

10E Work and MND

Information for people with or affected by motor neurone disease or Kennedy's disease

When facing the challenges of MND or Kennedy's disease, you and your carer may be thinking about whether to continue in employment. This can be an emotional choice, as it is likely to affect your finances and sense of purpose.

This information sheet explores the options available, including:

- 1: **Making your choice**
 - 2: **What are my rights?**
 - 3: **What do I need to think about if I want to continue working?**
 - 4: **What do I need to think about if I decide to leave work?**
 - 5: **What if I'm self-employed?**
 - 6: **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.



Patient Information Forum

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



“People with MND commonly give up work due to the impact of the condition and family members may often reduce or stop work altogether to provide care. Over one-fifth (21%) of MND carers have had to reduce their work hours with a further third (36%) leaving full employment altogether. This is having a major impact on household income – 58% of carers said that current carer related benefits do not cover earnings from loss of employment.”

*The MND Carer Triple Burden:
Rising Costs, Falling Earnings and Benefits Shortfalls
(MND Association - 2024)*

1: Making your choice

Thinking about leaving work can cause financial worry and feel emotionally challenging. This is your decision but may not feel like a free choice if you have MND or you're supporting someone who has been diagnosed. Take time to adjust before making any big decisions.

If you're living with Kennedy's disease you may be able to continue working, depending on how the condition affects you. However, you may need support and find this sheet helpful.



“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.”

Whatever your circumstances, you may want to continue working. However, employment may not be a priority for you.



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

If you do leave work, you may feel a loss of purpose and social contact, but it can give time for other plans. This will depend on your symptoms or caring responsibilities, financial situation and personal wishes.

It may help to discuss concerns with family and friends. If making this decision feels distressing, ask your GP or neurologist for a referral for counselling, but there may be a waiting list. Some employers offer counselling services.

Our helpline, MND Connect, can provide practical information, emotional support and guidance about services (see *Further information* at the end of this sheet for contact details).



Our booklet, *Telling people about MND*, can help open conversations with colleagues, family, children, friends and health and social care professionals.

2: What are my rights?

You have the same employment rights as other employees, but there are additional rights for disabled workers and unpaid carers.

Right to time off for family and dependants

Any employee has the right to time off if a family member or dependant is in an emergency.

This means that if you're a carer and the person you support needs urgent treatment, you can leave work to take appropriate action.

There is no set limit to how long you can take, as this depends on the situation, but it is usually one or two days at a time. Your employer can still pay you for the time taken off, but they don't have to.

Your employer mustn't treat you unfairly, dismiss you or make you redundant for taking time off in emergency situations, and they also can't refuse you 'reasonable' time off.

To find out more about time off for family and dependants, search for *time off for family* at: www.gov.uk or for Northern Ireland at: www.nidirect.gov.uk

Awareness of your legal Rights can help you when making decisions. Find out more about the following Acts for England, Wales, Northern Ireland or Scotland at: www.legislation.gov.uk

Rights in England

Equality Act 2010

The Equality Act 2010 protects people in England, Wales and Scotland from discrimination (being treated unfairly for being who you are). The Act protects you from discrimination in the workplace if you're disabled.

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.

Have a conversation with your employer about reasonable adjustments in your workplace, for example, installing a ramp for access or changing your equipment.



“I have a new chair at work to support my head a little more and brakes on it to stop it from rolling away when I try to get up.”

Care Act 2014

This Act applies to people living in England. The Care Act 2014 sets out your legal right to assessment and support.

Under the Act, it is your right to have a needs assessment or carer’s assessment if:

- you need support because of illness or disability
- you are providing care for someone.

It is your local authority’s legal duty to promote your wellbeing every time a decision is made about you. If you’re living with MND, they must focus on your wellbeing in your needs assessment. If you’re a carer, your local authority must consider the impact of your caring responsibilities on your wellbeing.

Under the Act, many different activities count towards wellbeing, including the ability to take part in work. The assessment should find out whether you want and feel able to continue working. For example, if you’re a carer, and unable to work due to caring responsibilities, you may be able to get support if this impacts on your wellbeing.

The Carer’s Leave Act 2024

This became law on 6 April 2024. If you are balancing unpaid care with paid employment, you have the legal right to up to five days of unpaid carer’s leave.

This will be less if you work part-time, based on the days you work. Some employers will give you paid leave but that is their decision, not in the Act.

If employed, you are entitled to unpaid leave to give or arrange care for anyone who is dependent on you. This means they rely on you because they have:

- a physical or mental illness or injury that means they're expected to need care for more than 3 months
- a disability (as defined in the Equality Act 2010)
- care needs as they are elderly

You are entitled to carer's leave from your first working day with your employer.

Employment rights, like holidays and returning to your job, are protected during carer's leave.

Rights in Wales

Equality Act 2010

The Equality Act 2010 and the Carers Leave Act 2024 apply to people living in England, Wales and Scotland.

See *Equality Act 2010* under the heading *Rights in England* for more information.

Social Services and Well-being (Wales) Act 2014

The Social Services and Well-being (Wales) Act 2014 aims to improve the wellbeing of people who need care and support, and for carers who need support.

One of the activities that counts towards wellbeing under the Act is your ability to take part in work. In the Act, it is your right to have an assessment if you're living with MND or Kennedy's disease, or if you're a carer.

If you're living with MND or Kennedy's disease and your assessment finds that you need support, your local authority has a legal duty to arrange or provide services for you, if help can't be found elsewhere.

If you're a carer, you will be entitled to support if:

- you need help meeting the needs of the person you're providing care for
- you can't meet the person's needs, either with help from friends and family or services you already have access to.

Rights in Scotland

Equality Act 2010

The Equality Act 2010 and the Carers Leave Act 2024 apply to people living in England, Wales and Scotland.

See *Equality Act 2010* under the heading *Rights in England* for more information.

The Public Bodies (Joint Working) (Scotland) Act 2014

The Public Bodies (Joint Working) (Scotland) Act helps to ensure a consistent provision of quality, sustainable care services for people in Scotland who need joined-up support and care, particularly people with multiple, complex, long-term conditions.

Rights in Northern Ireland

Disability Discrimination Act 1995

If you're living with MND or Kennedy's disease in Northern Ireland, the Disability Discrimination Act 1995 protects you from being discriminated against at work for being disabled.

Your employer must not treat you unfavourably for being disabled and has a legal responsibility to make reasonable adjustments in the workplace, to prevent you from being disadvantaged to non-disabled people.

Carers Leave Act 2024 does not apply in Northern Ireland, see:
www.nidirect.gov.uk/articles/caring-someone-while-working

Carers and Direct Payments Act (Northern Ireland) 2002

The Carers and Direct Payments Act (Northern Ireland) 2002 sets out your right to an assessment if you are providing care for someone in Northern Ireland, whether or not they are getting help from social services.



For more information, see:
Information sheet 10B – *What is social care?*

3: 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 have MND and wish to continue working for as long as possible, you need to plan ahead, as the condition 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.

If you're living with Kennedy's disease, symptoms are similar to those of MND but are usually milder and progress more slowly.

However, disability will increase with either condition, which means daily tasks take longer to complete. Adapting your home or workplace can help, and specialist equipment may prolong your independence.

Discussion with your health and social care team

If you're living with MND or Kennedy's disease, seek an assessment by your health and social care team to work out suitable support for your current and future needs.

Some equipment may be free or available on loan through NHS or government schemes. Equipment to support independence at home and in the workplace may enable both you and your carer to stay at work for longer.



For helpful resources select the options for *Mobility*, *Personal care* and *Social care* on our care information finder:

www.mndassociation.org/careinfofinder

Ask your health and social care team for advice on how to manage any symptoms likely to affect your work. You may wish to use the NICE guideline on MND to open this conversation. The guideline sets out recommendations for health and social care professionals about the treatment and care of people with MND.

If you have MND, the NICE guideline recommends that health and social care professionals assess you for possible changes to daily living needs. This may include providing equipment and adaptations to help you take part in daily living activities. Work is included in the guideline as a daily living activity.


If you're a carer, the NICE guideline recommends that health and social care professionals inform you of your legal rights to social care support, employment rights and benefits.

The NICE guideline is for health and social care professionals, but could help your employer check if they're supporting you in the best way possible. It may also help them when applying for an Access to Work grant if you're disabled (see the heading *How can Access to Work help me?* for more details on this scheme).


 See our Information sheet 1A – *NICE guideline on motor neurone disease* and our pocket guide: *What you should expect from your care*.

Discussion with your employer

Tell your employer about the diagnosis as soon as possible, as they may be able to help. If you're living with MND or Kennedy's disease, it will be difficult to keep the condition 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. You may want to discuss how your colleagues will be informed about your situation too.


 Our booklet *Telling people about MND*, can help open conversations with colleagues, family, children, friends, and health and social care professionals.

If you're a carer, the level of care you provide is likely to increase as the disease progresses. Let your employer know about your situation to give them a better understanding of your current and possible future needs. They may be able to make adjustments to help you continue working, if needed.

Ask your employer about the following:

- adapting your working environment if you have MND or Kennedy's disease (see heading *How can Access to Work help me?*)
- changing from physical tasks to desk-based tasks if your symptoms place you or others at any risk
- working from home
- flexible or reduced working hours (see heading *How do I arrange flexible working hours?*)

If you're a carer, you may need to provide a period of more intensive care at some point, for example if the person you support needs treatment and recovery time. In this case, you may wish to ask your employer if paid or unpaid leave is available. This decision will be up to your employer, based on the particular situation.

 See our guide *Caring and MND: support for you*.

How do I arrange flexible working hours?

Flexible working can help you find balance between your job and your needs. 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, and working from home.



“I am on a six hour a week annualised contract... I don't work two consecutive shifts as I find I'm tired after six hours at work and need an easy day the following day.”

Ask your employer for a flexible working change in writing or by email, and state that it is a statutory request. List the:

- date of application
- the change you need
- when you would like this to start
- whether this is to support you with a disability or to support as a carer
- the date of any previous applications you've made (as you can only make one formal application for flexible working each year).

The longest it can take for your employer to decide is 2 months (14 weeks in Northern Ireland), unless they agree a longer time period with you. If you feel you may benefit from flexible working, it is best to plan ahead and apply for this early.

It may help to explain how you think this could affect the business. For example, it may help them keep your expertise for as long as possible or you could cover lunchtimes for them on shorter days.

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 existing work patterns or recruit extra 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.

You can find more information by searching for *flexible working* at: www.gov.uk or for Northern Ireland, at: www.nidirect.gov.uk

How can Access to Work help me?

If disability makes it difficult to do your job, Access to Work may help you remain at work for longer.

The Access to Work scheme helps employers get grants to provide disabled employees with:

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



“Access to Work has provided hands free telephone equipment and they were particularly helpful.”

The following steps need to happen to get an Access to Work grant:

1. Discuss your diagnosis with your employer and what help you need. It will help your application if you have already explored ‘reasonable adjustments’ with your employer before applying for Access to Work (see section 2: *What are my rights?*).
2. If you live in England, Scotland or Wales, you can apply for Access to Work online at: www.gov.uk/access-to-work/apply
You can also contact the Access to Work scheme (see the heading *Useful organisations* in section 6: *How do I find out more?* for details) or seek advice from your Disability Employment Adviser (DEA) at your local Jobcentre.
If you live in Northern Ireland, seek advice from an Employment Service Adviser at your local Jobcentre or Jobs and Benefits office.
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.

If you are receiving certain benefits, it could affect your ability to get an Access to Work grant. Contact a benefits adviser before applying for Access to Work for information on how benefits may impact on your eligibility. The MND Association Benefits Advice Service may be able to help with this (see *Further information* at the end of this sheet for contact details).

Access to Work isn't available in the Channel Islands or Isle of Man, but your employer still has a duty to provide you with reasonable adjustments to avoid you being disadvantaged to non-disabled people (see section 2: *What are my rights?*).

Can I take Statutory Sick Pay (SSP)?

There may come a time with MND or Kennedy's disease 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. It will be helpful to keep your employer updated on your situation 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 (please note that you may not be paid SSP for the first three days of sickness)
- 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 may be able to claim new-style Employment and Support Allowance (ESA) based on your National Insurance record and/or Universal Credit instead.

You may be able to claim other benefits too. Some of these are paid regardless of household income, such as Personal Independence Payment (PIP), which can support extra daily living and mobility costs if you are disabled.

You should also enquire at the local Council about help with Council Tax. Some of that help is based on income and savings, but other things can impact, such as living alone, having a carer, or if your property has been adapted because of a disability.



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. Income from this and your employer may affect your entitlement to other benefits, where your finances and other assets are assessed (known as means testing).

Long term sick pay can be expensive for your employer, so it is worth discussing your options with them. For example, they may be willing to provide a lump sum 'good service' exit payment, but this could also affect means-tested benefits. 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 new-style ESA and you may also qualify for Universal Credit instead.

The MND Association Benefits Advice Service can provide guidance on claiming benefits. For more information and contact details, see *Further information* at the end of this sheet.

What is 'permitted work'?

You may be able to carry out certain types of paid work, even if unemployed and claiming new-style Employment and Support Allowance (ESA). This is known as 'permitted work', which allows you to work a limited number of hours per week and earn up to a set amount of money 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 how long you can do this work, but there will be a limit to your hours per week and amount you can earn when claiming ESA. This is fixed at 16 hours per week at the National Living Wage rate. You can find out more by searching for *ESA* at: www.gov.uk or for Northern Ireland at: www.nidirect.gov.uk

You can earn a limited amount of money while claiming other benefits, such as Universal Credit. 'Permitted work' rules don't apply, but there is a 'work allowance' if you aren't fit for full-time work. However, this will affect the amount of benefit you receive. Contact our Benefits Advice Service (see *Further information* at the end of this sheet for details) or check the rules with the Department of Work and Pensions.

Find contact details for different benefits by searching for the relevant benefit at: www.gov.uk or for Northern Ireland at: www.nidirect.gov.uk.

Employment disputes or guidance on options

There may come a time when it is no longer possible for you to carry out your usual work duties with MND or Kennedy's disease. Your employer cannot dismiss you on this basis. They must look at other options for you, such as shorter hours, lighter tasks or other 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 your employer hasn't answered any concerns you have, about any aspect of your employment, ask for advice from an independent adviser or your local authority Welfare Rights Service.

You may also find it helpful to contact the following:

- Acas - The Advisory, Conciliation and Arbitration Service
- The Department for Work and Pensions (DWP)
- Citizens Advice
- MND Association Benefits Advice Service or an independent advice agency (www.advicelocal.uk) for information on any benefits you may be entitled to.



For more information and contact details, see *Useful organisations* in section 6: *How do I find out more?*

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 Trade Unions Certification Officer, which is a public body listing details of most trade unions (see *Useful organisations* in section 6: *How do I find out more?* for contact details).

If you're a carer, your local carer's organisation may also be able to support you.

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

If you decide to leave work, think carefully about your options and discuss them with your family, friends or independent advisers before approaching your employer.

Timing of any arrangements can be managed with help.

Ask your employer what happens with the following options:

- taking paid or unpaid leave to explore your options – this decision will be up to your employer, and based on the particular situation
- taking sick leave, when needed (see heading *Can I take Statutory Sick Pay?* in section 3: *What do I need to think about if I want to continue working?*)
- 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?* in this section)
- taking voluntary redundancy, if available.

Ask an accountant or independent financial adviser, regulated by the Financial Conduct Authority, to help review your finances and options before leaving work.

Finding out which benefits you might be entitled to receive may also be helpful. Our Benefits Advice Service can help you with this. For contact details in *Further information* at the end of this sheet.

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 laws, 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 applies.

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

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 in the pension
- pension payments may prevent you from receiving certain benefits or reduce the amount you are entitled to receive (see 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).

If you are working and receiving benefits, the MND Association Benefits Advice Service can inform you on the impact of taking early retirement on any benefits you may get. See *Further information* at the end of this sheet for details.

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 or Kennedy's disease, or you are a main carer, it is your right to have an assessment to review your needs. See section 2: *What are my rights?* for more information.

You will be financially assessed to see if you need to contribute to the services agreed in your support plan. Services can be arranged for you, or you can choose to select through direct payments.



For more about direct payments, see:
Our information sheet 10B – *What is social care?*

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

The MND Association Benefits Advice Service can help with queries about the benefits you may be entitled to with MND or Kennedy's disease, or as a carer.

If you speak little or no English and don't have anyone to speak on your behalf, we can arrange for an interpreter to join your call with the Benefits Advice Service.

For contact details, see *Further Information* at the end of this sheet.



See also Information sheet 10A – *Benefits and entitlements*

The MND Association may be able to offer some financial support for a variety of needs. Statutory funding and services must have been explored first (those provided by the NHS or the government).

In most cases, the initial request must be made through a health and social care professional, following assessment of your needs.

Contact our Support Services team, see *Further information* at the end of this sheet for 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, an 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 and your partner's savings, income and other assets (known as capital) above the limit where you can receive certain means-tested benefits.

5: 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, your finances can be affected in unexpected ways. GOV.UK provide a quick guide on Universal Credit and self-employment at: www.gov.uk/government/publications/universal-credit-and-self-employment-quick-guide



See also our Information sheet 10A – *Benefits and entitlements*.

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
- the MND Association Benefits Advice Service or an independent benefits adviser to explore what you may be entitled to. Some benefits depend on the amount of National Insurance you have been paying.

See also *Can I take Statutory Sick Pay?* and *What is Permitted Work?* in section 3: *What do I need to think about if I want to continue working?*

6: How do I find out more?

Useful organisations

We do not endorse organisations but have included this list to help you search for further information. Details are correct at the time of print but contact our MND Connect helpline if you need help to find a service (see *Further information* at the end of this sheet for helpline details).

Acas (Advisory, Conciliation and Arbitration Service)

Information, advice and other services for employers and employees.

Telephone: 0300 123 1100

Text Relay: 18001 0300 123 1100

Website: www.acas.org.uk

Access to Work

Advice on how your employer can support you in your workplace.

England, Wales and Scotland helpline:

Telephone: 0800 121 7479

Textphone: 0800 121 7479

Website: www.gov.uk/access-to-work

Northern Ireland:

Contact a work coach in your local Jobs & Benefits office for advice on Access to Work. Locate your nearest branch by:

Telephone: 0800 353 530

Website: www.nidirect.gov.uk/articles/access-work-practical-help-work

Email: HealthandWorkSupportCo-ordination@communities-ni.gov.uk

Adult social care services (sometimes called social services)

For adult social care contact your local authority.

England: search for *local councils* at: www.gov.uk

Wales: search for *find your local authority* at www.gov.wales

Northern Ireland: search for *health and social care trusts* at: www.nidirect.gov.uk

Scotland: search for *health and social care* at: www.mygov.scot

AdviceLocal

Help to find local support on employment, housing, benefits and more.

Website: www.advicelocal.uk

Advicenow

Free online information about Rights, benefits and legal issues.

Website: www.advicenow.org.uk

Advice UK

Use their search facility to find local independent advice agencies.

Telephone: 0300 777 0107

Website: www.adviceuk.org.uk

Age UK

Advice and information services for people in later life, including benefits.

Telephone: 0800 169 8080 (England)

0292 043 1555 (Wales)

0289 024 5729 (Northern Ireland)

0845 125 9732 (Scotland)

Email: through the relevant website contact pages

Website: www.ageuk.org.uk (England)

www.ageuk.org.uk/cymru (Wales)

www.ageuk.org.uk/northern-ireland (Northern Ireland)

www.agescotland.org.uk (Scotland)

Carers Trust

Support and services for carers.

Telephone: 0300 772 9600 (England)
0300 772 9702 (Wales)
0300 772 7701 (Scotland)

Email: info@carers.org

Website: <https://carers.org>

Carers UK

Information, support, and local opportunities for carers.

Telephone: 020 7378 4999 (England)
029 2081 1370 (Wales)
028 9043 9843 (Northern Ireland)
0141 378 1065 (Scotland)

Email: advice@carersuk.org

Website: www.carersuk.org (England)
www.carersuk.org/wales (Wales)
www.carersuk.org/northernireland (Northern Ireland)
www.carersuk.org/scotland (Scotland)

Certification Officer

Help with finding a trade union.

Telephone: 0330 109 3602

Email: info@certoffice.org

Website: www.gov.uk/government/organisations/certification-officer

Citizens Advice

Free and confidential advice to help to resolve legal, money and other problems.

Telephone: 0800 144 8848 (Adviceline England)
0800 702 2020 (Advicelink Wales)
0800 915 4604 (Advice NI helpline)
0800 028 1456 (Scotland helpline)

Website: www.citizensadvice.org.uk (England)
www.citizensadvice.org.uk/wales (Wales)
www.citizensadvice.org.uk/nireland (Northern Ireland)
www.cas.org.uk (Scotland)

Department for Work and Pensions

Responsible for welfare, pensions and various disability and ill health benefits.

Email: ministers@dwp.gsi.gov.uk

Website: <https://www.gov.uk/government/organisations/department-for-work-pensions>

Disability Action

Support for Northern Ireland, including guidance on employment for disabled people.

Telephone: 028 9029 7880

Email: hq@disabilityaction.org

Website: www.disabilityaction.org

Disability Law Service

Free legal advice and representation for disabled people.

Telephone: 020 7791 9800
Email: advice@dls.org.uk
Website: www.dls.org.uk

Disability Rights UK

Information, products and services developed by and for disabled people.

Telephone: 0330 995 0400
Email: enquiries@disabilityrightsuk.org
Website: www.disabilityrightsuk.org

Financial Conduct Authority (FCA)

Find a list of regulated and approved financial advisers on their website.

Telephone: 0800 111 6768
Email: Submit a query via the contact form at: www.fca.org.uk/contact
Website: www.fca.org.uk

GOV.UK

Government online information for England and Wales, including employment and benefits guidance.

Website: www.gov.uk

GOV.SCOT

Government online information for Scotland, including employment and benefits guidance.

Website: www.gov.scot

Jobcentre Plus

For assistance with job seeking and benefits. Find an office:

Website: <https://find-your-nearest-jobcentre.dwp.gov.uk/>
(England, Wales and Scotland)
www.nidirect.gov.uk/contacts/jobs-and-benefits-offices
(Northern Ireland)

New claims only:

Telephone: 0800 055 6688
Textphone: 0800 023 4888
Welsh language: 0800 012 1888

MND Scotland

Supporting people affected by MND in Scotland.

Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: www.mndscotland.org.uk

Money Helper

Free, impartial advice, set up by HM Government and Money and Pensions Service.

Telephone: 0800 138 7777 (English)
0800 138 0555 (Welsh)
Typetalk: 18001 0800 915 4622
Email: via enquiry form on website
Website: **www.moneyhelper.org.uk**

NI Direct

Government online information for Northern Ireland, including employment and benefits guidance.

Website: **www.nidirect.gov.uk**

The Pension Service

For queries and claims about pensions.

England, Wales and Scotland:

Telephone: 0800 731 0469
Textphone: 0800 731 0464
Website: **www.gov.uk/contact-pension-service**

Northern Ireland:

Telephone: 0808 587 0892 (Enquiries)
0808 100 6165 (Pension Credit)
0808 100 2658 (State Pension)
Textphone: 0808 100 2198 (Pension Credit and State Pension)
Email: pensionservice@dfcni.gov.uk
if you are transgender with a claim or query,
email: knockbreda.makethecall.scr@dfcni.gov.uk
Website: **[https://www.nidirect.gov.uk/contacts/
northern-ireland-pension-centre](https://www.nidirect.gov.uk/contacts/northern-ireland-pension-centre)**

Scope

Information on all aspects of living with a disability, including welfare benefits.

Telephone: 0808 800 3333
Email: helpline@scope.org.uk
Website: **www.scope.org.uk**

Trade Unions Congress (TUC)

Help to find trade unions relevant to your work sector.

Telephone: 020 7636 4030
Email: info@tuc.org.uk
Website: **www.tuc.org.uk**
www.tuc.org.uk/tuc-scotland
www.tuc.org.uk/wales
www.ictuni.org (Northern Ireland)

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

Ingrid Unsworth, Specialist Occupational Therapist, Betsi Cadwaladr University Health Board, Wales

Gary Vaux, Head of Money Advice Unit, Hertfordshire County Council

References

References used to support this information are available on request from:
email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park, Northampton NN3 6BJ

Further information

We have related information sheets you may find helpful:

1A – *NICE guideline on motor neurone disease*

10A – *Benefits and entitlements*

10B – *What is social care?*

10C – *Disabled Facilities Grants*

10D – *NHS Continuing healthcare*

10G – *Support for families with children*

11C – *Equipment and wheelchairs*

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

What you should expect from your care – our pocket-sized booklet detailing the main points from the NICE guideline on MND. It can be used to help open conversations with professionals about your care

Making the most of life with MND – our booklet on quality of life and maintaining hobbies and interests with MND.

Personal care with MND - our booklet contains information about equipment and services that could support you to prolong independence with everyday tasks and how to access them.

Getting Around – our booklet features helpful driving, transport and holiday guidance focusing on different ways to get out and about with reduced mobility.

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

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park, Northampton NN3 6BJ

Support Services

For guidance on our services and financial support.

Telephone: 0808 802 6262

Email: support.services@mndassociation.org

Website: **www.mndassociation.org/getting-support**

MND Association Benefits Advice Service

Find current contact details for England, Wales and Northern Ireland

at: **www.mndassociation.org/benefitsadvice** or contact our MND Connect helpline for guidance: **0808 802 6262**

MND Association website and online forum

Website: **www.mndassociation.org**

Online forum: **<https://forum.mndassociation.org>** or through our website

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our 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, Francis Crick House, 6 Summerhouse Rd,
Moulton Park, Northampton NN3 6BJ

Last revised: December 2024
Next review: December 2027
Version: 1

Registered Charity No. 294354
Company Limited by Guarantee No. 2007023
© MND Association 2018

