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Benefits and entitlements and how to fast track claims

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

If you're living with motor neurone disease (MND) or Kennedy's disease or if you're providing support as an unpaid carer, you may be able to claim:

- benefits offering financial support
- entitlements offering other types of support.

Find the content you need using the following numbered sections:

- 1: **Where do I get guidance on benefits and entitlements?**
- 2: **What can I claim?**
- 3: **How do I fast track a claim?**
- 4: **What do I need to do when making a claim?**
- 5: **Can I challenge a decision?**
- 6: **How do I find out more?**

This information applies to people living in England, Wales and Northern Ireland. If you live in Scotland, contact MND Scotland for advice. See *Useful organisations* in section 6: *How do I find out more?* for contact details.



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 or Kennedy's disease.



Patient Information Forum

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

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: www.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. 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 3: <i>How do I fast track a claim?</i>
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 <i>income tax</i> at: www.gov.uk

1: Where do I get guidance on benefits and entitlements?

Can I get any advice on benefits?

This information sheet is a starting point, but details can change between revisions. Find up to date guidance on government websites.

Check if you qualify, how much you could receive and how to claim, by searching for benefits at:

England or Wales: **www.gov.uk**

Northern Ireland: **www.nidirect.gov.uk**

Scotland: **www.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: **www.advicelocal.org.uk**.

See *Useful organisations* in section 6: *How do I find out more?*

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: **www.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: **<https://mndscotland.org.uk/support/benefits-advice>**

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 *living abroad and benefits* at www.gov.uk

2: What can I claim?

We have put the benefits and entitlements you may be able to get into categories, based on how they can support you. These are:

- disability benefits
- support for carers in England, Wales and Northern Ireland
- support for carers in Scotland
- health and work-related benefits
- other health and social care entitlements
- support with the costs of housing
- help with living costs
- urgent support.

Search for *benefits and pensions rates* on www.gov.uk.



See our wider resources for specialist financial support:
Information sheet 10G - *Support for families with children*
Our booklet: *Finding your way with bereavement*

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 3: *How do I fast track a claim?*

Apply online at: www.gov.uk/attendance-allowance/how-to-claim, by post or over the phone.

If you apply online, your claim starts on the date you make your claim. If you print and post the form, the claim will 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:

Telephone: **0800 731 0122**

Textphone: **0800 731 0317**

Relay UK (if you cannot hear or speak or 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. See *What do the words mean?* earlier in this sheet or contact a benefits adviser.

If you live in certain areas of Scotland, you will need to apply for Pension Age Disability Payment instead of AA. This applies to Aberdeen City, Argyll and Bute, Highland, Orkney Islands and Shetland Islands. Pension Age Disability Payment will be available to every area in Scotland from 22 April 2025.

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 (see next) at 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:

www.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. See *What do the words mean?* earlier in this sheet or contact a benefits adviser.

If you are awarded the higher rate for the mobility part of PIP or score 10 points or more on the mobility assessment, you may be eligible for a blue badge or vehicle tax discount. You need the higher rate for a Motability scheme vehicle.

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.



For more on driving and the Motability Scheme, see our booklet: *Getting around*.

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: www.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: <http://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.

Support for carers in England, Wales or 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:
www.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 help or 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)

This is an extra amount of money that you may be able to receive as part of certain 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.



Contact our Benefits Advice Service.
See section 1: *Where do I get guidance on benefits and entitlements?*

Carer's Credit

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

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

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)

New Style Employment and Support Allowance (ESA) can help if you are:

- under State Pension age, and have a disability or health condition that affects how much you can work and
- not being paid Statutory Sick Pay (SSP) (see *Other health and social care entitlements* for more details).

You will also need to have previously worked as an employee or have been self-employed and paid enough National Insurance contributions. This would need to be in the two previous tax years, for example, a 2025 claim will look at your contributions for 2022/23 and 2023/24.

You can check your national insurance record here:

www.gov.uk/check-national-insurance-record

Whilst your claim is being assessed you will normally receive an assessment rate for at least 13 weeks, or until the medical assessment is completed, whichever comes last. Once a decision has been made you will be placed into one of the 2 groups listed below. If you qualify for fast tracking, you do not have to attend this assessment. See section 3: *How do I fast track a claim?*

People who receive ESA are placed into either:

- **the support group**, where you do not have to take part in work-related activity and will receive a higher rate of ESA. If you make a new ESA claim and have a progressive and lifelong illness (such as MND or Kennedy's disease), you are eligible for the enhanced disability premium and should not need to have any further assessments to be able to continue claiming.
- **the work-related activity group**, where you will need to be in contact with a work coach at the jobcentre, and possibly complete some work-related activities like re-training or volunteering. You do not have to look for work. If a review is needed, you would need to be reassessed. People in this group are not eligible for the higher rate of ESA that those in the support group get, nor the enhanced disability premium unless they get PIP. You should **not** be placed into this group if you are living with MND or Kennedy's disease. If you are, contact our Benefits Advice Service who can advise (see section 1: *Where do I get guidance on benefits and entitlements?*).

New Style ESA will be paid for only a limited time if you claim and are placed in the work-related activity group, then the benefit will be paid for 12 months. If you are placed in the support group, the benefit can be paid for as long as you qualify for criteria for the support group.

Before a work capability assessment, most people are asked to attend a 'health and work conversation' with a work coach to understand your condition better.

You may not have to attend this conversation, if you are:

- in hospital
- a medical professional has said you might have 12 months or less to live.

If you are invited to a 'health and work conversation', contact our Benefits Advice Service for guidance. If you do get an invite, it is important to respond.

If you don't, your claim may stop. (See section 1: *Where do I get guidance on benefits and entitlements?*).

Although this benefit is not affected by income, earnings or savings, the amount paid may reduce because of certain payments, such as a private pension.

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

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 often has an impact on the other benefits you may be able to receive.

For England, Wales and Scotland, see if you qualify at:
www.gov.uk/universal-credit/eligibility

For Northern Ireland, find out more about Universal Credit at:
www.nidirect.gov.uk/campaigns/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, as they can advise on your options. Other benefits and the amount of savings you have may affect the amount of UC you receive. See section 1: *Where do I get guidance on benefits and entitlements?*

You can apply for Universal Credit online or call the UC helpline. If the process of claiming and managing your UC benefit isn't accessible for you, reasonable measures should be made to allow you to receive and manage the benefit.

Citizens Advice also provide a 'help to claim' service:
If you live in England and Wales visit: www.citizensadvice.org.uk/helptoclaim
If you live in Scotland visit: www.cas.org.uk/helptoclaim

GOV.UK have created a website on UC, at:
www.understandinguniversalcredit.gov.uk

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 instead to claim New Style Employment and Support Allowance, Universal Credit or a mix of both instead. See *Health and work-related benefits* for details.

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

Other 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.



For more about the Blue Badge scheme, see our booklet: *Getting around*.

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.

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.

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.



For details about continuing care, including how to claim, see: Information sheet 10D – *NHS Continuing Healthcare*

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.



For details, see: Information sheet 10F – *Personal health budgets*

Social care and direct payments

With motor neurone disease (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.

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 work out the support you need. Unpaid carers can also have a carer's assessment for their needs.

To arrange an assessment:

In England and Wales: contact your local authority.
See: www.gov.uk/find-your-local-council

In Northern Ireland: contact your local health and social care trust.
Search for health and social care trusts at: www.nidirect.gov.uk

In Scotland: contact your local council.

See: www.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.



For more details about social care, direct payments and the different approaches in England, Northern Ireland and Wales, see: Information sheet 10B – *What is social care?*

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 partial 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: www.nhsbsa.nhs.uk/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: www.gov.wales/low-income-scheme-help-nhs-health-costs.

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

In Scotland: www.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.

Support with the costs of housing

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 on a low income from benefits or employment.

If you receive Housing Benefit and you're under State Pension age, you will be invited at some point in 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.

Housing Benefit counts towards the benefits cap if you are of working age and is means tested.

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. For more see, Universal Credit in section 2: *What can I claim?*

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 *Useful organisations* at the end of this sheet for contact details).

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

The following are ways to get help with your Council Tax bill in England, Wales or 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) with adaptations to 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.

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 be called the 'severe mental impairment discount'
- live-in carers looking after someone who isn't their partner or child.

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.

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. You can claim this reduction from your local authority. It is not being replaced by Universal Credit and needs to be claimed separately.

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 Relief: 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.

You can also find out more about what support is available at:
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 loans from the government to help with emergency household costs, like buying a cooker or fridge. Budgeting Advances are not taxable.

You need to have been getting Universal Credit for over six months to be able to apply for a Budgeting Advance. If you qualify, the advance will be paid as part of your Universal Credit payment. You must pay back the advance by receiving smaller UC payments until the loan is paid back.

See if you qualify: www.gov.uk/universal-credit/other-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. Please contact our helpline MND Connect for information:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

MND Association financial support

The MND Association offers 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:

Telephone: **0808 802 6262**
Email: **mndconnect@mndassociation.org**
Web: **www.mndassociation.org/grants**

You can view information about all our services at:
www.mndassociation.org/support-and-information

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 be able to 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 for the payment, 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: **www.mygov.scot/winter-heating-payment**

Winter Fuel Payment

Winter Fuel Payment is an annual tax-free payment for people living in England, Wales and Northern Ireland and born on or before 23 September 1958. From Winter 2024 onwards, you need be receiving certain benefits to be eligible for the payment. This one-off payment is usually paid automatically.

For more information see: **www.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 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**, which 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 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', which you or your partner may be entitled to 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: 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:

www.nidirect.gov.uk/articles/about-pension-credit

Urgent support

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:

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.

3: How do I fast track a claim?

With MND or Kennedy's disease, your claim for certain benefits 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.

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 you 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, from 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 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

We have an information sheet for professionals that you may wish to share with them, called *P5 - Providing medical evidence for benefit applications made by people with MND*. This can be found at: **www.mndassociation.org/publications**

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 reviewed after this time. 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:

Telephone: **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: www.mndassociation.org/benefitsadvice

4: What do I need to do when making a claim?

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.

If you have any accessibility needs when making a claim, ask the provider if forms are available in other formats, for example large print.

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. During the process you may be asked to complete more forms or provide further supporting evidence. This isn't unusual, but it helps to give as much detail as you can on the claim form and:

- try not to make your difficulties and symptoms sound more manageable than they are
- emphasise that your symptoms will get worse over time, and that these changes can be rapid
- send in supporting evidence or a letter from your health and social care team
(It is not unusual to be asked to pay a small charge for this type of evidence. The DWP say they will contact GPs for further information if required.)

You can choose to provide this information from the beginning of your claim if you feel you want to.)

- provide the best possible contact for further evidence that may be needed, such as your MND care centre or network co-ordinator, or consultant or specialist nurse from your neurological clinic
- keep a file of all communications during your claim, including a copy of the claim form if you can (this may help if there are any problems, or you need to challenge a decision).

Example of how to answer the questions:

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 what to claim for, and how to answer questions and fill out forms. See section 1: *Where do I get guidance on benefits and entitlements?*
- An independent benefits adviser can assist with making claims. See *Useful organisations* in section 6: *How do I find out more?*
- Some benefits have a dedicated helpline that can provide information and guidance about making a claim. These phone numbers are usually provided on the benefit pages of government websites. Search for the benefit you want to claim at www.gov.uk, for Northern Ireland at www.nidirect.gov.uk or for Scotland www.mygov.scot/browse/benefits
- The Department of Work and Pensions have a home visiting service in England, Wales or Scotland. Find out more at: www.gov.uk/support-visit-benefit-claim
- The Make the Call service in Northern Ireland, can provide home visits to support with form filling and face to face help. See: *Useful organisations* in section 6: *How do I find out more?*
- 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. See *Useful organisations* in section 6: *How do I find out more?*
- Citizens Advice (CA) have Help to Claim advisers. Search for *help to claim* at: www.citizensadvice.org.uk

5: 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:

In England and Wales: www.gov.uk/appeal-benefit-decision

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

For Scotland visit: www.mygov.scot/disagree-decision

You can also contact the helpline relating to the benefit you wish to appeal (contact details are provided at www.gov.uk, www.nidirect.gov.uk and www.mygov.scot for each relevant benefit or entitlement).

Our Benefits Advice Service can also support you with appealing against a decision. See section 1: *Where do I get guidance on benefits and entitlements?*

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.

6: How do I find out more?

Useful organisations

We cannot endorse organisations, but the following may help you search for further information. Our MND Connect helpline can help you find external services if details change. See *Further information* at the end of this sheet to contact our helpline.

Advice NI

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

Telephone: 0800 915 4604

Email: advice@adviceni.net

Website: www.adviceni.net

Advice Now

Rights and legal issues in England and Wales, with support on appealing PIP and ESA decisions, including a mandatory reconsideration support tool.

Website: www.advicenow.org.uk

Advice UK

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

Website: www.adviceuk.org.uk

Age UK

Advice and information service for older people, including information on benefits.

Telephone: 0800 169 8080 (England)
0845 125 9732 (Scotland)
0292 043 1555 (Wales)
0289 024 5729 (Northern Ireland)

Email: through the relevant website contact pages

Website: www.ageuk.org.uk (England)
www.agescotland.org.uk (Scotland)
www.agecymru.wales (Wales)
www.ageni.org (Northern Ireland)

Carers UK

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

Telephone: 0207 378 4999

Email: advice@carersuk.org

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

Citizens Advice

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

Telephone: 0800 144 8848 (Adviceline England)
0800 028 1456 (Scotland helpline)
0800 702 2020 (Advicelink Wales)
0800 915 4604 (Advice NI helpline)
Relay UK - if you can't hear or speak on the phone, you can type what you want to say: 18001 then the Adviceline or Advicelink number above.

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

Department for Communities

Responsible for benefits in Northern Ireland.

Address: Causeway Exchange, 1-7 Bedford Street, Belfast BT2 7EG

Telephone: 028 9082 9000

Website: **www.communities-ni.gov.uk**

Department for Work and Pensions (DWP)

Responsible for awarding benefits in England and Wales.

Address: Caxton House, Tothill Street, London SW1H 9NA

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

Disability Law Service

For legal advice and information on benefits.

Address: The Foundry, 17 Oval Way, London SE11 5RR

Telephone: 0207 791 9800

Email: benefits@dls.org.uk

Website: **<https://dls.org.uk>**

Disability Rights UK

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

Telephone: 0330 995 0400 (for general enquiries)

0330 995 0404 (Personal budgets helpline)

Email: enquiries@disabilityrightsuk.org

personalbudgets@disabilityrightsuk.org (Personal budgets helpline)

Website: **www.disabilityrightsuk.org**

GOV.UK

Online government guidance for benefits and entitlements in England and Wales.

Website: **www.gov.uk**

GOV.SCOT

Online government guidance for benefits and entitlements in Scotland.

Website: **www.gov.scot**

Independent Age

Free information and advice for older people and their families on care and support, money and benefits, and health and mobility.

Telephone: 0800 319 6789

Email: advice@independentage.org

Website: **www.independentage.org**

Jobcentre Plus

Information and assistance with employment and benefits.

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

Make the call (*Northern Ireland only*)

For queries about benefit entitlement in Northern Ireland.

Telephone: 0800 232 1271

Website: www.nidirect.gov.uk/contacts/make-call-service

MND Scotland

Support for people with MND in Scotland.

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: www.mndscotland.org.uk

Money Helper

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

Telephone: 0800 138 7777

0800 138 0555 *Welsh language*

Typetalk: 18001 0800 915 4622

Website: www.moneyhelper.org.uk

NHS Business Service Authority

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

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

NI Direct

Online government information about benefits and entitlements in Northern Ireland.

Website: www.nidirect.gov.uk

Northern Ireland Pension Centre

For general enquiries, reporting a change of circumstance, making a State Pension claim, or applying for Pension Credit.

Address: PO Box 42, Limavady BT49 4AN

Telephone: 0800 587 0892

Email: pensionservice@dfcni.gov.uk

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

The Pension Service

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

Telephone: 0800 731 0469

0800 731 0456 *Welsh language*

Relay UK - if you can't hear or speak on the phone, you can type what you want to say: 18001 then either of the numbers above.

Website: **www.gov.uk/contact-pension-service**

The Advocacy People

Provide free independent and confidential advocacy services.

Telephone: 0330 440 9000

Email: info@theadvocacypeople.org.uk

Website: **www.theadvocacypeople.org.uk**

Turn2us

Helps people in financial hardship gain access to welfare benefits, charitable grants and support services. The website also has a benefits calculator, a grants search and 'find a local adviser' tool.

Telephone: 0808 802 2000

Email: info@turn2us.org.uk

Website: **www.turn2us.org.uk**

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

References

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

Or write to: Information feedback, MND Association, Francis Crick House,
6 Summerhouse Rd, Northampton NN3 6BJ.

Further information

We provide information sheets and publications on the following subjects:

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*

You can also refer to our guides and tools:

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

Living alone with motor neurone disease or Kennedy's disease - This guide explores the likely challenges when living alone with either condition and offers information resources that can help.

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

Personal care with MND - Suggestions on ways to manage everyday tasks such as washing, dressing and intimate care with MND.

Getting around – Driving, transport and holiday guidance for people with MND or Kennedy's disease.

Finding your way with bereavement – our booklet on managing the emotions felt with bereavement and finding practical support. Includes information on bereavement benefits you may be entitled to.

You can download most of our publications from our website at:

www.mndassociation.org/publications or order in print from the MND Connect helpline.

The helpline team can also answer questions about this information, and direct you to our services and to other support:

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

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

MND Association Benefits Advice Service

Find current contact details for England, Wales and Northern Ireland at:

Website: www.mndassociation.org/benefitsadvice

or contact our MND Connect helpline for guidance: **0808 802 6262**

MND financial support

Telephone: 0808 802 6262

Email: support.services@mndassociation.org

Website: www.mndassociation.org/support-and-information

MND Association website and online forum

Website: www.mndassociation.org

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

MND Campaigns

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society. Many of our campaigns are related to the benefits system.

Email: campaigns@mndassociation.org

Website: www.mndassociation.org/campaigning

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.

If you would like to provide feedback on any of our information sheets, you can access an 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, Northampton NN3 6BJ



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