

LONG COVID: MANAGING COGNITIVE CHANGES



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What is cognitive dysfunction/brain fog?

People with Long Covid can find it difficult to concentrate and remember information in the same ways that they did before they were ill. For some people, their cognitive symptoms are mild and infrequent. Others can struggle to cope with daily activities.

Some people call this 'brain fog'. Other people call it 'cognitive dysfunction'. Both terms are valid ways to describe how much harder it is to carry out usual 'thinking skills'.

People describe feeling overwhelmed, 'constantly jetlagged', and that it takes them a lot longer to understand and take in information, which makes having conversations, writing, and reading harder. Errors in some work tasks may be more common, and you may find yourself getting tired much more quickly than before.

You may recognise some of the following difficulties.



The above examples can then form a **vicious circle** – the more effort it takes, the quicker you'll get mentally tired, which in turn makes it even harder to process information, which in turn makes you even more tired, and so on.



If you get stuck in this vicious cycle, then eventually things can reach the point where 'something gives'. Sometimes, at that point people will find themselves being more **irritable** with people than they usually would be, or they feel overwhelmed and start to feel panicky.

Breaking this cycle is likely to be one of the most helpful things that you can do for yourself to reduce the impact of brain fog.

What causes cognitive problems after Covid-19?

There is no single reason why Covid-19 seems to affect the brain. The cause is likely to be different from person to person and may also be different on different days for the same person. Here a few proposed reasons:



- Fatigue We know that fatigue and brain fog are closely linked, and many people find that as fatigue improves, they notice less brain fog. Fatigue is especially common symptom with Long Covid and can be brought on not only by physical activities but also emotional, social, and cognitive demands.
- 2) Changes with the brain Recent evidence suggests that the Covid-19 infection may damage crucial brain regions because the immune system activates the defence response of the brain tissue, known as neuro-inflammation (Horowitz, et al. 2023). This can also cause cells not to produce enough energy and makes it difficult for the brain cells to talk to each other efficiently (Abdel-Mannan, et al. 2020; Francis, et al. 2022; Song, et al. 2021; Yongzhi, 2021).

These inflammatory effects sometimes don't automatically disappear once you start feeling better.

However, it is important to note that we don't yet know the longer-term prognosis of Long Covid, and cognitive problems do improve for some people (Fernández-de-las-Peñas, et al. 2023), especially once fatigue is able to be managed.





3) Dysautonomia – Dysautonomia is where the body's Autonomic Nervous System (ANS) is out of balance. The ANS controls the sympathetic and parasympathetic nervous system, otherwise known as the 'fight or flight' and the 'rest and digest' response.

In Long Covid it is suspected that the body stays in the **fight or flight** response. For some people, this can then become a cycle where increased anxiety leads to increased stress which activates the fight or flight response.

Long Covid symptoms are made worse and there is less energy, which worsens cognitive problems. This is why the management of brain fog is not just about activities for your brain but managing all aspects of Long Covid.



4) Post Exertional Symptom Exacerbation (PESE) – PESE is when symptoms worsen following going beyond your 'energy budget'. This can vary from person to person and can be due to physical, cognitive, social, or emotional effort. Brain fog can be one of your early warning signs that you may be working beyond your energy budget and may be time to take a rest or complete an activity that can boost your energy levels. This can also prevent an episode of PESE.

It is important to note that other health conditions can also cause brain fog, such as vitamin deficiencies, medication side effects, underactive thyroid, and obstructive sleep apnoea, so seek help from a healthcare professional if you continue to experience cognitive dysfunction after Covid-19.



How to use this booklet

The LOCOMOTION study is researching the best ways to treat and support people living with Long Covid (see https://locomotion.leeds.ac.uk/ for further information), by bringing together Long Covid clinics and researchers to explore questions such as:

- What interventions may help people return to work? •
- How can wearable technology be used to track and self-manage Long Covid symptoms? •
- How can Long Covid clinics be developed? •

Patients, researchers, and healthcare providers working on the LOCOMOTION project have come together to create this booklet that can help you manage usual activities if Long Covid has impacted on 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 worth trying out a few different strategies a few times, to get an idea what helps you and what doesn't.

In each section you can add your own reflections, personal strategies, and goals.

Important: You may wish to break up reading this booklet over a period and reflect on each section, to get the most out it and avoid worsening your fatigue.

If you are having cognitive problems at work, this information may also help you to talk your employer about what types of work accommodations could be supportive to help you to stay in work.

Most people living with Long Covid find that making some changes to the following areas can help improve cognitive performance over time by:

- 1) Understanding how brain fog affects you and altering the way that you approach activities that you need or want to do (this booklet offers some strategies you may like to try in Section 1).
- 2) Making some focused improvements to the most powerful contributors to brain function (see further information booklets):
 - a. Working towards quality sleep and rest: LOCOMOTION Sleep and Rest Booklet.
 - b. Addressing current psychological stresses, anxieties, and low mood: LOCOMOTION Movement Booklet





It is likely that concerns about your cognition are impacting on your wellbeing, and it may help to get some extra support with this from someone you trust or healthcare professional.

Remembering that this is a natural response to what you are experiencing can help, and that there is hope that you can gradually overcome these problems with time, effort, and patience.

General principles

In traditional approaches to cognitive rehabilitation therapy after mild acquired brain injury, there are **two** ways of trying to improve thinking skills (Barman, et al. 2016).

These are:

- Strategy Training (also known as 'compensatory strategies'), which aims to minimise the difficulties by using external or internal aids (see section 1). This approach can be particularly helpful for people who are back at work or are preparing for getting back to work. It can also be particularly reassuring as there is always a backup system for remembering details or when to do something.
- Process Training aims to restore cognitive processes by retraining or practising a focused thinking skill such as concentration, synthesising information, or recall (remembering). Process training often involves paper and pen exercises which stimulate specific areas of the brain (see section 2)

Functional Activities Training involves applying the above two types of training into **specific areas of daily life**. It may for example, involve practising these skills as preparation for getting back to work with tasks at home.







Section 1: Practical strategies from the 'compensatory approach'

Often it is a difficulty with **concentration** that causes other problems. For example, what we might think of as being a memory problem (e.g., remembering to meet someone at a certain time) might well actually be a concentration difficulty (e.g., because there were several things going on at once when you were told the information, therefore it never 'went in' in the first place).

The harder the mental effort required to concentrate, the quicker you will become fatigued. A conversation with several 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 several people are saying whilst also filtering out the distractions of what's going on around you.

So, wherever practical, **reduce the effort needed to concentrate**. Sometimes we do this naturally, for example turning off the car radio when we approach a busy junction so that we can concentrate better. Reducing the effort means that you will not get so fatigued so quickly and risk starting the vicious circle below.



A key strategy is doing **one thing at a time** and avoiding multitasking (i.e., doing several tasks at the same time such reading an email whilst talking to someone). Importantly, it also means **reducing distractions** (such as noise or things you can see), so turning off the TV to concentrate or wearing noise cancelling headphones when reading an email for example.

Multitasking is generally a bad idea for everyone because each task gets completed less effectively and causes a temporary increase in the body's stress response.

You can also reduce the amount of input that your brain is having to deal with **by prioritising**, **planning**, **and pacing** (also known as the '3 P's') your daily activities:





1. Prioritisation

If you feel bombarded with tasks, make a list, prioritise what is most important, and then tackle them one at a time. "To do" lists work for some people but it is easy to feel overwhelmed and spend all your energy on small tasks and never have the energy or time to do what really needs doing. If so, try to have two lists: a list of everything that needs doing, and then make a second list of the 1, 2, or 3 things that need to be done



today, and how you are going to do them. Some people like mind-mapping digital apps (like Monday.com or Wrike) to organise their thoughts and move around tasks to 'need to be done', 'Things I have energy to do today' and 'to be done sometime in the future'. For instance, you may prioritise making dinner and replying to an email today, put off grocery shopping to tomorrow, and accept that it doesn't matter if the grass gets cut or not.

Remember to be **realistic** with your list and not expect yourself to be able to do everything that you would set yourself pre-illness. Working within your energy abilities is important for maximising your thinking skills. If you are finding that it is difficult to get all the important tasks done on your list, consider extending the timeframes for completion or if this is not possible, ask for help from family or friends if you can **delegate** some tasks to them. Most people want to support their loved ones but often are unsure how, so being specific in your requests can be helpful.



- Always ask yourself "Does this task really need to be done at all, am I the only person who can do it, or can it be done later at a time that suits me best?" (e.g., ironing).
- If you struggle keeping on top of emails, see if your system has 'tags' that you can use to highlight and prioritise messages so you can find emails that are from a specific person, or relate to a specific project more easily.



2. Planning

- If you do need to do the task, can you **modify** it? (e.g., you might be able to adjust the ironing board so you can sit down to iron your shirt)
- Many tasks are more cognitively challenging than most people think. It can really help to plan where you do them, keeping noise and visual distractions to a minimum whenever possible (for example, clearing the area you are working in, closing your email, and switching off your phone).
- You might find it helpful to keep a **diary** that includes your symptoms (see resource section). This can help you work out if some activities or symptoms make your brain work less well and help you to plan and adapt your day. For example, if you know **when you are most focussed** and productive you can plan to do more demanding tasks at this time of day. You might find it helpful to share this with your line manager to help them support you at work.
- You might find that you now need to attend more medical appointments than you used to. This can mean visits to unfamiliar places. If you have the time, it can help to practice your journey in advance. This can help you recognise the route, be familiar with the parking location



and payment processes, and where entry doors or reception are. It can also be helpful to set aside time each day to make sure you are ready for the following day. You can use this time to make sure you know where everything is that you'll need.

3. Pacing

If you think that by **taking a rest when you get exhausted**, you're managing your fatigue well, this is not the case.

The way to beat the mental tiredness part of this vicious circle is to reduce the demands upon yourself (as much as possible) so that you don't reach 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 (known as pacing), alongside allowing yourself more time for specific tasks when planning.





Pacing applies to thinking activities as much as physical activities such as walking and house jobs.

• The key is to **stop before you've gone too far**. Different activities might have different limits for you, and it'll be a matter of **trying different time limits** until you're confident you've found a manageable length of time on a task without the effects of fatigue kicking in.

To start with (and on bad days) you might need to aim for 2-5 minutes of focus before resting and build up from here.



Alternatively, you can set yourself **regular**, **scheduled** times of the day when you will take your breaks. If you can do this, it has the advantage of establishing a routine that makes it easier to plan your tasks within it, and helps other people get into the habit of not placing demands upon you at set times of day.

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 many of us do to relax are in fact very demanding on our attention (i.e. looking on the internet, watching television, reading, speaking to friends, or texting). This can explain why someone may think that they are managing their fatigue well but are still struggling. They might think they are taking regular rest periods to break the vicious circle, but in fact their rest periods are just a different sort of mental exertion, so are not really rest periods at all!

- It can be extremely helpful to break up cognitive activities with physical movement to minimise the risk of fatigue crashes later. This may look like 20 minutes of thinking work, with 5-10 minutes of chair stretching/chair yoga (see this animation for ideas: <u>The Importance of Taking</u> <u>Breaks - The Wellbeing Thesis</u>) or sitting in your garden with a drink and giving attention to what you can hear, feel, smell, and see.
- As far as it is in your power, do not say 'I've nearly finished, just another ten minutes...' because your brain fog will get worse, and you will take longer to recover from it. Challenge any thoughts you have about 'I should....' with the alternative thought that '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.



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Memory aides can be helpful:

- Make and use lists.
- Leave **reminder notes** where you will see them. Pairing frequent activities with frequently forgotten tasks boosts memory. The fridge door is often a good place at home for reminders, 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 electronic calendars will let you use different colours for different types of meetings or appointments. The visual effect of seeing different colours can help, providing you do not suffer from problems with colour vision.
- Some people find that the act of **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 diary or notebook in your pocket instead or put up a temporary whiteboard at home in your kitchen to jot down tasks for the week.
- Making **mental associations** in your mind: e.g., remembering the name of a new colleague called Catherine by linking the name to a friend also called Catherine.



• **Chunking** (group like items together): e.g., remembering items on a shopping list by sorting them into categories.

Set a goal here to try one of these techniques:

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

Can you think of any other strategies that could help?

Losing common items or getting stuck in the middle of a task:

We know that a routine can help memory by reducing the 'cognitive load', i.e., how much your brain must process. To avoid overwhelming your brain, it can be helpful to get into the following routines:

- Having specific **'homes'** for things that are commonly misplaced such as wallet, keys, or glasses. When setting 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 routinely **talk out loud** while you are completing the task to focus your brain. For example, "I have opened the fridge to put away the milk".
- You can also help yourself focus on a multi-step task by getting in the habit of repeating the sequence either 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 so fear taking too much) 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. They want to help you take your medicines safely and may have suggestions.
- Get a **pill box** so you have a visible reminder whether you have taken your medication or not. All pharmacies sell these. An alternative is writing the day of the week on a blister packet with a





permanent marker so you can look and check you've taken today's dose. Never take two doses at once if you do forget a dose.

- Have a routine and 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 nighttime pills next to your toothbrush. Linking events makes it more likely you will remember and more likely this will become automatic.
- Set reminders on your phone or Alexa device (e.g., have an alarm called 'inhaler' at 8am).

Cooking:

- Avoid multitasking 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 you have energy you can cook, on days when you don't have the energy to cook, you'll have home cooking you can microwave. Pre-cut vegetables and frozen prepared vegetables can save energy.
- If you get muddled with recipes and forget if you have added an ingredient, get into the habit of putting everything you need out at the beginning and put things away as you use them. You then have a visual reminder if you've left anything out.





When to tell someone if you are concerned:

If you are worried for your safety because of cognitive changes (for example, frequently leaving the gas/oven on or you live alone), please seek further help via your GP. You do not need to struggle alone.

If you are worried about your ability to do your working role safely, you may wish to talk to your line manager about this, or request a referral to occupational health.

ACAS (https://www.acas.org.uk/advice) is a good source of advice should you feel that your concerns have not been handled adequately.

If you have significant and on-going cognitive changes following Covid-19 infection or have experienced episodes of acute delirium (confusion), loss of movement, sensation or vision, a referral to a neurologist may be required (usually through a GP or Long Covid rehabilitation service).

Section 2: Practical strategies from the 'remedial approach'

Memory exercises

You can help keep promote brain function by learning something new or starting a hobby. You can also re-train your brain by targeting specific areas of thinking that you would like to work on (such as memory or focus).

*You may find you can only concentrate for a few minutes at a time to start with, but you can aim to spend longer on them as you begin to feel less fatigued, remembering that the aim is to stay in your energy envelope.

Please note that we only recommend challenging your thinking skills when you are less fatigued, and your thinking skills are at their best.



Examples of exercises:

- The card game 'snap' might help sharpen your sustained focus, as well as speed up your processing and reaction times.
- The card game (also known as Concentration, or Matched Pairs) might also help with visual memory. Start with 3 or 4 pairs of cards, mix and lay them face up for a few minutes. Then turn them over and try to remember where the pairs are. Increase the number of pairs over time.
- Simple word or number games might also help there are many to choose from on your tablet or computer, or you can buy puzzle books if you find electronic screens too tiring.



• You can also try to actively recall the last few minutes of something you've just watched or listened to. Spend 5 minutes in a quiet place, really focusing on that information and try to write or verbally recall what you have heard and understood. Try focusing on the meaning of the words not just the words. This can be a particularly helpful exercise if you find that you are struggling to follow conversations or programmes on TV.

Familiar household tasks can also be used in process training such as alternating attention in cooking between two components of a meal (i.e., making toast whilst alternating between checking on a frying egg).

In fact, the **best rehabilitation for your thinking skills is your everyday tasks**. For example, if you lose concentration when reading a book, think about what can be adapted. It could be reducing distractions, limiting how long you read, or reading something less challenging.

Set a goal here to try one of these techniques:

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

Can you think of any other strategies that could help?



A Final Word

The most important goals are:

- 1) To reduce how often you experience brain fog
- 2) To reduce **how severe** it is when it happens.

The two key strategies are:

- 1) Where you can, reduce the level of concentration required.
- 2) Plan regular, effective rest periods.

Sometimes there will be obstacles because of work or family demands. The key is to come up with a realistic plan that is at least giving yourself more rest than you are currently getting, even if it isn't the 'perfect' plan. Even breaking up one long spell of mental exertion by taking a ten-minute break is better than nothing.

Sometimes the obstacle will be the pressure that we put on ourselves. Stopping before you've finished a task doesn't always come naturally. It's easy to feel guilty. But maybe some of the things you usually feel you 'should' do aren't what you 'should' be doing now.





How to start...

Think about how you have spent the day so far (or how you spent yesterday). Were there parts of the day when you felt overwhelmed or were struggling because you were trying to think about too many things at once? Make a note of these:

Now, decide how you could do things differently when that situation comes up again (i.e., allowing more time, more rest periods, reducing distractions, do one thing at a time, say 'no' or ask 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.

Section 4: Helpful Services and Resources

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: <u>https://longcovid.physio/brain-fog.</u>
- Peer support can be access through the largest Long Covid online group (requires a Facebook account): <u>https://www.facebook.com/groups/longcovid</u>

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 Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (CFS/ME) also experience brain fog, and the main **ME charity website** provides freely available information on managing cognitive problems (<u>https://meassociation.org.uk/literature/items/cognitive-dysfunction-brain-fog/</u>) and also offer peer support: <u>https://meassociation.org.uk/</u>
- The Royal College of Speech and Language Therapists has developed factsheets on cognitive related speech difficulties: <u>https://www.rcslt.org/news/new-long-covid-guidance-and-patient-handbook/</u>
- For an activity diary template, see page 19 of the CFS/ME workbook developed by **Torbay and South Devon Trust:** <u>https://www.torbayandsouthdevon.nhs.uk/uploads/25262.pdf</u>

Fatigue:

 The Royal College of Occupational Therapists has developed useful guidance on managing Long Covid related fatigue: <u>https://www.rcot.co.uk/recovering-covid-19-post-viral-fatigue-andconserving-energy</u>

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 (Denis, et al. 2020; Espie, et al. 2019): <u>https://www.sleepio.com/sleepio/nhs/120#1/1</u> - 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, see: <u>https://www.acas.org.uk/advice</u>

Diet:

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



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