

P5

## Providing medical evidence for benefit applications made by people with MND

### Information for health and social care professionals

**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 terminal illness' 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 from our website at [www.mndassociation.org/publications](http://www.mndassociation.org/publications)

See page 4 for details of how to order copies.



Sometimes, our new patients don't know that they are entitled to these benefits. In our clinics I always advise our patients to apply for them as soon as possible, and help them to do so."

Gitana, MND Coordinator

## 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 health and social care 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 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 neurological clinic.

#### 4 Use the Special Rules for terminal illness and DS1500 certificate

If someone is applying for Attendance Allowance, Personal Independence Payment, Employment and Support Allowance or for a reassessment of Disability Living Allowance, the claim will be fast-tracked and considered for benefits under the 'Special Rules for terminal illness' provisions if a DS1500 is signed. This means the claim will be processed in days rather than months and the lengthy claim forms for PIP/AA 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 with a DS1500. A claim made under the normal 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 DS1500 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 a DS1500 form, and will be asked to send it in. The claim will then be completed.

## How MND qualifies for the Special Rules

In order to satisfy the Special Rules provisions fully, the person must be terminally ill. Legislation defines that: 'a person is "terminally ill" at any time if at that time the person suffers from a progressive disease and the person's death in consequence of that disease can reasonably be expected within six months.'

MND is a terminal, rapidly progressive disease. As a result, people with MND will pass the diagnosis element of Special Rules on the DS1500 form, as it is a terminal condition. However, the prognosis element can be problematic.

It is important to remember that MND is unpredictable. The DS1500 certificate only asks if there is a reasonable expectation that their prognosis could be six months. It does not mean that someone is going to die within six months, 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.<sup>1</sup> The MND Association strongly recommends that a Special Rules application using form DS1500 should be 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 six month prognosis is 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 six month period. Delays mean that someone may be living without any kind of financial support for many months.

## Reference

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

## Acknowledgements

Thank you to the following people for their valuable contributions to this information sheet:

**Sarah Hale, Advice Services Manager, Community Law Service, Northampton and County**

**Jackie Hankins, Welfare Rights Manager, Neath Port Talbot County Borough Council**

**Gitana Zvikaite, MND Coordinator, MND Care Centre, Barts Health NHS Trust, Royal London Hospital**

## How the MND Association can support you and your team

We support health and social care professionals to provide the best possible care for people living with MND, their carers and families. We do this in a number of ways:

### MND Connect

Our helpline offers help, information and support, and signposting to other services and agencies. The service is for people living with MND, carers, family members, health and social care professionals and Association staff and volunteers who directly support people with MND.

Telephone: **0808 802 6262**

Email: **[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**

Please contact MND Connect if you have any questions about the information in this publication.

### Information resources

We produce high quality information resources for health and social care professionals who work with people with MND. We also have a wide range of resources for people living with and affected by MND.

Downloads of all our information sheets and most of our publications are available from our website at **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)**. You can also order our publications directly from the MND Connect team.

### MND Association website

Access information for health and social care professionals on our website at **[www.mndassociation.org/professionals](http://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, such as conferences and masterclasses. Find out more at **[www.mndassociation.org/education](http://www.mndassociation.org/education)**

### MND support grants and equipment loan

Where statutory funding or provision has been explored and is not available, we may be able to provide a support grant or equipment loan.

Our support grant service consists of providing care grants and quality of life grants for people with MND. This service is supported by MND Association branch and group funds, and by the Association's central fund.

Our equipment loan service is focused on three core items of equipment to help people with day-to-day tasks and communication:

- riser-recliner chairs
- specialist communication aids
- portable suction units.

For suction units, a small charge is made to statutory services for carriage, maintenance and cleaning.

Referrals for support grants or equipment loan need to be made by an occupational therapist, speech and language therapist or other relevant health or social care professional. For enquiries about MND support grants or equipment loan, call the MND Support Services team on **01604 611802**, email **[support.services@mndassociation.org](mailto:support.services@mndassociation.org)** or visit **[www.mndassociation.org/getting-support](http://www.mndassociation.org/getting-support)**

### Wheelchair service

If you are seeking information on wheelchairs, or if there are delays in assessment or provision of an appropriate wheelchair for someone with MND, our wheelchair service may be able to help, through training, joint assessments, advice or support. For our wheelchair service, call MND Connect on **0808 802 6262** or email **wheelchairs@mndassociation.org**

### Communication aids service

This service helps people affected by MND and health and social care professionals with queries about communication aids. The service provides limited financial support for communication aids or some items on loan, if unavailable or delayed through health and social care services. Our aim is to improve provision and information on a local and national level, through collaboration with professionals. Call **01604 611767** or email **communicationaids@mndassociation.org**

### Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure. Contact the Research Development team on **01604 611880** or **research@mndassociation.org**. Alternatively, visit **www.mndassociation.org/research** for more information. For the latest research news, visit our research blog at **www.mndresearch.wordpress.com**

Our peer-to-peer research and care community blog (RECCOB) has a number of reporters who write updates on MND-related workshops and events around the world. Subscribe for email alerts at **www.reccob.wordpress.com**

### International Symposium on ALS/MND

Each year we organise the world's largest clinical and biomedical research conference on MND. It is the premier event in the MND research calendar for discussion on the latest advances in research and clinical management, attracting more than 800 delegates from at least 30 countries. Find out more at **www.mndassociation.org/symposium**

### MND Association membership

Join us now and help fight MND. Membership costs £12 for individuals. It is free for people with MND and for carers, spouses or partners of people living with MND. Call **01604 611855** or email **membership@mndassociation.org**

## Local support

### Regional care development advisers

We have a network of regional care development advisers (RCDAs) covering England, Wales and Northern Ireland. RCDAs have specialist knowledge of the care and management of MND. They work closely with local statutory services and community care providers to ensure effective support for people affected by MND. RCDAs provide education for health and social care professionals in MND, and are champions at influencing care services in their respective areas.

### MND care centres and networks

Care centres and networks are teams of professionals who are specialists in MND. We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer

### Branches and groups

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

### Association visitors (AVs)

Association visitors provide one-to-one local support to people affected by MND. Managed by regional care development advisers, they are volunteers with experience of MND who can visit people affected by MND within their homes or contact them by telephone, email or through local support groups. They can also provide a link with health and social care professionals. You may be in contact with Association visitors following up on queries from the families they support.

Please send us your feedback on  
**Providing medical evidence for benefit applications  
made by people with MND.**

Thank you for taking the time to provide your feedback on one of our information resources.

This questionnaire can be accessed online if preferred, using the following link:  
[www.surveymonkey.com/s/professionalinformation](http://www.surveymonkey.com/s/professionalinformation)

**What is your profession or specialism?**

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**Did you find this resource useful?**

Yes    Somewhat    Not really    No   Please explain your answer

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**Will this information resource help you to provide people affected by MND with any of the following? (tick all that apply)**

- |   |  |
|---|--|
| <input type="checkbox"/> an increased understanding of their symptoms           | <input type="checkbox"/> more confidence                       |
| <input type="checkbox"/> an increased understanding of their condition          | <input type="checkbox"/> improved quality of life              |
| <input type="checkbox"/> more independence                                      | <input type="checkbox"/> a greater ability to maintain dignity |
| <input type="checkbox"/> an increased ability to raise awareness of their needs |  |

**Were there any particular topics that were useful to you?**

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**Was there any information that you didn't find useful or relevant?**

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**Are there any other MND-related topics that you'd like more information about?**

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**Do you have any other feedback about this resource or our other information for professionals?**

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**Would you be happy to help us improve our information by becoming an expert reviewer?**

Yes (please include your email address below)    No

**Do you have any experiences of working with people with MND you could share as an anonymous quote or case study for future resources?**

Yes (please include your email address below)    No

Please return your completed form to:

Education and information team  
MND Association  
PO Box 246  
Northampton NN1 2PR

Name:

Email:

## About us

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND.

Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

## Our mission

We improve care and support for people with MND, their families and carers.

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

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

## About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound and feeling.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- It affects people from all communities.
- Some people may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia.
- MND kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is up to 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- MND kills six people per day in the UK.
- It has no cure.

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## MND Association

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