

# About me and MND

REGISTRY VERSION

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## My details and my needs

This is a health record form designed so you can easily complete, update and share your details.

Use this form as it suits your circumstances, there is no need to fill out unnecessary details or sections.

**LAST UPDATED:**

Format DD/MM/YYYY

**MINDAUS**  
**PARTNERSHIP**

# If you are helping with my care or treatment:

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I have motor neurone disease (MND) and symptoms can vary from person to person. I carry this information with me to help you understand my needs, who I am and things I like or dislike.

Even if I cannot communicate easily, I can hear you and would like to be included in all discussions, wherever possible. See page 7 for my communication needs.

## Contents

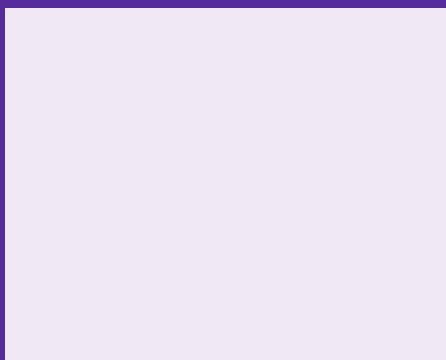
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### Please note

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I should not be given the following medicines as I am allergic or will react to them



### Please note

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- Oxygen should be used with caution with MND
- It may not be possible for me to lie flat if I have breathing difficulties

See page 8 for my breathing needs.

# My Details

Name	First	Last
Maiden name (if applicable)		
Gender	<input type="radio"/> Male	<input type="radio"/> Female <input type="radio"/> Other
Main hospital attended for MND (name)		
Medical Record Number (MRN) at this hospital (if known)		
Secondary hospital or health service (name)		
MRN at this hospital or health service (if known)		
Address		
Suburb	Postcode	
State	<input type="radio"/> ACT <input type="radio"/> Northern Territory <input type="radio"/> Victoria <input type="radio"/> Tasmania <input type="radio"/> Queensland <input type="radio"/> South Australia <input type="radio"/> Western Australia <input type="radio"/> NSW	
DOB	Format DD/MM/YYYY	
Home Phone	Area code	8 digits
Mobile	10 digits	
Email		
Preferred language		
Interpreter required?	<input type="radio"/> Yes	<input type="radio"/> No
Preferred contact method	<input type="radio"/> Phone <input type="radio"/> Email	<input type="radio"/> SMS <input type="radio"/> Phone my carer
Medicare no	10 numbers	
Pension no		
Private Health Fund	<input type="radio"/> Yes	<input type="radio"/> No
Name of fund		
Fund no		
DVA card	<input type="radio"/> Yes	<input type="radio"/> No
DVA card type	<input type="radio"/> Gold <input type="radio"/> White <input type="radio"/> Repatriation Pharmaceutical Benefits Card	
DVA number		

## NDIS

Are you currently an NDIS participant?	<input type="radio"/> Yes	<input type="radio"/> No	
Are you eligible for the NDIS? (under 65 years)	<input type="radio"/> Yes	<input type="radio"/> No	
NDIS number	9 digits		
NDIS plan management (select any that apply)	<input type="radio"/> Self	<input type="radio"/> Plan Managed	<input type="radio"/> Agency (NDIA)

## NDIS SUPPORT COORDINATOR DETAILS

Name	First	Last
Business Phone	Area code	8 digits
Mobile	10 digits	
Email		

## MY AGED CARE

Have you been referred for aged care support services via My Aged Care (MAC)?	<input type="radio"/> N/A	<input type="radio"/> Yes	<input type="radio"/> No	
Have you been assessed as being eligible for a community home care package?	<input type="radio"/> Yes	<input type="radio"/> No		
What level package were you assessed as needing?	<input type="radio"/> One	<input type="radio"/> Two	<input type="radio"/> Three	<input type="radio"/> Four
Are you receiving a community home care package?	<input type="radio"/> Yes	<input type="radio"/> No		
What level package are you receiving?	<input type="radio"/> One	<input type="radio"/> Two	<input type="radio"/> Three	<input type="radio"/> Four

## My Principal Carer's Details

Name	First	Last	
Relationship to me	<input type="radio"/> Spouse/Partner	<input type="radio"/> Child	<input type="radio"/> Sibling
	<input type="radio"/> Other relation	<input type="radio"/> Friend	<input type="radio"/> Other
Address	<input type="radio"/> Address is same as mine		
Suburb	Postcode		

Home Phone	Area code	8 digits
Mobile	10 digits	
Email		
Preferred language		
Interpreter required?	<input type="radio"/> Yes	<input type="radio"/> No
<b>MY EMERGENCY CONTACT DETAILS (if different to My Principal Carer)</b> <input type="radio"/> N/A		
Name	First	Last
Phone	10 digits	

## My Legal Documents

I have the following documents in place to help guide professionals about my care and treatment in specific circumstances:

**I have an Advance Care Directive (ACD)** ☐ Yes ☐ No

**I have any of the following documents (select all that apply)**

☐ An Enduring Power of Guardianship

☐ A Medical Power of Attorney

☐ An Anticipatory Direction

☐ I have completed a Do Not Resuscitate (DNR) Form

☐ I have organ and/or tissue donation forms

These documents are kept:

# My MND

Type of MND	<input type="radio"/> ALS – Bulbar Onset <input type="radio"/> ALS – Cervical Onset <input type="radio"/> ALS – Diaphragmatic Onset <input type="radio"/> ALS – Lumbar Onset <input type="radio"/> Flail arm <input type="radio"/> Flail leg <input type="radio"/> PLS (Primary Lateral Sclerosis) <input type="radio"/> Undifferentiated
I was diagnosed with MND	DD/MM/YYYY
<b>My most recent ALSFRS-R score</b> If needed, this resource can be found here: <a href="#">Complete the ALSFRS-R</a>	48 ▼ /48
Date test completed	DD/MM/YYYY

## MY RECENT SYMPTOMS

Please record your symptoms as they have been over the last two weeks.

Date completed	DD/MM/YYYY			
Fatigue	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Pain	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Muscle cramps/twitching	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Excessive saliva	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Constipation	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Disturbed sleep	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Shortness of breath	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Stiffness/spasticity	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Choking sensation	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Depression	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe
Extreme/inappropriate emotions	<input type="radio"/> None	<input type="radio"/> Mild	<input type="radio"/> Moderate	<input type="radio"/> Severe

# My Needs

## MY COMMUNICATION

☐ I have no difficulty communicating

☐ I have some difficulty communicating

☐ I have great difficulty communicating

**I communicate using the following techniques or aids (select any that apply)**

☐ I write using paper, pen, boogie board, or Notes on my phone or device

☐ I use a text to talk app on my smart phone or tablet

☐ I use a communication board

☐ I use a voice amplifier

☐ I use an Eye Gaze device or computer

☐ I use a computer operated by a switch

Additional information if necessary

## MY POSITIONING

How you position my body is important and may take some time.

**My most comfortable position is (select one)**

☐ In bed

☐ In my wheelchair

☐ In a comfortable chair, e.g. recliner

Other (please explain)

### When I am in bed

**I can lie flat**

☐ Yes

☐ No

**Move myself**

☐ Yes

☐ No

**I need help to (select any that apply)**

☐ Sit up

☐ Turn over

☐ Change position

**I need to use (select all that apply)**

☐ An adjustable bed

☐ Extra pillows

☐ Pressure relieving mattress

☐ Bed cradle

☐ Neck support when sitting up

**I am more comfortable in bed when (extra detail if necessary)**

<b>When sitting, I can</b>		
<b>Move myself in a chair</b>	<input type="radio"/> Yes	<input type="radio"/> No
<b>I need to use (select all that apply)</b>	<input type="radio"/> A lift or electric recliner	<input type="radio"/> Pressure relief
	<input type="radio"/> Head or neck support	<input type="radio"/> An electric wheelchair
<b>I am more comfortable when seated if (extra detail if necessary)</b>		

**MY BREATHING**

<b>I have breathing difficulties</b>	<input type="radio"/> Yes	<input type="radio"/> No
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**Please note:** MND can cause respiratory muscle weakness. It may be dangerous to give me Oxygen therapy. Please contact my Principal Carer and/or my Primary Health Contact if unsure.

<b>I have breathing difficulties when I am</b>	<input type="radio"/> At rest	<input type="radio"/> Moving around	<input type="radio"/> Moving a lot
<b>I have a tracheostomy and need full breathing support at all times</b>	<input type="radio"/> Yes	<input type="radio"/> No	

Please contact my Principal Carer and/or my Primary Health Contact for details of my ventilation or my non-invasive ventilation needs.

<b>I use non-invasive ventilation (NIV)</b>	<input type="radio"/> Yes	<input type="radio"/> No	
<b>In the last week, I estimate that I used NIV for</b>		<b>hours per day</b>	
<b>I use NIV</b>	<input type="radio"/> Whenever I sleep	<input type="radio"/> When needed	<input type="radio"/> Most of the time
<b>With NIV, I am</b>	<input type="radio"/> Independent	<input type="radio"/> Need some assistance	<input type="radio"/> Need full assistance
<b>The following can help relieve my breathing difficulties (select all that apply)</b>	<input type="radio"/> Suctioning	<input type="radio"/> Assisted cough techniques	
	<input type="radio"/> A fan	<input type="radio"/> Positioning	
<b>Other measures that help (please explain if necessary)</b>			

**MY EATING AND DRINKING NEEDS**

<b>I have made changes to the way I eat or drink because of a change in my swallowing</b>	<input type="radio"/> Yes	<input type="radio"/> No	
<b>I can eat and drink by mouth</b>	<input type="radio"/> Yes	<input type="radio"/> Some types	<input type="radio"/> No
<b>I need help to eat and drink</b>	<input type="radio"/> No	<input type="radio"/> Some help	<input type="radio"/> I need to be fed
<b>I use adapted cutlery and crockery</b>	<input type="radio"/> Yes	<input type="radio"/> No	



I need my fluids at the following consistency (using the International Dysphagia Diet Standardisation Initiative levels)	<input type="radio"/> Level 0 – Thin (No thickening needed)			
	<input type="radio"/> Level 1 – Slightly thick			
	<input type="radio"/> Level 2 – Mildly thick Previously Level 150 (mildly thick) – ¼ thick or nectar			
	<input type="radio"/> Level 3 – Moderately thick Previously Level 400 (moderately thick) – ½ thick or honey			
	<input type="radio"/> Level 4 – Extremely thick Previously Level 900 (extremely thick) – full thick or pudding			
I need my food at the following consistency: (using the International Dysphagia Diet Standardisation Initiative levels)	<input type="radio"/> Level 7 – Regular (normal food)			
	<input type="radio"/> Level 6 – Soft and bite sized			
	<input type="radio"/> Level 5 – Minced and moist			
	<input type="radio"/> Level 4 – Pureed (equal to thickness of Level 4 liquid)			
	<input type="radio"/> Level 3 – Liquidised (equal to thickness of Level 3 liquid)			
I avoid the following foods (select any that apply and choose whether allergy, intolerance or lifestyle choice)	<input type="radio"/> <b>Gluten</b>	<input type="radio"/> Allergy	<input type="radio"/> Intolerance	<input type="radio"/> Lifestyle choice
	<input type="radio"/> <b>Dairy</b>	<input type="radio"/> Allergy	<input type="radio"/> Intolerance	<input type="radio"/> Lifestyle choice
	<input type="radio"/> <b>Peanuts</b>	<input type="radio"/> Allergy	<input type="radio"/> Intolerance	<input type="radio"/> Lifestyle choice
	<input type="radio"/> <b>Soy</b>	<input type="radio"/> Allergy	<input type="radio"/> Intolerance	<input type="radio"/> Lifestyle choice
	<input type="radio"/> <b>Eggs</b>	<input type="radio"/> Allergy	<input type="radio"/> Intolerance	<input type="radio"/> Lifestyle choice
	<input type="radio"/> <b>Shellfish</b>	<input type="radio"/> Allergy	<input type="radio"/> Intolerance	<input type="radio"/> Lifestyle choice
	<input type="radio"/> <b>Red meat</b>	<input type="radio"/> Allergy	<input type="radio"/> Intolerance	<input type="radio"/> Lifestyle choice
	<input type="radio"/> <b>White meat</b>	<input type="radio"/> Allergy	<input type="radio"/> Intolerance	<input type="radio"/> Lifestyle choice
	<input type="radio"/> <b>Fish</b>	<input type="radio"/> Allergy	<input type="radio"/> Intolerance	<input type="radio"/> Lifestyle choice
	<input type="radio"/> <b>Other (please explain)</b>			
I prefer the following foods, drinks or supplements (please explain)				
I use Tube Feeding (PEG)	<input type="radio"/> Yes	<input type="radio"/> No		

I use tube feeding (select any that apply)	<input type="radio"/> For hydration	<input type="radio"/> To top up my meals
	<input type="radio"/> For all food and drink	<input type="radio"/> I need help with my tube feeds
	<input type="radio"/> For medication	<input type="radio"/> I need tube feeding but enjoy small amounts of food by mouth

Details of my tube feeding and preferred times of the day	
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After my tube feeding, please leave me sitting up for 30 minutes.

## MY PHYSICAL ABILITY

I have weakness in my (select any that apply)	<input type="radio"/> Upper limbs	<input type="radio"/> Lower limbs
	<input type="radio"/> Head/neck	<input type="radio"/> Trunk
I use	<input type="radio"/> Arm/wrist splints	<input type="radio"/> Leg/foot splints
	<input type="radio"/> Head/neck support	
I can walk	<input type="radio"/> Yes	<input type="radio"/> No
	<input type="radio"/> With support or aids	
I need help to transfer to (select all that apply)	<input type="radio"/> Not needed	<input type="radio"/> Bed
	<input type="radio"/> A chair	<input type="radio"/> Toilet

I use the following equipment to move around (complete if necessary)	
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I use the following equipment to do things (complete if necessary)	
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I need rest when (complete if necessary)	
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## MY PERSONAL CARE

### I need help with

Personal hygiene	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Some
Showering	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Some
Dressing	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Some
Toileting	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Some

The following things are important to me when being given personal care (explain as desired)

## MOUTH CARE AND SALIVA MANAGEMENT

I need help with mouth care

☐ Yes

☐ No

I like to brush my teeth

☐ Once a day

☐ Twice daily

☐ Three times daily

I use mouth swabs in addition

☐ Yes

☐ No

I have excessive saliva

☐ Always

☐ Sometimes

☐ No

I manage excessive saliva with the following (select all that apply)

☐ Medication

☐ Suction

☐ Clothing protection

☐ Clearance techniques

☐ Swallowing

☐ Wiping mouth

Other (please explain as necessary)

## MY EMOTIONS AND BEHAVIOUR

MND can cause some unexpected symptoms. The following may help you to understand what is happening if I react in an unexpected way

# My Past Medical History

Please select any of the medical or psychiatric conditions with which you have been diagnosed

☐ Anxiety

☐ Asthma

☐ Cancer

☐ Depression

☐ Diabetes

☐ Heart disease

☐ High blood pressure

Other (please add below if necessary)

## The medicines I currently take are:

(Please include prescription and over the counter medicines.)

Medicine	Date started (mm/yy)	Dose	What it is for	Times	I take it as follows
					▼
					▼
					▼
					▼
					▼
					▼
					▼
					▼
					▼
					▼

### MY ALLERGIES

I should not be given the following medicines as I am allergic to them or will react with them

# My Life History

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This optional section gives you an opportunity to introduce yourself to someone with as little or as much information as you would like to share.

<b>My life so far (eg, married at 18, had four kids, just celebrated 30th wedding anniversary)</b>	
<b>My work</b>	
<b>My family and friends</b>	
<b>Important daily routines</b>	
<b>Things and hobbies that interest me</b>	
<b>Things that I like hearing someone talk about</b>	
<b>Music or radio stations I like to listen to</b>	
<b>Television shows I enjoy</b>	
<b>My favourite films</b>	
<b>My favourite books</b>	
<b>My blog or website</b>	
<b>Things that annoy me</b>	
<b>Things that worry and upset me</b>	
<b>Things that make me feel better if I am anxious or upset</b>	

# My Healthcare Team

These health professionals are my regular contacts and know my needs.  
They can answer queries about my treatment, care and management of symptoms.

Please let my Primary Health Contact know as soon as possible if I am receiving  
urgent or emergency care. Thank you.

This section is designed to contain the details of any of your healthcare team.  
Add as many team members as you like.

## PRIMARY HEALTH CONTACT

Role	Name	Telephone	Email
▼			

## OTHER TEAM MEMBERS

Role	Name	Telephone	Email
▼			
▼			
▼			
▼			
▼			
▼			
▼			
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# My Appointments



This document was based on a document called 'Understanding my needs' which was developed by the MND Association of England, Wales and Northern Ireland. They have graciously given us permission to use and modify their form.

This 'About me and MND' document was developed and modified with the assistance of the following people:

- Mr Geoff Thomas, OAM, Thomas MND Research Group
- Mr Jerry Packer, RN, Support Services Manager, MND Association of South Australia
- Ms Allegra Stocks, Senior Speech Pathologist
- Mr Paul Cafarella, Health Psychologist, Manager of Ambulatory Respiratory Care, Flinders Medical Centre, South Australia
- Ms Carol Birks, Chief Executive, MND Association of Australia
- Associate Professor Paul Talman, Neurosciences Department, Barwon Health, Victoria
- MiNDAUS Partnership
- Ms Catherine Hansen, RN, Thomas MND Research Group

This document is dedicated to Mary Thomas.

**MiNDAUS**  
**PARTNERSHIP**