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Disability Neuropsychiatry 3DN

## Health status and service use of people with motor neurone disease

### Background

People with motor neurone disease (MND) have complex care needs that require multi-disciplinary support from a range of mainstream and specialist health services. Meeting complex care needs requires service planning to ensure needs are met. Few studies have looked at the health service use of people with MND, with none looking at the mental health service use of this population. This is a gap in knowledge, particularly given the link between MND and neuropsychiatric symptoms including those of frontotemporal dementia (FTD), depression, apathy, and disinhibition.

This research, conducted by [3DN at UNSW Sydney](#) therefore aimed to:

- look at the physical and mental health needs of people with MND,
- see whether people with MND use mental health services more or less than the general population and people with other neurological disorders (such as Alzheimer's disease and Parkinson's disease),
- examine whether mental health is associated with going to hospital for physical health conditions, and
- help mental health services to better meet the needs of people with MND.

### What we did

- This research used a large, anonymous linked dataset of health records from 2001-2015.
- We looked at 2370 adults who were admitted to hospital in New South Wales (NSW) with a recorded diagnosis of MND.
- We looked at when people were first admitted to hospital where MND was recorded\*, the year prior to this, and the three years following this (the 'follow-up period').
- We had access to information about admissions to hospital (public, private and multi-purpose day hospitals), admissions to psychiatric wards (hospital wards specialising in the treatment of serious mental health concerns), and visits to outpatient mental health services (e.g. an appointment with a psychologist at a clinic or attending a mental health day program). However, we did not have information about all health service usage such as visits to general practitioners (GPs), or private mental health practitioners (e.g. psychologists and psychiatrists).
- We looked at how people with MND use mental health services, and whether this differs compared to the NSW general population (approximately 5 million adults), and people with other neurological disorders (n = 66, 451 were included in this analysis).
- Lastly, we examined how mental health can affect physical health care usage.

\*People's first admission to hospital where an MND diagnosis was recorded does *not* necessarily mean they were diagnosed at this time- they may have been diagnosed some time earlier.



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## What we found

### Reasons for admissions to hospital

The most common reasons people were admitted to hospital (principal diagnoses) in the year **before** their first hospital admission where MND was recorded in the dataset were:

1. Going to hospital for e.g. examinations or investigations (such as scans) or rehabilitation care- 23.2% of care episodes
2. Nervous system disorders (including disorders such as Alzheimer's disease and Parkinson's disease)- 13.2%
3. Symptoms (such as difficulty swallowing) or abnormal test results - 9.2%
4. Injury and poisoning- 9.1%
5. Respiratory disorders (such as pneumonia)- 7.4%

The most common reasons people were admitted to hospital **when MND was first recorded** in the dataset were:

1. Nervous system disorders (including MND itself)- 45.4% of care episodes
2. Going to hospital for e.g. examinations, investigations or rehabilitation care- 11.8%
3. Respiratory disorders- 10.7%
4. Symptoms or abnormal test results- 7.3%
5. Injury and poisoning- 7.0%

### What does this mean for people with MND?

- People with MND are admitted to hospital for varied health conditions and may need diverse types of support to meet their health needs.
- The most common reason people were admitted to hospital in the year before their first hospital admission where MND was recorded may reflect people seeking a diagnosis when symptoms of MND start appearing.

### How can this information help people with MND?

- MND and associated conditions such as frontotemporal dementia can increase the risk of injury and choking. People with MND and caregivers can speak with their GP, neurologist or [MND Association](#) advisor about strategies to reduce the risk of injury and choking, and about assessments offered by health professionals such as occupational therapists.
- People with MND can have breathing difficulties and respiratory disorders caused by respiratory muscle weakness. GPs, neurologists, and [MND Association](#) advisors can give advice on how to manage this. MND Australia also have [resources](#) on this topic. If someone with MND is having difficulty managing shortness of breath, they should consult their GP or neurologist immediately.



## Mental health needs and service usage of people with MND

### Most common mental health diagnoses

For people admitted to psychiatric wards and general hospital wards with a mental health diagnosis recorded, the most common mental health diagnoses are shown in Table 1. Rates of organic mental health disorders (mental health conditions caused by changes in the brain e.g. dementia) and mood disorders (such as depression where people feel very low or down) were the most common, and were highest in the year after people were first admitted to hospital for MND in our dataset. It is important to note that these results do not represent the overall percentage of people with MND who have each mental health concern. These results only report the rates for people admitted to hospital, but do not take into account those who sought treatment elsewhere (such as their GP), or did not seek treatment at all.

Table 1. Mental health diagnoses for people with MND admitted to hospital

Diagnosis	% of people with MND with recorded diagnosis		
	Year 1 (n = 2370)	Year 2 (n = 1071)	Year 3 (n = 630)
1. Organic mental health disorders (e.g. dementia or delirium)	13%	8%	9%
2. Mood disorders (e.g. depression)	8%	4%	3%
3. Anxiety disorders (e.g. panic disorder)	5%	3%	2%
4. Mental and behavioural disorders due to substance use (use of alcohol and drugs)	2%	1%	1%
5. Schizophrenia	1%	<1%	1%

n=number of people analysed each follow-up year (deaths account for decreasing number of people over time)

## Mental health service usage

Compared with the **general NSW population**, people with MND\* had a:

- **Higher rate of inpatient mental health service use** (2.23 times the rate).
- **Higher rate of outpatient mental health service use** (3.58 times the rate).

\*After adjusting for age and sex (a statistical procedure to adjust for any differences in age and sex between the groups)

Compared with people with **other neurological disorders**, people with MND\* had a:

- **Lower rate of inpatient mental health service use** (0.24 times the rate).
- **Lower rate of outpatient mental health service use** (0.51 times the rate).

\*After adjusting for sex, age, remoteness of area (metropolitan area or rural and remote), socioeconomic status of area, and the Charlson Comorbidity Index (measure of comorbid, or other, medical conditions).

The use of mental health services was highest in the year after people's first admission for MND.

People with MND were more likely to use hospital-based care for mental health concerns if they:

- were male
- were closer to the first admission recorded in the dataset
- had more comorbid health conditions

### What does this mean for people with MND?

- People with MND have a high level of need (using mental health services around three times more often than the general population), and our data likely does not show the full extent as support from some services e.g. general practice and support groups is not captured. Further, the focus of hospital admissions for people with MND may be on physical needs, rather than mental health needs which may go unaddressed.
- Mental health service use was highest in the year after people's first admission for MND. Therefore, it is important that mental health support is readily available for people with MND early in the course of their illness. This may reduce the need for admissions to hospital for mental health concerns.
- There are several possible reasons why people with MND are using mental health services less often than people with other neurological conditions:
  - Some neurological disorders are more frequently associated with severe mental health symptoms (such as psychosis associated with Huntington disease), requiring people to use more hospital or outpatient mental health services.
  - People with MND may be more likely to receive support and treatment elsewhere that is not captured by our data (e.g. via their GP, support groups or private mental health practitioners), or they may be receiving satisfactory mental health treatment, reducing the need for hospital or outpatient mental health service visits.
  - Alternatively, they may not be receiving the support they require (e.g. if other health concerns take priority, or appropriate and accessible support and treatment are not available).



### How can this information help people with MND?

- Everyone should have access to mental health support if they feel they need it. Such support is not just for serious mental health disorders, but also for managing and coping with changes in one's life caused by MND.
- Symptoms of depression include feeling sad or hopeless for a prolonged time, or losing interest in things you enjoy. Symptoms of anxiety can include feeling very worried or fearful, on edge, tense and restless, and having difficulty concentrating. People with MND can experience depression and anxiety, and may need support, particularly earlier in the course of their illness.
- People with MND and families and carers can look out for common symptoms of depression, anxiety and other mental health concerns and seek help early. They can talk to their GP, neurologist or [MND Association](#) advisor about getting help. This may involve developing a management plan that could include a referral to e.g. a psychiatrist, psychologist, or counsellor. Professional care is often required in addition to support groups.

### The relationship between mental health and going to hospital for physical health conditions

We examined whether having a mental health diagnosis affects how often, and how long, people stay in hospital for physical health conditions. We looked at people with MND who had mental health diagnoses (recorded during hospital admissions, or when they used outpatient mental health services), compared to those who had not. We found:

- people with MND with mental health diagnoses went to hospital for physical health conditions significantly **less** often than those with MND who did not have mental health diagnoses,
- but both groups spent a similar amount of time in hospital per year for physical health conditions. This indicates longer stays per admission for people with MND who have mental health conditions.

### What does this mean for people with MND?

- Research has found that for people in general, mental health concerns can make it more difficult to seek appropriate care for physical health. It is therefore possible that people with MND and mental health concerns experience barriers to accessing appropriate care for physical health problems. However, further research would need to be carried out with people with MND to see if this is the case.
- Alternatively, longer hospital admissions for people with MND and mental health concerns may mean people receive the treatment they need for physical health problems during their stay, making it less likely that they need to be re-admitted to hospital later. We would have to carry out further research to investigate which one of these explanations is most likely.

### How can this information help people with MND?

- People with MND and family and carers can speak to their GP and other health professionals about the relationship between mental health and physical health, and how this may affect them.
- Poor mental health can lead to physical health conditions such as feeling very tired and having little energy to do daily activities (lethargy), not having much appetite, and problems with sleep. Getting treatment and support early can help to improve symptoms and physical health.

### Potential future research directions

This study provides the first insight into how people with MND use mental health services in NSW, their mental health needs, and the impact of mental health on physical health care use. Whilst this information will help health professionals and mental health services to better meet the needs of people with MND, many questions still require answering. Future research could look at the health service needs of people with MND more widely, including health care costs, to guide service development and health policy in this area. This project also provides an opportunity to link other datasets including the MND Registry which will allow for inclusion of clinical assessment data related to genetics and disease progression. Analysis of other sources of information on health service usage, such as GP records, could provide a more complete picture of the mental and physical health care needs of people with MND.

### Available project factsheets

Fact sheets are available from the 3DN [MND Project Page](#) for the following groups of people:

[People with MND](#)

[People with MND- Plain English version](#)

[Families, friends, and carers of people with MND](#)

[For health professionals – factsheet](#)

[For health professionals – 1-page poster](#)

[Postcard to take to GPs/neurologists](#)

### Links with further information about MND, frontotemporal dementia, and mental health

[MND Australia](#)

[Dementia Australia](#)

[Beyond Blue](#)

[healthdirect](#)

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