



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 a 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.


This information sheet is designed to let you know some of the benefits and entitlements you may qualify for.

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 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
- 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. Some changes may mean you need to switch to another benefit, such as Universal Credit.
- means testing** Looking at yours and your partner's income, savings and other assets (known as capital) to work out the level of benefit you should get. We have said where benefits and entitlements are means-tested in this sheet.
- Severe Disability Premium (SDP)** A premium that may be paid on top of certain benefits you get, if you live alone and nobody caring for you receives Carer's Allowance. Contact a benefits adviser for more information. Getting the SDP may mean you can stay on your existing benefits for longer, before moving over to Universal Credit.
- special rules for terminal illness** A system where claims for benefits can be fast tracked if you have a terminal illness. There are some rules about this. See section 3: *How do I fast track a claim?* 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 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

 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*

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

Can I get any advice on benefits?

The MND Association Benefits Advice Service provides advice by phone and email for people living with or affected by MND and Kennedy's disease in England, Wales and Northern Ireland. The service is provided in partnership with Citizens Advice Cardiff and the Vale, and Advice NI. Qualified advisers can help identify benefits you may be entitled to and advise on how to claim. This service is confidential, impartial and free.

You can email the Benefits Advice Service by going to our website, at:
www.mndassociation.org/benefitsadvice

Telephone: 0808 801 0620 (**England and Wales**)
0808 802 0020 (**Northern Ireland**)

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. See *Useful organisations* in section 6: *How do I find out more?* for national organisations that may also provide independent advice.

How do I find out if I qualify?

You can find out about different types of benefits and entitlements in this sheet. Find out if you qualify by contacting our Benefits Advice Service, or another independent benefits service. See *Can I get any advice on benefits?* above for details.

You can also find out more about benefits, including whether you're eligible, how much you can get and how to claim, by looking them up 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**

If information about a benefit or entitlement can be found on any other website, we will state this in this sheet.

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

Disability benefits

The benefits in this section are the main disability benefits in the UK.

Attendance Allowance (AA)

You can get Attendance Allowance (AA) if you first make a claim when you are of pension age or over and have difficulties or need help with personal care or keeping safe. It is:

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

You do not need to have a carer to be able to get AA.

AA has two rates:

- **the lower rate**, which is paid if you regularly need help with personal care or keeping safe in the day, or have repeated or prolonged difficulties and need someone with you at night.
- **the higher rate**, which is paid if you need a large amount of help both in the day and at 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.

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, your benefits will stop.

If you were 65 or over and getting DLA on 8 April 2013, you will keep getting DLA unless your circumstances change and you need to be reassessed. You may be able to get the Severe Disability Premium on top of your DLA (for more information see *What do the words mean?* or contact a benefits adviser).

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 are 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 who have difficulties with daily living or getting around. PIP has replaced DLA for most adults (see previous heading). If you get PIP and you are under pension age, it will carry on when you are over pension age. How much you can get 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 details about the Motability Scheme, see:
Information sheet 12B – *Choosing the right vehicle*.

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 care 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 someone who gets AA, PIP for daily living, or the middle or higher rates of the care part of DLA.

Carer's Allowance is:

- taxable
- not means-tested, but you can only claim if you earn up to £123 a week.

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 to 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 £123 a week.

Depending on what other benefits you receive, you may be able to get an underlying entitlement of Carer's Allowance instead of the benefit itself. This can result in a top up premium being added to other means-tested benefits. You will need to apply for Carer's Allowance to find out if you can get this premium. 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.

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 cannot get Carer's Allowance.

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.

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 *Statutory Sick Pay* in *Other health and social care entitlements* for more details).

There are two types of ESA:

- **Contribution-based ESA**, which you can claim if you have enough National Insurance contributions. This is not means-tested, but is taxable.
- **Income-related ESA**, which you can claim if you do not have enough National Insurance contributions to claim contribution-based ESA, or as a top up to contribution-based ESA. This is means-tested, but is tax free.

Universal Credit is replacing income-related ESA. Only people who receive the Severe Disability Premium on another benefit can make a new claim (see *What do the words mean?* or contact a benefits adviser for more information). You can still make new claims for contribution-based ESA, but this is now called 'new style' ESA instead.

You will need to attend a work capability assessment to work out if you should receive ESA and which of the two groups listed below you should be placed in. If you qualify for fast tracking, you will 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. With MND, ESA is usually given for three years before you need to be assessed again. 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 will not need to have any further assessments to be able to continue claiming. If you began claiming ESA before September 2017 and are in the support group, you will need to have a final assessment to confirm you can continue claiming (if you find yourself in this situation and need support, contact the Benefits Advice Service).
- **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 Severe Conditions Exemption. You should not be placed into this group if you are living with MND. If you are, contact our Benefits Advice Service who can advise (see section 1: *Where do I get guidance on benefits and entitlements?* for details).

Before your work capability assessment, you may also be asked to attend a 'health and work conversation' with a work coach. Most people have to go to this conversation and take part. However, some people may not have to attend this conversation, including:

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

Contact the Benefits Advice Service if you are asked to go to a 'health and work conversation' (see section 1: *Where do I get guidance on benefits and entitlements?* for details).

Universal Credit (UC)

Universal Credit (UC) helps support you if you are out of work or on a low income. It is:

- means-tested
- not taxable.

Universal Credit is made up of a standard allowance, plus 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?*).

Universal Credit is now in place across the UK for new claims and people on other benefits who have had a change in circumstance. 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
- Child Tax Credit and Working Tax Credit.

Anyone currently claiming any of these benefits will be invited at some point to make a claim for Universal Credit instead. When you are invited will depend on where you live, but the DWP and Department for Communities plan to move everyone across to UC by 2023 (you may hear this being called 'managed migration'). Until then, your current benefits will continue unless there is a relevant change in your circumstances, or a new claim is made for one of the above benefits.

If you get the Severe Disability Premium on top of any of your benefits, you may not need to apply for UC until the DWP or Department for Communities moves you over through managed migration, even if you have a change of circumstance.

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 get. See section 1: *Where do I get guidance on benefits and entitlements?* for details.

UC is usually claimed 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. 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 job centre to have an interview and possibly create a 'claimant commitment' with a work coach. You will be asked to complete a questionnaire about 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. You may also have to have a medical assessment.

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

Other health and social care entitlements

There are other health and social care entitlements you may be able to get if you're living with MND or Kennedy's disease.

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. 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).

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.

Ask your GP or health and social care team for advice about how to be assessed for CHC.



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 provided by the NHS to support your health and wellbeing needs, if you have a long term condition or get CHC (see previous heading). This does not include primary or emergency healthcare, such as GP services or A&E, which will still be provided as usual.



For details, see:
Information sheet 10B – *Direct payments and personalisation*

Personalisation, Citizen Directed Support and Self Directed Support

These are the names used across England, Wales and Northern Ireland for how people can personalise their social care. Ask for a needs assessment to work out what care support may help you, and a financial assessment to work out how much money you may need to pay towards this.

Direct payments: These enable you to select services for yourself, rather than having them arranged for you by adult social care services. If you choose this option, you will receive the money in direct payments to your account. There can be additional work involved in managing direct payments, if you use them to pay for someone to provide regular personal care (known as a Personal Assistant), rather than agency care workers.

England: You can get a personal budget from your local authority which sets out what it will cost to meet your needs, and how much they will pay towards it. The budget can be managed by:

- the local authority
- another organisation
- you or a trusted person, through direct payments.

Disability Rights UK run a helpline and email service that provides advice and information on Personal Budgets. Search for *Personal budgets helpline* at: **www.disabilityrightsuk.org** or contact the helpline:

Telephone: 0330 995 0404 (there may be a charge for calling)

Wales: You can receive direct payments to select and pay for the social care services you wish to receive.

Northern Ireland: You can get a personal budget from your local health and social care trust that sets out the amount they believe it will cost to meet your needs, and how much they will pay towards it. The budget can be managed by:

- the trust
- the trust, but you decide what is done with the money (this is called a 'managed budget')
- yourself, through direct payments.



For more detail, see:
Information sheet 10B – *Direct payments and personalisation*

Prescription charge exemption and help with sight tests and dental charges (England only)

This means you will not have to pay for NHS prescriptions in England if you have a continuing physical disability that means you cannot leave the house without the help of another person. All prescriptions are free in Wales and Northern Ireland.

If you are getting certain means-tested benefits, you may also be entitled to:

- a free sight test and a voucher towards the cost of glasses
- help with the cost of dental charges.

If you are on a low income, you can apply for the NHS Low Income Scheme, where you may be able to get full or partial help with:

- prescription charges
- dental costs
- eye care costs
- healthcare travel costs.

If you are not entitled to a prescription exemption or the NHS Low Income Scheme, 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, including dental, no matter how many you need. If you purchase the 12 month certificate you can make 10 monthly payments by direct debit.

For more information and to check if you're eligible for this type of support, visit: www.nhsbsa.nhs.uk/check-if-youre-eligible-help or ask your GP or another health and social care professional for information.

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
- 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 both. See *Health and work related benefits* for details.

Support with the costs of housing

You may be entitled to financial support with housing costs or help to adapt your home if you're living with MND or Kennedy's disease, or caring for someone with either condition. See below for the benefits you may be entitled to.

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
- the Northern Ireland Housing Executive.

If you feel this would be useful, ask for an assessment from an occupational therapist and apply as early as possible rather than waiting until the adaptation is needed. The application process can be time consuming.



For details about these grants, see:
Information sheet 10C – *Disabled Facilities Grants*

Housing Benefit

Housing Benefit provides support for people paying rent who are on a low income from benefits or employment. Housing Benefit:

- counts towards the benefit cap
- is means-tested.

New claims can no longer be made 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.

However, if you get the Severe Disability Premium (see *What do the words mean?* at the front of this sheet), you:

- can make a new claim for Housing Benefit (if you are eligible)
- will not have to apply for Universal Credit until the DWP or Department for Communities moves you across (rather than a change in circumstances meaning you need to apply for UC).

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 nine Universal Credit payments in a row, while unemployed
- you have been receiving certain means-tested benefits for 39 weeks or more
- you are entitled to claim Pension Credit (you won't have to wait 39 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, 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. 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.

SMI used to be paid as a benefit. If you get SMI as a benefit instead of a loan, you will be contacted at some point to discuss your options.

Help with Council Tax in England and Wales

See below for ways you may be able to get help with your Council Tax bill in England or Wales.

Disabled Band Reduction Scheme: A reduction on your Council Tax bill to the band below what you usually pay, if you live in a property that has been adapted or made bigger because someone living there is disabled.

Single Person Council Tax Discount: A 25% discount on your Council Tax bill if there is only one person living in your home who 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

The following benefits and entitlements may help support you with the cost of living.

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 parking if you have a blue badge. Contact your local authority to find out more about the scheme.



For more details about the Blue Badge scheme, see:
Information sheet 12A – *Driving*

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.

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

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. There does not need to be an assessed need for these other grants

Contact our Support Services team for details:

Telephone: 0808 802 6262

Email: support.services@mndassociation.org

You can view information about all our services at:

www.mndassociation.org/support-and-information

Your regional care development adviser (RCDA), Association visitor (AV) or local branch or group 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 older and receive certain benefits.

It is:

- means-tested
- not taxable.

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

Income Support

Income Support is extra money to support you if you are on a low income, under pension age and either:

- on a low income
- not working, or
- working less than 16 hours a week.

Income support is:

- means-tested
- not taxable.

You can only make a new claim for Income Support if you get the Severe Disability Premium (for more information, see *What do the words mean?* or contact a benefits adviser). If you are currently receiving Income Support, you will be invited at some point to apply for Universal Credit instead.

Pension Credit

Pension Credit supports people of pension age who are on a low income from getting a reduced state pension. (Some people get a reduced state pension due to not paying enough National Insurance throughout their life.)

Pension Credit is:

- means-tested, although there is not a fixed savings limit like other means-tested benefits
- 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 no longer available for new claims.

If you live with a partner, you must both be of pension age to be able to get Pension Credit. However, if one of you were eligible for Pension Credit before 15 May 2019, you can make a claim until 13 August 2019, which may be back dated for 3 months.

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.

Tax Credits

Tax Credits are payments to provide support if you have children or are working and earning a low income, or both.

Tax Credits are:

- means-tested
- not taxable.

Only people who get the Severe Disability Premium can make new claims for tax credits. All other new claims need to be for UC instead. See *Universal Credit in Health and work related benefits* for more information.

Winter Fuel Payment

Winter Fuel Payment is a yearly grant for people over Pension Credit age. It is:

- not means-tested
- tax free.

This one-off payment is usually paid automatically to people who receive a state pension.

Urgent support

The following explain some extra payments and support that may be available to help manage emergency situations.

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.

If you feel this would be helpful, ask a health or social care professional about this service (such as your GP or a social worker). 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 a benefit, you may be able to get this paid early (known as an advance). 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. You will have to pay a benefit advance back by receiving less money in your following benefit payments.

3: How do I fast track a claim?

People with a terminal illness can use 'special rules' to fast track claims for Disability Living Allowance, Personal Independence Payment, Attendance Allowance, Employment and Support Allowance, and Universal Credit. 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.

The person living with MND does not have to make the claim 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.

This means the claim will be processed as quickly as possible and the award will be paid much faster. 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.

To be eligible for fast tracking, the person's GP, consultant or specialist nurse must state they 'would not be surprised' if the person died within six months. However, if a person is fast tracked for benefits, this award may be given for up to three years before being reviewed.

People with MND may be guided into fast tracking when they first start the claim process. This is usually by telephone, so ask about fast tracking if it is not explained. If the person is not fast tracked at first contact, there will be notes about special rules in the claim pack, which will be sent out when completing a physical claim form.

In this case:

- complete the special rules section of the claim form (whether on the form or by telephone)
- ask for form DS1500 from the person's MND care centre or network co-ordinator, GP, specialist nurse or consultant, who will complete it. They must sign the DS1500 form, then you or the professional can send it to the Department for Work and Pensions (DWP) to support the claim. Send the DS1500 form with the benefit claim if possible, but don't delay the claim if you think getting the DS1500 will take time. It can follow later, if needed.

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

Healthcare professionals can now submit a DS1500 report for PIP online, shortening the time it takes to arrive with the DWP. Contact the MND Association Benefits Advice Service for more information. See section 1: *Where do I get guidance on benefits and entitlements?* for contact details.

The start date of your claim is important, as any award 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 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:

Telephone: 0808 801 0620 (England and Wales)

0808 802 0020 (Northern Ireland)

Email: through the benefits advice page on our website:

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 information 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 before getting your payment, as the application process can take some time.

Will I need to provide any other supporting evidence?

With disability benefits, explain how your condition affects your daily living. 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, as this may be helpful
- 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:

- The MND Association Benefits Advice Service, who 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?* for organisations who may be able to provide free benefits advice.
- 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**
- The DWP home visiting service in England or Wales. This service is not always offered, so you may need to ask for it. For more information, see: **www.gov.uk/support-visit-benefit-claim**
- The Make the Call service in Northern Ireland, who can provide home visits to support with form filling and face to face advice, if needed. 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 *Further information* in section 6: *How do I find out more?* for contact details.
- The Pension Centre in Northern Ireland, which may contact the Improving Benefit Uptakes Outreach team, who can provide home visits if necessary. See *Further information* in section 6: *How do I find out more?* for contact details.

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 challenge this (make an appeal), 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: 0808 802 0020

Email: through the benefits advice page on our website at:
www.mndassociation.org/benefitsadvice

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 decisions and a mandatory reconsideration support tool.

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

Advice UK

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

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

Telephone: 0300 777 0107

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

Age UK

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

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

Telephone: 08000 678 1602 (England)

08000 223 444 (Wales)

0808 808 7575 (Northern Ireland)

Email: through the relevant website contact pages

Website: **www.ageuk.org.uk** (England)

www.ageuk.org.uk/cymru (Wales)

www.ageuk.org.uk/northern-ireland (Northern Ireland)

c-App

Help preparing for ESA and PIP, including the application process, assessments and your rights.

Website: **www.c-app.org.uk**

Carers UK

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

Telephone: 0808 808 7777

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: 03444 111 444 (England)

03444 77 2020 (Wales)

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

Information for disabled people, including advice on benefits. They also have a helpline that provides information on personal budgets.

Address: Plexal, 14 East Bay Lane, Here East, Queen Elizabeth Olympic Park,
Stratford, London E20 3BS
Telephone: 0330 995 0400
0330 995 0404 (Personal budgets helpline)
Email: enquiries@disabilityrightsuk.org
personalbudgets@disabilityrightsuk.org (Personal budgets helpline)
Website: **www.disabilityrightsuk.org**

GOV.UK

For online government guidance on benefits and entitlements for people living in England or 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: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA
Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: **www.mndscotland.org.uk**

Money Advice Service

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.moneyadviceservice.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

For online government information about benefits and entitlements for people living 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 BT9 4AN

Telephone: 0800 587 0892

Email: pensionservice@nissa.gsi.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 Pensions Advisory Service

Free and impartial guidance on pensions.

Address: 11 Belgrave Road, London SW1V 1RB

Telephone: 0800 011 3797

Website: **www.pensionsadvisoryservice.org.uk**

seAp

Provide free independent and confidential advocacy services.

Address: PO Box 375, Hastings, East Sussex TN34 9HU

Telephone: 0330 440 9000

Email: info@seap.org.uk

Website: **www.seap.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: 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, PO Box 246, Northampton NN1 2PR

Further information

We provide information sheets and publications on the following subjects:

1A – *NICE guideline on motor neurone disease*

10B – *Direct payments and personalisation*

10C – *Disabled Facilities Grants*

10D – *NHS Continuing Healthcare*

10E – *Work and motor neurone disease*

10F – *Your rights to social care*

10G – *Support for families with children*

12A – *Driving*

12B – *Choosing the right vehicle*

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

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, PO Box 246, Northampton NN1 2PR

MND Association Benefits Advice Service

Telephone: 0808 801 0620 (England and Wales)

0808 802 0020 (Northern Ireland)

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

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: **<http://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.

Website: www.mndassociation.org/campaigning

We welcome your views

Your feedback is really important, as it helps us to develop new materials and improve our existing information, for the benefit of people living with MND and those who care for them. 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, PO Box 246, Northampton NN1 2PR



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