



10A

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 are living with motor neurone disease (MND) or providing support as an unpaid carer you may be able to claim:

- benefits offering financial support for specific needs
- entitlements offering other types of support.

If you are living with Kennedy's disease or provide care, you may also be able to claim some of the benefits and entitlements mentioned in this sheet.

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.

**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 calculator at: www.gov.uk/benefit-cap
Benefit calculator	Calculators to 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 have to tell the Department for Work and Pensions (DWP) if your circumstances change. In Northern Ireland, you have to inform the Department for Communities (DFC). Some changes may mean you need to switch to another benefit, such as Universal Credit.
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.
Severe Disability Premium (SDP)	A premium that may be paid on top of certain means tested benefits you get, if you have nobody caring for you who receives Carer's Allowance.
Special rules for end of life (SREL):	A system where claims for Employment and Support Allowance (ESA), Universal Credit (UC), Disability Living Allowance (DLA), Personal Independence Payment (PIP) and Attendance Allowance (AA) can be fast tracked if you have a terminal illness. There are some rules about this. See section 3: <i>How do I fast track a claim?</i> for more information.
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 about 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: **www.gov.uk**

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

Can I get any advice on benefits?

You can find out about different types of benefits and entitlements in this sheet. Details can change between revisions, but you can find up to date information about benefits and entitlements on government websites. In England or Wales, search for the benefit you want to claim at: **www.gov.uk** In Northern Ireland search at: **www.nidirect.gov.uk** You can check whether you're eligible, how much you could receive and how to claim.

MND Association Benefits Advice Service

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

Qualified advisers 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 a translation between English and your chosen language as 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.

Other local independent advice centres may also be able to support with benefits advice, such as your local authority, local carer's organisation or local Citizens advice. You can find them through: **www.advicelocal.org.uk**. See *Useful organisations* in section 6: *How do I find out more?* for national organisations that may also provide independent 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?

In this sheet, we have placed benefits and entitlements into groups, based on how they can support you. These are:

- disability benefits
- support for carers
- health and work related benefits
- other health and social care entitlements
- support with the costs of housing
- help with living costs
- urgent support.

For information and support about health and social care benefits you can contact our MND Connect Helpline:

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org



For information on financial and other support for families with children affected by MND, see: Information sheet 10G – *Support for families with children*



For information on benefits relating to bereavement and funerals, see our booklet: *Finding your way with bereavement*

Disability benefits

Attendance Allowance (AA)

You can get Attendance Allowance (AA) if you are pension age or older and need help with personal care or keeping safe. 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 means-tested
- 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 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 if you are claiming under 'Special Rules'. See section 3: *How do I fast track a claim?* for more details about Special Rules.

If you telephone the Attendance Allowance 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

If you get AA, you may be able to get the Severe Disability Premium added to pension credit or housing benefit. For more information, see *What do the words mean?* or contact a benefits adviser.

Disability Living Allowance (DLA)

Disability Living Allowance (DLA) has two parts, a care part to help with care needs and a mobility part to help with getting around. **New claims for DLA can now only be made for people aged under 16.**

DLA is:

- not means-tested
- not dependent on National Insurance contributions
- tax free.

DLA is being replaced by Personal Independence Payment (PIP) for people aged over 16. If you were under 65 on 8 April 2013 and getting DLA, the Department for Work and Pensions (DWP) will contact you to invite you to apply for PIP instead. If you do not reapply when you receive this, your benefit will stop.

If you were 65 or over and getting DLA on 8 April 2013, you will keep getting DLA unless you have a change in circumstances and you need to be reassessed.

Northern Ireland: In Northern Ireland, if you were 65 or over on 20 June 2016 and getting DLA, you will **not** have to claim PIP instead. If you were under 65 on this date and still getting DLA, you will be contacted and invited to apply for PIP instead.

Payments are available in Northern Ireland to help with the transfer from DLA to PIP, if this transfer means you will receive less money. See *Supplementary payments in What do the words mean?* at the front of this sheet for more information.

Personal Independence Payment (PIP)

Personal Independence Payment (PIP) is for working age disabled people and people with a long term health condition, who have difficulties with daily living or getting around. PIP has replaced DLA for most adults (see previous heading). If you are receiving PIP when you reach pension age, it may carry on if you still qualify. To qualify for PIP you will need to be assessed. This may be done by phone or face to face. The amount of benefit you receive through PIP is based on how your condition affects your daily life and how you get around (your mobility).

PIP is:

- not means-tested
- not dependent on National Insurance contributions
- tax free.

PIP has a daily living part and a mobility part. If you qualify, you may get money for one or both parts, either at a standard or enhanced rate. If you get PIP for daily living, you may be able to get the Severe Disability Premium (for more information, see *What do the words mean?* or contact a benefits adviser).

If you are awarded the enhanced rate for the mobility part of PIP, and this has 12 or more months to run, you can use this for the Motability Scheme if you wish.



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

When PIP is awarded, it 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 your PIP award to be reviewed contact the Benefits Advice Service for support: **www.mndassociation.org/benefitsadvice**

The DWP has developed a series of videos about the PIP process at: **<http://bit.ly/understandingPIPvideos>**

Northern Ireland: Payments are available in Northern Ireland to help with the transfer of DLA to PIP, if this transfer means you will receive less money. See *Supplementary payments* in *What do the words mean?* at the front of this sheet for more information.

Support for carers

If you are a carer for someone with MND or Kennedy's disease, you may be entitled to the following support.

Carer's Allowance

This is an allowance to help if you're providing care, for at least 35 hours each week, for someone who gets AA, PIP for daily living, or the middle or higher rates of the care part of DLA. You can only claim if you earn up to £139 per week after deductions. Carer's Allowance is taxable, but not means-tested.

Carers who get Carer's Allowance are **not** affected by the benefit cap. However, if you receive other benefits you may not be able to get Carer's Allowance as well. Contact a benefits adviser before applying for Carer's Allowance to see if it will affect any other benefits you receive, or the benefits of the person you're caring for.

Tell the DWP if you have a change in circumstance as soon as possible. You will have to pay back any Carer's Allowance overpayments, including if you start to earn over £139 a week after deductions.

Depending on what other benefits you receive, you may have an underlying entitlement of Carer's Allowance instead of the benefit itself. This can result in a top up premium 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. See *Carer premium* below for more information.

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

This is an extra amount of money that carers may be able to get as part of certain means-tested benefits. It is not a benefit in its own right. Unlike carers allowance, there is no earnings limit.

For more information, contact the MND Benefits Advice Service. See section 1: *Where do I get guidance on benefits and entitlements?* for contact details.

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 who is disabled, but you cannot get Carer's Allowance.

Health and work related benefits

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

Employment and Support Allowance (ESA)

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

- under state pension age, and disability or illness is stopping you from working
- not being paid Statutory Sick Pay (SSP) (see *Other health and social care entitlements* for more details).

Universal Credit is replacing income-related ESA. However, one type of ESA is still available. You can still make new claims for contribution-based ESA, but this is now called 'new style' ESA.

A work capability assessment looks at whether you should receive ESA and which of two groups you should be placed in (see 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), you are eligible for the Severe Conditions Exemption and should not need any further assessments 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 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 Severe Conditions Exemption. You should not be placed into this group if you are living with MND. If you are, contact the Benefits Advice Service who can advise (see section 1: *Where do I get guidance on benefits and entitlements?* for details).

Before a work capability assessment, most people are asked to attend a 'health and work conversation' with a work coach. You may not have to attend this conversation, if you:

- are eligible for fast tracking (see section 3: *How do I fast track a claim?*).
- spend over 35 hours a week caring for someone.

If you are invited to a 'health and work conversation', contact the 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?* for details).

Universal Credit (UC)

This benefit provides support to you if you are out of work or on a low income. Universal Credit is means-tested but not taxable. It is only for people of working age (16 to 66th birthday). If you are a couple where one partner is 66 or over and you are jointly making a claim for pension credit or housing benefit, you will be directed to universal credit instead until both of you are 66.

Universal Credit is a standard allowance, that may include extra amounts for some housing costs, being responsible for children, being unfit for work and work-related activity, or being a carer. You can apply for UC using the fast tracking process (for more information, see section 3: *How do I fast track a claim?*).

Contact the MND Association 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?* for details.

Universal Credit is in place across the UK for new claims and people on other benefits who have had a relevant change in circumstance. For working age people, UC 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.

Anyone currently claiming any of these benefits will be invited to claim for Universal Credit (UC) by the end of 2024. You may hear this being called 'move to UC' or 'managed migration'. Until you are contacted by the DWP or Department for Communities your current benefits will continue unless there is a relevant change in your circumstances, or a new claim needs to be made for one of the above benefits or if you voluntarily transfer.

Seek specialist advice before moving from your current benefits onto UC. Some people receive less money on UC than with their current benefits and once a new application has been made you cannot go back.

If you are going to lose money by moving onto UC, it is better to wait until the DWP contact you. This is because as part of 'move to UC' you may qualify for top up or transitional payments to ensure that you receive the same amount you would have on your old benefits. If you do qualify for the extra payment amounts this would continue unless you have a change in circumstances.

UC is usually claimed and managed online. However if this is not possible, the DWP or Department for Communities may be able to visit you, or you may be able to apply over the phone. 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 may also provide a 'help to claim' service in your area (search for *help to claim* at: **www.citizensadvice.org.uk**)

If you are unable to work due to disability or illness, you will need to go to the jobcentre to have an interview and possibly create a 'claimant commitment' with a work coach. You will be asked to complete a questionnaire called a UC50 on how your illness affects your everyday life and ability to complete certain activities. You will then have to attend a work capability assessment to work out if you are entitled to UC, without having to look for work. The work capability assessment works in the same way as described in the section about Employment and Support Allowance.

You won't have to create a 'claimant commitment' if your application is being fast tracked. See later section 3: *How do I fast track a claim.*

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 sickness.

SSP is not means-tested and is taxable.

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're eligible.

If SSP has ended, or you are self-employed, you may be able to instead claim 'new style' Employment and Support Allowance, Universal Credit or a mix of both. See *Health and work related benefits* for details.

Other health and social care entitlements

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 (sometimes called domiciliary care) or in a care or nursing home and have any questions about how this affects your benefits, contact the Benefits Advice Service.

You need to be assessed to see if you qualify for NHS CHC. You can receive CHC as a personal health budget in England (see *Personal health budgets* next).

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 CHC, but health and social care trusts are encouraged to use the principles followed by the rest of the UK.



For details about continuing care and 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 to individual need so that people can personalise their care. This is called personalisation in England, self directed support in Northern Ireland and citizen directed support in Wales.

In each case, your needs will be assessed to work out the support you need. Unpaid carers can also have a carers assessment for their needs.

In England and Wales contact your local authority to arrange an assessment with adult social care services – find your local authority at: **www.gov.uk/find-your-local-council**

In Northern Ireland contact the local health and social care trust where you live to arrange an assessment with adult social care services. For contact details, search for *health and social care trusts* at: **www.nidirect.gov.uk**

A financial assessment may be needed for any social care services you agree to receive. Unlike NHS healthcare, social care may not be free. The financial assessment works out how much you might receive towards the costs and how much you may have to contribute.

You can then have care services arranged for you or choose to receive direct payments to select 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, travel for treatment and eye care. To check if you're eligible for a prescription charge exemption certificate or the NHS Low Income Scheme visit:

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

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

In Northern Ireland and Wales

In Northern Ireland and Wales all prescriptions are free.

In Wales you may be able to get help with the cost of sight tests and eye care, NHS dental treatment, and travel costs. To check if you're eligible for this scheme visit:

www.healthcosts.wales.nhs.uk/low-income-scheme

In Northern Ireland you may be able to get help with the cost of sight tests and eye care, NHS dental treatment, and travel costs. To check if you are eligible for this help visit:

www.nidirect.gov.uk and search for *help with health costs*.

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. DFGs are means-tested in most cases.

The grant is provided by your local authority in England or Wales, or in Ireland, by the Northern Ireland Housing Executive.

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.



For details about these grants, see:

Information sheet 10C – *Disabled Facilities Grants (DFG's) and home accessibility.*

Housing Benefit

Housing Benefit provides support if you are paying rent on a low income from benefits or employment.

Housing Benefit counts towards the benefits cap if you are of working age and is also means tested. However, most people can no longer make a new claim for Housing Benefit.

If you are already claiming Housing Benefit, you will be invited at some point to apply for Universal Credit (UC) instead, which includes a housing cost element. If you have a change in circumstance, you may also have to apply for UC instead of continuing to claim Housing Benefit. By 2025, the only people getting housing benefit will be people aged 66 or over.

Seek independent advice before applying for UC as you may receive less benefit. However, there are payment schemes you may qualify for 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 one of the following describes you:

- you have had three Universal Credit payments in a row, while unemployed
- you have been receiving certain means-tested benefits for 13 weeks or more
- you are entitled to claim Pension Credit (you won't have to wait 13 weeks before applying if so).

You can only get this support for the interest on a mortgage or loan, not the amount borrowed.

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

You will need to pay back this loan, including the 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. 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 and Wales

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

Disabled Band Reduction Scheme: This reduces your Council Tax bill to the band below your usual payment, if you live in a property that has additional space which makes living with MND easier.

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. It does not apply in Wales.

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 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.

Household Support Fund

The Government has allocated funds to local authorities until March 2024, 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.

Pensioner Cost of Living Payment

People getting state pension and receiving the Winter Fuel Payment will automatically receive £300 per household as a top up to their 2023 Winter Fuel Payment.

Cost of Living Payment

Households on certain means tested benefits will receive up to £900 per household automatically paid by the Department for Work and Pensions (DWP). The first instalment of £301 was paid in April - May 2023. The second and third instalments will be paid in Summer 2023 and Winter 2024. To find out more about these payments see:

www.gov.uk/guidance/cost-of-living-payment

Disability Cost of Living Payment

In the Summer and Autumn of 2023, people claiming certain disability benefits will automatically receive £150. For more about this payment see:

www.gov.uk/guidance/cost-of-living-payment

Blue Badge scheme

Blue Badge can help you park on the street in restricted areas, close to your destination, either as a passenger or driver. Off-street car parks, such as those provided in local authority, hospital or supermarket car parks have separate rules, but they may 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*.

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 Universal Credit payments until the loan is paid back.

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 Support Grants

The MND Association provides MND Support (Care) Grants where a need has been assessed by a health or social care professional and where social services or the NHS cannot provide support.

We also provide Quality of Life Grants, Carer's and Young Carer's Grants, and Young Person's Grants for people living with or affected by MND, or Kennedy's disease. These grants do not have to be assessed by a health or social care professional.

We also provide a Cost of Living Support grant which is a one off payment up to £350 that can be used in any way to help with the rising cost of living with MND.

Contact our Support Services team for details:

Telephone: 0808 802 6262

Email: support.services@mndassociation.org

Web: www.mndassociation.org/grants

You can view information about all our services at:

www.mndassociation.org/support-and-information

Your Association visitor (AV), local branch or group, or regional MND Association staff member may also be able to provide further information on MND support grants.

Cold Weather Payment

The Cold Weather Payment is paid 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 are working age or over and receive certain benefits.

Cold weather payments are means-tested and are not taxable.

You do not need to claim for Cold Weather Payment. If you qualify for the payment, it will be paid automatically.

Winter Fuel Payment

Winter Fuel Payment is a yearly grant for people of state pension age. It is not means tested and it's tax free.

This one-off payment is usually paid automatically to people of state pension age. You do not need to be receiving your pension.

Pension Credit

Some people get no, or reduced state pension due to not paying enough National Insurance throughout their life. Pension Credit supports people of pension age who are on a low income from getting a reduced state pension. Or who do get a full state pension but may have additional needs such as a severe disability, additional costs due to a disability or are a carer.

Pension Credit is means-tested, although there is not a fixed savings limit unlike other means-tested benefits and it is not taxable.

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.
- **Savings Credit**, which is an extra payment for people who have a moderate work or personal pension, or savings. This is generally no longer available for new claims, for more information contact a benefits adviser.

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 the Benefits Advice Service before starting the new claim. They can help check how this may affect other benefits first.

Pension Credit has additional payments within it, one of which is known as the Severe Disability Addition, which you may be entitled to if you receive certain disability related benefits and live alone or with a partner or spouse who also gets certain disability benefits. You may also be entitled to more money if you're a carer. Contact the Benefits Advice Service for more information at www.mndassociation.org/benefitsadvice or contact our MND Connect helpline for guidance: **0808 802 6262**

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 or Wales
- 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.

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. For example, you may have to wait five weeks for your first Universal Credit payment, 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 acts like an interest free loan that you 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, your claim for certain benefits may be fast tracked. The definition of 'terminal illness' was changed for some benefits in April 2022 and for all other benefits in April 2023.

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 available of 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.

The SR1 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 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 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 the person with MND is not passed for fast tracking, they 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.

In this case:

- complete the Special Rules section of the claim form or by telephone
- ask for form SR1 to support the claim, from the person's MND co-ordinator, GP, specialist nurse or consultant, who will complete it. (The SR1 can only be signed by one of the above.)

- you or the professional send the completed SR1 to the Department for Work and Pensions (DWP). Send with the benefit claim if possible, but don't delay the claim, as the SR1 can follow later, if needed. The health professional can also obtain and submit it electronically: **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/propublications**

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're making a claim for Attendance Allowance and have a signed SR1 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 reapply, contact the MND Association Benefits Advice Service for assistance.

If you or your healthcare team are in any doubt about whether a diagnosis of MND qualifies for special rules, contact the MND Association 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 the forms are available in other formats, for example large print.

You may have to wait to receive a claim payment, as the application 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 will help if you can 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 that these changes can be rapid
- send in supporting evidence or a letter from your health and social care team. (You may be asked to pay a small charge for this type of evidence. The DWP say they will contact GP's for further information if they require it, however it may help to provide this information from the beginning of your claim)
- 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 MND Association Benefits Advice Service, can provide guidance on what you are entitled to, how to best answer questions and filling out forms. For contact details, see section 1: *Where do I get guidance on benefits and entitlements?*
- An independent benefits adviser, who can also 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**, or for Northern Ireland at **www.nidirect.gov.uk**
- Ask about the DWP home visiting service in England or Wales if it is not offered. For more information, see: **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. For contact details, see *Useful organisations* in section 6: *How do I find out more?*
- The Pension Service in England and Wales, which operates the Local Service Referral scheme to help people of pensionable age with Pension Credit and state pension queries. They can help complete forms. See *Useful organisations* in section 6: *How do I find out more?* for contact details.
- Citizens Advice (CA) have Help to Claim advisors who can assist you with the early stages of a UC claim, see: **www.citizensadvice.org.uk/about-us/contact-us/contact-us/help-to-claim**

5: Can I challenge a decision?

If you are not happy about a decision regarding 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. You can find further details about the appeals process by searching for *benefits appeals* at: **www.gov.uk** or for Northern Ireland, search for *appeals* at: **www.nidirect.gov.uk**

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

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

A local independent advice centre may also be able to advise (where a benefit service is offered), such as your local authority, local carer's organisation or local Citizens Advice.

6: How do I find out more?

Useful organisations

We do not necessarily endorse the external organisations listed here. These have been provided to help you search for further information if necessary. Details are correct at the time of print, but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline (see *Further information* at the end of this sheet for details about our helpline and how they can support you).

Advice NI

Provides 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

Online information on rights and legal issues for people in England and Wales. The website also has a guide on appealing PIP and ESA decisions and a mandatory reconsideration support tool.

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

Advice UK

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

Address: Suite 610, 150 Minories, London, EC3N 1LS
Telephone: 0300 777 0107
Website: www.adviceuk.org.uk

Age UK

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

Address: 7th Floor, One America Square, 17 Crosswall, London, EC3N 2LB
Telephone: 08000 678 1602 (England)
00300 303 44 98 (Wales) – charged at local rate
0808 808 7575 (Northern Ireland)
Email: through the relevant website contact pages
Website: www.ageuk.org.uk (England)
www.ageuk.org.uk/cymru (Wales)
www.ageuk.org.uk/northern-ireland (Northern Ireland)

Carers UK

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

Address: Carers UK, 20 Great Dover Street, London, SE1 4LX
Telephone: 0808 808 7777
Email: advice@carersuk.org
Website: www.carersuk.org (England)
www.carersuk.org/wales (Wales)
www.carersuk.org/northernireland (Northern Ireland)

Citizens Advice

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

Telephone: 0800 144 8848 (England)
0800 702 2020 (Wales Advicelink)
Relay UK - if you can't hear or speak on the phone, you can type what you want to say: 18001 then 0800 144 8884
Textphone: 03444 111 445
Website: www.citizensadvice.org.uk (England)
www.citizensadvice.org.uk/wales (Wales)

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: 020 7791 9800

Email: advice@dls.org.uk

Website: **www.dls.org.uk**

Disability Rights UK

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

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

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**

Independent Age

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

Address: 18 Avonmore Road, London W14 8RR

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

For queries about benefit entitlement in **Northern Ireland**.

Telephone: 0800 232 1271

Website: www.nidirect.gov.uk/campaigns/unclaimed-benefits

MND Scotland

Support for people with MND in Scotland.

Address: 6th Floor Merchant Exchange 20 Bell Street Glasgow G1 1LG

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.

Address: Holborn Centre, 120 Holborn, London EC1N 2TD

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

NIDirect

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 7898

0800 731 7936 *Welsh language*

If you use the Next Generation Text service, place 18001 before either of the above numbers to text the Pension Service instead of calling.

Website: Search for *pension service* at: www.gov.uk

The Advocacy People

Provide free independent and confidential advocacy services.

Address: PO Box 375, Hastings, East Sussex, TN34 9HU
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 has a benefits calculator, a grants search and 'find a local advisor' tool.

Address: Hythe House 200 Shepherds Bush Road, Hammersmith W6 7NL
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 main guides:

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

Caring and MND: support for you – comprehensive information for family carers, who are supporting someone living with MND

Caring and MND: quick guide – the summary version of our information for carers

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

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 Support Grants and equipment loan

Telephone: 0808 802 6262

Email: support.services@mndassociation.org

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

MND Association website and online forum

Website: **www.mndassociation.org**

Online forum: **<https://forum.mndassociation.org>** or through the 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. To feedback on any of our information sheets, access our online form at:

www.smartsurvey.co.uk/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email: infofeedback@mndassociation.org

Or write to:

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

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