

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 help you.

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

One of the primary challenges is the complexity of caring responsibilities. Many carers find themselves providing distance caring, while still attending to the physical, emotional, and medical needs of their parents and juggling relationships with the person they care for and 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 a child. Initially identifying themselves as a carer is often the first barrier in terms of getting 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 conditions, 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 confronted about 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. The next section of this guide discusses the changing roles of caring for a parent and how to discuss this with your parent and other members of your family.

When you are comfortable with this situation, you need to consider who else may need to know and recognise that you need additional support. A good place to start is the GP as you may need more medical support due to your caring role.

You should also consider speaking to social services. You can get a Carers Needs Assessment whether the person you provide care for gets any assistance or not.

You should also consider talking to your employer if you are employed. You have additional rights within employment law and may have further contractual support which means you do not need to take holiday time to get to appointments or emergencies. It also means your employer can be more flexible with your needs to support you to stay in work.



You can find out more about getting a carer's needs assessment by visiting our pages on carers assessments here: www.carersuk.org/wales/help-and-advice/practical-support/carers-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 to their pride as well as honest about what they need in the way of support to live the most fulfilling life possible.

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

Becoming a carer for a parent is the ultimate shift in power across any social dynamic. The people who raised you to the person you are, are now the person in need of that care and attention.

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 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.

However, the sooner the conversation happens, the easier it is to deal with without also considering the additional emotions of a condition or conditions they are facing. However, most of us only have that conversation after the caring role has begun.

So it is important to choose a moment where the situation is relaxed, all parties have time to discuss everything and nobody feels ambushed. It's also a good idea to have this in a private setting so no one is concerned by eavesdroppers.

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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 is part of the parent in needs life, you have siblings or a partner who will be providing care for your parent or be actively supporting you as a primary carer, they should be included in the conversation with the parent. They may have little to add to the initial conversation, but their inclusion will make sure they feel involved and informed which, will strengthen your connections as a family.

It is really important they understand what you are doing and how you are now involved in your parent's life. They may want more information or to be kept updated. They may even choose to get more involved. You need to give them the option of understanding the situation.

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If your other parent, siblings or partner will not be actively involved in the care or supporting you to care, you still need to have conversations with them about the situation.

It is really important they understand what you are doing and how you are now involved in your parent's life. They may want more information or to be kept updated. They may even choose to get more involved. You need to give them the option of understanding the situation.



Understanding medical issues and decisions

For many carers of parents beginning their caring role, it was getting to grips with medical terms and what this means for their parents was the first hurdle of their caring role. It is not uncommon for carers to feel overwhelmed by the different names and what this means now and in the future.

This can be particularly tricky at the early stages of a caring role when you, as the carer, are not necessarily in those medical appointments so the information is not being explained to you directly.

It is important to understand the direct conditions your parents have and what medications are being taken to help control those issues.



What to do?

Agree expectations with your parent

The first thing you need to do is discuss what your parent's wishes are. Many parents will not want to share their weaknesses with their children however you are not empowered to support them if you are not given the correct information that allows you to make smart decisions.

If they are not willing to share these medical concerns, you have to forgive yourself if the medication process goes wrong. You can provide support without the right information.

If your parent or parents are 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. 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 word it in different ways.

The better you understand the condition, the more you can do to support your parent. If you're concerned, go back to a professional

Often a doctor or other medical professional gives you an explanation and everything falls into a new pattern of normal. However, sometimes, what has been said does not tally with what is actually happening.

If this is the case, go back to your GP or, if you have the ability to, the professional you last spoke to. Sometimes a series of conditions can present similarly but need different types of treatment. If it doesn't seem right, then ask.

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 be 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 creating unusual scenarios as a carer.



For further information visit:

Support in the home

Unfortunately, as people get older, they become far more likely to have multiple conditions affecting them at once. This often means one condition can inhibit another one from getting treated or create a far more complex caring scenario.

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 some 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 this kind of change could feel like a big step in their eyes, or an act of giving up 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 this support could gradually be built up as time goes on and trust builds.

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.

The emphasis on how this could help you could go some way to helping to convince them. As many people fear losing independence, it might also help to explain how this could help them live more independently.

Private or council support?

The choice of private or council support is up to your parent or parents receiving care and you and the other people caring for them. It is often best to have a discussion around the prospect of paying for care and agreeing on a plan of action while carefully considering the pros and cons. This guide will explain the basics here.

What is council support?

Council support is when the person you care for has a disability needs or care needs assessment 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 in the care plan from in-house support which may happen once a day or multiple times a day, to access to adaptations to the home so they can move around more easily, to 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 environmental needs.

For instance, someone with a religious belief that a person from another gender may not see them naked can request to only have assistance being cleaned by someone of their own gender.

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

Depending on your financial situation, you may or may not have to pay for council-provided support. This will depend on the financial situation of your parent or parents.

A capital limit of £24,000 is applied regarding people's savings and assets. Your home will not be taken into account. Any capital or savings you have below £24,000 has to be fully disregarded as part of the means test.

Authorities can only charge service users a maximum of £100 per week for home care regardless of which services they receive and regardless of how much you have in savings.

If you are in a couple, the financial assessment will only take into account your assets, but this does include capital that is shared between you and your partner, which is presumed to be shared equally until evidence proves otherwise.

If you have less than £24,000 in savings or assets but have an income, this income will be taken into account when determining if you need to contribute to your care and how much.

Welsh Government guidelines specify that you must have a minimum level of income to live on, so you will pay however much the means test determines you can afford.

For example, if the services you are offered may have cost £70, they may only cost you £25. In many cases, they may not charge you at all.

If your capital is over £24,000, the local authority can charge you the maximum amount for the services (up to £100 per week).



However, this does not mean you will automatically be charged £100 per week – if the service they provide you costs less than £100, for example £50, then that is how much you'll be required to pay.

Limitations

One of the biggest limitations of council support is that you are unable to choose your provider. This often means 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 pull the contract. This can be time-consuming and a little disheartening.

On the other hand, if the service you require costs more than £100 a week, say £110, the maximum amount you would have to pay would still be £100.

There is a cap in Wales of £100 a week for home care. The local authority will pay for the rest.

If you need to make a complaint, see our complaints guide here: <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 the council system is 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/>

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>

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 are more 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

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



Find out more about Direct payments here:

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



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 for support 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 with the council has happened as a template for what 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>

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.

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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 requiring multiple paid carers.



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.

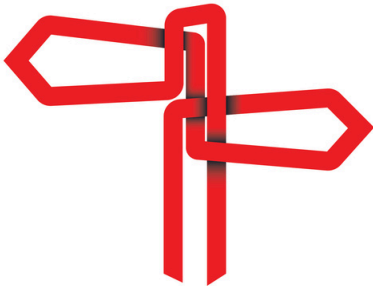
If you pay for private support and it does live up to expectations, you are still able to complain to the agency providing care and then the Care Inspectorate Wales if they do not fix the issue.

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/>

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/global/assets/age-cymru/documents/information-guides-and-factsheets/fs46w.pdf>



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 as only so many people want this type of work. This also pushes up costs as demand exceeds supply.

There is also the management 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 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 and they or you wish to pay to be completed.

Cleaning services

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

This can cost anything from £10 to £50 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 mental health ramifications for older people if they can access open, outdoor spaces easily.

Gardening services start at £25 and costs increase depending on the size of the garden and the desired effect.

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 activity and community centres for older people to get together and commune across Wales.

Many have special facilities or days for people with specific illnesses or conditions while most cater for these conditions every day.

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 assess that your parent needs more help than can be provided and a new place to live is best 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 our parents to stay close to us and for us to provide for them. Therefore, it is 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, just because you have someone getting support in a care home, you are still providing some unpaid care for the person you care for.

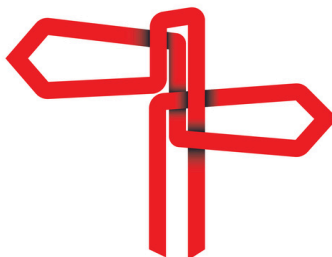
The type of care has likely changed though with more emphasis on emotional and financial support than physical care.

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 quality and the 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 quick find some support for you or look at the Looking After Someone Guide as a great starting point for finding about unpaid care in Wales.

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 resource to find and access the services available to you and your parent.



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.

[Link to our guide/webpage](#)

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 social services/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. For example??



Managing a parent's affairs

One of the most common elements of care, carers of parents spoke about was managing the financial or medical decisions of the parent they cared for.

There are different ways of looking after someone's affairs and these can be sorted out 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

You are twice as likely to continue full-time employment as someone who cares for a parent as someone who cares for a partner or child. There are a large number of factors that affect this including that most people who provide care for a parent do not live with that parent, a care of a parent has additional familiar responsibilities such as children of their own which, in turn, leads them to be financially responsible for more people than the majority of other types of unpaid carer.

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

This guide was proudly supported by



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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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