



10E Work and MND

Information for people with or affected by Motor Neurone Disease (MND) 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. The content includes:

- 1. How do I make my 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 content has been evidenced, user tested and reviewed by experts. See: piftick.org.uk



This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.



This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 6: **How do I find out more?**



"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. How do I make my choice?

Whether diagnosed with MND or Kennedy's disease, or supporting someone who has had that diagnosis, you may face decisions about employment. You may want to continue working or employment may not be a priority for you.



"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."



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

Thinking about leaving work can cause financial worry. It can also feel emotionally challenging. It is your decision but may not feel like a free choice if you experience rapid changes with MND. Take time to find out all your options and the support available before making any big decisions.

With Kennedy's disease, you can usually continue working depending on your symptoms. However, you may also need support and find this sheet helpful.

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 section 6: **How do I find out more?** for contact details and our guide: **Telling people about MND**.

2. What are my rights?

All employees share the same general employment rights, 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: gov.uk or for Northern Ireland at: 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: legislation.gov.uk

Rights in England

Equality Act 2010

The Equality Act 2010 protects people in England, Wales and Scotland from discrimination (unfair treatment for being who you are). The Act protects you from discrimination in the workplace if you're disabled by a physical or mental impairment.

This is where your ability to perform day-to-day activities has been reduced either substantially or long term. MND is recognised in the Act as a progressive condition which will cause disabilities and 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 reasonable adjustments, like adjusting work hours or providing adapted equipment, so you are not at a disadvantage to non-disabled people.

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 if you live in England and sets out your legal right to assessment and support. You have the right to a needs assessment if affected by illness or disability, or a carer's assessment if you support someone.

With MND or Kennedy's disease, your local authority must focus on your wellbeing in your needs assessment. If you are a carer, your local authority must consider the impact of your caring responsibilities on your wellbeing.

Your ability to take part in work counts towards wellbeing.

Your needs assessment should find out whether you want and feel able to continue working. Your carer's assessment should look at whether you're unable to work due to caring and what support you'll need if this impacts your wellbeing.

The Carer's Leave Act 2024

This became law on 6 April 2024. If balancing unpaid care with paid employment, you have the right to five days of unpaid carer's leave for full-time work, less if part-time. Some employers give 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 and expected to need care for more than three months
- a disability (as defined in the Equality Act 2010)
- care needs as they are elderly.

You are have the right to carer's leave from your first working day with an employer. Other rights, like holidays and returning to your job, are protected with 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.

Social Services and Well-being (Wales) Act 2014

The Social Services and Well-being (Wales) Act 2014 aims to improve wellbeing if you need care and support, or for carers who need support. Wellbeing includes your ability to take part in work.

You have the right to assessment with MND or Kennedy's disease and if your assessment agrees 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 have the right to a carer's assessment and will be entitled to support if your assessment finds that:

- 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.

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

The Public Bodies (Joint Working) (Scotland) Act helps 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, this Act 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 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.

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

3. What do I need to think about if I want to continue working?

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. With Kennedy's disease, symptoms are similar to 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.



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

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

Ask your health and social care team for advice on how to manage any symptoms likely to affect your work. They can help you find out about available support.



Search by need using our Care information finder: mndassociation.org/careinfofinder with resources on mobility, personal care and social care, including information sheet: **10B What is social care?**

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.

As 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 information sheet: **1A NICE guideline on motor neurone disease** and our pocket booklet: **What you should expect from your care** which is easy to take with you to appointments.

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 too.



See our guide: **Telling people about MND**.

Ask your employer about the following:

- adapting your working environment if you have MND or Kennedy's disease, or working from home
- changing from physical tasks to desk-based tasks if your symptoms place you or others at any risk
- flexible or reduced working hours.

If you're a carer, the level of care is likely to increase as the disease progresses. Let your employer know to help them understand your current and likely future needs.

They may be able to make changes to help you continue working. If you need to help the person you support through treatment and recovery time, ask your employer about paid or unpaid leave. This will be up to your employer, based on the 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 work life 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.

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

The longest it can take for your employer to decide is two 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: gov.uk or for Northern Ireland at: nidirect.gov.uk



"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."

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. This 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.

If you are receiving certain benefits, they 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 section 6: **How do I find out more?** about our services.

Access to Work isn't available in the Channel Islands or Isle of Man. However, your employer there still has a duty to provide you with reasonable adjustments to avoid you being disadvantaged to non-disabled people.



"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.
2. If you live in England, Scotland or Wales, you can apply for Access to Work online at: gov.uk/access-to-work/apply You can also contact the Access to Work scheme or seek advice from your Disability Employment Adviser (DEA) at your local Jobcentre. If you live in Northern Ireland, you can 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.

Can I take Statutory Sick Pay (SSP)?

With MND or Kennedy's disease, you may need sick leave at times. Your employer is legally bound to manage this and help you return to work where possible, if that's what you want. It helps to keep your employer updated on your situation while away. As an employee, you may be able to get Statutory Sick Pay (SSP) during sick leave, even if you have just started. To get SSP for an absence, 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.

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.

Can I claim Employment and Support Allowance (ESA) or other benefits?

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.

If your employer has an occupational sick pay scheme and keeps you on sick pay for as long as they can, 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 need to be assessed (known as means testing).

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.



See information sheet: **10A Benefits and entitlements**. To contact us about our financial support, including our MND Association Benefits Advice Service, see section 6: **How do I find out more?**

You should also enquire at your 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.

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.

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 can help you take part-time work or start a 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', monitored through your 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: gov.uk or for Northern Ireland at: 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 or check the rules with the Department of Work and Pensions.

Find contact details for different benefits by searching for the relevant benefit at: gov.uk or for Northern Ireland at: 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 (advicecelocal.uk) for information on any benefits you may be entitled to.



See section 6: **How do I find out more?** for contact details.

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.

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. 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 if you take:

- paid or unpaid leave to explore your options – this decision will be up to your employer, and based on the particular situation
- sick leave, when needed
- a lump sum payment instead of long-term sick pay, if an exit payment is available from your employer
- early retirement due to ill-health, if your pension enables this choice
- voluntary redundancy, if available.

Get help to review your finances and options before leaving work. Ask for this guidance from an accountant or independent financial adviser who is regulated by the Financial Conduct Authority.



"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."

Finding out which benefits you might be entitled to receive may also be helpful. Our Benefits Advice Service can help you with this.



See section 6: **How do I find out more?** for contact details.

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. 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 then 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?

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 section 6: **How do I find out more?** for contact details.

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
- 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).

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

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).

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. With MND or Kennedy's disease, or as a carer, it is your right to have an assessment to review your needs.

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.

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 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.

The MND Association may also 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.



See section 6: **How do I find out more?** for contact details. See also our information sheet: **10A Benefits and entitlements**.

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 stay self-employed for financial reasons or because you enjoy this work. You may want to stop working or reduce your hours. Whatever you do, finances can be affected in unexpected ways.



See section 3: **What do I need to think about if I want to continue working?**

GOV.UK provide guidance on Universal Credit and self-employment at:
[gov.uk/government/publications/universal-credit-and-self-employment-quick-guide](https://www.gov.uk/government/publications/universal-credit-and-self-employment-quick-guide)

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
- as self-employed through an agency, or by contracting or sub-contracting.

6. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Acas (Advisory, Conciliation and Arbitration Service)

Information, advice and other services for employers and employees.

Tel: 0300 123 1100
Text Relay: 18001 0300 123 1100
Website: acas.org.uk

Access to Work

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

Tel: 0800 121 7479 (England, Wales and Scotland)
0800 353 530 (Northern Ireland)
Textphone: 0800 121 7479 (England, Wales and Scotland)
Email: HealthandWorkSupportCo-ordination@communities-ni.gov.uk
Website: gov.uk/access-to-work (England, Wales and Scotland)
search for: access to work at nidirect.gov.uk (Northern Ireland)

Adult social care services

Contact them to arrange a needs assessment or carer's assessment.

Website: Search for:
find your local council at gov.uk (England and Wales)
health and social care trusts at nidirect.gov.uk (Northern Ireland)
find my council at careinfoscotland.scot (Scotland)

AdviceLocal

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

Website: advicelocal.uk

Advicenow

Free online information about your Rights, benefits and legal issues.

Website: advicenow.org.uk

Advice UK

Use their search facility to find local independent advice agencies.

Tel: 0300 777 0107
Website: adviceuk.org.uk

Age UK

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

Tel: 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: ageuk.org.uk (England)
ageuk.org.uk/cymru (Wales)
ageuk.org.uk/northern-ireland (Northern Ireland)
agescotland.org.uk (Scotland)

Carers Trust

Support and services for carers.

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

Email: info@carers.org

Website: carers.org

Carers UK

Information, support, and local opportunities for carers.

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

Email: advice@carersuk.org

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

Certification Officer

Help with finding a trade union.

Tel: 0330 109 3602

Email: info@certoffice.org

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

Citizens Advice

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

Tel: 0800 144 8848 (England)
0344 477 2020 (Wales)

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

Department for Work and Pensions

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

Email: ministers@dwp.gsi.gov.uk

Website: gov.uk/government/organisations/department-for-work-pensions

Disability Action

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

Tel: 028 9029 7880

Email: hq@disabilityaction.org

Website: disabilityaction.org

Disability Law Service

Free legal advice and representation for disabled people.

Tel: 020 7791 9800

Email: advice@dls.org.uk

Website: dls.org.uk

Disability Rights UK

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

Tel: 0330 995 0400

Email: enquiries@disabilityrightsuk.org

Website: disabilityrightsuk.org

Financial Conduct Authority (FCA)

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

Tel: 0800 111 6768

Email: Submit a query via the contact form at: fca.org.uk/contact

Website: fca.org.uk

Government information

Online government information about benefits and support.

Website: gov.uk (England and Wales)

nidirect.gov.uk (Northern Ireland)

gov.scot (Scotland)

Jobcentre Plus

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

Website: find-your-nearest-jobcentre.dwp.gov.uk (England, Wales, Scotland)

nidirect.gov.uk/contacts/jobs-and-benefits-offices (Northern Ireland)

New claims only:

Tel: 0800 055 6688

Textphone: 0800 023 4888

Welsh: 0800 012 1888

MND Scotland

Care, information and research funding for people affected by MND in Scotland.

Tel: 0141 332 3903

Email: info@mndscotland.org.uk

Website: mndscotland.org.uk

Money Helper

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

Tel: 0800 138 7777 (English)

0800 138 0555 (Welsh)

Typetalk: 18001 0800 915 4622

Email: via enquiry form on website

Website: moneyhelper.org.uk

The Pension Service

For queries and claims about pensions.

England, Wales and Scotland:

Tel: 0800 731 0469

Textphone: 0800 731 0464

Website: gov.uk/contact-pension-service

Northern Ireland:

Tel: 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: nidirect.gov.uk/contacts/northern-ireland-pension-centre

Scope

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

Tel: 0808 800 3333

Email: helpline@scope.org.uk

Website: scope.org.uk

Trade Unions Congress (TUC)

Help to find trade unions relevant to your work sector.

Tel: 020 7636 4030

Email: info@tuc.org.uk

Website: tuc.org.uk (England)

tuc.org.uk/tuc-scotland (Scotland)

tuc.org.uk/wales (Wales)

ictuni.org (Northern Ireland)

Acknowledgements

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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 resource are available on request:

Email: infofeedback@mndassociation.org

Or write to:

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

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this sheet.

Information sheets

- 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

Booklets

- What you should expect from your care
- Personal care
- Getting around
- Caring and MND - quick guide

Large guides

- Living with MND
- Caring and MND - support for you

Search for information by need at: mndassociation.org/careinfofinder

Find information for professionals at: mndassociation.org/professionals

Download our information at: mndassociation.org/publications

Find information in other languages at: mndassociation.org/languages

Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: mndassociation.org/mndconnect

Tel: 0808 802 6262

Email: mndconnect@mndassociation.org

Support services

Find out about our support services at: mndassociation.org/our-services

Local and regional support

Find out about our branches and groups at: mndassociation.org/local-support

MND Association Benefits Advice Service

For help to identify claims and how to apply, visit: mndassociation.org/benefitsadvice or call our MND Connect helpline.

Tel: 0808 802 6262

MND Association website and online forum

Website: mndassociation.org

Online forum: forum.mndassociation.org

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 MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on this or any of our information sheets, access our online form at:
smartsurvey.co.uk/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
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at:
infofeedback@mndassociation.org

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Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
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Email: enquiries@mndassociation.org
Website: mndassociation.org

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