About me and MND

REGISTRY VERSION

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:

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.

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Please note

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

Please note

- 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	◯ Male	◯ Female	◯ 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	◯ ACT	◯ Northern Territory	◯ Victoria	◯ Tasmania
	◯ Queensland	◯ South Australia	◯ Western Australia	
DOB	Format DD/MM/YYYY			
Home Phone	Area code	8 digits		
Mobile	10 digits			
Email				
Preferred language	English			
Interpreter required?	◯ Yes		◯ No	
Preferred contact method	◯ Phone		◯ SMS	
	◯ Email		◯ Phone my carer	
Medicare no	10 numbers			
Pension no				
Private Health Fund	◯ Yes		◯ No	
Name of fund	ACA Health Benefits Fund			
Fund no				
DVA card	◯ Yes		◯ No	
DVA card type	◯ Gold	◯ White	◯ Repatriation Pharmaceutical Benefits Card	
DVA number				

NDIS

Are you currently an NDIS participant?	◯ Yes	◯ No	
Are you eligible for the NDIS? (under 65 years)	◯ Yes	◯ No	
NDIS number	9 digits		
NDIS plan management (select any that apply)	◯ Self	◯ Plan Managed	◯ 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)?	◯ N/A	◯ Yes	◯ No	
Have you been assessed as being eligible for a community home care package?	◯ Yes	◯ No		
What level package were you assessed as needing?	◯ One	◯ Two	◯ Three	◯ Four
Are you receiving a community home care package?	◯ Yes	◯ No		
What level package are you receiving?	◯ One	◯ Two	◯ Three	◯ Four

My Principal Carer's Details

Name	First	Last	
Relationship to me	◯ Spouse/Partner	◯ Child	◯ Sibling
	◯ Other relation	◯ Friend	◯ Other

Address

☐ Address is same as mine

Suburb	**Postcode**

Home Phone	Area code	8 digits
Mobile	10 digits	
Email		
Preferred language	English	
Interpreter required?	◯ Yes	◯ No

MY EMERGENCY CONTACT DETAILS (if different to My Principal Carer) ◯ 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	◯ ALS – Bulbar Onset
	◯ ALS – Cervical Onset
	◯ ALS – Diaphragmatic Onset
	◯ ALS – Lumbar Onset
	◯ Flail arm
	◯ Flail leg
	◯ PLS (Primary Lateral Sclerosis)
	◯ Undifferentiated
I was diagnosed with MND	DD/MM/YYYY
My most recent ALSFRS-R score If needed, this resource can be found here: Complete the ALSFRS-R	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	☐ None	☐ Mild	☐ Moderate	☐ Severe
Pain	☐ None	☐ Mild	☐ Moderate	☐ Severe
Muscle cramps/twitching	☐ None	☐ Mild	☐ Moderate	☐ Severe
Excessive saliva	☐ None	☐ Mild	☐ Moderate	☐ Severe
Constipation	☐ None	☐ Mild	☐ Moderate	☐ Severe
Disturbed sleep	☐ None	☐ Mild	☐ Moderate	☐ Severe
Shortness of breath	☐ None	☐ Mild	☐ Moderate	☐ Severe
Stiffness/spasticity	☐ None	☐ Mild	☐ Moderate	☐ Severe
Choking sensation	☐ None	☐ Mild	☐ Moderate	☐ Severe
Depression	☐ None	☐ Mild	☐ Moderate	☐ Severe
Extreme/inappropriate emotions	☐ None	☐ Mild	☐ Moderate	☐ Severe

My Needs

MY COMMUNICATION

◯ I have no difficulty communicating	◯ I have some difficulty communicating	◯ I have great difficulty comunicating

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)

When sitting, I can

Move myself in a chair	◯ Yes	◯ No	
I need to use (select all that apply)	☐ A lift or electric recliner	☐ Pressure relief	
	☐ Head or neck support	☐ An electric wheelchair	
I am more comfortable when seated if (extra detail if necessary)			

MY BREATHING

I have breathing difficulties	◯ Yes	◯ No	

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.

I have breathing difficulties when I am	☐ At rest	☐ Moving around	☐ Moving a lot
I have a tracheostomy and need full breathing support at all times	◯ Yes	◯ No	

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

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

MY EATING AND DRINKING NEEDS

I have swallowing difficulties	◯ Yes	◯ No	
I can eat and drink by mouth	◯ Yes	◯ Some types	◯ No
I need help to eat and drink	◯ No	◯ Some help	◯ I need to be fed
I use adapted cutlery and crockery	◯ Yes	◯ No	

I need my fluids at the following consistency (using the International Dysphagia Diet Standardisation Initiative levels)

- ◯ Level 0 – Thin (No thickening needed)
- ◯ Level 1 – Slightly thick
- ◯ Level 2 – Mildly thick
  Previously Level 150 (mildly thick) – ¼ thick or nectar
- ◯ Level 3 – Moderately thick
  Previously Level 400 (moderately thick) – ½ thick or honey
- ◯ 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)

- ◯ Level 7 – Regular (normal food)
- ◯ Level 6 – Soft and bite sized
- ◯ Level 5 – Minced and moist
- ◯ Level 4 – Pureed (equal to thickness of Level 4 liquid)
- ◯ 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)

☐	**Gluten**	◯ Allergy	◯ Intolerance	◯ Lifestyle choice
☐	**Dairy**	◯ Allergy	◯ Intolerance	◯ Lifestyle choice
☐	**Peanuts**	◯ Allergy	◯ Intolerance	◯ Lifestyle choice
☐	**Soy**	◯ Allergy	◯ Intolerance	◯ Lifestyle choice
☐	**Eggs**	◯ Allergy	◯ Intolerance	◯ Lifestyle choice
☐	**Shellfish**	◯ Allergy	◯ Intolerance	◯ Lifestyle choice
☐	**Red meat**	◯ Allergy	◯ Intolerance	◯ Lifestyle choice
☐	**White meat**	◯ Allergy	◯ Intolerance	◯ Lifestyle choice
☐	**Fish**	◯ Allergy	◯ Intolerance	◯ Lifestyle choice
☐	**Other (please explain)**			

I prefer the following foods, drinks or supplements (please explain)

I use Tube Feeding (PEG) ◯ Yes ◯ No

I use tube feeding (select any that apply)	☐ For hydration	☐ To top up my meals
	☐ For all food and drink	☐ I need help with my tube feeds
	☐ For medication	☐ I need tube feeding but enjoy small amounts of food by mouth
Details of my tube feeding and preferred times of the day		

After my tube feeding, please leave me sitting up for 30 minutes.

MY PHYSICAL ABILITY

I have weakness in my (select any that apply)	☐ Upper limbs	☐ Lower limbs
	☐ Head/neck	☐ Trunk
I use	☐ Arm/wrist splints	☐ Leg/foot splints
	☐ Head/neck support	
I can walk	◯ Yes	◯ No
	◯ With support or aids	
I need help to transfer to (select all that apply)	☐ Not needed	☐ Bed
	☐ A chair	☐ Toilet
I use the following equipment to move around (complete if necessary)		
I use the following equipment to do things (complete if necessary)		
I need rest when (complete if necessary)		

MY PERSONAL CARE

I need help with

Personal hygiene	◯ Yes	◯ No	◯ Some
Showering	◯ Yes	◯ No	◯ Some
Dressing	◯ Yes	◯ No	◯ Some
Toileting	◯ Yes	◯ No	◯ 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
					Injection
					Injection
					Injection
					Injection
					Injection
					Injection
					Injection
					Injection
					Injection

MY ALLERGIES

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

My Life History

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

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

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

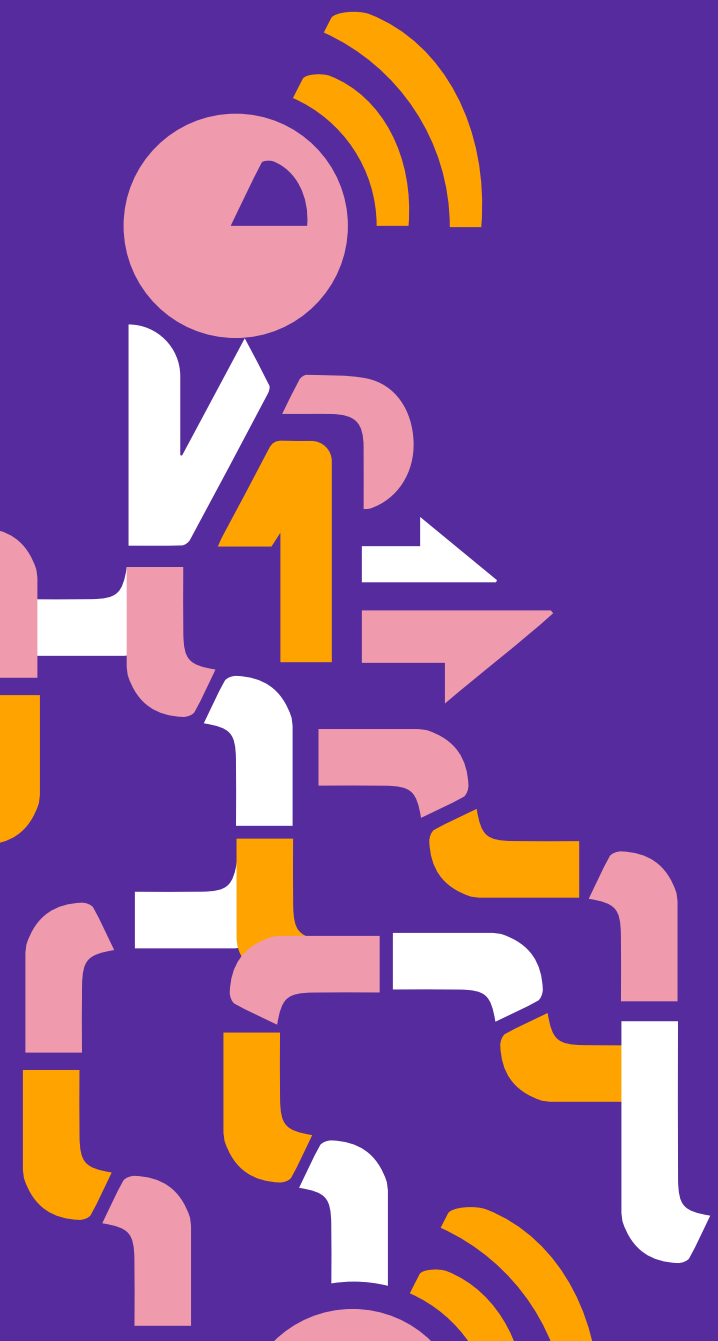
Role	Name	Telephone	Email
Speech Pathologist			

OTHER TEAM MEMBERS

Role	Name	Telephone	Email
Speech Pathologist			
Speech Pathologist			
Speech Pathologist			
Speech Pathologist			
Speech Pathologist			
Speech Pathologist			
Speech Pathologist			
Speech Pathologist			
Speech Pathologist			
Speech Pathologist			
Speech Pathologist			
Speech Pathologist			
Speech Pathologist			

My Appointments

Name of Team Member	Date of Appointment	Time



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:

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- MiNDAUS Partnership
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This document is dedicated to Mary Thomas.

MiNDAUS PARTNERSHIP