carers
WALES

2024/25

Caring for a child

Information and support for carers in **Wales**

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Contents

About this guide

This guide has been co-produced alongside carers of children and aims to provide you with information, resources and tips to help you.

Unpaid carers of children in Wales can face a multitude of challenges that can significantly impact their lives. These challenges stem from the complex needs of the children they care for, as well as systemic issues within the healthcare and social support systems.

One of the primary challenges is the sheer intensity of caring responsibilities. Many carers find themselves providing round-the-clock care, attending to the physical, emotional, and medical needs of their children without respite. This constant demand can lead to exhaustion, stress, and burnout among carers, affecting their own well-being.

How is a carer for a child defined?

A carer for a child is anyone who provides primary or secondary support to a child who has a disability, illness, mental health concern or other physical or mental condition. A child can be any age. This guidance is not for a parent of a child who does not have additional needs.

For further information visit:

https://www.carersuk.org/wales/help-and-advice/practical-support/arranging-care-and-support-for-someone/support-when-caring-for-a-child/

Identifying as a carer

On average it takes 2 years to identify as a carer. Carers of children often fail to recognise the additional support they're providing their child, seeing it as part of their normal duty as a parent. Initially identifying themselves as a carer is often the first barrier in terms of getting support.

Carers of children who have an obvious genetic disability or disorder, or have an accident that changes their cognitive or physical abilities, are often funnelled directly into a path of identification while those with children with hidden disabilities face a struggle in terms of:

- raising the subject with professionals
- waiting lists for diagnosis
- the disappointment of seeing their child miss key milestones
- having to explain to family about their child's disability
- difficulty connecting with other parents

"As soon as the leukaemia was diagnosed, I was immediately given information on support groups in and out of hospital. I was also given info on where I might some financial support"

"no one believed us when [our son] didn't sit up at the right time. It was always 'be patient'. 'Oh, Little boys take a bit longer'. We could see it, couldn't we, but no one would see it"

Getting recognised

If your child is missing milestones such as walking or talking, you should be communicating this with your paediatrician. This does not mean your child has an illness or condition but this can be an early sign of a difficulty they may face in later life.

If this is the first indication, then this is also the first opportunity to start becoming more aware of your rights as a carer and your child's rights as someone who needs more support.

Reach out to charities specific to carers like Carers Wales and to condition specific charities if you have a suspicion you know what condition your child might have.

After diagnosis

If your child does receive a diagnosis, then you should inform your family, your GP and start communicating with their school.

You should also ask for the latest information from carers charities and condition-specific charities, so you have the latest information on your rights and what you are entitled to as a carer of a child.

Challenges of caring for a child or children

Getting support from school

Carers of children tell us that they encounter obstacles in accessing appropriate support from schools and understanding the structure of educational assistance for their children. Teaching staff may lack knowledge, leading to delayed intervention and support. Transitioning from mainstream to specialist schools can pose a challenge, and many parents felt overwhelmed navigating the educational system.

> “When he started school, he was still unsteady on his feet. We told the school this but they said he would learn. It wasn’t until the start of Year 2 that they asked us in for a chat and then started talking about support”

Common concerns included:

- Difficulty accessing information on support for disabled children in mainstream schools
- Difficulty accessing information on specialist schools
- Difficulty understanding the structure of support and how it is funded
- Lack of knowledge from teaching staff
- Lack of interest from teaching staff
- Complexities of missing a lot of school due to disability
- Difficulty in transferring from mainstream to specialist school
- Understanding that education lasts much longer
- Accessing later life education

Accessing support from your child’s school

Gaining access to additional support for your child is a step-by-step process.

It can be a frustrating, sometimes long-winded but ultimately rewarding process of getting the right building blocks in place so your child can excel to the best of their abilities. What excelling looks like is completely different for each child.

The first step is to communicate with the School:

- Request a Meeting: Arrange a meeting with the school's Special Educational Needs Coordinator (SENCO) or the headteacher to discuss your child's needs and the support available.

- Provide Information: Share detailed information about your child's condition, including any medical reports or educational assessments, to help the school understand their needs.

For further information visit:

carersuk.org/wales/help-and-advice/factsheets-and-guides/our-factsheets

This should lead to one or multiple of these scenarios:
Individual Education Plan (IEP):

- Work with the school to develop an IEP, which outlines specific learning goals and the support your child needs to achieve them. This plan should be reviewed regularly.

Special Educational Needs (SEN) Support:

- Ensures that your child is receiving SEN support if they have been identified as needing additional help. This may include tailored teaching strategies, classroom aides, or specialized equipment.

Education, Health, and Care Plan (EHCP):

- If your child's needs are more complex, apply for an EHCP through your local authority. This plan provides a comprehensive outline of the education, health, and social care support your child requires.

These processes will put in support for your child. This could be a teaching assistant providing additional support as part of a group, this will be define as 1 to a number of students. This could be 1 to 1 support where your child gets personal support from one teaching assistant all to themselves.

For further information visit:

https://www.gov.wales/guide-parents-about-rights-under-additional-learning-needs-aln-system-html

These support plans can support in other ways. They may need a quiet room for when they get overwhelmed, more time to do work if they struggle to concentrate or additional food or drink breaks if they need to eat or drink for medicines.

The system in Wales is student led and their needs should be accomodated to support them having the most success they can within their schooling time.

You can gain further support through:

School Policies and Resources:

Access Policies: Familiarise yourself with the school's policies on inclusion and support for children with disabilities.

Support Services: Inquire about available support services, such as counselling, speech therapy, occupational therapy, and after-school programs.

Parent Carer Support Groups:

- Join Groups: Connect with local parent carer support groups or organisations which can provide advice, support, and advocacy services.
- Network: These groups often have valuable insights into navigating the education system and accessing available resources.
- Education Authority: Contact your local authority for information on additional support services and funding options available for children with disabilities.

Family Information Services: Utilise family information services offered by local authorities to find out about local support groups, respite care, and other services.

Financial Assistance:

Grants and Benefits:

Explore potential financial assistance options, such as Disability Living Allowance (DLA) for children and Carer's Allowance for parents, which can help with the additional costs of caring for a disabled child.

Mental Health and Wellbeing:

Support for Carers:

Take care of your own mental health and wellbeing by accessing support services for carers, including counselling and respite care, to ensure you can continue to provide the best care for your child.

Disability Rights and Advocacy:

Know Your Rights:

Familiarize yourself with your child's legal rights under the Equality Act 2010 and the Special Educational Needs and Disability (SEND) Code of Practice.

Seek Advocacy:

If necessary, seek advocacy support from organizations such as the Disability Law Service or SNAP Cymru to ensure your child receives the appropriate support and accommodations.

Accessing Social Services support

Parent carers often struggle to access social services support due to availability of services, lack of information, and funding limitations. Coordinating support between social services and schools can be a significant challenge. Many parent carers feel overlooked and underserved by social services, relying instead on sporadic assistance from charities.

Many parent carers report a lack of understanding of what is a parents responsibility and what is a carers responsibility and have indicated that there is a lack of services specifically for parent carers.

Common issues:

- Getting social services to talk to their child's school
- Understanding that parents as well as their children need support
- Lack of information on what type of support is available
- Lack of funding

> "I just get signposted to charities and those disappear after like a year"

> "Don't make me laugh. [Carer's Needs Assessments] aren't worth the paper they are written on. I was told 'our need is not enough for support'"

Support for you

Remember that when caring for someone else, you have to be well yourself otherwise you are unable to continue supporting your loved one.

Use this section to quickly find some support for you or look at the Carers Wales Looking After Someone Guide as a great starting point for finding about unpaid care in Wales.

Know Your Rights:

Familiarise yourself with the Welsh Government Charter for Unpaid Carers in Wales. This document outlines your legal rights under the Social Services and Well-being (Wales) Act 2014.

Seek Information:

Your local authority must provide information, advice, and assistance about support services. Make use of this resource to find and access the services available to you and your child.

Request an Assessment:

You have the right to a carers' needs assessment. This assessment helps identify the support you need and how the local authority can assist you. It is not affected by your financial situation, but you may be asked to contribute to the cost of support.

Advocate for Your Voice:

During the assessment, express what matters to you as a parent carer. Your input should influence decisions about your support. Link to self advocacy guide

Early Intervention:

Seek support from your local authority as early as possible as there can often be a wait to be assessed.

Explore Financial Assistance:

Apply for grants if available. Speak to your local carers support service or use a tool like Turn2Us grant search.

Connect with Support Groups: Join local support groups or online communities.

Connecting with other carers can provide emotional support and practical advice.

Stay Informed:

Keep up-to-date with any new support packages or initiatives.

Relationship strain

Anyone with a child knows that their relationship with their partner changes intrinsically. However, the challenges of having a child with a disability can strain a relationship in unique and devastating ways that cannot be foreseen.

Despite these challenges, many couples find strength in their relationship through mutual support, understanding and sharing the caring experience.

Commons issues are:

- Mourning the loss of a future for your child
- Mourning your own future
- Stress
- Loss of personal time

> "My ex couldn't look at our children anymore. I hate him for leaving but even I know his heart broke every time he looked at them. He never sees them. Don't think he can cope"

> "Not sure we're very healthy [together] but we make it work. We do have long times not talking though. Especially when things are tough. You just don't see the others [viewpoint] when you're too involved.

> "We're stronger together but only when we realized we had to make time for fun stuff. It was great to re-find ourselves"

Mourning the dream

It is healthy to mourn your preconceived hopes for your child and the experiences you had hoped to share. For some, this was looking forward to standing on the side of a sports field cheering your child on.

For others, it can be sharing academic or artistic goals that they may no longer be able to practically achieve.

Every disability or illness is different and every person who reads this will have their own imagery of what they will miss out on.

It is extraordinarily difficult to admit this to yourself and even harder to share with your partner. However, they too will be mourning their hopes and expectations.

Sharing this loss and feeling this sorrow is not an admittance of defeat but a chance to bond further with the person who will go through these upcoming challenges with you.

Time to recalibrate

Admitting that there is loss and grief from the mourning of a dreamed future means you can also come together and start building a different dream for your child and yourself.

Often this is celebrating the challenges they overcome whether it be in line with everyone else or when they are ready. This can be their first word, toilet training or learning to make themselves a sandwich.

These successes are just as impressive as another child excelling at their ability level and you should proclaim your pride just as loudly.

There are also plenty of opportunities for your child to be involved in activities now, and in the future.

As they grow, find out what means the most to them and make that part of your plan. All parents find their children have a mind of their own and do what is right for them. A child with an illness or disability isn't any different and you still get to go on the most exciting ride of your life learning and growing with them.

Once the mourning is over, it's about finding the fun and excitement wherever possible.

Staying connected

The additional strain of someone with extra need can put more pressure on a relationship. You are likely to find you have less time as your child needs more direct input, the cost of caring for someone is higher and the decisions you are making can be more frequent and high stakes.

> "My child sings their feelings with Disney songs. We've been able to use this to find out how they are and connect in ways we never thought possible"

Communication

All good relationships are centred around good communication.

Getting in front of a potentially hurtful or distressing situation gives you chance to consider the potential problem and allows both sides to think about what is important to them. This also means taking time to talk and listen. If one side is doing all the talking, it may seem like you have come to an agreement but the other side may simply not be engaging or not listening properly. This can escalate a small concern into something far more painful.

It is also okay to disagree. This is when talking is most important. Sometimes this means discussing things over several occasions or asking for people who you both respect to have an opinion to help guide both of your thinking.

Most importantly of all, it has to be about all aspects of your relationship. It is incredibly easy to make your whole world your child even when they do not have additional needs so many carers of children fall into this issue. Sometimes you have to remember, even when tired, aggravated and lost that you love your partner and talking about your shared or individual interests was how you connected in the first place.

So many who contributed to this guide said remembering to find a part of themselves that wasn't a carer was the key to staying connected.

Learn and lean into your individual strengths

Caring for anyone who has additional need is a tsunami of new learning. Caring for a child with extra needs exacerbates this as they are continuously learning, achieving and changing so what is right for them is in constant flux.

Both partners have to find ways to be involved and be part of their child's lives. It is unfortunately common for one side of the relationship to lead on the caring side which can turn into resentment towards the other partner. Less well known is the other partner can feel boxed out from their child as they do not know how to get involved and can feel resentment for not having the opportunity.

Ideally, start with a plan and make sure both partners are doing all elements. Often partners have confided that they find they are naturally gifted at different elements and the sharing of care naturally develops.

“My husband has always needed less sleep than me so he was always the one to get up at 5 and do the morning shift. I was better rested and it gave me more tolerance for his need to have the occasional ‘him’ day”.

If one side of the partnership starts to take on the lion's share of responsibility, talk to each other. It may be appropriate at the time due to work commitments, other caring responsibilities or other outside influences.

However, this doesn’t mean this should stay as a permanent state of affairs.

Keep communicating, making sure both are involved, even on a conversational level for the short time and, as life evolves, find ways to come back together and share the care again.

Find ways to be kind to each other

From coming home with a favoured treat to securing time so the other partner can do a club or activity, acts of kindness between you will help strengthen your relationship through the most trying situations.

Your lives are busy so there is often less opportunity to do the bigger shows of love so doubling down on small acts of love means all the more.

> “My partner will do our lunches before work. Never says anything. Just there ready for me. It means waking up a few minutes early but it means the world to me”

Find ways to have fun together

One of the biggest difficulties is the lack of time to spend as a couple. Often children with additional needs require you to be near them at all times and do not have the sleeping patterns to steal time together after they go to bed.

It is also more difficult to find people to take care of your child, whether that be family or professional, as your child or the babysitters may not be capable.

This often means finding other ways of having fun around them. This can be done in any number of ways.

Some people listen to podcasts, either together or independently, so they can discuss them with each other around their child's needs.

Others do puzzles or word games that be picked up and put down around their caring role.

These shared experiences keep a connection and will be unique to the two of you.

When the chance to have alone time does occur, it's also vital for both parties to do everything in their power to grasp the opportunity.

Sadly, these can be infrequent so the extra effort both sides put in should mean all the more.

Remember it's difficult for both of you

It doesn't matter how old your child gets, there will be times when their disability or the situation you find yourself in, can get you down. This may happen at the same time but often happens individually.

It's okay to ask for extra help and you need to listen when your partner requests the same. It may not even make sense to you. Different people will have different triggers. It can be difficult to find empathy when these situations occur especially when they seem inconsequential to you.

You are a partnership so, sometimes, one side has to pick the other up. If you feel like they are not reciprocating, then you need to communicate this with your partner. Perhaps they have not realized how strongly they are relying on your strength and do not see that you are in need of some of theirs.

Just remember you are in this together.

There is no one perfect way to deal with relationship strain. Ultimately, you have to work on this alongside your caring role and trust in your partner to put the effort in as well.

Puberty

Parent Carers can struggle with a lack of guidance and support when navigating their child's puberty, leading to feelings of inadequacy and frustration.

Communication barriers with professionals and discomfort discussing sensitive topics often exacerbate parental stress. Concerns about their child's mental health and well-being during puberty were prevalent in the carers we spoke to.

Common issues were:

- Lack of information
- Lack of comfort when talking to professionals
- Lack of comfort talking to family
- Idea that they are doing something wrong or illegal
- Depression and other mental health conditions

> "I never find anyone to give me advice how to cope"

> "I was told they wouldn't notice and then my GP just closed down the subject"

How to approach puberty

Puberty is often a taboo subject for many carers of children. There can be a lack of guidance and support navigating this delicate situation which can lead to feelings of inadequacy and frustration. Children with illnesses or disabilities may experience puberty in different ways which further complicates matters.

This does not mean they do not experience body changes, sexual desires or social or physical awkwardness but they may interpret these feelings in different ways. This is particularly common for children on the autism spectrum who's bodies may be more disrupted by hormone imbalances that can lead to depression or hyper activeness.

How to approach puberty

There isn't a single way to approach puberty with a child with an illness or disability. You are the best person with the best place judgement of what they are and are not ready to understand and cope with.

These guidelines should be considered with your best judgment.

Be upfront about the changes ahead

Puberty is something that, without medically needed intervention, is going to happen to your child. Hiding this fact will not help the process.

Within your child's understanding, start introducing the idea of changes before puberty begins so the idea and any questions can be answered before the process unsettles them further

Don't be afraid to answer questions

Your child is going to be experiencing many new feelings and desires. They may not know how to deal with these appropriately or rationally. The best way to support them is to be open and honest.

A child with additional needs who is discovering masturbation may need to be taught about privacy. Equally, they may need to be retaught about boundaries, especially as peers will also be developing at the same time.

It is far better to discuss why these behaviours should be conducted in a certain way than to try and discourage or excuse them which will only alienate them from their peers.

You can also reinforce this by your own actions. For instance, asking to hug them as a prompt on touching or knocking on their bedroom door before entering to teach them about privacy. These actions can support your child in learning how to cope with their new reality.

Be judgement free

All teenagers are curious, push boundaries and make mistakes.

Having a disability does not prevent this. Stay calm when these lapses of judgement occur and use them as learning experiences.

Be matter of fact if an error has caused hurt to another or they have put themselves in harm and make sure they understand their error if punishment is appropriate.

It is important that they continue to trust you so you can support them through this transition.

Anger, sadness and hyperactivity

Many children with illnesses and disabilities can react in a more extreme way to the hormonal imbalances of puberty.

This can lead to emotional swings but is often most notable as a combination of anger, sadness (or depression) and hyperactivity.

If your child is showing these signs, you need to speak to your doctor or paediatrician as there may be underlying causes that need medical attention.

What if I have concerns?

If you have any concerns whether they be behavioural, emotional or physical you must get medical support through your doctor or paediatrician.

You should also speak to your social work team if you have one and the school. It is much easier to approach this as a whole than to try and solve any concerns on your own.

Transition into Adult Care

Parent carers can often feel fear and uncertainty regarding the transition from children's social services to adult services. A lack of information, poor communication, and fear of losing vital support services can be major concerns.

It may be helpful to know that there is no single point of transition. The change from childhood to adulthood services should be a gradual one.

Ideally, the transition should begin during your child's early teenage years.

> "I don't even know when the switch might happen. Was put on notice at 15 but not sure if it will happen today or when he's 18. My friends son didn't transition across until 19"

They should be supported by a named worker who should consider what support they will need as part of a review including:

- your child's health
- their emotional and communication needs
- their mental capacity (ability to make their own decisions)
- any peer support, coaching or mentoring they need
- their ideas and plans for the future
- any advocacy needs.

> "The unease crosses the whole family. The change effects us all."

Your child should be as fully involved as possible about any decisions related to their future aspirations and needs.

You should also be able to have a say and play a central role in decision making as their carer or parent.

Your local council has a duty to help prevent your own needs from escalating so that you can continue your caring responsibilities if you want to.

Continued Education

Every local authority has a duty of care to provide young people up to the age of 25 with special needs support if required.

In schools, children who need extra help with learning should have additional support in the form of a development plan. You can work with the school to help develop an appropriate plan for your child to help them reach their potential.

When a child is about to turn 16, the local authority should prepare a pathway plan to help that young person with the transition to adulthood. The pathway plan is designed to build upon the child's existing care and support plan.

Continuing Health Care

Applications for support in the form of adult Continuing Health Care support or adult social care funding can be made from the age of 17, although the process of transition can begin from 16 or earlier.

It is important to be aware that the transfer of support will not happen until the individual turns 18. The child will need to be assessed by health and social care professionals to see if they are eligible for this support.

Preparing for care away from the home

Parent carers often struggle with the complex decision of transitioning their adult disabled children into independent living or long-term care. Concerns about losing connection with their children and a mistrust of care services are common. Discussion around care options, involving family members, and creating transition plans are essential but can be challenging.

Common issues include:

- Lack of knowledge on what options there are for adults who aren't able to care for themselves
- Distrust in the system that they will get the care they require
- Concerns of losing the connection with their child
- Concerns around what access they would have to their child
- Concerns around cost
- Concerns around medical knowledge

> "Already have mine going to a residential twice a month. I want them to know I am not the only person to support them"

Parent carers have told us:

Whether independent living for a child is appropriate depends on the child and the parents.

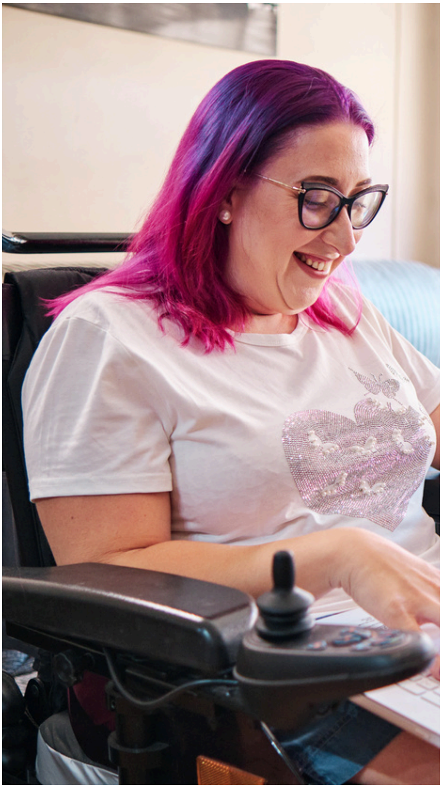
- How will the child cope?
- How will the parents cope if they stay and if they go?
- What other family members might this effect?
- Age, illness and other factors should also be considered

All adult children should be introduced to independent living / respite early on so they get used to and even excited about their 'holidays'

How someone should be cared for should be discussed on a frequent basis

If anyone in the family is expected to help, this should be discussed with them and a new plan has to be formed if they choose to opt out

A transition plan should be made when the carer gets to a certain point of age, to ease the transition of the child.



Tips for parent carers

Caring for a sick or disabled child can be physically and emotionally demanding. It's crucial to prioritise your own well-being to continue providing the best care for your child. This section offers practical self-care tips, resources for mental health support, and strategies for managing stress and burnout.

1. Seek Support Groups and Networks:

Join local support groups and networks specifically tailored to carers of disabled children. These groups provide a supportive environment to share experiences, seek advice, and access valuable resources.

2. Advocate for Improved Services:

Collaborate with other carers to advocate for improved services and support systems for disabled children and their families. This can include lobbying local authorities and policymakers for better access to education, healthcare, and social services.

3. Utilise Available Resources:

Familiarise yourself with available resources, such as Carers Needs Assessments, support organisations, and online platforms offering guidance and information for carers. Stay informed about eligibility criteria and application processes to access necessary support.

4. Build Relationships with Professionals:

Foster positive relationships with healthcare professionals, educators, and social workers involved in your child's care. Effective communication and collaboration can facilitate access to appropriate services and support.

For further information visit:

https://www.carersuk.org/wales/help-and-advice/your-health-and-wellbeing/me-time-sessions/metime-sessions/

5. Educate Yourself:

Take advantage of training workshops, seminars, and online courses aimed at enhancing your knowledge and skills in caring for disabled children. Empowering yourself with relevant information can help you navigate challenges more effectively.

6. Prioritise Self-Care:

Make self-care a priority by carving out time for relaxation, hobbies, and social activities. Remember that taking care of yourself is essential for maintaining your well-being and resilience as a carer.

7. Seek Financial Assistance:

Explore financial assistance options available to carers, such as carer's allowance, disability benefits, and grants. Understanding your entitlements and accessing available financial support can alleviate financial strain.

For further information visit:

https://www.carersuk.org/wales/help-and-advice/financial-support/

8. Peer Support:

Connect with other carers through peer support initiatives, where you can share experiences, offer mutual support, and exchange practical tips for coping with the challenges of caring for disabled children.

9. Stay Informed and Proactive:

Stay informed about policy changes, developments in disability rights, and opportunities for advocacy and activism. Being proactive in staying abreast of relevant issues can empower you to advocate for change and contribute to improving the support available to carers.

For further information visit:

https://www.carersuk.org/wales/help-and-advice/guides-and-tools/being-heard-a-self-advocacy-guide-for-carers/

10. Access Respite Care:

Utilise respite care services to take breaks from caring responsibilities and recharge. Respite care can provide you with much-needed rest and relaxation while ensuring your child's needs are still met.

For further information visit:

https://www.carersuk.org/wales/help-and-advice/your-health-and-wellbeing/taking-a-break/

Support from Carers Wales

Carers Wales, part of Carers UK, is here to listen, to give you expert information and advice that's tailored to your situation, to champion your rights and support you in finding new ways to manage at home, at work, or wherever you are.

Every day, Carers Wales hears from people who need help with looking after a friend, family member or partner.

They might be new to caring and struggling with navigating the maze of services or they may need extra support to cope with the pressures of caring.

They may be wary of accessing service or not feel supported by the community in which they live.

Having the right information at the right time can make a huge difference for the carer and the person they care for.

Our 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 and factsheets offer the help you need:

carersuk.org/wales/help-and-advice/

If you are new to caring and don't know where to turn first, using our free online tool, Upfront will point you in the right direction.

Upfront is an online tool that gives you your own personalised guide to caring.

As well as covering practical and financial support, it includes information to help with managing the impact of caring on health and relationships:

carersdigital.org/upfront/

Join Carers UK

However caring affects you, your partner or your family, we are here for you. By joining Carers UK, you can be part of a supportive community and a movement for change, working together for a society that respects, values and supports all carers.

carersuk.org/join

Our main guide to caring is called Looking after Someone, and it contains a wealth of information and support for carers, including an overview of the support that may be available to carers in Wales: https://www.carersuk.org/wales/ looking-after-someone. This guide is also available in Welsh and a number of other languages.

carers
WALES

In Wales, in a typical week there are 311,000 people looking after family or friends who are older, disabled or seriously ill.

However caring affects you, we’re here.

For information and tailored support, contact the Carers UK

Helpline:
E: advice@carersuk.org
T: 0808 808 7777

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