MND Association | For professionals

P5

Providing medical evidence for benefits applications

Motor Neurone Disease (MND) results from the progressive loss of motor neurones in the brain and spinal cord. These are the nerve cells that control movement. It leads to muscle weakness and can cause difficulties with movement, breathing, swallowing and speaking.

People with MND may apply for disability and 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.

1. **The importance of medical evidence**
2. **How professionals can help**
3. **How MND qualifies for the Special Rules**
4. **Further information**

Information to share with people with or affected by MND:

Information sheet 10A – Benefits and entitlements

See page 7 for details of how to order publications.

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 **mndassociation.org/benefitsadvice** for current contact details, or contact our MND Connect helpline for guidance. Call 0808 8026262 or email mndconnect@mndassociation.org.

1. The importance of medical evidence

The disability and employment benefits systems are 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.

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 anxiety 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.

2. How professionals can help

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.

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.

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 contact details of a person who can provide additional evidence. Encourage the person with MND to provide the name of the coordinator at their MND care centre, if relevant, or the name of their specialist nurse or consultant at their neurology clinic.

Use the “Special Rules for End of Life”

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.

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 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 Payment 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 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.

3. How MND qualifies for the Special Rules

The disability and 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. 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 considered for all people 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.

4. 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 **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.

References

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

How we can support you and your team

Our MND Connect helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. They can also provide further information about our services mentioned below.
Email: **mndconnect@mndassociation.org**
Tel: **0808 8026262**

MND Association website

Our website offers supporting information on MND, our work, services, and how to get involved.
mndassociation.org/professionals

Stay updated on events, publications and opportunities for professionals.
mndassociation.org/educationupdate
X: **mndeducation**
Bluesky: **mndeducation.bsky.social**

Information resources

We produce high quality information for people with MND, carers, families and professionals, available in multiple formats and languages.
mndassociation.org/pro-info-finder
mndassociation.org/careinfofinder

Education

Our education programme aims to improve standards of care and quality of life. Opportunities include webinars and face to face equipment training.
mndassociation.org/education

MND Professionals' Community of Practice

A peer led group supporting cross disciplinary learning in MND care. Membership can contribute to CPD and offers access to networking and learning events.
mndassociation.org/cop

Local support

We offer online and local peer support, plus trained volunteers who provide practical help by phone, email or visits.
mndassociation.org/local-support

We fund and develop specialist care centres and networks across England, Wales and Northern Ireland, offering multidisciplinary care.
mndassociation.org/care-centres

Financial support

We offer a range of grants to support people living with MND, their families and unpaid carers. These are not in place of any statutory funding that should be available.
mndassociation.org/getting-support

MND register

The Register aims to collect information about everyone with MND in England, Wales and Northern Ireland to support care planning and research.
mndregister.ac.uk

Research into MND

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND. We also produce information sheets on MND research for people with or affected by MND.
mndassociation.org/research

Acknowledgements

Thank you to the following people for their valuable contributions to this information sheet, and earlier versions:

Colette Bloomfield	MND Care Centre Co-ordinator and Neurosciences Nurse, Barts Health MND Care Centre
Gitana Zvikaite	MND Co-ordinator, MND Care Centre, Barts Health NHS Trust, Royal London Hospital
Jackie Hankins	Welfare Rights Manager, Neath Port Talbot County Borough Council
Sarah Hayle	Chief Executive, Community Law Service

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 **smartsurvey.co.uk/s/mndprofessionals** or email your comments to education@mndassociation.org.

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

How to order our publications

Our publications are free for anyone with or affected by MND or Kennedy's disease, including professionals. Health and social care professionals can also order items on behalf of someone with or affected by MND or Kennedy's disease.

Download from **mndassociation.org/publications** or contact MND Connect to order hard copies. Call 0808 8026262 or email mndconnect@mndassociation.org.

Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

Tel: 01604 250505
Email: enquiries@mndassociation.org
Website: mndassociation.org

Registered Charity no. 294354

Created: May 2023
Next review: May 2026
Version: 2

MND Association

Every day we support people affected by Motor Neurone Disease. Because with MND, every day matters.