

Carers Rights Guide 2016

Looking after someone



Photo: Chris Steele-Perkins / Magnum

Contents

About this guide	3
Welcome	4
Need to talk?	6
Need more information?	7

Benefits	8
-----------------	----------

Find out what benefits you and the person you care for are entitled to.



Other financial help	12
-----------------------------	-----------

Find out what other financial help you and the person you care for may be entitled to.



Practical support	16
--------------------------	-----------

Find out about assessments and the support that social services can provide.



Technology	20
-------------------	-----------

Make life easier with health and care technology.



At work	24
----------------	-----------

Find out about your rights at work and get help with juggling work and care.



Other help	26
-------------------	-----------

Find out where to go for information, and contact details for useful organisations.





Photo: Chris Steele-Perkins / Magnum

About this guide

Across the UK today 6.5 million people are carers, supporting a loved one who is older, disabled or seriously ill.

Whether you've been caring for years or are just starting out, it's important to be aware of your rights and where to go to get help.

The **Carers Rights Guide** is here to outline your rights as a carer, and to give you the full picture of the practical and financial support available.



This symbol means there is a Carers UK factsheet available where you can find more information. You can download all of our factsheets for free on the Carers UK website (visit carersuk.org/factsheet) or if you are a carer you can order a free printed copy by contacting the Carers UK Adviceline.



Carers UK Adviceline

When caring affects you and your family, we're here to give you expert advice, information and support.

0808 808 7777

advice@carersuk.org



@carersuk



/carersuk

carersuk.org

Welcome

Every day 6,000 people start caring for a family member or friend. Helping a loved one get the most out of life can be incredibly rewarding, but it can also be very tough.

Getting the right advice as soon as you start caring can make a huge difference. And even if you've been caring for decades, it is vital that you make sure you are getting all the support you are entitled to. The Carers Rights Guide is here to give you an overview of the financial and practical support that is available to you.

In England, the Care Act was implemented in 2015 and brought new rights for carers to receive services and get support. Find out more about these new rights on pages 16-17.

We still have a long journey ahead to make sure every carer gets the support they need to have their own life alongside caring.

We believe that no one should have to care alone. When you join Carers UK as a member, you can strengthen our voice, stay up-to-date on the latest developments and help deliver lasting change.

You also become part of our supportive community of carers. The Carers UK online forum is here 24/7, for when you need to talk to people who understand the ups and downs of caring.

And whoever you are and whatever you're going through, the Carers UK Adviceline is here when you need expert advice and information.



Heléna Herklots
Chief Executive
Carers UK



As the number of people caring continues to rise, it is vital that we provide the understanding and support our colleagues need, as well as helping support our customers who may be carers.

As the Board Champion for Carers & Disability at Sainsbury's, I am proud to be part of an active partnership with Carers UK. Since 2010 this partnership has helped us shape our flexible working policies and raise awareness of the support available. We're very proud to be one of just a few FTSE 100 companies with a specific policy to support carers in the workplace.

This year we sponsored materials for Carers Week and Carers Rights Day and held fundraising and awareness-raising events in many of our stores, celebrating the 50th Anniversary of Carers UK. A number of colleagues, who are also carers, shared their stories for an online film showing what it is like to juggle working life with caring commitments.

Our work with Carers UK helps to make Sainsbury's a great place to work.



Tim Fallowfield

Corporate Services Director and Company Secretary
Sainsbury's plc





0808 808 7777
advice@carersuk.org

Need to talk?

Caring can present all kinds of challenges, from filling in forms to coping with emotions. We're here for you with advice, information and support every step of the way.

Carers UK Adviceline

You can talk to us five days a week, no matter where you are in the UK or how complex your query is. We can check which benefits you are entitled to and advise on financial and practical matters related to caring. Our listening service is there for you to talk through your caring situation with a trained volunteer who has experience of caring and understands what you are going through.

0808 808 7777 | advice@carersuk.org

Monday to Friday, 10am to 4pm. Listening service available Mondays and Tuesdays, from 9am to 7pm. Free from any landline and most mobile phone networks.

Carers UK forum

Our warm and welcoming online community is a place where you can share what's on your mind, day and night. You can talk about real issues with people who understand and who can support you through everything caring has to throw at you.

carersuk.org/forum





Need more information?

Having the right information at the right time can make a huge difference – whether you're just starting out in your caring journey, or have been caring for years.

The Carers UK **website** is the first port of call if you're looking for information about any aspect of caring. Whether you're grappling with Carer's Allowance, trying to find practical help or exploring what technology is available to make caring easier, our advice pages offer the help you need. carersuk.org/help

Our **factsheets** break down the complex issues simply and accurately so you get the full picture of the support available and how to get it. carersuk.org/factsheets

Our **self-advocacy toolkit** is here to help give you the skills and confidence you need to face the challenges of caring – from learning how to navigate a confusing system to how to communicate effectively. carersuk.org/self-advocacy

Our **Upfront online guide** gives you information tailored to your situation as you get started in your caring role. As well as the practical and financial support covered in this guide, you'll find information to help you manage the impact of caring on your health and relationships. carersuk.org/upfront



Benefits

Find out what benefits you and the person you care for are entitled to.



Nearly 8 out of 10 families caring for someone say it has had an impact on their finances.

It is important to know what benefits you and the person you care for are entitled to. It might make a difference to your pension entitlements in the future or bring in extra money to help pay for care.

The benefits system

The benefits system is complicated. Finding out what you are entitled to can be difficult and many people miss out. The Carers UK website covers the main conditions for each benefit and how to apply.

Carer's Allowance is the main benefit for carers. You may be eligible if you are looking after someone for 35 hours a week or more. There are also benefits to help pay for the extra costs of long-term illness or disability. They are not dependent on how much money you have, but there are important criteria that you need to fulfil in order to receive them.



Factsheet: Carer's Allowance

Download for free at carersuk.org/carersallowance

Factsheet: Disability Living Allowance

(for children under 16 years old)

Download for free at carersuk.org/dla

Factsheet: Personal Independence Payment

(for people aged 16-64 years old)

Download for free at carersuk.org/pip

Factsheet: Attendance Allowance

(for people aged 65 years old and over)

Download for free at carersuk.org/aa

Getting a benefits check

The benefits system has been subject to a lot of changes over the past few years, and more changes are underway. By getting a benefits check you can make sure you are claiming all the benefits you are entitled to.

By phone or email

The Carers UK Adviceline can carry out a benefits check for you – call **0808 808 7777** or email advice@carersuk.org

Online

You can get a benefits check online by visiting either of the following websites:

- www.entitledto.co.uk/benefits-calculator
- www.turn2us.org.uk/benefits_search.aspx

This will take about 20 minutes to complete.

These online tools are not suitable for everyone. Special rules apply to some groups of people, for example: students, people under 18, people in permanent residential care, UK nationals who live abroad and people who are not British or Irish citizens.

Face-to-face

You may be able to get a face-to-face benefits check from a local advice centre, such as your local Citizens Advice Bureau, Carers Centre, Age UK or disability charity. Contact the social services department of the person you look after and ask them what advice services there are in your area. You could also ask about getting a benefits check locally when you have your carer's assessment (see page 16).





Photo: BBC

Norman's story

When Norman started caring for his wife Ros, he was unaware of his rights and where to go for help. A call to the Carers UK Adviceline changed everything for him.

My wife Ros was diagnosed with MS when she was 38 years old.

At the time I had a well-paid job which I enjoyed. However, the cost of care workers for Ros put a big dent in our finances.

Ros' health deteriorated to a point where I had to give up work to care full-time. Our money soon ran out.

Suddenly I was in serious financial trouble. Unable to afford the mortgage any more, we ended up losing our house.

My call to the Carers UK Adviceline was the first time I felt listened to. I spoke to an Adviser who talked through my situation with me in detail, and let me know what my options were.

It was a huge relief to know that there were other people out there going through a similar thing.

If I had got this information when I first started caring for Ros, I'm sure our life would have been quite different.



Photo: Chris Steele-Perkins / Magnum

Join Carers UK

However caring affects you and your family we're here for you. By joining Carers UK you can be part of a supportive community and a movement for change.

As the UK's only national membership charity for carers, we offer you 50 years' experience of providing support and campaigning for change.

When you join us you get:

- support from other carers
- a say in our future
- the latest news, information and campaign updates
- to be part of a UK-wide movement of carers supporting each other and pushing for lasting change

Caring for someone you love can be a joy but it can also be tough and you can feel very alone.

Carers UK was my lifeline when I didn't know what to do or who to turn to.

Join us today for free:

carersuk.org/join | join@carersuk.org | 020 7378 4997



@carersuk



/carersuk

carersuk.org

Other financial help

Find out what other financial help is available.



Some of the financial help listed here is dependent on whether you or the person you care for are claiming other benefits. The benefits system has been subject to a lot of changes over the past few years so it is important to stay up to date on the latest information.

The Carers UK website covers all of the main conditions for each benefit and information on how and where to apply – visit carersuk.org/advice

For expert advice and information about benefits contact the Carers UK Adviceline on **0808 808 7777** or at advice@carersuk.org

Help with Council Tax

Visit carersuk.org/counciltax to find out more about help with Council Tax and what to do if you disagree with a decision.



Factsheet: Help with Council Tax

Download for free at carersuk.org/counciltax

Council Tax Reduction / Support

Each council has its own rules for Council Tax Reduction which helps people on low incomes with paying their Council Tax. To apply contact your local council benefits department.

Disability reduction scheme

You may be able to pay less Council Tax under the disability reduction scheme if your home has had work carried out on it to help you or someone else living there with a disability.

Council Tax discounts

People who live alone qualify for a 25% Council Tax discount. If



there is no one in the property, the discount will be 50%.

Certain people, including some carers and people with a severe mental impairment, are not counted when the council works out how many people live in a property. This means that in some circumstances the home may be classed as empty and you may qualify for the full exemption.

Protecting your pension

For every week that Carer's Allowance is paid you are credited with a National Insurance contribution. This is very important, as if you are unable to work or have cut down your working hours as a result of caring, your State Retirement Pension may be at risk because of the reduction in your National Insurance contributions.

If you are a carer but are not entitled to Carer's Allowance, you may be able to claim Carer's Credit which can help to make sure you do not miss out on National Insurance contributions while you are caring.

Visit carersuk.org/pension to find out more about pensions and carersuk.org/carerscredit to find out if you qualify for Carer's Credit.

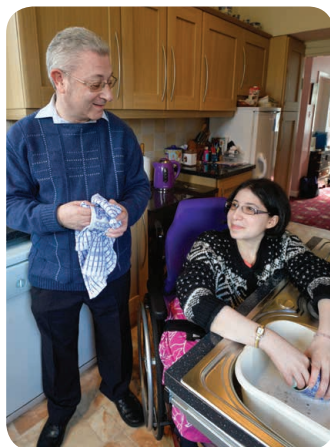
If you claim Carer's Allowance and are thinking about deferring your pension, you need to seek advice as in most cases you will not be any better off. In some cases you could actually lose out.

For more advice on deferring your pension contact the Pension Service on [0345 606 0265](tel:03456060265).

Adapting your home

If you need to adapt your home to make it suitable for a disabled person you may be able to get a Disabled Facilities Grant to help with the costs.

Find out more at carersuk.org/disabledfacilitiesgrant





Help with fuel costs

There are a number of ways you can get financial help with fuel costs or reduce your energy bill. Find out more below and at carersuk.org/fuel

Winter Fuel Payments

If you have reached the qualifying age you may be entitled to a Winter Fuel Payment to help pay winter bills. This can be £100-£300 depending on circumstances.

Warm Home Discount

The Warm Home Discount scheme means you could get a discount on your electricity bill if you meet certain criteria.

Cold Weather Payments

If you're receiving certain benefits you may be able to get a Cold Weather Payment for each week that the average temperature in your local area is at, or below, freezing.



Photo: Chris Steele-Perkins / Magnum



Help with health costs

If you are getting certain benefits (and your income is below a certain amount) you qualify for help with NHS health costs. This includes free prescriptions, free dental treatment, free NHS eye tests and vouchers to help pay for glasses/contact lenses, as well as reimbursement of fares to hospital for treatment for you or your child. You can also claim for the fares of a companion who needs to travel with you for medical reasons.

If you are aged 60 and over, you can get free prescriptions and NHS eye tests regardless of your income.

If you don't qualify for free NHS benefits but have a low income, you may be able to get help with health costs from the NHS Low Income Scheme. Prepayment certificates for prescriptions can also reduce costs if you regularly pay for medication.

Find out more at carersuk.org/healthcosts

Budgeting Loans

If you are getting certain benefits you can get a Budgeting Loan to help pay for essential things like rent, furniture, clothes or hire purchase debts. The smallest amount you can borrow is £100. Budgeting Loans are interest-free so you only pay back what you borrow. You normally have to repay the loan within 104 weeks.

Find out more at www.gov.uk/budgeting-loans

Help from your local council

Your local council may have a scheme to help people in a crisis and/or those who cannot afford to buy household goods like fridges, freezers, beds etc.

You should get in touch with your local council to see what help they can offer. The Child Poverty Action Group has a website that can link to your local scheme – visit www.cpag.org.uk/lwas



Practical support

Tell social services that you are a carer and find out what practical support is available.



You may also need practical support to care. This could be someone to sit with the person you care for while you go out, equipment to help you to lift the person you care for or information about local carers' groups. The social services department for the person you care for is the place to start.

In April 2015, the Care Act 2014 and the Children and Families Act 2014 came into force, and have strengthened the rights of carers in the social care system. As a carer, you no longer have to request an assessment – social services should offer you one if you appear to have or will have needs for support. There are also new national rules for deciding who is eligible for care and support.



Factsheet: Assessment and the Care Act

Download for free at carersuk.org/careact

Carers UK has useful information about your rights and how to assert them when asking for practical support – visit carersuk.org/careandsupport

Carer's assessment

Any carer who appears to have a need for support should be offered a carer's assessment by the local authority.

You can have an assessment no matter what your level of need, the amount of care you provide or your financial means. You can have an assessment whether or not the person you care for has had a needs assessment or if they have been considered to be not eligible for support.

The assessment will look at how caring affects your life, and whether



you are able or willing to carry on caring. Following the assessment, social services will decide if you are eligible for support to be provided either to you as a carer or to the person you care for to reduce the impact of caring on you. You will be eligible if caring has a significant impact on your wellbeing.

Whether social services will pay for any support provided will depend on your financial situation (if services are provided to you) or on the financial situation of the person you care for (if services are provided to them as a result of your assessment).

Even if you are not considered to be eligible for support, social services must provide you with information and advice on local services to prevent your needs from developing further.

For more information about carer's assessments you can visit carersuk.org/carersassessment or contact the Carers UK Adviceline on 0808 808 7777 or at advice@carersuk.org

Needs assessment

If the person you care for appears to have a need for support they should be offered a needs assessment by the local authority.

The person you care for can have an assessment no matter their level of need or their financial means.

The assessment will look at their physical, mental and emotional needs. Carers are entitled to be involved in the assessment.

Following the assessment, social services will decide whether the person you care for is eligible for support. Whether social services will pay for any support provided will depend on the financial situation of the person you care for.

Even if the person you care for is not considered to be eligible for support, social services must still provide them with information and advice.

For more information about needs assessments you can visit carersuk.org/needsassessment or contact the Carers UK Adviceline on 0808 808 7777 or at advice@carersuk.org



Direct payments and Personal budgets

The help that either you or the person you care for are offered following an assessment may not be in the form of services. Instead you may receive money.

A direct payment is a cash payment that is given instead of community care services and is intended to give individuals greater choice about their care.

A personal budget is an allocation of money to an individual to pay for social care.

As a carer you may get either direct payments or a personal budget to help to pay for services or products that would help you.

Find out more at carersuk.org/directpayments



Photo: Chris Steele-Perkins / Magnum



Coming out of hospital

Deciding to care, or continue caring, for someone who is coming out of hospital can be very difficult. One important thing to remember is that it is your choice whether or not to take on a caring role.

Our factsheet *Coming out of hospital* outlines your rights as a carer during the hospital discharge procedure, the steps that should be followed before the person you care for is discharged from hospital, and what to do if things go wrong.



Factsheet: Coming out of hospital

Download for free at carersuk.org/hospital

Taking a break / respite

Caring for somebody can be a full-time job, so breaks are vital to your own wellbeing and quality of life.

Our factsheet *Taking a break* outlines the different types of breaks that are available, how to get alternative care and how to plan and fund your break.



Factsheet: Taking a break

Download for free at carersuk.org/break



Photo: Chris Steele-Perkins / Magnum



Looking after someone?

Whoever you're sharing care with, our app helps keep everyone in the loop.

Because sharing care is easier when you do it *jointly*



Jointly makes sharing care with others easier, less stressful and a lot more organised:

One central place to store and share the important information about the person you are looking after.

Simple, intuitive group communication to keep everyone informed and better connected.

Shared **task lists and calendar** to help co-ordinate responsibilities and organise what needs to be done.

Works across **different devices**: smartphone, tablet or home computer / laptop.

Available at **jointlyapp.com** and through the Apple App Store and Google Play Store.

Technology

Find out how health and care technology can make life easier for you and the person you care for.

Health and care technology can help make your home safer, your life easier and provide independence for the person you are looking after.

You may be able to access health and care technology through a needs assessment (see page 17) if you are caring for an adult or an assessment for your family if you are caring for a child.

You can also pay for some services, but if you need adaptations first check if you are entitled to a Disabled Facilities Grant (see page 13).

Equipment and changes to your home

Carers UK has put together a list of room-by-room ideas including items of equipment, smaller adaptations and larger adaptations.

Before purchasing any equipment it is a good idea to ask your social worker or GP if you can be referred to an occupational therapist. It's an occupational therapist's role to offer an independent opinion and advice about equipment and adaptations which may help meet your needs and those of the person you look after.

Find out more at carersuk.org/equipment

Telecare and telehealth

Telecare and telehealth have huge potential to help disabled or elderly people to live independently in their own homes and give you – as a carer – peace of mind that they are safe and well.

Telecare consists of a range of unobtrusive sensors positioned throughout the home which can detect if there is a problem, such as a gas leak or fire, or if the person you look after has a problem and needs assistance.

It also includes wearable technology that can detect falls and locate a person if they have wandered. Alerts are then sent to an individual, a group of nominated responders or a monitoring centre who can respond to the problem detected.





Technology

Telehealth is a way of monitoring a person's health remotely, through equipment they have in their home. It can monitor conditions such as asthma, heart failure, diabetes, chronic obstructive pulmonary disease (COPD), stroke and hypertension. This information is then sent to an expert monitoring centre, either through the internet or telephone connection.

Find out more at carersuk.org/telecare

Mobile and internet

Everyday technology – such as the internet or your mobile phone – can take the stress out of a whole host of tasks such as shopping and coordinating care for the person you look after.

Find out more about the products and services available at carersuk.org/everydaytechnology



There must be other people going through this.



Hi there, I care for my mum. Things have been tough lately...



At work

Let your workplace know that you are a carer and find out what support is available.



If you juggle work and care, telling your employer that you are a carer is not always an easy step. However, there may already be support, advice and information for carers within your workplace.

Ask your employer if they have a carers policy. Some companies operate counselling services and have advice packs for carers. Trade unions can also be a good source of support. You may find that your colleagues are supportive, or even in similar caring situations themselves.

Our business forum Employers for Carers helps employers improve their understanding and provide better support for carers balancing the demands of work and caring. To find out more visit www.employersforcarers.org

Flexible working

Working carers have the legal right to request a flexible working pattern from their employer to help them balance their work and caring responsibilities. Employers can only refuse requests for certain specified reasons and should deal with requests in a 'reasonable manner'.

You can find more details on how to apply for flexible working and download our free guide at carersuk.org/flexibleworking

Time off for emergencies

You have the right to take a 'reasonable' amount of time off work to deal with an emergency involving a dependant. This right also includes some protection from victimisation and dismissal at work. It is at the employer's discretion whether this leave is paid or unpaid.

Find out more at carersuk.org/timeoff



Parental leave

If you have worked for your employer for at least a year and are responsible for a child, you are entitled to 18 weeks unpaid parental leave (per parent per child) before your child's fifth birthday (18th if they are disabled and receiving Disability Living Allowance).

Find out more at carersuk.org/parentalleave

Jobcentre Plus support for going back to work

If you decide to return to work Jobcentre Plus may be able to help by offering courses to help you improve your skills or a work-focused interview.

Find your local centre at www.gov.uk/contact-jobcentre-plus

Giving up work

Many people feel forced to give up work when faced with intensive caring responsibilities. This is a big step and it is important to understand all the implications it could have on your income, quality of life and future pension entitlements.

For expert advice and information on giving up work call the Carers UK Adviceline on **0808 808 7777**.

Find out more at carersuk.org/giveupwork

Protection from discrimination

The Equality Act 2010 provides carers with protection from some forms of discrimination. For example, employers and providers of goods and services must not treat carers less favourably than those without caring responsibilities.

If you feel that you have been discriminated against at work because of your role as a carer, contact the Carers UK Adviceline on **0808 808 7777** or at advice@carersuk.org



Other help

Find out what other help is available where you live and nationally.



You may decide that you want to arrange some additional care yourself, such as for extra help around the house.

You can find services in your area by looking at your local council website or by visiting www.findmegoodcare.co.uk

If you are going to buy in a lot of care or you are going to have it over a long period of time, it is a good idea to get advice from Carers UK, your local carers' or disability organisation or Age UK.

You may not have to pay for all of the care if you have an assessment by your local council. You may also benefit from financial advice if you are facing large care bills.

For expert advice and information on accessing care contact the Carers UK Adviceline on [0808 808 7777](tel:0808 808 7777) or at advice@carersuk.org

Useful organisations

There are a range of national organisations that can provide help. We've listed some of these below.

There are also many support groups and organisations ready to help locally. Visit carersuk.org/localsupport to see what is available where you live.

Alzheimer's Society

National and local information, advice and support for people with Alzheimer's and their carers.

www.alzheimers.org.uk | 0300 222 11 22

Age UK

Information, advice and support for the over 60s.

www.ageuk.org.uk | 0800 169 6565



Care Quality Commission

The independent regulator of health and social care in England. Tell them about your experience of care services:

www.cqc.org.uk/share-your-experience-finder

03000 61 61 61 | enquiries@cqc.org.uk

Carers Trust

In partnership with a network of local centres they provide advice, information and support to carers. www.carers.org | 0844 800 4361

Citizens Advice

Local offices for advice/representation on benefits, debt and housing.

www.citizensadvice.org.uk

Contact A Family

Information/support to families who care for children with a disability or special need. www.cafamily.org.uk | 0808 808 3555

Disabled Living Foundation

Advice and information on equipment for independent living.

www.dlf.org.uk | 0300 999 0004 | Textphone: 020 7432 8009

Independent Age

Information and advice, practical help and emergency financial aid for older people on very low incomes.

www.independentage.org.uk | 08003196789

Mencap

Information and advice for people with a learning disability, their families and carers.

www.mencap.org.uk | 0808 808 1111 | Minicom: 0808 808 8181

Rethink

Information, advice and community services for people affected by severe mental illness and their carers.

www.rethink.org | 0300 5000 927



Keep in touch

Carers UK Adviceline

For expert information and advice about caring.

0808 808 7777

(open Monday to Friday,
10am-4pm)

advice@carersuk.org

carersuk.org/advice

Carers UK

20 Great Dover Street
London SE1 4LX

020 7378 4999

info@carersuk.org



Carers UK is here to make life better for carers.

Across the UK today 6.5 million people are carers, supporting a loved one who is older, disabled or seriously ill. However caring affects you and your family, we are here for you.

By joining Carers UK, you can be part of a supportive community and a movement for change.

We're the UK's only national membership charity for carers, with 50 years' experience of providing support and campaigning.

Together we can make life better for carers.

carersuk.org/join

Proudly supported by

