

## *Friend or Family Support*

You may not think, or want to think of yourself as a carer. Caring for someone can happen quickly, or it can happen gradually over time. The support you provide is very important. We have produced this advice to support both the person living with Long Covid, and the person who cares for them. Every caring situation is unique, it might be providing support with everyday jobs around the home, emotional support, help with administrative tasks or giving personal care. Long Covid will affect not only the person living with the condition, but also the people close to them. You might choose to fill this document in together.

## *How to support me...*

My pre-crash/pre-flare symptoms include...

My common symptoms when I am in a crash/flare include...

When I am in a crash or flare, you can help me by...

When I am **not** in a crash or a flare, you can help me by...

I also want you to know...



## How to support someone living with Long Covid

Some people don't like to think of themselves as a carer, you may have other words for this – supporter, relative, partner, friend. We will use the term carer to describe the role of looking after someone close to you who could not manage without your help.

The person living with Long Covid will need more support than usual, which will help them as they recover or manage their condition. This is a fluctuating condition by nature, meaning that a person will likely have good and bad days. A selection of ways you may be able to help and support them is listed below.

### General advice

***Conserve Energy*** The person will need to prioritise rest to best recover or manage. With Long Covid, pushing past pain or fatigue will not help. Find ways to help with practical tasks (e.g. housework, admin, childcare, lifts) so they can conserve their energy to best look after their health.

***Understand the Condition*** Try to have a good understanding of the condition, there are some useful links listed below. Remember that energy will be used up not just with physical activity, but also mental and emotional activity. You could ask the person about how cognitive and emotional activities affect them. You may want to fill in the first page of this information sheet together, as particular symptoms and needs will vary from person to person.

***Appointments*** People have told us that having someone close to them attend appointments can be helpful. 'Brain Fog' is a common symptom of Long Covid, writing down questions to bring with you to an appointment, taking notes during the appointment or having someone with you can be helpful.

***Without Judgement*** Try to approach situations without judgement and with flexibility. Show the person that you accept and care for them whatever they are experiencing.

*Don't take it personally* The person may need to opt out of things or take part to a lesser extent to look after their health in the long term. They may need to plan any activity much more than others, and there will be times where they may drop out at late notice – this condition is unpredictable.

*Keep inviting them* It will help them feel included, even if they cannot come.

*Ways of communicating* Figure out ways of communicating on a bad day, when they may not be able to have a proper conversation – written cards, a tick-list or agreeing an emoji text are just some ideas

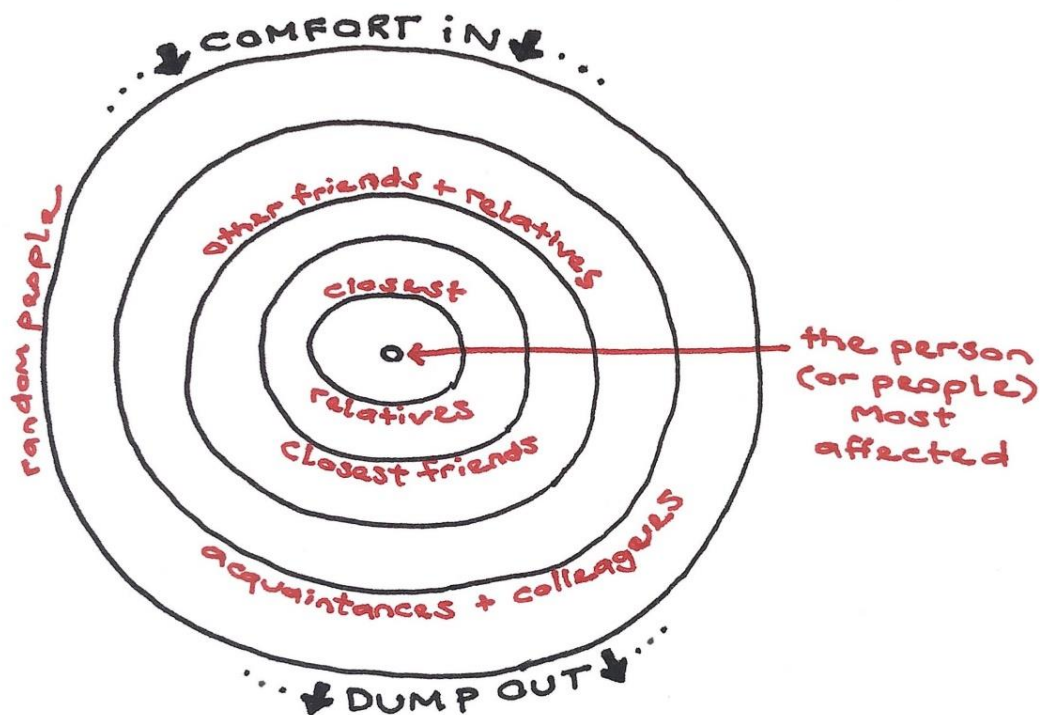
*Allow time and space to rest* Think together about how you may be able to adjust enjoyable activities to fit around what they can manage. Keeping fun in your lives is important!

*Acknowledge* you will both make mistakes as you navigate the journey with Long Covid – be kind to yourself and the person you care for – you are both human.

*Acceptance* As best you can, accept they may be very different from day to day.

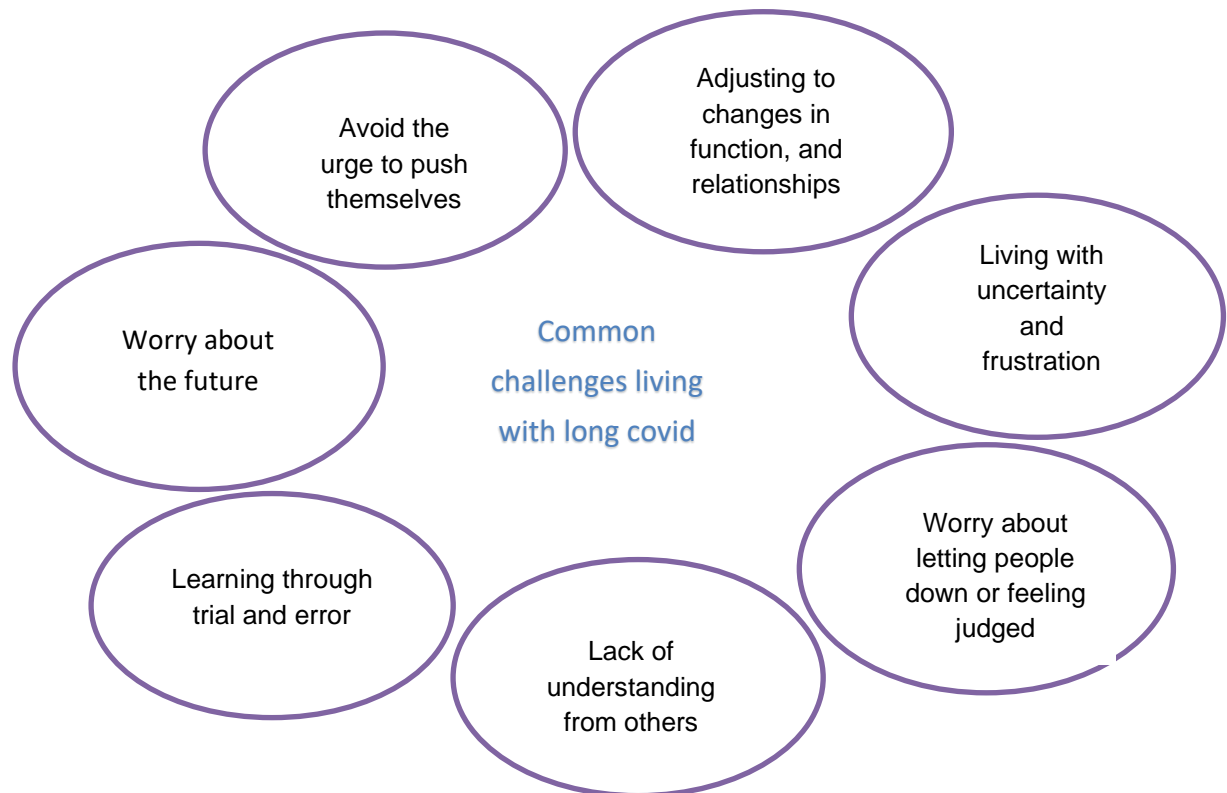
## Ring Theory

Use the “rings theory”: think of the person with Long Covid as the centre and draw a ring around them. Draw another ring around that – in there put the people closest to them (certain family members, partner, close friends), the next widest ring will be less close to them (perhaps other family members, less close friends etc), a wider ring after that will be even less close (maybe colleagues, neighbours acquaintances) and even wider may be people they meet in a shop, friends of friends, people on the internet etc. Think of where you are in those rings. For anyone in a ring closer to the centre than you (which will always include the person with Long Covid), offer support, comfort and a space to listen: “comfort in”. Anyone in a ring further out can be where you “dump out” as a carer, who you can seek out for support, and where you can vent about your own struggles with the situation.



## The impact of Long Covid on carers

There can be many common emotional and social challenges encountered when living with Long Covid, alongside dealing with the symptoms themselves.



### Common challenges for you as a Carer

- Worry about the future
- Living with uncertainty
- Frustration
- Adjusting to changes in the person's function
- Adjusting to changes in your relationship
- Dealing with unpredictability of the condition
- Attending lots of appointments

Long Covid will affect not only the person living with the condition, but also the people close to them. It is understandable for you both to feel frustrated with the situation, miss how things used to be, and worry about what things will look like in the future. They are the person who will need the most support in the situation, and at the same time you will likely share a lot of the challenges as the person you care for.

It will be important to make sure you take breaks and time for self-care as looking after someone else has its own stresses and can be very tiring. Think of the emergency instructions for oxygen masks on airplanes – the crew tell you to put your own mask on before helping others with theirs. The reason for this is if you try to help someone else before yours is on, you may both pass out from lack of oxygen. The same applies to caring – you will be the best support you can be if you are also taking care of yourself and avoid burning out.

## Tips for self-care

Think about others you can call in on for practical support for you to take a break. Sometimes thinking about specific tasks for people you know can be helpful (e.g. my brother can help with childcare on a Friday afternoon, my friend can bring a meal round when they come over to visit).

Make sure not to neglect your own physical and mental wellbeing, including maintaining social connections. As mentioned above, looking out for your own needs alongside those of the person with Long Covid will ultimately ensure you are in a good position to provide care.

As best you can, try to find restorative activities for yourself. Depending on your situation, are there any restful activities you can engage in together with the person you're caring for?

Try to plan in regular breaks from caring as a preventative measure to manage your stress.

Going back to the “ring theory” – who around you are helpful sources to vent or lean on for support, and are further out on the rings? It is understandable that you may also need emotional support in your role.

Just as you need to be accepting and patient with the person you're caring for, try to adopt this attitude for yourself. You will both be going through various emotional and practical challenges, and it will take a lot of trial and error.

It is understandable if you feel stressed with the situation. While they won't change the situation itself, relaxation techniques can help you to take a pause and step back from the situation, even if just for a few moments.

If you are providing a high level of care and feel you need extra support, you can request a carer's assessment from your local authority (see links below)

## Long Covid and intimacy

People tell us that sex and intimacy is a forgotten area that it can be affected by any chronic illness, and Long Covid is no exception. Your intimate/sex life may be affected by Long Covid – this may be due to both physical and emotional changes. There may be concerns about exacerbating symptoms for one or both of you.

Feeling unwell can impact desire, feelings of stressed or anxiousness can impact desire too. The changes brought about by Long Covid may make a person feel less confident about their body. The change in the dynamics of your relationship may also affect how one or both of you feel about intimacy

Intimacy can mean different things for different people, and the same goes for the idea of sex. Talking to your partner about ways you can be intimate that feel manageable for them, and perhaps agreeing what does not feel manageable may increase their sense of control and safety in the situation. See if you can brainstorm together and be creative about what feels intimate for you both, or ways you may be able to adapt physically.

Helpful book around chronic illness and sex: **SEX-INTERRUPTED: Igniting Intimacy While Living With Illness or Disability**

## Places to look for further support or information

An Information Pack about the Long Covid Service was sent to you whilst on the waiting list for Long Covid Service. This has a wide range of information about the condition. You may wish to share this with those you feel close to, as a Carer you might wish to read this to increase your knowledge of the condition.

[Long Covid Information | North Bristol NHS Trust \(nbt.nhs.uk\)](https://nbt.nhs.uk)

North Bristol Trust has a series of videos about Long Covid Syndrome





[Long Covid | London South Bank University \(lsbu.ac.uk\)](https://www.lsbu.ac.uk)

London South Bank University, people living with Long Covid, their Carers and NHS workers have produced materials about what it's like to live with Long Covid.



**Resources and support for carers. These are not specific to Long Covid Syndrome.**

Carers UK offer advice and support for anyone providing unpaid care to a friend or family. They have a helpline (Number 0808 808 7777) open Monday to Friday, 9am – 6pm and are contactable by e-mail ([advice@carersuk.org](mailto:advice@carersuk.org))

Carer Support Centre is a charity providing information, advice, and support to carers of any age in Bristol and South Gloucestershire. They can be contacted on 0117 965 2200 or by visiting their website using the QR code:



**Relationship counselling**

If you feel you are facing problems in your relationship that could benefit from counselling, Relate provide counselling to support relationships.

