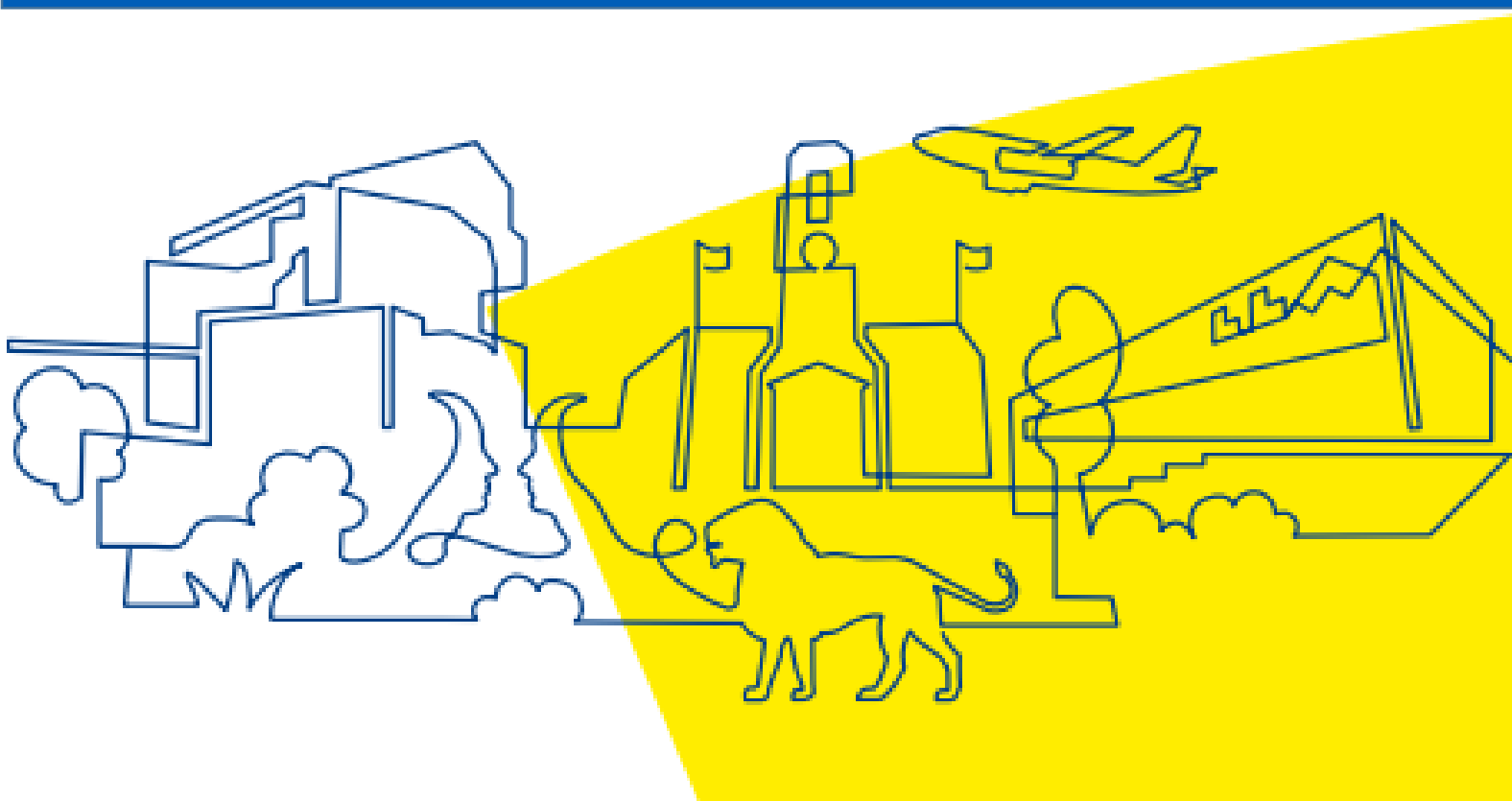


Bedfordshire Chronic Fatigue Syndrome Service

Carers of People Living With ME/Chronic Fatigue Syndrome



We promise to work together creatively to: learn 'what matters' to everyone, achieve a better quality of life and continuously improve our services.

We care . We respect . We are inclusive.

Carers

NICE guidelines state that “to facilitate effective management of the condition, healthcare professionals should aim to establish a supportive and collaborative relationship with the person with ME/CFS and their carers.”

How your loved one might be feeling:

ME/CFS can be debilitating with the main symptoms being fatigue, brain fog, post exertional malaise (PEM) and unrefreshing sleep

Your loved one may also have additional symptoms like pain, headaches, bowel issues, dizziness, nausea and other psychological difficulties.

How your loved one feels is invisible where they may look well but feel the opposite

Their symptoms are often fluctuating and variable and disproportionate to the amount of activity undertaken



Emotional impact:

- Lack of motivation
- Worries, low mood
- Feeling hopeless
- Feeling isolated – no one gets it
- May lead to unhelpful coping mechanisms

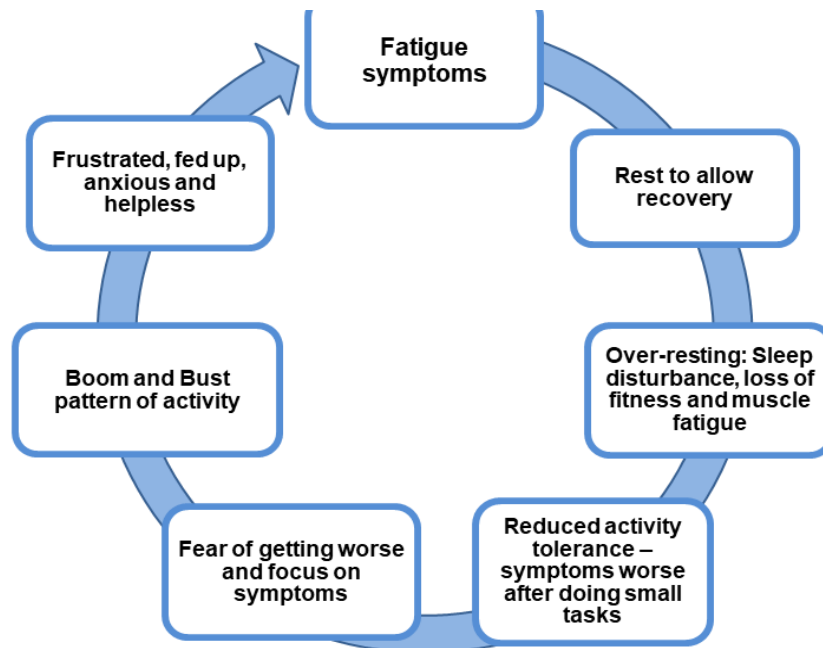


In treatment, areas to work on but not restricted to:

- Understanding the fatigue/ condition
- Routine
- Identifying and understanding energy limits
- Activity management
- Sleep management
- Managing brain fog
- Returning to valued activities including work/study
- Acceptance, managing thoughts and feelings related to the fatigue.
- Accommodate
- Adapt



One of the contributors to ME/CFS is Boom and Bust patterns:



What we know:

There may be changes to some roles and relationships within families and friends

There may be increase in overall symptoms for the short term

You may want to help by taking some of their responsibilities, but this can add to the overall loss of tolerance to activities

It is important to persevere and support with the care plan that your loved one is working towards in treatment

Research shows that ME/CFS patients whose family members are supportive and involved in the specialist care plan report better emotional and behavioral adjustment.

Managing changes to social, work or study commitments:

Try to encourage your loved one to keep in contact with friends especially outside of the family unit

If in person is not possible then via social media

Offer validation with positivity that things will improve in the longer term by following the treatment plans



Looking after someone with ME/CFS:

- Being a carer for your loved one with ME/CFS is not easy
- It is equally important to look after yourself too
- Your loved one needs to be validated and believed
- It is not helpful to compare your loved one to what they could do previously
- You need to manage your own expectations



Caring is an admirable role but can be isolating:

- ❖ 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.

Your own wellbeing as a carer:

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

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



Please take time out and ensure your own wellbeing is a priority

Supporting yourself while caring for someone – From Mind UK

Learn how to manage your own wellbeing while caring for someone else. Get information and tips on looking after your mental health and finding support.

How to look after yourself as a carer

When you spend a lot of your time focusing on someone else, you may feel as if you have no time for yourself. But looking after your own wellbeing is important for you and for them.

We have listed some self-care ideas that others have said they find helpful. Even trying one small thing might help you feel more able to cope:



- **Share how you feel**
- **Try to be realistic**
- **Find ways to stay organised**
- **Support their independence**
- **Find positives in your relationship**
- **Take a break and make time for yourself**
- **Look after your physical health**

What to do if you can't cope

Sometimes the pressure of caring for someone else can build up until it feels like you can no longer cope. This is completely understandable, but may be a sign that you need to try and look after yourself. If you are feeling desperate and in crisis, you won't be able to keep supporting someone else.

Try and take a small break. If that's impossible, have a moment to yourself and take some long deep breaths. Knowing that things will get easier in the future can help you feel a little calmer.

If you need help or advice for yourself now:

- You can talk to the [Samaritans](#) 24 hours a day on **116 123**. They are there to listen and to help you find a way through.
- Call the Carers UK helpline from Monday to Friday, 9am – 6pm on **0808 808 7777**. Use the [Carers UK local support search](#) – a tool for finding support in the area you live. At the end of this page there is info on organisations who can help you in your local area
- Think about who you could contact for support. It might help to make a note of your next steps so you feel more in control.

Share How You Feel

It's important to have someone to talk to, especially if you're struggling to cope. You could:

- **Share your feelings with someone you trust, such as a family member, friend or neighbour**
- **Join a support group for carers**
- **Contact the Carers UK helpline**
- **Talk to others on the Carers UK forum**
- **Talk to someone through online mental health tools.**



Not all of these options may feel right for you. Or you might feel like you have nobody to share your feelings with. If you are feeling isolated or alone, our pages on coping with loneliness offer more information.

Try to find someone you can be honest with about your feelings, without judgement.

Try to be realistic

If you take too much on, you may feel as if you never achieve anything. Try to get a clear idea about what you can do. By accepting the things that you can't change or do alone, you may feel more able to cope. You could try identifying and writing down:

- **A list of all the support needs of the person you are caring for**
- **What you can do and what you'll need help with**
- **How you'll know when you need a break.**

Respite is possible – and necessary. You can't give your all as a carer. You have to save a bit of yourself just for you.



Find Ways to Stay Organised

Staying organised can help you feel more in control. You could keep a schedule or planner of your daily routine. Make sure that you keep all important information and medication in one place. But don't be hard on yourself if you get muddled or things get lost. You've got a lot to think about.

If you feel comfortable using technology and have access to a smartphone, you can stay organised digitally. Find out more about carer-specific technology, apps and online services on Carers UK.



It may also help to tell someone else where the information is and what to do if you become unwell. This could be a friend, family member or paid worker.

Support Their Independence

It's important to help them have some control over their care. You may find this means taking a step back or supporting decisions that are not what you would do. But it may also mean that you can find a balance in your relationship, and perhaps a little more time for yourself.

Work with them to find out:

- **How they can help themselves**
- **What support they need from you**
- **Whether there are times that they can cope on their own.**



Find Positives in your Relationship

Looking after someone can change your relationship with them. Sometimes you may feel close and connected. But at other times you may feel angry and irritated. It can help to talk openly and honestly to find ways of coping together.

You could try to:

- **Consider yourself as their friend, partner or family member first and foremost**
- **Talk together about how to strengthen positive parts of your relationship**
- **Find common interests or hobbies to do together as well as day-to-day responsibilities.**



Take a Break and Make Time for Yourself

Try and take a break, especially if you're worried about your own mental health. You may not be able to take a break whenever you need one, but it's important to have some time that's yours.

You may need an hour or two to clear your head, or a day to help you feel more rested. You could go out, have a nap or turn your phone off for an agreed period of time. Try to make time for things you enjoy.

If possible, try and plan regular breaks into your routine. This can allow you to:

- **Make plans in advance**
- **Give you something to look forward to**
- **Make sure the person you look after knows what to expect.**

Look After Your Physical Health

It's important to try and make time to look after your physical health as best you can.

- Try and eat as healthily as you can and do some kind of regular physical activity.
- Try to get enough sleep, as a lack of sleep can make it harder to cope with everyday challenges. It can also make stress and depression worse.
- Use relaxation techniques, as these can help your mind and body feel more rested. You need just a few minutes a day to do most of these exercises.



Support for Carers Including Young Carers in BLMK

Carers in Bedfordshire: <https://carersinbeds.org.uk/>

Carers in Milton Keynes: <https://carersmiltonkeynes.org/>

Carers in Luton: <https://carerscentral.org.uk/>

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

Your local Citizens Advice Bureau

ME Association: Caring for a person with ME/CFS

Carers Allowance ME Association: <https://meassociation.org.uk/wp-content/uploads/CARERS-ALLOWANCE-JANUARY-2020.pdf>

Bedfordshire Talking Therapies: <https://www.elft.nhs.uk/bedfordshire-talking-therapies>

Bedfordshire Chronic Fatigue Service: beds.cfs@nhs.net