



about me and MND

My details and my needs

Abstract

This form is a health record which can be completed at any time and shared with health providers as desired. It means that many things do not need to be explained repeatedly. It may be particularly helpful when there is verbal communication difficulties.

Last updated:

Catherine Hansen

[Email address]

My Details

Name		First		Last	
Maiden name (if applicable)					
Address					
Suburb				Postcode	
State		ACT Northern Territory South Australia Tasmania Queensland Victoria Western Australia			
DOB		Format dd/mm/yyyy			
Home Phone		Area code	8 digits		
Mobile		10 digits			
Email					
Preferred language					
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		Select from list from https://www.privatehealth.gov.au/dynamic/Insurer			
Fund no					
DVA card		Yes		No	
DVA card type		Gold	White	Repatriation Pharmaceutical Benefits Card	
DVA number					
Are you eligible for the NDIS? (under 65 years old)				Yes	No
NDIS number					
NDIS Plan Manager		Self		Agency	Other- select from list
NDIS Case Coordinator details					
Name					
Phone number					
Email					
Are you registered for My Aged Care?				N/A	Yes No
MAC Level	One	Two		Three	Four

My Primary Carer's Details

Name	First	Last			
Relationship to me	Spouse /Partner		Child	Sibling	Other relation
	Friend		Other		
Address address is the same as mine (If selected, autofills)					
Suburb			Postcode		
Phone	10 digits				
Email					
Preferred language					
Interpreter required	Yes			No	

My Emergency Contact details (if different to My Primary Carer) N/A

Name	First	Last			
Phone					

My Legal Documents

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

I do not need to, or do not wish to fill out this section: Yes No

I have an Advanced Care Directive (ACD)	Yes	No
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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:

Free text field

My MND

Type of MND:

ALS (Amyotrophic Lateral Sclerosis- sometimes called Classic ALS)

PBP (sometimes called Bulbar Onset ALS or MND)

PMA (sometimes called ALS with predominant lower motor neurone involvement)

PLS (sometimes called ALS with predominant upper motor neurone involvement)

Unsure

Date diagnosed:

My most recent ALSFRS-R score

/48

Date test completed:

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

This section is not applicable to me

Undo:

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, eg, 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 Primary Carer and/or my Primary Health Contact if unsure.

I have breathing difficulties when I am :

At rest

Moving around

Moving a lot

I use non-invasive ventilation (NIV) Yes No

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- Extremeley 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 tube feeding but enjoy small amounts of food by mouth

I need help with my tube feeds

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:

Not needed

Bed

A chair

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): :

I need rest when (complete if necessary):

My Personal Care

I need help with:

personal hygiene:	Yes	No	Some
showering:	Yes	No	Some
dressings:	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
- Swallowing
- Clearance techniques

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 for which you have been diagnosed:

Anxiety

Asthma

Cancer

Depression

Diabetes

Heart disease

High blood pressure

Other (please add below if necessary):

My medications

Please enter any medicine you take, including ones that you take without prescription:

Medicine and dose

What it is for

time(s) it is taken

I take it as follows

Select from time field, half hour increments, 12 hour clock or 'as needed' (allow multiple selections)

Add another medication

Medicine	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

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.

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 Care Team

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

Please let my main professional MND 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 care team, and details of the next appointment. Add as many team members as you like.

Add a Care Team member

Contact a Care Team member

Name Select if this contact is your main MND professional contact	First	Last	
Role	Select from list		
Address			
Suburb		Postcode	
Phone	10 numbers		
Email	Email field		
Next appointment	Date field		

