

Carers Rights Guide 2016

Looking after someone



Photo: Chris Steele-Perkins / Magnum

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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 or Carers Wales 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



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.

The new Social Services and Well-being (Wales) Act is due to come into force in April 2016, changing the way in which social services operates in Wales. See pages 18-21 to find out how these changes could affect you.

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 and Carers Wales team are here when you need expert advice and information.



Keith Bowen
Director
Carers Wales



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





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/wales/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

Find out which benefits you may be entitled to 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 Cymru 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 Wales

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

As part of Carers UK, the 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 Wales 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



@carerswales



/carerswales

carerswales.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](https://www.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](https://www.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](https://www.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.

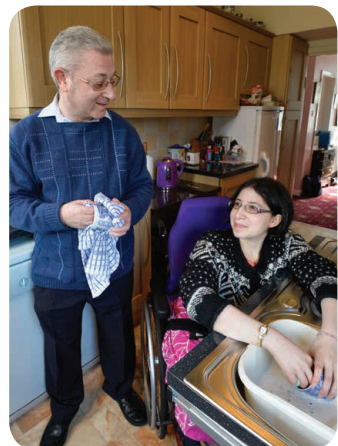
If you claim Carer's Allowance and are thinking about deferring your pension, you need to seek advice as in most cases you will not be any better off. In some cases you could actually lose out.

For more advice on deferring your pension contact the Pension Service on **0345 606 0265**.

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 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 NHS eye tests regardless of your income. In Wales everyone qualifies for free prescriptions.

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.

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

The Discretionary Assistance Fund can pay grants to people on a low income who are either in an emergency or who have no other way of affording essential household items such as fridges, freezers, cookers etc. For more details or to make an application call 0800 859 5924 or visit www.gov.wales and search for 'Discretionary Assistance Fund'.



Practical support

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



You may 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.



Factsheet: Assessments – your guide to getting help in Wales

Download for free at carersuk.org/assessments

From April 2016 the Social Services and Well-being (Wales) Act 2014 will come into force and will give you equivalent rights to those you care for. See pages 18-21 for more information.

Community care assessment

To determine what help is needed and how they can help, social services will first need to carry out a community care assessment.

This is done for the person who needs the care and will focus on their needs, but should also look at the role of the carer and the help they provide.

Find out more at carersuk.org/communitycareassessment

Carer's assessment

A carer's assessment is for people who provide 'regular and substantial' care for someone such as a partner, friend or relative. No definition of 'substantial' is given, so if you feel the care you provide will impact on your life, work or family, and you will be caring regularly, you are entitled to a carer's assessment. You can have a carer's assessment



whether or not the person you care for has had a community care assessment or want one themselves.

Social services should tell you about your right to a carer's assessment, but you will still need to ask them to carry out an assessment for you. Following the assessment, you will be given information about any services and support they can give you.

To find out what your carer's assessment should cover and what sort of help social services can give you visit carersuk.org/carersassessment

Direct payments

Since 2004, it has been mandatory in Wales for social services to offer direct payments to all individuals, including carers, who are eligible to receive them and want them.

These are payments given instead of community care services and are intended to enable individuals to buy their own care that they have been assessed as needing from social services. This enables individuals to have greater choice and flexibility about how their assessed care needs are met.

In April 2011 new regulations came into force to extend the current system in Wales to include people who lack capacity.

Find out more at carersuk.org/directpayments or to get expert advice and information on direct payments contact the Carers UK Adviceline.



The Social Services and Well-being Wales Act 2014

What does it mean for you?

The Social Services and Well-being (Wales) Act will come into force in April 2016 and will repeal almost all existing community care legislation.

For the first time there will be completely separate social care legislation for Wales and England.

The Act in Wales applies to people in need, of any age, and introduces important new rights for carers. The Act removes the requirement that you, as a carer, must be providing 'a substantial amount of care on a regular basis' to have a carer's assessment, as the previous legislation required. The Act also gives you, as a carer, a clear right to receive services following a carer's assessment, where your needs meet the national eligibility threshold.

The Act sets out new obligations on local authority social services relating to assessments, provision of information and advice, preventative services and duties to shape local services and make sure that there are enough services of the right kind to provide the extra help people need so that they can do the things that are important to them.



Factsheet: Assessments – your guide to getting help in Wales

Download for free at carersuk.org/assessments

Information, Advice and Assistance

Each local authority in Wales must provide an Information, Advice and Assistance (IAA) service for everyone in their area and where appropriate give assistance to access these services.

This service will act as a first point of entry to provide information to help people understand how the care and support system operates in their area and the types of service, including carers' services, that are available. It must also cover how to access these services and how to raise concerns about the well-being of people who may appear to have needs for care and support, including carers.

Carers' assessments and eligibility

The Act means that any carer who appears to have a need for support, or is likely to do so in the future, should be offered an assessment by the local authority.

As a carer you will be entitled to 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 community care assessment/needs assessment or if they have been considered not eligible for support.

The assessment will look at how caring affects your life, and whether you are able and willing to carry on caring. It should also look at whether you work or wish to do so and/or whether you are participating or wish to participate in education, training or any leisure activity.

In carrying out the assessment the local authority must seek to identify the outcomes that you wish to achieve and assess whether, and to what extent, the provision of support could contribute to you achieving these outcomes.

Carers' assessments and eligibility (cont)

Following the assessment, social services will decide whether you are eligible for services to be provided to you as a carer or whether services will be provided to the person you care for to reduce the impact of caring on you. The decision about whether social services pays for services to support you 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). The maximum you can be charged for non-residential social services in Wales is currently £60 per week.

As a minimum, social services must provide all carers, including those not considered eligible for support, with information and advice on local services that may be available that would help prevent your needs for support developing further.

A local authority may combine an adult or children's assessment and a carer's assessment if it considers it would be beneficial to do so and if the person being cared for (or person with parental responsibility, in the case of a child) agree.

Through the assessment process the local authority must identify any needs for a disabled person that would be deemed eligible for care and support if you were not meeting those needs. This is so that the local authority is able to respond appropriately and quickly if you become unable or unwilling to meet some or all of the identified care and support needs.

Assessments for people with care needs

The Social Services and Well-being (Wales) Act 2014 places a duty on the local authority to carry out an assessment of an individual where it appears to the local authority that an adult or child may have a need.

To determine what is needed and how they can help, social services will carry out a needs assessment. This is done with the person who needs the care or support, and must be carried out no matter what their financial situation. When carrying out the needs assessment the local authority must involve you, where feasible.

When carrying out the assessment the local authority must take into account the circumstances, strengths and capabilities of the person being assessed. They must look at the outcomes they want to achieve and any barriers to them being achieved or risks if they are not achieved.

When the assessment is completed, social services will decide whether the person meets the national eligibility threshold. Where they are eligible, social services will carry out a financial assessment to decide how much the person needs to contribute towards their care. At present the maximum local authorities can charge for non-residential social services is £60 per week.

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 community care assessment (see page 16) 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 and both smaller 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 is 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 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 who is using it 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.

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. The information is then sent to an expert monitoring centre, either through the internet or telephone connection.

Find out more at carersuk.org/telecare

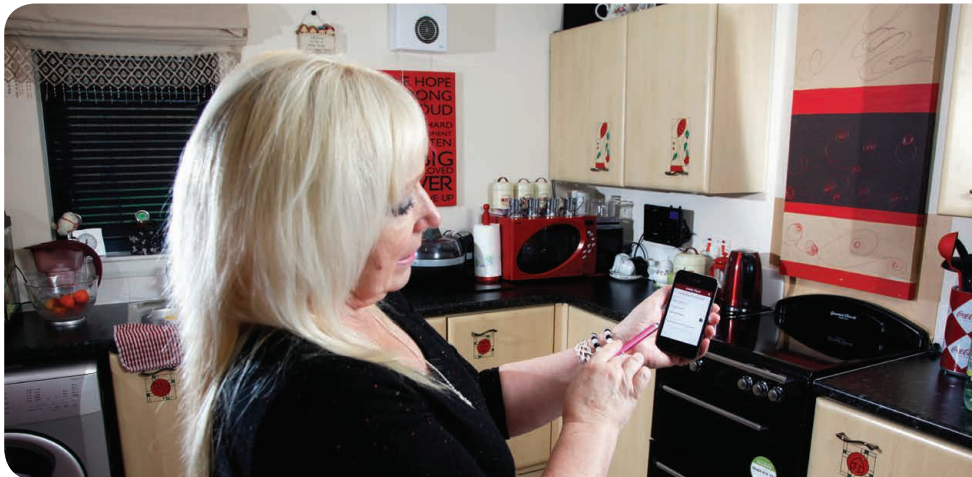
Mobile and internet

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

jointly

Developed by carers for carers, Jointly is an innovative mobile and online app from Carers UK to make caring a little easier, less stressful and a lot more organised. To find out more visit www.jointlyapp.com



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.cssiw.org.uk

Buying in care

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 Wales, your local carers' or disability organisation or Age Cymru.

For expert advice and information on accessing care contact the Carers UK Adviceline on [0808 808 7777](tel:08088087777) 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 Cymru

Information, advice and support for the over 60s.

www.ageuk.org.uk/cymru | 08000 223 444



Carers Trust Wales

In partnership with a network of local centres they provide advice, information and support to carers.

www.carers.org | 029 2009 0087

Citizens Advice

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

www.adviceguide.org.uk

Contact A Family

Information/support to families who care for children with a disability or special need.

www.cafamily.org.uk/wales | 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

Hafal

Hafal is the principal organisation in Wales working with individuals recovering from serious mental illness and their families.

www.hafal.org | 01792 816 600

Independent Age

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

www.independentage.org.uk | 0800 319 6789

Mencap

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

www.mencap.org.uk/wales | 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

Carers Wales

Unit 5
Ynys Bridge Court
Cardiff CF15 9SS

029 2081 1370
info@carerswales.org

Carers UK

20 Great Dover Street
London SE1 4LX

020 7378 4999
info@carersuk.org



Carers Wales works as part of Carers UK to make life better.

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

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Sainsbury's