Work and MND

Information for people with or affected by motor neurone disease

Whether living with motor neurone disease (MND), or a main carer, you may be concerned about whether to continue your employment or not. This can be a difficult choice, as it is likely to affect you financially and emotionally.

This information sheet will help you think about ways to keep working for as long as possible – if that is what you wish – or how to leave work in a way that feels right for you.

The content includes the following sections:

1: Making a difficult choice
2: What do I need to think about if I want to continue working?
3: What do I need to think about if I decide to leave work?
4: What if I’m self-employed?
5: How do I find out more?

This symbol is used to highlight our other publications. To find out how to access these, see Further information at the end of this sheet.

This symbol is used to highlight quotes from other people with or affected by MND.

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

www.england.nhs.uk/tis
1: Making a difficult choice

Thinking about leaving work can cause financial worry and feel emotionally challenging. It is your decision, but may not feel like free choice with MND, which can be upsetting. Take time to adjust before making any big decisions.

“The decision about work was one of the most difficult I faced. Ultimately I decided to carry on with my life as normally as possible for as long as I could. Remaining in employment was part of this plan.”

However, if your work has been stressful or physically hard, leaving may be a relief. Or it may not be a priority for you.

“When I was told my diagnosis, work was the last thing on my mind.”

Yet work provides a sense of purpose and social contact. This can be difficult to leave behind and you are likely to feel a sense of loss.

Leaving work may provide time for other plans, but this will depend on your symptoms, your financial situation and what you want or feel able to achieve.

If you decide to leave work and find this particularly distressing, it can help to tell your family and friends about your concerns. You can also ask your GP or neurologist for a referral to counselling, although there is often a waiting list.

Our helpline, MND Connect, can provide a listening ear and guidance about services (see Further information at the end of this sheet for contact details).

2: What do I need to think about if I want to continue working?

“I was determined to carry on teaching and I believe my pupils benefit from having me as a positive role model.”

If you wish to continue working for as long as possible, you need to plan ahead, as MND is unpredictable. You are unlikely to have the same symptoms, in the same order as someone else. The speed at which symptoms get worse can also vary.

Ask your health and social care team for advice on how to manage anything likely to affect your work.

MND means that daily tasks take longer to complete. Adapting your home or workplace can assist and specialist equipment can help you remain independent for as long as possible.
Assessment by your health and social care team is advised, to work out suitable support for your current and future needs. Some equipment may be free through the NHS or government schemes.

Consider telling your employer about your diagnosis as soon as possible, as they may be able to help. It will be difficult to keep MND private, as the physical symptoms will increase.

“One manager was sorry to hear about my diagnosis, but relieved I wasn’t drinking at lunch, as he thought my speech occasionally sounded slurred in the afternoon and was thinking of having a quiet word with me.”

Early discussion gives your employer time to make arrangements to help you keep working and you may want to discuss how your colleagues will be informed about your situation.

“My colleagues never made me feel a burden or embarrassed. They were fantastic. Their support kept me going at work for longer than I expected I could do it.”

Ask your employer about the following options:

• the Access to Work scheme and adapting your working environment (see heading How can Access to Work help me?)
• working from home, which depends on the effects of MND, but may be suitable if you work by computer, email or telephone
• flexible or reduced working hours (see heading How do I arrange flexible working hours?)
• changing from physical tasks to desk based tasks.

Do my employment rights change with MND?

You have the same employment rights as other employees, but there are additional rights for disabled workers. Your employer must respect these rights, which are governed by the Equality Act 2010.

In the Act, a person has a disability if:

• they have a physical or mental impairment
• their ability to perform day-to-day activities is reduced substantially or long term.

MND is recognised in the Act as a progressive condition which will cause disabilities.
Your employer:

- must not treat you less favourably because of disability (you cannot be made redundant simply because of this)
- has a duty to make appropriate changes, known as ‘reasonable adjustments’ to avoid you being disadvantaged to non-disabled people, such as adjusting work hours or providing adapted equipment.

**How can Access to Work help me?**

The Access to Work scheme helps employers get grants to provide:

- equipment or adaptations to enable employees with disabilities to do their work
- travel costs by taxi if you can no longer drive or use public transport
- a support worker in the workplace or a communicator for support at job interviews.

The following steps need to happen to obtain a grant:

1. Discuss your diagnosis with your employer and what help is needed.
2. Contact the Access to Work scheme (see the heading *Useful organisations* for details of Access to Work centres) or seek advice from your Disability Employment Adviser (DEA) at your local Jobcentre.
3. Give your National Insurance number to the Access to Work adviser and answer their questions about your health to help them understand your needs. Tell them who to contact at your place of work.
4. Agree to an appointment with the Access to Work adviser, who will arrange this. They need to speak to you and your employer to determine the right level of support.
5. Check through their completed application form, which they will send through the post for you and your employer to agree. Once you send this back to them you should hear back within two weeks.
6. Wait for their letter to tell you the level of support agreed.

**How do I arrange flexible working hours?**

From 30 June 2014, every employee has the statutory right to request flexible working after 26 weeks of employment. This might include:

- flexible start and finish times, or compressed working hours (working your agreed hours over fewer days)
- annualised working hours (your hours are worked out over a year)
- job sharing, part-time work, term-time work, home working or teleworking.
To make a request, you must do this in writing, showing the date, the change you are seeking and when you would like this to take effect. State whether this is to support you with a disability or to support someone else (if you are a carer). Include the date of any previous application for flexible work.

It may help to explain how you think this could affect the business – for example, it may save the business money if you work less hours.

Your employer must consider your request and can only refuse if there is a business reason from the following list:

- the burden of additional costs is too heavy
- they are unable to reorganise work amongst existing staff or recruit additional staff
- it will badly affect quality, performance or ability to meet customer demand
- there is not enough activity for the periods you want to work
- there are planned structural changes to the business.

**Can I take Statutory Sick Pay (SSP)?**

There may come a time with MND when you need to take sick leave. Your employer is legally bound to manage this and help you return to work, if this is possible and what you want. Keep your employer updated while away.

If employed, but unable to work because of illness or disability, you may be able to get Statutory Sick Pay (SSP), even if you have just started your job. To get SSP you must:

- tell your employer that you are sick
- have been sick for at least four days in a row, including days you do not normally work
- provide some form of medical evidence from the eighth day of your illness, if asked by your employer.

Your GP can provide medical evidence using a Fit Note, which states whether or not you may be fit for work. When this advises you ‘may be’ fit for work, your employer should make arrangements to assist your return.

If you are still unable to work after 28 weeks or cannot get SSP, you can apply for Employment and Support Allowance (ESA) or Universal Credit.

You may be able to claim other benefits too. Some of these are paid regardless of income, such as Personal Independence Payment (PIP).

For more information about benefits, see:
Information sheet 10A - *Benefits and entitlements*
If your employer has an occupational sick pay scheme, they may offer to keep you on sick pay for as long as they can. In this situation, you may still be able to claim ESA after 28 weeks of SSP, but income from this and your employer may affect your entitlement to other benefits, where your finances are assessed (known as means testing).

Long term sick pay can be expensive for your employer, so it is worth discussing options. For example, they may be willing to provide a lump sum ‘good service’ exit payment, but this could also affect benefits where income and savings are taken into account. Try to be fully informed before making any decisions.

If you are self-employed you cannot claim SSP, but you may be able to claim ESA or Universal Credit. Check with your local JobCentre Plus to see if you will qualify.

**What is ‘permitted work’?**

If you are unemployed and claiming Employment Support Allowance (ESA), you may be able to carry out certain types of paid work and still receive ESA. This is known as permitted work, which allows you to work a limited number of hours and earn up to a set amount while claiming. This may enable you to take part-time work or begin a new self-employed activity.

This also applies if you have an illness or disability that severely limits your ability to work. In this instance it is known as ‘supported permitted work’, which is monitored by someone from a local council or a voluntary organisation that arranges work for disabled people.

There is no limit to the number of hours per week or how long you can do this work, but there will be a limit to the amount you can earn and still claim ESA. You can find out more by searching for ESA at [www.gov.uk](http://www.gov.uk) and referring to the page on eligibility.

You can work a number of hours and earn a limited amount while claiming other benefits, such as Income Support or Universal Credit. This is likely to affect the amount of benefit you receive – check the rules with the office or contact for each benefit.

**Employment disputes or guidance on options**

There may come a time when it is no longer possible for you to carry out your normal duties with MND. You employer cannot dismiss you on this basis. They must look at other options for you, such as shorter hours, lighter tasks or reasonable adjustments to your place of work. This may affect your contract, but your employer must follow the correct process.

“Employers are often unclear about their obligations towards disabled employees. A little bit of knowledge before discussing your needs with an employer can be very helpful indeed.”
If you have any concerns about your employment, contact an independent adviser or your local authority Welfare Rights Service for advice.

You may also find it helpful to contact the following:

- Acas - The Advisory, Conciliation and Arbitration Service
- The Department of Work and Pensions (DWP)
- Citizens Advice Bureau (CAB)

For more information and contact details, see Useful organisations later in this sheet.

A trade union can also help. They can negotiate with an employer on your behalf or provide guidance about:

- your contract (whether you wish to continue or leave work)
- discrimination in the workplace and your rights as an employee
- useful support options and schemes in your work sector.

“I had difficulty representing myself. Ultimately I stepped aside and allowed my representative to speak on my behalf. This took a lot of pressure off me.”

You usually have to join a trade union as a member, which involves a subscription fee. You can find out which trade union is recognised in your workplace by looking for trade union details on staff notice boards or your work intranet. You can also ask your employer, the Trade Unions Congress (TUC) or the Certification Officer, which is a public body listing details of most trade unions (see heading Useful organisations for contact details).

3: What do I need to think about if I decide to leave work?

You may wish to discuss available options with your family, friends or independent advisers, before approaching your employer. However, it is important to make the right choice for you, as well as those close to you. If you decide to leave work, the timing of this can be managed with help. Ask your employer what happens with the following options:

- taking paid or unpaid leave while you explore your options – this is at the discretion of your employer
- taking sick leave, when needed (see heading Can I take Statutory Sick Pay (SSP)?)
- taking a lump sum payment instead of long term sick pay, if an exit payment is available from your employer
- taking early retirement due to ill-health, if your pension enables this choice (see heading Is early retirement a good option?)
- taking voluntary redundancy, if this is available.
We recommend asking an accountant or trusted financial adviser to help review your finances and options before leaving work. Also find out which benefits you may be entitled to receive (see heading *What financial support is available?).

**Will I need an Occupational Health Assessment?**

Your employer may refer you for an Occupational Health Assessment if they feel your condition affects your ability to work effectively or safely in your job.

You cannot be dismissed because you have become disabled, but – in line with disability discrimination legislation – the assessment report will help your employer think about ways to help you keep working, if you wish to do this.

However, if your condition is unlikely to improve and assistance is no longer helping (where adapting your place of work, changing your tasks, flexible working and extra support have all been tried), then retirement due to ill health may be considered.

You or your employer can suggest this. An Occupational Health Assessment will be required and your GP or another health and social care professional will answer questions about your health. The final report allows you to apply for release of pension funds if retirement due to ill-health is applicable.

**Is early retirement a good option?**

State Pension cannot be claimed until you reach pensionable age. You can find government advice about this through the GOV.UK online service at: [www.gov.uk/early-retirement-pension/state-pension](http://www.gov.uk/early-retirement-pension/state-pension)

However, you may be able to retire early with an occupational or private pension. In most cases, 55 is the earliest age you can do this. This may be flexible with ill-health, depending on your pension agreement.

Early retirement usually means you will receive smaller payments, although some providers will boost these payments if illness affects life expectancy.

Pension schemes vary widely. In some cases you may be able to access a lump sum or tax-free lump sum, incentives for early retirement or a refund of contributions (known as a cash transfer sum).

Check your pension details with an independent pension adviser.
Whether to retire early or not needs thought. Your decision may be influenced by:

- the rules of your scheme and the amount available within the pension
- pension payments may prevent you from receiving certain benefits or reduce the amount you are entitled to receive (see the next heading *What financial support is available?*)
- the rate at which your MND is progressing and whether you wish to stay employed so your family can benefit from death in service payments (if available).

**What financial support is available?**

Leaving work is likely to have a financial impact and care needs can be expensive, especially if you need extra help at home. If you are living with MND, you can ask for a care assessment (often referred to as a Community Care Assessment) to review your home care needs. Carers can also access a Carer’s Assessment to review their needs.

You will be financially assessed to see if you need to contribute to these care services. Services can be arranged for you or you can choose to select and buy services for yourself.

For more information see:

Information sheet 10B – *Direct payments and personalisation*

During the assessment, ask for advice about claiming benefits. You may be able to claim various entitlements, especially if you leave work.

For more information see:

Information sheet 10A – *Benefits and entitlements*

The MND Association loans certain items of equipment and provides MND Support Grants for a variety of needs. All statutory funding and services must have been explored first (those provided by the NHS or the government).

In most cases, the initial request for equipment loan or an MND Support Grant must be made through a health and social care professional, following an assessment of individual need (see *Further information* at the end of this sheet for our Support Services contact details).

**What do I need to know about personal investments?**

You may have investments, such as insurances, personal pensions, savings, stocks, shares or other arrangements. Review these before making decisions about reducing your hours or leaving work.

Each scheme will vary, so ask your provider, accountant or a trusted financial adviser for advice. Try to gain as much advice as possible before taking any action.
Think about how your decisions could affect other finance. For example:

- reducing your hours might impact on the pay-out for work-related schemes or pensions, where the sum is based on your final salary
- there may be a best time to sell stocks and shares
- taking lump sum payments may be helpful, but could take your capital above a point where you can receive certain benefits.

4: What if I’m self-employed?

You may be working:

- as a sole trader or freelance consultant
- in a partnership or as a limited company
- as self-employed through an agency, or by contracting or sub-contracting.

You may want to continue self-employment for financial reasons or because you enjoy this role.

Whether you continue, work less hours or stop can affect your finances in unexpected ways.

For example, if your net profit reduces, you may be able to claim Working Tax Credit or Child Tax Credit.

Seek advice from:

- an accountant to review your income, investments and tax
- a legal expert specialising in self-employment or company law if you are subject to any contracts
- a benefits adviser to explore what you may be entitled to, but this may depend on the amount of National Insurance you have been paying.

Also see Can I take Statutory Sick Pay (SSP)? and What is Permitted Work? in section 2: What do I need to think about if I want to continue working?
5. How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information.

The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline (see Further information at the end of this sheet for details).

**Acas: Advisory, Conciliation & Arbitration Service**
Confidential advice on unfair dismissal or flexible working.
Address: Euston Tower, 286 Euston Road, London NW1 3JJ
Telephone: 0300 123 110
Website: [www.acas.org.uk](http://www.acas.org.uk)

**Access to Work**
Advice on how your employer can support you in your workplace.

Address: Jobcentre Plus, Access to Work Operational Support Unit, Harrow
Jobcentre Plus, Mail Handling Site A, Wolverhampton WV98 1JE
Telephone: 0345 268 8489
Email: atwosu.london@jobcentreplus.gsi.gov.uk

**Cardiff centre: For South West England, Wales, West Midlands and East Midlands**
Address: Jobcentre Plus, Access to Work Operational Support Unit,
Alexandra House
377 Cowbridge Road East, Cardiff CF5 1WU
Telephone: 02920 423 291
Email: atwosu.cardiff@jobcentreplus.gsi.gov.uk

**Glasgow centre: For Scotland, North West England, North East England, Yorkshire and Humberside**
Address: Jobcentre Plus, Access to Work Operational Support Unit, Anniesland JCP,
Baird Street, Glasgow G90 8AN
Telephone: 0141 950 5327
Email: atwosu.glasgow@jobcentreplus.gsi.gov.uk

**Northern Ireland:**
Contact an Employment Service Adviser in your local Jobs & Benefits office or JobCentre for advice on Access to Work. You can locate your nearest branch by:
Telephone: 0800 353 530 (free phone)
**Advicenow**
An independent, not-for-profit website providing up-to-date information on rights and legal issues. Online information only.
Website:  [www.advicenow.org.uk](http://www.advicenow.org.uk)

**Age UK**
Advice and information services for people in later life, including support on benefits.
Address: York House, 207-221 Pentonville Road, London N1 9UZ
Telephone: 0800 169 6565
Email: contact@ageuk.org.uk (England)
enquiries@agecymru.org.uk (Wales)
info@ageni.org (Northern Ireland)
Website:  [www.ageuk.org.uk](http://www.ageuk.org.uk)

**Certification Officer**
An organisation that can help you find a trade union.
Address: 22nd Floor, Euston Tower, 286 Euston Road, London NW1 3JJ
Telephone: 020 7210 3734
Email: info@certoffice.org
Website:  [www.certoffice.org/Nav/Trade-Unions.aspx](http://www.certoffice.org/Nav/Trade-Unions.aspx)

**Citizens Advice Bureau (CAB)**
Free and confidential advice to help to resolve legal, money and other problems.
Telephone: 08444 111 444 (for England, or contact your local CAB branch)
0844 477 2020 (for Wales)
Website:  [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk) (main site)
[www.adviceguide.org.uk](http://www.adviceguide.org.uk) (online help)
[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk) (for Northern Ireland)

**Department of Work and Pensions**
Responsible for welfare, pensions and various disability and ill health benefits.
Address: Caxton House, Tothill Street, London SW1H 9NA
Telephone: 0845 604 3719
Email: ministers@dwp.gsi.gov.uk
Website:  [www.gov.uk/government/organisations/department-for-work-pensions](http://www.gov.uk/government/organisations/department-for-work-pensions)

**DIAL UK**
Information on all aspects of living with a disability, including welfare benefits.
Address: St Catherine’s, Tickhill Road, Doncaster, South Yorkshire, DN4 8QN
Telephone: 0808 800 3333 (helpline)
Email: helpline@scope.org.uk
Website:  [www.scope.org.uk/support/disabled-people/local-advice](http://www.scope.org.uk/support/disabled-people/local-advice)
Disability Law Service
Assistance on disability law.
Address: 39-45 Cavell Street, London, E1 2BP
Telephone: 020 7791 9800
Email: advice@dls.org.uk
Website: www.dls.org.uk

GOV.UK
Government online information about employment support and benefits.
Email: different contacts are given on the website for various subjects
Website: www.gov.uk (England and Wales)
www.nidirect.gov.uk (Northern Ireland)

Health at Work Wales
Provides employers and employees with free, confidential advice on work related health issues and how to make reasonable adjustments to support in the work place.
Telephone: 0800 107 0900
Website: www.healthatworkwales.org.uk

Jobcentre Plus
For assistance with job seeking and benefits. The GOV.UK website enables you to search for the address of your local Jobcentre Plus and access a variety of telephone numbers.
New claims only:
Telephone: 0800 055 6688
Textphone: 0800 023 4888
Welsh Language: 0800 012 1888
Email: Through website pages only
Website: www.gov.uk/contact-jobcentre-plus (England and Wales)

MND Scotland
Care, information and research funding to support people affected by MND in Scotland.
Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA
Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: www.mndscotland.org.uk

NIDirect
Government advice on health and social services for Northern Ireland.
Address: Castle Buildings, Stormont, Belfast BT4 3SJ
Telephone: 028 90520500 (main switchboard)
0800 220 674 (benefit enquiry line)
Email: through website contact page
Website: www.dhsspsni.gov.uk
The Pensions Advisory Service
Guidance on pensions, including state, company, personal and stakeholder schemes.
Address: 11 Belgrave Road, London SW1V 1RB
Telephone: 0845 601 2923 (pensions helpline)
0845 600 0806 (pensions helpline for women)
0845 602 7021 (pensions helpline for self-employed)
Email: enquiries@pensionsadvisoryservice.org.uk
Website: www.pensionsadvisoryservice.org.uk

The Pension Service
For queries and claims regarding state pensions.
Telephone: 0345 6060 265
Textphone: 0345 606 0285
0800 99 1234 (pension credit claims/queries)
0845 601 8821 (Northern Ireland)
Website: www.gov.uk/contact-pension-service
www.nidirect.gov.uk (for Northern Ireland. Search for pensions.)

Adult social care services (sometimes called social services)
For adult social care contact your local authority through your area telephone directory, or search for local councils at GOV.UK
Website: www.gov.uk
www.nidirect.gov.uk (for Northern Ireland. Search for health and social care trusts.)

Trade Unions Congress (TUC)
Help to find trade unions relevant to your work sector.
Address: Congress House, Great Russell Street, London WC1B 3LS
Telephone: 020 7636 4030
Email: info@tuc.org.uk
Website: www.tuc.org.uk/tuc/unions_main.cfm or www.worksmart.org.uk/

Acknowledgements
Many thanks to the following for their valuable guidance in the development or revision of this information:

Rosemary Bell, Senior Welfare Rights Officer, Newcastle City Council
Michael Leonard, Specialist Disability Employment Adviser, Jobcentre Plus
Neil Arnott, Social Welfare Training Limited, Bristol
Sarah Hayle, Advice Services Manager, Community Law Service, Northamptonshire
References

References used to support this information are available on request from:

email: infofeedback@mndassociation.org

Or write to:
Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

Further information

We have related information sheets you may find helpful:

10A – Benefits and entitlements
10B – Direct payments and personalisation
10C – Disabled Facilities Grants, home adaptations and housing issues
10D – NHS Continuing Healthcare

You can also refer to our main guides:

Living with motor neurone disease – our guide to MND and how to manage its impact, including guidance about your finances

Caring and MND: support for you – comprehensive information for family carers, who are supporting someone living with MND

Caring and MND: quick guide – the summary version of our information for carers

You can download most of our publications from our website at:
www.mndassociation.org/publications or order in print from the MND Connect team, who can provide additional information and support:

MND Connect
Telephone: 0808 802 6262
Email: mndconnect@mndassociation.org
MND Association, PO Box 246, Northampton NN1 2PR

Support Services
(INCLUDING equipment loan and MND Support Grants)
Telephone: 01604 611802
Email: supportservices@mndassociation.org

MND Association website and online forum
Website: www.mndassociation.org
Online forum: http://forum.mndassociation.org or through the website
We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: www.surveymonkey.com/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email: infofeedback@mndassociation.org

Or write to:
Information feedback, MND Association, PO Box 246, Northampton NN1 2PR