



Providing medical evidence for benefits applications

People with motor neurone disease (MND) may apply for disability/employment benefits. Some applications require a health and social care professional to provide medical evidence on their behalf.

This information sheet provides guidance to GPs, neurologists and the wider health and social care team, who may be asked to provide medical evidence to support a claim.

It also explains how, when a diagnosis of MND has been confirmed, the 'Special Rules for End of Life' (known as Special Rules) can be used to fast-track claims, for the following benefits:

- Attendance Allowance
- Personal Independence Payment (PIP – the benefit that has replaced Disability Living Allowance for new and existing claimants born after 8 April 1948)
- Disability Living Allowance (DLA – only available via reassessment for claimants who were aged 65 or over on 8 April 2013)
- Employment and Support Allowance (ESA)
- Universal Credit.

The disability/employment benefits system is complex. Whatever the award being applied for, you can help to reduce stress for people with MND when called upon to provide medical evidence for an application.

Information you can share

Our resources for people affected by MND include:

Information sheet 10A: *Benefits and entitlements*

Download at www.mndassociation.org/publications or contact MND Connect. Call 0808 802 6262 or email mndconnect@mndassociation.org

MND Association Benefits Advice Service

We can provide free, confidential and impartial advice to people with MND and their carers on any benefits they may be entitled to. Visit www.mndassociation.org/benefitsadvice for current contact details, or contact our MND Connect helpline for guidance. Call 0808 802 6262 or email mndconnect@mndassociation.org

The importance of medical evidence

Detailed and accurate medical evidence can make a big difference to a claim. It can:

- speed up the process of the claim, helping to ensure it is dealt with quickly and with a greater chance of success
- reduce the potential stress of claiming benefits for the person with MND
- potentially avoid the person having to attend a face-to-face medical assessment, which may be conducted by an assessor with no specialist knowledge of MND.

How professionals can help

1 Provide detailed, up-to-date evidence

Benefit claims made by people with MND are often refused or awarded a lower rate than would normally be expected because insufficient or conflicting medical evidence has been provided.

It is critical that the medical evidence adequately reflects the person's current situation, and is descriptive and explicit about the impact MND has on their daily living, mobility or ability to work, confirming the progressive nature of their symptoms. It should take account of unpredictability, fatigue, time taken to complete an action and the after-effects of carrying out the task.

Medical evidence must focus on how MND affects the individual, and not simply be a general description of what MND symptoms include.

2 Consider your wording

The wording used on a claim form is crucial to whether or not a benefit is awarded. The following examples illustrate the degree of detail we recommend:

Example with not enough detail: Mr X has lower limb weakness and needs help with walking.

Replace with: Mr X has lower limb weakness and can only walk 20 yards, with assistance. His ability to walk is further limited by extreme fatigue and he needs to stop and rest for ten minutes afterwards, as he finds it very painful and tiring.

Example with not enough detail: Mrs Y has upper limb weakness and needs help with dressing.

Replace with: Mrs Y is unable to dress without assistance. Even with help it takes an hour to dress. Mrs Y needs to stop for rests continually, as it is very tiring for her and causes significant pain in her arms and shoulders.

3 Provide the best contact details

With an application for Personal Independence Payment, Attendance Allowance or for a reassessment of Disability Living Allowance, the person with MND will be asked for the contact details of a person who can provide additional evidence. We would advise you to encourage the person with MND to provide the name of the care centre coordinator at their MND care centre, if relevant, or the name of their specialist nurse or consultant at their neurology clinic.

4 Use the 'Special Rules for End of Life'

Recent changes to Special Rules

As of April 2023, the 'Special Rules for Terminal Illness' (SRTI) which applied to people who have 6 months or less to live have changed to the 'Special Rules for End of Life' (SREL), which now apply to people who have 12 months or less to live.

The DS1500 form has been withdrawn, and replaced with a new form known as the SR1 form.

The claim will be fast-tracked and considered for benefits under the Special Rules provisions if an SR1 form is signed. This means the claim will be processed in days rather than months, and most of the lengthy claim forms for Personal Independence Payments or Attendance Allowance do not need to be completed. Additionally, the claimant will not have to attend a face-to-face medical assessment, as entitlement to the highest rates of these benefits is automatic.

A claim made under the normal benefit rules can be switched to a Special Rules claim at any time during the claim process. GPs, neurologists and specialist nurses can help by completing form SR1 to show the person with MND is eligible for these rules.

The person with MND may have their application fast-tracked under the Special Rules during the initial phone call they make to enquire about Personal Independence Payment. They should tell the call handler at this stage that they want this to be considered as a Special Rules case. They will be asked whether they already have or are going to get an SR1 form, and will be asked to send it in. The claim will then be completed.

How MND qualifies for the Special Rules

MND is a terminal, rapidly progressive disease. As a result, people with MND will pass the diagnosis element of Special Rules on the SR1 form, as it is a terminal condition. However, the prognosis element can be problematic.

It is important to remember that MND is unpredictable. The forms only ask if there is a reasonable expectation that their prognosis could be 12 months. Completing an application using the Special Rules does not mean that someone is going to die within the specified timeframe, only that it is a possibility.

A claimant who successfully applies through Special Rules can usually continue to claim for up to three years before reassessment.

A third of people with MND die within a year of diagnosis and more than half die within two years.¹ The MND Association strongly recommends that a Special Rules application is actively considered for all people diagnosed with MND. There may be an exception where MND presents with noticeably slow progression or limited symptoms.

As the prognosis timescales are a guideline only, there is no sanction on any health or social care professional who has declared someone terminally ill, should that person live beyond the specified period. Delays mean that someone may be living without any kind of financial support for many months.

Further information

The Department for Work and Pensions (DWP) has published a number of useful resources for healthcare professionals who complete medical reports for DWP or one of its assessment providers. Visit www.gov.uk/government/collections/healthcare-practitioners-guidance-and-information-from-dwp to access these resources, including "*DWP factual medical reports: guidance for healthcare professionals*" which is focused on Special Rules.

Reference

¹ SEALS Registry (for background information on SEALS see *Neuroepidemiology* (2007) 29:44-8).

Acknowledgements

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How we can support you and your team

MND Connect

Our helpline offers help, information and support, and signposting to people living with MND, carers, family and health and social care professionals.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

Information resources

We produce high quality information resources for people living with MND, carers, family members and health and social care professionals.

www.mndassociation.org/publications

MND Association website

We have a wide range of information to support health and social care professionals working with people affected by MND.

www.mndassociation.org/professionals

Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND. Opportunities include online modules and face-to-face training.

www.mndassociation.org/education

Support grants and equipment loan

Where statutory provision is not available, we may be able to offer a support grant or loan equipment.

www.mndassociation.org/getting-support

Research into MND

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure.

www.mndassociation.org/research

MND register

The MND Register of England, Wales and Northern Ireland aims to collect information about every person living with MND to help plan the best care and discover more about the cause of the disease.

www.mndregister.ac.uk

Regional staff

We have a network of regional staff with specialist knowledge of MND. They work closely with local statutory services and community care providers. Contact MND Connect for further information.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

MND care centres and networks

We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist multidisciplinary care for people with MND.

www.mndassociation.org/care-centres

Branches and groups

We have volunteer-led branches and groups nationwide providing local support and practical help to people with MND and their carers.

www.mndassociation.org/branchesandgroups

Association visitors (AVs)

AVs are trained volunteers who provide one-to-one local support to people affected by MND. They can support people affected by MND in person, by telephone or by email or through support groups.

www.mndassociation.org/associationvisitors

We value your feedback

Your feedback helps improve our information for the benefit of people living with MND and those who care for them. Visit www.smartsurvey.co.uk/s/mndprofessionals or email your comments to infofeedback@mndassociation.org

If you would like to help us by reviewing future versions of our information resources, please email us at infofeedback@mndassociation.org