Meeting the health needs of people with motor neurone disease

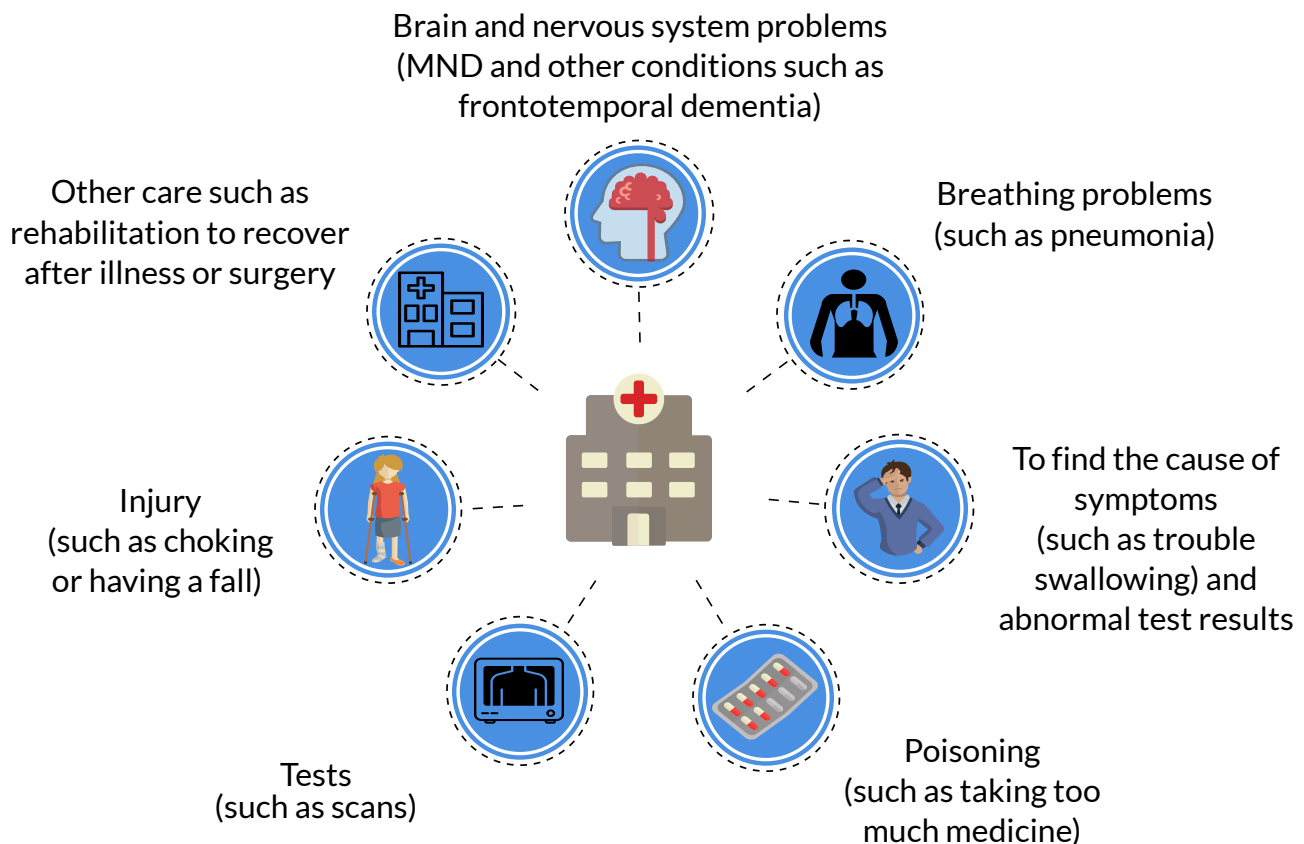This fact sheet is **for people with motor neurone disease (MND)**.

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 you are finding it hard to cope you can speak to your family and friends, your MND Association advisor, general practitioner, or neurologist.
- 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:

Brain and nervous system problems
(MND and other conditions such as
frontotemporal dementia)

Other care such as
rehabilitation to recover
after illness or surgery

Breathing problems
(such as pneumonia)

Injury
(such as choking
or having a fall)

To find the cause of
symptoms
(such as trouble
swallowing) and
abnormal test results

Tests
(such as scans)

Poisoning
(such as taking too
much medicine)

How this information can help you

- Speak to your GP, neurologist, or MND Association advisor about strategies to **reduce your risk of injury**.

- Consult your GP or neurologist immediately if you are having **difficulty managing shortness of breath.**

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

How this information can help you

- If you feel very low or down, or very anxious, **seek help early. You can talk to your GP, neurologist or MND Association advisor**. They can help find the right support for you.

- Support is not just for serious mental health conditions, **but also for coping with changes in life**.

How to find mental health services

- Your GP is the best place to start. They can make a diagnosis, discuss different treatment options, and refer you to a mental health specialist if required.

- You could also speak to your neurologist, MND Association advisor, or other organisations such as Beyond Blue (1300 22 4636). See healthdirect for mental health helplines.

The relationship between physical and mental health for people with MND
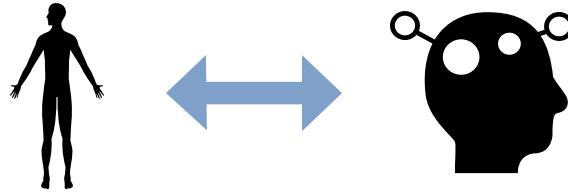
We looked at how <u>physical health</u> is affected by mental health. People with MND who had mental health conditions:

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 you

- 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 you with managing your physical health conditions.**

- Speak to your GP and other health professionals about the association between mental health and physical health, and how this may affect you.

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 and see our results report for more detailed information.

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