

A guide to work

Information for patients with Long Covid



Introduction

You may be experiencing a longer-than-expected period of illness, with ongoing fluctuations in symptoms and this is likely to be having an influence on your ability to return to work. You may have already attempted a return to work, with mixed success, or be back at work and struggling to cope with meeting demands and expectations. Or you may be planning a return to work soon.

This booklet aims to support you with your work plans, to help facilitate a more successful return to work or support you to sustain work, if you have returned but are struggling.



What is your work goal?

An important first step when thinking about your work role is to think about your overall goal.

What do you want your long- term work goal to look like?

Examples of work- related goals might look something like this:

- I would like to return to my original job and my full- time hours within the next three months
- I would like to return to my original job but would like to reduce my hours for now
- I would like to return to my workplace but need to consider a different role as my current job is too demanding right now

It is important to consider where you are now, in terms of your health and the cluster of symptoms you are experiencing. You may need to be honest and realistic- with a degree of self- kindness and acceptance of where you are right now. Trying to return to work too early, pushing through symptoms and hoping things will improve on their own, are likely to lead to perpetuating cycles of symptom fluctuation.

Consider what your overall work goal looks like and make a note of it here:

Specific

Measurable

Achievable

Realistic

Timely

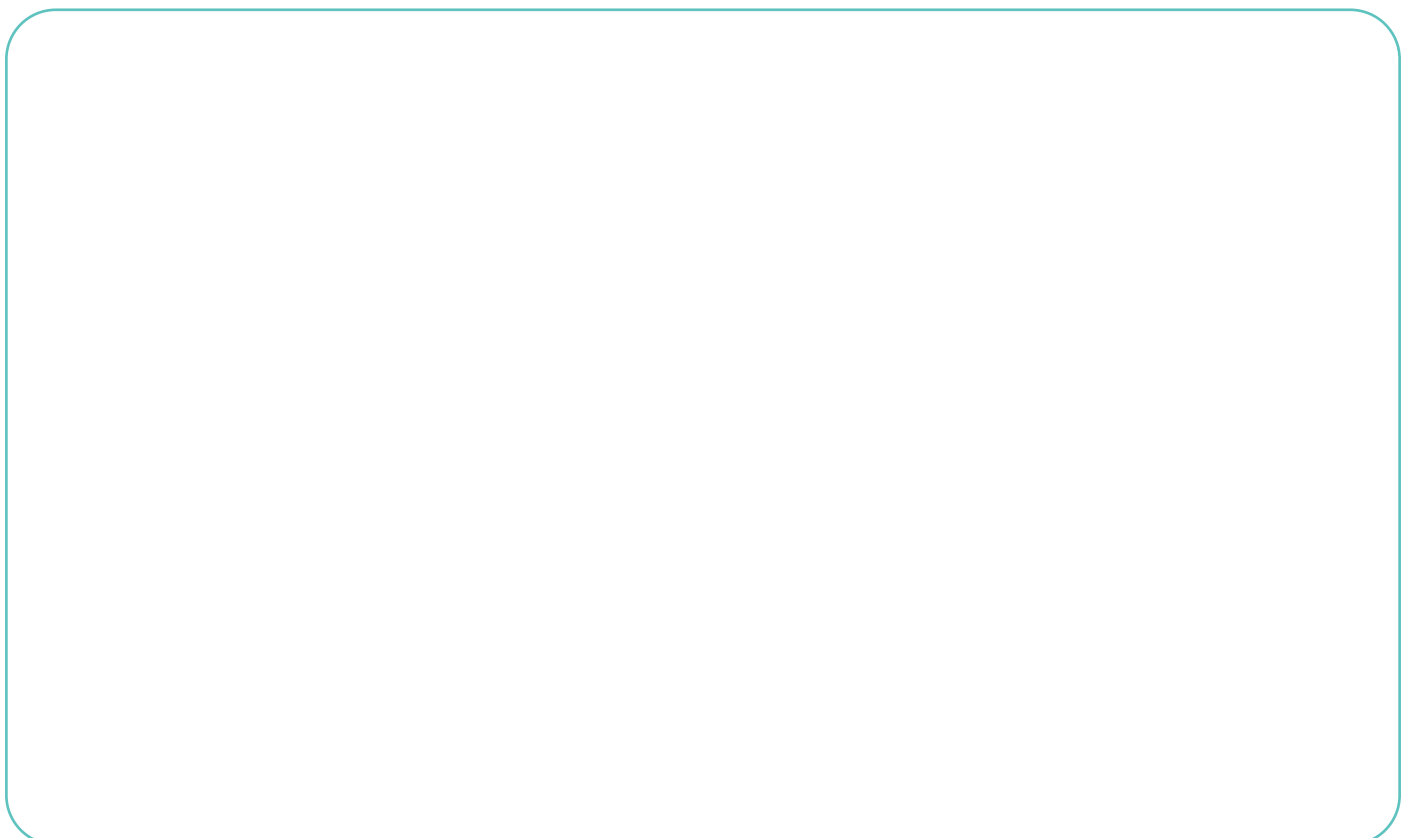
Breaking down your work goal

Now that you have given thought to your work goal, it would be helpful to carry out an analysis of your current job and all the things you do in a day and week when at work. Give thought to the routine tasks and the less obvious ones too! Are you the person who always makes the tea, or the person people come to with issues?

Here are some points to guide you:

- Start with the time that you need to get up to get ready for work.
- Then think about when you leave the house- how long does it take you to get to work? How do you get there?
- What time do you get to work?
- Do you 'hit the ground running' as soon as you get to work?
- Make a comprehensive list of all the things you do at work. Include physical tasks, cognitive tasks, emotionally demanding tasks and social interaction
- Think about how much time you might spend on the above tasks. For example, do you sit in front of a computer most of the day (cognitive) or are you on your feet and moving around a lot? (physical)
- Think about any additional tasks you may be doing, like being responsible for a colleague's leaving present/card. Are you the person colleagues come to with their 'problems'?
- Do you take breaks, or is there a tendency to keep going as there's always so much to do?
- Do you stay back or start early, to get all the tasks completed?
- What time do you get home from work, how do you get home and how long does it take?
- What happens after work – do you have commitments outside of work such as parenting, caring, being in a team or on a committee?

Write your key roles and responsibilities here (your job description might help you)



Your health

Whether you are currently off work, planning an imminent return, or are back to work but struggling, it is important to consider the Long Covid symptoms that you are experiencing and the challenges they present.

Ask yourself:

- Do my symptoms continue to fluctuate?
- Do I feel stuck or fear moving forward in case symptoms worsen?
- Do I feel like I'm in a boom and bust cycle- trying to push through symptoms, which leaves me feeling worse afterwards?
- Do I spend days off/weekends recovering, ready for a busy week back at work?

Write down the issues you are facing with your health at the present time:

Physical (walking, exercising, sensations (tingling, pain, balance, dizziness)

Cognitive (memory, concentration, 'brain fog', planning, organisation)

Emotional (frustrated, irritated, anxious, low mood, angry)

Fatigue (energy levels, boom and bust, stuck, stopping distances, current baselines)

Communication (social interaction, group versus one-to-one interaction)

Working out possible solutions

Completing the boxes on the previous page has hopefully helped you to consider your health in more depth, and breaking things down can help you consider possible solutions in the context of your work role.

Below are some examples to guide you with thinking about the current challenges you face, by putting them into the context of your job and thinking about possible solutions.

Following this, you will find a blank template, so you can complete your own.

Physical

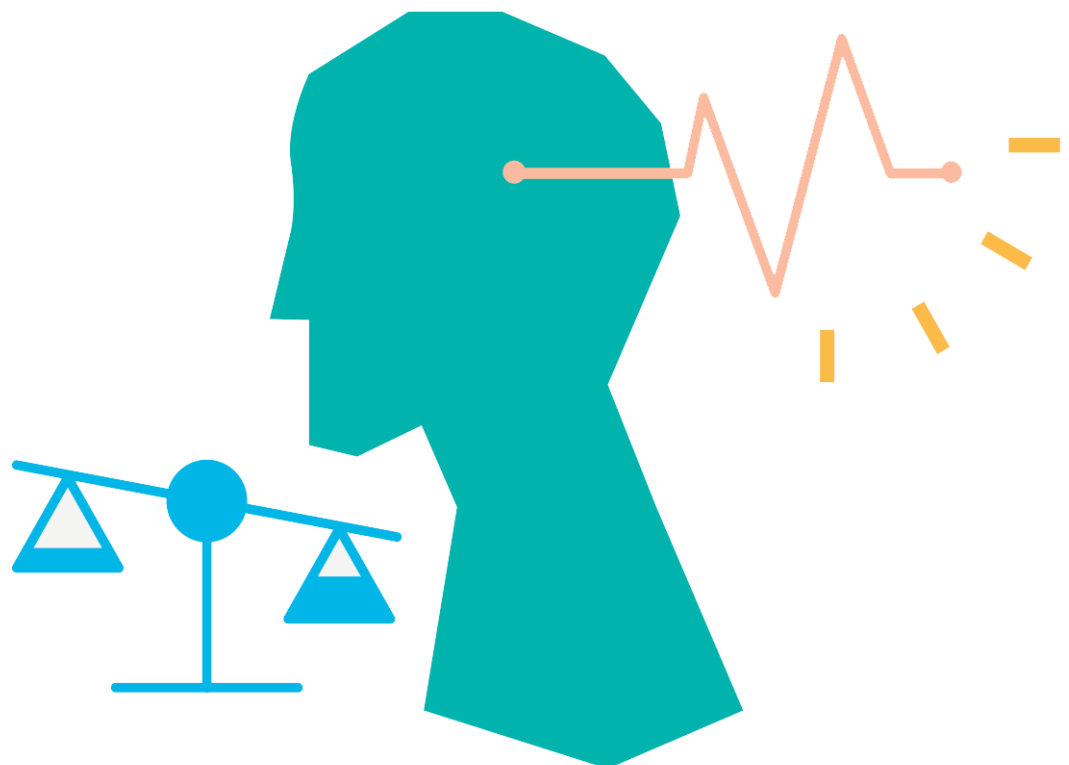
Current issues

I am struggling to walk for more than 10 minutes, without pain and tingling in my legs

I commute to work - I cycle, take the train and a short walk to the office

Possible solutions

- Allocation of parking space that is nearer to the office, will reduce how far I need to walk
- Planning the day ahead, so that equipment needed is close by, will reduce how much I walk around.
- I will ask my colleagues for support, so that I can work on building up my walking distance over time
- While off work, I plan to practice parts of this journey, using graded steps, to give me the best chance of this being achievable on my return to work
- Initially I will ask a colleague for a lift rather than taking the train.
- I will consider if a different starting time would make the commute less busy so I can get a seat on the train.



Cognitive

Current issues

'Brain fog' means I'm struggling to focus during meetings

I can't retain information. I feel like I can't remember anything

Possible solutions

- I'll ask those involved if we can spread meetings out through the day or week, so they are not all lumped together. Try to time limit them too
- I'll 'cushion' this demanding, cognitive activity with short, quality rest breaks either side. I'll use my deep breathing strategies, as I find these helpful (I'll only be able to do a couple of minutes though, as I'll be limited for time)
- While I'm off, I'm going to think about what my current baseline is and give thought to how much I push beyond this. I'll break down reading into smaller chunks and do some relaxation in between, as this is helpful. I'll also mix up the cognitive demand with some gentle, physical movement
- I will use external memory aids like a diary, list or notebook to keep a log of what I need to do and tick off each item as I go
- This will help to retrain my cognitive skills as each time I look at my prompt it helps me retain the information

Emotional

Current issues

I feel so anxious, I feel like I can't cope with my job demands

I'm frustrated about how long it's taking to get better, when will this end?

Possible solutions

- Breaking down my work demands into more manageable chunks will help me to feel a little more in control of my work demands. I'll speak to my manager about the most demanding aspects of my job and see if these can be reduced in any way for now.
- I'll plan my working day and week as much as possible, so I am using the concepts of the 4Ps (planning, pacing, prioritising and trying to remain positive)
- I'll use my relaxation and breathing techniques and try to be kinder to myself and accept where I am now, rather than trying to keep fighting

Fatigue

Current issues

I get to the end of the day and I'm totally exhausted. I come home and fall asleep

My days off are spent recovering from the time I spend at work. I can't do things with my family on days off/weekends

Possible solutions

- I'll apply pacing strategies and will plan my day, so that I am taking more control of stopping distances
- I'll talk to my employer and ask if I can break my allocated 1 hour lunch break, so I have two 15-minute breaks (morning and later in the afternoon) and take 30 minutes at lunch time. My work is desk based, so I'll fit a short walk into one of my breaks
- I need to readdress my work life balance and think if the hours I'm currently working are too much for me currently. I will discuss this with my manager and see if a plan to adjust hours, with a review can be considered
- I will try to keep to a routine at weekends as this can help with energy levels. This may mean getting up at the same time, and scheduling timed periods of activity balanced by effective rest.

Communication

Current issues

I'm worried that people won't understand my long covid symptoms and that I'm struggling right now

I struggle at work if there are lots of people around and its noisy

Possible solutions

- While I'm off, I'll make sure I stay in contact with my employer and that I'm working through strategies to support me. I'll keep lines of communication open as best I can
- I'll only share what I feel is necessary with my colleagues and I'll ask my manager to support me with this
- Discuss this with my manager. I'll ask if there are working from home opportunities, that I can use the quiet area to work in more often or if I can use earphones from time to time, if I am not able to cope with the noise

Now consider your own...

Physical

Current issues

Possible solutions

Cognitive

Current issues

Possible solutions

Emotional

Current issues

Possible solutions

Fatigue

Current issues

Possible solutions

Communication

Current issues

Possible solutions

Possible work adjustments

You have broken down your working day and given thought to everything you do. You now have a good idea of the current difficulties you face, or, if you are off work currently, an idea of potential challenges you may face when you return to work. The challenges and possible solutions you have come up with should provide the basis for conversations with your employer. Through completing the above exercise, hopefully you can feel more confident to have more meaningful conversations with your employer and make your return to work as sustainable as possible.

Some points to guide you:

- If fatigue is a significant issue at present, can short, but more regular rest breaks be supported, to help you spread energy supply more evenly through the day
- Do you have access to a quiet area, this is especially helpful if you work in an open plan or noisy environment?
- If you are in a physical job role, are there opportunities to sit down to do your job, rather than always standing?
- Can a workbase assessment be completed, to ensure your environment is ergonomically set up to best suit your individual needs?
- Can a parking space nearer to your workplace be arranged?
- Can equipment/assistive devices be considered to support you in doing your job?
- Can work from home opportunities be considered?
- Can work hours be re-organised. For example, a 9-day fortnight or if part time, working non-consecutive days?
- Can you use annual leave more flexibly, to allow you to take more regular days off?

Keeping in touch with your employer

If you are currently off and are planning your return to work, it is recommended you keep in touch with your employer from the earliest point possible, to let them know of your plans and wishes. Keeping lines of communication open, from an early point, will ensure both you and your employer are on the same page with return to work plans.

We would suggest advising your employer of your plans to return to work via a letter or email, so that both you and your employer have a record of what has been agreed.

Points to include within the letter or email:

- How long you have been signed off work
- That they are aware you are off with symptoms related to long covid
- That you are receiving advice/support/rehab/ guided self-management to help you with management of symptoms
- That you hope to receive their support with aiding a successful return to work
- That a future meeting would be helpful, to begin discussions around possible adjustments to support a return to work

Top tips for being 'work ready'

If you remain signed off but are now considering how to get back to work, there are things you can be putting in place, that will give you the best conditions to make this as smooth a journey as possible.

It is helpful to start setting yourself some small, achievable goals, that will feed into the bigger goal that you set at the start of this booklet.

Through doing some day-to-day activities while at home and by thinking about your current baseline, you can begin to give yourself some feedback about where you are right now and set small, incremental goals to try and build your activity tolerance.

Some examples may include:

- Sorting through paperwork
- Answering emails or searching websites
- Reading- in manageable chunks
- Cooking yourself a meal or making a drink
- Meeting up with a friend
- Gentle exercise or movement- short stroll outside
- Sitting in the garden everyday
- Talking to a friend on the phone

The basic principles are to start with a comfortable level of activity that you can replicate consistently, without experiencing a flare up of symptoms, (as this may indicate you are pushing above your current baseline).

Remember, your baseline should include:

- A comfortable level of activity
- A manageable level on a regular basis
- A level you can manage without increasing symptoms

Re-establishing work readiness

When we are working, we are in a routine or pattern. While you have been off work, you may have found that you have moved away from these established routines, as your body tries to recover from the longer-term impact of the Covid-19 virus. You may find that you sleep later into the day, go to bed later at night or that eating patterns have changed. Starting to re-address these potential imbalances will support you in building strong foundations to your work plans.

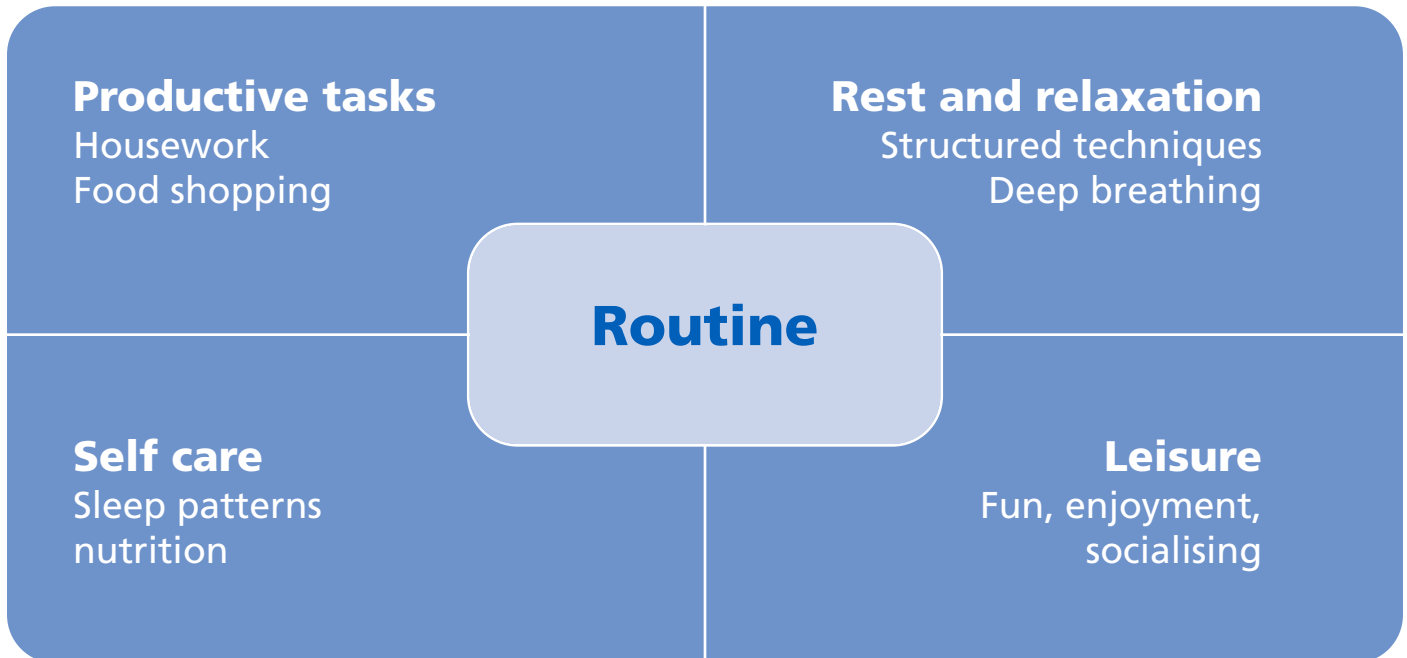
Looking at the role of circadian rhythms may be helpful here. This is commonly known as our internal body clock. It is a 24-hour cycle that regulates bodily processes to adapt to environmental changes for example, sleep-wake cycles, body temperature, appetite, memory, production of hormones and activation of the immune system.

When working optimally, our circadian rhythm responds to changing levels of light and darkness. If our bodily perception of daylight and darkness is influenced artificially by modern lighting, increased use of screens, by staying up late and sleeping later into the day, we risk interfering with the delicate balance of the circadian rhythm.

By reconnecting with the natural cues and daytime routines that the circadian rhythm needs to work optimally, it is possible to improve the quality and pattern of sleep.

You can set yourself small goals to change your routine so that it becomes more in tune with your Circadian rhythm and is more conducive to returning to work.

It may help you to consider a balance within these four domains and if there is a mixture of these throughout your day:



Diet

Try to make sure you are eating a well- balanced diet and try to keep or re-establish a routine with meal- times. Stay hydrated and avoid stimulates such as caffeine and sugary snacks. These may perk you up in the short term but are likely to be short lived and leave you experiencing a sugar or caffeine 'crash'.

Sleep

- Try to stick to a more regular sleep/wake routine
- Have a wind down routine before going to sleep- have a look at sleep hygiene advice for further tips and hints on this
- Positively influence circadian rhythms through reducing screen time before going to bed
- Avoid alcohol or stimulants such as caffeine. Think about your own cut off time for this
- Avoid drinking fluids too late before bed, as this may increase your need to use the toilet during the night

Planning your return to work

If you have been off work for some time, it is reasonable to suggest that a phased return to work is likely. This will give you the best conditions to make your return to work as sustainable as possible.

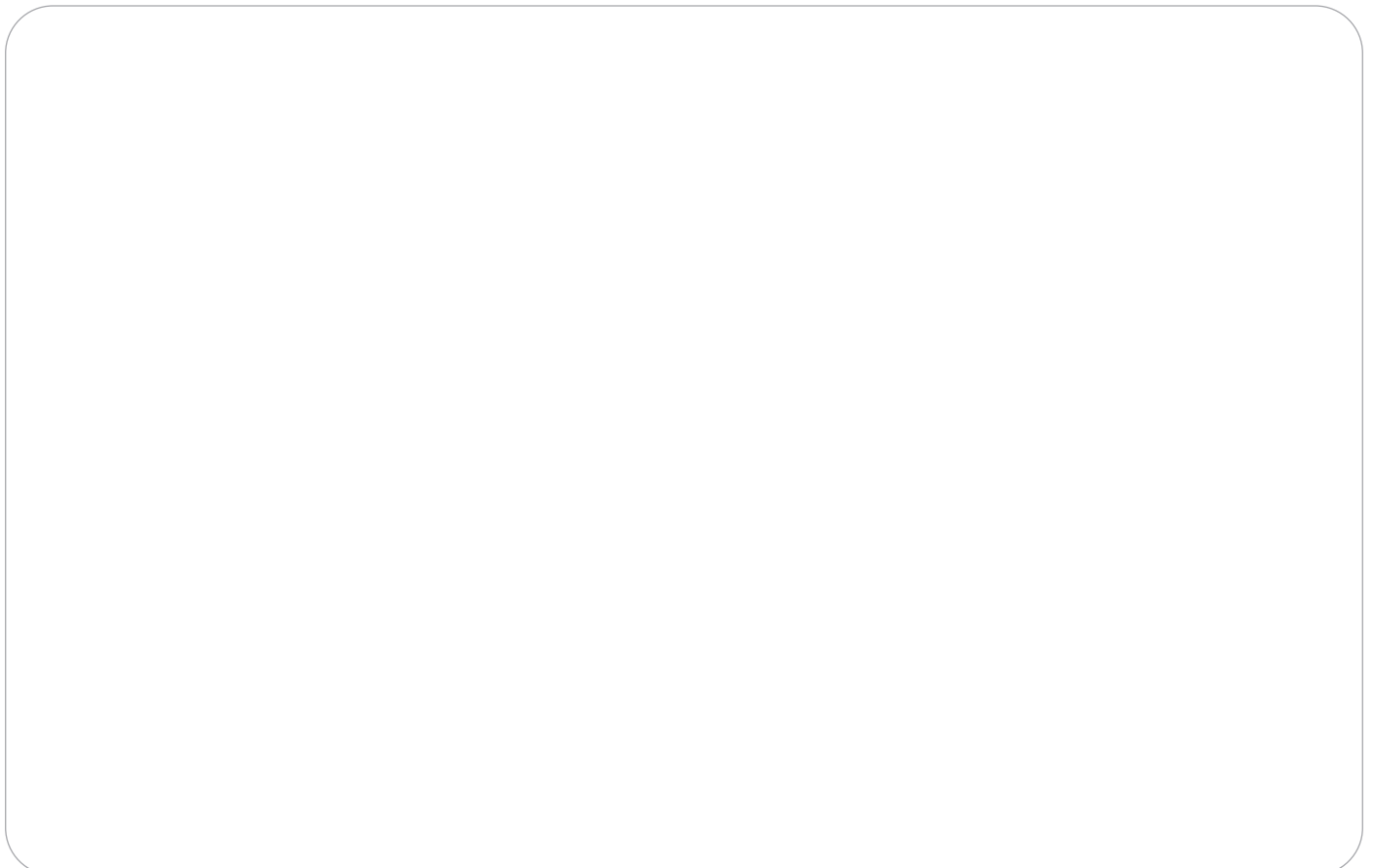
A phased return needs to be agreed with your employer and may have already been discussed during the 'keeping in touch' conversations you may have had.

Your employer should have a policy that informs your organisation's phased return structure- usually an absence management policy. It would be helpful to view the policy, so you are informed of what to expect. It may be helpful to ask for a copy of the relevant policy while you are off and planning your return.

Some examples may include:

- Returning on reduced hours that are gradually increased over a number of weeks (you may need to negotiate a longer period of time than the policy stipulates). A regular review with your line manager at regular points along this process can be helpful
- Changing the hours you work initially, such as starting late or finishing early, to avoid travelling during rush hour
- Changing some duties or temporarily reducing some duties
- Sharing tasks with a colleague
- Working from home opportunities
- Thinking about the roles and responsibilities you have outside of work and if adjustments can be made to the way these are done

Use the space below to consider you own ideas for a phased return to work.



Additional resources

We hope this booklet has given you a starting point, from which to continue your journey towards a successful and sustainable return to work. For further advice, you may wish to explore these helpful organisations information:

www.acas.org.uk

The Advisory, Conciliation and Arbitration Service (ACAS) is an independent public body that provides free and impartial advice on employment rights, best practice and policies, and resolving workplace conflict.

www.gov.uk/access-to-work

Access to Work is a Government grant that supports people with a physical or mental health disability to either find work or to stay in employment. Have a look at the website for eligibility and further details.

www.som.org.uk

The Society of Occupational Medicine has some useful Covid-19 specific resources, including a booklet called '*Covid-19 return to work guide for recovering workers*'.

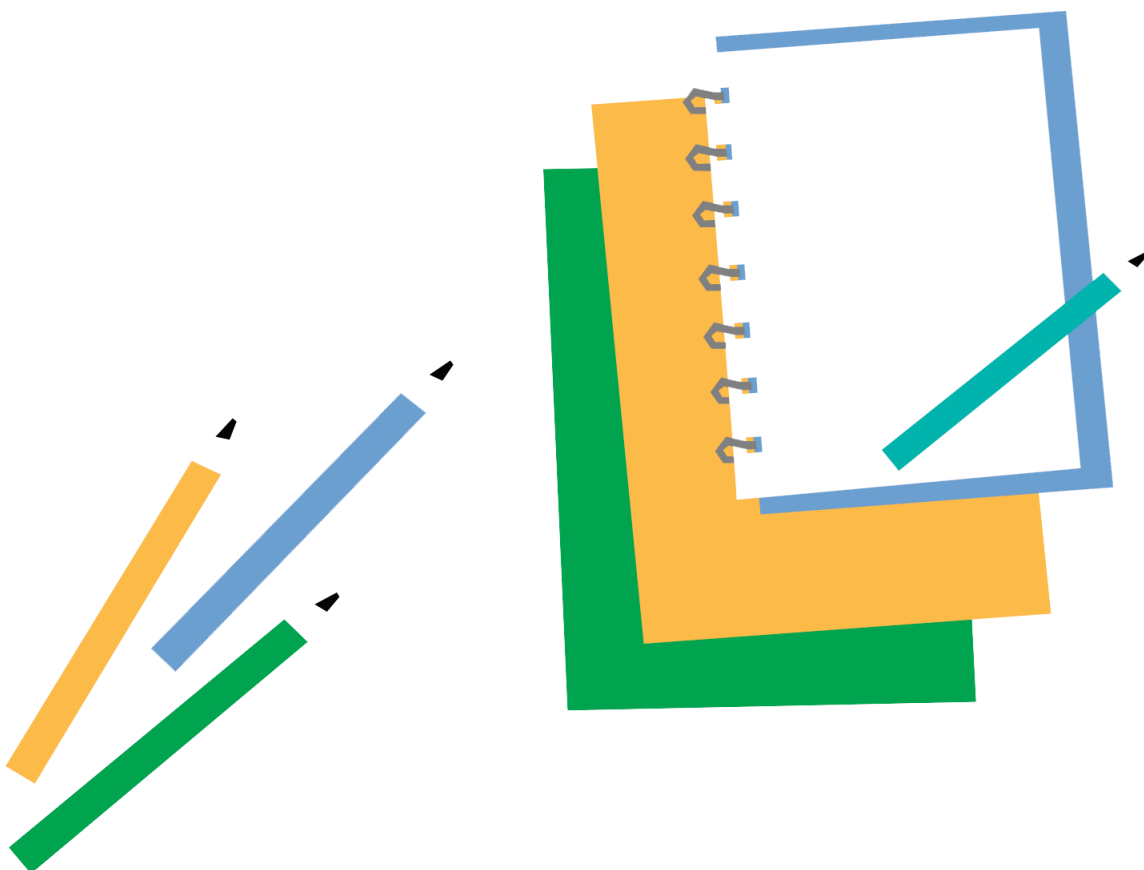
https://www.som.org.uk/COVID-19_return_to_work_guide_for_recovering_workers.pdf

www.yourcovidrecovery.nhs.uk

An NHS online resource offering support with ongoing Covid-19 symptoms. This includes a section on returning to work.

Special thanks...

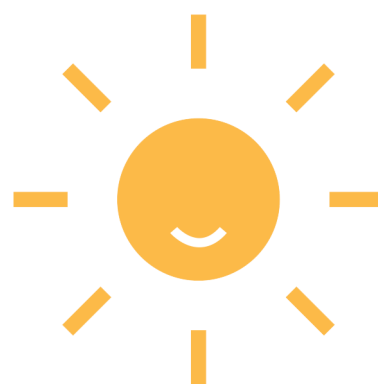
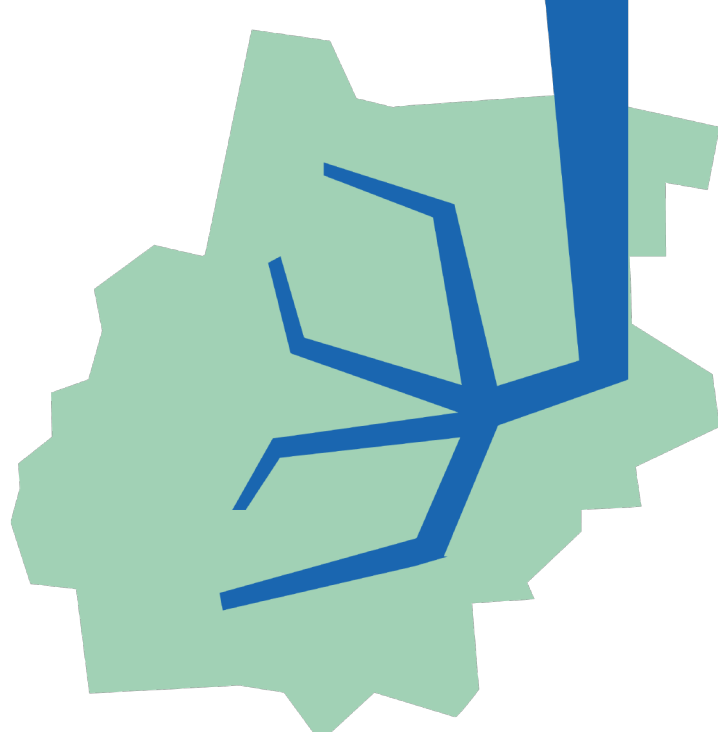
To the Leeds Long Covid Community Rehabilitation Service for its kind permission to use its work booklet and supporting us in writing this booklet.



Contact us

Post-Covid Service

Redshank House
Hinchingsbrooke Business Park
Kingfisher Way
Huntingdon
PE29 6FN



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Patient Advice and Liaison Service (PALS)

If you have any concerns about any of CPFT's services, or would like more information please contact: Patient Advice and Liaison Service (PALS) on freephone 0800 376 0775 or e-mail pals@cpft.nhs.uk

Out-of-hours service for CPFT service users

Please call **NHS 111, option 2** for mental health crisis advice and support.

HQ Elizabeth House, Fulbourn Hospital, Cambridge CB21 5EF.

T 01223 219400

F 01480 398501

www.cpft.nhs.uk

