

Understanding my needs:

a personal record to
help you support me with
motor neurone disease



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 3 for my communication needs.

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PLEASE NOTE

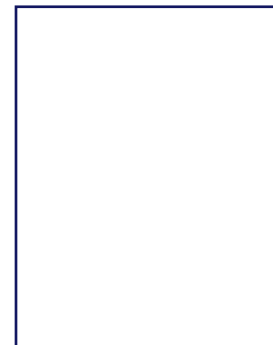
I should not be given the following medicines as I am allergic or will react to them:

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 5 for my breathing needs

My photo



Understanding my needs: with motor neurone disease (MND)

My health and social care team is listed on page 13. They can answer queries about my treatment, care or management of symptoms.

Please let my main professional contact know as soon as possible if I am receiving urgent or emergency care.

My details

My name:

Name I like to be called:

Where I live (area not full address):

Who I live with:

My telephone number:

My email:

Date of birth:

NHS number:

Personal contact, who has my permission
to be informed about my health:

Main carer:

Carer telephone number:

GP name:

GP address:

GP telephone number:

My 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 plan:
- I have made advance statements about my care:
- I have an end of life care plan:
- I have made an Advance Decision to Refuse Treatment (ADRT):
- I have arranged for Lasting Power of Attorney (LPA):
- I have completed a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form:
- I have organ or tissue donation forms:

These are kept in:

*If you need these and I am unable to provide them for any reason, please ask **My team** as shown on page 13.*

My communication needs

- I have no difficulty communicating:
- I have some difficulty communicating:
- I have great difficulty communicating:
- I am also: sight impaired hearing impaired

Please make it easy for me to ask for help. I prefer to communicate using the following techniques or aids:

I use voice banking or message banking:

My first language is: I may need a translator:

My positioning

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

My most comfortable position is:

In bed

I can lie flat: yes no

I can move myself in bed: yes no

I need help to: sit up turn over change position

I need to use: an adjustable bed extra pillows pressure relief

I am more comfortable in bed when:

When sitting

I can move myself in a chair: yes no

I need to use: a riser recliner chair pressure relief head or neck support

I am more comfortable when seated if:

My breathing

PLEASE NOTE

MND can cause respiratory muscle weakness. It may be dangerous to give me oxygen therapy. Please contact my health and social care team if unsure (see page 13).

I have breathing difficulties: yes no

This happens when I'm: at rest moving moving a lot

I use non-invasive ventilation (NIV): at night as needed all the time

I use invasive ventilation (tracheostomy):

The following can help to relieve my breathing difficulties (such as a suction machine, a device to help me cough or positioning):

My eating and drinking needs

By mouth

I have swallowing difficulties: yes no

I can eat and drink by mouth: yes some types at my own risk no

If you wish to query my choice to eat or drink at my own risk, please ask **My team** see page 13.

I need help to eat and drink: yes some help no

I use adapted cutlery and crockery: yes no

I need food: as regular (7) soft and bite sized (6) minced and moist (5)
puréed extremely thick (4) liquidised moderately thin (3)

I need thickener in drinks: not required – thin (0) slightly thick (1)
mildly thick (2) moderately thick (3) extremely thick (4)

I have the following food intolerances or allergies:

I prefer the following foods, drinks or supplements:

By tube feeding:

I use tube feeding: to top up my meals for all food and drink no

I need tube feeding, but enjoy small tasters of food by mouth:

*I accept that tasting food is at my own risk – ask **My team** if you need guidance (see page 13).*

I need help with my tube feeds: yes no

Details about my tube feeds and preferred times of day:

My physical ability

I have weakness in my: upper limbs lower limbs head/neck trunk

I use: arm/wrist splints leg splints head or neck support

I can walk: yes no with support or equipment

I need help to transfer to: bed a chair the toilet

I use the following equipment to move around:

I use the following equipment to do things:

I need rest when:

My medication

I have an MND Just in Case kit to help with breathlessness and anxiety: yes no

This is kept in:

The medicines I take

Medicine and what it is for:	To be given at the following times:	How I take it:

My personal care

I need help with personal hygiene:

yes

some

no

The following things are important to me when being given personal care:

My thinking and behaviour

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

My medical conditions

In addition to MND, I have these other conditions *(such as diabetes, asthma or depression)*:

My life

My life so far:

My work history:

Family and friends:

Important daily routines:

Things and hobbies that interest me:

Things I like to hear 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 or upset me:

Things that make me feel better if I'm anxious or upset:

My photos

The following photos may help you understand me, and the people, places or pets that are important to me:

Use this space to add some favourite photos...

My team

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

Please let my main professional contact know as soon as possible if I am receiving urgent or emergency care. Thank you.

Name and role	Contact details
<i>Main MND professional contact:</i>	

Once you have completed this form with your details, keep it with you. It has been designed to help people understand your needs, when they provide care. Please do not return it to the MND Association, thank you.

Date(s)
<hr/> This record of my needs was created on: <hr/>
<hr/> It was last checked on: <hr/>
<hr/> Signature: <hr/>

We welcome your views

The MND Association encourages feedback about any aspect of the information we produce. If you would like to provide feedback about *Understanding My Needs*, please:

email: infofeedback@mndassociation.org

or write to: Information feedback, MND Association, Francis Crick House (2nd Floor),
6 Summerhouse Road, Moulton Park, Northampton NN3 6BJ

References

References used to support this information are available on request from:

Email: infofeedback@mndassociation.org

Or write to: Information feedback at address shown above.

Acknowledgements

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Further information

We can help you find out more about MND at the MND Association. Our MND Connect helpline is for professionals as well as people with or affected by the disease. The helpline team can provide information, direct you to our national and regional services, and to other organisations as appropriate.

mndconnect

0808 802 6262

mndconnect@mndassociation.org

Find our information for people with or affected by MND at:

www.mndassociation.org/publications

Find information for professionals at:

www.mndassociation.org/professionals

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