

Caring for a person with ME/CFS

Understanding the role of caring for a loved one



Including:

- Wellbeing as a carer
- What's involved
- Illness management
- What help a carer can provide for a person with ME/CFS
- Help and support
- Stories from carers
- Social media feedback
- ME and my carer
- Providing information to help your carer



CARING FOR A PERSON WITH ME/CFS

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Changing Attitudes and Improving Lives

DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS or Long Covid.





“I need help with everyday things: cooking, cleaning, transport, remembering to take meds, other reminders. Sometimes my partner can tell I’m fatigued before I can verbalise it.”

INTRODUCTION

Caring is vitally important but it can be quite isolating and, if you are new to caring, it can be hard knowing what to do. We understand the difficulties of being a carer and are here to help.

ME/CFS is one of the hardest conditions to manage and can represent a real challenge to the people who have it and to those who care for them. Symptoms and severity can be unpredictable. For a loved one it can be very difficult to watch a previously active and engaged partner or family member suddenly be unable to cope on their own.

This disabling illness affects each person differently and can mean a big adjustment for those who have had to suddenly become carers. People with ME/CFS might be bedbound with very severe symptoms, be unable to communicate, be sensitive to stimuli, be restricted in what they can eat or drink, and require 24-hour care. But even those who are less affected or who have reached a period of relative stability, will need help with some aspects of their daily lives.

The problems you face as a carer will also vary and for each carer they will be different in some respects. Caring isn’t just about providing physical help to a person who is limited in how much they can do for themselves, it often involves emotional support and encouragement as well.

ME/CFS has a range of symptoms that are the same for most people, but the severity of those symptoms can fluctuate and are adversely affected by activity. This can make the condition and the degree of help required on any particular day quite unpredictable.

In this leaflet we hope to provide you with a basic review of caring for an adult with ME/CFS and provide some real-life examples based on community feedback.





“My husband has been a rock throughout. He also fills in memory gaps which I seem to have, particularly regarding events when I was more ill. I do recall being home alone once and unable to leave the chair to get food. Thankfully, my brother arrived and cooked me poached eggs!”

YOUR OWN WELLBEING AS A CARER

Caring is an admirable role, but it can be isolating. This is why it is so important to maintain or establish a good support network. Facing these challenges alone can impact your own health. Please ensure you take breaks for yourself, and prioritise your own wellbeing as much as is possible.

A carer is someone who, often without payment, provides practical and emotional support to a partner, parent, child, relative, friend or neighbour who could not manage on their own.

Taking on the role of a carer is often in addition to your existing roles as a partner, husband, wife, sister, brother, mother, or father - and it can feel overwhelming.

But caring can also be very fulfilling. It is often something you want to do especially when you see the toll that ME/CFS is having on a loved one. For many, caring isn't a choice. It is something natural and it can bring you closer together.

It will really help if you can try to:

- Keep your own personal networks going and take time out to enjoy them.
- Ask for help when you feel you need it. This might be from a GP who should be notified of your new responsibilities as soon as possible.
- Establish routines where you can. Write a list of what you need to do each day. Try to organise your caring responsibilities.
- Look for help and support locally, such as social services, carers groups, and local ME/CFS groups.
- Try to remain positive. This may not always be possible but ensure you have someone you can share your problems with, e.g. a therapist, GP, partner, friend, or local carers group.

Taking on a caring role for someone with ME/CFS can mean:

- Loss of freedom and choice.
- Frustration.
- Isolation.
- Financial difficulties.



YOUR OWN WELLBEING AS A CARER

All these things may leave you feeling as though your life is going to be very different.

In addition, you may find that your relationship with the person you care for has changed and this is why it is so important to maintain or establish a good support network. Facing these challenges alone can impact your own health. Please take time out and ensure your own wellbeing is a priority.



“I’ve had to have help changing my bed sheets, help with school runs and shopping. I have meals cooked for me, lifts to appointments, and medications collected”

There is help and support available and we list the main options on pages 11 and 27.

As a carer you may be entitled to receive:

- Income support with carers allowance or with a grant to make adaptations to your home.

The MEA has published a free leaflet, **Carers Allowance and Carers Benefits**, which can be downloaded from our website:

<https://tinyurl.com/yc23cz5z>

- Income support with Personal Independence Payment for the person you care for, or from social care services following a needs assessment.
- Emotional support.
- A voice for your concerns.
- Training and education along with current news and issues.
- Activities to maintain your health.
- Details of local groups for carers.

WHAT MIGHT CARING INVOLVE?

Try to understand how the person with ME/CFS is feeling both emotionally and physically. Showing a person that you understand can help them enormously.



“My carer helps me to get out of bed, get to the toilet, with cooking and making drinks. She also encourages me to try and move around, helps me take my medication on time, helps with the laundry, does all my housework, and helps me with getting in and out of the shower and the bath”

It can be very hard watching someone who is bedbound by ME/CFS. You might feel you are doing very little to help, but nothing could be further from the truth.

While a person is acutely affected, helping them to manage basic functions is vital, as is maintaining effective communication with health and social care services.

Being present, listening to their needs, being responsive, and treating them with tenderness are essential. You need to acknowledge the reality of what they are feeling and provide encouragement when it is required.

For many people, it will have been a viral infection that triggered their symptoms and resulted in a diagnosis of ME/CFS. Because symptoms can be similar, it can often feel as if the infection never went away. With no effective treatment, and with the loss of independence and other significant changes to pre-illness lifestyles, ME/CFS can naturally affect mental health as well. If you think that the person you care for is having mental health issues, then speak with a GP as soon as possible so that help can be arranged.

It is important to encourage proper convalescence when the condition is acute and to adopt measures that help conserve energy so that a point might be reached where symptoms are more stable and an increase in activity can gently be supported.

Managing ME/CFS is a challenge. It is only natural to want to try and push through limitations in an effort to return to normality, but we are conditioned to believe that illness in general can be quickly overcome. But a sensible approach to early management can lead to a better chance of improvement down the road.

Chronic illnesses like ME/CFS restrict a person’s ability to function at a normal or pre-illness level, and they demand a change in mental attitude. It is hard to learn how to accept, adapt, and accommodate ME/CFS – and often this can only be achieved by learning to accept the condition.

ILLNESS MANAGEMENT

Physical, mental and emotional activities all use energy. Resting, sleeping, moving around, reading, texting, household chores, conversations, etc. are all activities that need to be taken into account when trying to manage ME/CFS.



“When I can venture outside, my carer will push the wheelchair, help me with the mobility scooter and the shopping, and is there on standby if I have an energy crash”

For people who are bedbound, activity might mean sitting up in bed for a while, or changing position, sitting in a chair, taking food or drink, having a conversation, or engaging in something that brings pleasure and engages cognitive function, like a card-game or watching/listening to a TV show or the radio for a short period.

Doing too much of an activity or engaging in an activity that is inappropriate, is likely to result in greater symptom severity and even relapse. Post-exertional malaise is such a key symptom of the condition that symptom exacerbations can be delayed by 24 hours or more. It is important to record each day’s activities and work out what seems possible based on your observations.

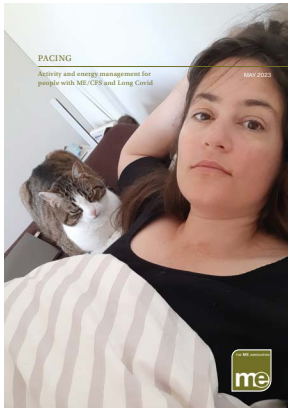
We recommend a management technique known as pacing and this requires a baseline of activity to be established. It can be especially difficult when a person is bedbound because they are only likely to accomplish basic necessities with your support. Reduce activities that are proving too much and don’t try to increase activity until symptoms have stabilised.

The idea behind pacing is that people do not do too much too soon and instead they aim to keep within an ‘energy envelope’. Once a baseline has been established and symptoms have stabilised, new activities can carefully be introduced - or the duration of existing activities extended. This can be hard when a person is bedbound but try to work out their routines and the activities that they can manage. Then, over time, you can both try to introduce new activities or increase the duration of existing activities once symptoms have stabilised and the person feels more comfortable.

Encouraging the person you care for is good, but it needs to be reasonable. You should aim to gently achieve a little each day but not too much – watching for signs of worsening symptoms. There will be times when the person you care for cannot do very much at all. Be present, attend to their needs as best you can, and seek help from professionals.

Keep a diary and try to establish some basic routines - you can summarise the diary when speaking with a GP and use it to monitor





Keep a diary and try to establish some basic routines - you can summarise the diary when speaking with a GP and use it to monitor changing needs and/or progress.



ILLNESS MANAGEMENT

changing needs and/or progress. Pacing is important - a little activity and then a proper rest with no distractions - and should not exacerbate symptoms, but the nature of ME/CFS means that people will still experience good and bad days, irrespective of what they might have been doing.

It is often best to agree between yourselves over a period of time what help is required and when, and then involve a GP and/or social care services.

The ME Association's leaflet, [Pacing: Activity and Energy Management](#) is free to download from our website.

WHAT KIND OF HELP CAN A CARER PROVIDE?

Some people with ME/CFS will need full-time care but even a person who needs limited care can present a challenge. We understand how difficult caring can be and how it can turn your life upside down. Whatever you are feeling is likely to be normal and very understandable.

We appreciate the effect of not knowing when or if things might improve. Both you and the person you care for want to return to the life you had and a life that is free of ME/CFS.

The uncertainty of not knowing how long it will last or when meaningful improvement might happen, and the daily toil of caring for someone with an illness that doesn't have an effective treatment, might seem very bleak.

But, while full recovery is rare, many with ME/CFS do see their symptoms stabilise and their functional ability improve over time. This can lead to a better outlook, greater independence, and a more fulfilling life for you both. So, please don't give up hope.

We recently asked on social media what help people actually received from their carers. You can read a selection of comments throughout this booklet and we have included two stories from carers at the end.



“I need help with everything. Feeding, drinking, taking medications, toileting, washing, teeth brushing, turning, getting comfortable, heating hot packs, mental stimulation, companionship, voting, writing, research, nutrition, clothes washing, food making, cleaning, washing up, clothes buying, food buying, toiletries buying, picking up meds from the chemist, calling out the GP if needed, buying presents and cards for other people, audiobook downloading, reading to, gentle massage, simple craft activities, keeping quiet, etc.”



WHAT KIND OF HELP CAN A CARER PROVIDE?

Most people receive help from their carers in the following areas:

- Attending appointments
- Bathing and toileting
- Creating a comfortable environment
- Dressing and undressing
- Driving
- Eating and drinking
- Emotional support and understanding
- Enjoyable activities
- Getting in and out of bed
- Household chores and responsibilities
- Medications
- Memory and concentration
- Mobilising
- Shopping
- Telephone calls
- Welfare benefits

VENTURING OUTSIDE

When a person's symptoms have stabilised, and they are able to leave their beds for greater periods of time, it is only natural for them to want to venture outside. It is good practice to have a safety net in place. Think about where they can rest in comfort should the exertion prove too much.

- **Wheelchairs:** Consider getting a wheelchair for outside use. It can help a person rest even when outdoors and can give greater independence. Motorised wheelchairs or mobility scooters are other options and some venues will let you hire them.



Remember that the journey itself can exacerbate symptoms, so allow time to rest or take breaks as needed during the trip.

VENTURING OUTSIDE

■ **Plan trips in advance:** The car can be a good place to rest and lie-down if needed after a journey, or if the activity proves too much. Think about places that are conducive to rest – know where you are going and what facilities are available when you get there. Remember that the journey itself can exacerbate symptoms, so allow time to rest or take breaks as needed during the trip.

■ **Toilets:** If the person has problems with irritable-bowel symptoms, then know in advance where the toilets are located. You might be able to obtain access to disabled toilets.

HELP AND SUPPORT

It can be hard for someone with ME/CFS to be put in the position of having to rely on you for help. This is especially true of adults who were previously independent. There will often be a period of adjustment as the person tries to accept their new circumstances, which can take a long time.

It is also important to look after yourself. If you become exhausted, frustrated, or depressed, you should consider finding someone you can share these feelings with. If you become exhausted, frustrated, or depressed, then you need someone you can turn to for help and support.

We know that ME/CFS affects more than the person who is disabled, but there is help and support available. We understand the confusion, frustration and mental strain of caring particularly when you are new to the role or having to also care for a family or need to work. We recommend you contact other charities like Carers UK and the Carers Trust whose sole focus is helping people like you.

You should reach out to your GP as soon as possible, explain your circumstances and ask for help. Review the situation and together form a care or management plan that might include home visits and regular monitoring, etc. Seek advice on welfare benefits, Carers Allowance, and social care services if you need them. Ask to see a counsellor if you think talking to a professional about your life as a carer would help. Try to involve family members and friends. You will often need to express your feelings in a safe and comfortable environment.





**CONTACT
ME CONNECT**

**FREEPHONE
0800 538 5200**

Monday - Friday
10am - 6pm
(Late night until 9pm
on Thursdays)

Saturday and Sunday
10am - 12 noon
7pm - 9pm

We aim to answer all
calls live.

You can also contact
ME Connect by email
to [meconnect@
meassociation.org.uk](mailto:meconnect@meassociation.org.uk)

or via social media
private message
(see last page).



HELP AND SUPPORT

Please do contact ME Connect on Freephone 0800 538 5200. Knowing what help and support is available can really help. We all understand the mental strain of caring, and the feeling that your life is dominated by ME/CFS. We are here to listen and can signpost you to services that might help.



HERE TO LISTEN

We are here to listen,
validate and empathise
with any issues you
might be facing.



VITAL SUPPORT

We are here to help
you make an informed
decision.



**SAFE
ENVIRONMENT**

We provide a safe,
confidential and
understanding
environment where
you can be heard
and understood.

CARERS CONNECTED

Carers Connected groups receive new members all the time. Please do get in touch if you would like to be introduced to someone who understands you and may become a very valued new friend.



If you would like to be put in touch with anyone in our ME Friends and Carers Connected groups, or to join one of our groups, please email Emma Jefferies at: emma.jefferies@meassociation.org.uk

Please note: By contacting the ME Association and showing interest in ME Friends/Carers Connected, you are giving the ME Association permission to share your contact details with other members of the charity. The charity does not accept responsibility for any issues or problems that might occur between individuals who have agreed to participate in ME Friends/Carers Connected. If any issues or problems do occur, you should contact the charity.

*Karen Galpin is
a full-time carer
for her daughter
Sophia, who has
severe ME/CFS*



*“Since becoming a
carer I have had to
learn an awful lot.
There’s no manual,
I get things wrong
and I’m still
learning”*

Karen Galpin
(Karen’s story)

KAREN’S STORY

I am a full-time, unpaid carer for my 31-year-old daughter Sophia.

I’m not sure when I became a carer exactly as Sophia’s physical health has slowly deteriorated over a period of six or seven years, with me gradually taking on more and more things that she could no longer do for herself. Sophia contracted Lyme disease some years ago but it took a long time to figure out what was causing so many of her symptoms, until we got a positive test via Germany. Sadly, despite travelling to the USA for treatment, she has continued to suffer with ongoing worsening pain and fatigue as well as POTS, gastroparesis and more recently severe vertigo. The pain is all over her body 24/7 and until recently no medical professional has been able to offer us an explanation for this or for her other symptoms. Due to her constant deterioration, and still having no care or treatment plan despite my pleas to our local pain team and neurologists, I contacted our local CCG in desperation and their unhelpful recommendation was to send her to an in-patient unit for medically unexplained symptoms (MUS). Needless to say, we did not take up this option. Since then we have engaged a private physician with a specialist interest in ME who understands the condition and who immediately recognised the majority of her symptoms. He offered a plausible explanation, confirmed that she has severe ME/CFS and has put together a plan.

I do almost everything for Sophia because she is now so incapacitated. She can no longer walk and spends 95% of the day lying in bed in a quiet, darkened room with dark glasses on. She can barely tolerate light, sound and movement and has only her unrelenting burning pain for company – apart from the odd 10 minutes here and there when I come in to feed her from a cup, wheel her to the bathroom or we have a little ‘chat’ where I talk quietly and do my best to interpret her whisperings. Anyone outside of the ME community looking inside our ‘bubble’ would be shocked by this alternative life – or should I say ‘existence’ – where the same four walls are your shrunken world and where you only interact with the same two people for a total of less than an hour a day. There are no distractions for someone with fatigue of this severity – no phone, laptop, music, films, radio, books, music or hobbies due to stimulation overload. We feel frustrated, trapped, lonely and isolated, cast aside by an ignorant and uncaring healthcare system, but are always there to support each other.

We carers do this job out of love and with compassion, stepping in where there is a shocking gaping hole in the health service. Like many carers, I became responsible for a loved one who, previously fit, well



“We carers do this job out of love and with compassion, stepping in where there is a shocking gaping hole in the health service”

Karen Galpin
(Karen's story)



KAREN'S STORY

and independent, became very sick. I now look after her every physical and emotional need day and night, with very little respite as we get no help or support from outside sources. Thankfully, I have my husband and Sophia's partner who help me enormously and allow me some time to do other things occasionally by way of a break. From a practical point of view the day-to-day jobs include shopping, cooking, feeding, cleaning, laundry, sourcing specialist clothing and equipment, corresponding with doctors, OTs and specialists and generally being her advocate, ordering medications, sorting finances, benefits, etc – the list is endless and the days exhausting. These are all the things she would dearly love to do for herself but simply can't. Attending to her emotional needs is way harder when she has been through so much and continues to endure so much suffering because of the ongoing abandonment by the health service. There are so many feelings and emotions that she can't process or articulate because of the fatigue and pain – loss, fear, anxiety, grief, anger and so much more. She has so much that she wants to say but is no longer able to participate in any form of talking therapy which could help her process these emotions. Her mind is active but trapped inside a dysfunctional body.

Since becoming a carer I have had to learn an awful lot (there's no manual, no 'how to' guide!) but I do get things wrong and am still learning. These are the things that help me but may not be appropriate for everyone:

- Reading lots and gaining knowledge about the condition and staying up to date with research which may hopefully one day lead to a better future. I need to understand what's happening to her body and this is my way of maintaining some level of perceived control when life is very much the opposite.
- Being accepting of this new life and everything it throws at you and trying not to let the frustration, anger, resentment, grief and feelings of loss overwhelm you (easier said than done of course). Over the years of her progressive illness we have continually had to get used to 'the new norm' as things slide further and her incapacity becomes greater. This is a tough one that I particularly struggle with.
- Not dwelling on or making comparisons with how things were pre-illness. Sophia was very fit, had an active social life and a great future ahead of her after graduating as a speech and language therapist. She is still beautiful of course – inside and out – but physically very different to





“It had to be pointed out to me how important self-care is when I’ve been in danger of burning out”

Karen Galpin
(Karen’s story)

KAREN’S STORY

her former self. I used to work in marketing and enjoyed travelling all over the world with like-minded friends to run marathons. Not any more. We have to believe that enjoyment of life and personal enrichment will come back, albeit in a different form perhaps.

- Not comparing our situation to that of others. Social media is a great place to stay in touch with the world when you are physically isolated, but it can seem like every other sick person you know is making progress, healing and recovering and getting back to a normal life while you are experiencing the opposite. It’s often a false picture and unhelpful.
- Finding time to have micro chats like a mum and daughter, rather than always like carer and patient. That’s a difficult one when there are so few opportunities to properly connect because of the limitations of the illness.
- Sharing decision-making wherever possible so that she’s not only involved but has a say in what we do – this can be very difficult when it takes her days to think about something but so important for her to maintain some level of control.
- Looking after myself. This is something I have not been good at in the past (and I’m still not great at it). It had to be pointed out to me how important self-care is when I’ve been in danger of burning out. I thought I could just keep going when times got tougher and tougher and would not reach out for help or for a chat because I’m so fiercely independent. Now I make sure I get out for a run or do yoga each day, fit in 10 minutes of meditation or reading and maybe speak to someone in my support network (usually my brothers) when I’m becoming physically and mentally exhausted and overwhelmed by everything.
- Me keeping in touch with her friends and passing on messages and pictures from them is so important when she’s feeling so isolated and it feels like the world is passing her by.
- Keeping hope alive. Always reaffirming to her that things can get better and that we will never stop looking for that golden key that will open the door to her return to her home in Cornwall with her partner and dog.

Caring for my daughter is by far the most demanding thing I have ever done – emotionally and mentally. I’ll happily admit that I often feel overwhelmed by the enormity of it. When things get too much, she



*“As a parent you
never expect these
things to happen”*

Kate Nairn
(Kate’s story)



KAREN’S STORY

worries about me and checks that I am OK and looking after myself. That has always been her way since she was a little girl – worrying about others and always putting others before herself. I am incredibly proud of her and she deserves the absolute best care in the world. ■

This story featured in ME Essential, Summer 2020, Issue 155.

Karen often posts about the struggles of being a carer. You can follow her here:

X.com/tenacious_mumma
instagram.com/shesoutrunning

KATE’S STORY

Our beautiful, clever, lively daughter Olivia was nine when we realised that something was wrong. Her physical health was deteriorating and she was constantly fatigued; light and sound started to become an issue and her cognitive functions seemed impaired. I remember her teacher raising concerns with us at the time when her health was failing; before long our GP had referred us to a paediatrician and eventually we had a diagnosis of Post Viral Chronic Fatigue/ME. Our regional ME Service helped to explain what was going on, how we could support her and how there was only so much fuel in the tank which had to last our lovely girl all day. School hours were reduced, activities out of school were scaled back and soon forgotten altogether as we battled to maintain a balance that would enable her to keep just a tiny bit of normality.

As a parent you never expect these things to happen. My husband and I did what any parent would do and threw ourselves into supporting our daughter and keeping life normal for her younger brother, trying to juggle our jobs and caring and medical appointments. We live on automatic pilot doing what needed to be done and are immensely grateful for supportive friends and family who keep us going.

By the time Olivia was 11½ there were signs of improvement and it seemed the battle had been won. It had been an immensely difficult time, particularly starting secondary school on a part-time basis when the school and fellow pupils had no comprehension of exactly what ME was. It certainly left its mark but there was a new normal until the



*“Looking back,
I wish I had had
counselling and
regret not seeking
professional help.
I mourned and
grieved for the life
we had lost”*

Kate Nairn
(Kate's story)

KATE'S STORY

summer of 2014, shortly after Olivia's 14th birthday, when everything seemed to be happening all over again. This time though, it was much worse and by September every part of her physical and mental state were affected. A visit to the GP was urgently followed by a referral to hospital where Olivia was admitted immediately. She remained there for three months – paralyzed, unable to move, walk, hold a cup, tolerate light, read or eat. She was fed through a Nasogastric tube and we were immersed in a whirlwind of being with her at hospital on a shift pattern of home, work, hospital, repeat. By December the situation was critical; it was clear that a specialist referral was required and we waited in hope for this to happen. Frustrated by the system and lack of specialist inpatient services, I bombarded the Prime Minister, our MP, Health Secretary and anyone I could think of to raise awareness. Unable to accept that Christmas would be spent in this way, we arranged for a hospital bed to be delivered to our lounge next to a downstairs bathroom and Olivia was transported back to us on the 23rd December so that we would all have Christmas under the same roof.

Assessments followed but still there was no hospital bed and we cared for her at home round the clock until finally a hospital bed became available in London in June. On a sunny summer day we travelled with our daughter from our home in Gloucestershire and made the first of what would be many trips over a hundred miles away to where she needed to be cared for best.

We juggled to keep things as normal as possible for our son; working, and maintaining life at home, with travelling up and down to hospital several times a week. We were all heartbroken, utterly exhausted, stressed, bewildered and living the worst kind of nightmare. Several times we came close to losing her and were always eternally grateful for the care that she received.

After 18 long months, Olivia was discharged to continue recovery at home; there was still a mountain to climb but at last she was home.

It is true that you have to look after yourself to enable you to look after others, but we gave no thought to ourselves as parents and carers. We were supported with family therapy sessions at hospital which were hugely helpful, and found great comfort in parent groups which were a reminder that we were not alone.

I struggled to cope but on a friend's recommendation found the closest yoga class I could and went along one evening. It saved my soul and enabled me to breathe and refocus. Despite it being 75 minutes out of



KATE'S STORY

my week which I could not afford, those minutes were precious and mine, and so quite often I would find myself at work in the morning, at hospital in London in the afternoon and then driving back with precision timing to collapse on my yoga mat for the class at 6.15pm sharp.



Looking back I wish I had had counselling. I mourned and grieved for the daughter and family life that we had lost; I had no idea how to deal with that and regretted not seeking professional help. At the time we were just trying to survive and only afterwards did I think to seek out charities and organisations which I wished I had found before.

We continue on a journey with ME which still affects each and every day for Olivia and for our family. The hardest part is sometimes not wanting to be nurse, doctor, therapist, counsellor, support worker or physio, but just wanting to be her mum. We are, though, hugely thankful for everyone who has cared for her throughout this time, and in addition, those who have cared for us – the carers – too. ■

This story featured in ME Essential, Summer 2020, Issue 155.

“The hardest part is sometimes not wanting to be nurse, doctor, therapist, counsellor, support worker or physio, but just wanting to be her mum”

Kate Nairn
(Kate's story)



FEEDBACK ABOUT CARERS

We asked the ME community to send their carers' stories into us and these are a few of the replies we received. You can read all the posts on our Facebook page here:

<https://tinyurl.com/5b7x5ver>



He can't go in the shops. The light and noise - even with eye and ear protection - is just too much.

I do not have M.E. but my husband does, and I am his carer. When he is at his worst, I do everything for him. When he was completely bedridden I would need to help him bathe and we'd have a bedside commode - although he couldn't always sit up to use it.

It's even more work when he was able to get out of bed for a few hours a week, I would help him to get dressed, with his hair, with brushing his teeth - when he could tolerate the brushing of teeth. I was always cleaning sun glasses, finding ear plugs to use with ear defenders, pushing him in the wheelchair to and from the car for medical appointments. He's a large man so it wasn't easy.

He can obviously no longer manage all the chores he once did around the house. I really wish he would never go out because it can make him much worse for weeks after, but he does relish his independence when he can manage it.

He can't go in the shops. The light and noise - even with eye and ear protection - is just too much. I work from home and he has a buzzer to ring if he needs me that goes off in my office. He can't talk on the phone so I have to do that for him.

He's always in tremendous pain so he needs a lot of leg-rubs throughout the day, and we also have a disabled daughter, so I have to try and care for her as well. The house has to be quiet, and temperature needs to keep being changed to suit his symptoms. I am up and down at least 20 times a day with water, food, and snacks. I try to keep the house dust free and chemical smells to a minimum, but even cooking can inflame his heightened sensitivities.

It's all the little things that add up to make caring for someone with M.E. such a challenge. ■



“I rely on my husband to be my unpaid carer. I had to take early retirement from work as I was not able to continue my teaching job which I loved. Mainly I am stuck in the house, often fed up and angry at the way M.E. robs you of life, identity and a sense of worth”



FEEDBACK ABOUT CARERS

I would be unable to manage my ME without help. I need someone with me all of the time to be able to say, “Can I help you?”, when it looks like I’m struggling or, better yet, they are able to pre-empt my needs.

My ME is currently moderate-severe, varying slightly day-to-day, and has been for many months. There had been a period of a few years when I was well enough to work full-time, but not now unfortunately.

My unpaid carer is my husband who works from home. He helps with practical things from preparing food to making calls on my behalf with regard to benefits, etc. He has advocated for me in a medical setting when I was particularly challenged by brain fog.

Having someone to comfort me and talk about my difficulties has been helpful (even more so than counsellors). Whilst I don’t need help bathing, I am more likely to become faint afterwards so my husband comes to sit with me as I lay on the bathroom floor to recover – bonding, eh? Being carried around the house or supported as I walk has become normal on the worse days.

Something that isn’t practical but is extremely beneficial would be having someone to talk to so that I can organise my thoughts. Each day I have a little energy to spend (I am gradually increasing my activity, very slowly) and it’s good to talk over the best use of my energy, for example, charity work, house work, treating myself in some way. Brain fog can make this difficult. ■

My carer helps with meals, drinks and snacks. Making sure I remember my medication on time. Assisting me to the bathroom and back to bed. Help with the shower, setting up shower chair and having clothing ready when I get out. Drying off after a shower and helping me dry my hair.

Driving to appointments and pushing the wheelchair during the appointment. Laundry and cleaning are another issue.

If you have two adults at home and one develops this disease, the entire home falls on the other and they probably have a full-time job as well. When this disease hits you like a lightning bolt and you go from your normal life one day to this life the next, no one in the medical field seems to be sure what you should be doing or the help that is available.

I was still trying to shower and I collapsed on the floor. Luckily, the only thing it hurt was my pride. No-one says, “you will need a shower chair,



“The times when I’ve needed most help is moving from the bed to the toilet and back again, when I need food and drink brought to me in bed, and help sitting up in bed”

FEEDBACK ABOUT CARERS

you will need help with meals, you will need a wheelchair, here is a disabled parking pass, etc”. We have had to fight for almost everything or pay ourselves for every need I have. It can be exhausting.

In the beginning we tried private care support to see if they could prepare my lunch and they said they could prepare it at 4pm, two days a week. I had two visits with them and they took my blood pressure and interviewed me for services, told me they couldn’t get here until one hour before my husband gets here anyway and then sent me a bill for £700.00! ■

*Information for
people with ME/
CFS to help their
carers*



'ME' AND MY CARER

For the carer

ME/CFS is a disabling illness – although the visible signs and restrictions that people normally associate with being disabled may not always be obvious.

Some people with ME/CFS often look well, yet feel ill. One minute they can do something and the next – they cannot.

ME/CFS is characterised by severe fatigue that is made worse by minimal physical or mental or emotional exertion.

Sufferers can be exhausted by a short conversation, by taking a shower or simply by going to the lavatory.

This is not tiredness. This is a complete and utter lack of energy, and it can be frightening in its intensity.

They frequently suffer from cognitive dysfunction (“brain fog”) which is an inability to think straight or to find words.

Even the most sympathetic person may not understand the difficulties with talking too much or too quickly, making too much noise, not providing appropriate meals, not being clear which areas of care need to be covered. Much of this ‘lack of communication’ will be because a sufferer does not have the strength or energy to go through the explanations.

Do you remember how ill you felt the last time you had flu or a really severe virus?

Your body ached. You felt dizzy. You were cold and shivery. You couldn't think straight. Every noise and bright light hurt your senses.

That's how people with ME/CFS feel when they are having a bad spell. And – for some – that is all the time. They may be too unwell to talk for more than a few moments.

ME/CFS is recognised by the World Health Organisation as a neurological illness. Although biomedical research is taking place, there is still no known cause, no simple diagnosis and no cure.

The severity and symptoms of ME/CFS varies from person to person and can fluctuate from day to day.

To help you to help them, ask the person you care for to complete (or answer with your help) the questionnaire starting on page 23.



*Information for
people with ME/
CFS to help their
carers*



'ME' AND MY CARER

For the person with ME/CFS

Few people really understand what effect ME/CFS has on you.

Even close members of your family do not always fully understand and – even if they do – they sometimes need reminding!

With outside carers, this may be a difficult problem as there are still a lot of people who do not know much about this illness.

To help you to explain the complexities of ME/CFS and how it affects you, we have devised a questionnaire that describes some of the basic characteristics of the illness and lists the symptoms you have and the degree to which you have them. It also spells out those tasks which are difficult or impossible for you to carry out unaided.

There is a space for your name, address and date of birth. This may be useful if you have carers from organisations such as your local authority. They can then keep a copy on file as well as you giving copies to all the carers who help you.

There is also a list of tasks and a list of symptoms with which you need help or are unable to manage. Tick those tasks and symptoms that apply to you.

At the end, add anything that you feel may be relevant to your ME/CFS.

To help you to help your carer, complete the questionnaire starting on page 23. Then arrange for photocopies and give the copies to any carer, friend or family member who needs to understand your symptoms. Ask for help completing the questionnaire if you need to.



Name

Address

Post code

Date of birth

How long I have had ME/CFS

Years: _____

Months: _____

Emergency contact

THESE ARE THE TASKS THAT I NEED HELP WITH (all, most, or some of the time):

All	Most	Some	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I require wheelchair assistance
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I am only able to walk a short distance
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I am unable to climb stairs
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I require help with washing and bathing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I require help with dressing/undressing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I require help with going to the lavatory
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I require help with shopping
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I require help with meal preparation
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I require help with eating

I need to take rests (add details) _____

Add anything that relates to your ME/CFS and is not included in the list



Use this space for any
additional information

HERE ARE THE SYMPTOMS THAT I HAVE
(all, most, or some of the time):

All	Most	Some	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Muscle fatigue
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Pain in my muscles
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Pain in my joints
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Pain in my nerves
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Pain in my glands
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Muscle spasms
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Cognitive dysfunction = brain fog
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Dizziness or balance problems
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Headaches (specify if migraines) _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Sensitivity to loud noises
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Sensitivity to bright lights
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Numbness
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Pins and needles
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Sensitivity to smells, e.g. perfumes
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Hypersomnia (excessive sleep)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Insomnia
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Poor quality sleep
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Unrefreshing sleep
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Palpitations
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Low blood pressure (leading to faintness when rising from a seated position)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Cold hands and feet
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Sore throats
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Enlarged glands
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Allergies (drugs) _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Allergies (chemicals) _____



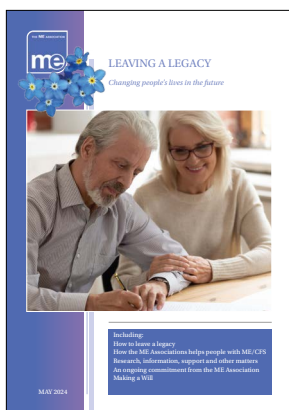
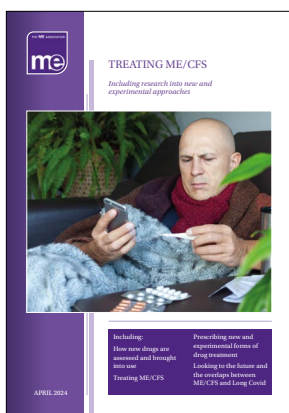
Use this space for any
additional information

HERE ARE THE SYMPTOMS THAT I HAVE (all, most, or some of the time):

All	Most	Some	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Allergies (other) _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Irritable Bowel Syndrome / indigestion
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Nausea and sickness
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Hearing problems - Tinnitus (strange noises in the ear)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Hearing problems - Extreme sensitivity to sound



The MEA offers a huge range of literature, most of which is free to download.



MORE INFORMATION

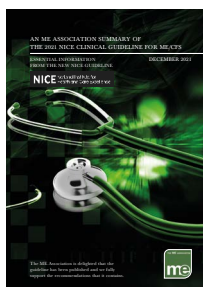
ME Association Literature:

Please make use of the ME Association resources.

We have an extensive range of booklets and leaflets on all aspects of care, social care, welfare benefits and grants, diagnosis, symptoms, drugs, comorbid conditions, vaccinations, and effective illness and symptom management. All of our literature is available to download free from the website:

<https://meassociation.org.uk/free-literature-downloads/>

NICE Guideline on ME/CFS: An ME Association Summary



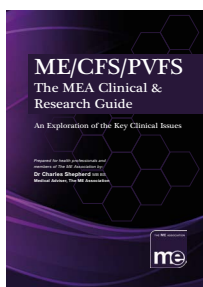
This booklet is recommended reading. It lets you know what to expect from the NHS and social care services with regard to symptom recognition, diagnosis, management, referral, and ongoing care and support.

You can download a PDF file of this item here:

<https://meassociation.org.uk/9d0l>

Books

ME ASSOCIATION ME/CFS/PVFS CLINICAL & RESEARCH GUIDE



The most comprehensive, evidence-based summary of ME/CFS/PVFS currently available. It contains everything that health professionals, patients, and the people who care for them need to know about this devastating neurological disease.

£10.00 – £25.00 (depending on where you live)

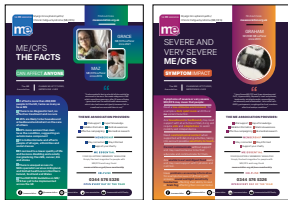
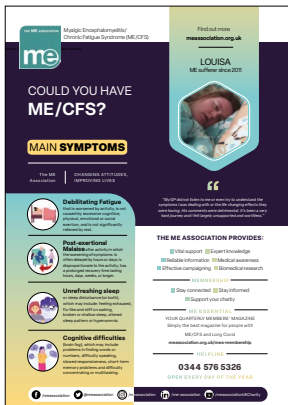
<https://meassociation.org.uk/pbme>

This book is also available for the Kindle and can be [purchased here](#).

Free copies are available to UK Healthcare Professionals. Please email admin@meassociation.org.uk or request one alongside our quarterly magazine, ME Medical:

<https://meassociation.org.uk/me-medical-magazine/>

Awareness: ME/CFS and Long Covid



Poster Pack: ME/ CFS & Long Covid

A selection of 5 posters that can help raise awareness of ME/CFS and Long Covid. If you want to share them virtually or print them yourself, you can select the download option at no cost (PDF) [here](#).

If you require them as hard copies, we ask for just £5 to cover the cost of postage and [they can be ordered here](#).



MORE INFORMATION

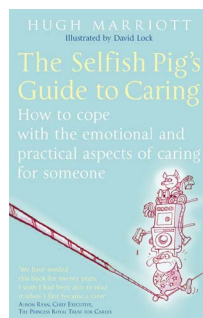
SEVERE ME – NOTES FOR CARERS by Greg Crowhurst



This illustrated guide with contributions from carers and those who are ill, from around the world, is packed full of practical tips, insights, guides and self-reflective exercises designed to raise awareness of how to care for someone with Severe/Very Severe M.E.

<https://tinyurl.com/2td5sjxn>

THE SELFISH PIG'S GUIDE TO CARING by Hugh Marriott:



How to cope with the emotional and practical aspects of caring for someone.

Although carers by definition are anything but selfish pigs, they are liable to feelings of guilt, probably brought on by fatigue and isolation. So Hugh Marriott has written this book for them and everyone who doesn't know what being a carer is all about.

<https://tinyurl.com/4uv4scab>

Charities for Carers

■ Carers UK: <https://www.carersuk.org>

Carers UK helpline: 0808 808 7777 from Monday to Friday, 9am – 6pm (including Bank Holidays).

■ Carers Trust: <https://carers.org>

Carers UK support line: 0300 772 9600 (Monday to Friday, 9am–5pm).

Note: Book links provided are for Amazon. There are many other retailers available if you prefer - just use Google to search the book title and author.



“Thank you for producing such a helpful magazine. The standard is consistently high and each edition is interesting and varied. I need all the help I can get and this magazine is consistently encouraging, realistic, and helpful.”



THE ME ASSOCIATION

Changing attitudes and improving lives...

■ **COMMUNITY:** We provide a safe and welcoming community for people affected by ME/CFS and Long Covid who come together and benefit from sharing their experiences. We provide membership, an essential support service, excellent website resources and we host engaging discussions on the most popular social media channels. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. Your subscription means that we can support more people, campaign more effectively and fund more medical research. Members receive the exclusive ME Essential magazine which carries the latest news, medical information, personal stories, and feature articles. **Join us today!**

■ **SUPPORT:** ME Connect is the charity’s support and information service. We listen and we understand. We provide a personalised service and we’re here when you need us most. Most of us have personal experience of these medical conditions, or care for a loved one that does. We are here Monday to Friday 10am - 6pm (late night until 9pm on Thursdays) and at weekends, Saturday and Sunday 10am - 12 noon and 7pm - 9pm. We’re ready and waiting to take your call, answer your email or respond to your message.

■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the **largest range of literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, to get an accurate diagnosis, a referral to specialists, and to obtain the healthcare that you deserve. We also provide an **e-newsletter** and free access on the website to **Medical Matters** and other relevant information.

■ **RESEARCH:** We fund medical research via the **Ramsay Research Fund** and are especially interested in research that can find diagnostic markers, causes, and treatments. We support the UK ME/CFS Biobank and the Manchester Brain Bank, and have invested over £1m in medical research in the last 10 years.

■ **MEDICAL EDUCATION:** We arrange training for healthcare professionals, offer a medical magazine, ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations from the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.



“The MEA is doing exactly what it said it would by providing support, actively lobbying for recognition, improvements to health and social care, and funding biomedical research.”



THE ME ASSOCIATION

Changing attitudes and improving lives...

■ **LOBBYING:** We campaign to raise awareness and bring about positive change. We believe in collaboration and work with the NHS and social care services, the Department of Health and Social Care, the British Association of Clinicians in ME/CFS (BACME), Forward-ME, the ME Research Collaborative (MERC), DecodeME, the All-Party Parliamentary Group (APPG) on ME, Physios4ME, the Chronic Illness Inclusion project (CII), Hidden Disabilities Sunflower, and Long Covid initiatives.

■ **HEALTH & SOCIAL CARE:** The charity works with healthcare providers to successfully implement the NICE Guideline recommendations on ME/CFS and Long Covid to ensure that everyone receives the very best healthcare, wherever they live in the UK. We want well-trained healthcare professionals providing excellent services because timely intervention can lead to better health outcomes and improved quality of life.

■ **DONATIONS:** Donations: In order to help more people and invest in medical research we depend on your generosity. If you feel able to make a donation or want to raise funds in other ways, please get in touch with the fundraising team: fundraising@meassociation.org.uk or you can **make a direct donation via the website.**

WHAT ARE ME/CFS AND LONG COVID?

We answer key questions about these medical conditions and compare similarities and differences. You'll also find the NICE Guidelines reproduced in full in an easy to use **database**.

MEDICAL MATTERS

Medical Matters is an easy to use online supplement to the more detailed literature. The same topic experts provide answers to commonly asked questions.

NHS REFERRAL SERVICES

If you need to locate an ME/CFS specialist service or Long Covid Clinic then we can help. We have listed all secondary care referral services in an easy to use **database**.

THE ME ASSOCIATION



ME CONNECT

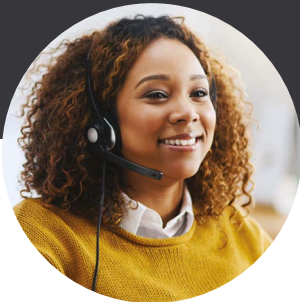
The Support and Information Service
for people affected by ME/CFS/PVFS
and Long Covid

3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message



Freephone
0800 538 5200

Monday to Friday 10am - 6pm
(Late night until 9pm on Thursdays)
Saturday & Sunday
10am - 12 noon & 7pm - 9pm



HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.



VITAL SUPPORT

We are here to help you reach an informed decision.



SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!



MEConnect@meassociation.org.uk



[X.com/meassociation](https://x.com/meassociation)



facebook.com/meassociation



instagram.com/meassociation

meassociation.org.uk