



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're living with or provide care for someone with motor neurone disease (MND), you may be able to claim:

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

If you're living with or supporting someone with Kennedy's disease, you may also be able to claim some of the benefits and entitlements mentioned in this sheet and find this information useful.

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

You can 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 appeal against a decision?

6: How do I find out more?

 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.



The MND Association has been certified as a producer of reliable health and social care information.

www.england.nhs.uk/tis

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 that working age people can get. People who get certain disability related benefits (Personal Independence Payment, Disability Living Allowance or Attendance Allowance) or Carer's Allowance aren't 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. You are legally required to inform the Department for Work and Pensions (DWP) if your circumstances change.

Means testing: taking your and your partner's income, savings and other assets (known as capital) into account to work out the level of benefit you should receive. We have noted the benefits and entitlements that are means-tested in this sheet.

Mitigations and supplementary payments (Northern Ireland only): mitigations are in place in Northern Ireland to reduce the impact of changes made to benefits in recent years. This is done by giving people payments to help cover some of the cost that has been lost due to changes made to their benefits. Contact a benefits adviser to find out more about supplementary payments if you live in Northern Ireland and think you may be able to get this support.

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 how this is defined. See section 3: *How do I fast track a claim?* for more information

Taxable benefits: benefits that you need to pay income tax on. We have noted the benefits and entitlements that are taxable in this sheet. You can also find a list of taxable and tax free benefits 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: Information sheet 14B – *Bereavement support*

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 or 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 by qualified advisers who can help identify benefits you may be entitled to and advise on how to claim. This service is confidential, impartial and free.

England and Wales

Telephone: 0808 801 0620

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

Northern Ireland

Telephone: 0808 802 0020

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

You can also start a live web chat with an adviser through our website if you live in England or Wales. See: **www.mndassociation.org/benefitsadvice**

Other local independent advice centres may also be able to support with benefits advice, such as your local authority, local carer's organisation or Citizens Advice Bureau. 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?

This information sheet aims to make you aware of the benefits you may be able to claim if you are living with or supporting someone with MND. If you're living with Kennedy's disease or a carer for someone with the condition, you may also be able to claim certain benefits. Different benefits and entitlements have different rules for qualifying.

You can find out if you qualify for certain benefits by contacting the MND Association Benefits Advice Service, or another independent benefits service. See *Can I get any advice on benefits?* above for details.

You can also find out if you are able to get certain benefits by looking them up on official 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 the information about a certain benefit or entitlement can be found at any other site to these, we will state this where relevant in this sheet. As well as the rules on qualifying for benefits, government websites often also have details on how to apply, and the amount you may be able to claim.

2: What can I claim?

We have categorised the benefits and entitlements you may be entitled to in this sheet by the ways they can support you. The categories 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)

Attendance Allowance (AA) is a benefit you can get if you first make a claim when aged 65 or over and have difficulties or need help with personal care. It is not means-tested, not dependent on National Insurance contributions and is tax free. You do not need to have a carer to be able to get Attendance Allowance.

Attendance Allowance has two rates:

- the lower rate, which is paid if you need frequent help with personal care, supervision throughout the day, or have repeated or prolonged difficulties at night and need someone to watch over you.
- the higher rate, which is paid if you need considerable help both day and night, or if you are terminally ill and 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) is for people aged under 65 at the time of their first claim. It has two parts, a care part to help with care needs and a mobility part to help with getting around. It is not means-tested, not dependent on National Insurance contributions and is tax free.

DLA is being replaced by Personal Independence Payment (PIP) and new claims can no longer be made if you are of working age. If you were under 65 on 8 April 2013 and still receive DLA, the Department for Work and Pensions (DWP) will contact you to invite you to apply for PIP instead. If you were over 65 and receiving DLA on this date, you will continue to receive DLA unless your situation changes 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 are 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 *Mitigations and supplementary payments* in *What do the words mean?* for more information.

Personal Independence Payment (PIP)

Personal Independence Payment (PIP) is for people aged 16-65 when they first claim. How much you can get through PIP is based on how your condition affects your day to day life and your mobility. It is not means-tested, not dependent on National Insurance contributions and is 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 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*.

PIP has replaced DLA for most adults. There are supplementary payments available in Northern Ireland to help with the transfer of DLA to PIP, if this transfer means you will receive less money. See *Mitigations and supplementary payments* in *What do the words mean?* for more information.

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

Support for carers

If you care for someone with MND, you may be entitled to the following support. You may also be entitled to this support if you care for someone with Kennedy's disease.

Carer's Allowance

This is an allowance to help if you're providing care for someone who is receiving AA, PIP for daily living, or the middle or higher rates of the care part of DLA. It is not means-tested, but you can only claim if you're earning no more than £120 a week. Carer's Allowance is taxable.

Carers who receive Carer's Allowance aren't affected by the benefit cap. However, if you receive other benefits you may not be entitled 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 may already receive, or the benefits of the person you're caring for.

Depending on what other benefits you receive, you may qualify for an underlying entitlement of Carer's Allowance rather than 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're entitled to this premium. See *Carer premium* below for more information.

Carer premium

This premium is an extra amount of money that may be available to carers as part of certain means-tested benefits. It is not a benefit in its own right.

Some of these means-tested benefits will be replaced by Universal Credit when it is fully rolled out. However, if you qualify, Universal Credit will have a Carer Element instead of a carer premium. See *Universal Credit* for more information.

For more information in England or Wales, search for *carer's allowance* at: www.nhs.uk
In Northern Ireland, search for *carer premium* at: www.nidirect.gov.uk

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 are not able to get Carer's Allowance.

Health and work related benefits

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

Employment and Support Allowance (ESA)

Employment and Support Allowance (ESA) can help if a disability or illness prevents you from working and you are not being paid Statutory Sick Pay (SSP). See *Statutory Sick Pay* in *Other health and social care entitlements* for more details on SSP.

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 don't 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.

You can no longer make a new claim for income-related ESA if the Universal Credit Full Service has been rolled out where you live (unless you have more than two children). You can still make new claims for contribution-based ESA if the Universal Credit Full Service has been rolled out where you live, but this will be 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 an assessment. See section 3: *How do I fast track a claim?* for details on fast tracking.

People who receive ESA are placed into either:

- the support group, where you don't have to take part in work-related activity and will receive a higher rate of ESA. If you have a lifelong illness such as MND and are making a new claim for ESA, you will be exempt from future reassessments to continue claiming in this group. If you are already getting ESA and are in the support group, you will need to have a final reassessment before you can be considered exempt.

- 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. You do not have to look for work. If a review is needed, you would need to be reassessed. 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, but isn't 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.

The Universal Credit Full Service started to be rolled out for new claims across England and Wales from May 2016, and will affect different areas at different times. It started to be introduced gradually across Northern Ireland from September 2017. By the end of 2018, the Universal Credit Full Service will have been rolled out to all areas of the UK.

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 to apply for Universal Credit instead. Until then, the claim will continue unless there is a major change in circumstance, or a new claim is made for one of the benefits UC is replacing (see above list). Other benefits and the amount of savings you have may affect the amount of UC you receive.

Contact a benefits adviser before applying for UC, as they can advise on your options. See section 1: *Where do I get guidance on benefits and entitlements?* for details.

If you are unable to work due to disability or illness, you will need to attend a work capability assessment to determine if you are entitled to UC, without having to look for work. You will be asked to complete a questionnaire about how your illness affects your everyday life and ability to complete certain activities. You may also have to attend a medical assessment.

GOV.UK have created an information document about UC that enables you to select from a list of titles that lead on to information and further GOV.UK links, at: www.gov.uk/government/publications/universal-credit-and-you

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.

NHS Continuing Healthcare (CHC)

NHS Continuing Healthcare (often called *continuing care*) is a package of funding and care for complex medical needs, provided by the NHS in England and Wales. You need to be assessed to see if you qualify for NHS Continuing Healthcare. If you qualify for NHS Continuing Healthcare, you can arrange to manage this yourself through a personal health budget and direct payments. See below heading *Personal budgets and personal health budgets* for more information.

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 NHS Continuing Healthcare.



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

Personal budgets and personal health budgets

Personal budgets and direct payments can be offered to a person to help them personalise their social care or healthcare.



For full details about personal budgets and direct payments, see
Information sheet 10B – *Direct payments and personalisation*

Personal budget for social care needs:

This is a statement from adult social care services that sets out the amount they believe it will cost to meet your needs, and how much they will pay towards it. You need to have a care assessment to work out what you need and a financial assessment to work out how much you may need to contribute.

Personal budgets for social care are only available in England, but you can still get direct payments in Wales and Northern Ireland to meet your social care needs.

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 this helpline)

Personal health budget for healthcare needs:

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 are getting CHC (see previous heading). This does not include primary healthcare, such as GP services, which will still be provided as usual. Personal health budgets are only available in England.

Direct payments:

These enable you to select services for yourself, rather than having them arranged for you. In England, direct payments are a way of managing a personal budget or personal health budget. In Wales and Northern Ireland, direct payments can be paid to help meet your social care needs. If you choose this option, you will receive the money in direct payments to your account.

Prescription charge exemption and help with sight tests and dental charges

This support is only available in England, as all prescriptions are free in Wales and Northern Ireland. This exemption means you will not have to pay charges on NHS prescriptions in England if you have a continuing physical disability that means you can't leave the house without the help of another person.

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

- 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.

For more information and how to apply, search for *Low Income Scheme* at: www.nhs.uk or seek advice from your GP or another health and social care professional.

If you aren't 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.

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. It is not means-tested, but 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 claim a means-tested top up benefit such as Income Support or Housing Benefit. If you live in an area where Universal Credit has been fully rolled out, you may be able to claim this instead. Seek advice from a benefits adviser if you are affected by this.

If SSP has ended, or you are self-employed, you may be able to claim Employment and Support Allowance or Universal Credit (if this has fully rolled out in your area) instead. See *Employment and Support Allowance* or *Universal Credit in Health and work related benefits* for details.

Support with the costs of housing

You may be entitled to financial support with housing costs, or entitlements to help you adapt your home for easier access or daily living if you're living with or supporting someone with MND or Kennedy's disease.

Council Tax discount - Disabled Band Reduction Scheme

The Disabled Band Reduction Scheme is a reduction on your Council Tax bill to the Council Tax 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. This reduction is available in England and Wales only. If you're living in Northern Ireland, see *Disabled Person's Allowance* below for a similar entitlement.

Council Tax discount - Single Person Discount

The Single Person Discount is a 25% discount on your Council Tax bill if there is only one person living in your home who qualifies for Council Tax purposes. This discount is only available in England and Wales.

People who are not counted as adults for Council Tax purposes include:

- children under 18
- full-time students
- people with a severe mental impairment. This may include someone with a confirmed diagnosis of frontotemporal dementia (FTD)
- live-in carers looking after someone who isn't their partner or child.

If there are no people regarded as adults for tax purposes living in your home, a 50% Council Tax discount may apply.

Council Tax Reduction

This is 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.

Council Tax Reduction is only available in England and Wales. If you're living in Northern Ireland, see *Rate Relief* below for a similar entitlement.

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 the Northern Ireland Housing Executive. If you feel this would be useful, 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*

Disabled Person's Allowance

Northern Ireland only

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

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 and is means-tested.

New claims cannot be made for Housing Benefit in areas where the Universal Credit Full Service has been rolled out. If you are already claiming Housing Benefit, you will be invited at some point to apply for Universal Credit instead, which includes a housing cost element.

Housing Benefit for Rates

Northern Ireland only

If you rent where you live in Northern Ireland, are on a low income and pay Rates, you may be able to claim Housing Benefit to help with paying your Rates.

Housing Benefit for Rates is being replaced with Rate Rebate in areas where the Universal Credit Full Service has been rolled out. You need to be getting UC in Northern Ireland to be able to apply for Rate Rebate.

Rate Relief

Northern Ireland only

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

Support for Mortgage Interest (SMI)

Support for Mortgage Interest (SMI) helps towards the interest payments on mortgages or loans for certain repairs or home improvements. You can only receive SMI if you have been receiving certain means-tested benefits for 39 weeks or more. If you're entitled to claim Pension Credit, you won't have to wait 39 weeks before applying. This support only applies to the interest on a mortgage or loan, not the amount borrowed.

SMI is paid as a loan, and will carry interest itself. You will need to pay back this loan with its 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 about an SMI loan. 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 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 are governed by 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 be receiving Universal Credit 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 have to pay back a Budgeting Advance by receiving reduced 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

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 cannot provide support. We also provide Quality of Life Grants, 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/getting-support

Your regional care development adviser, Association visitor 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're working age or older and receive certain benefits. It is a means-tested payment, but is not taxable. You don't 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 under pension age and

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

It is a means-tested benefit, but is not taxable. It is made up of a basic payment and an extra premium if you or the person you support receive certain benefits, such as Carer's Allowance. If you're not working due to sickness, you would claim ESA rather than Income Support.

If you are unable to claim ESA, contact our Benefits Advice Service, who can provide support. See section 1: *Where do I get guidance on benefits and entitlements?* for contact details.

New claims for Income Support can no longer be made in areas where the Universal Credit Full Service has been rolled out. 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 qualifying age who are on a low income. It is means-tested, but 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 retirement 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 if you are making a new claim for Pension Credit.

There isn't a fixed savings limit for Pension Credit, unlike most other means-tested benefits. 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 is also getting certain disability benefits. You may also be entitled to more money if you're a carer.

Tax Credits

Tax Credits are means-tested payments to provide support if you have children or are working and earning a low income, or both. They are not taxable.

If you are in work but on a low income, you may be entitled to Working Tax Credit, depending on how many hours you and your partner (if you have one) work each week.

If you have dependent children, you can claim Child Tax Credit. If you live in a Universal Credit Full Service area, you can only claim Child Tax Credit if you have more than two dependent children. Otherwise, you will need to claim Universal Credit 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 tax free, and is not means-tested. This one-off payment is usually paid automatically to people who receive a State Pension. You need to claim Winter Fuel Payment if you don't receive a State Pension and are over Pension Credit age.

Urgent support

The following explain some of the 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 council)
- Discretionary Support loans or grants in Northern Ireland
- Assistance Payments in Wales.

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, you may be able to get an advance on the first payment of certain benefits if you have to wait for it to be paid. 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.

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, eg their carer.

When a person is fast tracked for a benefit, they don't 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.

Special rules state that the person's death should be reasonably expected within six months. However, awards passed under special rules may be given for up to a three year period.

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)
- request the form DS1500 from the person's doctor, nurse or consultant, who will complete it. They must sign the DS1500 form, then you 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 health and social care 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 a PIP assessment online, shortening the time it takes for the form 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. The DWP will let you know their decision. If successful, the award may be given for up to three years, and reviewed after this time.

If you or your doctor 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 depending on which benefits you're claiming)
- 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 special requirements when making a claim, ask the provider if the forms are available in alternative formats, for example large print.

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

Will I need to provide any other supporting evidence?

With disability benefits, you may need to explain how your condition affects your daily living. Give as much detail as you can on the claim form and:

- try not to make light of your difficulties
- 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 co-ordinator if you attend a care centre or network, or your 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 appeal).

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, contact our Benefits Advice Service or another independent benefits adviser. See section 1: *Where do I get guidance on benefits and entitlements?* for details.

Some benefits also have dedicated helplines that can provide information and guidance on making a claim. These numbers are usually provided on the benefit pages of government websites. Search for the benefit you want to claim at **www.gov.uk** for England and Wales, or **www.nidirect.gov.uk** for Northern Ireland, and go to the *How to make a claim* section.

If you need help filling out application forms, the DWP's home visiting service may be able to assist you. This service is not always offered, so you may need to ask for it if you think it may be helpful.

In England and Wales, the Pension Service also operates the Local Service Referral scheme to assist people of pensionable age with Pension Credit and state pension queries. They can help complete forms. Northern Ireland no longer has pension advisers, but the Pension Centre may contact the Improving Benefit Uptakes Outreach team. Advisers from these teams can provide home visits if necessary.

Contact the Pension Service, or for Northern Ireland the Northern Ireland Pension Centre:

Telephone: 0800 731 7898 (England and Wales)

0800 587 0892 (Northern Ireland)

Textphone: 0800 731 7339 (England and Wales)

If you have to wait for an appointment with the Pension Service, a local independent advice centre may also be able to help (where a benefit service is offered), such as your local authority, local carer's organisation or a Citizens Advice Bureau.

5: Can I appeal against 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, 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 *appealing against a benefits decision* 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 a Citizens Advice Bureau.

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 (Northern Ireland only)

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

Telephone: 028 9064 5919

if part of a Benefits Advice Service query, call: 0808 802 0020

Email: info@adviceni.net

if part of a Benefits Advice Service query, 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. The website also has guides on appealing ESA and PIP decisions.

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

Email: mail@adviceuk.org.uk

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 55 6112 (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

Websites providing information on 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
028 9043 9843 (Northern Ireland)

Website: **www.carersuk.org**

Citizens Advice

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

Telephone: 03444 111 444 (England, or contact your local Citizens Advice Bureau)
03444 77 2020 (Wales)

Textphone: 03444 111 445

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

Department for Work and Pensions (DWP)

Responsible for awarding benefits.

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

Email: ministers@dwp.gsi.gov.uk

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

Disability Law Service

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.

Telephone: 0800 169 0190

0800 169 0207 *Welsh language*

Textphone: 0800 169 0314

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

Make the Call (*Northern Ireland only*)

For queries about benefit entitlement in Northern Ireland.

Telephone: 0800 232 1271

Website: **www.nidirect.gov.uk/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.

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

Telephone: 0800 138 7777

0800 138 0555 *Welsh language*

Email: enquiries@moneyadviceservice.org.uk

Website: **www.moneyadviceservice.org.uk**

NIDirect

For online government information about benefits and entitlements for people living in Northern Ireland.

Website: **www.nidirect.gov.uk**

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*

Textphone: 0800 731 7339
0800 731 7013 *Welsh language*

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**

Scope

Information and advice for disabled people, including information on benefits.

Address: 6 Market Road, London, N7 9PW

Telephone: 0808 800 3333

Email: helpline@scope.org.uk

Website: **www.scope.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 an 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

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

We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them. If you would like to provide feedback on any of our information sheets, you can access an online form at: **www.surveymonkey.com/s/infosheets_1-25**

or request a paper version by email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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