



# Caring for adults with ME

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# Becoming a carer

Husbands, wives and partners often find themselves in the role of primary carer when their 'other half' becomes ill. Or you may find yourself in a caring role for your sibling, parent or child (of any age) with ME.

It can take time for you to adjust to the changes in your relationship and to understand and accept the limitations and fluctuations in the health of the person you're caring for.

Work might be affected and if so, your financial situation (see below) may also change.

Please don't doubt yourself or the person you care for just because other people may be ill-informed about the condition.

The lack of awareness and knowledge about ME among some health and social care professionals means that accessing the right support can be challenging. This means having resources to self-manage symptoms is essential.

Carers have talked to us about how important [pacing](#) is not just for their loved ones with ME but also for them as carers.

Pacing is a self-management technique that aims to balance energy and rest – and caring is a role that takes a lot of energy.

Combining knowledge, skills and strategies to inform your daily and weekly routines, pacing aims to make things more manageable.

Tips shared include:

*"Go back to basics. Do activities for a small amount of time and then stop."*

*"Don't let your battery run down: stop well before energy runs out."*

*"Accept that sometimes you need to cancel plans on the day as the price you pay later will be too much."*

Of all the challenges faced by people with ME and those who care for them, it's the lack of understanding about ME and its impact that they tell us causes the most problems.

This can come from professionals, the public and even friends and family.

Misunderstanding and disbelief can create a real sense of grief and bewilderment for someone with ME, which takes a toll on those supporting them.

When people with ME and carers contact Action for ME, they often tell us they feel a sense of relief and validation. They feel seen and heard, not doubted or judged.

Our [Information and Support Service](#) team can share information and self-advocacy resources that you and/or the person you care for can use to help professionals better understand what you need, including the adjustments you are entitled to.

## Looking after yourself

As [Carers UK](#) says: "Caring can be extremely rewarding, but there's also nothing more challenging than focusing on someone else's needs without neglecting our own. Whether caring around the clock, or balancing caring with work and family life, it can be exhausting."

Carers of people with ME have told us the importance of prioritising what is meaningful for them – what gives you pleasure, fun or joy? This can be looking out at nature, stroking a pet, listening to music.

They also talked about the challenges of being expected to respond positively to suggestions other people make about improving your situation – however well-intentioned – and instead, working with where you are now.

Acceptance is hard. It can look like surrendering to your current circumstances – but it's not about giving up responsibility, rather a conscious decision to make choices and let go of what no longer works for you and/or the person you care for.

This includes your own or others' expectations and standards that are no longer realistically achievable.

It's important that you let your GP know you are a carer as they may be a useful source of information about medical and community services and support, including priority flu vaccination.

If you become unwell, your GP needs to know that this could impact the person you care for.

Connecting with other carers to share experiences, feel heard and know that you are not alone can be valuable.

Carers UK offers [a range of online meetups](#) for carers to get together and enjoy relaxing activities.

## Getting a carer's assessment

Carers UK advises: "Getting a carer's assessment could be the first step to gaining vital support. It's your chance to discuss the help you need as a carer. Find out how it could make life easier for you and the person you care for.

In Scotland, this is usually referred to as an adult carer support plan and in Wales, it is often called a carer's needs assessment."

For more information on carer's assessments and other support in each region, visit:

- England - [www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers](http://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers)
- Scotland - [www.gov.scot/policies/social-care/social-care-support/](http://www.gov.scot/policies/social-care/social-care-support/)
- Wales - [www.socialcare.wales/](http://www.socialcare.wales/)
- Northern Ireland - [www.nidirect.gov.uk/articles/arranging-health-and-social-care](http://www.nidirect.gov.uk/articles/arranging-health-and-social-care)

The person you care for may also be entitled to [social care support](#) from the local council.

It may be worthwhile checking on the services that could provide urgent care, if you're unable to care due to illness or an accident.

Carers UK has [useful information](#) on planning for emergencies, including where to find local practical support.

## Work and finances

Millions of people in the UK now juggle their unpaid caring responsibilities with paid employment, which can be very challenging.

Carers UK offers [detailed information](#) on carers' rights at work, including flexible working, taking time off and protection from discrimination.

[Carer's Allowance](#) is one of the welfare benefits for people who are giving regular and substantial care to disabled people.

Carer's Allowance is a taxable benefit and forms part of your taxable income. Citizens Advice has guidance on this and other welfare benefits in England, Scotland, Wales and Northern Ireland.

[Turn2us](#) is a national charity providing practical help to people who are struggling financially. They offer a welfare benefits calculator and information about grants you might be able to apply for.



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