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:

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	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				
Are you eligible for the NDIS? (under 65 years old)	Yes ◯	No ◯		
NDIS number				
NDIS Plan Manager	Self ◯	Agency ◯	Other- select from list	
NDIS Support Coordinator details				
Name				
Phone number				
Email				
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 MAC level 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 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	English			
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 ◯

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 (Amytrophic 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: mm/yyyy

My most recent ALSFRS-R score 48 /48

Date test completed: Date of test

My recent symptoms

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

Date completed: Date completed

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

This section is not applicable to me ☐ *It is applicable (enable section)* ☐

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 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):

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

☐ 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):

Medicine	Date Started (mm/yy)	Dose	What it is for	Times	I take it as follows
				11:30pm	Injection
				11:30pm	Injection
				11:30pm	Injection
				11:30pm	Injection
				11:30pm	Injection
				11:30pm	Injection
				11:30pm	Injection
				10:30pm 11:00pm 11:30pm	Injection
				11:30pm	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 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 (tick a box below to nominate your primary) 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;
Add as many team members as you like.

Role	Name	Address	Telephone	Email	Primary Contact
Speech Pathologis					☐
Speech Pathologis					☐
Speech Pathologis					☐
Speech Pathologis					☐
Speech Pathologis					☐
Speech Pathologis					☐
Speech Pathologis					☐
Speech Pathologis					☐
Speech Pathologis					☐
Speech Pathologis					☐
Speech Pathologis					☐

My appointments		
Name of Team member	**Date of appointment**	**Time**