

Money and finances are a huge cause for concern for most people, especially when the financial implications of living with MND hit home. However, there are sources of support available to help you through the difficult times. It is estimated that more than £5 billion of benefits go unclaimed every year by people who are entitled to them.

It is almost certain that no-one will ring your doorbell and offer to make sure you are receiving all the benefits to which you might be entitled. However, there are people who can help you maximise your entitlements, provided you knock on their doors.

MND Scotland offers a Welfare & Benefits Service that can offer advice and information about benefit entitlement to people affected by MND. We can visit you at home, or offer advice by phone or e-mail. Claiming benefits is not always a straight-forward process and we aim to help make it as easy as possible. We can offer a range of services from providing basic advice to helping complete application forms, liaising with various agencies and finding different sources of financial help.

Sometimes, benefits are not always financial. There is also a range of practical resources that can improve your social situation and make life easier. Many people find that applying for a disabled persons parking badge (Blue Badge) can make life easier, while others find that a National Entitlement Card for free bus travel can help them to maintain their independence in the early stages of their illness.

There is a wide range of benefits available to people with MND, their carers and families. It is not possible to give specific advice as to who is, or who is not, entitled to particular benefits or entitlements in a factsheet like this as each person or family is dealt with on an individual basis based on their unique set of circumstances. Some benefits take into account any income or savings that you have (these are called “means tested benefits”), while others do not. The only way you will find out if you qualify is to ask an expert to assess your entitlement to claim any benefits. Our Welfare & Benefits Officer will be happy to do this for you. Alternatively, you can use the benefit calculator available on www.entitledto.co.uk. This website allows you to estimate your entitlement to benefit if you provide details about your current circumstances. However, we have provided a quick guide to some benefits that some readers may be entitled to claim.

Attendance Allowance is a tax-free benefit for people aged 65 or over with a long term illness or disability who need help with their personal care or who need supervision to remain safe. It is not means tested (i.e. you can still claim regardless of how much income or savings you have) and is not dependent on the amount of national insurance contributions you have made.

Attendance Allowance is awarded at two different rates; the higher rate and the lower rate. The amount that you are awarded is determined by the level of help that you require. The amount that you receive is normally paid in addition to

MND Scotland is the working name of the Scottish Motor Neurone Disease Association, the only charity funding research and providing care and information for those affected by MND in Scotland.

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almost any other benefit you already receive, e.g. state pension or pension credit. It will also be paid in addition to any private or occupational pensions that you receive.

If your circumstances change, your entitlement to Attendance Allowance can also be increased to reflect this (e.g. from lower rate to higher rate). You need to notify the Disability Benefits Centre (DBC) that deals with your claim and they will send a new form for you to complete. This is known as a review of benefit. A decision-maker will look at your claim again and, if you meet the criteria, your benefit will be increased.

Disability Living Allowance (DLA) is a benefit for children and adults under the age of 65 who need help to look after themselves and/or find it difficult to walk or get around. It is tax free, not means tested and you do not need to have paid any national insurance contributions.

DLA is divided into two parts. Firstly, there is a **care component** which recognises the need for extra help with personal care. This is paid at three different levels; higher rate, middle rate and lower rate. The level of award is determined by the amount of help that you need.

DLA also has a **mobility component** payable when there is a need for additional help to overcome walking difficulties. This is paid at two different levels; higher rate and lower rate. Again, the level of entitlement is dependent upon your level of need.

You can be paid either the care component or the mobility component on its own, or both components at the same time. They can also be paid in any combination of award levels, e.g. highest rate care and higher rate mobility, or

middle rate care and lower rate mobility. Like Attendance Allowance, DLA is paid in addition to any earnings or other income that you may have. It is almost always paid in full on top of social security benefits or tax credits.

If your circumstances change, your entitlement to DLA can also be increased or decreased to reflect this (e.g. from lower rate mobility to higher rate mobility). You need to notify the Disability Benefits Centre (DBC) that deals with your claim and they will send a new form for you to complete. You can have either one or both of your components reviewed, but if you only wish one part of your benefit to be looked at, it is important to identify that your other circumstances remain the same. It is possible that your award is reduced following a review.

Employment and Support Allowance (ESA) was introduced in October 2008 to replace Incapacity Benefit and Income Support paid on incapacity grounds. ESA is a single benefit with two elements: a contributory element which is linked to national insurance contribution records; and an income-related element which is means tested.

Following an application for ESA, entitlement to the contribution-based element will be considered in all cases. You may get contribution-based ESA if you have paid enough national insurance contributions.

If you claim the income-related element then your entitlement to that element will be considered as well. For this element, your income and capital (savings, shares, other property, etc.) will be looked at before establishing any entitlement to payment. You will not be eligible if your income is in excess of £16,000, and savings over £6,000 will reduce your entitlement.

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When someone becomes entitled to ESA they will enter a 13-week assessment phase. During this period they will receive a basic rate of payment dependent on their age and whether they are making a claim as a single person or as a couple. During this time you may be asked to complete a *Work Capability Assessment* to determine your suitability for work..

When the 13 week assessment period is over (or before), a decision will be made as to whether or not you are entitled to continue claiming ESA. You will also be paid at a new rate, depending on your level of need.

If you are not entitled to ESA, your entitlement to claim other benefits will be assessed. You will not be asked to pay back any benefit that you have already received.

Income Support is means tested and is intended to provide basic living expenses for you and your partner, if you have one. You may be eligible for Income Support if you fall into one of the following categories:

- you are incapable of work through ill health or disability;
- you are a recognised carer; or,
- you are a lone parent with childcare responsibility.

The amount you receive will depend upon your individual circumstances but it does not depend on your national insurance contributions. It can be paid on its own if you have no other income, or it can top-up other benefits or earnings from part-time work up to the basic amount the law says you need to live on. You will not be eligible for payment if your savings are in excess of £16,000. Savings between £6,000 and £16,000 will reduce your eligibility on a sliding scale.

Income Support is often referred to as a “passport benefit” because it also opens up other avenues of entitlement. If you are in receipt of Income Support, regardless of how much, you may also be entitled to help with mortgage interest payments and certain other housing costs. You may also qualify for Housing and Council Tax Benefit.

Other sources of support for people in receipt of Income Support include free prescriptions and dental treatment, help from the Social Fund, free school meals, and help with hospital fares.

Pension Credit is a means tested benefit that replaced Income Support for people aged 60 or over. It is made up of two elements; **guarantee credit** and **savings credit**.

If your income falls below the minimum level set out by the government (known as the ‘appropriate minimum guarantee’), the guarantee credit element makes up the difference.

Savings credit can be paid if either you or your partner is aged 65 or over. It is intended to provide extra money for people who have made modest provision for their retirement.

Like Income Support, Pension Credit can meet mortgage interest payments and may entitle you to Housing and Council Tax Benefit. If you receive the guarantee credit this will open the door to full Housing and Council Tax Benefit entitlement and you may get help with health costs such as free dental treatment and hospital fares. If you receive either element, you may qualify for help from the Social Fund and energy efficiency grants.

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Carer's Allowance is a benefit that can be claimed if you regularly spend at least 35 hours per week caring for someone who is severely disabled. You do not have to live with the person that you are caring for, but you must be caring for someone who is in receipt of Attendance Allowance or DLA at the middle or highest rate of the care component.

Carer's Allowance will not be paid to you if you are in receipt of earnings in excess of £95.00 per week. Carer's Allowance is not normally payable if you are in receipt of any 'earnings replacement benefit' of more than the rate of Carer's Allowance (i.e. if you are already in receipt of a state benefit that is paid at a higher rate than the amount of Carer's Allowance that is payable, then you will not receive a monetary payment). You will be recognised as a carer and you will have an underlying entitlement to Carer's Allowance. You will also be credited with national insurance contributions.

For carers, the question of applying for benefit can seem like a remote and distant possibility. If you are still in employment it might be possible to continue working in the early stages of caring for someone with MND, but, sooner or later, most carers feel the need to spend increasingly more time at home. Eventually, the question may arise of whether to continue to work or become a full time carer. No-one can make this decision for you; it is yours alone and will be influenced by many factors that only you can judge.

These factors might include the quality and frequency of support from external home-care agencies, family and friends, your personal finances and how easy it would be to get back into work at a later date. You might have the right to request a flexible working pattern from your employer to help you balance work and

caring in the short term. Some large employers, particularly government agencies and local government, offer career breaks which would allow you to take time out, but preserve your job until the agreed date of your return. If you work for a large company it is worth enquiring if such a facility exists.

It is also worth considering that if you are paid Carer's Allowance, the person you care for will not be eligible for additional payments within their own benefit entitlement that they may otherwise have received. It is for this reason that there are occasions when it is not always advantageous to claim Carer's Allowance even if you are eligible to do so.

Child Tax Credit is an income-related payment for people who are responsible for caring for children. Your income and capital will be considered when calculating an entitlement to this benefit. You do not need to be in work to qualify for this benefit.

Working Tax Credit is a means-tested payment for those in low-paid work. If you are over 25 and work for 30 hours or more each week, you may be eligible for a top-up payment of Working Tax Credit.

If you have a dependent child, or are physically or mentally disabled, or are aged 50 or more, and if you work at least 16 hours a week, then you may qualify for a top-up payment.

Housing Benefit can be paid to people on a low income who have to pay rent to either a social landlord (e.g. council, housing association) or a private landlord. It is sometimes referred to as a rent rebate or rent allowance.

If you are in receipt of the guarantee credit of Pension Credit, Income Support, income-based Jobseekers' Allowance or

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income-based ESA, you may qualify for a full rebate. You do not qualify for Housing Benefit if you have savings in excess of £16,000.

Housing Benefit is administered by your local authority.

Council Tax Benefit can help you pay your council tax. It is means tested and is administered in a similar way to Housing Benefit. It is awarded as a rebate towards your council tax liability.

Savings of more than £16,000 will disqualify you from being awarded this benefit.

Please note that Council Tax Benefit will not make any payments towards the cost of water and sewerage rates that are included on your council tax bill. All tenants are liable for water and sewerage rates regardless of any benefit entitlement that they may have.

Council Tax Discounts and Exemptions can reduce the amount of council tax that you are liable to pay depending on your circumstances.

The **Disability Reduction Scheme** means that homes adapted for people with a disability can qualify for a discount on the amount of council tax that they pay. This normally means a reduction of the banding of your property's council tax level (e.g. from a Band D to a Band C). Some carers can be disregarded for council tax discount purposes. Carers who live with the person they are caring for (except spouses/partners) can be disregarded. Also, resident carers providing care on behalf of a local authority, government department or charity are disregarded if they are employed for at least 24 hours per week.

Home Improvement and Repair Grants can be paid where a home needs to be adapted for a disabled person. Grants for repairs and adaptations to properties are available from local authorities. Your occupational therapist, or other person recommending the adaptations should be able to advise you on how to make an application.

Winter Fuel Payment is an annual payment which is paid to those aged 60 or over who are on qualifying benefits around November each year. You should automatically receive a payment if you have previously received one, or if you are in receipt of any other social security benefit.

Social Fund Community Care Grants are non-repayable grants available to those on a qualifying benefit such as Income Support, Pension Credit, income-based Jobseeker's Allowance or income-based ESA, to help you buy items that will support your independent living in the community.

Grants vary in size and can be offered to cover or partially cover expenses for items that are needed by an individual or family. These grants are not designed to replace services or provisions supplied by the NHS or social services.

TV licence concessions are available to everyone aged 75 and over, or younger persons living in certain kinds of accommodation such as care homes or sheltered accommodation.

The Blue Badge Scheme provides a range of parking concessions for people with severe mobility problems who have difficulty using public transport. The scheme is designed to help severely disabled people to travel independently, as either a driver or a passenger, by allowing them to park close to their

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destination. You can apply for a badge even if you cannot drive or do not have a car of your own.

You will be entitled to a badge if you are in receipt of the DLA mobility component at the higher rate. If you are not in receipt of higher rate DLA mobility, then you may still qualify if your mobility is restricted. You will require your doctor to complete a short medical report within the form to confirm that you have poor mobility.

The scheme is administered by your local authority. In all cases, you will need to provide a passport-sized photograph to be added to your badge. Some local authorities, but not all, also charge an administration fee for your badge. Further information is available on Factsheet 17, Motoring and MND.

A **National Entitlement Card** for free bus travel in Scotland is available if you have been diagnosed with a progressively degenerative condition, such as MND, which severely impedes your mobility and ability to carry out day to day activities. You will need a letter from your consultant confirming your diagnosis and that it severely impedes your mobility.

The **Disabled Persons Railcard** is available to anyone receiving Attendance Allowance, Disability Living Allowance or who is banned from driving because of epilepsy. The card costs £18 for one year and offers a 33% discount on most rail fares for the cardholder and a companion. For more information contact www.disabledpersons-railcard.co.uk/ot.

Bereavement Benefits

(This section is also reproduced as the separate Factsheet 46.)

After the death of a loved one the financial implications can take a while to register, but eventually, concerns about

funeral costs as well as the cost of day to day living will surface.

Funeral Payments are administered by the Social Fund. They are intended to assist with the basic cost of funeral provision.

You can apply for a Funeral Payment if you, or your partner, accept responsibility for the cost of a funeral and if you, or your partner, are in receipt of a qualifying benefit. This includes:

- Income Support
- Pension Credit
- income-based Jobseekers' Allowance or ESA
- Child Tax Credit, at a rate that exceeds the family element (basic level)
- Working Tax Credit, at a rate that includes the disability or severe disability element
- Housing Benefit
- Council Tax Benefit

In order to be eligible for a Funeral Payment, you must also be able to identify that it is reasonable for you to accept the responsibility for the funeral costs. This may be because you are a spouse or partner, or a close relative or friend of the person who has died.

You cannot get a payment as a close relative or friend if:

- The person who died had a partner; or,
- There is a parent, son or daughter who is over 18 and is not in receipt of a qualifying benefit, unless they were estranged from the person who died; or,
- There is a close relative who was in closer contact with the person who died than you were, or had equally

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close contact and is not getting a qualifying benefit.

Funeral Payments will not cover every aspect of planning a funeral. They will only cover the following costs:

- The necessary costs of purchasing a new burial plot with exclusive rights plus necessary fees, or the necessary costs of cremation including medical fees
- The cost of documentation required to release the assets of the person who has died
- The reasonable costs of transport for the portion of the journeys in excess of 50 miles, undertaken to transport the body within the UK to a funeral director's premises or a place of rest and to transport the coffin, bearers and mourners in two vehicles to the funeral
- The necessary costs of one return journey from your home for you, or your partner, to arrange or attend the funeral if you are responsible for the funeral costs
- Up to £700 for other funeral expenses (or £120 if you have a pre-paid funeral plan that does not cover these expenses)

Money can be deducted from a Funeral Payment if there are any funds available from the estate of the person who has died. This includes lump sums from insurance policies, pensions or burial clubs. Other assets that can be considered include contributions from relatives or charities, or funds available through a pre-paid funeral plan.

Claims must be submitted within 3 months of the date of the funeral.

Bereavement Payment is a tax-free lump sum of £2,000 for spouses or civil

partners. You must have been under state pension age when your spouse or civil partner died, unless they were not in receipt of a Category A state pension. Your entitlement is also dependent upon your spouse or civil partner's national insurance contribution record.

If you were living with another person as part of a couple but you were not married at the time of your partner's death, you will not qualify.

Widowed Parent's Allowance is a regular payment for bereaved men and women who have at least one dependent child or qualifying young person.

Payments are dependent on your spouse or civil partner's national insurance contributions. If your spouse or civil partner met the national insurance conditions then the full rate is payable. If it was incomplete, you will receive a proportionately reduced amount of Widowed Parent's Allowance.

You can receive Widowed Parent's Allowance until you have no further entitlement to Child Benefit or until you live with another partner. It cannot be paid to you beyond state pension age (currently 60 for women and 65 for men).

Bereavement Allowance is payable if you were aged 45 or over when your spouse or civil partner died. It is payable for 52 weeks from the date of his/her death. You cannot claim Widowed Parent's Allowance and Bereavement Allowance at the same time.

The amount you are paid is dependent on your age when your spouse or civil partner died. Like Widowed Parent's Allowance, the amount you receive will be reduced if your spouse or civil partner's national insurance contribution record was incomplete.

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Bereavement Allowance cannot be paid beyond state pension age.

Other benefits may be paid in place of Widowed Parent's Allowance or Bereavement Allowance. Bereavement and widow's benefits overlap with contributions-based Employment and Support Allowance (ESA), Incapacity Benefit, Carer's Allowance, contributions-based Jobseeker's Allowance, Maternity Allowance and state pension. You cannot receive two overlapping benefits at the same time, so you will receive the higher of the overlapped benefits.

State pension entitlements are re-assessed by the Pension Service when your spouse or civil partner dies. Your spouse or civil partner's national insurance contribution record will be considered along with your own and your own entitlement to state pension will be adjusted accordingly.

This will be arranged as quickly as possible following the return of the DB8 death notification to the Pension Service. Sometimes, the Pension Service will arrange to visit you and they will also look at any entitlement to Pension Credit. This will be adjusted to take into account your change of circumstances.

Sources of Support and Further Information

MND Scotland Welfare & Benefits Officer

76 Firhill Road, Glasgow, G20 7BA
Telephone No: 0141 945 1077
E-mail: vicki.cahill@mnd.org.uk
Website: www.mndscotland.org.uk

Carers Scotland

91 Mitchell Street, Glasgow, G1 3LN
Telephone No: 0141 221 9141
E-mail: info@carerscotland.org
Website www.carerscotland.org

Princess Royal Trust for Carers

Telephone No: 0141 221 5066
Website: www.carers.org

Citizens Advice Bureaux

Website: www.cas.org.uk

Disability Benefits Helpline

Telephone No: 08457 123 456
Website: www.disabilitybenefits.co.uk

Direct Gov Website: www.direct.gov.uk/

Entitled To Website:

www.entitledto.co.uk/ (an online calculator for benefits entitlements)

Disability Alliance Website:

www.disabilityalliance.org

Disabled Persons Railcard:

Tel 0845 605 0525
www.disabledpersons-railcard.co.uk/ot

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Useful contact numbers

Benefit	Contact Number
Attendance Allowance	08457 123 456
Bereavement Benefits	0845 608 8602
Carer's Allowance	01253 856 123
Child Benefit	0845 302 1444
Child Tax Credit	0845 300 3900
Council Tax Benefit	Contact your local authority
Disability Living Allowance	08457 123 456
Employment & Support Allowance- to make a new claim	0800 055 66 88
Home Improvement grants (Care & Repair Scotland)	0141 221 9879
Housing Benefit	Contact your local authority
Income Support- to make a new claim	0800 055 66 88
Pension Credit	0845 60 60 265
Social Fund	Contact your local Jobcentre Plus
TV Licensing concessions	0870 241 6468
Working Tax Credit	0845 300 3900

General Benefit Enquiries

Benefit Enquiry Line- 0800 88 22 00

Open from 8.30am to 6.30pm, Monday – Friday, and from 9.00am to 1.00pm on Saturdays