Living well with Long-COVID

Workbook

For use with the Post-COVID group programme

Edited by:

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Name:

safe • compassionate • joined-up care
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Introduction

This booklet is designed to accompany the group intervention programme for people attending the Post-COVID service at CDDFT.

Our group programme is a series of 7 sessions, each 1 hour long, delivered virtually.

The aim of the programme is to provide information and strategies to help and support you to manage your Post-COVID.

This workbook has been developed to go alongside the virtual sessions to provide additional information and to be a resource for you to refer back to.

There are exercises for you to do, which are designed to help you to apply the information to your own individual situation. Throughout each section there are points to give you chance to pause and reflect. At the end of each section is a task or exercise to help you apply everything you have learned in that section.

Working through the exercises alongside the sessions will help you to get the most out of the course.

Ideally, we recommend working through the book alongside the course, working through one section each week. Avoid reading ahead if possible as there is a lot of information, and usually people find the best results if they allow time to think about and apply each section in turn, rather than trying to do everything at once.

At any point, if you need help or support please contact the Post-COVID team.
Meet the team…

These are the staff from the Post-COVID service who deliver our group programme sessions:

**DR CAROLINE GIBSON, MBChB DFSRH MRCGP DipBSLM/IBLM**

Dr Gibson is one of the Clinical Lead GPs for the Post-COVID service at County Durham and Darlington NHS Foundation Trust. She has over 18 years’ experience of working in the NHS and has been working as a GP in the in the County Durham area since 2012. She has a specialist interest in Lifestyle Medicine, with a postgraduate diploma in Lifestyle Medicine, and is an active member of the British Society of Lifestyle Medicine. She is a qualified accredited health coach and has a role working as a Regional Mentor for Health Coaches for NHS England. Dr Gibson is also director of an independent health coaching lifestyle medicine practice, Wellbeing Doctor Ltd.

**HANNAH WYLIE**

Hannah is an Advanced Physiotherapist (PT) working within CDDFT Long Covid Service. She has over five years of experience as a Physiotherapist within CDDFT. As a Physiotherapist she has developed an interest in assessing and managing individuals living with persistent or long-term conditions, impacting both physical and mental wellbeing. Hannah has also completed training in assessment and management of breathing pattern disorders, Motivational Interviewing, Cognitive Behavioural Therapy and Acceptance Commitment Therapy. She is an active participant of both the Chartered Society for Physiotherapy and the national allied health professional Long COVID networks, which help share and develop professional best practice.

**SARAH RICE**

Sarah is an Advanced Occupational Therapist (OT) working within CDDFT Long Covid Service. She has twenty years of experience as an OT, covering a broad range of acute, community and voluntary sector services within both physical and mental health areas. She has a special interest in Palliative Care and its truly holistic approach to assessment and treatment, taking into consideration mind, body, spirit, is central to her ethos of care. She has completed training and developed skills in Cognitive Behavioural Therapy (level 2), therapeutic hypnosis, Postural Stability Instructor (Later Life Training) falls prevention/ risk management and Advanced Communication Skills.
MARIA BROMAGE

Senior therapist, Tees, Esk & Wear Valley, NHS Mental Health Foundation Trust.

Maria trained as Occupational Therapist working in mental health after she qualified. Maria developed a specialist interest in Cognitive Behavioural Therapy (CBT) and gained her PG diploma in 2012. Maria works as a CBT Therapist in persistent physical symptoms service in County Durham and Darlington working in a holistic way focusing on both a person’s physical and mental health and the relationship between the two. Maria has a specialist interest in trauma and is also a practicing EMDR therapist.

KIRSTEN MILLER

Advanced Physiotherapist, County Durham & Darlington NHS Foundation Trust

MARGARET OMOLE

Margaret Omole is an Advanced Occupational Therapist (OT) working within CDDFT Long Covid Service. She has over 13 years’ experience working as a specialist Occupational Therapist providing condition management rehabilitation which impact on both mental and physical wellbeing. She has further training in Motivational Interviewing, Behaviour Activation, Acceptance and Commitment Therapy, Compassion Focused Therapy and Mindfulness. She is a member of the British Pain Association, an active member of the Occupational Therapy Pain Network and the Allied Health and Therapies Long Covid Network.
How this course works

This workbook is designed to go alongside the online virtual course delivered by staff at County Durham and Darlington NHS Foundation Trust.

GROUP ONLINE SESSIONS

- You will receive an email containing:
  - An electronic link to the live virtual sessions
  - An electronic version of the workbook
- You can request a paper/hard copy of the workbook to be sent if required.
- It is a course of 7 virtual online sessions.
  - Usually the sessions run once per week, for 7 weeks, at the same time each week
  - Occasionally we may change the schedule (for example around bank holidays) we will give you plenty of notice of any changes.
- The platform we use is Teams LIVE

DURING THE SESSIONS

- You can hear us, but we can’t hear you – the only way we can communicate is via the chat / Q&A function.
- At the beginning of the session please put your FULL NAME in the chat box to register your attendance.
  - This is the only way we will know you have attended.
  - If you have not registered your attendance and we haven’t heard from you, one of the team will ring you to check you are ok.
- If you need to leave early, please let us know in the chat
- Please type questions and comments in the chat box – please use the anonymous option for comments, alternatively comments will be anonymised by our facilitators.
  - You can type in questions and comments at any time during the presentation. We might not answer them immediately, but we will have plenty of time at the end of the session to cover all comments and questions then if they haven’t already been answered.
- Our Co-presenter will ask questions for you
- Chat box will be moderated
- Please keep your devices on silent during the session to avoid distractions
• You might find it useful to have pen, paper, and your workbook available

• **Please Do not record the session.** Post-COVID syndrome is still a new condition, and our understanding of the best advice and treatments are developing all the time. We regularly review and update our sessions to ensure we provide the most up-to-date information; therefore, sessions may change in line with the latest evidence-based practice.

**HOW TO USE THIS BOOK**

• This book contains the same information as we discuss in the sessions during the course.

• During the sessions you have opportunity to hear the material being explained and can ask as many questions as you like.

• The booklet is designed to be a memory aid after the sessions.

• There are questions and short exercises throughout the book to give you time and space to think about how what you have learned might apply to your own situation.
UNDERSTANDING POST-COVID

What is Post-COVID?
Let’s start by looking at the medical definitions of what Post-COVID is:

**Acute COVID**
- Symptoms of COVID-19 infection at 0-4 weeks from initial infection

**Prolonged-COVID / On-going symptomatic COVID-19**
- Symptoms lasting greater than 4 weeks, but up to 12 weeks from initial infection
- Approximately 20-25%, i.e., 1 in 4 people, who get COVID, will still have ongoing symptoms up to 12 weeks after their initial infection.

**Post-COVID Syndrome**
- Persistent symptoms greater than 12 weeks from initial infection

“Long-COVID”.
- There is no agreed medical definition regarding what ‘Long-COVID’ is.
- ‘Long-COVID’ as a name started on social media and has been adopted for use widely
- Sometimes it refers to symptoms after 4 weeks, sometimes it refers to symptoms after 12 weeks.
- For clarity, throughout this book, we will use ‘Post-COVID’ to refer to symptoms over 12 weeks after initial infection

What are the symptoms of Post-COVID?
The most common symptoms are fatigue, breathlessness, brain fog, and mental health difficulties such as anxiety and depression. However, there are many different symptoms that can be caused by Post-COVID.

Some of the most common symptoms of Post-COVID are shown in the diagram below:
Post COVID is different for everyone
Some people have lots of these different symptoms, and some people have just one or two symptoms.

For example, in our clinic we are seeing people with fatigue as their only symptom, but we are also seeing people with fatigue, and breathlessness and depression and other symptoms.

Symptoms can exist in any combination with any severity.

Symptoms change and vary over time
Many people find that Post-COVID symptoms change over time. You may have good times and bad times. This may occur over the course of a day, over a few days, or over weeks at a time. All of these are possible patterns with Post-COVID.

This variability of symptoms over time is called a relapsing-remitting pattern.

Who gets Post-COVID?
Anyone can get Post-COVID
Post-COVID has been reported in all age groups.

Risk factors for Post-COVID
Some things have been identified as making people slightly more likely to get Post-COVID after their initial infection, including older age, being female, being overweight or obese, and having asthma previously.

What happens in the body in Post-COVID?
Before we look at what Post-COVID is, it is useful to have an understanding about how the body is supposed to work when it is functioning normally, and you feel well. Then we will go on to look at what changes in the body when you get ill.
The stress response system

Anything that puts the system under stress causes a stress response. This stress-response system evolved hundreds of thousands of years ago, back in prehistoric times, when we had to be prepared to run away from life-threatening danger, such as a hungry sabre-toothed-tiger, at any moment. In modern life, those types of life-threatening events are thankfully rarer, but the body responds the same way, whether the stress is running away from a tiger, or if we are running late for work.

For example, when we are late for work—our brain sees that we’re going to miss the bus and sends out signals via nerves and hormones to put the body into action. Those signals act on the adrenal glands which produce hormones like adrenaline, and then adrenaline acts on all the rest of the body, which responds to those signals by making changes and taking actions which help us run for that bus.

This diagram shows how adrenaline works on lots of different bits of the body:

Some bits of the body work faster and harder (heart / lungs / liver). This helps the body take in more oxygen, and to get it to the muscles which then help us escape that tiger or run for the bus.

Other bits of the body slow down, such as the gut and reproductive organs. Because the body is interested in immediate survival, it puts less urgent things on hold—such as digestion and reproduction.

When the system is under stress, the other thing that happens is a general inflammatory response through the whole body—a whole cascade of chemical messengers and hormones send signals to the immune system to be prepared for injury or illness.

What is happening in the body?

As well as hormones there is also a network of nerves also controlling all the parts of the body. This is the autonomic nervous system, and this is made up of the sympathetic nervous system and the parasympathetic nervous system. The
sympathetic system can be thought of as the “yes” or “on” switch, and the parasympathetic is the “off” switch.

The sympathetic system is often referred to as driving the “fight or flight” response. As an opposite of this, the parasympathetic system causes the body to “rest and digest”.

The sympathetic and parasympathetic systems and their main actions are shown in the diagram below:

The system is designed to work in balance

Usually, our bodies work in a balance between the sympathetic and parasympathetic state, with most of the time spent in the resting (parasympathetic state).

When the brain spots a threat or stress, it activates the sympathetic “fight or flight” response. All of this is very useful when the threat to the system lasts for a short time. For example – we run for the bus or away from the tiger. The system goes onto high alert for a few minutes, then goes back to doing what it should be doing to keep looking after our longer-term interests.

HOWEVER, when ‘threats’ to the system go on for a long time – whether that is stresses such as emails, intake of too much sugar in the diet for a long time, or infections that last a long time, the balance of the system is tipped towards being constantly on ‘high alert’.

At first, the system works to fight infection.

It’s really useful for the system to mount that “fight” response when we first get COVID, because we need our immune system to turn on to get rid of the infection. But once an infection is cleared, usually the system should settle back down to its resting state. Part of what happens in Post-COVID, is that the inflammatory response keeps going.
In Post-COVID the system has become unbalanced…

After illnesses, such as Post-COVID the balance between the two sides of the autonomic nervous system is upset, so there is too much "on" and not enough “off”.

…this leads to the symptoms that you feel.

When the ‘on’ systems are in charge, those changes in the body keep going, such as high heart rate, faster breathing rate. This leads to the symptoms we feel, for example a faster than usual heart rate may be felt as palpitations, a higher than usual breathing rate may be felt as breathlessness.

Reflective exercise

What symptoms have you had? What might be happening in your body?

Take a moment to think about your own symptoms, and what might be happening in your body which is contributing to your symptoms.

Some examples are shown below. Use the spaces to fill in your own symptoms.

<table>
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<th>Change</th>
<th>What does that cause?</th>
<th>symptoms</th>
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<td>Heart - circulation system</td>
<td>System in a high stress state / Too much “on”</td>
<td>Heart beats faster</td>
<td>Fast pulse palpitations</td>
</tr>
<tr>
<td>Gut - gastrointestinal system</td>
<td>Not enough parasympathetic action (not enough “off”)</td>
<td>Gut moves slowly</td>
<td>bloating</td>
</tr>
</tbody>
</table>
Medical diagnostic tests

Unfortunately, medicine is limited in its capabilities. Because nervous system is working in this balanced way all the time, both parts of the system are normal body processes. There isn’t yet a way to recognise when the balance has changed.

The tests that we do have access to only take a snapshot of how things are at any one point in time, but the system works in this constantly changing and balancing state, which isn’t shown in blood tests or scans that we currently have. This leads to the situation that when you go to the doctors, and are sent for tests and investigations, they often come back normal. In the case of Post-COVID, this does not mean that there is no problem, it just means that the tests haven’t been able to show it.

Tests are important to make sure there are no other conditions causing your symptoms.

For people with suspected Post-COVID, tests are still useful though. Having normal tests (such as blood tests and a chest x-ray for example) enables the medical team to rule out other medical conditions which could give similar symptoms to post-COVID syndrome. An example of this is anaemia, which can also cause tiredness and fatigue, but needs specific further tests and treatments.

How am I feeling?

How you feel at any one moment is affected by lots of different things. It’s not all about the balance of the nerves and hormones in the stress response system that is just one aspect of it. There are multiple inputs into how you feel at any one given time. So far, we’ve only concentrated on one bit, the next step is to look at all the different factors that affect how you feel right now.

The diagram below shows some of the things that are affecting you right now:
How you feel right now depends not only on the effect that Post-COVID may be having on your body, but also on things such as the temperature of your environment (are you too hot or cold?). Are you hungry? Did you sleep well last night? What else is going on in your life? Are you feeling stressed?

For each of these factors, we can think a bit more about why each one might be affecting you at this moment. For example, what physical activity have you done today? How much did you do? How hard was it? When thinking about environment, this can include anything external in the world around you, so might include aspects such as housing, work, but also external things directly affecting the body like medication.
Reflective exercise:
Thinking about the symptom web above, consider what impacts each of the factors for you personally.

Some parts of the web might have more things than another depending on your individual symptoms or experience.
SUMMARY

Post-COVID is complex. Different people have different symptoms, and the same person will have different symptoms at different times.

Medical tests are likely to be normal, but all this means it that the tests aren’t showing how you are feeling right now.

The symptoms that you have are affected by lots of different factors in addition to Post-COVID.

There is no specific treatment for Post-COVID, but by addressing the other things which are contributing to your symptoms may help you to feel better.

FURTHER READING

Links & Resources

- [https://www.yourcovidrecovery.nhs.uk](https://www.yourcovidrecovery.nhs.uk) - NHS site to support COVID recovery
- [https://covid19-recovery.org](https://covid19-recovery.org) a UK based site including patient stories and a resource library
- [https://library.nhs.uk/coronavirus-resources/older-people/](https://library.nhs.uk/coronavirus-resources/older-people/) - support for older people

Support for anosmia:

- [https://www.fifthsense.org.uk/about-fifth-sense/](https://www.fifthsense.org.uk/about-fifth-sense/) - support for people with smell and taste disorders
- [https://abscent.org/nosewell](https://abscent.org/nosewell) -smell training
UNDERSTANDING BREATHING & BREATHELESSNESS

Changes in your breathing or breathlessness is one of the most common symptoms of Post-COVID. Ongoing breathlessness does not often reflect the severity of initial COVID infection.

Breathlessness can be healthy

Before we look at how your breathing might be impacted by Post-COVID it is helpful to understand more about breathing without illness or infection.

Healthy breathlessness is a normal part of life and is something most people will have experienced, most commonly through exercise or physical activity. When we are expecting to feel breathless, such as during exercise, we can even find it positive and enjoyable. In fact, the degree of breathlessness may be used as a measure of how hard you are working.

Breathlessness is a normal adaptation of the body to doing some exercise or a change in activity. Your brain notices that your muscles are working harder, so need more oxygen, so it sends signals to your lungs and chest muscles to take faster or deeper breaths, which allows you to get more oxygen in and your body works more efficiently. This does you good as your cardiovascular fitness (how well your heart and lungs work) improves. When you stop exercising, the breathlessness is dismissed, forgotten about and you move on.

This is summarised in the diagram below:
Breathlessness through illness

When the body is unwell, for example with COVID infection, your breathing pattern will change. Your body needs more oxygen to produce the energy needed by the immune system to fight the infection. Therefore, taking faster deeper breaths or breathing through your mouth is a normal response to illness. However, because the body is under stress, it might seem frightening or feel threatening.

Also, with COVID, there is and has been lots of fear and anxiety around the pandemic and add to that the isolation that has also been necessary from isolating and lockdowns, then all this adds to the sense of fear that we have.

As the acute infection improves and your body recovers, your breathing should return to normal. Think back to the stress response, switching off the ‘fight or flight’ response. However, for some people with Post-COVID this does not happen so easily, and these changes can be habitual. Some of these changes may be conscious and some may be unconscious meaning you might not be aware of them.

This can lead to pattern of avoidance, often stemming from fear. When we become frightened/fearful that you won’t be able to breathe, you may avoid things which make you breathless, often making you less active. In turn this can make you breathless by reinforcing the ‘stress response’ making you feel worse. This can cause lots of other symptoms which you might not directly link to your breathing. Some people may find this all very worrying.

This is summarised below:
Reflective task:

What are the things/tasks which make you most breathless?

Have you continued to do these or avoided them?

‘Good breathing’ – what are we aiming for?

To help understand how your breathing may have been affected by COVID infection and Post-COVID, it is useful to understand what ‘good breathing’ is. We have all been breathing our whole life, however it is normally an automatic process, and we often don’t give it any thought until something changes. As mentioned earlier your breathing will change with activity but should return to normal within a few minutes.

At rest your breathing should feel regular, relaxed, and rhythmical and barely noticeable to you or others around you. The abdomen or tummy should gently rise and fall through relaxed breathing, as the diaphragm works. The breath should enter and leave mostly through the nose (most commonly) and the breath out will normally be slightly longer than the breath in (normally between 8-12 times a minute). Your body doesn’t need a big breath at rest, you need approximately 300-500mls of air (your lungs total capacity is approximately 2.5-3 litres). Overall breathing at rest should require minimum effort.

Altered breathing pattern

What do we mean by an altered breathing pattern?

Some of the most common changes in breathing pattern are taking bigger breaths, quicker or erratic breaths, noisy breathing, upper chest breathing and mouth breathing. All of this means your body is not working in the most efficient way and can upset the ‘bodies balance’ further, switching on or keeping on the ‘fight or flight’ mode. This may lead to worsening of other symptoms such as fatigue or headaches.

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<th>Upper chest breathing</th>
<th>Uses more energy/ causes more fatigue, reduced blood gas stability, less capacity for change</th>
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<td>Mouth breathing</td>
<td>Bypasses the nose which filters, warm and humidifies air before it gets to the lungs. Meaning drier and colder air</td>
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reaches the lungs, sometimes causing chest pain or tightness

| Noisy breathing | Often indicates large gasps of air through the mouth or nose, meaning a larger breath than is needed at rest. Likely increasing energy expenditure |
| Faster breathing | Taking more breaths than needed at rest, can cause dizziness or light headedness, often as lungs don’t empty properly between breaths |
| Air hunger | Coughing, gasping, yawning, or sighing at rest to encourage a larger breath |

How else might your breathing be affecting you?

Changes in your breathing can also cause symptoms or sensation in other ‘systems’ of the body. Although these are caused by your breathing, they can seem unrelated and difficult to understand. They include:

| Dizziness | Chest tightness |
| Lump in the throat | Racing heart |
| Chest pain | Anxiety |
| Tingling in hands, feet, or face | Confusion / detachment |
| Changes in bladder or bowels | Bloating |

All these symptoms are distressing and if noticed or assessed in isolation may result in lots of different medical tests, such as scans. However, if the symptoms are being caused by a change in your breathing pattern, it is likely medical tests will be normal.

This can lead to frustration and people commonly feel disbelieved, however understanding of the impact of your breathing on symptoms can be helpful in gaining control over symptoms.

What else can affect breathing?

As well as the internal factors above your breathing can also be influenced by lots of other factors. Think back to the symptom web (p16), all those things can also impact your breathing. For example, your breathing is greatly influenced by activity, if you increase or change your activity such as a walk or partaking in a long conversation, you may feel more breathless. However now consider you do the same activity, but we change the environment, perhaps you are wearing a face covering or are in a busy or stressful environment. Does the feeling of breathlessness change depending on the environment?
Some people with Post-COVID and an altered breathing pattern find mask wearing challenging. This may be because wearing a mask often encourages mouth breathing, which may be reinforcing an underlying altered breathing pattern.

Stress and/or panic can greatly impact your breathing and perception of breathlessness. It is important to be aware of triggers for panic and have strategies or techniques in place to help manage this. Some things including food or drinks may contain substances which can induce or influence panic. Some of these things may be things you could control and limit, such as caffeine, alcohol, some recreational drugs, and certain additives in foods. However, others may be out of your control, such as medications, for example Salbutamol or Beta Blockers, but being aware of this can increase your control and help you plan management strategies.

Reflective task: Assessing your own breathing
Understanding what should be happening when you breathe can help you to notice the changes in your breathing pattern.

Have a go at following the diagram below. If this feels overwhelming to start with, start with just the first couple of steps.

This should only take a couple of minutes and you should try when you are feeling calm and relaxed.

- Sit or half lie comfortably
- One hand on the tummy and one hand on chest
- Feel – Where is the movement?
- Is the breath smooth?
- Can I hear my breath?
- Where is the breath going? Mouth/Nose
- Is the breath regular?
- How many breaths am I taking in one minute?
- Do I get the urge to sigh, yawn, gasp or cough?
Now what?

After following the above, you might have noticed more about your breathing… sometimes just awareness is enough. Recognising and being aware of the changes is important to help start to retrain your breathing.

Most people find this quite difficult at first, and often slip back into unhelpful breathing patterns. Don’t beat yourself up when it goes wrong, gently practice correcting it.

Like trying anything new, this can be challenging and frustrating initially, as you try to make changes you might experience different or worse sensations initially. If this happens stop, take a break, and try again later. It is important not to force it. When retraining or resetting breathing it is best to start with small and regular practice. Aim for 2-3 minutes at a time, start 2-3 times a day and increase this up to every hour as it becomes easier.

It is often best to take one aspect and start there, don’t try everything at once. For example, can I make my breathing less loud? Can I direct the breath to the tummy? Don’t expect recovery to be quick. It is also common to find progress can slip backwards after you have made some improvement, this is entirely normal, don’t worry about it and just keep gently practicing.

Some specific techniques…

**Air hunger**

- Acknowledge the feelings of needing more air.
- Notice - when does it happen more?
- Sensation of running out of air, consider breathing punctuation- think where would the comma be? Take a calm breath, help to reset your normal breathing pattern.
- Position - if your arms are up/in use this can increase the demand on your body, and you may find increased air hunger or other changes to your breathing pattern. Consider practicing breathing in different positions (once you can do so comfortably at rest)

**Upper chest breathing**

- “Hi-Lo” technique: one hand on tummy, one on chest - increases awareness.
- When lying down, try putting something light on upper chest.
- Lying down – increases the body’s base of support and encourages relaxation/reduces load.
- The beach pose - encourages upper shoulders and chest to relax, so more likely to do diaphragm breathing.
The nose

- Be aware
- Try to make breathing quiet
- Feel the breath - notice something other than the actual breathing, is it cold? Is the air warm?
- Some people find it helpful when practicing use either the hand beneath the chin or some tape to keep the mouth closed. However, for some people this can induce panic, so only do so if you feel comfortable to do so

ENO BREATHE

- Group by the English National Opera, specifically created for Post-COVID
- 6 week virtual group based on basic nursery rhymes (well known to a lot of people)
- Good and long standing evidence that singing can help and improve breathing
- You are on mute throughout the session -not just for singers
- Referral must be completed through the Post-COVID Service – if you would like to be referred, please contact a health care professional in the team

SUMMARY

- Breathlessness can be normal and part of enjoyable experience. However, breathlessness related to illness can feel very different and evoke fear.
- During an acute illness your body might need to breathe differently initially, this only becomes a problem if it does not return to normal after the acute infection or illness.
- Lots of different factors will impact breathing. Good breathing is quiet, rhythmical, diaphragmatic, and relaxed.
- Recognising what may have changed with your breathing pattern can help you make positive changes in your breathing.

FURTHER READING

- Asthma UK and British Lung Foundation. Long COVID | British Lung Foundation (blf.org.uk) – support with breathing and managing breathlessness
- A helpful video about breathing: https://youtu.be/76YC2qlwblU
- Book – How to take a breath, Tania Clifton-Smith
Section 3 - Fatigue

MANAGING FATIGUE

Fatigue is frequently reported as one of the most debilitating symptoms of Post-COVID.

What is fatigue?

Fatigue is a feeling of extreme exhaustion which limits or impacts your daily activity. Fatigue is different to tiredness – fatigue means things which would previously have refreshed you such as sleep, hobbies or exercise no longer do so. Fatigue is often described as a weariness, weakness, lack of energy or ‘crashing’ sensation.

‘A distressing lack of vitality’
NOT ‘just tired’

As fatigue is something which is ‘invisible’ to other people, it is often not noticed by other people. This can lead to friends and family saying, ‘you look better’ or things such as ‘come on, pull yourself together’. When living with debilitating fatigue this can be difficult to hear and can make people feel disbelieved. This in turn can make fatigue symptoms worse.
What does fatigue mean to you?

Fatigue can be an overwhelming symptom that leaves you with little or no energy to do the simple everyday things that you would usually take for granted.

Fatigue is very specific to each person – so how long it lasts and how symptoms affect you is unique to you. You may be able to add to the areas on this slide – but this is generally what fatigue includes…

- You may sleep for long periods but not feel refreshed
- Reduced motivation to do things due to lack of energy
- Decreased concentration, attention, and memory

Types of fatigue:

Fatigue includes both physical and mental and cognitive fatigue. Often individuals living with Post-COVID are much more aware of the physical fatigue than they are of cognitive or mental fatigue.

Physical Fatigue

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

Mental and Cognitive Fatigue

Mental and cognitive fatigue is also extremely common for individuals living with Post-COVID. It is often described as ‘brain fog’ (discussed in the next section) and can include inability to concentrate, problem solve or communicate normally.

Reflective Question:
What types of fatigue are you experiencing?

What causes fatigue?

There are many different causes of fatigue, here are just a few examples:

- **Viral infection** (as in Covid-19, but also other viral infections i.e. glandular fever/flu)
- **Anaemia** - Reduced blood cells to carry oxygen around the body
- **Changes in metabolism** - Abnormal chemical reactions in the body
- **Disease** – Including long-term conditions and cancer
• **Treatments** – fatigue may be one of the side effects of medications and treatments

Fatigue can be a normal part of the body’s response to infection and illness and allows the body to rest and recover. Sometimes following the first phase of an illness fatigue can continue, this is often called post-viral fatigue and can have a significant effect on your daily life.

**Fatigue and Post-COVID**

Fatigue is a very common symptom of COVID-19. Most patients have ongoing fatigue. Studies show between 53% - 94% of patients report fatigue as a symptom of Post-COVID syndrome. It’s certainly the most common symptom we see in clinic.

**What is contributing to fatigue in Post-COVID?**

As shown in the diagram, many things contribute to fatigue…

- **Infection itself** - thought to be a disruption in inflammatory response signals and immune, viral, and endocrine system not working properly (NICE guidelines, 2021).
- **Sleep** routine and pattern is affected and lots of people experience disturbed sleep
- **Environment** – this includes all external factors, examples include:
  - distance in home layout/ work layout
  - People around us, and their level of understanding of how we are feeling
- **Activity** – this includes all the activity we do in everyday life, e.g., moving around, climbing stairs, carrying out work tasks, walking to shops etc.
  - Consider the **type** of activity you are doing – i.e., WHAT it is you have to do?
  - Also think about the **intensity** of the activities you do, i.e., HOW HARD
In terms of activity, it’s important to realise that pushing an already exhausted body can make things worse (see section on post-exertional malaise on p32 below). Even if you’re the type of person who usually thinks, I’ll get on with it and be fine, for many people “pushing through” can delay recovery further!

- **Lack of vitamin D** – seen in many patients. Vitamin D is important for immune system working properly and promotion of sleep
- **Stress/anxiety** – has a physical effect on the body as well as a psychological effect. (See section 5, p56). You also need to think about your personality type and what kind of pressure you put on yourself.
- **Genetics** – everyone’s inbuilt capacity to function is different.
- **Diet** - With little energy, you may tend to go for ‘easy options’ food wise i.e. microwave meals/ high sugar foods. This could have further negative impact as your body struggles without essential nutrients to function efficiently. This is explored further in section 6 (p.69)

Although rest is important in recovery, unlike normal tiredness, fatigue does not improve with rest alone.

All of this means you may struggle, or not be able to resume your usual activities.

**Reflective Question:**
Which of the factors listed above may be contributing to any fatigue you have?

---

**Boom: Bust Cycle**

It is common that your fatigue levels will fluctuate. At times, you may feel that you have a little more energy, during this period you may try to achieve more while you
can, but you may find this leads to increased fatigue and longer periods of inactivity. This is called a ‘Boom:Bust’ cycle.

As your fatigue level will fluctuate day to day it can be difficult to find a level of activity which does not reinforce the Boom:Bust cycle. It is important to try to find a level of activity you can manage that does not result in excessive levels of fatigue, which can also cause increased brain fog, disturbed sleep, and problems with your breathing.

Continuing to reinforce the Boom:Bust cycle of activity will lead to a vicious cycle of reducing activity over time leading to a reduction in function. This often means that fatigue will have a big impact on your daily life, roles, and routines, such as your ability to work or look after children or family. This can cause people a lot of frustration and may impact a person’s mood or make them feel more anxious. In turn, this increases energy expenditure, leading to less energy or more fatigue. There is no quick fix to take away fatigue immediately, but there are strategies to help adapt and manage it until it subsides.

**Post exertional malaise**

Post-exertional malaise (PEM) or post-exertional symptom exacerbation (PESE) relates to a disproportionate and often delayed response to an activity which would previously require low effort. It most commonly related to fatigue; however, it may be an exacerbation or a flare up of any of your Post-COVID symptoms. It is a common symptom of Long COVID and approximately 75% of individuals living with Post-COVID still experience PEM at 6 months post initial infection.

PEM could occur following a range of tasks including, but not exclusive to, daily activities (e.g., a shower), a social activity (e.g., a phone call with a friend), reading or desk work or spending time in a loud, bright, or busy environment. Following an activity, symptoms may typically worsen after 12-48 hours. This can make symptoms feel much more unpredictable, as you may not notice change in symptoms until the following days.

This creates a ‘Boom Bust’ cycle of activity: a period of increased activity followed by a period of increased symptoms, reduced activity and limited function. To help manage PEM it is important to first **stop** over exertion and establish a functional baseline. Rest is an extremely important part of this process, as we will see below.

**How fatigue affects you**

As mentioned already, fatigue can affect you as an individual in lots of different ways. Physically you may feel weak and drained as you try to do activities. It can also affect your thinking skills, you may struggle to concentrate for long periods, or process lots of information at once. You can become trapped in the vicious cycle shown below…
Our patients with Post-COVID tell us that it affects all areas of their everyday life including:

- Roles and routines – whether that be as parent, carer, partner, etc. All of these make up who we are and our sense of self
- Reduced concentration – ‘brain fog’ affecting thinking skills and struggling to process lots of information at once
- Frustration due to lack of understanding from others (friends, family, and professionals).
- Affects restful sleep
- Employment
- Over time, all of this can lead to low mood and anxiety, reduced motivation and less patience

**Overall, there is a negative effect on the quality of life**

We are discovering the effects of Covid-19 from people like yourselves and whilst there is no long history of treating fatigue for this virus, there are tried and tested ways of managing fatigue for other conditions which may be helpful for you.

**WHAT CAN HELP TO MANAGE FATIGUE?**

All daily tasks require the body to use energy through moving and thinking, we usually take this for granted, it happens automatically and with ease. Fatigue can make you feel out of control with your life.

Fatigue management can help you to understand how to make the most of your body’s available energy and to conserve that energy so that it’s most useful to you whilst you recover. It’s about finding ways to balance your physical, social, and emotional needs when your energy levels are reduced.
Pacing

Although there’s no long history of evidence for treating fatigue in Post-COVID as it is a new condition, managing fatigue from other conditions is well known and professionals have lots of experience managing and helping with strategies for fatigue.

Pacing is a self-management strategy which helps to conserve energy and avoid PEM. To pace effectively you need to first find your baseline – this is a level of activity which you can manage on both good and bad days. An activity diary can be useful to help discover your baseline. To best understand your baseline, it is important to recognise early warning signs or triggers to prevent ‘crashes’ or exacerbations of symptoms.

When implementing pacing strategies, it is important to think about your activities over the period of days, weeks and sometimes months. To avoid a prolonged Boom:Bust cycle.

The “three P’s”

Prioritise, Plan, Pace

**Prioritise**

Firstly, it is important to prioritise which activities or tasks are important to you. To do this it is important to know what you normally do in a typical day – often we complete lots of daily tasks without consciously thinking about them. For this you need to think of everything you do in a day – e.g., Getting out of bed, cleaning teeth, washing face, using stairs… Break it down into smallest tasks as they all take energy. An activity diary may help you to review this, see p43 for an example of an activity diary.

Once you are aware of daily tasks consider splitting tasks into categories such as: must do, could do, delegate or dump.

Think about what you want to do, what you need to do and things you’re willing to hand over to others until you recover.

**Plan**

Once you have decided which tasks or activities are important, it is then vital to plan these over the period of days or weeks, with adequate rest periods in-between. Be realistic about what you can manage at present, even though it may be frustrating compared to what you are used to be able to do.

Aim to do the things that are important to you when you are least tired. This may seem like common sense but it’s difficult to do when you’re in a mind-set of high self-
expectation. Often people may be thinking about what they feel they ‘should’ be doing. Self-compassion and acceptance that things are different, for now, is helpful.

Use a fatigue diary to work out the times in the day when you feel best and when you feel most tired and from this a plan can be made.

It can be helpful to interloop different types of activity, spreading out similar activities over the periods of the day. For example, separate tasks requiring a lot of concentration (such as dealing with finances) by doing something more physical (having a shower) in between.

**Pace**

If you have prioritised and planned activities effectively, you should then be able to follow your plan and complete planned activities/tasks. It is important to stick to the plan as much as possible. Sometimes once you start a task, you may think ‘I feel ok’ and try to do more than you originally planned. This can lead to a ‘bust’ or exacerbation in symptoms.

Think about spreading tasks through the day. For example, if it is important to you to cook an evening meal, then prepare veg on a morning if your energy levels are higher then. Think about organising your workspace so that things you need are close to hand. You also need to plan regular rests when you DO NOTHING AT ALL! This might difficult if you are kind of person who is always on go, but it is the only way to look after yourself whilst you recover!

**The 'Human Battery'**

It may be helpful to think about your energy in terms of a battery – just like for your mobile phone battery. **Every task, big or small requires energy.**

You make sure your phone battery stays topped up – it’s important to do this for your own energy stores. **When the battery is flat, there is no option but to stop and ‘re-charge.’**

If we feel like we are fully charged and have lots of energy, it is tempting to do lots and push our limits, only this flattens the battery faster. A drop in energy and trying to ‘run on empty’ can mean that even minimal activity can lead to prolonged fatigue.

**But** it is possible to avoid flattening the battery entirely by learning to manage activity and ration the energy for when it is really needed. Then over time the battery capacity can be increased, building energy levels over time.
To do this you can use the pacing strategies – this helps to avoid draining the battery, taking purposeful, planned rests will help to the battery charge.

Remember to keep your battery charged over **days, weeks, and months**. If some energy is left in the battery at the end of each day, it can be used by your body to grow and repair, and build up reserves for future use with other activities you previously may not have been able to do.

Reflective question:
How often do you let your battery drain down to empty?

______________________________________________________________________________

How do you feel when your battery is ‘empty’?
______________________________________________________________________________

______________________________________________________________________________

What do you do to ‘recharge’?
______________________________________________________________________________

Effective rest

Rest means doing nothing at all! True rest occurs when you **physically** and **mentally** ‘switch off’.

Ideally aim to adopt a ‘doing’ and ‘rest’ pattern through the day.

The important thing is to improve the quality of your rest. Don’t think you are resting when you are sitting down and using your mobile phone or reading online. Aim to recharge and let go of things that don’t need to be done.

There are many different rest and relaxation techniques. What each person finds relaxing will be specific to each person, depending on what they prefer. Use relaxation techniques that work for you.

**Examples of some relaxation techniques that may be helpful are:**

- Mindfulness and meditation (apps)
• Progressive relaxation – working through each muscle group from head to toe to relax the whole body
• Visualisation – See yourself in your mind’s eye, being in your most relaxing place (for example, a place by the sea or in the countryside). Guided visualisations can be useful and there are various online resources to help with this. (see resources p44-45)
Many patients with Post-COVID report problems with their sleep.

It is common for sleep patterns to change when someone experiences post-viral fatigue. Some people will find it harder to get to sleep or wake often in the night, whereas other people may find they are sleeping far more than usual.

Insomnia is difficulty or inability to get enough sleep. People with Post-COVID are more likely to have persistent insomnia as the other symptoms all influence how much you may try to get rest, how much sleep you feel you need, and when you sleep.

If you do not get enough sleep, or your sleep is poor quality, this can lead to:

- Changes in mood
  - Increased anxiety
  - Depression
- Appetite changes
  - Feeling more hungry
  - Craving sugary or unhealthy foods
- Poor memory
- Poor concentration
- Feeling more tired
- Less energetic
- Slower healing or recovery
- Reduced immune function

Managing your sleep patterns can have a positive impact on fatigue management.
HOW TO HELP SLEEP BETTER

PRACTICAL STEPS FOR SLEEP HYGIENE – TOP 10 TIPS

1. Keep a regular sleep routine

   Sleep is controlled by the ‘body clock’ – an area of the brain called the suprachiasmatic nucleus (SCN), it works best with regular routine and predictability.

   Stick to getting up and going to bed at the same time (within an hour) each day. Try to do this regardless of how tired you feel at that moment.

   Keeping your routine stable means you are more likely to get to sleep and wake up with ease.

2. Daylight

   The body clock is heavily influenced by light, exposure to light sends strong waking up signals to the brain. Try to get as much daytime light as possible.

   Keep lights in the evening low. Especially avoid ‘blue light’ (from screens, phones, TV, computers) in the evening. Totally avoid screens for 2hrs before bedtime.

3. Caffeine

   Caffeine is found in coffee and tea, and also in cola and chocolate. Caffeine keeps the brain awake by blocking sleep hormones. It takes a long time for the body to clear caffeine out of the system, for example, if you have a coffee at midday, a significant proportion of it is still in your body at 8pm!

   Limit the overall amount of caffeine you have. Keep the caffeine you do have to before midday.

4. Bedroom environment

   Make your sleeping environment as helpful possible to create good conditions for sleep. An ideal sleep environment is dark, peaceful, and comfortable.

   Keep the temperature cool – not too cold, but not too warm or hot.

   Avoid bringing distractions, or anything that will stimulate your brain and ‘wake it up’ in to the bedroom, keep the bedroom for sleep and sex only.

   Because light disrupts sleep, keep electronic devices gadgets, TV, phones out of the bedroom.

5. Keep physically active

   Being as physically active has been shown to be linked to better quality sleep, fewer wakening’s, better mood, and strengthens sleep routine. For people
with Post-COVID, being physically active may be more difficult, but working within your own capabilities, and being as active as you are able, will help sleep. However, avoid intensive activity shortly before bed.

6. Bedtime routine

Support and train your body clock by creating bedtime habits to encourage the brain to associate the routine with going to sleep.

Some suggestions of relaxing activities include meditation, relaxation techniques, reading, listening to relaxing music. A warm bath before bed can be relaxing, and helps lower the body core temperature which promotes sleep.

Allow yourself adequate down-time to do this.

7. Eating & drinking

The body clock is influenced by food, and vice-versa. Having breakfast helps us get in the habit of waking up and getting up. Having regular mealtimes through the day also supports the body clock.

Avoid eating in the 2hours before bed.

8. Alcohol

Alcohol is a sedative. It is a common misconception that alcohol helps sleep. In reality, alcohol suppresses consciousness but does not produce good quality sleep.

Minimise alcohol intake overall, and totally avoid alcohol for 3hours before bed.

9. Medications

Lots of medication can affect sleep. Some cause drowsiness, which then upsets the natural sleep cycle, others cause insomnia. Combinations of medications can cause extra effects. Be cautious about over-the-counter medications and supplements, which may also have an effect. Speak to your community pharmacist or clinician for specific advice for your situation.

Sleeping tablets, in general, are unhelpful because they are a sedative. Although they suppress consciousness, the quality of the sleep is poorer compared to natural sleep.

10. Medical conditions

Lots of conditions affect sleep, including pain, itch, restless legs, mental health, sleep apnoea, and many, many more. If the conditions are properly diagnosed and treated, it can help sleep. For further specific help, you may need to see a health professional, or a GP.
OTHER FACTORS AFFECTING FATIGUE & ENERGY LEVELS

In this section we will look at some other factors which are closely connected to our energy levels:

- Nutrition
- Pain
- Heart rate
- Exercise

Nutrition & fatigue

The body needs the right balance of energy intake, and nutrients for repair and maintenance, to function well. This is explored in detail in the ‘Diet & Nutrition’ section – see section 6, p69

Pain & fatigue

One common symptom people in clinic report is joint and muscle pain, or generalised body aches and pains. The physical and emotional energy you use in trying to deal with pain can make you feel fatigued. Pain can also contribute to loss of sleep or prevent you from sleeping well, which then adds to fatigue.

In turn, less sleep decreases pain threshold (pain tolerance), so it can effectively appear that pain feels worse.

Sleep is necessary for body to heal/repair itself. A well-rested body has better chance of feeling physically better as sleep supports a stronger immune system and reduces inflammation.

Heart rate

Some people experience increased heart rate or palpitations as result of COVID. If this happens, it usually affects you when you change position, for example standing up. Change of heart rate during activity is a normal body process, and an exaggerated heart rate response can be related to fatigue, and often feels worse when fatigue is worse, as the body is working harder to keep up. Pushing an already exhausted body can also lead to other symptoms such as post-exertional malaise (p32).

Activity, exercise & fatigue

Before looking into resuming activity, it’s important to focus on fatigue management techniques in the first instance. Once you’ve established ways to manage your fatigue and no post exertional malaise, you can look at resuming some activity/exercise.
Although doing exercise may seem to contradict managing fatigue, some specific exercise can be helpful. The specific exercise level that is right for you will be individual to your situation – it may be stretches, short walks, gentle swims, or cycles. It may be helpful to discuss the right level for you with a physiotherapist. Even if you are usually someone who exercises a lot, the level that is right for you now may be a lot less than you have done previously, and this can be built up gradually.

**Fatigue & you**

Your fatigue levels will fluctuate. At times, you may feel that you have a little more energy, there can be a tendency to try to achieve more while you can, but this can lead to increased fatigue and longer periods of rest, as described in the section ‘Boom:Bust’ above (p31) The key is to try to find a level of activity you can manage that does not cause excessive levels of fatigue. It is important to learn to recognise your own triggers of fatigue.

Your fatigue level will still fluctuate but by trying to avoid over-activity or too much rest it stays in a more stable range.

Being aware of your type of personality may help you manage your fatigue too. For example, are you the type of person who feels you usually ‘need’ to finish things once you’ve started them? For people like this, it may take more adjusting to managing your fatigue. However, if you’re usually more laid back and have a flexible approach to life you may find using the suggestions from this section easier.

**Reflective question.**

What effect might your personality be having on fatigue?

_____________________________________________________

_____________________________________________________

Are you the sort of person who feels a need to get everything ‘done’ and ‘perfect’?

_____________________________________________________

_____________________________________________________

Do you tend to push yourself hard?

_____________________________________________________

_____________________________________________________

_____________________________________________________
Before you are able to start and manage your activities and fatigue. It can be helpful to understand your daily routine and current activity level in more detail.

Completing an overview activity diary can also be useful to help identify and patterns or triggers for symptoms.

You may find this link useful to help with strategies to conserve energy: https://www.rcot.co.uk/conserving-energy

| Day       | 00 | 01 | 02 | 03 | 04 | 05 | 06 | 07 | 08 | 09 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 |
|-----------|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|
| Monday    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
| Tuesday   |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
| Wednesday |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
| Thursday  |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
| Friday    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
| Saturday  |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
| Sunday    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |

**KEY**

<table>
<thead>
<tr>
<th>R - Rest</th>
<th>Sitting or lying quietly, but not sleeping</th>
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</thead>
<tbody>
<tr>
<td>B - Busy</td>
<td>Busy time; doing a lot, few breaks</td>
</tr>
<tr>
<td>M - Moderately active</td>
<td>You’re active but not madly busy</td>
</tr>
<tr>
<td>S - Asleep</td>
<td>Sleeping</td>
</tr>
<tr>
<td>C - Crash</td>
<td>When fatigue stops you doing anything</td>
</tr>
</tbody>
</table>
SUMMARY – MANAGING FATIGUE

• Concentrate on activities that you can comfortably manage
• Do small amounts of the things that give you comfort and pleasure
• Common sense and acceptance are key
• Keep a good sleep routine
• Keep hydrated, eat well, and stay gently connected with others
• Give your body the time to heal and recover
• Manage any negative thoughts of frustration or 'should' statements
• Be kind to yourself

FURTHER READING – WEBSITES & LINKS:

For further information about fatigue and pacing:
• Royal college occupational therapy site for managing fatigue post-COVID - Recovering from COVID-19: Post viral-fatigue and conserving energy - RCOT

The Sleep Charity
• Free online information leaflets and other help & support focussed on sleep - https://thesleepcharity.org.uk/information-support/

Websites for sleep help:
• Information to help understand insomnia and sleep disturbance - https://www.nhs.conditions/insomnia
• Information resource to understand sleep disturbance and tiredness - https://www.nhs.uk/live-well/sleep-and-tiredness
• Understanding sleep disturbance and management strategies - https://www.nhs.uk/oneyou/every-mind-matters/sleep

Apps for mindfulness

• Headspace https://www.headspace.com/
• Calm https://www.calm.com
• Insight https://insighttimer.com/
Section 4 – “Brain fog”

NEGOTIATING BRAIN FOG

In this section…

- What is cognition and brain fog?
- Understanding memory
- Thought processing and how to manage difficulties
- Understanding attention and how to cope with difficulties
- Return to work planning

WHAT IS BRAIN FOG?

Since you’ve had COVID you may have struggled with what has been termed ‘brain fog’ - Let’s start by trying to understand it. Brain fog is not a medical or scientific term; it is used by people to describe how they feel when their thinking is sluggish, fuzzy, and not sharp. Brain fog is thought to involve both physiological and psychological factors and is a very common symptom for people living with Post-COVID.

Brain fog is…

- Difficulty remembering things
- Foggy thinking
- Problems with processing thoughts
- Communication difficulties
- Issues with attention and concentration
- Variable - better some days than others

Meaning all those mental processes that seemed to work automatically for you in the past, have become a problem since Post-COVID.

What causes brain fog?

The exact reason why brain fog happens is currently unclear, however research is continuing to learn about the impact of Post-COVID on patients all of the time. It is thought that brain fog is caused by both physical and psychological processes, there is also an element of the inflammatory process which occurs in the body in response to infection. Brain fog is also linked to fatigue and when you are more fatigued, brain fog tends to be worse. All these elements combine to contribute to the sensation and perception that we know as ‘brain fog’.
Brain fog causes many problems…
Just like physical fatigue, mental fatigue can also impact on our ability to do daily tasks and things that we usually take for granted. This may include:

- Managing money
- Reading
- Making shopping lists
- Speaking with people
- Ability to return to work

How does the brain work?
To help with our understanding of what brain fog is, first, let’s take a step back and look at how the brain works when it is functioning well.

What is cognition?
Even before we start talking about what cognition is, it’s important to know that from moment to moment your body’s senses pick up information from the world around us, and from inside the body.

We perceive and process all of this information into our immediate experience of the world – it’s not simply based on input to the brain from the senses, it is also influenced by our own expectations, our past experience and the context in which we see it.

For example, you the smell of burning toast coming from your kitchen and see some smoke starting to form - this triggers your memory of what the smell and sight of burning toast mean and what to do next, along with your thought processing skills to remove danger…then you remember how to pop up the toast from the toaster and decide to do this.

All of this happens so fast that we often take it for granted.
Cognition involves all the mental processes that allow us to perform meaningful actions and behaviours. It includes learning, recognition, memory, attention as well as the ability to plan, monitor and adapt to the changing information around us. Different parts of the cognitive system operate together to reach a common goal.

For example, making a telephone call involves finding the number, remembering it long enough to dial, memory regarding the information you are speaking about and listening to the other person.

Cognition is a combination of:

- Memory
- Thought processing
- Attention
- Communication

All these areas are important but different – to function properly we need them to work together.

Brain fog may mean that you are having difficulty with any of the areas of cognition. You may be finding just one part difficult, but more than likely you will have a combination of problems with them all.

All these areas of cognition are important in daily life, without them it is more difficult to engage in meaningful activity.

The next section will look at each area of cognition in turn.

Understanding memory

Memory is an ongoing system which continues to develop and change over time. Memory is a bit like a filing cabinet or a bookshelf, with memories or facts organised in a particular way.

1. Encoding - the brain’s ability to write the information received by senses into the brain’s filing cabinet
2. **Storage** - ability to retain / keep information in the brain. Can be split into short-term and long-term memory. A messy cupboard vs a tidy cupboard being easier to find things. Also, can be split into factual knowledge, and processes (e.g., walking)

3. **Retrieval** - getting relevant information back out the brain when it is needed. This relies on memories being stored in the right place (e.g., short vs long term memory).

**There are different aspects to memory**
- **Register** – stores and recognises sensory experiences.
- **Short-term store** - few seconds up to couple of minutes
- **Long-term store** – enormous (possibly unlimited) capacity
- **Working memory** – controls processing, moves items between the short- and long-term memory

**There are different types of memory**
Different types of memory include recall of facts and being able to remember processes or procedures (sometimes called muscle memory).

**Problems you may be having with memory**
Individuals we are see living with Post-COVID tell us they are having problems with lots of things connected to their memory.

**Examples of memory difficulties in Post-COVID:**
- Forgetting where you have put things
- Unable to remember phone messages
- Forgetting directions
- Getting lost
- Losing items
- Forgetting where things belong
- Forgetting what people tell you
- Forgetting what you need to do
- Going off on tangents when having a conversation
- Difficulty following a conversation.
Reflective exercise
What problems are you experiencing with memory?

__________________________________________________________________________

__________________________________________________________________________

What effect has this had?

__________________________________________________________________________

__________________________________________________________________________

Strategies to help memory

1. **Making associations** - linking events or facts together. E.g., remember to take your medication after you brush your teeth.
2. **Chunking** - keep similar information together e.g., shopping list, use of journals
3. **Making mental pictures** - images help, seeing it “in your mind’s eye”
4. **Repetition** - helps the encoding process and gives more time for your brain to process
5. **Mnemonics** – using the first letter of a word to remember a collection of things. Often used to remember spelling. For example, other= **O**nly **T**igers **H**unt **E**vil **R**abbits
6. **Rhymes** – rhyming phrases link the auditory part of the brain in, giving it a different way to ‘hook’ into the memory.
7. **Diary / Calendar** – gives a visual reminder of appointments / plans
8. **Journal** - allows time, uses physical writing which introduces a different way
9. Phone/smart device **alarms** – timely reminders, reduces the need for the brain to be keeping track of multiple things at once.
10. Whiteboards / **post-it** notes – gives a visible reminder.

**The strategies that work best are the ones that are meaningful to you**

Can you think of anything else which you might find useful?
Make a note here

---

**Thought processing**

Thought processing includes many aspects which we often use in daily life:

- Ability to sequence; compare, rank, make choices, follow logic, follow rules, predict, question, analyse, link ideas, synthesise, form judgements and opinions, change ideas, imagine...
- Ability to problem solve and plan
- Awareness of own thinking processes

So much of our day to day lives involves processing. You may have found that your own usual thinking processes are not what you would expect at present.

Thought processing can also affect communication i.e., word finding difficulties, slowing of processing what others are saying during a conversation.

**How might brain fog and fatigue be affecting communication?**

- Slow to process what other people are saying
- Word finding: having difficulty finding the right word to use
- Selecting the right topic: not making sense in conversation
- Difficulty reading/ writing and understanding the information
- Slower talking: not getting your words out as quickly as normal
- Putting words together in a clear message
Strategies to help with thought processing difficulties

1. **Slow down!** Don’t rush, take your time
2. **Let people know** that you are struggling - let them know you have had COVID, and this is how you are struggling. People often want to help, but they are busy and might forget
3. Tell people **how** to help
4. **Plan** - Time your interventions for when you are at your best
5. **Describe** what it is that you are trying to say. Work around a word if you can’t find it
6. Use an **alternative** word / phrase
7. **Write** things down
8. Give yourself **time**. Take a few minutes and try again in a bit - frustration raises anxiety levels and then makes it worse
9. **Technology** can help. Use predictive text apps

The strategies that work best are the ones that are meaningful and useful to you

**Can you think of anything else which you might find useful?**

Make a note here

---

safe • compassionate • joined-up care
Attention

Attention is needed for all the other cognitive skills. If you have problems attending then you won’t get the full information, which then leads to problems understanding and/or remembering it.

Attention is part of our everyday language, we ask others to ‘pay attention’, we try to ‘catch’ attention from another, we often say we are ‘absent-minded’ when our attention wanders.

There are many different types of attention - selective, divided, switched, sustained, search/scan, concentration, vigilance.

During everyday activities we use ‘low level attention’, which is an alertness used for familiar tasks which are almost automatic, but higher levels of attention are needed when trying to perform a task in a noisy or unfamiliar environment.

Examples of difficulties people with brain fog and fatigue are having:

- Unable to ignore distractions
- Difficult to focus on more than one thing at same time
- Difficult to move or ‘switch’ your attention between one and another
- Trouble when trying to scan/look for items, e.g., when shopping or at work
- Difficult to concentrate on one thing for a length of time.
- Trouble detecting signals (e.g., timer)
- Easily distracted

Strategies to help with attention difficulties

- Focus on tasks for short time
- Shut out distractions
- Have a balance of activity in the day
- Take regular breaks
- Try and decrease stress/worry/tension
- Take time out from an activity if it is overwhelming
- Start small and for a short time
- Prepare and plan
- Complete tasks when you are less fatigued
- Anything else?
Just like when we are physically fatigued, we need to be doing the 3 P’s (pace, prioritise, plan) for our brains as well! You may find these suggestions useful…

1. **Don’t overdo it** - Focus for a shorter time.
2. Remove/limit **distractions** - think about environment for challenging tasks.
3. Have a **balance** of activity types - cognitive / physical / emotional.
4. Take regular **breaks** – consider what a restful task is for you.
5. **Reduce stress** - Try to decrease stress / worry / tension – try to empty your mind and give a task your full attention.
6. **Rest** - Take time out and change activity.
7. **Start small** and increase gradually. E.g., do an activity for a short length of time initially, then build up to spending longer on it.
8. **Prepare and plan** - e.g., make sure you have things you need to hand before you start a task.
9. **Timing** - plan important tasks for when you are feeling well, know you will have the most energy.

As with the other areas of cognition, the strategies that will work best are the ones that are **meaningful** and **useful** to you.

*Can you think of anything else which you might find useful?*

*Make a note here*
Here is a summary some of the practical tips to help manage brain fog.

Remember the strategies that will work the best are the ones that are meaningful to you.

- Which ones do you think might be helpful?
- How can you put them into practice?
- Write your ideas / plan in the circles.
Section 5 – Living with Post-COVID

Living with Post-COVID

What is it like to live with Post-COVID? In this section we will share the experience of what our patients tell us, and also from evidence in the medical literature. We will share experience from patients with Post-COVID, but also from patients with other long-term conditions, as there are many similarities with many long-term illness, and useful strategies can be shared across both groups.

The purpose of this section is to think about how both the COVID-19 pandemic and Post-COVID have made us feel, and how our mood and relationships are affected.

How has Post-COVID affected your life?

Lots of different aspects of life are affected by Post-COVID:

- Relationships
- Leisure time
- Finances
- Job

This probably is something you have thought a lot about. From experience in our clinic, we have heard from almost all our patients how Post-COVID is having a significant impact on their lives. The diagram above shows some of the areas that are reported most. The effects of Post-COVID are individual to each person, each person may be affected in one, some or all the areas described.

Relationships – this can be with spouse/partner, children, friends, or colleagues. Changes in relationships can be related specifically to symptoms or related to
change in the roles and responsibilities within those relationships. This can have a huge impact on your mood and the way you feel.

**Job** – Post-COVID symptoms can have an impact on your job role and ability to participate in activities. Being unable to fulfil, or having anxiety related to whether you will be able to manage fulfilling your normal roles and responsibilities can lead to a negative spiral of thoughts and emotions. Further information about work p91.

**Finances** – following on from any impact on your occupation/job, this can have a direct impact on finances or money. Employment uncertainty can be an extremely stressful time and lead to worry and anxiety, even without illness. Therefore, the impact on top of being unwell may be more severe.

**Leisure** – normally leisure time would help to balance usual day to day worries or stresses – but when we are experiencing increased pressure on the other areas as we have discussed above, this can mean less time or priority is placed on the things we would normally enjoy. Additionally, since the beginning of the pandemic, there have been many restrictions in place in the form of lockdowns etc, which have limited our access to the activities we would usually use for rest and relaxation.

As shown in the diagram above, all these factors will impact on each other, and they will rarely exist in isolation – this can make each more difficult to deal with.

**Reflective exercise.**

Think about this in relation to your own life – are there any specific issues resulting from COVID-19 which have impacted your life in each of the following areas?

<table>
<thead>
<tr>
<th>Relationships</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Job</td>
<td></td>
</tr>
<tr>
<td>Finances</td>
<td></td>
</tr>
<tr>
<td>Leisure Time</td>
<td></td>
</tr>
<tr>
<td>Other?</td>
<td></td>
</tr>
</tbody>
</table>
We don’t know everything but…

Listening to people’s experiences of COVID and Post-COVID, it is having a significant impact on people lives and people are reporting loss, change and uncertainty and we know that these can lead to depression and anxiety. Whilst a lot about Post-COVID is unknown there is lots which is known about depression and anxiety.

We do know that:

Depression is associated with loss (Post-COVID and the lockdowns have caused losses associated with roles, jobs, finances, identity, people can’t do things the way they used to).

Anxiety is associated with uncertainty and change (what is Post-COVID? How long will it last? What will happen to my future? What do new rules and changes mean for me?)

Anxiety is associated with traumatic and fearful experiences (a lot of people’s experiences of COVID were both of these)

Post-COVID also associated with both anxiety and having experienced traumatic events.

Depression

Some people may have some experience of anxiety and depression, as they are very common conditions, which affects approximately a third of people at some point in their lives. For others it may not be something they are familiar with.

Let’s think a bit more about what some of the symptoms of depression are:
Some of the symptoms of depression are shown in the word cloud above. Notice how similar the symptoms of depression and Post-COVID can be.

Reflective exercise:
How do you think this impacts on Post-COVID symptoms?

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

How will it impact on recovery?

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

Anxiety

Some symptoms of anxiety are shown in the word cloud below:
There is a lot of similarities between the symptoms of Post-COVID and the symptoms of anxiety. Both anxiety and depression have lots of physical body symptoms that themselves can cause worry and anxiety.

And, for people who are experiencing anxiety and/or depression together with Post-COVID, having symptoms of one may lead to triggering or worsening of the other.

**How recovery is affected by the way you feel.**

One of the aims of this section is to invite you to be explore how physical health and mental health impact on each other. We are not saying mental ill-health causes Post-COVID, but we do know that our mood can impact on things like our choices and perceptions and interpretations of our experiences.

Here, we are encouraging you to think of the links between your mood and your Post-COVID symptoms.

Although we often think of physical and mental health separately, they are very much dependent on each other, and it is useful to think that both are interlinked and related.

**How recovery is affected by the way you feel**

- Recovering from Post-COVID is a process of rehabilitation. It takes **time**, **patience**, and **effort**.
- One of the things we do know so far is that recovery can be a winding path and may not always follow the pattern you would expect.
- Part of any recovery is to get to become more aware of your personal experience and recovery – can you spot any patterns? Or triggers? What approach works for you?
- Some things which support recovery may be obvious and known, some may be more subtle and less obvious. Keeping diaries can sometimes help identify things which help or hinder your recovery.
There is still a level of uncertainty around Post-COVID still some uncertainty around COVID.

This can be really hard at times.

Below are 4 examples of types of thoughts people have expressed about their situation. When you read each one, notice how you feel.

I’m going to try going to see some friends tomorrow, it will be nice to see everyone

I’m scared about seeing friends, what if I get COVID again?

I feel a bit worse today, I’m never going to get better, I need the doctor to do another test, I’ll have to stay in bed, I can’t do anything.

I feel a bit worse today, that happens sometimes, I’ll set a few goals for today that are manageable with rest in between and I’ll probably feel better in the next few days.

Reflection:
Do you notice how your own thoughts and perspectives make you feel?

________________________________________________________________________

________________________________________________________________________

Which make you feel excited, happy?

________________________________________________________________________

________________________________________________________________________

Which make you feel scared and anxious?

________________________________________________________________________

________________________________________________________________________
How recovery is influenced by the way you feel

Sometimes it's helpful to think about how our thoughts affect our feelings, behaviours, and physical symptoms. Once we know this, we can start to make changes.

The examples below illustrate how a different perspective can either help you or hold you back. Our perception and how we talk to ourselves can impact on how we feel and what we do.

In Example 1 above the interpretation depicts failure and hopelessness, which can lead to feelings of depression and low mood. The feedback arrows highlight how these can both contribute to your physical symptoms and what you do.
This second example uses the same situation but shows a different interpretation. This demonstrates a more compassionate approach, a recognition of what has been done, which in turn, can help motivate us in our recovery. There is still some physical impact, but it’s different to the first scenario. Importantly the feelings are different as is the outcome.

It is important to note that we are not saying that it is always possible to view every situation as positive. This section is not about trying to see everything as positive, but we do hope to get you thinking about whether the way you may view something can be helpful or unhelpful to you and your recovery. It will shape how you are feeling. If we view things in a way that is more helpful, when it is possible, the outcome should be better for us?

Reflective exercise
Is this a pattern described above something that you recognise?

Think about the examples above— do they feel familiar? Can you think of any examples in your life which are similar?
Can you identify any thoughts and feelings which you have?

Can you identify whether those thoughts help you or hold you back?

Is it all in my head?

Often it can seem that if we think about mental health impacting on symptoms it means that those symptoms are not real and are all in people’s heads. That’s not true! The symptoms are very real. But we are highlighting that mood and emotion have an impact on us. They can affect what we do and what our bodies feel like. This **does not** mean it is all in your head.

How can depression and anxiety affect your symptoms?

So how does anxiety and depression affect you physically? Anxiety and depression affect systems within our body. You may have heard of the fight or flight response and you may have heard about cortisol and endorphins. There are physical changes which happen in our body when we in a state of real or perceived danger. These changes will add to already existing symptoms.
Take a moment to reflect…
How might this impact on Post-COVID symptoms? …. 

How will it impact on recovery?

What does your body do?

What does your body do when you are anxious or depressed?
Some of the ways your body changes are illustrated above. In your calm, rest and relax (parasympathetic) state, you feel well. When you are in your fight or flight (anxiety response) your sympathetic system is activated and you can feel physical changes in the body such as raised heart rate or breathing rate, and this can lead to symptoms. This is explored further in the section 1. (p11)

Brain and body connection
These are only some examples of how your feelings effect what happens in your body.
So, it is as important to manage the way you feel as it will also manage your body. The two are completely linked.
Some strategies to help with anxiety and low mood

Understanding the link between your symptoms and how you feel can be extremely helpful in helping you recognise, monitor, and manage symptoms.

Reflective exercise
Think about the examples given above to help explore some daily situations that you have experienced.
Reflective exercise
After reading this section about the impact of stress and mood on physical symptoms, can you think of:

- 3 things you have learned?
- 3 things you would like to change?

Write your answers in the space below.

3 things you have learnt
1. 
2. 
3. 

3 things you would like to change
1. 
2. 
3. 

Summary
- Recovery and rehabilitation takes time
- Your experiences are real
- Accepting where you are allows you to move into recovery
- Mood and our perceptions can impact and influence physical symptoms
- Start to notice what could be impacting on your recovery
- Access support, you don’t have to do things alone
- Be kind to yourself
Further reading – websites & links

Talking Changes
- Psychological therapies for anyone over age 16 in the County Durham & Darlington area.
- You can access by self-referral – just get in touch online or phone
- [https://www.talkingchanges.org.uk](https://www.talkingchanges.org.uk)
- 0191 333 3300

Recovery College
- A range of online educational courses and resources for people who might be struggling with mental health issues, families, friends, mental health workers and anyone else who might be interested.
- [https://www.recoverycollegeonline.co.uk](https://www.recoverycollegeonline.co.uk)

Mindfulness
- NHS TEWV Trust provides mindfulness courses as part of their NHS service, with a useful introduction to mindfulness available free on their website
- Online courses are available to adults (aged 18+) living in County Durham and Darlington, Teesside, and most of North Yorkshire, who:
  - have experienced repeated episodes of depression
  - are stressed by parenting or caring for someone with mental ill health or a learning disability
- [https://www.tewv.nhs.uk/about-your-care/treatments-therapies/mindfulness-cognitive-therapy/](https://www.tewv.nhs.uk/about-your-care/treatments-therapies/mindfulness-cognitive-therapy/)

Apps
- Headspace: Meditation app. Free trial available, then requires paid subscription. [https://www.headspace.com](https://www.headspace.com)
- Calm: Meditation app. Free trial available, then requires paid subscription. [https://www.calm.com](https://www.calm.com)
Section 6 – Diet & Nutrition

Diet & Nutrition - Section Outline:

- Stress Response System
- Energy regulation
- Fatigue and diet
- Nutrients
- Vitamins
- Meet your microbiome
- Diet and mood
- Food choices

Stress Response System

Previously, in section 1 (p11), we looked at how anything that puts the system under stress causes a stress response. We described those sources of stress on our body's system might be illness or infection, but it might be extra demands on the system like having to run fast to deal with a threat. In prehistoric times that might have been running away from a bear, but now it's more likely to be running for a bus or train. And our body mounts the same response to mental or psychological stresses such as life events, whether that is too many emails, or the car breaking down.

We also mentioned that the other response that the system makes is increased INFLAMMATION throughout the body. This is a cascade of chemical messengers and hormones that the cells of the body makes – this has lots of effects, but one of the things it does is make the immune system more active.

Energy regulation

Sympathetic system can be thought of as “yes” or “on”.
Parasympathetic is “off”.

Usually, the two sides of the system work in a finely tuned balance.

After illnesses, such as Post-COVID the balance between the two is upset, so there is too much "on" and not enough “off".
Thinking specifically about nutrition and the digestive tract, stress leads to changes in the digestive system. This may lead to poor digestion of food, so it is less effective at absorbing the nutrients we need. It may also cause symptoms such as bloating and nausea (sickness).

How does what we eat affect us?

There are many things which influence our brain regarding food – and this relationship works 2 ways - we all know that the food we eat (or don’t eat) has an effect on our body.

We are familiar with this at the most basic level – our need to fuel our body. We know that if we need fuel our body sends the brain signals of hunger – it starts as a little nudge, but then gets stronger, our stomach starts growling, we feel irritable and grouchy, but left too long we might start feeling tired, and weak and dizzy. When we are well fed, we get the opposite, we feel full, and warm and content.

Other factors are shown in the diagram below:

**Things that affect our nutrition:**

**Nutrients:** whether the body is getting enough of the building blocks that it needs to grow and repair and run the body’s processes.

**Fatigue:** see below.

**Gut Flora:** our microbiome may have a profound effect on our nutrition and health.

**Sleep:** if we are under-slept and tired, we crave sugary foods to keep us going.
Stress: high stress levels lead to increased stress hormones in the body. This can influence our food choices. This can then lead to choosing unhealthier high sugar and high fat options.

Culture: our conscious choices about what foods to eat – this may include religious / cultural dietary restrictions, or choosing to follow a particular way of eating (e.g., vegan).

Habit: the power of habit and sticking to what we know is very strong.

Environment: is often underestimated, but just think about your experience. When it is freezing cold outside, what do you want to eat? Warm soups and stews and casseroles - we don’t call it winter food for no reason! Conversely in summer we reach for ice cream and salads and light summery choices.

Why is nutrition important in Post-COVID?
Eating the right diet is crucial to keep well physically and mentally. A key part of your recovery is to make sure your diet is healthy.

Nutrients

Macro-nutrients
Macro nutrients are the nutrients that the body needs in bigger amounts. These are divided into:

- Protein
- Fats
- Carbohydrate

Protein
What is protein used for?
Proteins are made up of amino acids, and the body uses these as building blocks for everything from DNA to cells and tissues like muscle.
Some common sources of protein in the diet:

### Fats

**What are fats used for?**

Fats can be used for energy. However, fats are also essential building blocks – for cell walls that hold all our cells together, for certain types of cells like nerve cells, and making hormones – which are essential for controlling all the processes in the body.

#### Some common sources of healthy fats in the diet:

- **Salmon** (1 fillet)
- **Olive oil** (1 tbsp)
- **Avocado** (half)
- **Hummus** (1 tbsp)
- **Chia seeds** (1 tbsp)
- **Full fat yogurt** (150g)
- **Mackerel** (1 fillet / tin)
- **Olives** (5 - 10)
- **Sardines** (palm size)
- **Dark chocolate** (2 square)
- **Nuts/seeds** (1 tbsp)
- **Nut butter** (1 tbsp)
- **Eggs** (2 - 3)
- **Coconut oil** (1 tbsp)
- **Flaxseed** (1 tbsp)

### Carbohydrates

**What are carbohydrates used for?**

Carbohydrates are used by the body for energy, they are our body’s main fuel. The carbohydrate used by the body’s cells is glucose. Glucose is used by the cells of the body to make energy.

Most of the glucose the body uses comes directly from the diet, but it can also be made by the body itself in the liver.
Some sources of carbohydrate in the diet:

Carbohydrates are the nutrients in food that are broken down into glucose, a source of fuel for the body. Carbohydrate containing foods can be divided into the following categories:

- Foods high in complex or less processed starchy carbohydrates which tend to break down into glucose more slowly (e.g. wholegrain bread, wholegrain rice).
- Foods containing natural sugars such as fruit, milk and yoghurt.
- Free sugars. Foods high in free sugars will turn into glucose quickly (e.g. sweets, sugar, honey). We try and minimise free sugars in the diet where possible.
  
  Note: Naturally occurring sugars e.g. lactose or fructose do not count as free sugars if they remain in the food (e.g. an apple does not count as free sugars, but will be treated as free sugar if removed from the food e.g. apple juice)

- Dietary fibre. Foods rich in dietary fibre promote digestive health. They are often found alongside in foods that contain complex / starchy carbohydrates as well as fruit and vegetables.

Micro-nutrients

Vitamins and minerals are ‘micro-nutrients’. These are substances which are needed in tiny amounts but are essential for the body’s functions to work correctly. Most vitamins and minerals are a bit like the oil in a car engine, they aren’t the fuel itself, but they are essential to keep the system running smoothly and efficiently.
We need a wide variety of vitamins and minerals, as shown in the diagrams above. For most people, a healthy balanced diet will provide all the vitamins and minerals needed. However, if your diet has been limited by illness such as COVID or Post-COVID then you may at risk of developing a lack (deficiency) of one or more vitamins or minerals.

Many vitamins and minerals are essential for proper working of the immune system and for growth and repair. Therefore, a deficiency may make symptoms of Post-COVID worse, or prolong recovery.

For some vitamins and minerals, levels can be easily checked. For example, iron is easily measured by a simple blood test. However, not all vitamins and minerals are as easily checked, because either we don’t have access to tests, or the tests just don’t measure them very well.

Replace proven deficiencies
If you have had a blood test which has shown a particular deficiency, or lack of a specific nutrient, your doctor will have discussed the most appropriate treatment for you regarding your individual position, and it is important to consider their advice.

Follow guidelines
For certain groups who are at higher risk of deficiencies then supplements are recommended in certain situations. For example, all women planning a pregnancy...
or who are pregnant are advised to take a folic-acid supplement to reduce the risk of spinal cord problems in their babies.

**Vitamin D**

During the autumn and winter, you need to get vitamin D from your diet because the sun is not strong enough for the body to make vitamin D.

But since it's difficult for people to get enough vitamin D from food alone, everyone (including pregnant and breastfeeding women) should consider taking a daily supplement containing 10 micrograms of vitamin D during the autumn and winter.

Between late March/early April to the end of September, most people can make all the vitamin D they need through sunlight on their skin and from a balanced diet. However, some people will not make enough vitamin D from sunlight because they have very little or no sunshine exposure.

The Department of Health and Social Care recommends that adults and children over 4 take a daily supplement containing 10 micrograms of vitamin D throughout the year if they:

- are not often outdoors – for example, if they're frail or housebound
- are in an institution like a care home
- usually wear clothes that cover up most of their skin when outdoors
- have dark skin – for example you have an African, African-Caribbean or south Asian background – you may also not make enough vitamin D from sunlight.

These groups should consider taking a daily supplement containing 10 micrograms of vitamin D throughout the year.

**Multi-vitamins**

At present, there is not enough scientific evidence to say that multivitamins are beneficial as a specific treatment for symptoms of Post-COVID.

However, it is worth considering if there is a likelihood you are not getting the full spectrum of vitamins and minerals from your diet for any reason that might be:

- Poor appetite
- Reduced ability to cook a range of foods due to fatigue or other symptoms
- Problems with eating due to fatigue.
- Loss of taste or smell resulting in lost weight due to reduced eating
- Restricted diet due to cultural/ethical/preference/choice.

In these circumstances it may be worth considering taking a trial of a multivitamin to see if this helps your symptoms. However, if you are taking other medications or are
unsure about the suitability of supplements for your individual circumstances, do speak to your pharmacist or doctor first.

**Malnutrition**

We are so used to following public health messages that are focused on weight loss, eating low fat products, eating more fruit and vegetables, less sugar, treats and puddings. This style of eating is not always recommended for people who have a small appetite, find they are losing weight, or who are finding it difficult or tiring to eat.

If you are concerned please contact your GP and ask for a referral to a registered dietitian.

**I am underweight or I have lost a lot of weight or I am struggling to eat enough. What should I eat?**

Minimising weight loss and regaining muscle strength is important for your recovery. It is important to monitor your weight and look out for signs of weight loss including your clothes and jewellery becoming loose.

Ask you GP to refer you to a dietitian for further advice and support, and in the meantime, you may find the information below helpful:

You may find meals a bit overwhelming at the moment but you should try to eat little and often, this may include three small nourishing meals plus nourishing snacks/drinks in between until your appetite picks up. Choose protein-rich (meat, fish, eggs, cheese, beans and lentils) and energy-rich foods. Serve food on small plates to make it more appealing.

Keep well hydrated by drinking plenty of fluids. Choose milk-based drinks as these provide additional nutrients like protein.
The gut and the immune system

When we eat, food travels down through the stomach to our small intestine, where it is digested and absorbed, then metabolised, ready to use as energy.

When we eat fibre, it travels straight through the small intestine, into the large intestine, undigested.

The lining of the gut is an incredibly thin barrier between the outside world and all the foods and substances that we ingest, and the inside of the body. That barrier needs to be effective at determining what is “good” for the body and what is “bad” or harmful. Because of this, 70% (over two-thirds!) of the body’s immune system is located along the gastrointestinal tract. Its job is to only let in that which is good or nutritious for the body, and to keep out anything harmful.

The immune system is directly involved in controlling the amount of inflammation in the body’s system, therefore, with so much of the immune system directly affected by the gut and the gut microbiome, you can see how there is a close link between what we eat, our gut microbiome, and the amount of inflammatory response in the whole body.

The gut microbiome consists of trillions of microbes – that is bacteria, viruses, fungi – living in the intestines. Altogether about 2kg of microbes live in the GI tract.

The gut microbiome has an essential role in helping digestion of food, synthesis of nutrients, and controlling our hormones and immune system.

The gut microbiome forms a protective layer over the surface of the gut lining which prevents damage to the delicate lining of our intestines.

What does the microbiome do?

1. **Digestion**

   The human body is unable to break down fibre in plant-based foods by itself, we just don’t produce the right chemical enzymes to break down all the different types of food that we eat. So, the bacteria do it for us, they produce the right enzymes to break through fibre to release the nutrients inside.
2. Nutrient production

The ‘good’ bacteria in our gut ferment the fibre into short-chain-fatty-acids (SCFA’s) which are healthy fuel for cells, especially the cells of the gut lining.

The microbiome also makes other nutrients which are then absorbed into the body.

3. Immune function

The SCFA’s made by the protective bacteria are also strong anti-inflammatory signalers so help the immune system to decrease inflammation in the whole-body system – which, as we have seen, is elevated in post-COVID.

If the microbiome is unbalanced, its protection of the gut lining does not work as well, so more toxins and inflammatory-causing signalers get absorbed.

Recent studies show that covid-19 affects the balance of the microbiome, with increase in certain species, and loss of diversity. By restoring the balance of the microbiome, function is restored, nutrition improves, immune function improves, and energy levels improve.

THE LINK BETWEEN DIET AND MOOD

We all have good days and bad days; we all have foods we like more, or like less. But is there a connection between feeling fine and the foods we have eaten? Do some foods make us feel grumpy? Is it possible to plan a diet for a good mood?

Vitamins and minerals

When you don’t eat enough nutrient-rich foods, your body may lack vital vitamins and minerals, which may affect your energy, mood and brain function. The table below shows how not getting enough of some vitamins/minerals can affect your mood, and what you can eat to replenish your body.

You should aim to get your vitamins and minerals from eating a healthy, balanced diet with plenty of fruit and vegetables.
Missing vitamin/mineral  | Effect on Mood  | Foods which can help
--- | --- | ---
**Iron**  
Not getting enough iron results in low levels of oxygen carrying haemoglobin in the blood, resulting in the condition anaemia.  
Feeling weak, tired and lethargic all the time.  
The risk of anaemia is reduced by eating enough iron, particularly from red meat, poultry and fish, beans and pulses, fortified cereals. Avoid drinking tea with meals.

**Thiamin B1, Niacin B3 or Cobalamin B12** (all B vitamins)  
Tiredness and feeling depressed or irritable.  
Fortified foods including wholegrain cereals, animal protein foods such as meat, fish, eggs and dairy.

**Folate / folic acid**  
Increased chance of feeling depressed, particularly important in older people.  
Folate is found in liver, green vegetables, oranges and other citrus fruits, beans and fortified foods such as yeast extract (marmite) and fortified breakfast cereals.

**Selenium**  
May increase the incidence of feeling depressed and other negative mood states.  
Brazil nuts, meat, fish, seeds and wholemeal bread.

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**Carbohydrate = Glucose = Brain Power**

To be able to concentrate and focus your brain needs enough energy, which comes from blood glucose. In fact, the brain uses 20 per cent of all the energy your body needs.

Glucose is also vital to fuel muscles and maintain body temperature. The glucose in our blood comes from the carbohydrates we eat – including fruit, vegetables, cereals, bread, rice, potatoes, sugars and lactose in milk.

Eating breakfast and regular meals containing some carbohydrate helps you have enough glucose in your blood.

Healthier sources of carbohydrates include wholegrains, vegetables, fruits, legumes and lower fat dairy foods. These are important sources of other nutrients as well, such as calcium and B vitamins.
Not having enough glucose in your blood (hypoglycaemia) can make you feel weak, tired and ‘fuzzy minded’. This may happen when you don’t eat enough carbohydrate-containing food, and is a particular risk if you have diabetes or do extreme exercise or manual labour. It can also happen if you follow a very restrictive diet or have irregular eating patterns.

Although glucose ensures good concentration and focus, once your blood glucose is within the normal range, you cannot further boost your brain power or concentration by increasing your glucose levels. If you are eating some carbohydrate foods, additional sugary ‘energy’ drinks are not needed and not helpful.

Comfort eating

There is a messenger chemical in the brain called serotonin, which improves mood and how we feel. Serotonin is made with a part of protein from the diet (tryptophan), and eating carbohydrate-rich foods may help more of this get into your brain.

This suggestion has been used to explain ‘carbohydrate craving’ – eating sweet, comfort foods to boost mood. There is not enough research to show that eating lots of protein foods containing tryptophan or eating a lot of carbohydrates can really support mood improvement in humans. But it may be that not eating enough carbohydrate (for example through a high protein/high fat diet) leads to low moods.

You also may have heard the idea that eating chocolate can make you feel happier, and there are observations that people feeling down are more likely to eat chocolate. This is probably because chocolate is a well-known reward and comfort food, rather than due to any potent physiological effects particular to cocoa.

Reflective exercise…

Do you eat “to cheer yourself up?”

_________________________

If so, what food do you choose?

_________________________

What effect might this have on your body?

_________________________
Caffeine and the ‘drug-effect’
Caffeine, found in coffee, cola and energy drinks, is often called a drug: it acts as a stimulant and can increase feelings of alertness, and counter the effects of fatigue. However it may be that some of the effects of caffeine actually ‘normalise’ the lower levels of alertness felt by regular users who have not consumed enough caffeine that day.

Too much caffeine, particularly in people who are not used it, may cause the adverse effects of irritability and headache. Such symptoms also occur with caffeine withdrawal in people used to lots of caffeine on a regular basis.

The gut-brain axis
There is some current interest in links between mood and the gut microbiome (the trillions of bacteria resident in the human colon).

Consistent research outcomes are needed before any valid claims can be made about this.

Omega-3 fats
Long chain omega-3 fats (found in fatty fish) supports the development of the foetus during pregnancy, particularly the brain. Some research suggests that diets containing omega-3 fats may help to reduce low mood states in adults.

So, does food affect mood?
There are many ways that foods can affect how we feel, just as how we feel has an influence on what foods we choose. Some of the mood/food effects are due to nutrient content, but a lot of effects are due to existing associations of foods with pleasure and reward (chocolate) or diet and deprivation (plain foods).

Some foods also have religious, economic and cultural significance, which will influence how we feel when eating them.

Summary
Feeling good comes from a diet that has enough healthy choice carbohydrate at regular times to keep blood glucose levels stable, and eating breakfast is a sensible habit.
Diets should also contain a wide variety of protein and vitamin and mineral containing foods to support the body’s functions.

As a rule, plenty of fruits and vegetables and wholegrain cereal foods, with some protein foods, including oily fish, will support a good supply of nutrients for both good health and good mood.

**FATIGUE AND DIET CHOICES**

As we have seen above, what we choose to eat can affect our energy levels, but our energy levels also influence what we choose to eat. In turn this can lead to a negative spiral, which worsens the problem and increases symptoms. For example, when fatigued, you may not have the energy to cook a balanced meal and are more likely to reach for more convenience foods, which are contain less quality nutrients. It also means that recovery is slower as healing is not as effective when the body is not fuelled as well.

![A negative spiral...](image)

**What to eat**

There is no “right” answer, and the best diet for any one individual may be different to another’s. Diet is very individual, depending on many factors, including personal tastes, culture, religion, medical conditions, ethical beliefs etc.

However, there are some broad evidence-based dietary principles which can be adapted to most individual’s situations:
• Increase whole foods
• Reduce processed foods
• Reduce refined sugar
• Swap to wholegrain carbohydrate sources such as seeded bread, wholegrain rice, pasta and cereals.
• Include a wide variety

What is a whole food?
A whole food is one that is eaten in its natural state (or with simple cooking). It is not processed and does not have any added ingredients such as flavourings, colourings, or preservatives. One simple way to think about it is that “a whole food has nothing added, nothing taken away”.

Whole foods can be spotted because they have usually just one ingredient, so there is no need for a complicated nutrition label. It is likely that the more ingredients there are on a label, the more processed and the less whole food that it contains.

Whole foods are often plant foods, and it important to aim for a wide variety and increase the proportion of fruit, vegetables and whole grains in the diet. These can be found in many forms, and fresh, frozen, dried types all count as whole foods.

Plant-based diet.
Our friendly gut-bugs in our microbiome love a variety of plant foods. Being plant-based does not have to mean plant-exclusive – instead, if you do want to include meat in your diet, try swapping it out for plant-based options some of the time so the overall amount of meat is reduced. Try to choose less processed options when you are having meat.

Eat a rainbow.
Include a wide variety of vegetables and fruit. The different colours are due to different types of healthy antioxidants and vitamins and minerals contained in the plants. So therefore, try to incorporate a wide variety into your diet.

Aim to have something of every colour everyday.
Healthy eating is NOT a diet, it a way of life.

Once you start thinking about your diet and what you want to be aiming for, it can be tempting to “go on a new diet” and try and totally overhaul your way of eating.

However, strict “diets” often fail – because they are too restrictive, or not realistic, or don’t account for ‘real life’ and everyday situations where following a strict specified diet is just not possible.

Instead, aim for manageable, sustainable changes. Some suggestions are:

• Portion control
• Reduce flour and sugar
• Avoid processed food
• Plan your meals in advance
• One extra vegetable with each meal
• Follow the 80:20 rule – try to stick to your plan at least 80% of the time, but don’t beat yourself up! Be kind to yourself and plan ‘treats’ into your way of eating, so you don’t feel like you are being restricted.
Reflective exercise

As we have described above, what you eat, and drink can have a big impact on your symptoms. However, making a small change to your diet can help with positive changes in how you feel.

Use the grid below to think about what are the small changes that you could make in your everyday diet, which you could maintain over time? Write your plan in the empty boxes.
SUMMARY

- Healthy eating is not a strict restrictive diet, instead it includes a wide variety of wholefoods such as fruit, vegetables and wholegrains.
- Small changes all add up and can make a big difference.

Resources & further reading:

- NHS Live Well & Eat well guides:
  - https://www.nhs.uk/live-well/eat-well/
- Your covid recovery: www.yourcovidrecovery.nhs.uk/your-wellbeing/eating-well/
- For anyone at risk of malnourishment https://www.malnutritiontaskforce.org.uk/eating-well-tips-everybody/what-are-barriers-keeping-well-nourished
- Food guide: https://food-guide.canada.ca/en/
- Plant-based health professionals factsheets: https://plantbasedhealthprofessionals.com/factsheets
- Forks over knives (plant-based recipes): https://www.forksoverknives.com
- Vitamin D: https://www.nhs.uk/conditions/vitamins-and-minerals/vitamin-d/

Books

- The Plant Power Doctor – Dr Gemma Newman
- The Four Pillar Plan – Dr Rangan Chattergee
Section 7 – Voice changes & communication changes Post-COVID

VOICE CHANGES

As a result of the COVID-19 virus you may experience some changes to the sound of your voice, and to your comfort and effort levels when using it. These changes are similar to the changes you would expect to experience with a cold or flu, but can be more intense and longer lasting. The following advice will help your vocal recovery.

Why May Your Voice Have Changed?

Vocal cords sit in the voice box (also known as your larynx or Adam’s apple) at the top of the wind pipe.

Pictures 1 and 2 are photos of healthy vocal cords:

In order to produce voice, we bring the vocal cords together (see picture 2) and gently blow air through them from the lungs below, which causes their delicate membranes to vibrate. This vibration is the sound of the human voice. Reduced breath support if you are short of breath can impact the power and volume of your voice.

When you have COVID-19 you may have experienced excessive and prolonged attacks of coughing. Coughing brings the vocal folds forcefully together to allow strong expulsion of air, clearing any mucus from your lungs and throat. This level of coughing gives the vocal cords quite a battering; consequently, they could become swollen and inflamed.

When vocal cords become swollen and inflamed, as they are in pictures 3 and 4, they can become stiff and less flexible. This means that they are unable to vibrate freely,
so the sound of the voice changes, often becoming rougher and deeper-pitched or possibly no more than a whisper. It can feel uncomfortable and hard work to speak when your vocal cords are in this state.

Pictures 3 and 4 show unhealthy swollen vocal cords:

What Can You Do To Protect Your Vocal Cords And Help Them To Heal?

- **Keep well hydrated.** Drink 1½ – 2 litres (4 – 5 pints) of fluid that doesn’t contain caffeine or alcohol per day (unless advised otherwise by a doctor).
- **Try gentle steaming with hot water** (nothing added to the water). Breathe in and out gently through your nose or mouth. The steam should not be so hot that it brings on coughing.
- When the virus is at its peak, coughing is likely to be intense and unavoidable. However, once this stage of the illness passes, **try to avoid persistent, deliberate throat clearing** and, if you can’t prevent it, make it as gentle as possible. Taking small sips of cold water can help to suppress the urge to cough.
- Chewing gum or sucking sweets can help promote saliva flow, which lubricates the throat and can help to reduce throat clearing. **Avoid medicated lozenges and gargles**, as these can contain ingredients that irritate the mucosal lining of the throat.
- You do not need to be on total voice rest, i.e. silent. **Using the vocal cords for a few short utterances every so often** during the day keeps them mobilised, and this is a good thing.
- **Always aim to use your normal voice.** Don’t worry if all that comes out is a whisper or a croak; just avoid straining to force the voice to sound louder.
- **Don’t deliberately choose to whisper;** this does not “save” the voice; it puts the voice box under strain.
- **Avoid smoking or vaping.**
- Avoid attempting to talk over background noise such as music, television or car engine noise, as this causes you to try to raise the volume, which can be damaging.

- If your voice is no more than a whisper do not attempt telephone, online chat, or video conversations. Once the voice starts to improve, avoid prolonged (more than 5 minutes) conversations by telephone, online chat, or video. Try to use text-based options instead.

- You may notice that your voice fatigues more rapidly than normal. This is to be expected. Take a break from talking when you experience vocal fatigue; this gives the vocal cords time to recover.

- In addition to irritation from COVID-19, reflux can also irritate the throat. To minimise any possible reflux, avoid greasy foods and highly acidic foods and drinks such as; citrus fruits and juices, vinegar and pickles, tomatoes and tomato sauces, fizzy, caffeinated and alcoholic drinks etc. It can also be beneficial to take a liquid alginate (e.g. Gaviscon Advance) following meals and before bed.

- Until the voice has returned to normal it is best to avoid “athletic” vocal activities such as shouting and singing.

Next Steps
The experience of being very ill and possibly receiving treatment in hospital can be emotionally draining and, for some people, deeply upsetting. Our emotions and voice are closely linked, so it is worth being aware that emotional recovery and vocal recovery often progress hand-in-hand.

If your voice has not completely returned to normal 6 – 8 weeks after starting with the COVID-19 virus symptoms, or you are experiencing constant throat clearing/feeling of a lump in your throat please let us know, as you may require a referral to ENT.
SWALLOWING DIFFICULTIES

If you are experiencing difficulties with

- Coughing/choking when swallowing food or drinks
- A wet or gurgly voice after swallowing
- Breathless when eating or drinking
- Recurrent chest infections with no known cause

after the onset of your COVID-19 symptoms, please let us know as you may require referral to Speech & Language Therapy.

COMMUNICATION CONCERNS

Have you or your family noticed a change in the way you communicate with people?

Such as:

- Difficulty making sense of what people say to you
- Struggling with reading or having a conversation
- Trouble with putting thoughts into words

after the onset of your COVID-19 symptoms, please let us know as you may require referral to Speech & Language Therapy.
Section 8 – Returning to work Post-COVID

RETURNING TO WORK WITH OR AFTER POST-COVID

There are many factors to think about when considering how and when to return to work after being off due to Post-COVID. These include:

- Impact of brain fog
- Impact from other symptoms
  - E.g., Breathlessness, fatigue.
  - As we have seen, there are many symptoms which people struggling with Post-COVID experience, and all will impact on return to work in different ways.
- Prevalence of working age people with Post-COVID
- Pressure to return to work.
  - This may be pressure from your employer, colleagues, or financial strain which necessitates return to work.
- Variable symptoms
  - It is very common for symptoms of Post-COVID to vary over time, this may be over the course of a day, or a few days or a week or so.
  - Sometimes the cause of variability can be identified, but it is not always easy.
  - When deciding about whether you are ready to return to work, look at your symptoms over at least a week (ideally longer). A symptom diary may help with this.
- Most employers would prefer you to be properly ready to return to work and be able to stay in work, rather than go back too soon, then need to go off again after a week or two because your symptoms have flared up.

Returning to work too early and needing to be off again is something we have seen with many of our patients and may be avoided by planning your return to work carefully and getting the right support in place. It is often counter-productive to return to work too soon.

Benefits of being in work

Being in work is known to be beneficial for health, and for lots of other reasons too:

- Financial independence
- Routine
- Connection with others
• Purpose
• Self-esteem

Most of our patients are very keen to return to work as soon as possible, but with ongoing symptoms, trying to return to the work you used to do but when struggling with fatigue, breathing pattern problems, chronic pain, brain fog, may feel impossible. The unpredictable and fluctuating nature of Post-COVID means that some returning workers may need to return to work slowly, over a long period of time, gradually building up work capacity.

You don’t necessarily always need to be 100% fit to return to work. If planned carefully, a supported return to work can be a valuable and effective part of your recovery. Though you should be able to manage a consistent level of activity over a period with some level of predictability before considering return to work, normally at least 50% of full function.

Things to consider when thinking about returning to work

• Manager’s awareness of Post-COVID and its impact
  o As Post-COVID is a relatively new condition, some managers/employers understanding of Post-COVID may be limited. There is specific information available to support employers of people with Post-COVID.

• Connect with your Occupational Health service.
  o If you are not sure who your Occupational Health service is, your line manager should be able to advise you.

• Individual plan
  o Post-COVID is variable between people, and everyone’s job roles are also different. Therefore, the adjustments each person may need for their specific job role are also different.
  o It should take into consideration the person, the environment that they are working in, the occupation that is being done.

• Make colleagues aware
  o Let your colleagues know what difficulties you are having, and how they might support you.
  o Post-COVID has been described as a ‘hidden’ illness, as people often look well, and many of the symptoms (e.g., fatigue) are not obvious to the people around them.
Links to short videos developed by Derby and Burton NHS Trust (used with permission):

- Managing COVID related symptoms during sickness absence: https://youtu.be/3fHeLbDo40U
- Return to work rehabilitation: https://youtu.be/29KcxHJb4qU
- Managing ongoing COVID related symptoms in the workplace: https://youtu.be/JNUBmWJgFms
- Supporting staff with ongoing COVID related symptoms to return to work: advice for managers: https://youtu.be/bryRdjIzqRM

Practical steps for returning to work

1. Stay in touch with your line manager – from the beginning and keep in touch regularly even before you are thinking about being ready to return to work.
2. Both worker and employer can bring ideas of what will help in the workplace.
3. Before your return to work, arrange a meeting to make a plan – if available in your workplace, include HR and/or Occupational Health representatives to support you.
4. Suggestions might include:
   a. extra breaks
   b. change of duties
   c. change of working time
   d. change of shift pattern
5. Look at work tasks
   a. What is the task being done?
   b. Timing of tasks / deadlines etc.
   c. Workload / quantity of work.
6. Workplace adjustments
   a. Different for everyone e.g.
      i. Someone working in an office might need breaks to get up and walk around
      ii. Someone working in a busy environment who is on their feet all the time - might need time to sit and be quiet.
7. Consider the commute and travel requirements associated with work.
8. Regular reviews
   a. Once you have a plan in place, it is never set in stone. Make sure your plan is reviewed at regular intervals and adjusted as necessary depending on how you are doing.
A word of reassurance: “although recovery from COVID-19 can be slow, many people improve with time, and treatments are expected to improve as more becomes known. Returning to work is part of the recovery, even if it must be flexible or involve reduced hours and pacing over many months”
Quote from: Supporting Occupational Health and Well-being Professionals, 2021

Summary

- Open and honest conversations with manager are key to successful return to work
- Meeting and planning to arrange return with adjustments in place – regular review.
- Be kind to yourself.

Resources & further reading:

- Support for workers returning to the workplace post-COVID COVID-19 return to work guide: For recovering workers | The Society of Occupational Medicine (som.org.uk) (accessed Jan 2022)
Section 9 – Self-management

SELF-MANAGEMENT - IN THIS SECTION:

- Your Post-COVID journey
- Self-management
- Managing setbacks
- Uncertainty of Post-COVID
- Goals

YOUR POST-COVID JOURNEY

Every person will experience living with Post-COVID differently to another, with varying symptoms and impact on daily life and function.

People often describe a feeling of Post-COVID and/or its symptoms being in the ‘driver’s seat of their life’ and being an observant passenger. This can often feel overwhelming and all consuming. Hopefully through understanding more about some of the symptoms and developing a toolbox of management strategies you may feel you able to ‘get back into the driver’s seat’.

What have you achieved so far?

When living with Post-COVID, you may find yourself comparing with your pre-COVID function or life and striving forward to return to this. However, this may be a huge jump from your current level of function and can make it difficult to notice small changes and improvements.
Remember that improvement will not always be quick or linear. Think of a long and winding country road, with lots of turns and bumps in the road. As you start to travel along the road you won’t be able to see the starting point. As your symptoms change over time and you develop self-management strategies, such as pacing techniques, your tolerance to activity might change. For example, you may be able to manage to prepare and cook a meal without a symptom flare up. However, if you are still not able to clear away and tidy up after the meal and then go for an evening walk as well, you may focus on this, you may not notice the progress that you have made.

As Post-COVID is a multifaceted condition affecting function in lots of different ways, it can be easy to become focussed on an area that is not changing or improving, when you may be making progress in lots of different areas. An example of this could be improving you breathing pattern which means, you are able to talk more easily without becoming breathless and walk on the flat further before becoming breathless. However, if you’re still waking up 2-3 times during the night and needing to nap for 30 minutes during the day, you may feel ‘nothing has changed.

Reviewing progress

To be able to notice the changes in your function and/or symptoms it is important to have a strategy to review symptoms.

When?

This can depend very much on you as individual. Some people find it helpful to review symptoms at regular intervals (e.g., fortnightly, monthly, or quarterly), others find it useful to use milestones. It is important to develop a strategy that works for you but don’t check too often. Progress will likely be slow and checking in more frequently can become frustrating. Day to day variability will also make it more difficult to see the larger picture when checking in too frequently.

How?

This process can be done in various ways, it maybe something you want to do alone, or it may be useful to review with a family member or close friend. Individuals living with Post-COVID often report that other people notice changes that they are not aware of themselves. Although some individuals may like to complete this process internally, it is often encouraged and beneficial to keep a record, perhaps using a written journal or using your phone. This is helpful to look back, especially if you are experiencing brain fog.
Reflective exercise…

Firstly, can you notice any changes or improvement in symptoms over the past weeks?

Next discuss this with a close friend or family member and ask if they have noticed any changes?

Now reflect did you both notice similar or different things?

Acceptance

Living with Post-COVID can bring unpleasant feelings/symptoms or thoughts. A lot of people find it tempting to try to fight against this or control these feelings however this often increases focus on specific feelings or symptoms and may make them feel worse, as well as being very energy consuming. Think about this in the context of the metaphor below.

‘Ball in a pool’ metaphor

Think about Post-COVID and the thoughts, symptoms and feelings associated with it, like a beach ball in a pool. You don't like these things. You don't want them and would like them out of your life. So, you try to push the ball under the water and out of your way. However, the ball keeps popping back up to the surface. So, you must either keep pushing it down or hold it under the water.

Struggling with the ball in this way is tiring and time consuming and keeps the ball close to you. If you were to let go of the ball now, it would pop up and float on the surface near to you, this might make you feel uncomfortable and you probably wouldn’t like it. But if you let it float there for a while without grabbing it, it would likely eventually drift off away from you. It would still be there, maybe more distant, but you would be able to use your arms and enjoy the pool.

Rather than spending your timing fighting with the ball.
‘The old me’
When you become unwell for an extended period of time, as discussed throughout the group programme, this can have a profound effect on both your physical and emotional wellbeing. People living with Post-COVID often express thoughts of the loss of ‘old self’ or their ‘old life’. This can lead you to put lots focusing on and comparing your current function or daily activity to your pre-COVID level. As described, in the metaphor above, this can be detrimental to effective self-management and can be extremely energy consuming. Acceptance is an important part of managing your Post-COVID symptoms, it is NOT giving up or giving in, but is about finding a better way to use your resources.

Reflective exercise…
What does acceptance mean to you?

Do you relate to the ‘ball in a pool’ metaphor? Can you think of anyways you could help allow ‘the ball to float’ rather than fighting it?

SELF-MANAGEMENT
Self-management is vital in managing any long-term condition, such as Post-COVID. It recognises that you as an individual living with Post-COVID is an expert in your own health and means you are ‘in the driver’s seat’ of your own health.

Symptom stability
As you now know most of the symptoms you experience with Post-COVID are intertwined, and one will likely impact on another, meaning it is important to manage the symptoms as a whole rather than focusing on specific symptoms in isolation.
Hopefully through techniques for managing symptoms including fatigue, brain fog and altered breathing, overtime you should notice some stability in your symptoms. This means that they are easier to predict and manage a consistent level of activity, reducing or avoiding the Boom:Bust cycle (see p31 to review Boom:Bust cycle). Through pacing activities and achieving symptom stability you may initially feel you are doing less than before, or ‘taking a backwards step’. As shown on the diagram below this may be true to begin with as you avoid large ‘booms’ or peaks in activity, but should also mean the intensity of the ‘crash’ will be less severe.

**Recognising triggers**

An important part of achieving symptom stability in Post-COVID is recognising any triggers your symptoms. Everybody living with Post-COVID will be affected differently, lots of things can have an impact on your symptoms, both positively and negatively. Understanding and recognising your triggers is crucial to help you recognise symptoms or early warning signs at the earliest point, if possible, stopping before you get symptoms and not because of symptoms.

Each element of the symptom web may have an impact on your symptoms. Think back to earlier reflective exercise (p18), review what you wrote here: has this changed at all? or are you aware of any other factors now?
Some examples are demonstrated here…

Activity

- Change in routine causes sleep disturbance and increased fatigue. For example, if you have school age children. When the children are off school and in the house for longer periods during the holidays, you may find you are more physically and cognitive active for longer periods. Meaning you do not take regular breaks. Leading to increased fatigue and/or breathlessness during the day and difficulty initiating and maintaining sleep at night.

Environment

- Changes in your environment can have a significant impact on your symptoms. For example, you may have returned to work on amended duties, working from home. On returning to a busy, loud, and bright office, you may have notice worsening fatigue and/or brain fog when completing the same workload due to the impact of a different work environment.

It is also important to remember that one symptom may be a trigger for another symptoms. For example, increased brain fog may lead to more stress and/or worry which could negatively impact sleep.

Reflective exercise…

It is helpful to identify triggers and look back at them when you notice a change in how you feel to help manage this.

Write some of your triggers in the spaces below.

<table>
<thead>
<tr>
<th>Things that <strong>positively</strong> impact symptoms</th>
<th>Things that <strong>negatively</strong> impact symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>e.g. good sleep hygiene</em></td>
<td><em>e.g. overactivity</em></td>
</tr>
</tbody>
</table>
What if things get worse?

Improving stability in symptoms is not a quick or linear process. This means that it is likely you will still get symptom flare ups or setbacks. This is commonly experienced by people living with Post-COVID and can be extremely frustrating. If you notice symptoms worsening or flaring up, it can be tempting to ignore this and ‘push through’. This can make symptoms worse causing a larger set back or flare up.

A common time to experience setbacks or flare up in symptoms is as your activity starts to increase and you are able to manage more day to day. For example, as you become more physically active as fatigue improves, you may notice difficulties with your breathing. This can happen as you focus on managing one symptom e.g., fatigue, your breathing may slip back into a less helpful pattern.

Early warning signs

Having a greater understanding of your symptoms and the pattern of your symptoms can be useful in early recognition of setbacks or symptom flare ups. Early warning signs can be used to help to try and slow or prevent a setback or flare up. You are trying to identify the first sign that your body gives you that you are doing too much. These will be very individual to you.

Reflective exercise...

Recognising the early warning signs for your symptoms can be helpful. These will be different for everybody and as discussed can be split into 3 categories.

You could discuss this with a family member or friend – they may notice things you don’t.
Recognising setbacks

Once you can recognise a setback or flare up in symptoms it is important to have a plan to help manage this. Below this Notice, Name and Neutralise technique can provide a simple strategy for this.

Notice – STOP

Start by noticing the setback by being aware of early warning signs.
Then STOP and reduce your activity at the earliest possible opportunity.

Name – REVIEW

Next review, what has caused the setback or symptoms flare up.
Can you recognise a trigger for the flare up? Was this an avoidable or unavoidable trigger? Has this happened before?

Neutralise – HELP

Now establish what strategies do you have in your toolbox which you can utilise to help develop symptom stability.

If you are unsure or are having difficulty with this step, who could help? This may be a family member initially or a health care professional.

Getting Stuck

Over time you might notice that you ‘get stuck’ with certain symptoms or activities. Although this will normally improve over time as your self-management skills improve, if you find you are ‘stuck’, and you have tried to utilise all the strategies in your toolbox, this may be a good time to discuss this with a health care professional.

Uncertainty of Post-COVID

The uncertainty of Post-COVID can make it feel very difficult to plan or set long term goals. As Long COVID is a new condition, not a lot is known about the long-term impact, although lots of people notice their symptoms improve and are able to have a good quality of life.

Remember it is normal to worry…

Due to this uncertainty around Post-COVID as you start to manage your symptoms better and you can do more day to day. You might find yourself worrying more when you are unable to finish tasks or feel you are ‘failing’. This is common when you are comparing to your pre-COVID self.
An element of worry is ok can be considered normal if it is managed well. Some strategies to help manage worry are linked here:

‘Worry tree’ https://www.getselfhelp.co.uk/docs/worrytree.pdf  
‘Worry time’ https://www.getselfhelp.co.uk/docs/WorryZones.pdf

Goals

As mentioned at the beginning of this section it is important to review your progress throughout your journey to notice changes and improvements. Setting goals can be a very useful way of doing this, to avoid becoming ‘lost’ in overwhelming symptoms. When starting to develop goals for yourself it is important that these are meaningful to you as this will help you to focus your rehabilitation on what matters to you.

Long term goals

Although long term goals are important to maintain your focus on what you would like to achieve. Long term goals can feel unrealistic and overwhelming at times when living with Post-COVID which is often relapsing and remitting in nature.

Remember you can’t jump from the bottom of a staircase to the top, without taking some steps in between.

Short term goals

Breaking your longer-term goals into smaller, more manageable chunks is important to see progress and improvement.

Using the SMART goal format (to the right) helps you to make sure that goals you set are something that will be relevant to you and that you will be able to achieve.

Reflective exercise…

Can you consider a long-term goal, or something you would like to achieve in the coming months, or longer?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Now can you try to think of 3 shorter term goals, which could help you to achieve the above long-term goal?

1. 

2. 

3. 

Summary

- Recognising your own personal Post-COVID journey is important and will help you to self-manage more effectively.
- Understanding your symptom triggers, patterns and early warning signs will help you to improve symptom stability and have more control over your symptoms.
- Setting both short- and long-term goals are important to help manage and monitor symptom changes and improvement.
References

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8. BDA (the British Dietetic Association) https://www.bda.uk.com/resource/carbohydrates.html
15. Asthma UK and British Lung Foundation. Long COVID | British Lung Foundation (blf.org.uk) – support with breathing and managing breathlessness