

10: Finance, work and social care

This section will help you identify financial support, work options and how to get your needs assessed for social care.

The following information is an extracted section from our full guide *Living with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: **www.mndassociation.org/publications**

The full guide can be ordered in hardcopy from our helpline, MND Connect:

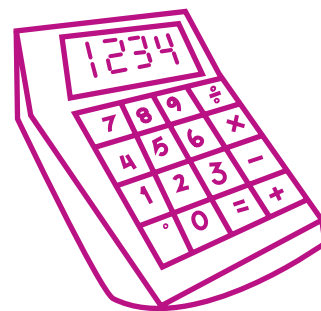
Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



**Living with
motor neurone disease**

10: Finance, work and social care



This section will help you identify financial support, work options and how to get your needs assessed for social care.

You may want to act quickly following a diagnosis of MND, but gather as much information as you can before making financial decisions. Some options can affect finances in unexpected ways.

Thinking about your financial needs is important and this section can help. However, this information does not represent legal advice and individual circumstances can vary.

We recommend asking qualified experts for advice, such as legal experts or benefits advisers, as relevant.

The financial impact of MND and getting help

With MND, your daily life has to adapt, which creates personal and emotional challenges. Over time, you may need increasing levels of care support and equipment. This can be costly.

“ We had to have our property converted at our own expense. We couldn't get help from our local council as we had savings, which we used up on this.”

If you work, you may also be thinking about whether to continue and how to manage your income. The financial impact of MND can feel overwhelming at first, but it helps to know where to seek guidance.

See Further information at the end of this section for resources and contacts.

Practical or financial support is available from:

- **Your place of work:** for changes to help you in the workplace, such as assistive equipment, flexible working, sick leave or early retirement.
- **Adult social care services:** for care support and services, following a needs assessment, or direct payments to select your own services.
- **Benefits and entitlements:** for financial support, where you qualify, often claimed through your local authority in England and Wales, or your local health and social care trust in Northern Ireland.
- **NHS continuing healthcare:** for fully funded health and social care support from the NHS, where primary health care needs have become complex and urgent.
- **Voluntary organisations and Trusts:** for possible grants, particularly those relevant to disabilities.
- **The MND Association:** for a range of support, including our Benefits Advice Service, and MND Support Grants. We also provide grants for carers, and children and young people who have a diagnosed parent or live in the same household as a diagnosed person.

The following information explores these types of support, but we provide other resources when you need more detail.

See Further information at the end of this section for other resources and Section 12: How we can help you, for details about our services.

In the United Kingdom, statutory services are those provided through health and social care. You have a legal right to their support if you qualify.

Your place of work

Can I take a break?

Taking time out after diagnosis may give you space to think about your options. However, paid and unpaid leave is at the discretion of your employer.

If you are an employee you may be entitled to take periods of sick leave, depending on your symptoms. If your employer does not operate their own sickness scheme, they still have a duty to pay you Statutory Sick Pay (SSP) if you qualify.

Will I have to leave work?

If you work, you may worry about continuing employment with MND. Your care needs will increase over time. This can be unsettling, but leaving work is a personal choice and everyone's experience is different.

" I miss getting up early to go to work and spending all day with other people."

Many people with MND find ways to adapt how they work and continue for as long as possible.

If your partner is your main carer and employed, juggling work and care can also be very challenging.

" Being a full-time carer deprived me of opportunities to earn money."

Both of you may need to consider your work options, which can affect you:

- sense of purpose and identity
- standard of living
- social network
- daily routines
- approach to accepting financial support.

MND symptoms can vary widely, but as physical tasks become harder, you may also feel increasing levels of tiredness. It may not be safe or legal to continue some types of work, such as driving heavy vehicles.

If you drive at work or socially, you are legally required to contact your car insurer and the DVLA to inform them of your diagnosis. You may be asked to take a driving assessment if you wish to continue driving. Adapted controls can help you prolong your driving ability.

It may be useful to discuss your employment options with:

- your partner, family and friends, especially your main carer
- your employer can apply for help to the Access to Work scheme if you need support to continue working, see www.gov.uk/access-to-work/apply
- a social worker from your local authority – or health and social care trust in Northern Ireland – and a benefits adviser at your local Jobcentre Plus
- your local Disability and Carers Service, Department of Work and Pensions (DWP) local service or, in Northern Ireland, your local social security office (for help with claim applications if MND means you need assistance)
- local care services and organisations
- an independent financial or benefits adviser about the impact on your income, entitlements and pension
- our MND Connect helpline and Benefits Advice Service.

See Further information at the end of this section.

Some of the options to consider are:

- shorter or flexible working hours, including home working and teleworking
- adapting your work environment (the Access to Work scheme may be able to help your employer with this and some occupational therapists too)
- voluntary redundancy, leaving work or early retirement
- a needs assessment by adult social care services to work out your current and future care needs.

Always take advice from a pensions adviser before making any decisions. For example, taking your pension through early retirement may affect your ability to claim certain benefits.

See *What about insurance and life cover?* later in this section.

Carers may also be able to get help from their employer, with flexible working, unpaid leave and other options.

“ I can still work part time, but due to my wage I cannot claim carers allowance.”

What if I'm self-employed?

You may be working:

- as a sole trader or freelance consultant
- in a partnership
- as a limited company
- through an agency as self-employed
- by contracting or sub-contracting.

“ I was always very fit, and I owned and worked in my own business about 60 hours a week. I continued with this for two years after diagnosis, then sold the business. I continued to work for the new owner for a while, but found it hard when it wasn't mine.”

You should seek advice from an independent financial adviser who can review your income, tax liabilities and any financial investments. They may be able to advise on the impact of any decisions which affect other financial matters. You may also need to seek advice from:

- a benefits adviser to look at possible entitlements, which may depend on the level of National Insurance you have been paying
- a legal expert specialising in self-employment or company law, if you are subject to any contracts or legal accountabilities.

What about insurance and life cover?

If you work, investigate your contract of employment, as you may be entitled to a death-in-service payment. If offered, this employee benefit pays out a tax-free lump sum if you are employed by the company at the time of your death. The pay out is usually between two and four times your annual salary.

If you are repaying a mortgage or other loans, these can also include life cover. Check your policy documents or contact the provider to find out.

“ With queries regarding critical illness cover, I had two small policies - one that has paid out a quarter of what I thought and the other still pending. I’m not an expert on these things but I didn’t realise that as my mortgage decreased, so did the projected sum. I had taken loans out to cover my kids’ university costs and the cover didn’t include those. We’re always wise after the event. My advice is to apply as quickly as you can after receiving confirmation of diagnosis. Some clinical consultants may be reluctant to complete forms sent from the insurance company and that may hold up proceedings.”

If you have any existing health-related insurance policies, explore these too. Find out if you qualify for an award following a diagnosis of MND. As with early retirement, take independent advice to check how any payment received could affect other options, such as benefit claims.

It may be difficult to get cover following diagnosis for health care, critical illness or life insurance. Some insurance companies may consider this, but it could be more expensive than expected and the potential award smaller than hoped. However, it’s worth exploring insurance as soon as you can.

Insurance offers and policies change frequently. Current offers that include MND may not be available for very long. However, new offers can also appear unexpectedly, so it may be worth rechecking companies at a later date.

See Section 6: *Getting around* for details about holiday insurance cover.

Adult social care services

Following a needs assessment – or community care assessment in Northern Ireland – you may qualify for care support arranged by adult social care services. You can also receive direct payments, which enable you to choose the support and services you prefer.

You have the legal right to apply for this type of support. If you meet the qualifying criteria, it is also your right to receive the support agreed in your care plan.

Your care needs will increase over time and you may wish to explore what is available. This can be done through a needs assessment for yourself and a carer’s assessment for your carer.

“ Being supported by a care company brings its stresses and challenges, but provision of committed compassionate care workers can help families immensely.”

For an assessment, contact adult social care services through your local authority in England and Wales, or your local health and social care trust in Northern Ireland.

“ Could examples be given of what type of support would be included within a care plan? I know everybody’s symptoms are different, but it may put it into context.”

Your needs assessment will result in a personal care plan, for agreed services. What’s included in the plan could be different to that of someone else with MND, as your needs will be determined by your personal situation.

Your care plan will need to be reviewed over time, to ensure it still meets your needs.

However, the assessment is an opportunity to explore available options. Try to find out about:

- what can be included in your care plan in terms of personal care or household support (as this may vary across regions)
- what support can be offered for you and what support can be offered for your carer (a joint assessment can be helpful if this feels right for you both)
- local care services and agencies, and what to expect
- community palliative care, day therapy units and hospice day care
- counselling and psychological support
- support to maintain interests and hobbies that are important to you
- respite services and emergency care cover if your carer is unable to support for any reason
- financial support and benefits advice
- useful local or national charities.

Ask for a separate assessment by an occupational therapist, who can look at how to prolong independence through:

- lifting, bathing and other aids to assist daily living
- appropriate seating
- advice about disabled facilities grants if you need to adapt your home.

Services agreed in your care plan are means tested. This means your finances are assessed to work out how much you may have to pay towards any costs. Some or all of the cost may be paid for you, depending on your finances. In Northern Ireland domestic care services are not charged, but there are exceptions such as meals on wheels, and a financial assessment may still be carried out.

You can choose to receive direct payments to allow you to choose your own services instead of having these arranged.

If you do this, you are responsible for keeping financial records. This may include employer records if you employ someone to help you with your care. There are agencies and brokers who can manage this process for you – ask about this at your needs assessment when discussing direct payments.



“ We have a problem recruiting as we are in a rural area... with social service carers we knew we would always have cover.”

Urgent or emergency care cover

If your carer is unable to provide support for any reason, contact your local adult social care services department. A limited out-of-hours Emergency Duty Team (EDT) may be able to arrange assistance, including bank holidays and weekends. It is worth keeping contact details for your local EDT to hand.

Making a complaint

If you feel that you are not receiving appropriate treatment or social care, you have the right to complain. In most cases, discuss your concerns first with the service or professional involved, as this may help to solve the problem. If not, you can take the matter further and there are organisations set up to help patients with queries and complaints.

The NICE guideline on MND is provided by the National Institute for Health and Care Excellence. It sets out recommendations for health and social care professionals on MND treatment and care, including guidance for carers. While not legally binding, professionals are expected to follow the recommendations. The guideline may support you when making a complaint and we provide information to help.

See *Further information* at the end of this section for details about patient councils, that can help with queries about care.

Benefits and entitlements

It is your right to claim benefits or other entitlements for financial support, where you qualify. These are usually provided by the Government, your local authority or Trust, to help you and your carer. Some of these benefits or entitlements are means tested, which means your income and savings are assessed to see if you qualify.

“ It seems to be very hard nowadays to get benefits and we certainly didn't know very much about claiming.”

If you are living with MND or Kennedy's disease, or a carer, our Benefits Advice Service can help. Trained advisers can identify benefits you may be able to claim if you live in England, Wales or Northern Ireland.

They can also advise on which benefits can be fast tracked, where you may be able to avoid a more lengthy assessment.

See Further information at the end of this section for more about this service and contact details.

Universal Credit

Various benefits can help with low income and housing. The main one is means tested and called Universal Credit. You may qualify if you have a low income (whether in or out of work). For new claims, Universal Credit has replaced the following benefits:

- Income Support
- Job Seekers Allowance (income-based)
- Employment Support Allowance (income-based)
- Housing Benefit
- Child Tax Credit
- Working Tax Credit

Disability and carer benefits

It's useful to be aware of the following:

Attendance Allowance: Not means tested. Available when you reach state pension age to help support with care costs. Attendance Allowance is not affected by the introduction of the Personal Independence Payment (PIP) – see later heading.

Carer's Allowance: Not means tested, as savings are not taken into account, but your earnings may affect your entitlement. For carers providing 35 hours or more of unpaid care a week to someone who gets Attendance Allowance, the middle/higher rate care component of Disability Living Allowance or the daily living component of Personal Independence Payment (PIP).

Carer's Credit: If caring creates gaps in a carer's work history, this credit protects their National Insurance to build qualifying years for state pension. Also available to those who cannot claim Carer's Allowance if their earnings are too high.

Carer Premium: A top-up to assist carers on a low income, who receive certain benefits. See also Universal Credit, which is gradually replacing various benefits, but will include a similar top-up called the Carer Element.

Council Tax Discounts: The following discounts only apply in England and Wales. For Northern Ireland, see Disabled Persons Allowance – Rates.

- **Disabled Band Reduction Scheme:** If you live in a bigger or adapted property due to disability, you may be able to avoid paying more in Council Tax.
- **Single Person Discount:** If there is only one person living in your home who qualifies for Council Tax purposes, a 25% discount may apply (someone with a confirmed diagnosis of frontotemporal dementia or FTD may be considered exempt for Council Tax purposes, along with children full-time students and some carers). If no-one living in your home qualifies for Council Tax, a 50% discount may apply.

Disability Living Allowance (DLA): Not means tested. This used to be provided to help people under 65, when assessed with care or mobility needs from disability. Personal Independence Payment (PIP) has now replaced DLA for new claims. Most existing DLA claims are gradually being transferred to PIP (you will remain on DLA if you were born on or before 8 April 1948).

Disabled Facilities Grant (DFG): Means tested. This local authority grant may be available towards adaptations to enable a disabled person to continue living in their home.

Disabled Persons Allowance – Rates: If additions or adaptations have been made to your home due to disability, you may qualify for this reduction in rates in Northern Ireland. For England and Wales, see Disabled Band Reduction Scheme.

Employment and Support Allowance (ESA): An allowance if your ability to work is limited by ill-health or disability. If you have paid enough National Insurance you may be able to claim contribution-based ESA, which is not means tested. If not, you may still be able to claim income-based ESA, which is means tested. In some cases you may be able to claim a combination of both types. See also Universal Credit, as this is replacing various benefits, including income-based ESA.

Personal Independence Payment (PIP): Not means tested. This is designed to help with some of the extra living and mobility costs of long-term illness or disability. PIP has now replaced Disability Living Allowance (DLA) for new claimants of working age and existing DLA claimants are gradually being reassessed and transferred to PIP (unless you are over 65 and applied for DLA before you were 65, in which case you will remain on DLA). Attendance Allowance (AA) will continue and is not affected by the change to PIP.

Rate Relief: Means tested. You may qualify for help to pay rates in Northern Ireland if you own your own property and are on a low income. For England and Wales, see Disabled Band Reduction Scheme.


NHS continuing healthcare and personal health budgets

NHS services for primary or emergency healthcare are free.

With a long term condition in England, you may be able to get a personal health budget agreed to select the health services you prefer. For example, you may wish to have regular complementary therapies to reduce anxiety. To find out what the NHS can provide, talk to your GP or health team. All primary and emergency health care remains free of charge.

In time, you may need more intensive support and become eligible for NHS continuing healthcare. Your primary need must be healthcare, and your needs complex and urgent. If you qualify, your social care and healthcare needs will be arranged and fully funded by the NHS in England. This type of funded care works in a similar way in Wales.

There are no guidelines for NHS continuing healthcare in Northern Ireland, but this type of care may be available. If you are resident there and need increased support, please contact your local health and social care trust.



“ I’ve heard that people struggle to get these care packages and have to really battle to get help?”

We provide information to help you, as the assessment process can be complicated.

See *Further information* at the end of this section.

Voluntary organisations and trusts

Many charities, voluntary organisations and trusts provide one or more of the following:

- guidance on financial matters
- funding or grants if you qualify against their criteria
- practical help in specific circumstances.

Ask your local authority for advice about organisations in your region in England and Wales, or your local health and social care trust in Northern Ireland.

“ Funding and grants can make the difference between being homebound and being able to get out.”

Our MND Connect helpline can also help you find relevant support and services.

How the MND Association can help you

Where statutory funding and services are not available or timely, we offer a limited amount of financial support, through care support and quality of life grants. These grants are available to people with MND or Kennedy's disease, and their carers. We also offer grants to support children and young people who live with someone who has been diagnosed or have a parent with the disease.

We consider a variety of needs such as respite care, adaptations and equipment rental, following an independent assessment of need and an application from a health and social care professional. We also loan certain items of equipment and aids, following similar criteria.

We can help direct you to appropriate services. You may also find it useful to contact your local authority or council about local services and discounts for people affected by disability, for example, local parking concessions through the Blue Badge scheme.

“ With funding, you can get help to take a break from home and the daily struggles of life with MND.”

What else do I need to think about?

When you feel ready to do so, you may want to:

- get your general financial affairs in order
- think about writing a will
- consider other options about future welfare, such as power of attorney to enable someone to make decisions on your behalf if you become unable to do so.

MND can affect speech and communication, and in some cases how you think and process information. It can be helpful to open sensitive or complex discussions as soon as you can. We provide information to support you and your family.

See Further information at the end of this section for resources and Section 11: Planning ahead.

Key points

- Try not to rush any financial decisions. Gather as much information as you can, before taking any action, as certain choices can have hidden consequences. For example, early retirement payments may affect benefit claims.
- When completing claim forms, give lots of details and try not to make light of any help you need. This will help you receive the level of support you really require. Emphasise the way MND progresses, as your needs will increase over time.
- Detailed examples of your challenges can improve applications. For example, 'Getting dressed can be difficult' is not very clear, but 'Getting dressed takes at least two hours, as I have to rest frequently and can't manage fastenings' gives a more complete picture.
- Regional support varies, so explore what is available during your needs assessment. We recommend asking about urgent or emergency care support.
- Ask for information from health or social care services, as needed. If you are disabled, it should be provided to you in a format that is accessible.
- If money problems occur, a reputable financial adviser or debt counsellor may be able to advise. Let your bank know what is happening and your mortgage company if you own property. They can help, but only if they know about your concerns.
- Ask your bank for guidance if you need a trusted carer, relative or friend to help manage your account. There may be procedures to follow or other help the bank can offer.
- You may also wish to consider setting up power of attorney for a trusted carer or relative.

See Section 11: Planning ahead for more on Power of Attorney.

Further information:

From our range of information sheets:

1A: Nice guideline on MND

10A to 10G:

Our range of sheets on benefits, social care, DFGs, work and MND, NHS continuing healthcare and family support

12A to 12C:

Our range of sheets on driving, choosing vehicles and travel

From our guides and other publications:

What you should expect from your care: our pocket guide on questions to ask at appointments, based on the NICE guideline.

MND Checklist: a questionnaire that helps you think about your condition and how to plan and prepare for your care needs.

Understanding my needs: a booklet in which you record your needs and preferences to guide all those involved in your care.

End of life – a guide for people with motor neurone disease: our comprehensive guide to planning ahead for future care, including information on finance and wills.

Caring and MND: support for you: a comprehensive guide for carers.

Caring and MND: quick guide: summary information for carers.

Telling people about MND: our guide to help open conversations about the disease with family, children, friends, colleagues and professionals.

Information to pass to your health or social care professionals:

P5: Providing medical evidence for benefit applications made by people with MND

Caring for a person with MND – a guide for care workers

Supporting children and young people close to someone with MND

Download our publications at:
www.mndassociation.org/publications
Or order them from **MND Connect**, our
support and information helpline:
Telephone: **0808 802 6262**
Email: **mndconnect@mndassociation.org**.

MND Connect can also help you find external services and providers, and introduce you to our services, where available in your area, including your local branch, group, Association visitor or regional care staff contact.

See Section 12: How we can help you.

MND Association Benefits Advice Service:

Our trained advisers can help you identify benefits you may be able to claim if living with MND or Kennedy's disease. This service is provided by Citizens Advice Cardiff and the Vale, and Advice NI. The service is available by telephone or email for people living in England, Wales or Northern Ireland, and there is also a web chat facility for those living in England or Wales. We may be able to arrange for an interpreter to join your call with an adviser if you struggle with English and have nobody to speak on your behalf.

Telephone: **0808 801 0620**

(England and Wales)

0808 802 0020

(Northern Ireland)

Email: through this webpage:

**www.mndassociation.org/
benefitsadvice**

Online forum:

A safe place to share information and support with others affected by MND at:
https://forum.mndassociation.org

Further sources of help can be found in Section 13: Useful organisations or try these contacts:

Government online information:

www.gov.uk for current details about benefits, entitlements and your state pension. For Northern Ireland visit **www.nidirect.gov.uk**

Local authority/health and social care trust:

Contact your local authority in England or Wales, or your local health and social care trust in Northern Ireland, for details about adult social care services and regional support organisations.

Working Families:

Advice on employment and work/life balance for parents and carers.

Telephone: **0300 012 0312**

Website: **www.workingfamilies.org.uk**

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

For references and acknowledgements please refer to the full guide, *Living with motor neurone disease*.

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



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