Support for carers

A carer is anyone who provides regular care and support to a partner, relative, or friend who need help and could not manage otherwise. A carer can be an adult or a child (also known as a young carer), and usually provide unpaid care. Many people in a caring role don’t always view themselves as being a carer. However, it is important to do so to ensure you are getting the right support.

Being a carer can have a significant impact on your own health and emotional wellbeing. To continue caring safely and effectively for the person you are supporting, you need to make sure your own needs are being met. It is very important that you have access to the right information, advice, and support when you need it.

If you are a carer, you should think carefully about:

- How being a carer affects you and the person you are caring for
- How much care and support you provide to the person you are caring for
- Where you can access information and advice
- What help and support is available to you
- If the person you are caring for would qualify for a care package; either through social services or continuing health are through the NHS.

There is support available to help look after your own wellbeing and to make things easier for you.

**Where can I get support?**

There is a wide range of support available for carers across the UK, through community carers centres, charity organisations, online forums, and support groups that provide practical and emotional support and information to carers. Carers can also access support from their GP and social care departments in their local council.

Support may include getting a carer’s assessment from your local council to identify your needs, what may help you, and to consider suitable options such as respite care. Support is also available for young carers to help them cope with the increased pressures they may be experiencing because of their caring responsibilities, as well as their everyday life.

Carers UK have a directory on their website of local support services for carers. The directory contains information and contact details for local carers' organisations across the UK, social care departments in local councils, and local providers of the Carer UK’s ‘Digital Resource for Carers’. You can search the directory for your local support service on the Carers UK website at the link below:

[Carers UK - Finding support where you live](#)
Barnardo’s young carers sub-hub provides a range of resources, tools, videos, and more to support families with young carers.

**Barnardo’s Young Carers Sub Hub**

Carers Trust can also provide tailored guidance, resources, and specialist support if you are a young carer.

**Carers Trust - Young Carers Help & Support**

**What is a carer’s assessment?**

A carer’s assessment is a tool that is used to identify your needs as a carer and to look at how you are coping. An assessment should also explore what help and support may be beneficial for you as a carer. A carer’s assessment is not the same as a care needs assessment. They are two separate assessments, although they may be completed around the same time. In Scotland, a carer’s assessment is called an adult carer support plan and in Wales, it can be called a carer’s needs assessment.

If you are an adult (aged 18 or over) and provide regular unpaid care and support to a partner, relative, or friend, you can get a carer’s assessment. The first step is to contact your local council’s social care department to request a carer’s assessment. If you are unsure about how to do this, you can contact MDUK’s care and support team on 0800 652 6352 or via email: info@musculardystrophyuk.org for further advice. Your local carers centre will also be able to advise you on how to request a carer’s assessment.

Any carer, who provides regular unpaid care, or appears to need support, is legally entitled to an assessment.

You can find the details of your local council by using the search tool at the link below:

**Find your local council - GOV.UK**

Carers UK can provide further help and advice about having a carer’s assessment:

**Carer's assessment | Carers UK**

If you are unsure about requesting a carer’s assessment, get in touch with our team to discuss how an assessment might be beneficial for you. A carer’s assessment can be a very important step in ensuring you have access to the right help and support.

**Parent carer’s needs assessment**

A parent carer is someone who provides extra care and support to their child (or children) because of disability or illness. This can also include grown up children who are over the age of 18. A parent carer is also legally entitled to an assessment. This is
called a parent carer’s needs assessment and you can request this from your local council.

A parent carer’s needs assessment is a tool that should be used to identify your needs as a carer and to explore what help and support is available for you. A parent carer’s needs assessment will usually be completed by your local council’s adult social care department.

You can contact MDUK’s care and support team on 0800 652 6352 or via email: info@musculardystrophyuk.org for further advice about parent carer’s needs assessments. Your local carers centre will also be able to advise you on how to request a parent carer needs assessment.

**Family Rights Group** is a national charity whose aims are to enable children to be raised safely and thrive within their family and community. More information about parent carer’s needs assessments can be found on their website which is linked below.

[Parent carer’s needs assessment - Family Rights Group (frg.org.uk)]

**Contact** are an organisation providing support, advice, and information to families with disabled children. They have produced a factsheet on carers assessments which is linked below.

[Carers-assessments.pdf (contact.org.uk)]

**Young carer’s needs assessment**

A young carer is a child under the age of 18 who provides regular unpaid care and support to a family member for a variety of reasons. A young carer will usually care for a close relative such as a parent or a sibling. A young carer’s needs assessment can be requested by the young person or by their parent or guardian. If you are aged between 14-17, you may also be able to request a young carer’s transition assessment.

To request a young carer’s needs assessment or a young carer’s transition assessment, you can contact the local council’s social care department. These assessments will usually be completed by a social worker.

Carers First works directly with, and for, thousands of unpaid carers, providing practical information and support and making it easier for them to continue living their lives to the fullest. More information about young carer’s needs assessments and young carer’s transition assessments can be found at the Carers First website linked below.

[Young carer's assessments for under-18s | Carers First]

More information about being a young carer and young carer rights can be found at the link below:
Mental health support

Caring for someone living with a muscle-wasting condition can often mean adjusting to a new and unexpected reality. Whilst caring for someone can be a very positive and rewarding experience, it can also lead to a range of changing emotions, which may be difficult to cope with and could impact your mental wellbeing.

It is important that every carer has access to the right support when it is needed. If you need support with your mental health, you can contact your GP surgery. Your doctor is likely to ask you some questions about your life and might ask you to fill out a questionnaire about your mood, thoughts, and behaviour. This can help them decide what kind of support might be most beneficial for you.

You can find out more about how to access mental health support at the link below.

Getting mental health support | Muscular Dystrophy UK

Mind is a mental health charity. They have lots of information and tips on looking after your mental health and wellbeing and finding support while caring for someone else.

Mind - Your mental health as a carer

Peer support

You may find that you want to talk to someone who understands what you might be going through, and has lived experience of being a carer. Our peer support volunteers understand what it’s like to care for a family member living with a muscle-wasting condition. They all have their own personal experience, and are passionate about providing much needed support to others. We can introduce you to one of our peer support volunteers so that you have a confidential and safe space to talk about the things that matter to you.

Our peer support is provided through the phone or via email, and all of our volunteers have been provided with training and support from members of the care and support team at Muscular Dystrophy UK. If you would like to find out how to access peer support you can complete our online form: Peer support for you | Muscular Dystrophy UK or contact our helpline on 0800 652 6352 or via email: info@musculardystrophyuk.org.
Financial Support

If you are providing regular, unpaid care to a partner, relative, or friend, you may experience additional costs that can lead to financial hardship. It is important to check what financial support you may be entitled to help with your everyday costs.

How to check if you are eligible for benefits or financial assistance

Understanding which benefits to apply for can be challenging and, where possible, you should seek specialist advice for more support. You can check if you're entitled to any benefits or financial assistance by using an independent, free, and anonymous benefits calculator. You will need to include information about yourself and your finances to get an estimation of the benefits you may get and how much the payments could be: Benefits calculators - GOV.UK.

You can also contact your local Welfare Rights Service and/or a local welfare benefits organisation who have specialist advisors that can provide you with free and confidential advice. Welfare Rights Service can also assist with completing benefit claim forms and can support you with challenging benefit decisions. You can find the details of your local Welfare Rights Service and local organisations through your local council: Find your local council - GOV.UK.

You can also contact Citizens Advice who will be able to give you information and advice and help you with applying for welfare benefits.

Please also contact our helpline if you are struggling to navigate the right support you should be entitled to.

Benefits - Citizens Advice

Below are some of the main financial benefits available to carers. Please note, if you are already receiving benefits or if the person you care for receives a benefit, it is important to check before making any new applications as this could impact on yours, and/or their existing benefit.

Carer’s Allowance

Carer’s allowance is the main benefit available for carers. The person you care for does not need to live with you or be a family member, but if you care for them with someone else, only one person is allowed to claim for Carer’s allowance. You and the person you care for will both need to meet certain criteria to be eligible for this benefit.

To be eligible, you:

- must be spending over 35 hours a week caring for someone with substantial care needs
must be 16 or over
must have been in England, Scotland, or Wales for at least two of the last three years
must be normally living in England, Scotland, or Wales, or live abroad as a member of the armed forces
should not be in full time education or studying for 21 hours a week or more
must earn less than £139 a week after tax, National insurance, and expenses (as of June 2023)

In addition to this, the person you care for must already be getting one of the following:

- Personal Independence Payment - daily living component
- Disability Living Allowance - middle or highest care rate
- Attendance Allowance
- Constant Attendance Allowance at or above the normal maximum rate with an Industrial Injuries Disablement Benefit
- Constant Attendance Allowance at the basic (full day) rate with a War Disablement Pension
- Armed Forces Independence Payment
- Child Disability Payment - middle or highest care rate
- Adult Disability Payment - daily living component at standard or enhanced rate

There may be some exceptions to the eligibility criteria. If you are unsure about your eligibility to Carer’s allowance, please contact the Department for Work and Pensions. Click here to check if you are eligible for carers allowance and apply online.

**Carer’s Credit**

Carer’s Credit is a National Insurance credit that contributes towards your State Pension. You may be eligible for Carer’s Credit if you’re caring for someone, who is 16 or over and under the current state pension age, for at least 20 hours a week. The person you’re looking after must be in receipt of the following:

- Personal Independence Payment - daily living component
- Disability Living Allowance - middle or highest care rate
- Attendance Allowance
- Constant Attendance Allowance
- Constant Attendance Allowance at the basic (full day) rate with a War Disablement Pension
- Armed Forces Independence Payment
- Child Disability Payment - middle or highest care rate
- Adult Disability Payment - daily living component at standard or enhanced rate

If the person you care for does not receive one of the listed qualifying benefits, it may still be possible to get Carer’s Credit. To find out further information on Carer’s Credit and how to apply please see here: https://www.gov.uk/carers-credit.

**Carer Premium or Carer Element**

If you are eligible for Carer’s allowance, you may also be able to receive a Carer Premium or Carer Element (if you receive Universal Credit). These are extra amounts you can receive in addition to other benefits. You may be able to receive Carer Premium if you are in receipt of other means tested benefits, such as housing benefit or Universal Credit. If you are of state pension age, Carer Premium is called a Carer Addition.

You can find out more about Carer Premium or Carer Element on the Carers UK website which is linked below:

*What is the Carer Premium? | Carers UK*

**Cost of living**

If you are a carer, you may already deal with additional costs and so you may be struggling to afford the essentials. The link below has information about the support you may be entitled to. You can also read the experiences of others living with muscle-wasting conditions and find out more about our cost of living campaign.

*Cost of living | Muscular Dystrophy UK*

Turn2us is a national charity providing practical help to people who are struggling financially. Turn2us have a grants search tool (linked below) which will show you grants that you may be eligible for. A grant is usually a small sum of money that you do not have to pay back. Many UK charities will provide grants to help with additional costs.

*Turn2us Grants Search*

You can also search online for grants and for other financial help which may be available.
Other useful links and resources

Most local areas have carer support groups and advice lines for carers and young carers. Follow the link below to find out what support is available for carers in your area:

Carers-support-services - Search (NHS)

Carers UK offers support and advice to carers and their families:

Carers UK

Mind are a mental health charity and have information available on the website about supporting yourself while caring for someone and where you can find support if you are a carer.

Where to find support for carers - Mind

Carers Trust partners with its network of local carer organisations to provide funding and support.

Carers Trust

Carers UK have developed a Digital Resource for Carers which brings together specially designed digital products and online resources, to help provide comprehensive information and support to carers.

Carers UK Digital Resource Guide

Carers UK have developed guide on self-advocacy which has been designed to help you communicate your needs with professionals, understand your rights, and look after your wellbeing.

Being Heard - a self-advocacy guide for carers | Carers UK