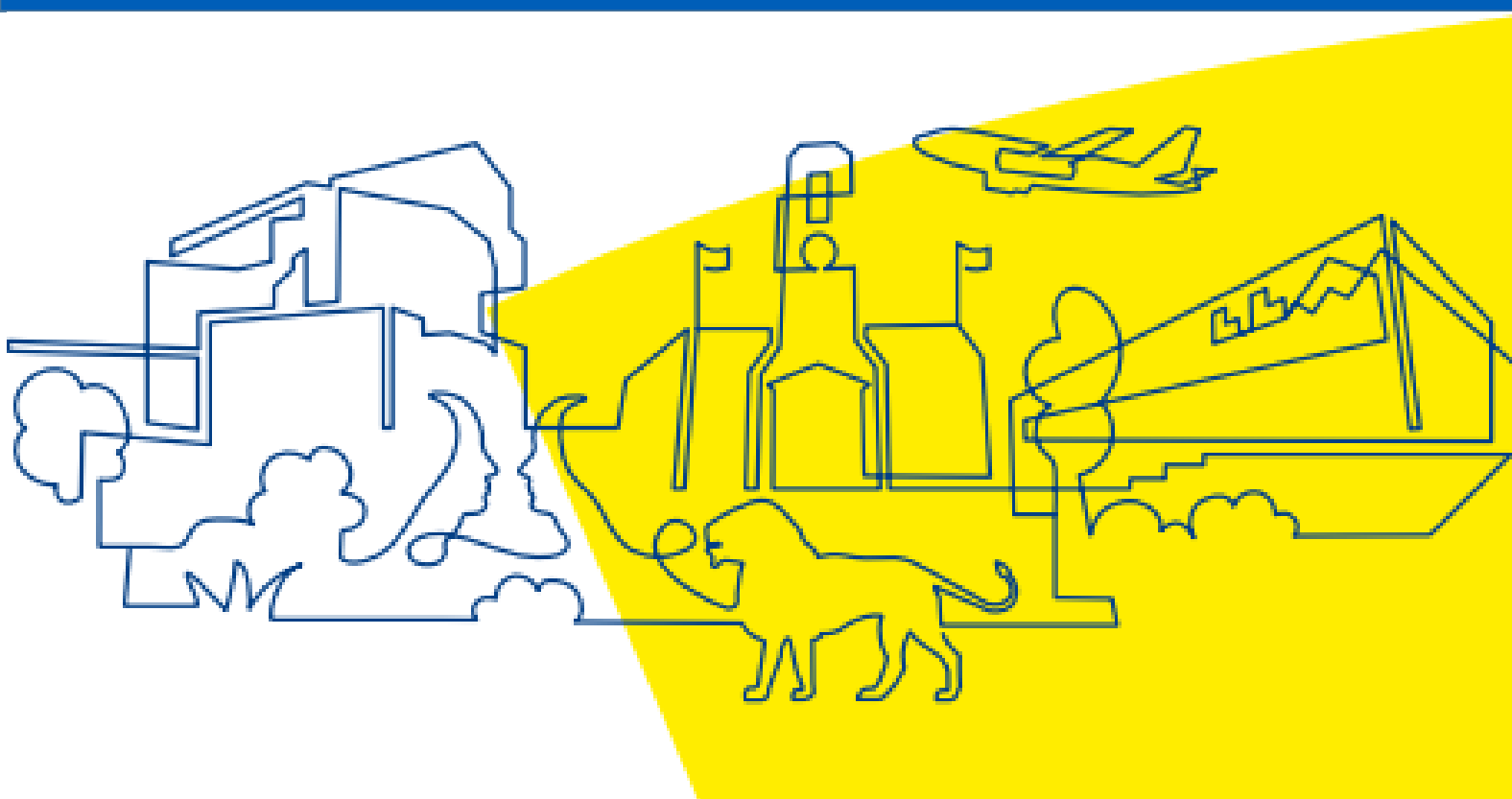




East London  
NHS Foundation Trust

Bedfordshire Chronic Fatigue Syndrome Service

# Carers of People Living With Post Covid Fatigue



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.**

## **Clinical Management of COVID-19 Patients: Living Guideline by the World Health Organization (WHO) States:**

*COVID-19 related impairments, such as fatigue, muscle weakness and cognitive impairment, might impact the performance of activities of daily living (ADL).*

*As people with post covid symptoms regain their strength and fitness, autonomy in ADLs will improve but some will need to accept additional support from a caregiver for a period of time.*

### **Post Covid Fatigue:**

Fatigue is very common after viral infections, such as COVID. Most people feel better within 12 weeks. However, for some people it can last much longer.

We are all familiar with feeling tired after a busy week caused by work, being a carer, intense exercise, or long periods of concentration. However, your loved one's experience of reduced energy levels is felt in a way that does not seem normal. They can feel extremely tired after minimal effort and experience no significant relief despite rest.

This feeling of extreme exhaustion is called fatigue, and it can interrupt your loved one's everyday activities. The usual things that refresh us such as sleep or doing a favourite activity no longer help. Because fatigue is invisible, it can be hard to understand its impact and how disabling it can be for your loved one.

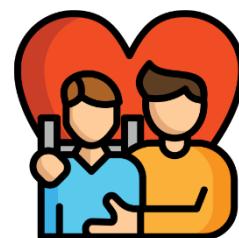
### **Commonly Reported Symptoms:**

- Difficulties with memory and concentration - brain fog, forgetfulness, easily distracted, reduced attention, concentration and focus
- Losing things
- Unable to follow a conversation
- Word finding difficulties
- Worries, low mood and motivation
- Worries about the future
- Feelings of hopelessness
- Reduced interest in valued activities and relationships



### **How to Support a Person With Post Covid Fatigue**

- Validation, being heard and understood
- Support and empathy from friends and family as well as others e.g. work
- Acceptance of the condition
- Encouragement from loved ones



### **What our Service Offers:**

We offer webinar based and 1-2-1 multi-disciplinary interventions and person-centred approaches in line with NICE guidelines

We are a team of Occupational Therapists, Physiotherapists and Psychologists

### **Main session focus areas:**

- Stabilisation of routines
- Identifying and understanding energy limits
- Sleep hygiene
- Understanding the condition and the fatigue
- Acceptance, managing thoughts and feelings related to the fatigue.



Despite vast amounts of ongoing research worldwide, there are currently no evidence-based medical treatments for Post Covid fatigue. There is lots of information about new treatments available on the internet and social media, but these treatments have not been tested in vigorous scientific trials. Subsequently, NHS England has yet to approve any medical treatments for Post Covid. We cannot prescribe experimental treatments for Post Covid or enrol you in any medical trials from this clinic.

### **How to be Referred:**

The challenges can be different for everyone but if your loved one is struggling, **please ask for help**. If their symptoms of post covid fatigue are getting worse, talk to their GP, so they can rule out any other conditions that could be causing their problems.

If their fatigue has become so severe that they often spend all day in bed, request that their GP refers them to the Post Covid Assessment Service. This service consists of GPs, specialist nurses, a respiratory physiotherapist, occupational therapist and a care coordinator. It offers a specialist review of health post covid and they can request advanced testing, as well as signposting to services tailored to your needs.

Once your loved one has been assessed by the medics in Post Covid Assessment Service, they will refer you to our Post Covid fatigue service (PCFS) for more specific and specialist assessment and treatment for post covid fatigue management.

## **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.

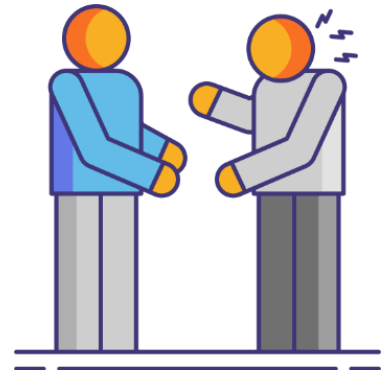
**If you need help or advice for yourself now:**

- 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
- And 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

Your local Talking Therapies - IAPT