



4: Carer's assessment

This section looks at how to get your needs assessed as a carer and how this can lead to support.

The following information is a section from our full guide *Caring and MND: support for you*.

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**

4: Carer's assessment

This section looks at how to get your needs assessed as a carer and how this can lead to support.



What is a carer's assessment?

It may feel difficult to ask for help, but caring can be challenging and your needs matter too. A carer's assessment can lead to support, to help you maintain your wellbeing.

"It's about finding solutions to problems to enable life to continue as positively and optimistically as possible."

A carer's assessment is an opportunity to discuss the impact of the caring role, which is important. If you ignore your own needs and care demands increase, you could reach crisis point. An early assessment not only provides possible support, but can help you plan how to manage unexpected situations. Even if you are coping well at the moment, it is worth being assessed to find out how to access services you might need in the future.

The assessment does not judge how capable you are as a carer, but helps professionals work out how to make your caring role easier. Depending on your needs, you may receive guidance, information or services, as appropriate.

If you have not been offered a carer's assessment, you can ask for one to be arranged. Contact adult social care services through your local authority in England and Wales, or through your local health and social care trust in Northern Ireland (we will use the term 'local authority or trust' for the remainder of this section).

If you agree, the assessment can be done by telephone or online in England or Wales, but you can ask for a face-to-face assessment. This allows for a more open discussion and can take place at an agreed location or at home. You may have someone with you to support, if wished. In Northern Ireland, assessment is occasionally completed by telephone, but usually face-to-face (not online).

The assessment results in an agreed support plan, which may include:

- provision of services or direct payments for you to arrange services of your choice, to meet the needs identified in your support plan
- referrals to other support, such as benefits advice
- plans for respite care and carer breaks
- assistance with travel
- suggestions for counselling
- information about support groups and voluntary support organisations.

The assessor should look at innovative ways to meet your needs if necessary. Be aware that there may be limits to the services that can be provided and you may have to contribute towards costs, as agreed through financial assessment. However, your leisure, training and work needs should be considered.

"I am a full-time carer, a full-time dad, a full-time homemaker and I'm trying to find work...there aren't enough hours in the day and not enough energy to do everything."

Do I qualify?

You usually qualify for support if you provide necessary care to someone and this is likely to impact on your wellbeing.

Being a carer does not guarantee access to services, but assessment helps you find out what is available.

See [Section 3: Your rights as a carer.](#)

Who attends a carer's assessment?

The assessment is usually carried out by a social worker, or an appropriate representative or contractor for adult social care services.

You can have a friend or someone to support you at the assessment if you wish.

The person you support can also have an assessment of their needs. There is a duty to ensure their eligible needs are met and services supplied to them may help you as a carer too.

If you both agree and find it comfortable to discuss the challenges you face as a team, a combined assessment can be carried out at the same time. You may prefer to have your carer's assessment on your own.

"It can be hard to talk about your issues if the person with MND is present."

If the person with MND sees themselves as more able than they really are, it may be difficult to 'tell it like it is' when they are listening. If you are finding it hard to cope in the caring role, it may also feel difficult to discuss concerns in front of the person you support.

"There's not much a carer can do when the person with MND tells health and social care professionals, 'I can manage. I don't need more support at the moment.' Also, we carers understandably want to praise the person's bravery and initiative, so we don't always ask for help either."

If you have a separate assessment, try not to feel guilty about doing this without the person you support. It is important to have your needs addressed.

Care needs increase with MND and can be very challenging. You should not have to wait until there is a crisis before being offered assistance.

If someone 18 or under is involved in support for someone, they are known as a young carer. They can also have their needs taken into consideration with a young carer's assessment.

See [Section 9: Support for young carers for details about support for young people and rights for young carers.](#)

What do I need to think about?

You may find it difficult to think about yourself when caring. If you feel under pressure, it may seem there is never enough time to get everything done and you may place your own needs second.

"Contacting adult social care services to ask for a carer's assessment seems a very useful thing to do."

Try to include a broad picture of your life at the assessment, including family, leisure and work, as this will help the assessor. They can advise how to balance other activities and routines with the caring role.

The assessment can help you consider the following questions:

- Do I need help?
- Am I willing and able to carry on caring?
- Can I continue to provide the same or increasing levels of care?
- How will caring affect my life?
- Are there any services that could assist me?

You may be happy to continue as a carer, but there could be circumstances that prevent this (for example, if you become ill, through family pressures or other reasons). Try to think ahead so that contingency plans can be made.

If you have children or other dependants, this may affect the type of support you need. Let the assessor know of any other responsibilities you have. The person you support may also be a carer for someone else, which may need to be discussed and alternative care provided as needed.

As the assessment does not judge your capability as a carer, there is no need to prove how well you cope or 'put on a brave face'. Try to have an open discussion about your needs and whether anything might cause your caring role to break down. Explain when you feel under pressure and what could help, to get the most suitable support for you.

It can help to explain the difference a particular type of support would bring, as this helps show the outcome you hope to achieve, rather than just talking about services.


How do I prepare for my assessment?

The thought of being assessed, and dealing with yet more information, may feel overwhelming on top of everything else. However, you may receive a pre-assessment form to complete before the appointment, which gives you an opportunity to make notes and feel more prepared. If not, ask to see a blank assessment form.

The exact content of any pre-assessment or final assessment forms can vary, as each local authority or trust may use their own version. However, the questions covered will be very similar. If you have a concern that does not appear to be included, you can still raise this with the assessor.

See the *Carer's assessment preparation form* in Part 4 of this guide, which can help you identify some of the areas that may be covered at assessment.

Keeping a diary in the run-up to the appointment is useful. If you make notes about your daily routines over a period of time, it provides good evidence for the assessor. It may also show how the person's care needs are increasing, which can help with forward planning.



“Keeping track – keeping a log. When? Time is taken up with tasks and when it’s not, you take a breather.”

It may feel difficult to track care tasks when you're so busy doing them. However, even if you only do this for a week, it can help you provide evidence at your carers' assessment. You don't need to write a lot of text, just note down each task you do, when you do it and how long it takes. This may help you access appropriate support to meet your needs.

See the *Care summary in Part 4 of this guide, to help you track care tasks.*

Before your assessment, consider how the caring role affects your:

- health and wellbeing
- relationships and family
- housing and living environment
- work and finances
- hobbies and interests.

If you are willing and able to provide the majority of care, be clear about the level of support you can continue to manage. This is particularly important if you are combining work and care, or if you have children or other dependants who also need your support.

An early assessment and the following questions may help you think more about your needs:

How I feel

- Am I getting enough sleep?
- Is my health affected?
- Do I get enough 'me time'?
- Can I go out if needed or wanted?
- Are other relationships affected?

Being a carer

- Does the person with MND need more support than I can give?
- Do I want to continue being a carer?
- Are there any changes that could make caring easier?
- Will I be unable to continue caring without support?

Further questions to ask at assessment

- What services can help me take a break?
- Where can we find emergency care cover if I am unable to support for any reason?
- How do I plan for urgent situations?
- Can I get support from other carers?
- Can I get any help with household tasks?
- Can I get any help with personal care during the day or night?
- Where can I get information about benefits and financial support?
- Where can I get information about balancing work with caring?
- Is there training on carer tasks?

See Section 5: *What kind of support is available? for more information about emergency care cover and planning for urgent situations.*

What happens at a face-to-face assessment?

You may decide to complete a self-assessment form, without an assessor. However, at a face-to-face assessment, the assessor will ask questions and help you:

- think about the help and support you may need
- find out which services and support may be available
- make decisions about the future.

The assessment form enables the assessor to record notes and provide you with your support plan, but does not represent the assessment process in itself. The focus should be on open discussion about your caring role to work out the support you need.

If you need further information on subjects such as benefits, leisure activities, education, training or work, you should be directed to other organisations or agencies for appropriate help.

Your assessment will review any risk of your caring role breaking down. For example, you may find it difficult to fit work commitments around the role. Or, there may be a more serious risk, such as health problems that could result in your hospital admission. Reviewing risk is particularly important with MND, as the disease will progress, which means the care demands will increase.

Following the assessment, you will receive a written support plan. This identifies your needs and any information, services or support that can be provided. Adult social care services should also liaise with other schemes on your behalf where relevant, such as housing.

The support plan will include recommendations, as agreed with you, such as:

- help with household tasks
- help to get around, for example, taxi fares
- technology to help you stay in contact with the person you support, or with services, such as a mobile phone or computer if you cannot easily access a computer elsewhere
- help to improve your health and wellbeing, such as a gym membership.

You should be offered an opportunity to give feedback about the assessment and raise any concerns you have.

Do I have to pay for carer services?

You may receive services free of charge or have to pay towards services you receive.

Where agreed services are chargeable, you will be financially assessed to see how much you need to pay (if anything).

The financial assessment will look at your income and capital (including any share of joint income or capital). This does not include the value of any owned property.

There is a financial limit known as the threshold, which will be explained to you.

If your income or capital is above the limit, you can still ask for your needs to be met. In this case, you can be charged for both the services provided and the cost of arranging and managing those services.

If required, you can have services arranged for you. However, where financial help is given for either part or all of the cost, you should be offered the choice of direct payments. These payments mean you can choose your own services, if you wish. This could include a wide range, such as gym membership and evening classes, or help with gardening and housework. Be aware that with direct payments, you are responsible for the money received and need to keep records.

See Further information at the end of this section about our publications on direct payments and other financial support.

You cannot be charged for services provided to the person you support (even if they help you), and the person you support cannot be charged for services provided to you.

You may also be able to claim certain financial benefits as a carer, such as Carer's Allowance. If you receive Carer's Allowance, it is not usually included as income in financial assessments.

See Section 5: Work and financial support.

See Further information at the end of this section about our publications on benefits and other financial support.

Northern Ireland

Please note that in Northern Ireland charges can be made for services to a carer following a carer's assessment. However, this is not common practice. If you are asked to contribute, you will be financially assessed to work out the level of payment required.

Services for the person you support

A needs assessment for the person you support looks at needs arising from their illness or disability. They will receive a care and support plan recommending information, services and support appropriate to their needs. This usually helps you as the carer too, by reducing the care demands you have to meet. It may include:

- adaptations or equipment at home to make it more suitable for limited mobility or other disability
- personal care at home by a care worker
- a temporary stay in residential care or respite care
- replacement care at home, so you can have a break
- meals delivered to their home or laundry services
- a place at a day centre
- assistance with travel.

If a care and support plan is agreed for the person with MND, they will be subject to a financial assessment to see how much they need to pay (if anything).

For example, respite care is usually funded as a care service for the person needing support, which would be considered as part of their financial assessment. You benefit by taking a break, but would not be financially assessed for this.

However, if you are given financial help to take a holiday away from home, this would be included in your financial assessment as direct support for you. This type of support will depend on your circumstances and what your local authority or trust can offer.

Northern Ireland

If services, such as respite care, are provided for the person you support, they can be charged separately for this help. Home care services (known as domiciliary care services) are usually provided free of charge in Northern Ireland.

What if something goes wrong?

Every local authority or trust is required to have a complaints procedure. If you are not satisfied with their response to any query or concern, you can make an official complaint.

The following may help guide you.

My carer's assessment has not been arranged or has been delayed:

Contact adult social care services through your local authority or trust to find out why. Let them know if your situation has become urgent or if the needs of the person you support have increased. Ask for an assessment date to be confirmed.

I filled in an assessment form and have been refused services:

Contact adult social care services through your local authority or trust and point out that you have not had a face-to-face assessment. You should be given an opportunity to meet with a social worker or other qualified representative to discuss your needs. This may help you provide more details about the challenges you face to gain the support you need.

The person I support has refused any external services or support:

Sometimes the person being supported may refuse outside help. This can be difficult, as it may leave you with little or no support as the carer. If this happens, your local authority or health and social care trust must consider how they can assist you. Contact them to discuss how else they can help.

I am unhappy with my carer's assessment:

If you are concerned about the way you were assessed or the outcomes in your support plan, contact adult social care services through your local authority or trust. Discuss the matter first, as there may be a simple solution. If you are not satisfied by their response, you can make a formal complaint. If your complaint is on behalf of the person with MND, you must have their consent if they are able to provide this.

My situation has changed or got worse:

Your support plan should be reviewed at an agreed date, but you can contact your local authority or trust at any point if you need to be reassessed. However, the more detail you provide about the progression of the disease at the first assessment, the more chance there is that future needs will be considered in your support plan. Making notes about the support you provide can help with this, even if you only do this for a week or two.

See earlier heading [How do I prepare for my assessment?](#) for details about tracking care demands to support your assessment.

I need help with my carer's assessment:

You can ask a trusted person to help you and act as an advocate, which means they can also attend the assessment with you. If you feel overwhelmed by the idea of a carer's assessment or by a poor result, it may help to discuss this. If you are in contact with one of our Association visitors, they can offer support. You can also contact our MND Connect helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Key points

- Your carer's assessment does not judge your ability, but helps identify how you might need support to continue the caring role and maintain your own wellbeing.
- Where services are agreed for either the person you support or yourself as the carer, you should be told about any charges before services have been arranged.
- You cannot be charged for services provided to the person you support (even if they help you), and the person you support cannot be charged for services provided to you.
- You and the person you support can be assessed together or separately. Ensure you let the assessor know which you prefer before any appointments are made.
- When being financially assessed, only your own income and savings (or part-share of joint income and savings) are usually taken into account. The value of any owned property is not included as savings.
- If you or the person you support refuse to do the financial assessment, you will be charged in full for services arranged.

Further information

We produce a wide range of publications about MND and the support that may be needed. The following may be useful in relation to this section:

From our information sheet range:

- 10A: Benefits and entitlements
- 10B: What is social care?
- 10C: Disabled Facilities Grants
- 10D: NHS continuing healthcare
- 10E: Work and MND
- 10F: Personal Health Budgets (England)

From our other publications:

Living with motor neurone disease: a guide about MND to help manage the impact from diagnosis onwards and maintain the best possible quality of life.

Personal care: our booklet about daily routines with MND.

Motor neurone disease checklist: a form to help a person with MND think about their care needs.

How to access publications and further information:

Most of our publications can be downloaded at: www.mndassociation.org/publications or you can order them from our MND Connect helpline:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

MND Connect can also help direct you to external services and providers, and introduce you to our services as available in your area, including branches and groups, Association visitors and regional staff.

See Section 11: How the MND Association can help you for details about our services.

Benefits Advice Service:

The MND Association Benefits Advice Service provides free, confidential and impartial guidance on any benefits you may be entitled to receive.

Telephone: **0808 801 0620**
(England and Wales)
0808 802 0020
(Northern Ireland)

Email: Through the website contact page at: www.mndassociation.org/benefitsadvice

Online forum:

The forum provides an opportunity to share information and experiences with other people affected by MND. Hosted by the MND Association at:

<https://forum.mndassociation.org>

Information for professionals

We provide information to help professionals support people with MND, their families and carers. This can be accessed at:

www.mndassociation.org/professionals

We have information to help professional care workers provide the best possible support to people with MND. See our:

Caring for a person with motor neurone disease: a guide for care workers

Care worker online module: our training for care workers at:

www.mndassociation.org/online-courses

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



Patient Information Forum