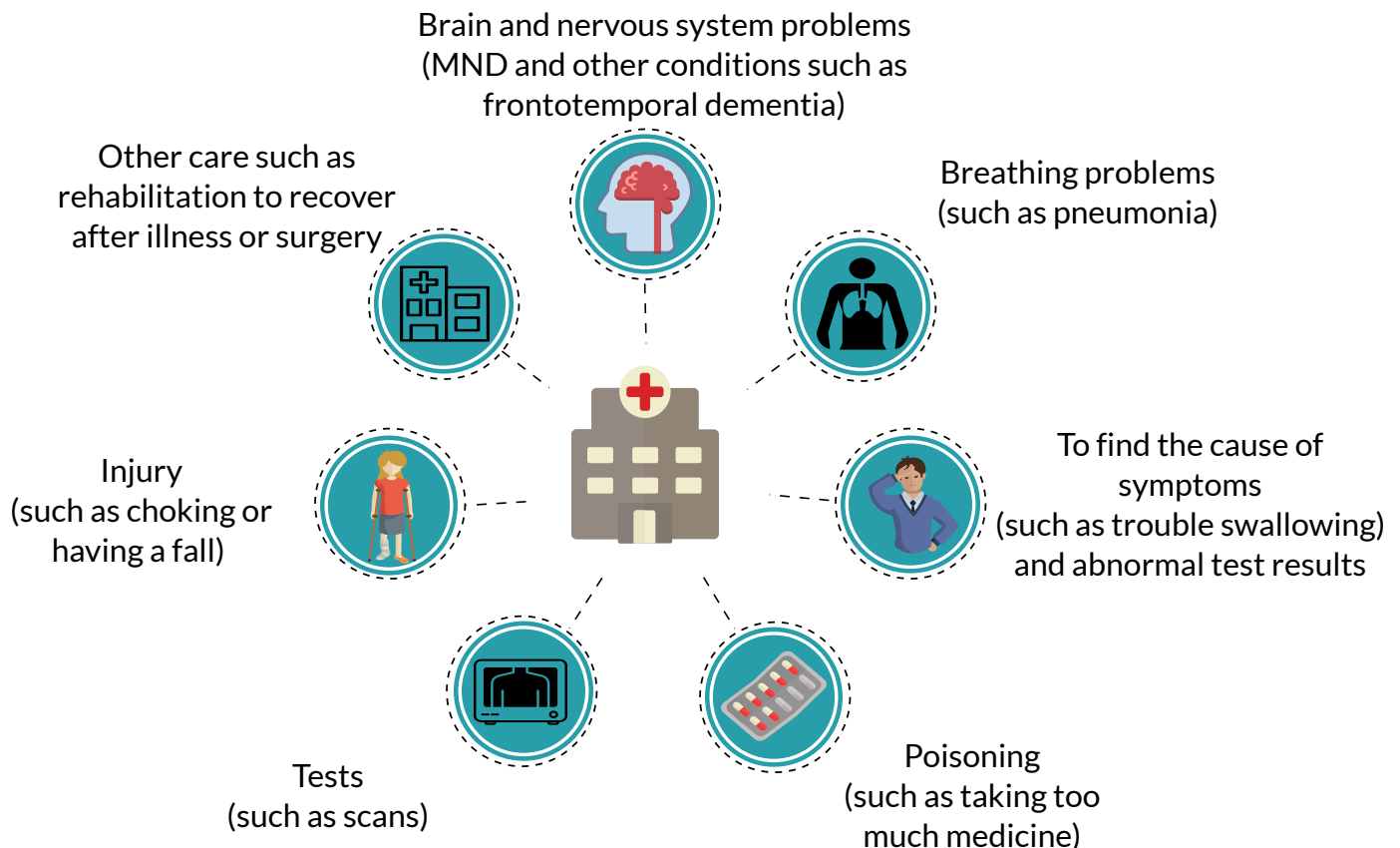
This fact sheet is for families, friends, and carers of people with motor neurone disease (MND). It provides information from a recent study on the mental and physical health needs of people with MND.

Main points

- Having support is especially important when people first find out they have MND.
- If your family member or friend needs support, their [MND Association](#) advisor, GP, neurologist, or other health professionals can help.
- Everyone should be able to get support for their mental health.

Reasons for going to hospital

The most common reasons people with MND went to hospital were for:



How this information can help

- People with MND may be less likely to go to hospital if they **have access to appropriate health services in the community**. Speak with the person you support and their health care team if they do not have access to necessary services.
- GPs, neurologists, and [MND Association](#) advisors can help with strategies to **reduce the risk of injuries and choking**.
- If the person you support is having **difficulty managing shortness of breath**, their GP or neurologist should be contacted immediately.

Mental health and MND

The most common mental health conditions for people with MND who went to hospital were:



- 1 Mental health conditions caused by changes in the brain (such as dementia)
- 2 Feeling very low or down (such as depression and other mood disorders)
- 3 Feeling very fearful or worried (such as having panic attacks and other anxiety disorders)

People with MND used inpatient and outpatient mental health services:

3 times more often
than the general
population



! Use of mental health services was highest in the year after people's first admission to hospital for MND in our dataset.



People can feel a lot of stress adapting to changes in their life caused by MND. However, support can make a difference. Everyone should have mental health support available, especially early in the course of their illness.

How this information can help

- If you notice that the person you support seems **particularly down** or **anxious**, **speak with them and ask how they are doing**. They may need some extra support. You can find information about [discussing mental health](#) at Beyond Blue (1300 22 4636).
- Seeking **help early is best**; GPs, neurologists and [MND Association](#) advisors can help.
- Some people may have trouble telling you how they are feeling, so you may need to rely more on **changes you see**.



How to find mental health services

- GPs are the best place to start. They can make diagnoses, discuss treatment options, and make referrals to a mental health specialist if required.
- Neurologists, [MND Association](#) advisors, and other organisations such as [Beyond Blue](#) (1300 22 4636) can provide help with finding the right mental health care. See [healthdirect](#) for a list of mental health helplines.

The relationship between physical and mental health for people with MND

We looked at how physical health is affected by mental health. People with MND who had mental health conditions:



Went to hospital **less** often for **physical health conditions** than people with MND who did **not** have mental health conditions,



but spent **more** days in hospital each visit.



Mental health concerns may make it more difficult for people to get appropriate help for their physical health.

How this information can help

- Poor mental health can lead to physical health problems such as having little energy to do daily activities, not having much appetite, and problems with sleep. **Getting treatment and support early** can help to improve these symptoms and **may help people manage their physical health conditions**.
- Together with the person you support, speak with their GP and other health professionals about the association between mental health and physical health, and **how this may affect them**.

Supporting you



- Caring for someone with MND can be stressful, overwhelming and complex. You can speak with your local [state MND Association](#) (1800 777 175) or GP if you need support yourself, or require extra information or assistance.
- [State MND associations](#) have information about carer workshops and programs, support groups, and events.

Further information can be found at organisations mentioned in this fact sheet:

- 3DN Project page- <https://3dn.unsw.edu.au/project/using-big-data-understand-health-status-and-service-use-people-motor-neurone-disease> for more information.
- MND Australia information resources- <https://www.mndaust.asn.au/Get-informed.aspx>
- State MND Associations (1800 777 175)- <https://www.mndaust.asn.au/Find-help/Support-from-state-MND-associations.aspx>
- Beyond Blue (1300 22 4636)- <https://www.beyondblue.org.au/>
- healthdirect- <https://www.healthdirect.gov.au/mental-health-helplines>

The information in this fact sheet is based on research by [The Department of Developmental Disability Neuropsychiatry \(3DN\)](#), UNSW Medicine, UNSW Sydney, Australia. Visit our [MND project page](#) for resources for people with MND and a more detailed [results report](#).

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