



Long COVID multidisciplinary consortium  
Optimising treatments and services across the NHS

FUNDED BY  
**NIHR** | National Institute  
for Health Research

# LONG COVID AND THINKING



**Authors:** LOCOMOTION Cognitive working group members, with contributions from the LOCOMOTION Patient Advisory Group and Dr. Andy Champion (Gloucestershire Hospitals NHS Foundation Trust)

Booklet adapted with thanks from the Leeds and Gloucestershire Long Covid Rehabilitation services.

**Date published:** 6<sup>th</sup> May 2024



## Contents

<b>How to use this booklet .....</b>	<b>3</b>
<b>What is brain fog? .....</b>	<b>5</b>
<b>What causes thinking problems after Covid-19? .....</b>	<b>7</b>
<b>General information .....</b>	<b>10</b>
<b>Section 1: Things that can help .....</b>	<b>11</b>
<b>1. Choosing what is most important to do: .....</b>	<b>13</b>
<b>2. Planning what you do carefully .....</b>	<b>14</b>
<b>3. Taking rest breaks before you need it .....</b>	<b>15</b>
<b>Where to get more help.....</b>	<b>27</b>



## How to use this booklet

---

The LOCOMOTION study is researching the best ways to help people living with long covid by working with long covid clinics to find out:

- What helps people back to work?
- How can wearable technology be used to control symptoms?
- How can long covid clinics be made even better?

(See: <https://locomotion.leeds.ac.uk/> for further information).

We have come together to create this booklet to help you to **understand** how long covid has impacted your thinking skills.

In this booklet we offer different **strategies** that have helped people seen in long covid clinics.

These may not work for all people as we are all different, but it is definitely worth **trying out a few different ones** a few **times** to get an idea of what helps you and what doesn't.

In each section, you can add your own notes and goals.



**Important:** You may want to break up reading this booklet, and think about each section to get the most out of it and avoid making your fatigue worse.

If you are having thinking problems at work, this information may also help you to talk to your employer about **what types of work changes** could help you to stay in work.



## What is brain fog?

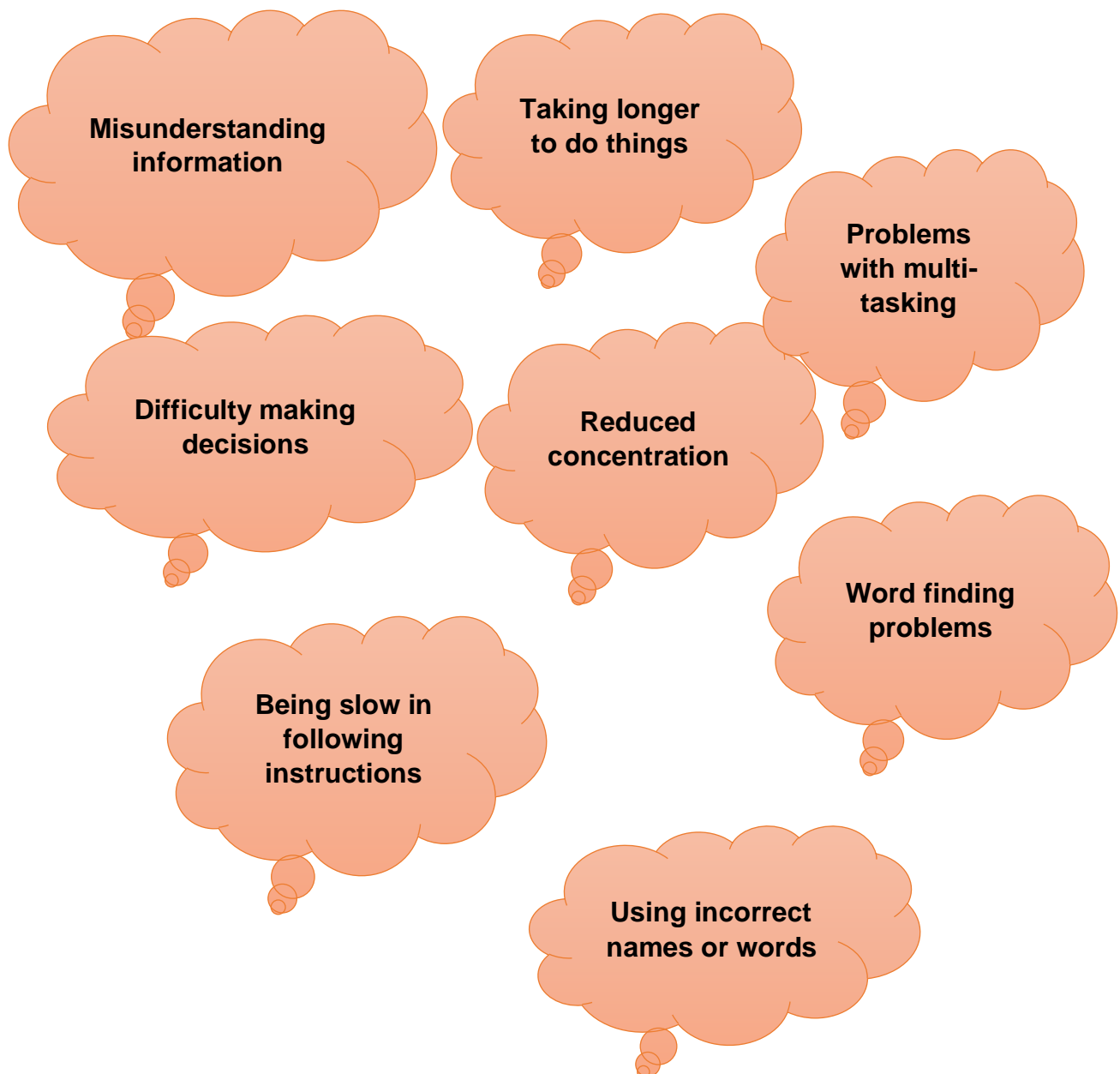
---

You might find it difficult to concentrate and remember information since you have had covid.

You may feel 'jetlagged' all the time, or like your thinking is much slower. It may feel tricky to take in information, which makes having conversations, writing, and reading harder. This is often called 'brain fog' and you are not alone. Lots of people experience this after a serious virus such as covid.

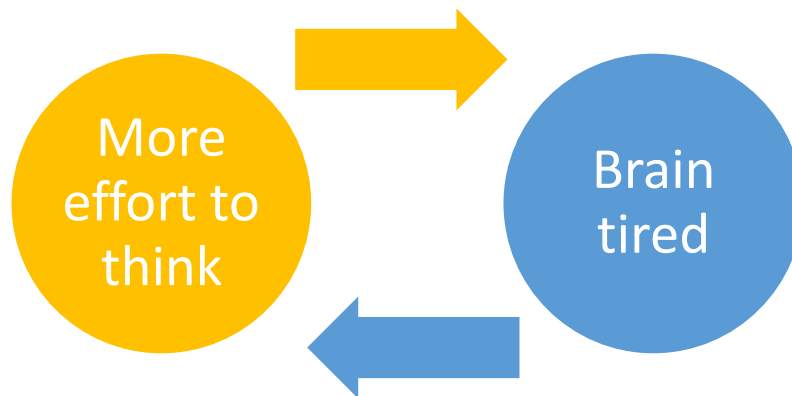
You may find that you make more errors at work now and you may find yourself getting tired much more quickly when you have to focus for a while.

## People with Long Covid describe this like:



## Why does this happen?

It takes more effort to use your brain now, so you get tired. This then makes it even harder for your brain to work, which makes you even more tired! This is like a domino effect:



If you get stuck in this domino effect, then you may find yourself getting moody with people or you might feel overwhelmed and panicky.

**Stopping this cycle** is likely to be one of the most helpful things that you can do for yourself.

## What causes thinking problems after Covid-19?

---

We don't know why Covid-19 seems to affect the brain.

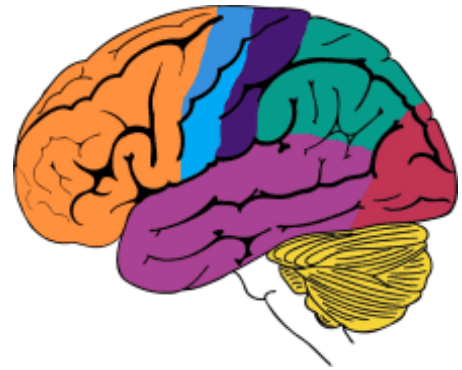
The cause is likely to be different for different people.

But here are few ideas that seem most likely:

1) **Tiredness** – We know that very bad tiredness that isn't fixed by rest (called fatigue) and brain fog are linked.

Some people find that as fatigue improves, they notice less brain fog.

Fatigue is very common with long covid and can be caused by physical and thinking activities, and also strong emotional feelings or situations.



2) **Changes with the brain** – The Covid-19 infection may damage brain areas because the brain protects itself so much that the brain cells cannot make the same amount of energy. This means that brain cells cannot talk to each other like normal.



3) **Being in ‘fight or flight’ all the time** – In long covid, we think that the body stays in fight or flight (this is where your body is ready to run away from danger or fight. It causes lots of changes in the body which are only supposed to happen for a very short time).

‘Fight or flight’ can make people feel very anxious over time and cause problems thinking.



4) **Going over your ‘energy budget’** from doing too much moving or thinking activities.

Brain fog can be a warning sign that you are working too hard and you need to take a rest or do something that helps your energy.



## General information

---

Long covid thinking problems are often compared to having a mild brain injury.

The most common way of helping thinking problems after a mild brain injury is called the **'compensatory'** approach.

This **uses different ways** of making up for difficulties, such as writing notes, using alarms and visual prompts **(see section 2 for further information)**.

It can be very helpful for people who are back at work or getting ready to get back to work.

Using this approach can also set your mind at rest that there is always a backup system for remembering details or for when you need to do something.



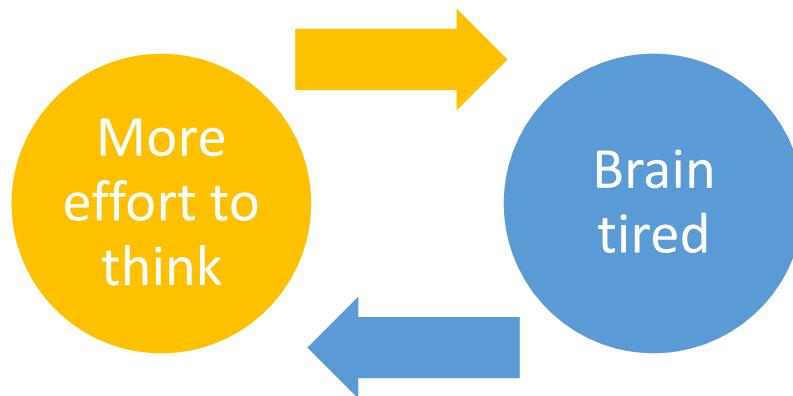
## Things that can help

---

Problems with **concentration** can cause other problems. We might think we have a memory problem but it is actually a concentration difficulty. For example, you may forget to meet a friend because there were a few things going on at once when you arranged it, therefore it never 'went in' in the first place!

The harder it is to concentrate, the quicker you will become fatigued. A conversation with lots of people in a busy place is harder than a conversation with one other person in a quiet room, because you need to concentrate on what many people are saying whilst also ignoring the distractions of what's going on around you.

So, wherever you can, **reduce the effort you need to concentrate**. Sometimes we do this anyway, for example, when we turn off the car radio as we get to a busy junction so that we can concentrate better. Reducing the effort means that you will not get so tired so quickly and set off the domino effect we mentioned earlier:



Try to:

- **Do one thing at a time** and don't multitask. For example, not reading an email whilst talking to someone
- Importantly, **get rid of distractions** (such as noise or things you can see). For example, turn off the TV to concentrate or wear noise cancelling headphones when reading an email for example.

You can also reduce the work your brain is having to do by:

## 1. Choosing what is most important to do:

- If you feel bombarded, **make a list**, work out what is most important, and then tackle one thing at a time.
- You could use different colours for:
  - ‘Things I have energy to do today’
  - ‘Things to be done sometime in the future’
- Remember to be **realistic** with your list and not expect yourself to be able to do everything that you would set yourself before.
- If you are finding that it is difficult to get all the important tasks done on your list, **think about extending the timeframes** for finishing it or ask for help. Most people do want to help but often are unsure how.



- Ask yourself:
  - Does this task really need to be done at all?
  - Am I the only person who can do it?
  - Can it be done later at a time that suits me best?

## 2.Planning what you do carefully

Can you **change how you do an activity to make it easier**? For example, you might change the ironing board so you can sit down to iron.

Many things are more challenging for our brain than we think. It can really help to plan **where** you do tasks, keeping noise and things in your sight to a minimum (for example, you could clear your desk, close your email and switch off your phone to help you concentrate)

You might find it helpful to keep a **diary** to help you work out which things make your brain work less well. For example, if you know **when you can concentrate best in the day**, you can plan to do harder tasks at this time. You could also share this with your manager to help them support you at work.



### 3. Taking rest breaks before you need it

**Taking a rest when you get exhausted** will not help you get on top of your fatigue.

You need to not get to the point of being exhausted in the first place.

The best way to do this is to have lots of **small breaks** from what you are doing and give yourself more time to do things.



This is for **'thinking' activities** much as physical activities.

The key is to **stop before you've gone too far**. This will be different times for different types of things so you will need to **try different time limits** until you're happy that you've found a perfect length of time on a task without feeling exhausted.



You can set yourself **regular, planned breaks** in the day.

If you do this, you can set up a routine that makes it easier to plan what you need to do, and helps other people not to put too much on you.

It is important you are **resting in the rest time** – don't check emails, scroll social media, or make phone calls. Instead, look out of the window, stand up and move around, have a drink of water or breathe fresh air in whatever way you can.

Remember, lots of things that we do to relax are very draining on our attention (i.e. looking on the internet, watching television, reading, speaking to friends, or texting).

It can be very good to break up 'thinking' activities with **moving about** to avoid exhaustion. This may look like 20 minutes of thinking work, with 5-10 minutes of chair stretching/chair yoga (see this animation for ideas: [The Importance of Taking Breaks - The Wellbeing Thesis](#))





Try not say ‘I’ve nearly finished, just another ten minutes...’ because your brain fog **will** get worse, and it **will** take longer to get over from it.

Try not to think ‘I should....’ And instead think: ‘I **should take a rest now** because I’ll be able to do a better job of what’s left if I come back to it later’.

**Working through the fatigue does not help.**



Write a goal here to try something you have read:

.....

.....

.....

.....

.....

.....

.....

.....

Did that work for you? If not, what could you try instead?

.....

.....

.....

.....

.....

.....

.....

.....



## Things to help with remembering:

- Use **lists**.
- Leave **reminder notes** where you will see them such as the fridge door, or next to your toothbrush or kettle.
- Use a **diary or calendar**. If you are a smartphone user, you might have apps on your phone that you can set for specific reminders.
- Some people find that **writing** something down helps them remember it. If this is you, you might not find electronic reminders helpful and you might want to carry a small notebook in your pocket instead or put up a temporary whiteboard at home in your kitchen to jot down tasks for the week.
- **Imagining links**: For example, remembering the name of a new colleague called Catherine by linking the name to a friend also called Catherine.
- **Putting similar** items together e.g. remembering items on a shopping list by sorting them into categories.



Write a goal here to try something you have read:

.....

.....

.....

.....

.....

.....

.....

.....

Did that work for you? If not, what could you try instead?

.....

.....

.....

.....

.....

.....

.....

.....



## If you lose things:

Try getting into a routine of:

- Having **'homes'** for things get lost most. When deciding on these 'homes', try to imagine you have lost the item. The first place you think of to look might be the best place to keep them.
- If you find that you tend to put things away in the wrong place it can help to **talk out loud**. For example, "I have opened the fridge to put away the milk".
- You can also help yourself focus on a complicated task by getting in the habit of **repeating the steps** out loud or in your head. For example, "wet hair, shampoo, rinse, conditioner, rinse"

## Word finding:

Forgetting a word or losing track of a conversation in mid-sentence is frustrating. The first thing to remember is that this happens to almost everyone at some point and that when it happens it is not as obvious to other people as it is to you.



It can be helpful to use another similar word, or to describe the thing you are trying to say.

For example, if you are trying to say 'oven', and you think through how you would use the oven you might quite quickly think 'the thing you cook food in/on', which would lead you to use the word 'cooker' instead.

### Medication:

If you struggle to remember to take medication (or can't remember taking the last dose) then consider the following strategies:

- Have a **list of your medication** so you know what you are taking and when. Talk to your community pharmacist or your GP if you need help. They may be able to **simplify** the number of doses or times of day you need to take your medication.
- Get a **pill box** so you have a reminder whether you have taken your medication or not.
- Have a **routine** to tie taking medication with something you do at the same time. For example, if you always have a cup of tea in the morning, put your morning pills next to

the teabags. If the last thing you do at night is brush your teeth, put your night-time pills next to your toothbrush.

- **Set reminders on your phone or Alexa device** (e.g., have an alarm called ‘inhaler’ at 8am)



### Cooking:

- **Try not to multitask** when cooking to avoid burning food and make sure you have a working **smoke detector**.
- Unless using a slow cooker, don't walk away from food when it is cooking and always use a **timer**. Even if you don't remember what the timer is for, you will know you need to check something.
- You may find it helpful to have a stool in the kitchen to manage energy levels when waiting for food to cook.
- Consider batch cooking and **freezing** portions of food. On days when you don't have the energy to cook, you'll have

home cooking you can microwave. Pre-cut vegetables and frozen pre-pared vegetables can save energy.



- If you get muddled with recipes, get into the habit of putting everything you need out at the beginning and put things away as you use them.

#### If you are worried:

If you are worried for your safety because you are frequently leaving the gas/oven on or you live alone, please get further help from your GP. You do not need to struggle alone.

If you are worried about working safely, you can talk to your manager or request a referral to occupational health.

If you have episodes of serious confusion, lose movement, feeling or vision, a referral to a neurologist may be required (usually through a GP or long covid rehabilitation service).





## A Final Word

The most important things are to decrease:

- 1) **How often** you experience brain fog.
- 2) **How badly** it is when it happens.

The key way to do this is:

- 1) **Reduce how much you need to concentrate on the task.**
- 2) **Plan regular rests.**

Sometimes there will be hiccups because of work, health or family needs. The important thing is to come up with a plan where you get **more rest** than you get now, even if it isn't the 'perfect' plan.

Breaking up one long spell of concentration by taking a 10-minute break is better than nothing.

Sometimes the **pressure that we put on ourselves** is actually the hardest thing to see. Stopping before you've finished something doesn't always come naturally. It's easy to feel guilty.



## How to start...

Think about how you have spent today so far (or how you spent yesterday).

Were there parts of the day when you **were struggling** because you were trying to think about too many things at once? Make a note of these:

.....

.....

.....

.....

.....

.....

Now, think about **how you could do things differently** (i.e., giving yourself more time, more breaks, getting rid of distractions, doing one thing at a time, saying 'no' or asking for help)

.....

.....

.....

.....



Try to get into the habit of **learning** from what went well and what didn't, then apply that to the days ahead. Think about the week ahead, looking out for things that you know will be tiring and what changes you can make in **advance** that will help you manage your fatigue mental better.

## Where to get more help...

---

### Long covid specific:

- Local **Long covid rehabilitation service**, if available in your local area. Referral is via your GP.
- The **Long covid Physio website** has a range of resources and podcasts around long covid symptoms, including cognitive dysfunction:  
<https://longcovid.physio/brain-fog>.
- Peer support can be access through the largest **Long Covid online group** (requires a Facebook account):  
<https://www.facebook.com/groups/longcovid>



## Further help for cognitive problems:

- **Headway** - the brain injury association | Headway provides further information leaflets and advice for people with acquired brain injury and may be applicable to your symptoms, especially around fatigue management.
- Other conditions such as CFS/ME also experience brain fog, and the main **ME charity website** provides freely available information on managing cognitive problems <https://meassociation.org.uk/literature/items/cognitive-dysfunction-brain-fog/#> and also offer peer support: <https://meassociation.org.uk/>.
- The **Royal College of Speech and Language Therapists** has developed factsheets on cognitive related speech difficulties. See: <https://www.rcslt.org/news/new-long-covid-guidance-and-patient-handbook/>
- For an activity diary template (see page 19 of the CFS/ME workbook developed by **Torbay and South Devon Trust**): <https://www.torbayandsouthdevon.nhs.uk/uploads/25262.pdf>

## Fatigue:

- The **Royal College of Occupational Therapists** has developed useful guidance on managing long covid related fatigue: <https://www.rcot.co.uk/recovering-covid-19-post-viral-fatigue-and-conserving-energy>



## Sleep:

- There are a range of **sleep aid digital apps** that blend a CBT approach with expert sleep techniques and allow you to build your own personalised programme then track changes over 6 weeks. Sleepio is the only NHS recommended and research supported app for insomnia (Dan Denis 1, 2020) (Colin A Espie 1 2, 2019): <https://www.sleepio.com/sleepio/nhs/120#1/1> - It is freely available in Scotland via NHS services or through some employer support schemes.

## Work:

- For employment related matters needing further guidance and advice: <https://www.acas.org.uk/advice>

## Diet:

- For access to food diary templates and webinar information on nutrition and Long Covid, see the **University of Plymouth** knowledge hub: <https://www.plymouth.ac.uk/research/dietetics-and-health/covid-knowledge-hub/nutrition-and-covid-19-recovery-talks>