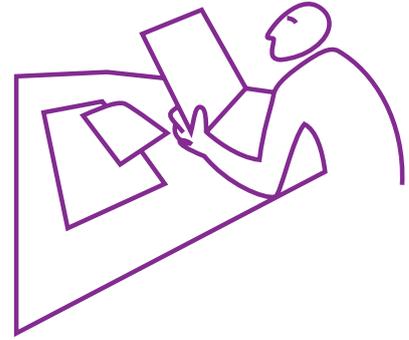


6: Work and financial support



This section looks at things you may need to think about if you are juggling work and care, or need financial support.

If you are employed and supporting someone with MND, you may be faced with some challenging decisions, such as:

- Can I continue working while caring?
- How do I access help to continue my work?
- How will I cope financially if I leave work to become a full-time carer?

It can be a confusing time. When a partner, relative or close friend is diagnosed with MND, it changes everything for them. If you find yourself taking on the role of carer, your life changes too. This can include your work.

Whether working or not, you may also find that finances are stretched. MND is a demanding disease and it can help to understand how to access financial support if needed. Especially if you become a full-time carer.

“I work, but I’m concerned about the future. We’re spending a lot of money on adapting our house, but I worry how long we can afford to stay here.”

See our information sheets 10A to 10F, for a range of guidance about financial support and social care.

Can I juggle work and care?

Being a carer and trying to keep up with your working life can be difficult, with many pressures. Decisions about whether to continue work or not can affect your:

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

Getting help is not always easy, but it helps to know who to ask. You may find it helpful to discuss your concerns with:

- your employer
- adult social care services
- your local job centre (about benefits)
- the person you support
- family and friends
- someone at a local carer centre.

You can also contact our MND Connect helpline, who can provide guidance and direct you to our regional services, branches and groups. There may be an Association visitor in your area who can support you through these decisions, by phone, email or home visit.

See Section 11: *How the MND Association can help you* for contact details and further information.

See also later heading in this section: *What if I am self-employed?*

What options do I have?

When making decisions about work, care and financial support, you may wish to consider the following:

- flexible working hours
- sharing care with family and friends
- a needs assessment for the person you support and a carer's assessment for yourself (which may lead to help from care services, care workers and financial support through direct payments or benefits)

See Section 4: Carer's assessment.

- adapting the home and using assistive equipment to help the person with MND remain independent for as long as possible
- day care centres
- leaving work to become a full-time carer
- voluntary redundancy if available
- early retirement (take advice, as this may affect other financial support, such as benefits)
- residential or nursing care for the person you support (this may not feel acceptable at first, but could become an option if the person's needs become complex and frequent medical interventions are needed).

Respite care for short regular breaks or longer breaks to take a holiday can also be helpful. If the person with MND has complex needs, they may need specialist care from care workers experienced with MND.

See Section 5: What kind of support is available? for more about respite and nursing care.

What is flexible working?

This is a way of working to suit your needs, such as:

- flexible start and finish times
- working from home
- job sharing

- working your agreed hours over fewer days (compressed working)
- part-time work
- your hours worked flexibly over a year (annualised hours).

You can find out more for England and Wales at: www.gov.uk/flexible-working or for Northern Ireland at: www.nidirect.gov.uk/flexible-working

It is everyone's right to make a request for flexible working, but you must have worked continuously for your employer for at least 26 weeks to apply.

Your employer can refuse a request if they have a good business reason for doing so, but you can appeal. This is usually done through the grievance procedures of the employing body, but you may also find it helpful to contact your local Citizens Advice Bureau. You can find out your nearest branch through your telephone directory or online at: www.citizensadvice.org.uk

Can I ask for paid or unpaid leave?

There may be times when you need to provide more intensive care. This can happen if:

- the person you support needs more care until additional care support is in place
- there is a breakdown in any professional care support
- the person you support has an accident or unexpected illness
- the person needs treatment and there is a recovery period.

A period of leave may be the solution.

Arranging paid or unpaid leave is at the discretion of your employer. It is worth finding out if you can get carer leave or compassionate leave. This may be useful if you need emergency leave at short notice. It can be less stressful if you know how this works in advance of urgent situations.

If you are thinking about leaving work, also ask if your employer would consider a career break. This may enable you to return to work if your caring responsibilities change.

How do I manage relationships at work?

If you are juggling work and care, it can affect the way you communicate with your colleagues.

“Dealing with work colleagues who don’t have much idea what caring is all about can be tricky, as you often don’t have the energy to talk about things.”

You may find that you:

- have less tolerance when annoyed by something
- feel different to others and distanced in conversations
- don’t know how to answer questions about your situation because you feel protective of the person you support
- feel too tired to be sociable
- feel vulnerable and emotional.

These are all natural reactions and to be expected.

If your employer provides counselling services or carer support, you may find this helpful. Ask human resources for details.

If you have a trusted colleague at work, it may help to let them and your manager know how you are feeling, as they may be able to support.

What if I decide to leave work?

Combining work and caring is not easy. You may have days when leaving work feels like the only option. At other times, you may feel more than able to cope. For many carers, work provides more than income, it helps maintain a sense of self and connection with the wider world.

It is quite normal to feel up and down when caring, and to change your mind, so think carefully before making any decisions.

“I can spend time with my wife, even though the circumstances and things I need to do for her weren’t planned.”

Everyone’s situation is different, but it helps to consider how leaving work will affect you in terms of:

- independence and social interaction with colleagues
- finance
- employment skills
- pension entitlement
- qualification for benefits.

Leaving work will impact on your income, but you may become entitled to certain benefits, which can help.

See later heading: *Which benefits and entitlements are important to explore?*

We recommend asking an independent financial adviser and a benefits adviser about income, pensions and benefits.

See our sheet 10E: *Work and motor neurone disease for more details about options for continuing or leaving work.*

What if I am self-employed?

If you are self-employed in any capacity and making decisions about your future, seek advice from an independent financial adviser. It is important to review your income, tax liabilities and any financial investments.

You may also wish to see:

- a benefits adviser to review any benefits and entitlements that may be available to you
- a legal expert specialising in self-employment or company law if you have any contract or legal accountabilities.

Which benefits and entitlements are important to explore?

If you have never claimed benefits before, it may feel daunting to do so. However, it is your right to claim. If you qualify, the financial support may help bring peace of mind.

Some benefits are **means tested**, where you or the person you support will be financially assessed. This means your income and savings are taken into account to work out how much you are entitled to receive.

The following list highlights benefits and entitlements relevant to MND and caring. Some of these apply to the person you support, but are included here as any help they receive can also help you in your caring role.

These brief descriptions will help direct you to key benefits and we recommend exploring these to understand the qualifying criteria.

“Support is out there, but you have to know the system and fight for it.”

We provide detailed information to help with this:

See our sheet 10A: *Benefits and entitlements for more information, contact details, who qualifies and how to claim.*

You can also find out more at:

www.gov.uk (England and Wales)
www.nidirect.gov.uk (Northern Ireland)
www.citizensadvice.org.uk

Attendance Allowance (AA):

For people aged 65 and over to help with extra costs if they have care needs. People with MND may be able to have their claim ‘fast tracked’, which can speed up the application process. Not means tested.

Carer’s Allowance:

For carers who provide care for 35 hours or more a week to support someone receiving AA, DLA or PIP. Not means tested.

Carer’s Credit:

If you are of working age and your caring role creates gaps in your work history, this credit protects your National Insurance.

Carer’s Premium:

If you can’t get Carer’s Allowance because you are being paid another benefit that overlaps with it, you can still get an extra amount known as the Carer’s Premium if you meet all the criteria for Carer’s Allowance. You must still make a claim for Carer’s Allowance to qualify.

Council Tax Benefit:

For anyone on a low income who needs help to pay their Council Tax bill. This does not apply in Northern Ireland (see Rate Relief instead). Council Tax Benefit is means tested.

Council Tax Reduction:

Available if you live in a larger property because the disability of the person you support requires an extra bathroom or kitchen, or a room mainly for their use. It also applies if internal spaces or doorways have been widened for wheelchair access.

Disability Living Allowance (DLA):

This used to be the main benefit for people with disabilities under 65, to help with extra costs from care or mobility needs. New claims now have to be made for the replacement benefit called Personal Independence Payment (PIP). Anyone under 65 who is already claiming DLA will be contacted at some point to let them know when their DLA will end and to make a new claim for PIP (see Personal Independence Payment in this list). Anyone over 65 will be able to retain their DLA award. Not means tested.

Disabled Facilities Grant (DFG):

A local authority grant to help towards the cost of adaptations or installations at home, to enable someone with disabilities to continue living there. A DFG can take a long time to agree and arrange, so it is important to plan ahead rather than waiting until point of need. DFGs are means tested.

Employment and Support Allowance (ESA):

For anyone whose ability to work is limited by ill-health or disability. Where enough National Insurance has been paid, contribution-based ESA may be awarded, which is not means tested. If not, income-based ESA may be available, which is means tested (see also Universal Credit).

Housing Benefit:

To help with the cost of rent if you are on a low income, whether working or not. This is means tested. (see also Universal Credit). In Northern Ireland you may also get Rate Relief.

Income Support:

For people of working age on a low income, this can also help you get other awards such as Housing Benefit. Means tested (see also Universal Credit).

Pension Credit:

This is sometimes referred to as State Pension Credit. This is for people of state pension age and there are two parts: the Guarantee Credit, designed to top-up your income to a guaranteed minimum level and Savings Credit to help those who have made some

retirement provision in addition to their state pension. Depending on your circumstances, you may get one or both of these elements.

Personal Independence Payment (PIP):

The main benefit for people with disabilities under 65, to help with extra costs from care or mobility needs. This is replacing Disabled Living Allowance (DLA) –see earlier in list. People over 65 can claim AA instead (see Attendance Allowance). People with MND may be able to have their claim ‘fast tracked’, which can speed up the application process. PIP is not means tested.

Rate Relief:

If you receive Housing Benefit in Northern Ireland, you may qualify for Rate Relief.

Social fund:

For people on a low income to help with certain one-off or occasional expenses, such as budgeting loans. These are means tested.

Tax Credits:

If you are responsible for a child or young person, you may qualify for Child Tax Credit. If you work and receive a low income, you may qualify for Working Tax Credit. You can often get both types of tax credits (see also Universal Credit).

Universal Credit:

For people on a low income whether working or not. This new benefit is replacing six other benefits:

- Jobseeker’s Allowance
- Housing Benefit
- Working Tax Credit
- Child Tax Credit
- Employment and Support Allowance
- Income Support

Universal Credit is only available in certain areas of England and Wales, but is gradually being introduced across the UK. It has not yet been introduced in Northern Ireland.

What is NHS continuing healthcare?

This care is provided by the NHS when someone has complex physical or mental health needs, resulting from disability, accident or illness.

See also NHS continuing healthcare in Section 5: *What kind of support is available?*

The care covers all needs, including health and personal care. It is either fully funded by the NHS or part of a shared care package between the NHS and adult social care services. This care can take place in a range of settings, including the person's home, nursing home or a hospice.

In the later stages of MND, care needs increase and you may find this overwhelming to manage alone. Although NHS continuing healthcare is not usually provided for MND in the early stages, it may be agreed if needs become complex and require frequent medical intervention. It is worth finding out about NHS continuing healthcare and how the application process works, so that you feel prepared in case it is needed.

See our sheet 10D: *NHS continuing healthcare for more information and how to apply.*

In England and Wales, NHS continuing healthcare follows similar rules, but there may be some differences in the systems used.

In Northern Ireland there is no guidance on NHS continuing healthcare. We recommend contacting your local health and social care trust for advice if care needs become complex.

Key points

- If you work, ask your employer about flexibility at work and how to take leave in urgent situations.
- Take advice from a wide range of people and advisers before making any decision that will affect your income or potential future benefits.
- Don't be afraid to claim benefits if needed, this is your right. Try to explore areas of financial support as early as possible to be aware of how to access help.
- Contact your local carer's centre or group who may be able to advise about support and services in your area.
- You can find out a great deal about social care support and financial support through a needs assessment for the person you support and a carer's assessment for yourself.

See Section 4: *Carer's assessment.*

Further information

We produce a wide range of publications about MND and the support that may be needed. The following may be useful in relation to this section:

From our information sheet range:

- 10A: Benefits and entitlements
- 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
- 12A to 12D:
our range of sheets on driving and travel

From our other publications:

Living with motor neurone disease: a guide about MND to help manage the impact from diagnosis onwards and maintain the best possible quality of life.

How to access publications and further information:

Most of our publications can be downloaded at: www.mndassociation.org/publications or you can order them from our MND Connect helpline:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

MND Connect can also help direct you to external services and providers, and introduce you to our services as available in your area, including branches and groups, Association visitors and your regional care development adviser (RCDA).

See Section 11: How the MND Association can help you for details about our services.

Online forum:

The forum provides an opportunity to share information and experiences with other people affected by MND. Hosted by the MND Association at:

<http://forum.mndassociation.org>

Information for professionals

We provide information to help professionals support people with MND, their families and carers. This can be accessed at:

www.mndassociation.org/professionals

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For references and acknowledgements please refer to the full guide, *Caring and MND: support for you*.

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

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



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

www.england.nhs.uk/tis