

Part 4: Helping you to keep track

Introduction

Personal details

Contact record

Appointment and communication record

Equipment record

Medication record

References

Acknowledgements

Index

We welcome your views

Introduction

The five forms on the following pages have been developed to help you keep important information in one place. It is your choice if you wish to use these pages or not, but they may help if you meet a wide variety of health and social care professionals.

You can also download and print these forms to carry around as separate sheets.

See *Helping you to keep track* at www.mndassociation.org/lwmnd

The five forms are:

1. Personal details:

to record basic information about yourself to save time at appointments.

We also supply a form in the folder of this guide, called, *Understanding my needs*.

This is designed to help hospital staff and care workers provide you with suitable support

2. Contact record:

to keep a central list of key people and services with their contact details.

3. Appointment and communication record:

to help you prepare for appointments and keep notes.

4. Equipment record:

to note the equipment you receive and contacts for support.

5. Medication record:

to note when and how much to take of any medication, nutritional supplement or tube feed.

Personal details

By recording your details here, you can use this page to show health and social care professionals if they need your basic information. This can be very helpful as you are likely to meet a wide span of professionals. Keep the guide safe if you complete this page, as it will contain confidential data.

My information:

Name:

Home Tel:

Mobile:

Address:

Email:

NHS number:

Date of birth:

My main contacts are:

Next of kin - Name:

Telephone:

Email:

Main carer - Name:

Telephone:

Email:

MND Association contact - Name:

Telephone:

Email:

GP - Name:

Telephone:

Address:

Name of my MND care centre, network or neurological service:

Telephone:

Address:

Contact record

This will help you keep a central record of all contacts for easy reference.

MND Association services

Name or organisation	Contact details
MND Connect	0808 802 6262 mndconnect@mndassociation.org
Association visitor	
Branch or group	
Regional care staff contact	
Support services (MND support grants and equipment loan)	0808 802 6262 support.services@mndassociation.org MND Association, Francis Crick House (2nd Floor), 6 Summerhouse Road, Moulton Park, Northampton NN3 6BJ
Switchboard	01604 250505 enquiries@mndassociation.org
Membership enquiries	01604 611855 membership@mndassociation.org

MND Association services (continued)

Name or organisation	Contact details
MND Association Benefits Advice Service	Free, confidential and impartial advice on any benefits you may be entitled to. Find current contact details for England, Wales and Northern Ireland at: www.mndassociation.org/benefitsadvice or contact our MND Connect helpline for guidance.
Communication Aids Service	0808 802 6262 communicationaids@mndassociation.org MND Association, Francis Crick House (2nd Floor), 6 Summerhouse Road, Moulton Park, Northampton NN3 6BJ
Online forum	https://forum.mndassociation.org
Website	www.mndassociation.org
MND Association publications	www.mndassociation.org/publications or contact the MND Connect helpline (see earlier in list)
MND Association information feedback	infofeedback@mndassociation.org

Healthcare services

Name or organisation	Contact details
NHS 111	Telephone 111 if you need urgent, but non-emergency medical help.
999 or Relay UK	Telephone 999 for emergency help. If you have speech difficulties, use Relay UK for emergency contact: https://www.relayuk.bt.com/how-to-use-relay-uk/contact-999-using-relay-uk.html
MND care centre or network	
Neurology clinic	
Consultant	
GP	
District nurse	
MND specialist nurse	

Healthcare services (continued)

Name or organisation	Contact details
Palliative care nurse	
Occupational therapist (OT)	
Speech and language therapist (SLT)	
Physiotherapist	
Dietitian	
Pharmacist	
Counsellor	
Psychologist	

Social care and related services

Name or organisation	Contact details
Adult social care services (local)	
Local authority (England and Wales) or local health and social care trust (Northern Ireland)	
NHS Wheelchair service (local)	
Jobcentre Plus (local branch)	
Carer's Allowance Unit	0800 731 0297 or textphone: 0800 731 0317 www.gov.uk/carers-allowance-unit
Citizen's Advice Bureau (local branch)	
The Pension Service	0800 731 7898 or textphone 0800 731 7339 www.gov.uk/contact-pension-service
Religious or spiritual guidance	

Social care and related services (continued)

Name or organisation	Contact details

Other contacts

Name or organisation	Contact details

Appointment and communication record

You may find this helpful to prepare for appointments and keep a record of what was said. List any questions beforehand and either make notes during the meeting or ask the health and social care professional to write down the answers for you. If you begin to attend a lot of appointments, you may wish to use this layout in a notebook instead.

Day, date & time	Who with	Questions you want to ask	Notes
<p>Example: Monday 25 July 2022 11.30am</p>	<p>My GP, Dr Smith</p>	<p>My joints feel stiff. What can I do to maintain flexibility?</p>	<p>Dr Smith recommended specific assisted exercises and will refer me to a physiotherapist with experience of MND.</p>

Day, date & time	Who with	Questions you want to ask	Notes

Day, date & time	Who with	Questions you want to ask	Notes

Day, date & time	Who with	Questions you want to ask	Notes

If you have a great many appointments, you may wish to use this layout in a notebook instead.

Equipment record

You can use this form to record any equipment you receive and who will be your main contact in case you need support.

Date	Item	Person or provider to contact	Contact number or email address
Example: 25 July 2022	Rollator walking frame	Anne Jones A Made-up Equipment Service	Add contact details as appropriate

Date	Item	Person or provider to contact	Contact number or email address

Date	Item	Person or provider to contact	Contact number or email address

Medication record

Keeping a record of any medications, nutritional supplements or tube feeds can help you, and those who support you, to track when you need to take each item.

Name of medications, supplements or tube feeds	Quantity, frequency and how taken	Date prescribed

Name of prescribed medications, supplements or tube feeds	Quantity, frequency and how taken	Date prescribed

Document dates:

Last revised: November 2022

Next revision: November 2025

Version: 1

MND Association

Francis Crick House (2nd Floor)

6 Summerhouse Road, Moulton Park

Northampton NN3 6BJ

Tel: 01604 250505

Website: www.mndassociation.org

Registered Charity No. 294354

© MND Association 2016

All rights reserved. No reproduction, copy or transmission of this publication without written permission.

**This resource has been evidenced,
user tested and reviewed by experts.**

For references and acknowledgements please refer to the full guide, *Living with motor neurone disease*.

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



The MND Association would like to thank the **Tesco Charity Trust**, and the **Evan Cornish Foundation** for their support which has made the production of *Living with motor neurone disease* possible.

