

10A

Benefits and entitlements and how to fast track claims

**Information for people with or affected by Motor Neurone Disease (MND)
or Kennedy's disease**

If you're affected by motor neurone disease (MND) or Kennedy's disease, you may be able to claim benefits and entitlements, offering financial and other support. The content includes:

1. **What do the words mean?**
2. **Where do I get guidance on benefits and entitlements?**
3. **Disability benefits**
4. **Support for carers**
5. **Health and work related benefits**
6. **Other housing support and health and social care entitlements**
7. **How do I fast track a claim?**
8. **What do I need to do when making a claim?**
9. **Can I challenge a decision?**
10. **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 10: **How do I find out more?**

This information applies to people living in England, Wales and Northern Ireland. We cover the main differences in Scotland, but ask MND Scotland for more guidance. See other organisations in section 10: **How do I find out more?** for contact details.

1. What do the words mean?

When applying for benefits, you may come across the following terms:

Benefit:	A payment of money made by Government to someone entitled to receive it.
Benefit cap:	A limit on the amount of benefit working age people can get. People who get certain disability related benefits or Carer's Allowance are not affected by the benefit cap. You can work out if you are affected by using the benefit cap information at: gov.uk/benefit-cap
Benefit calculators:	These help you work out what benefits you could be entitled to.
Change in circumstances:	A change in your financial position, home situation or condition. For example, needing a stay in hospital may affect certain benefits. By law, you must tell the Department for Work and Pensions (DWP) if your circumstances change. In Northern Ireland, you must inform the Department for Communities (DFC). Some changes may mean you need to switch to another benefit, such as Universal Credit.
Eligibility criteria:	The rules used to work out if you qualify for a claim.

Means testing:	Your income and partner's income, savings and other assets (known as capital) are assessed to work out the level of benefit you should get. We have shown where benefits and entitlements are means-tested in this sheet.
Severe Disability Premium (SDP):	A premium that may be paid on top of certain means tested benefits you get, if you live alone (or with another disabled person) and have nobody caring for you who receives Carer's Allowance/UC Carer's Element. Contact a benefits adviser for more information.
Special rules for end of life (SREL):	Under special rules for terminal illness, claims may be fast tracked for Employment and Support Allowance (ESA), Universal Credit (UC), Disability Living Allowance (DLA), Personal Independence Payment (PIP) and Attendance Allowance (AA). See section 7: How do I fast track a claim?
Supplementary payments (Northern Ireland only):	Payments are available in Northern Ireland for people who have lost out on money due to changes made to their benefits. Contact a benefits adviser to find out how supplementary payments work if you live in Northern Ireland.
Taxable benefits:	Benefits that you need to pay income tax on. We have noted the benefits and entitlements that are taxable in this sheet, but you can also find a list by searching for income tax at: gov.uk

2. Where do I get guidance on benefits and entitlements?

This information sheet is a starting point, but details can change between revisions. Check if you qualify, how much you could receive and how to claim on the following government websites:

England or Wales: **gov.uk/browse/benefits**
 Northern Ireland: **nidirect.gov.uk/campaigns/guide-benefits**
 Scotland: **mygov.scot/browse/benefits**

Your local authority or council may have a welfare rights service, and some public sector landlords have housing staff who give benefits advice to their tenants.

Benefits advice is often given by local carer organisations or Citizen's Advice. Find help in your area at: **advicelocal.org.uk**

MND Association Benefits Advice Service

Contact our Benefits Advice Service to chat to qualified advisers who have an understanding of your condition. They can help identify benefits you may be entitled to and advise on how to claim. This service is confidential, impartial and free.

Find current contact details for England, Wales and Northern Ireland at: **mndassociation.org/benefitsadvice** or contact our MND Connect helpline for guidance: **0808 802 6262**

Let the adviser know if you need an interpreter for your chosen language. It should be possible to provide this. You can also start a live web chat with an adviser through our website if you live in England or Wales.

If you live in Scotland, contact the free Welfare and Benefits Advice Service through MND Scotland: **mndscotland.org.uk/support/benefits-advice**



See also section 10: **How do I find out more?**

Benefits and entitlements for UK nationals living abroad

If you are a UK national living abroad, you may still be entitled to some benefits. For more information search for: living abroad and benefits, at **[gov.uk](https://www.gov.uk)**

What can I claim?

The following sections list relevant benefits and entitlements in common categories to help you identify what you may need.

3. Disability benefits

Attendance Allowance (AA)

You can claim Attendance Allowance (AA) if you are state retirement age or older and need help with personal care or keeping safe. It does not cover mobility needs. You do not need to have a carer to be able to get AA and it may help you access more benefit support.

Attendance Allowance is:

- not dependent on your income or savings
- not dependent on National Insurance contributions
- tax free.

If you are getting Personal Independence Payment (PIP) or Disability Living Allowance (DLA) when you reach pension age, you keep those benefits and can't claim Attendance Allowance (AA).

AA has two rates:

- the lower rate, which is paid if you need regular help with personal care or someone with you during the day or at night.
- the higher rate, which is paid if you need help or someone with you throughout both day and night, or a medical professional has said you're nearing the end of life.



See section 7: **How do I fast track a claim?**

Apply online at: [gov.uk/attendance-allowance/how-to-claim](https://www.gov.uk/attendance-allowance/how-to-claim), by post or phone.

If you apply online, your claim may start on the date you make your claim. If you print and post the form, the claim will usually start from the date that DWP receives it. If you call the helpline to get an application form, the date of the claim will start from the date of your phone call. You need to send the form back within six weeks of your telephone call or give a reason why you can't return the form by then.

Attendance Allowance helpline:

Tel: 0800 731 0122

Textphone: 0800 731 0317

Relay UK: if you cannot hear or speak on the phone add 18001 before the telephone number.

If you get AA, you may be able to get the Severe Disability Premium added to pension credit, council tax support, or housing benefit.

If you live in certain areas of Scotland, you may need to apply for Pension Age Disability Payment instead of AA.

Disability Living Allowance (DLA)

Disability Living Allowance (DLA) has mostly been replaced by other benefits for adults aged 16 or over. You can start a new claim if you are under 16 and live in England, Wales or Northern Ireland but you will be invited to apply for PIP at 16.

You will continue to get DLA and not be invited to PIP if you are born on or before 8 April 1946 or under the age of 16.

If you live in Scotland and are under 16 you can apply for Child Disability Payment, which will then carry on until the young person reaches 18.

DLA is:

- not dependent on your income or savings
- not dependent on National Insurance contributions
- tax free.

If you are disabled, live in England or Wales and you're aged from 16 up to State Pension age, see Personal Independence Payment (PIP). If you've reached State Pension age, see Attendance Allowance (AA).

In Northern Ireland, if you are already getting DLA with a lifetime award and over State Pension age, your DLA will continue if you meet the eligibility criteria. You will not be reassessed for PIP. You can find out more on the NI Direct website:

nidirect.gov.uk/articles/disability-living-allowance-adults

If you live in Scotland and have not yet reached State Pension age, you can apply for Adult Disability Payment.

Personal Independence Payment (PIP)

PIP helps people from age 16 up to State Pension age, who have difficulties in daily living or getting around with a long-term condition. PIP has replaced DLA for most adults born after 8 April 1948.

To qualify, you need to request the application form by telephone. This is normally followed by a medical assessment by phone, video call or face to face.

PIP is:

- not dependent on your income or savings
- not dependent on National Insurance contributions
- tax free.

PIP has two parts - a daily living part and a mobility part. If you qualify, you may get money for one or both parts, either at a lower or higher rate. If you get PIP for daily living, you may be able to get the Severe Disability Premium.

Depending on the points you score in the section: Planning and Following a Journey, you may qualify for a Blue Badge or a vehicle tax discount. You need to be awarded the higher rate (enhanced) to apply for a Motability scheme vehicle. This may vary across regions, so check your government website for more information.



See our booklet: **Getting around** for driving and the Motability Scheme.

If awarded PIP before you reach your 66th birthday, you can keep it if you still have the same needs. As it can include help with mobility, it is usually preferable than switching to Attendance Allowance, which doesn't.

Your PIP is usually reviewed every few years to ensure the level of entitlement is correct. PIP can be awarded as an ongoing benefit, and people living with a serious illness such as MND or Kennedy's disease may receive a light-touch review after 10 years. However, your entitlement could still be subject to review.

If you are contacted by the DWP for a PIP review, contact our Benefits Advice Service for support at: mndassociation.org/benefitsadvice where you can live chat with an adviser or fill in an online form. You can also call the helpline for free on: 0808 801 0620.

The Department for Work and Pensions (DWP) has developed a series of videos about the PIP process at: bit.ly/understandingPIPvideos

If you live in Scotland, you will need to apply for Adult Disability Payment (ADP) instead of PIP. If you are currently receiving PIP, you will be moved to ADP by Spring 2025.

4. Support for carers

Support for carers in England, Wales and Northern Ireland

Carer's Allowance

This is taxable allowance to help if you're providing care for at least 35 hours each week. The person cared for needs a 'qualifying benefit' such as AA, PIP for daily living or either of the top two rates of DLA Care.

Whether you can claim depends on how much income you earn, after deductions. However, only your wages count towards this, not your partner's or the person you are caring for. Your claim also depends on how much State Pension you receive, but if you receive Pension Credit, your payment may increase.

Find out if you qualify and the income limits, at: gov.uk/carers-allowance/eligibility

Tell the DWP of any changes in circumstance as soon as you can, including extra income after deductions. This is because you usually have to pay back any overpaid Carer's Allowance.

Contact a benefits adviser before applying for Carer's Allowance. They can help you work out if it will affect any other benefits, that you or the person you care for receive.

For example, there could be an underlying entitlement of Carer's Allowance, even if you don't qualify for the payment itself. This can result in a top up premium (see next heading), or element being added to other means-tested benefits. You find out if you can get this entitlement when you apply for Carer's Allowance.

Carer Premium (known as the Carer Element if paid as part of Universal Credit)

You may be able to receive this extra amount within other benefits, such as income support, pension credit or income related employment and support allowance. It is not a benefit in its own right and unlike carers allowance, there is no earnings limit.

Carer's Credit

This is a National Insurance credit to help build your entitlement for a State Pension. It ensures there are no gaps in your National Insurance record if you cannot get Carer's Allowance but spend time caring for someone for at least 20 hours a week.

For more information see: gov.uk/carers-credit/how-to-claim

Support for carers in Scotland

If you live in Scotland, you will need to apply for Carer Support Payment instead of Carer's Allowance. This new scheme became available from November 2024.

If you are currently receiving Carer's Allowance, you will be automatically moved over to the new scheme by Spring 2025.

For more information see: mygov.scot/related-benefits/support-carers

5. Health and work-related benefits

These benefits can support you if being disabled or unwell has an effect on your finances or ability to work.

New Style Employment and Support Allowance (ESA)

You can this benefit if you meet the requirements. This includes not being entitled to jobseeker's allowance or statutory sick pay. As well as having paid enough national insurance contributions in certain tax years.

The work capability assessment will determine if you are placed in the support group or work-related activity group. These two groups have different rates of ESA. The new style ESA is limited to 12 months.

Universal Credit (UC)

This benefit provides support if you are on low income or need help with living costs. Universal Credit is means-tested but not taxable. In England and Wales, it is normally paid monthly, but in Scotland it is twice monthly.

To claim you must:

- live in the UK and have less than £16,000 in savings
- be aged 18 or over (exceptions can be made if you're 16 or 17)
- be under State Pension age.

Universal Credit is in place across the UK for new claims. For working-age people, it replaces the following means-tested benefits:

- Income Support
- Income-based Jobseeker's Allowance
- Income-related Employment and Support Allowance
- Housing Benefit, (unless you live in certain types of accommodation such as, some types of supported living or sheltered accommodation.)
- Child Tax Credit and Working Tax Credit.

Universal Credit may impact on other benefits. Find out more at:
[gov.uk/universal-credit/eligibility](https://www.gov.uk/universal-credit/eligibility) (England, Wales and Scotland)
nidirect.gov.uk/campaigns/universal-credit (Northern Ireland)

GOV.UK have also created a website on UC, at:
[understandinguniversalcredit.gov.uk/new-to-universal-credit](https://www.gov.uk/understandinguniversalcredit/new-to-universal-credit)

If you have a joint claim as a couple and one partner reaches State Pension age, you continue to claim UC as a couple until both reach State Pension age. Any State Pension paid, will affect UC as income.

If you are on any of the benefits that UC is replacing, you will receive a notice about changing to UC. You must act on this notice, or your benefits will stop. When you are taken over to UC, you should not be worse off benefit-wise.

Contact our Benefits Advice Service before applying for UC, for guidance. Any other benefits and the amount of your savings may affect the amount of UC you receive.



See section 2: **Where do I get guidance on benefits and entitlements?**

You can apply for Universal Credit online or call the UC helpline. If you find it difficult to claim or manage your UC benefit, let them know you need support for this.

Universal Credit – health element

If you are unable to work due to a health condition or disability, you may be entitled to the health element of Universal Credit (UC).

You can qualify if:

- You have been assessed and found to have limited capability for work-related activity after a Work Capability Assessment (WCA), or
- You are terminally ill under the Special Rules for End of Life (SREL), or
- You are moving from Employment and Support Allowance (ESA) and already get the support component.

From 6 April 2026, there will be changes to this element within Universal Credit:

- Existing claimants will continue to receive the current higher rate of the health element (around £423 per month in 2024/25) and this will rise with inflation until at least 2029/30.
- New claimants from 6 April 2026 will receive a reduced rate which will be frozen until 2029/30. Unless you are able to apply under Special Rules (using an SR1) or you meet the new 'severe conditions' criteria.

To meet the severe conditions criteria the impact of your condition must be experienced at all times, or whenever they try to do the activity described by the descriptor that leads to the LCWRA element, the condition must be permanent (for the rest of your life) and diagnosed by an NHS health professional.

If you are moving from ESA to UC, you should not have to re-apply or be reassessed if there is no break in your claim. However, after 6 April 2026 you may be capped at the lower rate unless you meet one of the conditions.

If you don't already have LCWRA as part of your UC claim and think you may qualify for this, you may wish to seek advice as soon as possible. Be aware that seeking a review allows whole award to be looked at again and therefore there is risk of the award changing in your favour, against your favour or remaining the same.

For up-to-date amounts and eligibility details, visit: [gov.uk/universal-credit](https://www.gov.uk/universal-credit)

Statutory Sick Pay (SSP)

Statutory Sick Pay (SSP) is paid when a person is employed and becomes unable to work for a period of time due to illness.

SSP is not means-tested and is taxable. SSP is payable for 28 weeks.

SSP is paid through your employer, who may also offer a company sick pay scheme. If you only receive SSP without additional sick pay from your employer, you may be able to get a top up payment through Universal Credit, if you qualify.

If SSP has ended, or you are self-employed, you may be able to claim New Style Employment and Support Allowance, Universal Credit or a mix of both instead.

If you cannot get SSP, you will need an SSP1 form from your employer to claim New Style ESA.

6. Other housing support and health and social care entitlements

Blue Badge scheme

Blue Badge can help you park close to your destination in restricted street areas, as a disabled passenger or as their driver. Off-street car parks, as for local authorities, hospitals or supermarkets, may also offer priority or free parking if you have a blue badge. Contact your local authority to find out more about the scheme.



See our booklet: **Getting around** for more on the Blue Badge scheme.

NHS Continuing Healthcare (CHC)

NHS Continuing Healthcare (also known as continuing care) is a package of funding to cover complex needs for both health and social care, provided by the NHS in England and Wales. If CHC funds any residential or nursing care you need, it can save you a lot of money in care home fees.



See information sheet: **10D NHS Continuing Healthcare**.

If you are receiving NHS CHC at home or in a care or nursing home and have any questions about how this affects your benefits, contact our Benefits Advice Service.



See section 2: **Where do I get guidance on benefits and entitlements?**

You need to be assessed to see if you qualify for NHS Continuing Healthcare. You can receive CHC as a personal health budget in England (see Personal health budgets below). Ask your GP or health and social care team for advice about how to be assessed for CHC.

In Northern Ireland, there is no guidance on NHS Continuing Healthcare, but health and social care trusts are encouraged to provide this support using the principles followed by the rest of the UK.

In Scotland, Continuing Healthcare has been replaced by a scheme called Hospital Based Complex Clinical Care. If the complex care needs can only be fully met by hospital care, this will be fully funded by the NHS. The local authority may be able to help with funding outside of hospital, in a community setting. For example, a care home, supported accommodation or in the person's own home with support.

Personal health budgets (England only)

This is an amount of money from the NHS to support health and wellbeing needs if you have a long-term condition or get CHC (see previous heading). It does not include primary or emergency healthcare, such as GP services, or Accident and Emergency (A&E), which are still provided.



See information sheet: **10F Personal health budgets.**

Social care and direct payments

With MND or Kennedy's disease, there may come a time when you need professional help with daily routines, personal care or equipment to prolong independence. This type of support is known as social care.



See information sheet: **10B What is social care?**

The approach to social care support can vary across the UK, but focus is given individual need so that people can personalise their care. This is called personalisation in England, citizen directed support in Wales, and self-directed support in Northern Ireland and Scotland.

In each case, your needs will be assessed to plan and agree your support and unpaid carers can also have a carer's assessment for their needs.

To arrange an assessment, contact your local authority in England and Wales:
[gov.uk/find-your-local-council](https://www.gov.uk/find-your-local-council)

In Northern Ireland, search for your local health and social care trust at:
nidirect.gov.uk/campaigns/universal-credit

In Scotland, contact your local council:
careinfoscotland.scot/find-my-council

Although it varies between each country, social care may not be free. If needed, a financial assessment works out how much you may receive toward the cost and how much you pay.

You can then have your care services arranged for you or choose to receive direct payments to select those services yourself.

Direct payments are paid into your account, but you need to keep records to manage these payments. This may include acting as an employer if you pay for your own regular care worker (known as a personal assistant), rather than having services arranged with varied care workers from an agency.

Prescription charge exemption, and help with sight tests and dental charges

In England

You do not have to pay for NHS prescriptions in England if you have an NHS prescription charge exemption certificate. People with certain medical conditions or those on certain means-tested benefits can apply for this certificate.

If you're on a low income, you can also apply for the NHS Low Income Scheme. You may be able to get full, or some help with prescription charges, the cost of dental care, and travel for treatment and eye care.

See if you qualify for prescription charge exemption certificate or the NHS Low Income Scheme at: [nhsbsa.nhs.uk/check-if-youre-eligible-help](https://nhs.uk/healthcarecosts/check-if-youre-eligible-help)

If you do not qualify for the above you can purchase a Prescription Prepayment Certificate (PPC), which means prescriptions will cost less over a 3 or 12 month period. The certificate covers you for all NHS prescriptions, no matter how many you need. If you purchase a 12-month certificate you can make 10 monthly payments by direct debit.

In Wales, Northern Ireland and Scotland

In Wales, Northern Ireland and Scotland all prescriptions are free.

You may also be able to get help with the cost of sight test, eye care, dental treatment and travel for treatment:

In Wales: gov.wales/low-income-scheme-help-nhs-health-costs

In Northern Ireland: nidirect.gov.uk/articles/help-health-costs

In Scotland: nhsinform.scot and search for: Help with health costs.

Prescription forms from England will be charged for at the current English rate in Scotland and may be chargeable in Wales and Northern Ireland.

Disabled Facilities Grant (DFG)

A Disabled Facilities Grant (DFG) helps towards the cost of adapting your home, to enable you to continue living there with a disability or long-term condition. DFGs are means-tested in most cases.

The grant is provided by your local authority in England or Wales or the Northern Ireland Housing Executive. It is not available in Scotland.

To apply for a DFG, contact your local authority in England or Wales. If you live in Northern Ireland, contact your local health and social care trust. They can arrange for an occupational therapist to assess your needs and apply for the grant on your behalf.

Ask for an assessment as soon as you start to need support as some local authorities will act quicker than others.



See information sheet:
10C Disabled Facilities Grants (DFG's) and home accessibility.

Housing Benefit

Housing Benefit provides support if you pay rent while on a low income from benefits or employment. Housing Benefit counts towards the benefits cap if you are of working age and is means tested.

If you receive Housing Benefit and you're under State Pension age, you will be invited at some point from 2025 to apply for Universal Credit (UC). UC includes a housing cost element to replace Housing Benefit. If you have a change in circumstance, this may prompt an early transfer to UC.

New claims for Housing Benefit can only be made if you've reached State Pension age or if you live in supported, sheltered or temporary housing.

Seek independent advice before applying for UC as you may receive less benefit. However, you may qualify for other support if this is the case.



See Universal Credit in section 5: **Health and work-related benefits.**

Support for Mortgage Interest (SMI)

Support for Mortgage Interest (SMI) helps towards the interest payments on mortgages or loans for certain repairs or home improvements.

You can only receive SMI if you own your own home or have bought a shared ownership property along with receiving one of the following benefits:

- Income Support
- Income-based Jobseeker's Allowance (JSA)
- Income related Employment and Support Allowance (ESA)
- Universal Credit (for 3 months in a row)
- Pension Credit.

SMI is paid as a loan by the DWP in England, Wales and Scotland, or the Department for Communities in Northern Ireland, which will carry interest.

You will need to pay back this loan with its own interest when you sell or transfer ownership of your home.

Taking out an SMI loan will not be the right choice for everyone, so seek advice before making a decision.

MoneyHelper (formerly the Money Advice Service) provide free, impartial advice on issues like this.



See contact details for other organisations in section 10:
How do I find out more?

If you face a sudden, large drop in income, contact your mortgage lender to see what help they can provide.

Help with Council Tax in England, Wales and Scotland

Disabled Band Reduction Scheme

This reduces Council Tax to the band below your usual payment, if you live in a property that has additional rooms (such as an extra bathroom, kitchen or other space) that make disabled living easier. This includes extra space for wheelchair use. It must be the main residence of at least one disabled person (adult or child), but they don't have to be the person paying the Council Tax.

Council Tax Reduction (sometimes known as Council Tax Support)

This reduction is given if you pay Council Tax and your income and savings are below a certain level. It is means-tested. Claim this reduction from your local authority. It is not being replaced by Universal Credit and needs to be claimed separately.

Single Person Council Tax Discount

This is a 25% discount on your Council Tax bill if only one person living in your home counts as an adult for Council Tax purposes.

People who do not count as adults for Council Tax purposes include:

- children under 18
- full-time students
- people with a severe mental impairment, which may include someone with a confirmed diagnosis of frontotemporal dementia (FTD). You may hear this called the ‘severe mental impairment discount’
- live-in carers looking after someone who isn’t their partner or child under the age of 15.

If there are **no** people living in your home who count as adults for tax purposes, a 50% discount may apply. If someone with a severe mental impairment lives alone, a 100% Council Tax discount may apply.

Help with rates in Northern Ireland

You may be able to get help paying your rates if you live in Northern Ireland.

Disabled Person’s Allowance

A discount in rates for people in Northern Ireland. This allowance is not means-tested. If a property has been adapted or has extra features to suit a disabled person’s needs, a 25% discount in your housing rates may be available.

Lone Pensioner’s Allowance

You may be able to get a 20% discount in your rates if you:

- own or rent where you live
- are aged 70 or over
- live alone.

Rate Rebate

You may be able to get help paying your rates if you:

- own or rent where you live
- are working age and on a low income
- are getting Universal Credit.

Rate Relie

You may be able to get help with your Rates if you own your property and are on a low income.

Help with living costs

An MND or Kennedy's disease diagnosis can bring financial challenges. Sometimes help is needed with everyday living costs. The rising cost of living has impacted many people, and the following schemes have been rolled out to help.

Find out more on available support at: [**gov.uk/cost-of-living**](https://www.gov.uk/cost-of-living)

Household Support Fund

The Government has allocated funds to local authorities until March 2026, to help provide additional support for families with children and pensioners. Funds can be used to provide support with food, clothing, energy and water costs. To find out more about the Household Support Fund contact your local authority.

Budgeting Advance

Budgeting Advances are government loans to help with emergency household costs, like buying a cooker or fridge. Budgeting Advances are not taxable. How much you get and the criteria for eligibility depends on the type you get. You must usually pay this back through your future Universal Credit payments. See the types and if you qualify at: [**gov.uk/universal-credit/get-advance-or-financial-support**](https://www.gov.uk/universal-credit/get-advance-or-financial-support)

Budgeting Loan

Budgeting Loans are interest free loans from the government to help with one-off expenses, such as buying essential items. Budgeting Loans are not taxable. You need to be receiving certain means-tested benefits to be able to apply for a Budgeting Loan. If you qualify, the loan will be paid on top of the benefits you receive. You must pay back a Budgeting Loan.

Charitable funding

Many charities and voluntary organisations provide help in specific circumstances.

MND Association financial support

We offer a range of financial support for people living with or affected by MND or Kennedy's disease. In most cases, this is after a need has been assessed by a health or social care professional and where social services or the NHS cannot help.

We may also be able to financially support wellbeing or cost of living, which do not have to be assessed by a health or social care professional.

Contact our MND Connect team for details or to help you identify external financial support and funding:

Tel: 0808 802 6262
Email: [**mndconnect@mndassociation.org**](mailto:mndconnect@mndassociation.org)
Website: [**mndassociation.org/financialsupport**](https://www.mndassociation.org/financialsupport)

Cold Weather Payment

The Cold Weather Payment is paid by the DWP every time there is a seven-day period of very cold weather between November and March. You may get this payment if you receive certain benefits. Cold weather payments are means-tested and not taxable.

You do not need to claim for Cold Weather Payment. If you qualify, it will be paid automatically. This payment is only available in England, Wales and Northern Ireland. If you live in Scotland, you may be eligible for the equivalent Winter Heating Payment.

Winter Heating Payment

This is only available in Scotland and has replaced the previous Cold Weather Payment scheme. It is not based on temperature changes and will be paid whatever the weather to people already receiving certain benefits. Find out more at:

mygov.scot/winter-heating-payment

Winter Fuel Payment

Winter Fuel Payment is an annual tax-free payment for people living in England, Wales and born before 22 September 1959. For more information see:

gov.uk/winter-fuel-payment

If you live in Scotland, you may meet the criteria for Pension Age Winter Heating Payment (PAWHP) which is also means-tested.

Pension Credit

Pension Credit supports people in England, Wales and Scotland of pension age who are on a low income from getting a reduced State Pension. It also supports those who do get a full State Pension but may have additional needs or costs for severe disabilities, responsibility for a child or young person, or are a carer.

For example, you may have full State Pension and not be eligible for Pension Credit, but an Attendance Allowance (AA) award would allow a severe disability premium in a Pension Credit amount. This would then mean that you could apply for Pension Credit.

Pension Credit isn't taxable but is dependent on your income and savings. It is made up of two parts:

- Guarantee Credit guarantees a minimum income by topping up any weekly income you have, including State Pension, to a certain amount.
- Savings Credit is an extra payment for people with a moderate work or personal pension, or savings, and who reached State Pension age before 6 April 2016.

If at pension age you are living with a partner who is claiming Housing Benefit in their name and who is thinking of making an application for Pension Credit, call our Benefits Advice Service before starting the new claim. They can help check how this may affect other benefits first.

There are also additional payments available which can form part of the Guarantee Credit. You or your partner may be entitled to this if you receive certain disability related benefits. You may also be entitled to more money if you're a carer. Find out what is available at: [gov.uk/pension-credit](https://www.gov.uk/pension-credit)

If you live in Northern Ireland, the eligibility criteria may be slightly different. For more information and how to apply visit:

nidirect.gov.uk/articles/understanding-pension-credit

Food banks

Some organisations provide essential food supplies via food banks for those in urgent need. The food is donated and given out by volunteers. Ask a health or social care professional about this service. If you qualify, you will be given vouchers to use at your local food bank.

Local Welfare Assistance schemes, Discretionary Support loans or grants, and Discretionary Assistance Fund

You may be able to get financial support to help you manage urgent situations if you:

- have applied for, or are receiving certain benefits in England, Wales or Scotland
- are on a low income in Northern Ireland.

This support includes:

- Local Welfare Assistance schemes in England (from your local authority)
- Discretionary Assistance Fund in Wales
- Discretionary Support loans or grants in Northern Ireland
- Crisis Grant or Community Care Grant as part of the Scottish Welfare Fund.

These types of urgent support should only be explored as a last resort, where no other funding is available.

Short term benefit advances

If you are in urgent financial need and waiting for the first payment of Universal Credit you may be able to get this paid early. These are called advance payments and are usually paid on the same day or the next working day. For more information, see: [gov.uk/universal-credit/get-an-advance-first-payment](https://www.gov.uk/universal-credit/get-an-advance-first-payment)

You may also be able to get an advance if your circumstances have changed and this means there is an increase in your benefit entitlement.

Any benefit advance is an interest free loan that you will have to pay back. This means you will receive less money in your following benefit payments.

7. How do I fast track a claim?

Fast tracking includes mention of end of life. Read the following when you feel ready.

With MND or Kennedy's disease, some benefit claims may be fast tracked under special rules. If you wish to claim under special rules, state this when you start the claim. If you or the person you are claiming for qualifies, the claim will be dealt with quickly and the highest rates for the relevant benefits will be given.

To be eligible for fast tracking, a GP, consultant or specialist nurse needs to complete a form called an SR1 if you live in England, Wales or Northern Ireland. In Scotland, this is a BASRiS form.

The SR1 or BASRiS form must state that the health professional would not be surprised if the person died within 12 months, known as a reasonable expectation of death.

In Northern Ireland, the same 12-month reasonable expectation of death applies across all applicable benefits ESA, UC, PIP, DLA and AA.

A healthcare professional completing the SR1 or BASRiS form does not mean death will definitely be within the stated time frame, only that it is a possibility. If the person survives longer, the benefit does not have to be repaid.



See our information sheet to share with professionals:
Providing medical evidence for benefit applications made by people with MND which can be found at: mndassociation.org/propublications

The person living with MND or Kennedy's disease does not have to make the claim themselves under special rules. It can be done by another person, such as their carer. When a person is fast tracked for a benefit, they do **not** have to:

- complete the longer claim forms or attend face-to-face assessments
- wait the usual qualifying period before payments start.

Some claims can take many weeks to complete without fast tracking. If you do not qualify for fast tracking, you will be redirected to a normal application, so there is nothing to lose by applying under special rules.

Ask about fast tracking if it's not explained when your first start the claims process. Fast tracking and special rules information will also be included in the claim pack, which will be sent to you when completing a physical claim form.

If special rules apply:

- complete the special rules section of the claim form or by telephone
- ask for form SR1 or BASRiS to support the claim, which can be provided and completed by the person's MND co-ordinator, GP, specialist nurse or consultant, who will complete it. (The SR1 or BASRiS can only be signed by one of the above.)
- you or the professional then send the completed SR1 or BASRiS to the Department for Work and Pensions (DWP). Send with the benefit claim, if possible, but don't delay the claim, as the SR1 or BASRiS can follow later if needed. The health professional can also obtain and submit it by email to: **form.e-SR1@dwp.gov.uk**

The start date of your claim is important, as most awards will be dated from this point. If successful, the award may be given for up to three years and then reviewed.

If you are making a claim for Attendance Allowance and have a signed SR1 or BASRiS form as well, you can telephone the Attendance Allowance helpline when you are ready to return your forms. Doing this means the claim date will start from the date of your phone call, instead of waiting for the forms to arrive by post.

Attendance Allowance helpline:

Tel: 0800 731 0122

Textphone: 0800 731 0317

If you come to the end of your award under the special rules and are invited to re-apply, contact our Benefits Advice Service for assistance.

If you or your healthcare team are in any doubt about whether a diagnosis of MND or Kennedy's disease qualifies for special rules, contact our Benefits Advice Service: **mndassociation.org/benefitsadvice**

8. What do I need to do when making a claim?

If you have accessibility needs, ask the provider if claim forms are available in other formats, for example large print. Ensure you have personal information available before making any enquiries. As well as your address and personal details, you will be asked for:

- your National Insurance number (if you have a partner, you may also need their National Insurance number)
- your bank account details (you should only be asked for these as part of an official assessment or application)
- details about your rent or mortgage
- details of your past or present employer
- details of other household income and savings.

You may have to wait before getting your payment, as the application process can take some time.

Will I need to provide any other supporting evidence?

With disability benefits you will be required to explain how your condition affects your daily living and your ability to remain independent. This may include being asked to complete more forms or provide further supporting evidence. It helps to give as much detail as you can on the claim form and:

- try not to make your difficulties sound more manageable than they are
- emphasise that your symptoms will get worse over time, and changes can be rapid
- send supporting evidence or a letter from your health and social care team (you may have to pay a small charge to get this type of evidence. The DWP say they will contact GPs for further information if required, but you can provide this at the start of your claim if you want to.)
- provide the best possible contact for further evidence if needed, such as your MND care co-ordinator, consultant or specialist nurse
- keep a file of all communications during your claim, with a copy of the claim form if you can (this may help with any problems or if you need to challenge something).

Example of how to answer claim form questions in detail:

Don't say:

"I find it difficult to get dressed."

Do say:

"I cannot do up buttons or zips anymore. Even with assistance it can take over an hour to get dressed and I find it very tiring."

Can I get help to make a claim?

If you need support to make a claim, including filling out forms, the following people may be able to help you:

- Our Benefits Advice Service can guide you on claims and how to fill out forms.
- An independent benefits adviser can assist with making claims.
- Some benefits have a dedicated helpline. Phone numbers are usually provided on the benefit page of the relevant government website.
- The Department of Work and Pensions have a home visiting service in England, Wales or Scotland.
- The Make the Call service in Northern Ireland, can provide home visits to support with form filling and face to face help.
- The Pension Service in England and Wales operates the Local Service Referral scheme. If you've reached State Pension age, this service can help with Pension Credit and State Pension queries, including support to complete forms.
- Citizens Advice (CA) have Help to Claim advisers.

9. Can I challenge a decision?

If you are not happy with a decision about a benefit or entitlement, you can ask for your claim to be looked at again by the authority that made the decision.

This is called a mandatory reconsideration.

You have one month to do this from the date on the decision letter, and you should receive a response within six weeks.

Provide additional evidence, if possible, for example a doctor's letter.

If you are still unhappy after this, you can then make an appeal, (challenge), but this may take some time to be heard.

You need to appeal within one month of receiving the decision on your mandatory reconsideration. However, this period of time may be extended to up to 13 months if there are special reasons for the delay in applying.

Find out more about appeals:

England and Wales: [gov.uk/appeal-benefit-decision](https://www.gov.uk/appeal-benefit-decision)

Northern Ireland: nidirect.gov.uk/appeal-benefits-decision

Scotland visit: mygov.scot/disagree-decision

You can also contact the helpline relating to the benefit you wish to appeal. Our Benefits Advice Service can also support you with appealing against a decision.



See section 10: **How do I find out more?** for contact details.

You may also be able to get guidance from your local authority or a local independent advice centre, such as carer's organisation or Citizen's Advice.

10. 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.



If you have speech or communication difficulties, download the Relay UK app to your smartphone, tablet or PC, or make a call using a textphone. For more on the service, see: relayuk.bt.com

Advice Now

Rights and legal issues in England and Wales.

Website: advicenow.org.uk

Advice UK

Includes a search facility for local independent advice agencies in the UK.

Website: adviceuk.org.uk

Advice NI

Free advice on welfare changes and benefits for people in Northern Ireland.

Tel: 0800 915 4604

Email: advice@adviceni.net

Website: adviceni.net

Age UK

Advice and information service for older people, including information on 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)

agecymru.wales (Wales)

ageni.org (Northern Ireland)

agescotland.org.uk (Scotland)

Carers UK

Advice, information and support for carers, including advice on benefits.

Tel: 0207 378 4999

Email: advice@carersuk.org

Website: carersuk.org (England)

carersuk.org/wales (Wales)

carersuk.org/ni (Northern Ireland)

carersuk.org/scotland (Scotland)

Citizens Advice

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

Tel: 0800 144 8848 (England)
0800 702 2020 (Wales)
0800 915 4604 (Northern Ireland)
0800 028 1456 (Scotland)

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

Citizens Advice help to claim service:

Website: **citizensadvice.org.uk/helptoclaim** (England and Wales)
cas.org.uk/helptoclaim (Scotland)

Government information

Online government information about benefits and support.

Website: **gov.uk** (England and Wales)
nidirect.gov.uk (Northern Ireland)
gov.scot (Scotland)

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**

Department for Communities

Responsible for benefits in Northern Ireland.

Tel: 028 9082 9000
Website: **communities-ni.gov.uk**

Department for Work and Pensions (DWP)

Responsible for awarding benefits in England and Wales.

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

Disability Law Service

For legal advice and information on benefits.

Tel: 0207 791 9800
Email: benefits@dls.org.uk
Website: **dls.org.uk**

Disability Rights UK

Advice for disabled people, with benefits information and a personal budget helpline.

Tel: 0330 995 0400 (for general enquiries)
0330 995 0404 (Personal budgets helpline)
Email: enquiries@disabilityrightsuk.org
personalbudgets@disabilityrightsuk.org (Personal budgets helpline)
Website: **disabilityrightsuk.org**

Independent Age

Free information and advice for older people and their families.

Tel: 0800 319 6789
Email: advice@independentage.org
Website: independentage.org

Jobcentre Plus

Information and assistance with employment and benefits.

Website: for England and Wales, search for: Jobcentre Plus, at gov.uk
for Northern Ireland, search for: jobs and benefits offices, at nidirect.gov.uk

Make the call (Northern Ireland only)

For queries about benefit entitlement in Northern Ireland.

Tel: 0800 232 1271
Website: nidirect.gov.uk/contacts/make-call-service

NHS Business Service Authority

Website includes a way to check if you can get a prescription exemption.

Website: nhsbsa.nhs.uk/check-if-youre-eligible-help

Northern Ireland Pension Centre

For general enquiries, making a State Pension claim, or applying for Pension Credit.

Tel: 0800 587 0892
Email: pensionservice@dfcni.gov.uk
Website: nidirect.gov.uk/contacts/northern-ireland-pension-centre

The Pension Service

All queries and claims about pensions for people living in England or Wales.

Tel: 0800 731 0469
0800 731 0456 Welsh language
Website: gov.uk/contact-pension-service

The Advocacy People

Provide free independent and confidential advocacy services.

Tel: 0330 440 9000
Email: info@theadvocacypeople.org.uk
Website: theadvocacypeople.org.uk

Turn2us

For a benefits calculator, a grants search tool and find a local adviser.

Website: turn2us.org.uk

Money Helper

Free and impartial money advice. You can use the webchat function on their website.

Tel: 0800 138 7777
0800 138 0555 Welsh language
Typetalk: 18001 0800 915 4622
Website: moneyhelper.org.uk

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Sarah Hayle	Advice Services Manager, Community Law Service, Northamptonshire.
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 About the NICE guideline on motor neurone disease
- 10B What is social care?
- 10C Disabled Facilities Grants and home accessibility
- 10D NHS Continuing Healthcare
- 10E Work and motor neurone disease
- 10F Personal health budgets
- 10G Support for families with children

Booklets

- What you should expect from your care
- Caring and MND: quick guide
- Living alone
- Personal care
- Getting around
- Finding your way with bereavement

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 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 give feedback on 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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Tel: 01604 250505
Email: enquiries@mndassociation.org
Website: mndassociation.org

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