

Part 4: Keeping notes

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

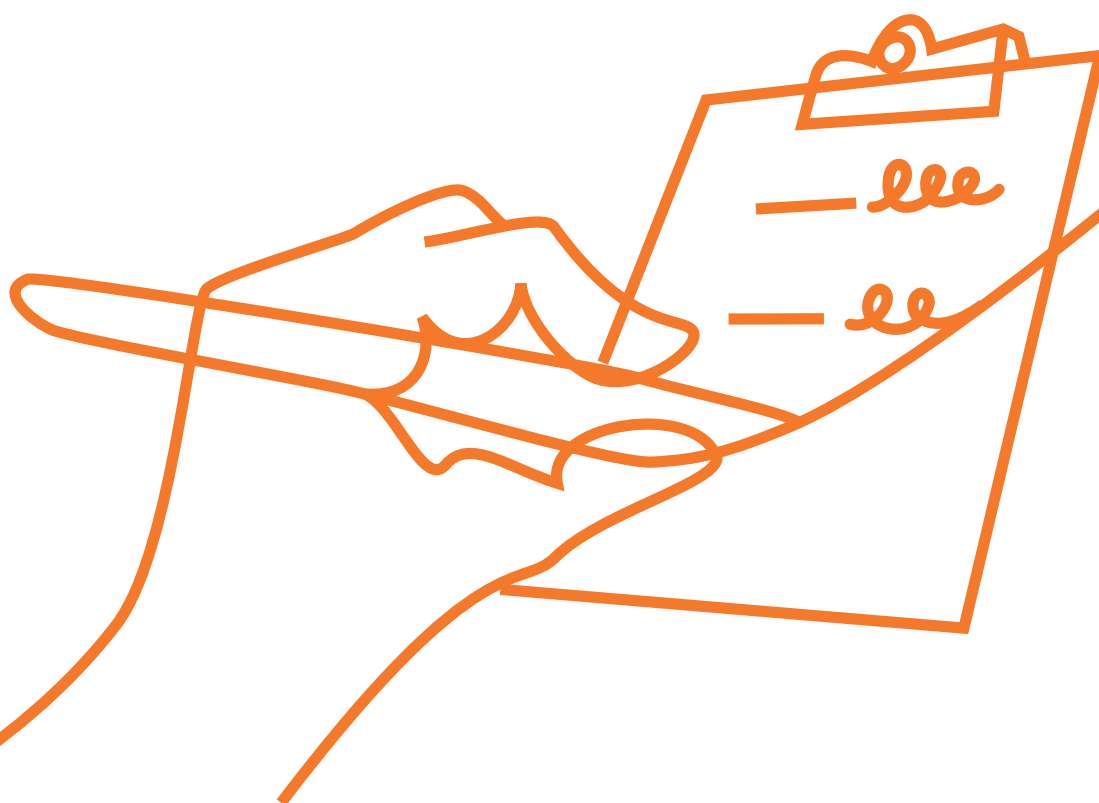
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You can order additional copies from our MND connect helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Or you can download and print copies at:
www.mndassociation.org/MNDguides



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 2016 | | |
| 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? *(eg illness or physical impairment)*

General information: (continued)

Do you have any other commitments? eg:

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 (*re: 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> | 01604 611802 equipmentloan@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 611855 membership@ mndassociation.org | | |
| MND Association information feedback | infofeedback@ mndassociation.org | | |
| MND Association online forum | http://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 | 0345 608 4321 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 please refer to the full guide, *Caring and MND: support for you*.

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

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



The MND Association has been certified as a producer of reliable health and social care information.

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