# Long Covid

A Guide for

Managers, Colleagues, Schools/Teachers, Friends & Family

A drawing of a rainbow

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**Introduction:**

The focus has been on supporting people to better health whilst, where possible, returning them to work. This guide has been produced to help managers, supervisors, colleagues, Schools, teachers & friends, to understand Long Covid, the side effects as well as what is involved in order to return successfully to work.

A plan has been developed with expert feedback from those who have experience of long COVID, clinicians and partners across the health and care system. It builds on the significant progress made over the past 2 years it sets out actions to ensure support is there for anyone in need, people who require specialist assessments or treatment can access care.

This guide is designed to offer support and understanding for people who have colleagues or friends of people on the ‘road to recovery’.

**Long Covid**:

Post COVID-19 Syndrome is also called long COVID. It describes the signs and symptoms that develop during or following an infection consistent with COVID-19, which continue for more than 12 weeks and are not explained by an alternative diagnosis.

The condition usually presents with clusters of symptoms, often overlapping, which may change over time and can affect any system within your body.

The severity of the illness after catching COVID-19 does not indicate whether you will go on to develop long COVID. In other words, you may have a mild dose of COVID-19 and then develop long COVID. Or, you may have been severely ill with COVID-19 and then suffer no longer term effects.

NICE has issued [official guidance](https://www.nice.org.uk/guidance/NG188) on best practice for recognising, investigating and rehabilitating people with long COVID. The guideline makes recommendations in a number of other key areas, including:

* Assessing people with new or ongoing symptoms after acute COVID-19
* Investigations and referral
* Planning care
* Management, including self-management, supported self-management, and rehabilitation
* Follow-up and monitoring
* Service organisation

The NHS has established 90 post COVID services, providing access to specialist diagnosis, treatment, and rehabilitation. These services offer an integrated multidisciplinary service including physical, cognitive, and psychological assessments, diagnostic tests, and management or appropriate onward referral to post COVID rehabilitation, treatment and other support.

**Common Symptoms**:

There are over 200 known symptoms of Long Covid, which can involve 10 different organ systems, according to the CDC, these symptoms include:

* Fever. [Coughing](https://www.everydayhealth.com/coronavirus/how-to-cope-with-a-covid-19-cough/)
* Difficulty breathing, or [shortness of breath](https://www.everydayhealth.com/breathing-difficulty/guide/)
* [Fatigue](https://www.everydayhealth.com/coronavirus/how-to-beat-covid-19-fatigue-and-get-your-energy-back/)
* [Brain fog](https://www.everydayhealth.com/coronavirus/brain-fog-a-covid-symptom-that-may-linger/) (difficulty thinking or concentrating)
* Joint or muscle pain
* [Headache](https://www.everydayhealth.com/coronavirus/how-to-cope-with-a-covid-19-headache/)
* [Diarrhoea](https://www.everydayhealth.com/coronavirus/could-your-digestive-issues-be-a-symptom-of-covid-19/)
* [Skin rashes](https://www.everydayhealth.com/skin-and-beauty-photos/common-skin-rashes.aspx)
* [Loss of taste or smell](https://www.everydayhealth.com/coronavirus/what-to-do-when-covid-kills-your-sense-of-smell-and-taste/)

Other new symptoms that were not part of the initial bout of COVID may develop for a period after the initial infection, these can include:

**General symptoms include:**

* Tiredness or fatigue that interferes with daily life
* Symptoms that get worse after physical or mental effort (also known as “post-exertional malaise”)
* Fever
* Difficulty breathing or shortness of breath
* Cough
* Pain in the Chest
* Heart Palpitations, Fast-beating or pounding heart.
* Brain fog, Difficulty concentrating.
* Headaches
* Poor Sleep
* Dizziness or feeling lightheaded when you stand.
* Pins-and-needles.
* Change in smell or taste
* Depression or anxiety
* Diarrhoea
* Stomach pain
* Joint or muscle pains
* Rashes
* Menstrual cycles changes.

This is not a comprehensive list. In a study published by the CDC, respiratory symptoms and musculoskeletal pain were the more common symptoms of long COVID.

**The emotional Impact of long COVID:**

The experience of having COVID-19 can be very frightening. It is understandable that the experience and then suffering from ongoing symptoms months after contracting the virus can have a huge emotional impact.

Having ongoing symptoms can cause common problems outlined on the next page:

* Feeling anxious when struggling to catch your breath and when your heart feels like its racing.
* Feeling low in mood.
* Poor sleep.
* Wondering if this will ever go away.
* Worries about getting back to work.
* Worries about family or friends becoming ill and suffering.
* Health experts not always being able to answer all your questions or give explanations.

If you were treated in hospital, you might also experience:

* Unpleasant images from your hospital stay, that might seem to come ‘out of the blue’.
* Nightmares.
* Feelings of panic with any hospital reminders.

**What can help:**

* Avoid watching too much news or social media if it’s making you feel anxious.
* Speak to family and friends.
* Try to do activities that you find enjoyable and relaxing.
* Don’t be too hard on yourself if there are things that you are finding harder to do
* Remind yourself that recovery takes time.
* Focus on what is in your control.

**Wellbeing Action Planning**:

One of the resources we can offer to help a successful transition back to work is a wellness action plan, this aims to offer the patient a place to explain what is happening to them, how it affects their work life balance now compared to their life before Covid. It can also be used as a tool to explain the support they now need to transition back to work.

It is important to remember that their symptoms are a normal part of their recovery following COVID-19.

Worrying and thinking about symptoms can often make them worse. This is partly due to paying attention to something will magnify or increase it.

Often symptoms are linked: meaning an increase in one symptom leads to an increase in another symptom. If they are fatigued their concentration will be affected, this in turn will affect their memory. These lapses of memory can increase anxiety, which increases fatigue. As you can see this goes round in a cycle. Therefore, an improvement in one area should lead to an improvement in another.

During the recovery they will have good and bad days, or ups and downs. This is normal and it is important not to dwell on the negative. Throughout their rehabilitation try to be kind, try to think what advice you might give to a friend rather than being too critical.

(Template at back of guide)

**Fatigue Management**

Fatigue is the most common debilitating symptom that is experienced in long COVID. It is often described as an overwhelming sense of tiredness which can be physical and mental.

Fatigue stops people from returning to work, cooking/ planning a meal, holding, and understanding a conversation and carrying out leisure or family activities.

**Physical fatigue:**

Some people find that when they are fatigued their body feels overwhelmingly heavy and that moving at all takes an enormous amount of energy.

It may be that specific muscles such as those in your hands and legs fatigue very easily and this can depend on the activity that you are doing e.g., writing, walking.

**Mental & cognitive fatigue:**

Many people find that when they are fatigued it becomes difficult to think, concentrate or take in new information and that memory and learning is affected. Some people find even basic word finding and thinking difficult.

The fatigue people are experiencing with long COVID leaves them exhausted after completing the most basic of tasks, and some people wake up feeling as tired as they did when they went to sleep.

Fatigue affects people in different ways, and it may change from week to week, day to day or hour to hour. It may also mean people have little motivation to do anything because they are so tired and/or know that undertaking the smallest task will leave them exhausted. This can make it difficult to explain to family/friends/colleagues.

Helping others to understand their fatigue and how it impacts on them can make a big difference to how they cope with and manage their fatigue.

**Pacing & Recovery**

**The 3 Ps Pace, Prioritise, Plan.**

When recovering from any serious illness most people will experience ups and downs with their symptoms for a variety of reasons.

People tend to use these symptoms to decide how much they do. So, on ‘good days’ they may try to do more, often trying to ‘catch up’ and very often overdoing it. This can result in experiencing a bad day and some people describe this as a ‘relapse’ when they might experience more symptoms and feel low and then are able to do very little.

It is important to remember that all activity takes energy, whether it is physical, mental, or emotional.

They might notice that when they ‘overdo’ things, their symptoms are worse, and they need to rest more.

Resting decreases the symptom so they are tempted to be active again. This is called the ‘boom and bust pattern’ and is detrimental to your recovery.

**Pacing**

Pacing is a strategy that helps to get out of this boom-and-bust cycle and helps to manage activities without aggravating the symptoms.

Developing an activity plan which allows them to stay within their current capabilities and therefore avoid ‘overdoing things’. The levels of activity can then be increased in a controlled way over time as their stamina increases.

By pacing activities, it can ensure that:

* They are controlling the demands they place on themselves.
* These demands are in line with their current capabilities.
* They are exposing their body and mind to these demands in a regular controlled way.

By deciding not to ‘overdo’ activity on good days, it is possible to avoid the severity of symptoms on bad days, therefore making it easier to predict the level of activity they will be able to achieve on any given day.

The first step is to think about how much activity they can carry out at the moment, even on a ‘not so good’ day.

It is important not to compare themselves to others or to how much they could do before.

From this, they will be able to set a baseline of activity. This is the amount of activity they should be able to carry out every day.

**Prioritise**

When energy supplies are limited, you may need to make sure that the energy you use is spent on activities that are the most important to you. It may also be useful to identify what activities in your day are necessary, i.e., which tasks ‘need’ to be done and which do you ‘want’ to do, what activities could be carried out at a different time or day, and which activities could somebody else assist with.

Prioritising activities is very individual and what may be a priority for some may not be for others. For example, it may be important for someone to use their energy to have a shower each morning and for someone else, they may limit this to three times a week to ensure they save their energy to carry out a leisure task that is important to them.

**Plan**

When planning a day or week, spread the activities out rather than trying to fit them all in one day. Think about when energy levels may be at their best and therefore completing high energy tasks at this time.

Can an activity be graded so that it doesn’t have to be completed all at once? E.g., cleaning one room as opposed to the whole of the house.

Before starting an activity, it is useful to think about what you may require completing that particular activity. It is helpful to have an organised working space and ensure that you have all items to hand to avoid having to use more energy going back and forth.

**Cognition:**

Cognition means someone’s ‘thinking skills. People can experience a range of difficulties with their thinking skills post-COVID-19. These difficulties include memory, attention, information processing, planning and organisation.

A common symptom experienced is Brain Fog. Brain Fog is a term used to explain a number of symptoms that affect someone’s ability to think. This involves feeling confused, disorganised, having memory problems, finding it hard to focus and having slower processing of information.

Brain Fog is often made worse by fatigue, meaning the more tired a person is, the more they notice increased difficulty with their thinking skills.

To support their thinking skills, consider the following:

* **Minimise distractions:** Try to work in a quiet environment with no background distractions. It may be helpful to:
  + Wear ear plugs
  + To let people, know that they should try not to interrupt you.
  + If you are distracted when reading text, block off parts of the text using paper, or use your finger as a marker.
* **Complete activities when less fatigued:** When completing a task that demands your thinking skills, plan this for a time when you are less tired. For example, if you tire as the day goes on - then do the more taxing tasks in the morning.
* **Say things out loud:** By saying things out loud like ‘what should I be doing now?’ or ‘Stay focused’ or by reading instructions out loud you can help yourself to stay on the right track.
* **Take frequent breaks:** If the problem is made worse by fatigue, work for shorter periods of time and take breaks. Use “little and often” as a guide and pace yourself.
* **Set yourself targets or goals:** Having something definite to work towards will help you stay motivated. Setting deadlines like “I’ll do that task at 10 o’clock”, instead of “I’ll do my work later on”.
* **Best time and apply structure:** Work out when your best time of day is for doing this kind of work. Try to set up your daily/weekly schedule to take account of this. It may help to plan activities ahead of time. Establishing a daily and weekly routine can also help. Keeping a record, or breaking things down into manageable parts can help, then if you get distracted you can pick up where you left off.
* **Use incentives:** When you achieve a target or goal reward yourself, try something very simple such as a cup of tea or coffee, letting yourself watch a TV programme or going for a walk.
* **One thing at a time:** Concentrate on one thing at a time, do not try to take in too much information at once, as this can lead to mistakes. Do one task then move on to the next.
* **Don’t rush things:** You may find that you tend to rush everyday tasks and end up making mistakes. Take your time and pace yourself.
* **Self-monitor or check and double check your work:** Do this with everything you do. It will be slow and hard at first, but it will become a habit as you get accustomed to it. This is the only sure-fire way of picking up on your own errors.
* **Gain control:** If in everyday conversation you feel you are being ‘overloaded’ and you cannot attend to all the information, ask the person who is talking to you to slow down and/or repeat themself. Be assertive and say something like ‘Excuse me, I think you have lost me, could you repeat that please?’
* **Aids:** Using lists, post it notes, diaries and calendars can all help support your memory and routine.
* **Repeating things:** Immediately repeating something can help.

**Communication:**

Sometimes people experience difficulties with their ability to communicate; this can affect the way that they communicate with other people.

***You may experience one or more of the following difficulties:***

* Understanding what people are saying to them
* Reading
* Putting thoughts and feelings into words
* Having a conversation
* Finding the correct word
* Having slurred speech.

These symptoms can be worse when they are fatigued or feeling stressed. Take time and let colleagues know this is part of long covid and use similar strategies to managing cognition listed above.

**Hobbies & interests**

After an illness they may feel different, they might not want to do the things they used to enjoy.

They may not feel like seeing lots of people at the same time, they might find it hard to concentrate to read or watch television. As they recover, their concentration will get better, and memory will improve.

Encourage activities that they enjoy doing while they recover; this might include starting a new hobby or finding different ways to continue with old hobbies.

It is important to have a balance of ‘work, rest and play’. Try to make sure that each day can be a good balance of ‘work, rest and play’ allowing time to do things they enjoy not only things that have to be done

**Return to work with long COVID:**

If they have a job to return to and wish to return to that job early discussions with the line manager, HR department and occupational health is often a good idea. This will help the employer develop a better understanding of their ongoing symptoms and manageable daily activity.

Returning to work after a long period of ill health can be difficult, a standard phased return can take 6-8 weeks. For a successful phased return, it is important to gain support from everyone around them.

In the case of Long Covid, the symptoms can still affect them during their return, and it may take longer for a successful phased return to be effective, therefore in the case of Long Covid we recommend 8-12 weeks for a phased return.

Before returning to work it is important to think about the physical and cognitive demands. Cognitive demands mean their thinking skills, examples might include attention, problem solving or organisation.

These skills should be compared to how much they can manage at home. Ideally the amount they can do at home should start to match the amount they need to do at work.

It can be helpful to get some ‘feedback’ on their current abilities. This is beneficial as they may have been out of work for some time and may not be aware of how tired or unfit, they are.

Through doing some normal day to day activities at home, they can begin to understand their current abilities.

Examples of activities to try (providing this is safe):

* Sorting through paperwork, and letters.
* Placing books or CDs in alphabetical order.
* Using a computer for email, research, or social media.
* Walking (how long and far will depend on their current abilities and symptoms).
* Helping with a mini-DIY project (do not use ladders or sharp tools).
* Making phone calls, e.g., to the bank, a local shop, ordering a family takeaway.
* Cooking themselves a meal/snack (if it is safe to do so).

Many of these activities need similar skills and abilities that are needed for returning to work. For example, using your home computer for emails and social media can help you to build up your typing skills and concentration.

**What can you as a manager or colleague do to support a successful return to work**:

The best way to support someone is to understand them, take time to listen to what affects them, what are the triggers for their symptoms, no two people will necessarily be affected in the same way,

To support a successful return to work it is often helpful to have a flexible phased return, with fortnightly review meetings with their line manager to agree the next phase of return or make alterations if things are going slower than hoped.

**Reasonable adjustments**

Reasonable adjustments may be required, this could be as simple as taking extra breaks to assist with energy levels or working part of the day initially to allow physical and mental stress relief, it could also be alterations to the workplace, less steps by working on a ground floor where there is no lift, finding a parking space closer to the office or building.

The alterations would always be patient led and dependant on their symptoms, Occupational Health can also help with suggestions on how this might work better, and there are grants that can be applied for to assist with costs incurred, (Access to Work)

The adjustments to their work are to help them manage their symptoms and aid a successful phased return to work, the wellness action plan can be a useful tool to assist with this and discussing it with their GP or long COVID rehabilitation team.

**Resources:**

Long COVID is a new illness, which we are learning more about every day. The following is a list of resources that have been developed to help clinicians adapt to and learn about long COVID.

Not all this information will be useful, but a better understanding can foster a better path to recovery.

1. <https://iapt.awp.nhs.uk/> -IAPT 01225675150
2. [Overview | COVID-19 rapid guideline: managing the long-term effects of COVID-19 | Guidance | NICE](https://www.nice.org.uk/guidance/ng188) - COVID-19 rapid guideline, National Institute for Health and Care Excellence (NICE)
3. [longCOVID\_guidance\_03\_small (fom.ac.uk)](https://www.fom.ac.uk/wp-content/uploads/longCOVID_guidance_04_small.pdf) - The Faculty of Occupational Medicine: guidance for return to work for patients with long-COVID
4. <https://evidence.nihr.ac.uk/themedreview/living-with-covid19/> - National Institute for Health Research (NIHR) resources: Living with COVID-19
5. <https://evidence.nihr.ac.uk/themedreview/living-with-covid19-second-review/> - Living with COVID-19 – second review
6. <https://www.yourcovidrecovery.nhs.uk/> - Your COVID recovery
7. <https://www.pslhub.org/learn/coronavirus-covid19/patient-recovery/resources-for-patients/post-covid-19-syndrome-what-support-can-patients-expect-from-their-gp-r3581/> - Patient safety learning and RCGP resource: Post COVID-19 syndrome: what support can patients expect from their GP?
8. <https://elearning.rcgp.org.uk/pluginfile.php/149508/mod_page/content/72/V2GA%20for%20publication%20updated%20Management%20of%20the%20long%20term%20effects%20of%20COVID-19_formatted_29.10.20.pdf> - The Royal College of General Practitioner’s (RCGP’s) response and top tips for caring for our patients: Management of the long-term effects of COVID-19
9. [C1669\_Long-Covid-Toolkit\_Advice-and-resources-for-healthcare-professionals-in-primary-care\_July-2022-1.pdf (england.nhs.uk)](https://www.england.nhs.uk/wp-content/uploads/2022/07/C1669_Long-Covid-Toolkit_Advice-and-resources-for-healthcare-professionals-in-primary-care_July-2022-1.pdf) - Long COVID: Advice and resources for healthcare professionals in primary care
10. <https://www.mind.org.uk/information-support/drugs-andtreatments/mindfulness/mindfulness-exercises-tips/> - Mindfulness exercises and tips:
11. <https://longcovidfdn.com/> - Long COVID-19 Foundation
12. <https://library.nhs.uk/coronavirus-resources/older-people/> - Older people
13. <https://covidpatientsupport.lthtr.nhs.uk/#/> - Covid-19 specific guidance
14. <https://icusteps.org/> - ICU Steps: the intensive care patient support charity
15. <https://www.yourcovidrecovery.nhs.uk/> NHS Your COVID recovery

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**Some information has been resourced from NICE & CDC websites**

**Thank you to Sarah Harvey for providing the Cover Graphic Image.**

**Wellness Action Plan template**

Name …………………………………………………………. Date ……………………………………

1. What were the working arrangements originally (before Covid) and what would you like to achieve now? If you’ve agreed anything with your manager include that,

An example might be your original working hours, against what you are capable of working now.

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1. Is there anything you cannot manage now that might have been part of your original duties, do you need to make your manager or colleagues aware?

An example might be if you prefer face to face conversations or digital communications when being allocated work, mentoring, or buddying to discuss things you might not want to contact your manager about, are you better in the morning or in the afternoon.

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1. What can be put in place to support your mental physical health at work by you, your line manager or colleagues

An example might be to have regular 1:1 meetings and catch-ups, working flexibly.

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1. How could poor mental physical health affect you and your work?

An example of this could include difficulty to make decisions, struggle to prioritise, poor concentration.

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1. What can trigger poor mental physical health for you whilst working?

An example could be, a change to your work pattern, tight deadlines, something not going well.

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1. What do you do to stay mentally healthy at work?

An example might be regular breaks including a lunch break away from your place of work.

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1. If you are starting to experience poor mental physical health what might your colleagues or line manager see in your behaviour?

An example of this could be tiredness, poor judgement, or fatigue.

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1. What do you want your colleagues or line manager to do if they see these signs?

An example might be to take you to one side and discreetly tell you about it or contact someone that you have notified them about in advance.

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1. Is there anything you could share that might support your mental physical health at work?

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Wiltshire Health and Care is committed to listening to and acting on feedback from patients, staff and the public, whatever their experience within our services. The administration and facilitation of any feedback is carried out by the PALS team. The team should be notified at the earliest opportunity regarding any complaints, concerns, compliments and feedback that is received.

Email: pals.wiltshirehealthandcare@nhs.net

Telephone: 01249 454395

Bath and Northeast Somerset, Swindon and Wiltshire Clinical Commissioning Group

Patient Advice and Liaison Team (PALS):

Email: [scwcsu.palscomplaints@nhs.net](mailto:scwcsu.palscomplaints@nhs.net)

Telephone: 0300 200 8844

This information sheet is available to order in other languages and formats. If you would like a copy, please contact us on 01249 454395 or email: pals.wiltshirehealthandcare@nhs.net