Caring for Caregivers

ME Association and 25% ME Group- May 2026

Introduction

Providing care to someone with severe or very severe ME/CFS can be both challenging and rewarding. It can feel isolating, and particularly if you are new to caring for someone with severe ME/CFS, daunting. 25% ME Group and ME Association recognise the value and importance of unpaid carers in supporting people who have severe and very severe ME/CFS. We would like to thank all those unpaid carers who support people with severe ME/CFS.

We have many carers who form part of our membership. Often, you are parents of a severely affected member, but we also have spouses, sons, daughters and siblings who care for a family member with severe ME/CFS; some of you care for more than one family member. We know many of you have been providing a high level of care for your loved one for many years with some of you providing around the clock care. We know within your role as the carer of a loved one you often wear many hats, providing personal care, emotional support and advocating for the person you care for.

In order to better capture the current experiences of unpaid carers of people with severe and very severe ME/CFS, the 25% ME Group and the ME Association ran focus groups covering healthcare, social care and caring in general, in 2024. As we find when working with people with severe ME/CFS, the carers were keen to share their experiences to aid and inform others. The information they provided and experiences they kindly shared have been invaluable in the production of this booklet.

This booklet has been produced to address the lack of resources available for carers of people with severe ME/CFS. It aims to put the information carers, particularly of people with severe and very severe ME/CFS, need in one comprehensive resource.

Definition of an Unpaid Carer

An unpaid carer is defined as anyone who provides care, unpaid, to another person who due to illness, disability, long term illness, mental health problem or an addiction cannot cope without their support. Neither the number of hours nor the types of tasks undertaken by the carer makes them an unpaid carer.

Some carers do not feel they meet the criteria to be a carer and have not been identified as such by health and social professionals. As such they become 'hidden carers.'

The Financial Impact of Caring

In 2025 Carers UK estimated there are 5.8 million unpaid carers, 3 million of whom provide over 35 hours a week of care. In 2023 the economic value of the contributions made by carers in England and Wales was £162 billion per year. https://meassociation.org.uk/ehd3 That is 29% more in real terms than in 2011. This is equivalent to the annual amount spent by the UK Government on the NHS.

Unpaid carers save the UK taxpayer a huge amount of money every year. Because of their efforts, the burden on social care and the NHS is that much less.

Despite the massive contribution and the huge financial saving unpaid carers provide to the economy Carer's Allowance is the lowest benefit of its kind at only £83.30 per week (financial year 2025/2026) for providing a minimum of 35 hours per week, pushing many carers into poverty.

Many unpaid carers do not feel valued or supported in the role they provide. Carers UK found that 90% of carers do not think Carer's Allowance offers sufficient financial support. https://meassociation.org.uk/ccsy Furthermore, Carers UK found that 1.2million unpaid carers live in poverty.

Many carers do not provide the 35 hours a week to meet the criteria and as such do not receive state support.

The Caring Penalty

It is recognised that unpaid carers face a 'pay penalty' for taking on caring responsibilities.

In 2023, The Joseph Rowntree Foundation estimated that unpaid 'social-care givers' (those who care for someone that is sick, disabled, or elderly) experience an average pay penalty of £414 per month (nearly £5,000 per year) reaching £628 per month (nearly £8,000 per year) after six years of providing unpaid care.
By the end of the sixth year, unpaid social-care givers will have foregone a cumulative total of more than £30,000 in gross pay on average.

These penalties are driven by carers leaving paid work and reducing their hours after they start providing care, set against the increases in pay that they would have otherwise experienced.
The caring penalty falls disproportionately on women and households in poverty.

The Impact of Caring

Being an unpaid carer can impact many aspects of the carer's life, including health, wellbeing, finances, employment/career opportunities and social/family life. A combination of these factors can impact on life choices. For example, the loss of identity and financial security when having to leave a career. The loss of identity was something raised by the focus group. Caring can also be rewarding; improving someone's quality of life is fulfilling.

NICE has produced guidance entitled *Supporting Adult Carers* (NG150). It covers support for adults who provide unpaid care for someone who is over 16 years old. It encompasses many aspects of caring including carers' assessments, practical, emotional and social support and training. It aims to help health and social care practitioners identify people who are caring for someone and give them the right information and support. We recommend unpaid carers read it, if they haven't already, and discuss it with the relevant professional.

Registering as a Carer with Your GP Practice

When you become an unpaid carer, it can be helpful to register as such with your GP Practice. It means that they are aware of your situation and can respond accordingly.

How to Register

1. **Contact your GP Surgery:** Speak to reception or the practice manager to let them know you're an unpaid carer.
2. **Fill out a Form:** You'll be asked to complete a simple form to be added to the practice's Carer's Register, a confidential list of patients with caring responsibilities.
3. **Use a Template Letter:** If you prefer, Carers UK offers a downloadable letter to send to your GP. See https://meassociation.org.uk/qcmv

Benefits of Registering

- **Flexibility:** More flexibility with appointments and repeat prescriptions.
- **Health Support:** Access to free flu jabs, COVID-19 vaccinations, and annual carer health checks to monitor your own physical and mental wellbeing.
- **Information & Advice:** Get relevant information and advice about your caring role and local support services.
- **Contingency Planning:** Allows the surgery to consider the person you care for if you become unable to do so.

A Carer Passport

A Carer Passport is a document or electronic record designed to quickly identify unpaid carers, allowing them to access support, services, or workplace flexibility. They are used in workplaces, hospitals, and communities to document necessary support and improve recognition, particularly for combining employment with care.

If the person you care for is in hospital and you have a Carer Passport you may be able to-

- continue to provide some of the care
- stay with the person outside visiting times
- have access to free or discounted parking and/or meals at the hospital

You can apply for one via your local council or carers support group.

For further information see https://meassociation.org.uk/1kjz

A Carer's Assessment

A Carer's Assessment, known as an Adult Carer Support Plan in Scotland, is undertaken by the local authority at the request of the unpaid carer.

A GP can refer you, or you can contact the local authority yourself. An unpaid carer is entitled to a carer's assessment regardless of whether the person they care for is in receipt of care from social services or NHS Continuing Healthcare.

A carer's assessment assesses **the impact** caring has on the unpaid carer. A carer's assessment looks at the care you provide, its impact on you and all aspects of your life including physical, emotional, work and relationships and looks at ways you can be supported. It also looks at the things you would like to be able to do in your day-to-day life.

https://meassociation.org.uk/1loz

Carers can be offered a range of services including-

- A home care worker to sit with the person with severe and very severe ME/CFS to enable you to go out. It is worth asking for this to be flexibly diarised. This can be either arranged and paid for by the local authority or via direct payments. If the direct payment option is chosen a separate bank account will be needed. Note the money you receive to buy care in may not cover as much care as a set number of hours funded directly by social services.
- Carer respite where a person goes into a care home or carers come to look after the person with ME to give the unpaid carer a longer break.

In addition, through the carer's assessment, you may be eligible for money to spend on jobs you would previously have done yourself around the house and garden including gardening and cleaning. Money to cover this is usually provided as an annual lump sum. You will need to open a separate bank account for this money to go into. Receipts have to be provided to the local authority to show how the money is being used. **This is not means tested.** If you are using an agency to do the jobs, ensure the local authority is told as they pay a higher rate for agency cleaners etc.

During a carer's assessment the local authority can make sure you are receiving the correct benefits and signpost on for further support if necessary.

Note if the person you care for needs change, eg post hospital admission, you can ask to be reassessed.

If the person that you care for is in receipt of NHS Continuing Healthcare funding or starts to receive it this will not affect the support you receive via your carer's assessment; you remain eligible for this.

Resources

https://meassociation.org.uk/gxg0

The 2022 National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care has a section on supporting unpaid carers https://meassociation.org.uk/ntza

Health and Wellbeing

Taking Care of Yourself

Self-care is paramount for carers. Due to the demands of caring, it is imperative to take care of your physical and mental health. 'Carer strain' is common among unpaid carers. Being time poor can lead carers to neglect their own health. This can also be coupled with financial stress.

The Care Act (2014) recognises that carers should be protected just as much as the people they care for, and it states that local authorities have a duty to protect carers, including their wellbeing.

NICE Guidance 150 *Supporting Adult Carers* outlines how health and social care professionals should support unpaid carers.

Physical Health

Maintaining good physical health is important and time spent doing an enjoyable activity can reduce stress. If you would like to do an activity but are not able to leave the person you care for to do so, consider asking your local authority to provide care during this time when you have a Carer’s Assessment.

Good moving and handling techniques help to prevent injury to the carer particularly when caring for people with very severe ME/CFS who are bedbound. Aids such as slide sheets can make moving and handling easier. An occupational therapist based with the local authority social services can do a home visit to assess what aids and adaptions might benefit you and the person you care for. Moving and handling courses for carers may be available.

Wellbeing

Many carers feel isolated and stretched either in their caring role or financially or a combination of both. Since the Covid pandemic we are aware of carers who have further limited their social contact, including with family members living outside the household, due to the risk of infection to the person with severe ME/CFS.

A lack of time to participate in non-care related activities may also impact a carer’s wellbeing. If you are short of time, even just standing in the fresh air for a few minutes can help you destress.

As has been mentioned carers may have to take on additional roles on top of providing care such as advocating for the person, managing their finances, applying for benefits on their behalf etc. There are forums where you can talk with other unpaid carers and share experiences. Local authorities usually have a carers’ group which anyone providing unpaid care can attend.

At 25% ME Group carers of people with severe or very severe ME/CFS can add their details when the person with severe ME/CFS joins, and be added the contact list to find other carers in similar situations. Carers have said this has helped them feel less alone in their caring role. It can also be a good way to share tips. Carers can also be on the 25% ME Group closed Facebook page.

Some of our focus group found other support networks, including from members of their church, beneficial. In some cases, the support was online. Our focus group found trying to continue doing things that they enjoyed prior to becoming a carer beneficial.

Some of the carers in our focus group had received counselling; either on their own or with their family/the person whom they care for. This was often to deal with situations that had occurred in the past relating to the person with severe ME/CFS. The carers felt counselling was more beneficial when the counsellor understood ME/CFS.

The GP can refer a person for counselling, or a person can also self-refer using Improving Access to Psychological Therapies (IAPT). MEA, Action for ME and 25% ME Group advertise counselling from people who understand ME/CFS. If you feel that you are struggling or that your mental health is suffering it is worth contacting your GP to discuss it.

Volunteering was also felt by our focus group to be beneficial. It serves as a change of scene doing something enjoyable, and friendships/support networks are often formed.

Guilt was a theme that came through in the focus group; particularly guilt around enjoying activities that the person they care for could no longer enjoy. However, the person receiving the care had typically told their unpaid carer not to feel guilty and to enjoy themselves.

Resources

NICE Guideline 150 *Supporting Adult Carers* https://www.nice.org.uk/guidance/ng150

Financial Support

Citizens Advice and Carers UK have detailed information on their websites about the financial support available to unpaid carers. They also have dedicated telephone lines to provide advice.

In brief-

Carer’s Allowance

Carer’s Allowance is payable to people who-

- Provide a minimum of 35 hours a week of unpaid care to someone.
- The person they care for must be in receipt of Personal Independence Payment (PIP) Daily Living Component or Disability Living Allowance (middle or high rate care) or Constant Attendance Allowance
- Are not in full time education- (classed as study more than 21 hours per week)

If you have been caring prior to applying for Carer’s Allowance, it can be backdated up to three months.

Carer’s Allowance isn’t **means tested** nor dependent on National Insurance contributions. However, it does provide Class1 insurance contribution credits. https://www.gov.uk/carers-allowance/eligibility

Carer’s Allowance and State Pension

Once pension age is reached carers cannot get the full amount of their state pension and Carer’s Allowance. If their state pension is over the amount for Carer’s Allowance their Carer’s Allowance will be stopped. If the pension being received is under the Carer’s Allowance threshold the difference will be made up by Carer’s Allowance.
https://meassociation.org.uk/mw3q

Devolved Nations

Scotland

Carer's Allowance is currently being replaced by Carer Support Payment in Scotland, but the amounts are the same. https://meassociation.org.uk/0i7z

Northern Ireland

For information on Carer's Allowance go to https://meassociation.org.uk/qwx8

Carer's Credit

Carer's Credit is available for people who provide care for more than 20 hours a week. Carer's Credit is a National Insurance credit that helps with gaps in your National Insurance record. Your State Pension is based on your National Insurance record. You do not get any money from Carer's Credit, rather National Insurance Stage 3 contributions are made so that your pension does not suffer as a result of caring. Carer's Credit is not means tested. People who claim Carer's Credit can also be working.

Means tested Benefits

Universal Credit (UC) is a means tested benefit available to people on low incomes and now encompasses other benefits including income support, housing benefit and working/child tax credits. https://meassociation.org.uk/4uvd

Carer's Premium

Carer's Premium forms a part of Universal Credit and can be claimed alongside Carer's Allowance. It can be included as part of other benefits including Universal Credit and housing benefit. An amount equivalent to the Carer Premium is used to calculate Pension Credit.

Resources

Citizens Advice

England and Wales https://meassociation.org.uk/938h

Telephone- England 0800 144 844

Telephone Wales-0800 024 1220

Scotland https://meassociation.org.uk/nmwh

Telephone -0800 023 2581

Northern Ireland https://meassociation.org.uk/ml32

Citizens Advice https://www.citizensadvice.org.uk/

Financial information

https://meassociation.org.uk/uaqc

Money Helper: Benefits you can claim as a carer- https://meassociation.org.uk/uaqc

Age UK- Carer’s Allowance https://meassociation.org.uk/g7i1

Other Financial Support for Carers

Other schemes which financially help unpaid carers include-

- Council Tax reductions- As a carer it is worth noting if the unpaid carer and the adult receiving the care are the only adults living in the property the carer is discounted meaning that the property is eligible for the 25% single occupier discount. The property is also eligible for a reduction in the council tax banding if a reception room is used as a bedroom or there is a room dedicated to therapy.
- Not paying car tax- if the car is registered in the disabled person’s name or if the registered owner of the vehicle uses the car for the disabled person who is in receipt of higher rate Disability Living Allowance (DLA), Enhanced Rate of the mobility component of Personal Independence Payment (PIP), Child Disability Payment (CDP), Adult Disability Payment (ADP), Scottish Adult Disability Living Allowance (SADLA) you are entitled to free car tax. If the person gets the standard rate mobility component of PIP you can apply for a 50% reduction in your council tax.
- People with severe ME/CFS may be in receipt of enhanced rate mobility PIP or high rate mobility DLA. This entitles them to a car via the Motability scheme. Under the scheme insurance, servicing and MOT and breakdown cover is provided free of charge**. However, the persons mobility component of PIP or DLA will be paid directly to the scheme.** Unpaid carers can drive them with the permission of the person in receipt of the benefit. However, it may not work out as the most cost-effective way to afford a car.

Carers Experiencing Financial Hardship

Grants and schemes are available to support people experiencing financial difficulty. As outlined previously, many households with a person with a long-term condition, such as severe ME/CFS, and an unpaid carer experience financial difficulty. Such grants and schemes factor in that a person is an unpaid carer.

Household Support Fund or Welfare Fund.

Each council has a Household Support Fund or Welfare Fund. This can provide support for essential purchases e.g., purchasing a cooker. It can also help to pay utility bills. This does not affect your entitlement to benefits.

Support with Utilities

Support with utility bills is available for people who are on means tested benefits.

Warm Home Discount

This is available to people on Universal Credit or the Guaranteed Element of Pension Credit and is worth £150. The energy supplier usually deducts this from the bill.

In Scotland you will need to apply for the Warm Home Discount.

Warm Home Discount- https://meassociation.org.uk/i4s6

Warm Home Discount-Scotland https://meassociation.org.uk/9vqj

Broadband Social Tariffs

Most Broadband providers provide a social tariff for people on means tested benefits. Social tariffs are cheaper broadband and phone packages for people claiming Universal Credit, Pension Credit and some other benefits. Prices per month range from £10-25.

Broadband Social Tariff https://meassociation.org.uk/iesi

Priority Registers

People with disabilities and long-term health conditions who rely on electricity, gas or water to meet their needs, for example for medical or mobility equipment, can go onto the Priority Services Register. **This is not means tested as it is a free service.** For example, if there is a power cut the person will be kept up to date automatically as to when power will be restored. The electricity supplier might supply the person with a generator if the electricity is going to be off for some time. Contact the energy supplier to join the Priority Services Register. Resources

Priority Services Register https://www.thepsr.co.uk/

Priority Services Water https://meassociation.org.uk/3bqh and https://meassociation.org.uk/jvm0

Household Support Fund https://meassociation.org.uk/u4ht

Working and Caring for Somone with Severe or Very Severe ME/CFS

Unpaid carers can find it very challenging to juggle employment with a caring role, for others caring for someone with severe or very severe ME/CFS will mean that employment is not sustainable. Some of our focus group had given up paid employment to provide full time care for the person with severe or very severe ME/CFS. Others welcomed the break from caring that paid employment provided. A sense of identity was closely linked to undertaking paid employment.

For carers wanting to continue with paid employment guidance is in place to support them.

The NICE Guideline, *Supporting Adult Carers*, recommends that 'Workplaces should offer flexible working arrangements to enable staff to balance caring responsibilities with work.' (NG150, 1.4.6)

The UK's Carer's Leave Act 2023 grants eligible employees the right to take up to **five days of unpaid leave per year** to provide or arrange care for a dependant with long-term care needs, effective from April 6, 2024. It offers legal protection against dismissal for taking the time off. This leave can be taken as full or half days, doesn't require evidence, and applies from day one of employment, though employers can postpone it if it disrupts business.

Working and Claiming Carer's Allowance

When claiming Carer's Allowance in the UK, you can work, but your **net earnings must not exceed £196 per week** (after tax, National Insurance, and half your pension contributions are deducted), and you must still provide **at least 35 hours of care** per week for the disabled person. You can also deduct certain care costs (for someone other than a close relative) and work-related expenses (like tools) from your earnings, which helps you stay under the limit.

Key Earnings Rules

- **Earnings Limit:** £196 per week (for 2025/26) after deductions.
- **Deductions Allowed:** Income Tax, National Insurance, half of pension contributions, and certain care/work expenses.
- **Care Cost Deductions:** You can deduct payments made to someone (not a close relative) to look after the person you care for or your other children (under 16) while you work, up to half your earnings.
- **Fluctuating Earnings:** If your income varies, the DWP can average it over a period (like 5 weeks) to check if you're within the limit.

Key Caring Rules

- **Care Hours:** You must spend at least 35 hours per week caring for someone who receives a qualifying disability benefit.

- **Care Activities:** This includes physical help, emotional support, and practical tasks like cooking or shopping.

Other Important Points

- **Work-Related Requirements:** Claiming Carer's Allowance usually exempts you from job-seeking activities.
- **Support at Work:** You can request flexible working or time off for emergencies, and you can apply for respite care for the person you look after.

Carers can work part-time but must balance their work hours and earnings with significant caring responsibilities to remain eligible for Carer's Allowance.

Resources

The right to flexible working https://meassociation.org.uk/flw1

The right to time off to care for dependents- Employment Act 1996
https://meassociation.org.uk/6xjd

Carers Leave Act 2024 https://meassociation.org.uk/611m

Being Paid to Look After a Family Member

It is becoming increasingly possible to be paid by the local authority to look after a disabled family member. In order for this to happen the person you are caring for needs to have had a social care assessment to ascertain their care needs and be given direct payments to purchase their own care.

Historically it has often not been possible to be paid to provide care for a family member, particularly if the carer and the person being cared for lived in the same house other than in exceptional circumstances. These included when there was no viable alternative available or for cultural or religious reasons. A parent might be able to be paid direct payments to care for their child because of the child's welfare.

Today, Carers UK says 77,00 carers receive direct payments to care for a family member.

It is worth noting that when you care for someone with severe or very severe ME/CFS, due to the very specific set of needs, such as only being able to provide care in very short sessions or the need for continuity of care in order to preserve existing low energy levels, it might be argued that a family member living with the person is the only viable way to meet the person's care needs.

In Wales, people can use direct payments to pay family members. Part 4 Code of Practice the Social Services and Well-being Act (Wales) 2014, paragraph 165 says: "providing safeguards are in place the employment of a relative living in the same household is often the most suitable way of providing care."

Before looking at being paid to care for a family member it is important to consider how entering into an employment contract might affect the relationship between you and the person you care for.

Forward Planning

A number of older carers, including those in our focus group, are worried about what would happen to the person they care for when they are no longer able to do so. Some people have found a benefit in integrating care support from the local authority which has enabled them to train home care workers to provide appropriate support for the person with severe or very severe ME/CFS when needed.

Lasting Power of Attorney

Some of the carers in our focus group stated that the person they cared for had taken out a lasting power of attorney (LPA).

There are two types of LPA; one for property and finance and one for healthcare and you can use both. These are legal documents enabling the person with severe ME/CFS (donor) to choose someone (attorney), generally a family member or trusted close friend, to manage their financial affairs and/or make decisions about their healthcare needs. In each case the donor can and often does appoint more than one attorney. The documents need to be registered with the Office of the Public Guardian. Note, even after it has been registered, LPA for healthcare can only be used once the donor is deemed to lack mental capacity. While the donor has mental capacity the donor can cancel either or both LPAs at any time.

You can draw up an LPA yourself, but most people have a solicitor assist with this.

Property and finance

This gives the attorney power to make decisions about the donor's money and property. This includes managing the donor's bank or building society accounts, paying bills and collecting benefits. The bank, building society, or anyone else with whom the attorney deals will want a copy of the LPA.

Health and Welfare

This gives the attorney power to make decisions about the donor's health and welfare. Decisions would include about treatments and hospitalisation. It can be registered with the Office of the Public Guardian but can only be used if the person has been deemed to lack capacity.

For more details and forms see https://www.gov.uk/power-of-attorney

Further Information

The ME Association and 25% ME Group have a range of additional material to help you and the person you care for.

https://meassociation.org.uk/

https://25megroup.org/