

LONG COVID -FOR FAMILY AND FRIENDS



WHAT IS LONG COVID?

Long Covid describes the symptoms that develop during or following a Covid-19 infection, which continue for more than 12 weeks and cannot be explained by an alternative diagnosis.

Long Covid a new condition, therefore we still don't fully the condition but research is ongoing. Most often people with Long Covid report clusters of symptoms that can fluctuate throughout the day and can impact any system within the body. The severity of illness after catching Covid-10 does not indicate the severity of your symptoms.

SYMPTOMS OF LONG COVID

- | | |
|--|--|
| <input type="checkbox"/> Fatigue | <input type="checkbox"/> Fatigue |
| <input type="checkbox"/> Breathlessness | <input type="checkbox"/> Palpitations/ heart issues. |
| <input type="checkbox"/> Headaches | <input type="checkbox"/> Pain |
| <input type="checkbox"/> Poor sleep | <input type="checkbox"/> Brain fog |
| <input type="checkbox"/> Post exertional malaise (PEM) | <input type="checkbox"/> Skin changes/ allergies |
| <input type="checkbox"/> Anxiety | <input type="checkbox"/> Low mood |

This list is not exhaustive but gives examples of the types of symptoms a person with Long Covid can experience. Let's look at some of these symptoms in more detail.

Fatigue

It is normal to feel tired after a day at work etc but unlike fatigue this is quickly relieved by rest. Fatigue is the most commonly reported symptom of Long Covid and is described as “Extreme and persistent tiredness, weakness, or exhaustion of mental and/or physical origin that is not relieved by rest.”(Dittner, 2004). Those with Long Covid often become exhausted completing everyday tasks that the majority of us take for granted. Fatigue is often categorised under the following energy uses:

- **Physical** e.g. walking, bending, sitting
- **Thinking** e.g. reading, following a Tv programme/conversation.
- **Emotional** e.g. how we feel about something.
- **Social** e.g. being around others, eye contact, non-verbal body language.

To manage fatigue, it is important to monitor and adjust every task in their life, to balance this with the energy they have. This is often referred to as living within their energy baseline.

Post exertional malaise

Post exertional malaise is a response to a trigger which can include stress, over exertion and infection, and can result in symptom exacerbation. For example – when attending a GP appointment a person with post exertional malaise may feel exhausted from the appointment but approximately 48 hours later their symptoms will worsen, which is called a post exertional malaise crash. Symptoms of post exertional malaise crash can include flu like symptoms, limbs heaviness, fatigue, disturbed sleep pattern and difficulty concentrating etc. Pushing through these symptoms can worsen the post exertional malaise crash therefore it is important that any activity must be monitored and balanced with significant rest.

POSTURAL TACHYCARDIA SYNDROM (known as POTS)

Postural tachycardia syndrome (PoTS) is when your heart rate increases very quickly after getting up from sitting or lying down. Some people report symptoms after standing on the spot e.g. washing dishes. Symptoms of POTS can include:

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|---|---|-----------------------------------|
| <input type="checkbox"/> Light-headedness | <input type="checkbox"/> Dizziness | <input type="checkbox"/> Fainting |
| <input type="checkbox"/> Trouble thinking | <input type="checkbox"/> Rapid increase in heart rate | <input type="checkbox"/> Weakness |
| <input type="checkbox"/> Blurred vision | <input type="checkbox"/> Digestive complaints | <input type="checkbox"/> Nausea |

Symptoms are often worse in the morning and can fluctuate day-to-day.

Cognitive Difficulties

Our brains need energy to function, examples of this include our ability to concentrate, learn new information or memory. People with significant fatigue often experience cognitive changes. This is sometimes referred to as ‘Brain Fog’ but is in fact difficulties with all aspects of cognition. Day to day examples include:

- Struggling to keep track of a conversation or chat for a prolonged period of time.
- Regular rests needed when trying to understand an e-mail etc.
- Learning new information is challenging, needing significantly more time and repetition.
- Struggles to sustain a number of mental tasks together.
- Increased word finding difficulties, particularly when fatigued.
- Sensitivity to light and noise e.g. bright lights in the supermarket can leave someone feeling exhausted.

Mental health

It is common with long term health challenges that people experience changes in their mood. This can present as:

- | | | |
|--|--|---------------------------------------|
| <input type="checkbox"/> Periods of low mood | <input type="checkbox"/> Increased anxiety | <input type="checkbox"/> Restlessness |
| <input type="checkbox"/> Frustration | <input type="checkbox"/> Temper | <input type="checkbox"/> Withdrawn |

Feelings of low mood are common after distressing events and major life changes. With Long Covid, especially with it being a new condition, it is normal to feel uncertainty about your health and this can lead to feelings of low mood and helplessness. Recovery can be slow as it takes time for our bodies to recover or adjust which in itself is difficult to manage. This can lead to feelings of frustration and a desire to push yourself, resulting in unhelpful thinking patterns which are not conducive to recovery.

Long Covid effects all aspects of a person's life, including work, hobbies, relationships etc. Support and understanding from friends and family is needed to help a person accept Long Covid and the impact this has on their lives.

HELPING SOMEONE WITH LONG COVID

- **Recognise** their Long Covid. Like other conditions such as ME, Long Covid is still dismissed/minimised by members of society. Long Covid is a real and debilitating condition and your recognition of this can help someone to accept their Long Covid.
- **Talk** together about Long Covid and **ask questions**. Long Covid is a new condition with many answers still unknown. Ask questions about Long Covid and work with your loved ones to best support them.
- **Accept** that planning can be difficult due to the fluctuating nature of Long Covid. Being **adaptable** and accepting of changes to your plan can remove the guilt someone with Long Covid can face.
- **Be ready for change**, something you may have done together for months, years etc may no longer be possible or may need to be adapted. For example shopping together, may be too exhausting and seated activities such as having lunch/coffee or going to 1 shop may need to be considered.

- **Promote** your loved ones independence but recognise that **help may be needed**.
- Long Covid is a complex condition with no known cure therefore **supporting** your loved one to **recognise their symptoms** can help them to start to **self-manage their condition**.

PRACTICAL APPROACHES TO COMMON PROBLEMS

Poor attention/easily distracted

- Give the person time.
- One talker at a time
- Reduce distractions in background such switching off TV/radio.
- Ensure you get persons attention when talking to them such as sitting close and maintaining eye contact.

Memory/forgetful

- Provide an organised living environment.
- Set up set places for keys, bags etc.
- Use external aids such as calendars, lists and repeat or write things down.
- Talk about the issue.
- Accept repetition.

Problems multi-tasking

- one activity/task at a time, preferable at a time when the person feels best.
- Consider the lighting, temperature and noise of the environment.

Pushing through tasks (work/chores) until exhausted

- Recognise that your friend/family member has a long term health condition which will impact their abilities.
- Gently encourage them to have regular breaks and rest periods to help manage and restore energy levels.
- Support breath work/relaxation/meditations.
- Encourage at least 2 targeted rest periods per day (minimum of 20 minutes).

Low mood

- Keep in contact.
- Listen to their concerns and talk about Long Covid.

- Provide structure and incentives.
- Encourage time out of the house e.g. short walk, sitting in the garden or going for a coffee if possible.

Fatigue

- Consider reducing regular daily routines.
- Prioritise meaningful daily activities to provide structure and that do not worsen symptoms.
- Break down tasks into bite sized chunks.
- Offer help but accept that this may not always be accepted.

Stress

- Provide an emotionally calm, relaxed environment.
- Try not to take it personally if a person forgets what you said or is unable to engage in activities with you as they previously did.
- Be patient.

SUPPORT FOR YOU

Caring for someone with a complex condition such as Long Covid is challenging. It is important to remember to look after yourself first. Additional support is available from local carers services. If you want a referral to one of these services please contact the Long Covid Service on

long.covid@ggc.scot.nhs.uk or 07855 988 800.

We will be happy to provide you with the information for local services.