

I have the
right to...

3: Your rights as a carer

This section provides an overview of your legal rights as a carer and how these are governed.

The following information is a section from our full guide *Caring and MND: support for you*.

Other sections, and the full guide, can be found online at: www.mndassociation.org/MNDguides

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

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



**Caring and MND:
support for you**

3: Your rights as a carer



This section provides an overview of your legal rights as a carer and how these are governed.

The caring role can be challenging. It is important to know your rights and entitlements, which can help you get the support you may need, either now or in the future.

No matter how willing you are to provide care for your partner, relative or friend, you may still need to be supported in this role. You may need financial support, help with care tasks, breaks to ensure your own wellbeing or ways to maintain your own life beyond the caring role.



“A carer is someone who helps another person, usually a relative or friend, in their day-to-day life. This is not the same as someone who provides care professionally or through a voluntary organisation.”

NHS Choices website 2016

To receive support, your needs have to be considered. This is done through a carer’s assessment arranged with your local authority in England and Wales, or health and social care trust in Northern Ireland. This section looks at how your right to assessment is governed.

See Section 4: Carer’s assessment for more details about how assessment works.

Your rights as a carer are governed in slightly different ways depending on where you live in the UK.

As a charity, we support people affected by MND in England, Wales and Northern Ireland. The following information looks at carer rights in these countries. If you live in Scotland, please contact MND Scotland for guidance.

See Section 12: Useful organisations for full contact details.

What are my rights as a carer in England?

In England, the Care Act 2014 came into force in April 2015, which sets out carers’ legal rights to assessment and support. This overview explains the main points, but you can find the full Act online. Search for Care Act 2014 at: **www.legislation.gov.uk**

See also Section 9: Support for children and young people for guidance about rights for young carers.

Before the Care Act 2014, you had no legal right to receive support as a carer in England and local authorities could provide support at their discretion. This meant the ability to have an assessment and the range of help varied, depending on where you lived. The Care Act means the rules for each local authority are now consistent across England.

You also had to provide a substantial amount of care on a regular basis to qualify for an assessment. This has changed with the Care Act. Local authorities now have a duty to support ‘where an individual provides or intends to provide care for another adult and it appears that the carer may have a level of need for support’.

Your views, wishes and feelings as a carer should be considered at assessment. This must take into account your ability and

willingness to continue caring, as well as any employment, education, training or leisure needs.

Do I qualify as a carer in England?

This is the first time there has been a legal duty for local authorities in England to promote carer wellbeing when making decisions about their needs. This means they must do what they can to 'prevent, reduce and delay' needs from developing.

This means **all** carers are now entitled to assessment by adult social care services and you may be referred by a member of the health and social care team. If not, contact your local authority, as adult social care services are one of their departments.

See Section 4: *Carer's assessment* for details about how to prepare for an assessment and what to expect.

Your wellbeing as a carer might be affected in various ways, such as not getting time to eat well or not being able to use recreational facilities that you previously enjoyed. It may also include your ability to work or remain responsible for the care of a child.

The person you support should also have a needs assessment to determine how they can be helped. You can have a joint assessment if you both agree.

Do I need to pay for any support as a carer in England?

Assessments should be carried out regardless of your financial circumstances, the amount of care you provide or any support already being received.

Once you have been assessed, your local authority must work with you to produce your support plan. This will decide how your needs could be met, which may include information and guidance, or services.

You will also be financially assessed for services you receive as a carer. This will tell you how much you might need to contribute and how much the local authority might pay.

However, you cannot be charged for any care supplied directly to the person you support, even if this helps you (for example, a care worker providing personal care). Your local authority must financially assess the person you support for care they receive.

Information about support for carers in England

The Care Act 2014 sets out a new duty for local authorities in England about information on social care. This requires them to provide more comprehensive information and advice about care and support in their area, for adults and their carers.

They should be able to tell you about:

- the way their systems work
- types of care and support, and the providers available
- how to access independent financial advice, including for benefits and financial support
- how to raise concerns about a person's safety or wellbeing.

Contact your local authority for more assistance. You can also find a wide range of content about adult social care from the online government service at: **www.gov.uk** or search for carer rights at: **www.nhs.uk**

What are my rights as a carer in Wales?

In Wales, carers' rights are currently under reform, but are likely to follow the same main principles as laid out in the Care Act for England. The following Acts govern your rights in Wales until 2016:

- The Carers (Recognition and Services) Act 1995 formally recognised the role and needs of carers and, for the first time, gave them a right to an assessment of their own needs.

- The Carers and Disabled Children Act 2000 extended this right to assessment and also gave the right to teenagers aged 16 and 17.
- The Carers (Equal Opportunities) Act 2004 significantly extended the rights of carers.

Under this governance, local authorities have a duty to assess your needs as a carer when an assessment or re-assessment of the person you support is taking place, provided that you provide a 'substantial amount of care on a regular basis'.

For more information about carers' rights in Wales, see: www.nhsdirect.wales.nhs.uk/doityourself/carers

See also Section 9: *Support for children and young people for guidance about rights for young carers.*

Do I qualify as a carer in Wales?

If you provide a lot of ongoing support, you should qualify. Even if you provide a limited amount of support and this has a big impact on your life, you can still be assessed. For example, you may be juggling work and care, which can be difficult. If the person you look after does not want to be assessed for help they need, you can still be assessed to consider any help you may need as the carer.

Once identified as a carer, you should be informed of your rights and your entitlement to assessment. Whether you wish to continue caring or not should be considered at assessment, and whether you need a break for education, training or a leisure activity.

What will change for carers in Wales?

In April 2016, this governance will change. In place of these separate Acts, The Social Services and Well-being (Wales) Act 2014 will be implemented, transforming how social services are delivered in Wales.

Similar to changes in England, you will no longer need to provide 'a substantial amount of care on a regular basis' to be able to have an assessment. The local authority will have a duty under the Act to undertake a carer's

assessment where it appears you have needs for support.

As with the Care Act for England, The Social Services and Well-being (Wales) Act 2014 requires the person conducting the assessment to pay regard to your views, wishes and feelings as a carer. This must take into account your ability and willingness to continue caring, as well as any employment, education, training or leisure needs.

Local authorities will have a duty to meet your eligible needs as a carer within a statutory support plan, which the local authority must regularly review.

Do I need to pay for any support as a carer in Wales?

If you have eligible needs, your local authority can charge for any care or support provided, but only where it has cost them to meet your needs. A financial assessment will take place to determine this and The Social Services and Well-being (Wales) Act 2014 states that the charge should be no more than is 'reasonably practicable for the person to pay'.

Information about support for carers in Wales

As in England, there will be a new duty on local authorities and Health Boards in Wales to provide people with information and advice relating to care and support. This will include assistance in accessing support, most likely through an Information, Advice and Assistance service.

Contact your local authority for more assistance. You can also find a wide range of content about adult social care from the online government service at: www.gov.uk or carer information at: www.nhsdirect.wales.nhs.uk/doityourself/carers

What are my rights as a carer in Northern Ireland?

If you live in Northern Ireland and provide a 'regular and substantial amount of care' for someone aged 18 or over, you have the right to an assessment of your needs as a carer. This is governed by the Carers and Direct Payments Act 2002. Find more information about the Act and your rights at: **www.nidirect.gov.uk/an-overview-of-carers-rights**

Legislation in Northern Ireland places a responsibility on health and social care trusts to inform carers of their right to an assessment of their needs. They should consider a carer's interests, such as work, study or leisure. They also have power to supply services directly to carers to help them in their caring role, with a carers' co-ordinator in each health and social care trust.

Contact your local health and social care trust to ask about assessment. They also have a responsibility to make sure a young carer's own wellbeing is looked after and that they receive the necessary support.

See also Section 9: Support for children and young people for guidance about rights for young carers.

Do I qualify as a carer in Northern Ireland?

There is no set definition of 'regular and substantial care'. However, if the support you provide affects you because of your age, health, work, studies, other activities or commitments, you may need to be assessed.

A carer's assessment means social services will look at your situation to see if you are entitled to any services that could make caring easier for you.

Do I need to pay for any support as a carer in Northern Ireland?

In Northern Ireland, the Carers and Direct Payments Act allows for charges to be made

for services to a carer following a carer's assessment. However, this is not common practice. If you are asked to contribute, you will be financially assessed to work out the level of payment required.

If services, such as respite care, are provided for the person you support, they can be charged separately for this help. Home care services (known as domiciliary care services) are usually provided free of charge in Northern Ireland.

Information about support for carers in Northern Ireland

Contact your local health and social care trust for details about carer support in your area. You can view online government information about carers' rights at: **www.nidirect.gov.uk/an-overview-of-carers-rights**

What about my employment and benefit rights as a carer in the UK?

If you are a carer in employment, you have the right in the UK to request flexible working and time off at short notice to help you in your caring role. Your rights in this area are governed by the Work and Families Act 2006 and the Employment Rights Act 1996, and in Northern Ireland by the Work and Families (NI) Act and the Employment Rights (Northern Ireland) Order 1996.

You may also be entitled to a range of benefits for financial support. If you have not claimed benefits before, it may feel uncomfortable to claim these at first. However, it is your right and may help if you reduce your working hours or decide to leave work during the caring role.

See Section 6: Work and financial support for more details about how to manage employment and caring, and the benefits that may be available to you.

Key points

- Ask for a carers' assessment if you have not been offered one. Contact your local authority in England or Wales, or your local health and social care trust in Northern Ireland.
- Be aware of your rights as a carer, whether you live in England, Wales or Northern Ireland. This can help you get an assessment, which may help supply the support and information you need.

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

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

Useful organisations:

You may also want to discuss carer rights with organisations who specialise in this area, such as:

- local carer centres, groups and charities provide support and guidance and are usually listed by your local authority
- national organisations such as the Carers Trust and Carers UK.

See Section 12: *Useful organisations* for suggested organisations offering support for carers in England, Wales and Northern Ireland.

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MND Association

PO Box 246, Northampton NN1 2PR

Tel: 01604 250505

Website: www.mndassociation.org

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

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

www.england.nhs.uk/tis