

Keeping notes

The four forms on the following pages can be printed out to help you keep notes about important records. You may find them helpful in discussions with professionals:

- 1 - Care summary
- 2 - Carer's assessment preparation
- 3 - Appointment queries
- 4 - Contact record

These forms can also be found in *Caring and MND: support for you* (they cannot be completed online).

Other sections, and the full guide, can be found online at: www.mndassociation.org/carerguide

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

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



**Caring and MND:
support for you**

Part 4: Keeping notes

This part of the guide includes the following write-on pages, to help you keep important records:

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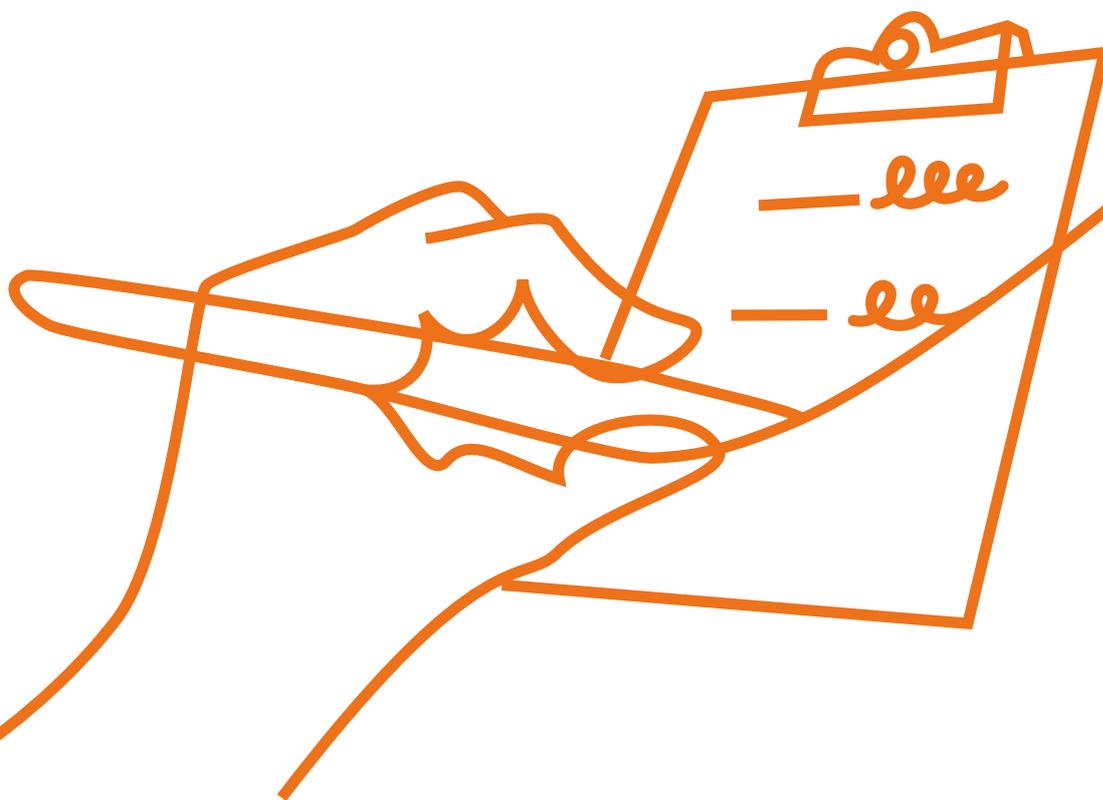
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Care summary

Keeping notes about the care tasks you do, can provide useful evidence for appointments or assessments with health and social care professionals.

You can use this *Care summary* to record your notes. It may help to mark tasks in your diary for a week or two. This will show how often you do things and how long they take. See the examples below:

Task	Frequency and time taken for each task		
	Date recorded	Date recorded	Date recorded
	12th January 2022		
Collecting prescriptions and medication	Once a month, but can take an hour to make the round trip and I hate leaving my husband on his own for this long		
Administering medication	Five times a day and can take up to five minutes each time, due to swallowing difficulties		

You only need to make notes against tasks that are relevant to the care of the person you support and you can add further tasks at the bottom of the summary table if necessary.

Add a date to the top of the column you are completing, as this will help you remember when you recorded the information. Use subsequent columns at later intervals to help track any increase in the levels of care over time.

Please see the following page for the full *Care summary*.

Task	Frequency and time taken for each task		
	Date recorded	Date recorded	Date recorded
Food preparation or cooking			
Housework			
Laundry			
Shopping			
Physical care <i>(such as helping the person get up from a chair or go upstairs)</i>			
Contacting, visiting or checking on the person <i>(to ensure they are safe and well)</i>			
Personal care <i>(such as dressing, washing, helping with toileting needs)</i>			
Overnight or night-time care			

Task	Frequency and time taken for each task		
	Date recorded	Date recorded	Date recorded
Administration for benefits or financial support			
Collecting prescriptions and medication			
Administering medication			
Assisting with medical or complementary treatments when appropriate			
Providing emotional support			
Assisting communication <i>(for speech impairment, hearing loss or if English is not the first language)</i>			
Arranging appointments or accompanying at appointments			
Driving or accompanying on travel			

Task	Frequency and time taken for each task		
	Date recorded	Date recorded	Date recorded
Assisting with leisure activities <i>(such as hobbies, interests, entertainment, etc)</i>			
Helping to contact services and support organisations			
Gardening			
House maintenance			
Looking after visitors			
Other task:			
Other task:			
Other task:			

Carer's assessment preparation

This item shows the typical questions that may be asked at a carer's assessment. The way you use this tool is entirely up to you. You may simply want to look at the questions before the assessment to think about your responses, or make notes to ensure you include key points. You may need extra paper if some of your responses need more detail.

There is a lot to consider and we have included as many prompts as possible to help prepare you. You may find just a few prompts are relevant, or all of them. Please note, the actual questions asked at the full assessment may vary between local authorities.

You may also wish to use other tools in this toolkit at your carer's assessment, such as the *Care summary*, to support and clarify your needs. You may find the *Care summary* helps at assessment too, also in Part 4 of this guide.

General information:

What is your relationship to the person you are caring for?

What is the nature of the cared for person's illness or disability?

What is your GP's name?

What are your GP's contact details?

What is your ethnic origin?

(Ethnic origin may be important in terms of accessing other services such as interpreters)

What is the ethnic origin of the person you are caring for?

(Ethnic origin may be important in terms of accessing other services such as interpreters)

Do you have any personal communication needs or wish to communicate in a preferred language?

Do you have any cultural or spiritual needs that need to be taken into consideration?

Do you have any personal health concerns? *(such as illness or physical impairment)*

General information: *(continued)*

Do you have any other commitments? For example:

Paid work Family, eg children Study or training Voluntary work Other

How long have you been a carer?

How many hours per week do you spend caring?

Are you willing and able to continue caring?

Other people in your household:

Who else lives in your household?

What is their relationship?

Are they involved in the care duties?

Their age if under 18?

Do you have any other comments concerning the impact on other people in your household?

Practical tasks:

Notes on level of care/input required:

Shopping

Laundry

Housework

Cooking

Correspondence

Administration/finance

What kind of support would help you with the above?

Personal care tasks:

Notes on level of care/input required:

Assisting with getting dressed

Assisting with eating/drinking

Assisting with toileting

Bathing and personal hygiene

Support during the night

What kind of support would help you with the above?

Tasks concerning getting around:

Notes on level of care/input required:

Providing transport

Arranging transport

Assistance when travelling

What kind of support would help you with the above?

Tasks concerning personal mobility:

Notes on level of care/input required:

Getting in and out of bed

Getting in and out of chairs

Getting in and out of shower/bath

Getting in and out of transport

Help using the toilet/commode

Assisting with exercise

Moving around

What kind of support would help you with the above?

Tasks concerning health:

Notes on level of care/input required:

Visits to GP/care centre/hospital

Visits to GP/care centre/hospital

Collecting medication

Medication giving or monitoring

Controlling medical equipment (*eg tube feeding*)

Breathing and respiratory issues

Urgent or emergency situations (*such as falls*)

Other health needs

What kind of support would help you with the above?

Tasks concerning communication:

Notes on level of care/input required:

Support with socialising

Advocating (*asking services for advice or support*)

Interpreting (*with language or speech impairment*)

What kind of support would help you with the above?

**Other issues experienced by the person
you care for, that you deal with:**

Notes on level of care/input required:

Mood swings/behaviour change

Lack of sleep or fatigue

Anxiety/fearfulness

Changes to thinking or reasoning

Difficulty with interests/hobbies

Financial hardship

Safety indoors/outdoors

Strain on your relationship

Strain on family/close friends

Maintaining social life

Housing adaptations

Other accommodation issues

Discrimination due to disabilities

What kind of support would help you with the above?

Other things to consider:

What problems and difficulties do you have as a carer?

What extra support would improve your quality of life or make life easier?

Would you like access to lists of care workers and services in the local area?
(This may be particularly important if either you or the person you are caring for decide to accept direct payments for social care or health care.)

Would you like access to a list of carer support groups and any local carer centres?

Would you like information on how to handle emergencies and who to contact?

Would you like a plan of action in place in case you need to be absent?
(eg you need hospital treatment.)

Would you like access to any other specific information or advice?

Do you need assistance with legal issues, such as Power of Attorney or making a will?

Are you likely to need respite care, or carer breaks, now or in the future?

Is there anything else that should be known regarding your caring role or personal situation?

How do you feel a full carer's assessment might be able to help you and what would you like this to do for you?

Would you like the carer's assessment to be conducted privately? (You can have a joint needs assessment with the person you support, if wished.)

Appointment queries

Both you and the person you support can use this notes page, or a copy, for appointments with health and social care professionals. It can help you prepare and group questions for suggested areas of concern.

You can use the notes area to record the responses of the health or social care professional. You may wish to use this as a guide only and create your own version, or use extra paper to record any notes.

Appointment with:

Date:

Area of concern	Questions	Notes
Symptom control, medication or treatments:	For example: <i>My wife has a very dry mouth, is there anything that can help?</i>	
Specialist equipment or medical equipment:		
Speech and communication:		
Personal mobility:		

Area of concern	Questions	Notes
Difficulties performing practical tasks and personal care needs:		
Difficulties with eating and swallowing		
Emotional issues and impact on personal relationships:		
Changes to thinking or behaviour:		
Financial issues:		
Housing issues or adaptations:		

Area of concern	Questions	Notes
Carer support and respite care:		
How to get further advice and information:		

Other things to consider:

Contact record

You may find you need to communicate with a wide range of people, services and organisations when supporting someone with MND. Keeping contact details together may help you save time. We have included telephone numbers and email addresses where possible, but you will need to add details for local contacts.

MND Association services

Name or organisation	Contact details	Dates contacted	Notes
MND Connect helpline	0808 802 6262 mndconnect@mndassociation.org		
Young Connect helpline	0808 802 6262 youngconnect@mndassociation.org		
Association visitor			
MND Association branch or group			
Regional care development adviser			
Support services <i>(for equipment loans, MND Support Grants, Carer Grants and the Young Person's Grant</i>	0808 802 6262 or 01604 611802 supportservices@mndassociation.org		

MND Association services

Name or organisation	Contact details	Dates contacted	Notes
MND Association switchboard	01604 250505 enquiries@ mndassociation.org		
MND Association membership	01604 611860 membership@ mndassociation.org		
MND Association information feedback	infofeedback@ mndassociation.org		
MND Association online forum	https://forum.mndassociation.org		
MND Association website	www.mndassociation.org		
MND Association publications	www.mndassociation.org/publications or contact the MND Connect helpline (see earlier in list)		

Medical contacts:

Name or organisation	Contact details	Dates contacted	Notes
MND care centre or network			
Consultant			
GP			
District nurse			
MND specialist nurse			
Palliative care nurse			
Occupational therapist (OT)			
Speech and language therapist (SLT)			

Medical contacts: (continued)

Name or organisation	Contact details	Dates contacted	Notes
Physiotherapist			
Dietitian			
Pharmacist			
Counsellor			
Psychologist			
NHS 111	Call 111 if medical help is needed fast, but it is not a 999 emergency.		

Social care and related services:

Name or organisation	Contact details	Dates contacted	Notes
Social services (local)			
Local authority main switchboard			
Wheelchair service (local)			
Jobcentre Plus (local branch)			
Carer's Allowance Unit	0800 731 0297 www.gov.uk/carers-allowance-unit		
Citizens Advice Bureau (local branch)			
The Pension Service	0800 731 7898 www.gov.uk/contact-pension-service		
Religious or spiritual guidance			

Social care and related services: (continued)

Name or organisation	Contact details	Dates contacted	Notes

Other contacts and organisations:

Name or organisation	Contact details	Dates contacted	Notes

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



Patient Information Forum