



10E


Work and MND


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

An MND or Kennedy's disease diagnosis might make you, and your carer, think about whether to continue in employment for as long as possible or leave in a way that is right for you. This can be a difficult choice, as it is likely to affect you financially and emotionally.

This information sheet explores the options available, including:


- 1: Making a difficult 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?**
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 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.



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


 *“Household income can change significantly when one member has MND. One reason behind this is the effect of MND on working patterns: working age people with MND inevitably leave work at some point during the course of the disease, and many family members decide to leave employment in order to provide care.”*

MND Costs campaign 2017


1: Making a difficult 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 provide care. 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.”*

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 any 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 have links to similar 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're caring for falls ill, 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, search for *time off for family* at: www.gov.uk or for Northern Ireland at: www.nidirect.gov.uk

If you wish to find out more about any of the following Acts in England, Wales or Northern Ireland, search for the relevant Act at: www.legislation.gov.uk

Rights in England

Equality Act 2010

The Equality Act 2010 protects people in England and Wales 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. This means that 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.

Rights in Wales

Equality Act 2010

The Equality Act 2010 applies to people living in England and Wales. See *Equality Act 2010* under the previous 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 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 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 information on equipment, see:
Information sheet 11C – *Equipment and wheelchairs*

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.

While this guideline is set out for health and social care professionals, your employer may wish to use it to check 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).


 For more information, see:
Information sheet 1A – *NICE guideline on motor neurone disease*
and our pocket-sized booklet featuring the main points from the NICE guideline:
What you should expect from your care

Discussion with your employer

Consider telling 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. Having an early discussion with your employer about your situation will give them a better understanding of your current and possible future needs as an employee. This may help them to make adjustments to enable you to remain at work, 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?* for information on possible funding)
- 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 and based on the particular situation.


 For more information on working with the caring role, 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."*

To make a request, you need to do this in writing or by email, stating that this is a statutory request, 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're a carer. You can only make one formal application for flexible working a year, so include the date of any previous applications you've made.

The longest it can take for your employer to decide is 3 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 could mean your expertise is retained for as long as possible and you may be able to cover lunchtimes before you go home if you work 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 work among 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.

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.”

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?*).

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 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 *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.

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 Employment and Support Allowance (ESA) 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.



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 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 ESA or 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'?

If you are unemployed and claiming Employment and 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 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 the hours per week you can do and amount you can earn while claiming ESA. You can find out more by searching for *ESA* at: www.gov.uk or for Northern Ireland at: www.nidirect.gov.uk

You can work a number of hours and earn a limited amount of money while claiming other benefits, such as Income Support or Universal Credit. However, this is likely to 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 relevant office or contact for each benefit. You can 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 you feel your employer is not upholding their obligations properly, that you're being made to leave earlier than is necessary, or have any other 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 for Work and Pensions (DWP)
- Citizens Advice
- MND Association Benefits Advice Service or an independent advice agency 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?

You may reach a point where you decide to leave work if you're living with MND or Kennedy's disease, or providing care to someone who has been diagnosed.

Think carefully about your available options and discuss them 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 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 *Is early retirement a good option?* below)
- taking voluntary redundancy, if this is available.

You may also wish to 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 more information about this service and contact details, see *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?

You may consider retiring early if you decide to leave work.

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

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 and buy them for yourself.

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 more information and contact details, see *Further Information* at the end of this sheet.



For more information on benefits, 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 MND Support Grant must be made through a health and social care professional, following an assessment of your needs.

For more information and contact details of our Support Services team, see *Further information* at the end of this sheet.



“My income is now much lower and my wife is working but doesn't earn a lot. The grants from the MND Association have made a tremendous difference to my family.”

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



For more information on Universal Credit, contact the MND Association Benefits Advice Service, or see: 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 contract

- 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 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 and Arbitration Service)

Information, advice and other services for employers and employees to help prevent or resolve workplace problems.

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 work place.
 England and Wales:

Telephone: 0345 268 8489
 Textphone: 0345 608 8753
 Website: www.gov.uk/access-to-work

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

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: www.gov.uk

or, if you live in Northern Ireland, search for *health and social care trusts* at: www.nidirect.gov.uk

Advicenow

An independent, not-for-profit website providing information on rights and legal issues.
Online information only.

Website: **www.advicenow.org.uk**

Advice UK

Network of independent advice agencies in the UK. You can use their website to search for local independent advice agencies.

Address: 101E, Universal House, 88-94 Wentworth Street, London E1 7SA

Telephone: 0300 777 0107

Website: **www.adviceuk.org.uk**

Age UK

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

Address: Tavis House, 1-6 Tavistock Square, London WC1H 9NA

Telephone: 0800 678 1174 (England)

08000 223 444 (Wales)

0808 808 7575 (Northern Ireland)

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)

Carers Trust

Support and services for carers in the UK.

Address: Carers Trust Unit 101, 164–180 Union Street, London SE1 0LH

Telephone: 0300 772 9600 (UK)

02920 090087 (Wales)

07826 930508 (Northern Ireland)

Email: info@carers.org.

Website: **<https://carers.org>**

Carers UK

Information, support and local opportunities for carers.

Address: 20 Great Dover Street, London SE1 4LX

Telephone: 020 7378 4999 (UK)

029 2081 1370 (Wales)

02890 439 843 (Northern Ireland)

Email: through the website contact page (UK)

info@carerswales.org (Wales)

info@carersni.org (Northern Ireland)

Website: **www.carersuk.org** (UK)

www.carersuk.org/wales (Wales)

www.carersuk.org/northernireland (Northern Ireland)

Certification Officer

Help with finding a trade union.

Address: Lower ground Floor, Fleetbank House, 2-6 Salisbury Square,
London EC4Y 8JX
Telephone: 020 7210 3734
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: 03444 111 444 (England, or contact your local Citizens Advice Bureau)
03444 77 2020 (Wales)
Website: www.citizensadvice.org.uk (England)
www.citizensadvice.org.uk/wales (Wales)
www.citizensadvice.org.uk/nireland (Northern Ireland)

Department for Work and Pensions

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

Address: Caxton House, Tothill Street, London SW1H 9NA
Email: ministers@dwp.gsi.gov.uk
Website: <https://www.gov.uk/government/organisations/department-for-work-pensions>

Disability Action

For information and support on a variety of topics including employment and training for disabled people in Northern Ireland.

Address: Portside Business Park, 189 Airport Road West, Belfast BT3 9ED
Telephone: 028 9029 7880
Textphone: 028 9029 7882
Email: hq@disabilityaction.org
Website: www.disabilityaction.org

Disability Law Service

Free legal advice and representation for disabled people.

Address: Disability Law Service, The Foundry, 17 Oval Way, London, SE11 5RR
Telephone: 020 7791 9800
Email: advice@dls.org.uk
Website: www.dls.org.uk

Disability Rights UK

Produce information, products and services developed by and for disabled people. Includes factsheets and an advice line.

Address: Plexal, 14 East Bay Lane, Here East, Queen Elizabeth Olympic Park
Stratford London E20 3BS

Telephone: choose the helpline you need here:
www.disabilityrightsuk.org/contact-us

Email: enquiries@disabilityrightsuk.org

Website: **www.disabilityrightsuk.org**

Financial Conduct Authority (FCA)

Regulates the conduct of financial services and markets in the UK. They provide a list of regulated and approved financial advisers on their website.

Address: FCA Head office, 12 Endeavour square, London E20 1JN

Telephone: 020 7066 1000

Email: consumer.queries@fca.org.uk

Website: **www.fca.org.uk**

GOV.UK

Government online information about employment support and benefits for people living in England and Wales.

Website: **www.gov.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.

Find an office:

Website: **<https://los.direct.gov.uk>** (England and Wales)
www.nidirect.gov.uk/contacts/jobs-benefits-offices-jobcentres-and-social-security-offices (Northern Ireland)

New claims only:

Telephone: 0800 055 6688

Textphone: 0800 023 4888

Welsh language: 0800 012 1888

MND Scotland

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

Address: MND Scotland, Unit 8, 76 Firhill Road, Glasgow G20 7BA

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: **www.mndscotland.org.uk**

Money Advice Service

Free and impartial money advice, set up by government

Address: Holborn Centre, 120 Holborn, London EC1N 2TD
Telephone: 0800 138 7777 (English)
0800 138 0555 (Welsh)
Typetalk: 18001 0800 915 4622
Email: enquiries@maps.org.uk
Website: www.moneyadviceservice.org.uk

NIDirect

Government online information about employment support and benefits for people living in Northern Ireland.

Website: www.nidirect.gov.uk

The Pensions Advisory Service

Guidance on pensions, including state, workplace, personal and stakeholder schemes.

Address: 11 Belgrave Road, London SW1V 1RB
Telephone: 0800 011 3797 (pensions helpline)
0345 602 7021 (helpline for self-employed people)
Email: through the website contact page
Website: www.pensionsadvisoryservice.org.uk

The Pension Service

For queries and claims about pensions.

England and Wales:

Telephone: 0800 731 7898 (England and Wales)
Textphone: 0800 731 7339 (England and Wales)
Website: www.gov.uk/contact-pension-service

Northern Ireland:

Telephone: 0808 100 6165 (Pension Credit)
0808 100 2658 (State Pension)
Textphone: 0808 100 2198
Email: pensionservice@nissa.gsi.gov.uk
Website: www.nidirect.gov.uk/northern-ireland-pension-centre-state-pension

Scope

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

Address: PO Box 833, Milton Keynes MK12 5NY
Telephone: 0808 800 3333
Text Relay: 18001 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.

Address: Congress House, Great Russell Street, London WC1B 3LS

Telephone: 020 7636 4030

Email: info@tuc.org.uk

Website: www.tuc.org.uk
<https://worksmart.org.uk>

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

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*

10F - Personal health budgets

10G – Support for families with children

11C – Equipment and wheelchairs

11D – Managing fatigue

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

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 equipment loan and MND Support Grants

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

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