

Caring for a parent

Information and support for carers in **Wales**

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About this guide

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

Unpaid carers looking after their parents in Wales can face a multitude of challenges that can significantly impact their lives. These challenges arise from the increasing complexity of parents' needs as they age, compounded by systemic issues within the healthcare and social care systems.

One of the primary challenges is the demanding nature of caring responsibilities. Many carers find themselves providing long-distance care whilst attending to the physical, emotional, and medical needs of their parents.

As well as juggling relationships with their other family members. This constant demand can lead to exhaustion, stress, and burnout among carers, affecting their own well-being.



For further information visit:

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



Identifying as a carer

On average, it takes 2 years to identify as a carer. Carers of parents often fail to recognise the additional support they're providing for their parent, seeing it as part of their normal duty as an adult child. Coming to see themselves as a carer is often the first barrier to accessing support.

Of course, for some people, they become carers for their parents much younger in life. If a parent has a long-term health condition like MS or mental health issues, they should be identified by the system earlier and given clear access to support paths.

“I thought of doctors and nurses when I thought about caring. It's only when I was stopped and considered what I did for my father-in-law did it click”

“We didn't talk about what we were doing for mum. It just was a bit more each time until we were never not there”

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Getting recognised

Often the first challenge for a carer of a parent is being recognised by the parent or parents. The next section of this guide discusses changing roles and how to discuss this with your parent and other members of your family.

When you and your family are comfortable with the caring situation, you need to consider who else may need to know and recognise that you need additional help. A good place to start is the GP as you may need more support from them during your caring role. Many surgeries will also have a Carer champion or Carers Support Service.

You should also consider speaking to your local authority. The local authority can supply you with information and advice, tell you about access to community support and provide a Carers Needs Assessment if, and when, your caring role needs more direct support.

You should also consider talking to your employer if you are employed. You have rights within employment law and you may have further contractual support which could mean you do not need to take holiday time to get to appointments or emergencies. It also means your employer has a duty to consider how they can be flexible to support your caring needs and stay in work.



You can find out more about getting a carer's needs assessment by visiting our website:

<https://www.carersuk.org/wales/help-and-advice/practical-support/carers-needs-assessment/>

Challenges of caring for a parent

Discussing a parent's needs

Becoming ill, developing a disability or simply being less able than you once were can be frightening, frustrating and anger-inducing. Whenever talking to a parent about elements of their lives that are now more restrictive, you need to be sensitive as well as honest about what they need in terms of support to live their most fulfilling life.

It is extremely difficult to look at a parent differently and often an illness or disability causes this to happen.

Carers said that they:

- Felt upset by how small their parents now appeared
- Wished they still had the same protection as when they were younger
- Didn't know how to communicate as effectively with their parent
- Were concerned about the potential of their parents being taken advantage of



Changing roles

Caring for a parent often means stepping into a new and unfamiliar role, one that can challenge the usual balance of the parent-child relationship. The people who once raised and cared for you are now the ones in need of your care and support.

It is difficult for both the parent being cared for and the child providing care to accept this change. Many of the carers we spoke to actively pointed out that this was a significant part of the challenge in getting support for themselves and their parent.

“My mum still wakes up early every morning in case she needs to make me breakfast before work. She hasn’t made my breakfast for 40 years”.

“He just plain refused. He thought I should just do it because I was his daughter”

“I had to pretend that I was living just after the war as my mum wouldn’t believe what year it was. Shingles and dementia brought about a whole make-believe world”



Getting support to help you care

Talking about providing care with a parent

We should all talk about the future and the possibility of care as soon as possible.

Understandably, most of us do not want to think of our parents as weaker or in need of support.

The earlier you have the conversation, the easier it is to manage - without the added emotional weight that often comes with a diagnosis or declining health. Yet, for many of us, that conversation only happens once the caring role has already begun.

It's important to choose a moment when everyone is relaxed, has time to talk, and doesn't feel caught off guard.

Having the conversation in a private setting can also help ensure that everyone feels comfortable speaking openly.



For more advice on talking to others, see our self advocacy guide:

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



Talking about providing care

If your other parent, siblings, or partner will be helping to care for your parent or supporting you as the primary carer, they should be included in the conversation.

Even if they don't have much to contribute at first, involving them helps ensure they feel informed and included - which can strengthen your relationships as a family.

Even if your other parent, siblings, or partner won't be actively involved in providing care or supporting you, it's still important to talk to them about the situation.

They need to understand the role you're taking on and how it affects your relationship with your parent.

They may want updates or more information and some may even choose to become more involved.

Giving them the opportunity to understand the situation helps avoid confusion and builds a shared sense of support.



Understanding medical issues and decisions

For many carers looking after a parent, understanding medical terms and what they mean is a major challenge.

It's common to feel overwhelmed by unfamiliar terminology and unsure about what it means for your parent now and in the future.

This can be especially difficult in the early stages of your caring role, when you may not be present at medical appointments and information isn't being shared with you directly.

It's important to understand your parent's specific conditions and the medications they're taking to manage them.



What to do?

Agree expectations with your parent

The first step is to talk with your parent about their wishes. Many parents are reluctant to share their vulnerabilities with their children but without the right information, it's much harder for you to make informed decisions and provide effective support.

If your parent is willing for you to be involved, you need to agree on what you are to be involved with.

Both you and your parent need to be comfortable with what you will know and how much time this will take.

The better you understand the condition, the more you can do to support your parent. If something doesn't seem right and you're concerned, go back to a professional.

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Going to appointments can be time-consuming and emotionally difficult for both parties. However, once you have discussed this, the process becomes much easier.



Never be afraid to ask more questions

To support your parent, especially if memory is a concern, you need to understand what you are being told. Never be afraid to ask the doctor to explain something again or explain it in a simpler way.

Common terms

Arthritis

Arthritis is a common condition that causes pain and inflammation in a joint.

Different kinds of arthritis and related conditions have different types of treatment. Understanding the type of condition will help support the parent you care for.

Hyperglycemia, Hypoglycemia and similar conditions

This is when the sugar in a person's blood gets too high or too low. Most commonly associated with diabetes, this and similar conditions can affect older people for a variety of reasons.

A condition like this is the most common type of illness that may require you to inject your parent with medication.

Being older

This is a catch-all term for a person getting older and having medical complaints that do not have an obvious cause. This can be a cause but if you have concerns, push for a reason behind the condition.

Dementia and other memory conditions

Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning. There are many different causes of dementia, and many different types.

Depending on the type of dementia, the progression and effect of the illness can change radically.

You should request more specific information on the type of dementia to better understand what to expect in the future.

Hearing and Sight loss

Hearing and sight loss are common in older people. Both have causes ranging from the easily fixable to the permanent loss of one or both senses. Pushing for the root cause rather than accepting this as a diagnosis can often create a better standard of life for your parent.

Loss of Mobility

Mobility problems may present as unsteadiness while walking, difficulty getting in and out of a chair or falls. There are common conditions in older people that can contribute to mobility problems, such as muscle weakness, joint problems, pain, disease, and neurological (brain and nervous system) difficulties.

Shingles

Shingles is an infection that causes a painful rash. Easily treatable and with an available vaccine, this condition can commonly interact with other health conditions in older people.



For further information visit:
<https://apphelp.nhs.wales/help/abbreviations-commonly-found-in-medical-records/>

Support in the home

As people get older its common for them to have multiple conditions which affect them, often creating a more complex situation for the person caring for them.

As soon as a parent has more than one condition, you need to discuss this with anyone else providing care for your parent.

Often this is a sign that the situation has changed significantly and care needs will require reassessment. See more about types of care later in the booklet.

Getting extra support set up at home for someone you care for can be challenging.

- They may resist the idea of accepting help outside of the family or having 'strangers' coming into the home environment.
- The prospect of change may seem daunting to them
- They may feel like they're giving up or losing more of their independence

How do I convince them to accept some extra help?

One way of approaching this is to suggest small changes or even a trial run and then support could gradually be built up as time goes on.

Helping the person you look after feel as involved as possible in the decision is important – as well as indicating that you need some extra help and support yourself.

Emphasising how the extra help could help you as a carer might help to convince them.

Having someone from outside of the family to provide care may also give them more independence.

Private or council support?

Agreeing on a plan of action thus considering the pros and cons empowers everyone to gain the correct support.

What is council support?

Council support is when the person you care for has a Disability Needs or Care Needs Assessment from the Local Authority to see what support they might need to continue living safely and happily at home.

These 'eligible needs' will form the basis of what support is offered and what services become available to you. This is called a care plan.

A range of topics can be included in the care plan, for example

- in-house support (which may happen once a day or multiple times a day)
- access adaptations to the home so they can move around more easily
- transport so they can access community services.

When a care plan is written, the wishes of the person who is receiving care must be taken into account. This includes cultural and other needs.

When a council and person getting support agree a care plan, this is offered to private companies who will bid to take on the contract.

Once this has been agreed between the private company and the council, the support should begin.

Cost

In Wales, local authorities use a means test to decide how much someone should pay towards their home care.

This test looks at a person's income, savings, and capital—but there are important rules to protect people from paying more than they can afford.

Capital and Savings

If the person receiving care (your parent, for example) has less than £24,000 in capital or savings, this amount is fully disregarded in the financial assessment.

That means it will not count towards how much they're asked to pay. Their home is also excluded from the means test for non-residential (home) care.

However, if they have over £24,000, the local authority can charge them up to the maximum weekly amount of £100, regardless of how much the services actually cost.

Income and Minimum Income Guarantee

Even if someone has less than £24,000 in savings, any income they receive will still be taken into account. That said, Welsh Government guidelines require that people receiving care are left with a minimum level of income to live on.

This is referred to as the Minimum Income Amount.

As a result, people are only asked to contribute what the means test shows they can reasonably afford. For example, if their assessed contribution is £25 per week, but the total cost of services is £70, they will only pay £25. In many cases, people may not be charged anything at all.

Couples and Joint Assets

If your parent is part of a couple, the financial assessment will only consider their own income and assets. However, joint savings or capital are assumed to be shared equally—unless there is evidence showing a different ownership split.

Maximum Weekly Charge

No matter what services are provided—or how many are used—the maximum charge for home care is capped at £100 per week under Welsh regulations. This applies even if someone has high levels of savings or income.

Limitations

One of the biggest limitations of council support is that you are unable to choose your provider. This often means as a carer, you need to monitor the service being provided and check that all the elements of the care plan are being enacted.

If the provider is not providing the support required, you have to first complain to the service provider and then, if the situation has not been rectified, complain to the council who can then choose to move or end the contract. This process can be time-consuming and a little disheartening.

If you need to make a complaint, see our complaints guide here: [carersuk.org/wales/help-and-advice/practical-support/arranging-care-and-support-for-someone/making-complaints/](https://www.carersuk.org/wales/help-and-advice/practical-support/arranging-care-and-support-for-someone/making-complaints/)

You may also find that there are some limitations on what the care worker can and can not do. For instance, some care workers are unable to provide medication or support someone to take medication.

This may mean that, despite having a care package, you still need to be there so your parent takes their medication.



Another limitation is that council systems are often less reactive to changes to the support your parent might need. If, for example, they have a fall and are in need of more care, the entire process of getting another care plan has to happen before permanent changes can happen.

For what can happen for short term changes of need, please see the coming out of hospital guide here:

<https://www.carersuk.org/wales/help-and-advice/practical-support/coming-out-of-hospital/>

Direct payments

You can take control of the type of care your parents receive by taking the support via direct payments.

Direct payments for the person being looked after commonly ongoing payments used to employ a care worker or personal assistant to help with their day-to-day needs or for a period of respite care.

These payments are usually an alternative to having those services provided directly by the council

A great resource for finding out more about care in the home for an older person is Age Cymru's guide 'Paying for care and support at home in Wales' which can be found here:

<https://www.ageuk.org.uk/globalassets/age-cymru/documents/information-guides-and-factsheets/fs46w.pdf>



NHS continued Health Care (CHC)

If your parent is ill or frail enough, they may be eligible for NHS-backed Continuing Health Care (CHC). This is a separate set of requirements and assessments from council-led support.

Someone eligible for CHC support is most likely to require professional 24-hour support in a care home setting. However, it is possible to care for someone in the home with CHC support.

You should carefully consider if this is right for you as the threshold for someone to get CHC support is very high therefore the level of care needed to support that person is also going to be very high.

Is this support available if my parent lives with me or moves in with me?

A person's need is assessed on their condition and what is available to them. There is no reason someone would be penalised by living with or moving in with a family member.

However, what type of support someone gets also depends on the expectations of what care they already receive.

For more on CHC:

<https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/>

If your parent says they do not need support washing because you will do it, it is highly likely this will not be considered a need and that support will not be granted.

You as a carer have the right to refuse to provide care if you are not willing or able to do so however that is not always obvious if you are volunteered into a role without your agreement.

What is private support?

Private support is when you or your parent go directly to a care at home organisation/agency and ask for support to begin for your parent.

This may be done after a care plan has been drawn up by the council to decide support should be provided or decided independently between your family and the agency depending on what you would like and your budget.

You can find providers on the Care Inspectorate Wales website:

<https://www.careinspectorate.wales/find-care-service>



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Cost

Care in the home can cost an average of £21 – £39 per hour depending on where you are in Wales.

This can vary according to your needs, for example, more specialist care may cost more, and some people with higher needs require multiple paid carers.

While visits are usually charged by the hour, most companies can be flexible offering half-hour visits or 15-minute visits, depending on the provider.

This is most commonly paid for each month but can be arranged weekly or fortnightly. There is no limitation to how much private care may cost.

Limitations

The primary limitation is often availability. Especially in rural areas, there is a lack of people able to provide the support required which leads to prices increasing and limitations on service provision.

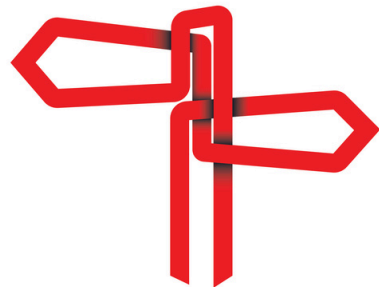
Price is also a concern for most people. Private support is significantly more expensive than council driven support where the limit is £100.

There is no limit to the cost of private support. In fact, it is not uncommon for most people to spend between £500 to £1100 per week on private support.

If you pay for private support and it doesn't live up to expectations, you are still able to complain to the agency providing care and then the Care Inspectorate Wales if they do not fix the issue.

You can find out more about complaints with our guide:

<https://www.carersuk.org/wales/help-and-advice/practical-support/arranging-care-and-support-for-someone/making-complaints/>



Live in care

Live in care is when you pay for someone to live with your parent or parents as a job.

This is usually through a private arrangement with a company or becoming an employer to pay for the care worker as an employee. Due to this private agreement, you and the person you employ can agree on the times they are available, what they are expected to do and how they will be compensated for their time.

Cost

A live-in professional care worker can cost around £900-£1400 per week on average depending on where you live in Wales. They are also not expected to contribute to council tax or bills when living with the person. You are still able to claim the council tax discount with a live-in care worker.

Costs can be higher than this depending on the type of care that is needed, with more specialist live-in care costing upwards of £3000 per week.

Limitations

Availability is the most common limitation, and this also pushes up costs as demand exceeds supply.

There is also the added responsibility of the legal requirements of having someone working and living in your parent's home. You are still paying for them to have a contracted amount of time working.

You cannot exceed employment law for working over the agreed hours and you may also have to negotiate different rates for day and night support despite where they reside.

You also need to consider the extra paperwork and responsibility of being an employer.



Other types of support in the home

Sometimes direct support is not needed by your parent or parents. However, there may be tasks that they cannot complete that they or you wish to pay to be completed.

Cleaning services

The most common services are cleaning services. This can range from cleaning the home to laundry services that take clothes and/or bed linen away to be cleaned.

This can cost anything from £25 to £70 depending on service level and location.

Gardening

Another common service is to commission a gardener or ground-clearing company to keep the garden tidy.

This has been shown to have positive effects on mental health for older people if they can access open, outdoor spaces easily.

Gardening services and costs vary depending on the size of the garden and the work needed.

It is common for the first service to be more expensive if they are clearing away a garden that has not been tended for some time.

Activity or community centres

There are a numerous activities and community centres for older people to get together across Wales.

Many have special facilities or days for people with specific illnesses or conditions and their carers to meet others in a similar situation.

To find a community centre near you, try www.dewis.wales

Grants and funds

Caring often brings unexpected costs and it can be difficult to make ends meet, especially if you have had to give up work or reduce your hours to care.

Some organisations and schemes can offer grants to carers who are facing particular financial difficulties. They could vary from enabling you to purchase certain disability equipment to taking a much-needed short break away.

Try Turn 2 Us for the best place to find grants and funds:

www.turn2us.org.uk/



Support in a residential or care home

Sometimes the amount of care your parent needs is higher than you or your caring circle can provide. There are numerous reasons for this. Sometimes the care need is too high, your parent is too isolated or their accommodation is no longer suitable for them amongst many other reasons.

It is not a failure to decide that your parent needs more help than can be provided at home and that residential or nursing care would be the best option for them.

What is the difference between a residential care home and a nursing care home?

The primary difference between a residential care home and a nursing care home is that a nursing care home always has a fully qualified nurse on site.

A **residential care home** is for people who only need assistance doing everyday tasks such as eating, washing or dressing. They still have 24-hour care provided for them.

A **nursing care home** is for people who have greater medical needs and need regular support to have treatment or have complex needs that require multiple people to support them.

Nursing care homes are significantly more expensive. The easiest way to define what type of care home your parent needs is to have a needs assessment through your council.



Where to find information

The best place to find information about care homes is via the Care Inspectorate Wales website. The Care Inspectorate Wales are the organisation in Wales that registers, inspects and takes action against care homes if they fail to live up to the organisation's standards and practices.

You can find an entire list of Care Inspectorate Wales approved homes here:

<https://www.careinspectorate.wales/find-care-service>

Talking to a parent about moving into a care home

It is an incredibly delicate subject talking about someone leaving their home and you have to be gentle when approaching the subject.

Sadly, many people get to breaking point before the subject is ever brought up.

It is completely natural to want your parent to stay close to you and to provide for them. Therefore, it is very difficult to admit the situation and can be even harder for the parent getting support to admit it.

“He just had to go. I wasn't able to care for him in the way he wanted or, to be completely honest, needed and it broke me inside”

In the same way you discussed caring for someone you need to

- Find a time where you are all relaxed
- Find a time when you can all have the conversation without time restraints
- Make sure you offer options and not make demands
- Enable everyone with a stake in the conversation to be involved.

Am I still a carer if someone moves into a care home?

Yes, even though your parent is getting support in a care home you are still providing some unpaid care for the person you care for.

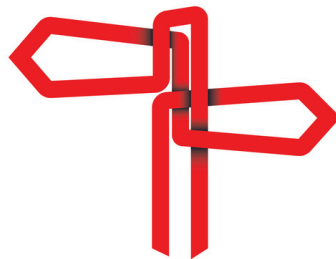
The type of care has likely changed though with more emphasis on emotional and financial support than physical care.

However, you can no longer claim Carer's Allowance or the care element of Universal Credit if someone goes into a care home as you are no longer satisfying the 35 hours per week care threshold of those benefits.

Cost

The cost of a care home can be significantly different depending on the level of care required and the scarcity of places available in your local area.

On average, a residential care home will cost anything between £800 and £1500 per week while a nursing care home will cost between £1000 and £2000 per week.



For more information, see our 'When Caring Ends or Changes' guide: <https://www.carersuk.org/wales/help-and-advice/practical-support/when-caring-ends-or-changes/>

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 use our Looking After Someone Guide as a starting point.

Know Your Rights:

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

<https://www.gov.wales/charter-unpaid-carers>

Seek Information:

Your local authority must provide information, advice, and assistance about support services.

Make use of this service to find and access the services available to you and your parent.



Request information and support:

Your council has to give you information and advice on what support is available to you in your community.

You can also ask for a Carers Needs Assessment if, and when, you need more personalised support.

<https://www.carersuk.org/wales/help-and-advice/practical-support/carer-s-needs-assessment/>

Advocate for Your Voice:

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

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

Early Intervention:

Seek support from social services/local authority as early as possible

Explore Financial Assistance:

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

<https://www.turn2us.org.uk/>

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. by becoming a member of Carers Wales

<https://www.carersuk.org/wales/get-involved/join-us/become-a-free-member/#>



Managing a parent's affairs

One of the most common issues affecting carers of parents is managing the financial or medical decisions of the person they care for.

There are different ways of looking after someone's affairs and these can be organised at different points of a caring journey.

If someone can make their own decision currently, you can

- Create a third-party agreement (mandate)
- Become an appointee
- Get ordinary power of attorney
- Get lasting power of attorney

If someone is unable to make their own decision now, you can

- You can become an appointee
- Become a court appointed depute



For more information, see our webpage:

<https://www.carersuk.org/wales/help-and-advice/practical-support/different-ways-of-managing-someones-affairs/managing-someone-s-affairs-england-and-wales/>

Work and care

People caring for a parent are twice as likely to be in full-time employment compared to those caring for a partner or child. This is often because they don't live with the person they care for and may also have children of their own. As a result, they are typically financially responsible for more people than most other types of unpaid carers.

Your rights

As a working carer, you have rights from two sources: The law gives you 'statutory rights' which everyone has. Your contract of employment gives you 'contractual rights' which can be more generous than statutory rights.

In essence, these rights are:

- The right to request flexible working
- The right to unpaid carer's leave
- The right to time off in emergencies
- Protection from discrimination



For a far more in-depth look into your rights as a working carer, see our working carers guide and employment hub:

<https://www.carersuk.org/wales/help-and-advice/work-and-career/carers-in-employment-hub/>





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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This guide is designed to provide helpful information and advice. While we work to ensure that our information is accurate and up to date, we would recommend contacting the Carers UK Helpline or visiting our website for more information.

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