

Managing your recovery from COVID-19 related fatigue

Contents

Welcome	3	Fatigue can affect more than the body	24
How to use this workbook	3	Sleep	28
Understanding fatigue	4	Is it possible to rest too much?	29
What is fatigue?	4	Preventing deconditioning and improving fitness levels	31
Why do some people get fatigue?	5	What if I do too much?	32
Managing and recovering from fatigue	5	Moving forward	34
Getting started	6	What should I do if my fatigue comes back or gets worse?	35
Understanding your fatigue	7	Recap	38
Patterns of fatigue	8	Finally	39
Managing your fatigue	9	Further reading and useful information	40
The three P's: Prioritising, Pacing and Planning	9	Useful links:	40
Finding your baseline	17	Meditation, mindfulness, and relaxation	40
Rest and relaxation	19	Apps	41
How do you relax?	19	Useful Reading	41
If you find it hard to relax, make a plan	21	Podcasts	42
The emotional effects of fatigue	22	Get in touch	42
Understanding how we react to illness	23	Acknowledgements	43

Welcome

You have received this booklet because you have had COVID-19 and are experiencing symptoms of fatigue as a result. This booklet has been designed to help you understand more about fatigue and provide you with strategies to manage your COVID-19 related fatigue as part of your recovery.

You will not find any information related to other COVID-19 symptoms in this booklet. If you are experiencing any other lasting complications related to COVID-19, it is advisable to speak to a medical professional about these separately.

How to use this workbook

This booklet is designed to be read slowly and in several sittings. Read a little at a time. Take a break. Reflect. Then read bit more.

Top tip: 'Pick and mix'

You might not find all of the strategies discussed in this booklet useful. Choose the ones that appeal to you and try these first.



Understanding fatigue

What is fatigue?

Fatigue is a feeling of extreme exhaustion that interrupts or stops you from doing everyday activities. The usual things that once refreshed you such as sleep, doing a favourite activity or pastime no longer seem to do so. Some people describe fatigue as like having 'brain fog', 'flat batteries' and 'being unplugged'.

Sometimes people who have had a viral infection such as COVID-19 experience fatigue once the initial infection has passed. The severity of fatigue is different for everyone. Some people will still be able to go about their daily lives but have general, yet constant feelings of tiredness. Others could have more debilitating fatigue, which severely restricts their ability to do everyday activities. People with severe fatigue can become almost completely inactive as a result.

Mental and emotional tasks (not just physical tasks) can be very tiring for people experiencing fatigue. This might not have been obvious previously but is entirely normal for those experiencing fatigue. It is also completely normal to find this period of fatigue distressing.



Why do some people get fatigue?

Understanding why you have become fatigued can, quite naturally, feel very important. The reality is that nobody knows exactly what sets off COVID-19 related fatigue or why some people are more prone to it than others.

The best guess is that it is likely to be linked to the severity of the inflammatory response that occurs when the body tried to fight the initial Covid-19 infection. It can take far longer to recover from the impact of this inflammation than perhaps people expected.

There are however, strategies to manage fatigue that other people have found useful, which might also help you on the road to recovery. We have set out some of these in this booklet and hope they help your recovery and prevent your fatigue from getting worse or coming back.

Managing and recovering from fatigue

Learning to manage your fatigue begins with acceptance. Accepting you are experiencing fatigue will help you to manage the condition better and understand the best course of action for you and your recovery.

It is normal for some people to take months to fully recover from fatigue, but recovery is possible. Experience tells us that whilst there are no shortcuts to quicken the recovery process, once you start to see measurable improvement in what you can do, you will begin to feel more optimistic about recovery.

It is also important to note that recovery from fatigue does not always mean a return to a pre-fatigue lifestyle. For a minority of people, recovery will mean learning to manage their fatigue long-term.



Getting started

The recovery journey from fatigue looks different for everyone and will take time, patience and practice. You will not get it right the first time. You may feel like you are going around in circles; however, each time you try, you will learn a little more about how to manage your symptoms. Once you feel you have your symptoms under control, you can learn how to increase the amount of energy you have, slowly over time.

Remember, acceptance of your fatigue is key. Some people adopt unhealthy behaviours to try and cope with fatigue where they either ignore, or take too much notice of their symptoms, becoming consumed by them. Others try and get through the day by drinking more caffeine or having more sugar in their diet. These are not effective strategies for recovery and can lead to symptoms becoming worse over time.

Top tip: Allowing time to recover from COVID-19 is important

A period of rest and recovery after COVID-19 is essential. Trying to rush back to previous levels of activity may be counterproductive.

Remember, COVID-19 related fatigue does not necessarily relate to how ill someone was with COVID-19. People who thought they recovered from the acute symptoms may still have persistent, extreme fatigue.

Understanding your fatigue

The first step in planning a fatigue management strategy is figuring out how you and your fatigue behave. Pacing is the name for a technique some people find useful in managing their fatigue.

It is important to recognise the various behaviours you may demonstrate during your day or week to progress towards modifying them. This will help you to understand how to adjust your activity to get the balance between activity and rest right for you.

Look at the diagram on the next page and decide which approach best reflects how you currently try to manage your fatigue.

To effectively manage and recover from fatigue, it is useful to recognise these behaviours and be able to modify them appropriately. Fatigue management is complicated, it takes time and as your fatigue improves, it changes again.

It is important to note here that fatigue can be a long-term condition for some so be kind to yourself. There is a balance to be struck, and a period of recovery may be appropriate while you learn how to manage the fatigue you are experiencing.

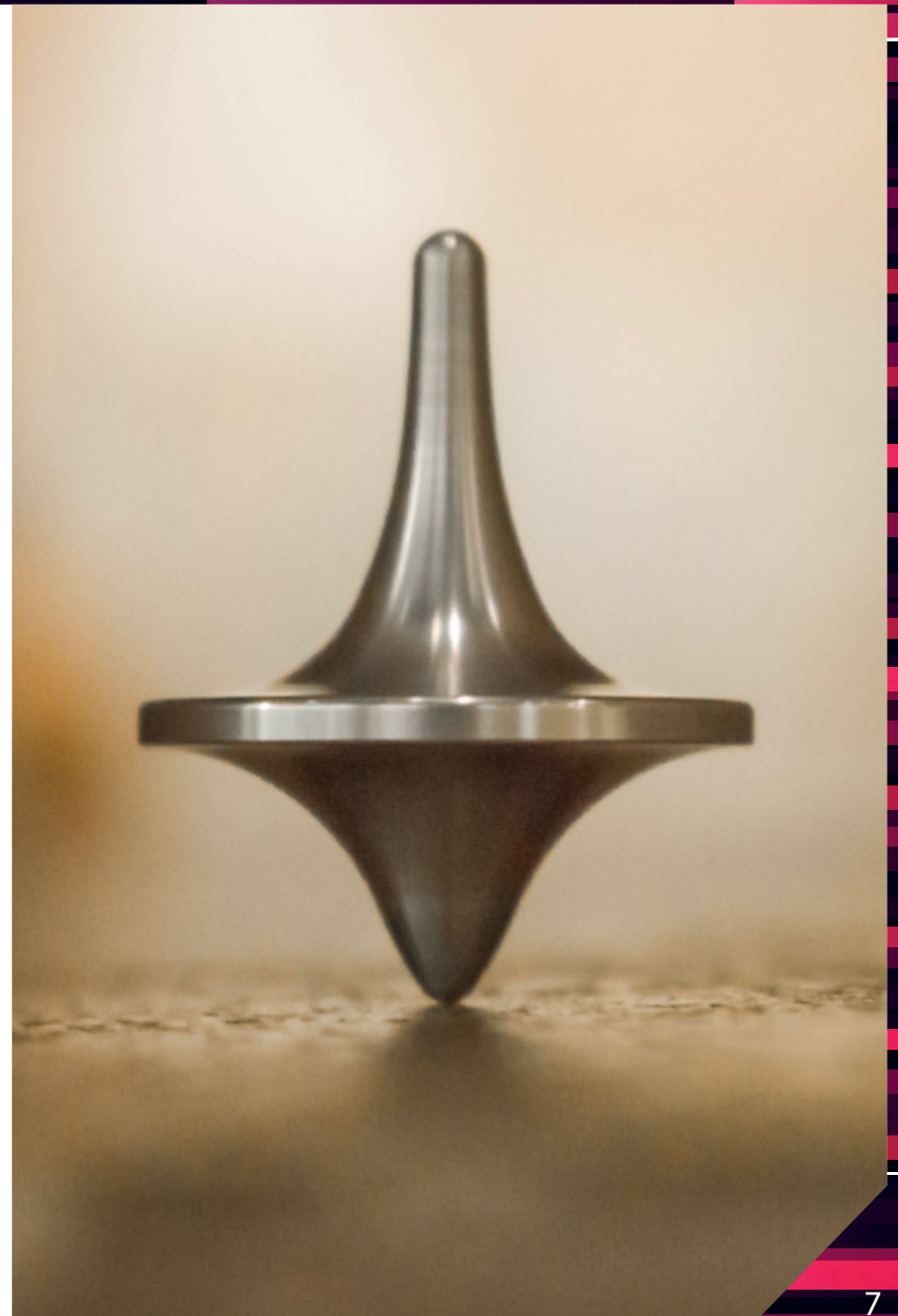


Figure 1: Patterns of Fatigue



Boom and bust –

This can happen on the days you feel well, and you jump at the chance to do as much as you can. You BOOM! You do more than your body was able to do and you spend the next few days recovering – you BUST!



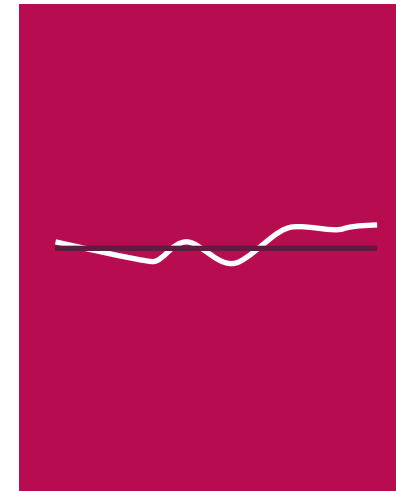
Avoidance –

You avoid the activities you know will make you feel worse. However, avoiding activity completely can lead to reduced physical function known as deconditioning. This can lower your mood (this is covered in more detail later in the booklet), especially if you find activity important and you find not doing it stressful.



Persistence –

Where you keep going and ignore your body. This leads to exhaustion or injury.



Task modification –

You modify the task or activity to match your current energy levels. You learn how your body responds to that task and activity in the hours and days afterwards.

Managing your fatigue

In this section, you will find some top tips and strategies to help you better understand and manage your fatigue.

The three P's: Prioritising, Pacing and Planning

1) Prioritising:

To be able to manage your fatigue effectively, you need to identify which tasks and activities make you feel more or less fatigued. You can then prioritise your time, activities, and energy levels accordingly.

People use different amounts of energy for different tasks. For example, you might use a lot of energy responding to friends and family on social media but find other daily tasks such as planning meals for the week take less energy.

You might find getting washed and ready for the day very tiring, while another person might find cooking more exhausting. There are no right or wrong activities; it's all about understanding how much energy they require.



Task: How much energy do tasks require?

Use the table below to write down all the tasks and activities that you do regularly and how much energy you feel that they require. Include things like showering and dressing, food shopping, housework, childcare, work and hobbies etc. When you've done this task, take a break.

High energy:

Medium energy:

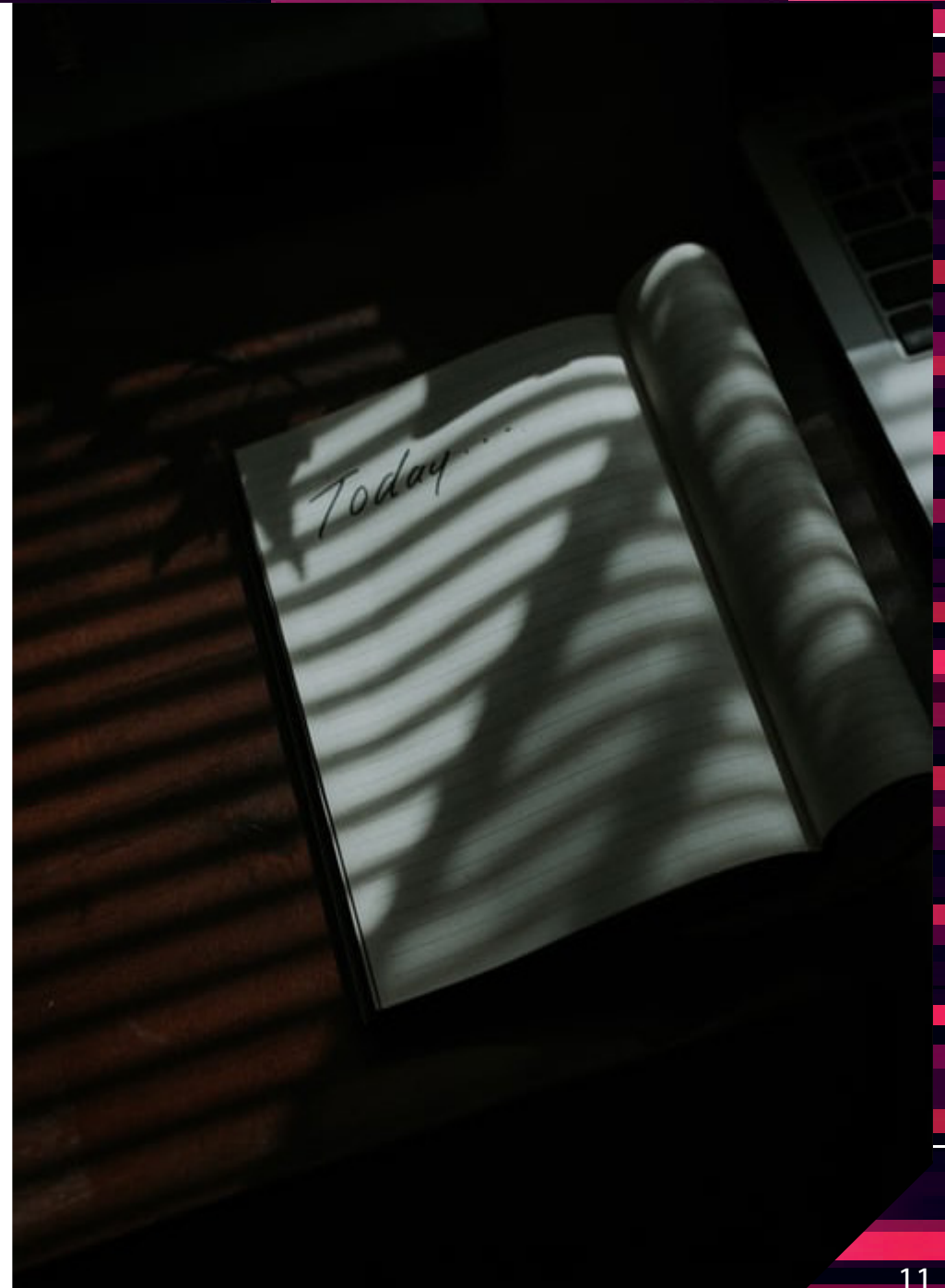
Low energy:

Now you have written down ALL the things that you do often and how much energy they take up, it is time to identify which of these things are high, medium or low priority:

- High priority or essential activities and tasks could be things that you have to do such as family commitments like childcare, or it could be things that you enjoy and are important for your mental health and wellbeing such as a hobby or interest. Another way to think about high priority activities is these are the things that you cannot or are not prepared to give up.
- Medium priority activities and tasks are those that can perhaps be done less often or by other people.
- Low priority activities can be put off until you begin to feel your fatigue has improved.

Top tip: Be kind to yourself

At this time, there may be some of these tasks and activities that you feel you are not able to do. This will be frustrating for you, but it is ok and perfectly natural when you are experiencing fatigue. Be kind to yourself and don't beat yourself up about the things you are finding challenging at this time.



2) Pacing:

Once you have identified which activities are essential for you to do, those you can seek help with, and those you may no longer be able to do at the moment, you can begin to think about pacing yourself. This involves changing your way of thinking about tasks to do them more slowly or break them up with rests to prevent making your fatigue worse. It may also involve asking others for help with certain things or having to put off doing certain things until you feel more energised.

Look at the activities you have ranked and ask yourself the following questions:

- Which activities make you feel fatigued or worsen your fatigue whilst you are doing them?
- Which are the activities that you feel ok doing but then seem to make you feel tired a few hours later?
- Which are the activities that you seem to feel ok doing but then feel worse a day or so after? (Sometimes the fatigue effects can be delayed and some people can feel worse for a few days afterwards.)
- Can you break up or space out any of the tasks that use up a lot of your energy and make your fatigue worse? For example: rather than clean a whole room in one go, could you spread it out over an entire day or a couple of days? Could you do the food shopping online instead of having to go to the shops? Can you plan a walking route that has places to stop and rest?
- Do you need to spend as much time doing those things as you have been doing?

- Can someone do any of the things for you instead, or help you with them? For example, could you get a friend or relative to help with school pick-ups and drops offs?
- Can you delay doing some things until you begin to feel better.



3) Planning:

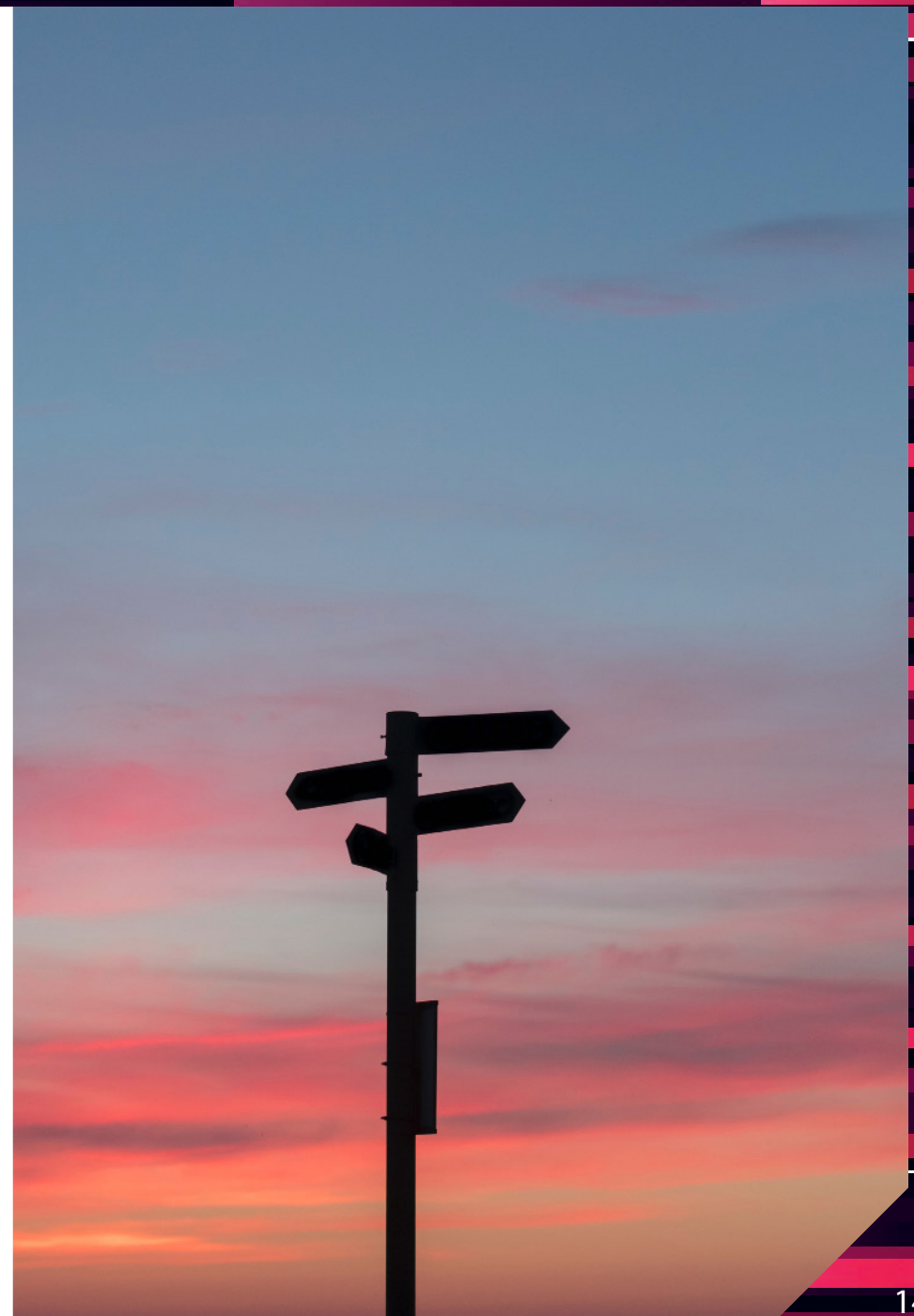
You should now have a better understanding of how all your activities and tasks affect your fatigue and how you could modify them. This next section will help guide you through planning to fit all these things into your life whilst managing your energy levels and fatigue.

When considering your plan for the week, it is also important to fit in times when you can rest and recover.

If you struggle with fitting in rest and recovery time, you can find some ideas later in the booklet to help you with this.

Mel's story

"I'd worked out by this point that I needed rest days before and after stressful things and that I could only manage a certain amount of time working. I'd start to feel this weight on my chest at about 2pm, and I'd think, right, time to go. Work were fantastic, thank goodness, about letting me work flexibly, so nobody thought anything of it. I used to have a rest in the car before I drove home and then another rest just before I picked my son up. I didn't understand why I had to do this at the time, just that it seemed to work. I didn't know how to make it any better. It just felt like I was stuck."



Task: Weekly planner

Some people find writing down their weekly plan and adding in times of the day and week where they will have planned rest breaks useful to help manage fatigue. Use the template below to help organise your time. Making a plan or routine can also reduce stress and anxiety, which can make fatigue worse, and can help you to find a baseline that your body responds well to. When you completed this task take a break.



Weekly Planner - Try using this to schedule in next week's activities and rests

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
0600-0700							
0700-0800							
0800-0900							
0900-1000							
1000-1100							
1100-1200							
1200-1300							
1300-1400							
1400-1500							
1500-1600							
1600-1700							
1700-1800							
1800-1900							
1900-2000							
2000-2100							
2100:2200							
2200-2300							
2300-0000							

Finding your baseline

Your baseline is the level of a specific activity you can achieve without creating a significant increase in fatigue symptoms. It is a starting point. It very much links to your pacing behaviours. If you currently experience the 'overspending' pattern of fatigue, a boom and bust, it is crucial to find your baseline to begin living within your energy means.

You will have to experiment to work out what your baseline is for any given activity, which may take time. In the early stages, you might find that your plan hasn't worked as well as you had hoped and you have to revisit it and make some further adjustments. This is completely normal when learning to manage fatigue.

Simon's story

"I knew I felt exhausted - I'd be doing something, and suddenly I would just feel drained, my heart would start beating, and I'd start sweating. I was determined not to give in, so I just carried on because I thought that's what strong people did. Then I'd feel awful for days afterwards. I realised that what seemed like random symptoms were a linked to doing too much a few days earlier. After that, I found it much easier to manage my activity to avoid this."

Many people with fatigue find it useful to understand how their body responds to the demands placed on it. When beginning to plan in pacing strategies, keeping a diary of how your body feels can be valuable to keep track of what works and just as importantly, what doesn't.

To do this, make a written note after each activity you have done. If you felt your fatigue symptoms worsen, highlight this and use this to plan for next time. For example, when you were completing an activity did you have to take a break during the task, as soon as you had completed the task, a few hours later, the next day, or a few days later?

- How long did the symptoms last?
- Did you notice any warning signs that your fatigue was beginning to get worse?

Your diary can help you to identify which activities you may need to take a break in between, or which days you may be better to plan in your rests.

As you notice improvements in your fatigue, you will find it easier to keep track of how your energy levels respond to activities and where you can do more things.

Top tip: Listen to your body

Try to remember how you feel when you do too much. Does your heart race? Do you start to sweat? Do you sense that you are doing too much? Do you need to sit down or do your muscles ache?

Write this down and keep it somewhere close to hand so that you can remind yourself to slow down when you start to feel this way.

By thinking about the symptoms you experience when you're pushing things too much; you can learn to spot them early, quickly and then slow down.

Allow yourself the luxury of properly relaxing when you think you have started to overdo it. You will find more information later in the booklet on how to relax if this is something that you tend to struggle with.

Rest and relaxation

Rest and relaxation are important in fatigue management, especially when you are recovering from an illness such as COVID-19. It is during rest and relaxation that your body takes time to repair itself.

Sitting down gives us rest from physical activities and tasks, but we often forget that mental or emotional tasks can be just as tiring as physical ones. Many stress triggers in daily life are continuous, and we do not always get time to rest and relax. If you find yourself sitting down but you are still thinking about everything you need to do, using your mobile phone or tablet for social media or worrying about something, then you will not get the rest your body needs.

Learning to relax and rest properly is a skill. It will take time and practice, so don't give up if you find it difficult!

People who are not used to taking rest breaks can feel guilty about doing so but try not to feel this way as it can make your fatigue worse.

Ask others to help you plan in your rest and where required (at work for example), provide permission for you to do so.

How do you relax?

Think about how you best relax. What leaves you feeling most refreshed afterwards? Do you enjoy having a bath, reading or talking to friends?

Some people find that listening to a short relaxation or mindfulness track can help them relax, especially if they are not in the habit of taking a rest. There are some options at the end of this booklet.

Others may find doing a restful activity that they enjoy relaxing, as it distracts them from overthinking.

Task: Your relaxing activities

Write down some activities that help you to relax in the box below.



If you find it hard to relax, make a plan

Sometimes even when you start to do the things you used to find relaxing, you just can't switch off. When you go to bed at night you still feel wired, unable to stop your mind from racing. This can be because you're overtired, and it takes a long time to wind down. Taking time to relax throughout the day can help to reduce this feeling of being wired or anxious at bedtime.

Creating a good sleep environment might also help. This includes avoiding using screens, caffeinated drinks or alcohol in the hour before bedtime. More information on sleep can be found on page 28 and at the end of this booklet.

Top tip: Plan time for relaxation

Relaxing is an essential strategy for managing fatigue and should be considered important and planned for. Use the information you have written down to help incorporate relaxing into your day.

For example, if anxiety is keeping you awake, try some simple relaxation exercises earlier on in the evening. Even gentle stretches can help to relax your body and help you begin to wind down in the evening before going to bed.



The emotional effects of fatigue

Experiencing fatigue can have a strong impact on your emotions, leading to stress, anxiety or even depression. If you are dealing with strong emotions, if you know that you are anxious, depressed, or are struggling with grief, then you may need some extra skills or help to deal with these.

You may find that scheduling your relaxation activities helps manage the emotions related to your fatigue. Links to 'further reading and useful information' can be found on page 40



Understanding how we react to illness

No one is ever only physically ill. Illness always has effects beyond the immediate symptoms.

Fatigue can have a profound effect on mood. Depression and anxiety, for instance, are common in people experiencing fatigue. If you have been experiencing your fatigue alone during lockdown this may also have had an emotional impact on you and due to the nature of COVID-19 you may feel a little nervous or shy when starting to see people again, or returning to work, education, or normal social situations. It is common for people who have stopped going out as much because of their fatigue to lose confidence in their social skills or in things that they used to do. It is perfectly normal to feel this way and you can regain your confidence again.

Top tip: Reward yourself

It can be enormously frustrating to feel drained of energy all the time, especially if you have always been very active. Sometimes medical professionals, spouses, family, or friends may not understand what you're going through, which makes the frustration worse. Communicating with people on how you are doing is key.

As you start to improve, it can be helpful to note down your progress so you can look back and see how far you've come when you have bad days. Give yourself positive rewards to look forward to. Organise a short trip out or meet up with friends.

Fatigue can affect more than the body

There are at least four areas of life that fatigue can impact which can affect your life.

Physical symptoms: how the fatigue makes you feel physically

Feelings and Emotions: thoughts and feelings related to what has happened

Behaviour: what you do in response to being fatigued

Thoughts and Beliefs: about your fatigue management and recovery

The example on the right is from someone who had fatigue. You can see the four areas where fatigue had an impact. The person in question worked hard at her job and was constantly worried about not doing well enough. She first experienced fatigue after a bout of illness. She was under pressure at work and was working for 14 hours a day.

Physical symptoms

- Extreme fatigue
- Brain fog and difficulty concentrating
- Some aching in her legs

Feelings and Emotions

- Constant anxiety and worry about not completing work tasks (feels like everything takes longer)
- Anxiety about getting ill again
- Low mood because life is now just a drudge

Behaviour

- Taking no breaks at all at work to try and get things done
- No time off work and no time for enjoyment to make deadlines
- Dropped her social life and stopped doing the activities she used to enjoy

Thoughts and Beliefs

- "I must push myself harder, otherwise I am going to lose my job"
- "I never get anything right because I can't concentrate and have no energy"
- "My colleagues will think I am slacking at my job if I slow down"

In the example, fatigue was only part of the problem. Treatment started with looking at the patterns of activity and rest. This plan included:

- Working less and spending more time doing enjoyable or relaxing activities.
- Using strategies to help her to improve her quality of sleep.
- Working on reducing her self-critical thoughts and worrying.

Gradually, she began to accept and trust that she was good at her job. She realised that some tasks were the responsibility of others and was able to reduce her workload. She was then able to reduce the number of unpaid hours she had been working. As a result, she began to feel better, and her fatigue improved.

This example may not be relevant to your specific situation but hopefully, it paints a picture of the different options and strategies that can help you manage your fatigue.

Also, you may need letters of support to explain and educate your employer about your new situation. Fatigue is recognised within the Equality Act 2010 and reasonable workplace adjustments may need to be made to allow you to continue to work without it impacting your health. Also, your family and friends may need some help to understand the issues you face. In which case, bring them to any medical appointments with you.



Task: A system management approach to illness

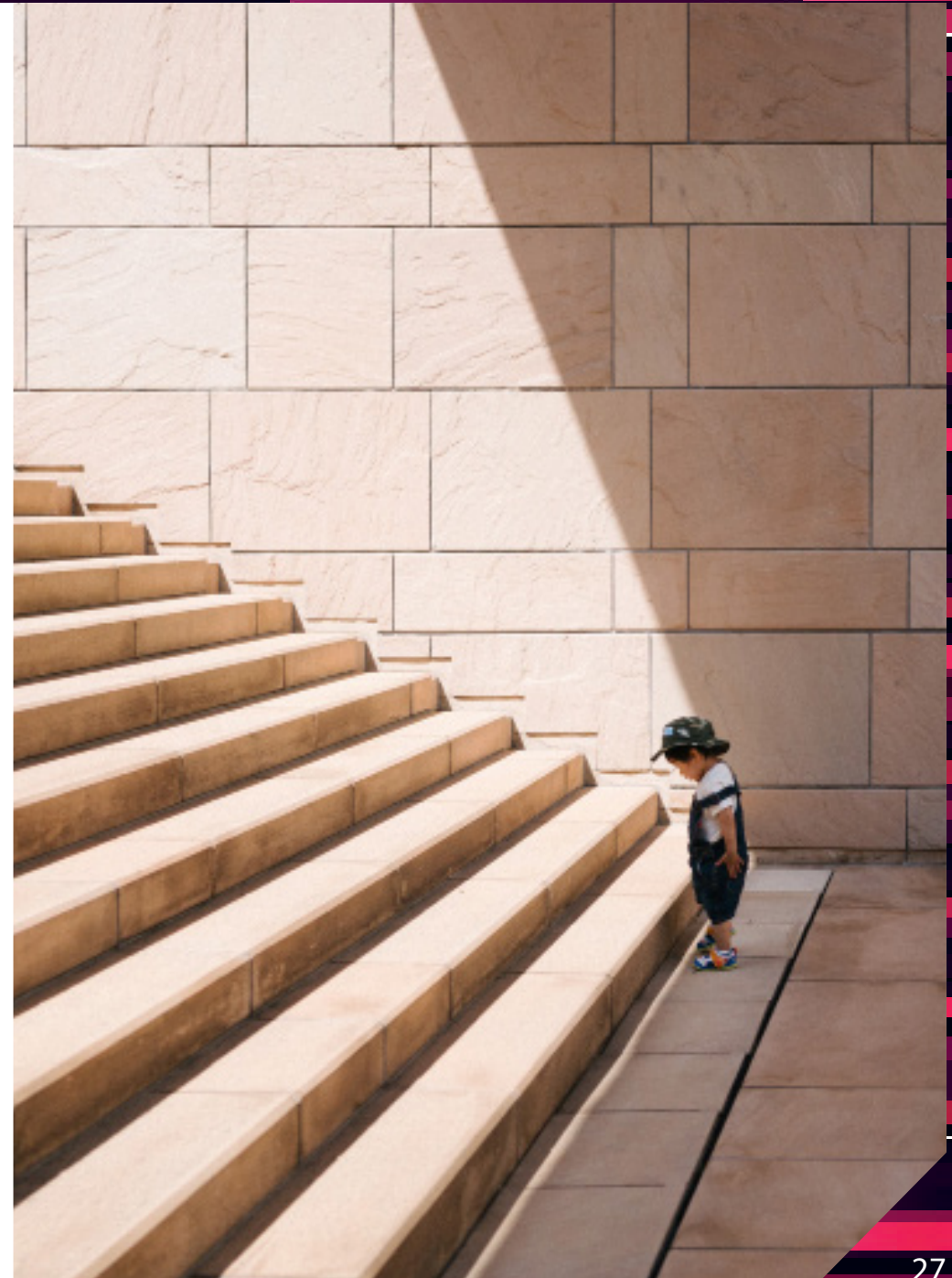
Use the table below to write down some of your symptoms, feelings, behaviours and beliefs in relation to your experience of fatigue.

Physical Symptoms:	Feelings and Emotions:
Behaviour:	Thoughts and Beliefs:

Take a few minutes to reflect on how your symptoms, feelings, behaviours and thoughts and beliefs have had an impact on your experience of fatigue.

Think about ways in which you could challenge your thinking, or change your behaviour to help you manage and recover from your fatigue. For behaviours, are you trying to do too much even though you are exhausted? Or for thoughts and beliefs are you ignoring your fatigue, hoping it will go away?

Consider if your feelings, thoughts and behaviours help or hinder your fatigue? Incorporate these changes into your plan.

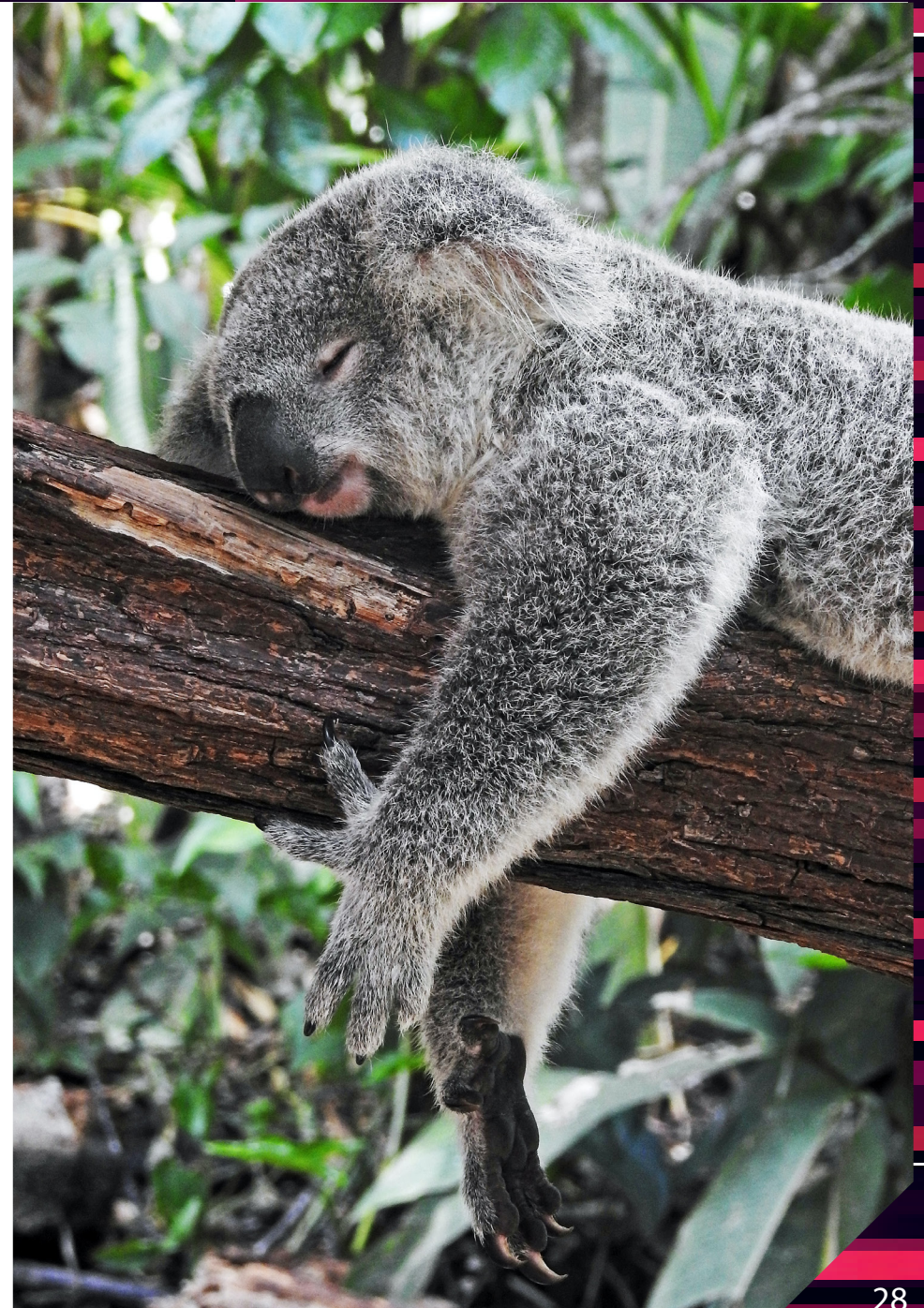


Sleep

It is not unusual for people with fatigue symptoms to wake up in the morning feeling as if the previous night's sleep has not restored them. Some people may be sleeping much more than usual, while others may have quite disturbed nights.

If you have difficulty getting off to sleep or staying asleep in the night, there are several things you can try:

- Go to bed and get up at a similar time each day.
- Have a wind-down routine in the evening where you feel relaxed before you go to bed. Try not to watch anything disturbing on TV before bed.
- Avoid the use of screen-based technology (e.g. mobile phone, tablet, laptop) in the hour before bed.
- Ensure the bedroom is an inviting place to be. Only use the bed for sleep or sex. Avoid using screens or doing crafts in bed. Do these elsewhere in the house.
- Avoid caffeine in the evening and avoid alcohol.



- If you struggle to fall asleep after going to bed, get up (e.g. after what feels like about 15-20 minutes). Go and sit elsewhere in the house. You may wish to read or do something else calming in low light before trying to fall asleep again but return to bed as soon as you feel sleepy. You can also use this technique if you wake during the night.
- If you struggle with worrying thoughts after you have switched off the lights, it may help to take 10 minutes earlier each evening which you dedicate to these concerns. Use a notepad to write a list of things that are concerning you on the left side of the page. On the right side of the page, write down some solutions, or things you can do about each of the concerns on your list. It may also help to have a blank notepad next to the bed to jot down any concerns/things you need to remember the next day if a thought comes into your mind preventing you from getting off to sleep.
- If we sleep too much, the quality of our sleep is likely to be reduced. If you are sleeping for more than 9 or 10 hours in 24 hours, it may be worth gradually trying to reduce the amount of time you spend asleep.

Is it possible to rest too much?

Although proper rest is extremely important when you are struggling with fatigue, reduced levels of daily activity can have a deconditioning effect on the body. This can happen if your fatigue means you have to avoid a lot of physical tasks that you previously did.



If you experience fatigue for a long period and have to reduce or even avoid the physical tasks that you used to do, you may feel like you have lost your strength. Due to the increase in rest, your muscles will likely become smaller in size and strength. This, in turn can make physical tasks feel even more demanding on your energy levels. You may struggle to lift your shopping bags more than usual, find getting up out of a chair more challenging, or feel weak doing any forms of exercise for a while.

You may also notice that your fitness levels reduce, and you get out of breath quicker. This is because you are not moving about as much or for as long and so your heart and lungs begin to reduce the capacity that they usually work at to help you move about.

These physical symptoms are completely normal to experience with fatigue that lasts a while and is called deconditioning. It is important not to let this worry you and play on your mind. Below are some tips to help you to keep as much of your strength and fitness as you can while you are recovering from your fatigue.

Top tip: Keep naps short

If you can't get through the day without napping, try to keep naps short and in the middle of the day (15-30 minutes).

Longer naps (over 60 minutes) taken later in the day will have an impact on night-time sleep.

Preventing deconditioning and improving fitness levels

There are strategies that you can use to limit the deconditioning effects of prolonged resting. These strategies are designed to help people who have had to rest unavoidably due to illness or fatigue for long periods.

During the period where your fatigue may be quite severe, and you are very limited in what you can do you may find these strategies useful:

- Take time to rest and relax in a comfortable sitting position. You may like to try practising some meditation techniques to help to relax your mind, rather than lying down all day.
- You could try some gentle stretches from your bed or chair to take your joints through their full range of movement. This can help to maintain your muscle length and joint movement.

Once you begin to feel like your fatigue is improving you may be able to extend what you do, little by little. We do mean a little! We advise that you make increases to your activity on a very gradual basis, taking time to assess how an activity is impacting your fatigue. For example, you stand up and sit down from a chair five times in a row to maintain muscle strength in your legs. If five times is too much take a rest in between each time you stand and sit back down again. Do not try to push through the fatigue. This leads to the boom and bust situation we discussed earlier. Steady and slow is the key.

Top tip: Bad days happen

If you have a bad few days, or a 'bust', you may need to rest more but try not to stop doing all activities. Just take things down a notch or two while you start to get back on track. This way, you won't lose all the progress you've made.

What if I do too much?

Under usual circumstances physical activity and progressing an activity or task is an excellent way to address any effects of physical deconditioning that have occurred because of illness or prolonged rest. However, in relation to COVID-19 related fatigue doing too much too soon can cause the symptoms to become worse.

Some people with fatigue who do too much activity for their personal circumstances relapse very easily, and their symptoms can become much worse. Yet some people respond well to activity and can progress relatively consistently over time. It is therefore important that you follow the Rest, Wait, Observe pattern after doing any exerting task or activity to understand your limits.

Rest - take a planned rest break after the activity that you want to improve upon.

Wait - see how the activity has affected your symptoms.

Observe - monitor how you felt during and immediately afterwards, a few hours afterwards and the following few days.

The word "REST" is spelled out using four light-colored wooden blocks with green letters. The blocks are arranged in a horizontal line on a white surface. The letters are R, E, S, and T, each on its own block.

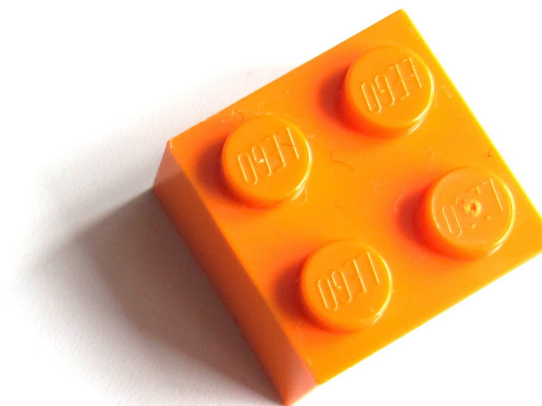
The only way to find out if your symptoms respond well to being more active is to try, very, very gently to do a little bit more, then Rest, Wait and Observe the effects.

For example, if you walk for 5 minutes one day and feel OK, and then go for 10 minutes the next day, you may relapse. So, it is safer to do 5 minutes one day, wait a couple of days and rest, then if you have no symptoms try 10 minutes the next time. It is essential for your recovery that you take the time to work out if physical tasks or activities always bring on bad fatigue symptoms, or if you can very gradually build up your activity.

If you experience no negative effects on your fatigue that is great progress.

If you do get symptoms, then you need to be very careful and try not to increase your level of activity just yet. If you find that your symptoms get worse, then make sure you rest enough and then go back to the previous level (e.g. 5-minute walk) and only progress when you feel confident that your body can cope with the extra time. Do this as many times as you feel you need to, trying out what level of activity works for your body. Prioritising rest, wait, observe is key here. You are not 'failing' if you don't progress quickly. It is not a race.

We suggest you take a break at this point in the booklet.



Top tip: Keep a diary

Keep a diary of how you feel when you are doing your activity and tasks, including how you feel immediately afterwards and over the next few days, to better understand your limits.

Moving forward

As we have acknowledged, acceptance is important for managing fatigue. It allows people with fatigue to fairly assess and adjust their lifestyle within their energy limits.

Acceptance is not giving up but finding a better way to use your resources. Do the things that you value most and maybe think about giving up the things you don't value as much.

Acceptance isn't always easy, and it can be complicated. It is acknowledging the reality of living with fatigue and the understanding that there is not a magic solution or medicine to take the symptoms away. Fatigue needs careful management. Strategies such as activity prioritisation, pacing and planning within a more achievable framework can be practised. This will allow you to lead your life without your symptoms impacting it to make you miserable. It takes a lot of hard work and courage to change behaviour to allow you to live a meaningful life within your current restrictions of fatigue.

Recovery from fatigue is an ongoing process as you explore what remains important to you and what has become valuable to you within your new circumstances.

Top tip: Other useful ideas

Some other things that you can do to help manage your fatigue include:

- Eating a balanced diet favouring freshly cooked meals rather than processed foods where possible.
- Avoid too much caffeine, sugar and alcohol as these can make fatigue symptoms worse.
- Maintain regular mealtimes and eating patterns and try not to skip any meals. This will help to keep your energy levels as consistent throughout the day as possible.
- Stay hydrated. Dehydration can increase the severity of fatigue symptoms.

What should I do if my fatigue comes back or gets worse?

The most important thing is DO NOT PANIC. Relapse often occurs when recovering from fatigue. It is normal for some people. It can be very frustrating, especially when you feel as though you have been making progress, but it can be part of the recovery journey. It doesn't mean you've failed.

Overspending your energy is usually the cause of a relapse and can be triggered by forgetting to pace yourself, too much activity, stress and worry, or a life event. Illness will also often cause a relapse because your body is using your limited supply of energy to fight off disease.

The effects of deconditioning on the body from reduced activity may lead to feeling weaker than usual, which can make activities feel more challenging to complete. Despite this, do not be tempted to try and push through. Remember the rest, wait, observe strategy.



The aim is to maintain a low level of function during bust or relapse periods.

- If you notice that you are particularly stressed, if you have a life event or begin to feel yourself becoming ill, reduce the amount of activity you are doing. This will give your body the best chance of recovering quickly and avoiding a relapse.
- During a relapse try to keep a low level of activity going to avoid deconditioning your body and undoing what you have already achieved. Remember what you have learnt. Employ all your relaxation strategies, and above all, be kind to yourself.
- If you have a setback, learn what you can from this episode to inform what you do in the future. Remember that you know more about managing your condition and are therefore in a much better position than you once were.
- Go back through this booklet and do the activities again to help you learn about your fatigue. Are there any similarities or differences from when you initially experienced fatigue? Use your planning skills to work out a new way to manage your symptoms if you need to.

Top tip: Develop a relapse plan

Develop a relapse plan early on while you are feeling better. This way you can remind yourself of what to do, and how to think so that you can improve more quickly if a relapse occurs. During a relapse all activities can be exhausting, but by having a plan ready, it is one less thing to worry about doing.

Top tip: Take the easy route

Be creative about making life easier for yourself. If you are preparing meals, what could you do to make cooking that little bit easier? Some people like to cook in stages, e.g. if you have a lot of chopping to do, don't do it all in one go. Try batch cooking with family or friends and have some spare portions in the freezer for a day when you are feeling more fatigued. On days when you feel like you can't cook, just keep it simple.

If you have children, could a friend help you out and drop your child off to do an activity one night a week? Prioritise what needs to be done and ask yourself whether you need to be the one to do it. If you got your clothes ready the night before, would that help in the morning?



Recap

Take the time to understand your personal fatigue circumstances and how your fatigue reacts to different tasks and activities.

Write a plan for yourself, stick to it, then review how things have gone and make changes accordingly.

You are unlikely to see changes overnight, so sticking to your plan is crucial.

Remember:

- Slow down. Prioritise quality periods of rest.
- Consider whether a task needs to be done or whether you have to be the one that does it. Is there an easier way for the task to be carried out?
- Try breaking up activities into smaller bite-size chunks, spread them out over time and intersperse them with rest breaks. This will help to conserve energy and reduce the boom/bust pattern of activity.
- Find your baseline and then plan to very gradually increase a chosen activity when you have observed its effects on your fatigue and are confident your energy levels are recovered enough to do so. Remember - REST, WAIT, OBSERVE – when increasing any activity.

Top tip: Useful analogy

Some people find this analogy useful. Try and think of your energy stores like a bank account. In your bank account, you have money which you need to spread over the week so that you are able to carry out your usual activities. If you “spend all of your money” on Monday, that would leave you with no money to spend for the rest of the week. Spread your energy out over the week and try not to use it all up on one day. By planning, stopping and reflecting, you will quickly learn what works best for you.

Finally

We hope that in using this booklet, you have learnt a little bit more about your Covid-19 related fatigue and gained some ideas on how best to manage it.

We encourage you to keep flipping through the pages and revisiting the activities that have been helpful to you.

You may wish to use the next pages for notes or fill in the graph to track your progress over time.

On pages 40 and 41, we have listed some places that offer sessions or courses that you may find helpful, along with some useful websites.

Finally, we would be delighted to receive feedback to improve the booklet for others and so we have added our contact details if this is something you'd like to do.



Further reading and useful information

Useful links:

Body Control Pilates

<http://www.bodycontrolpilates.com>

ME Association

<https://www.meassociation.org.uk/information-and-support-line/information/>

ME Research UK

<https://www.mereseach.org.uk/what-is-me/>

NHS CFS info

<https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/>

POTS UK

<https://www.potsuk.org/>

Royal College of Occupational Therapists

<https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19-0>

Meditation, mindfulness, and relaxation

Frantic World

<http://franticworld.com/free-meditations-from-mindfulness/>

Get Self Help

<http://www.getselfhelp.co.uk>

NHS Choices

<https://www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep/>

<https://www.nhs.uk/conditions/stress-anxiety-depression/mindfulness/>

The Sleep Council

<https://sleepcouncil.org.uk/>

YouTube - search 'meditation'

<http://www.youtube.com>

Apps

Calm App

Headspace App

Useful reading

Don't Sweat the Small Stuff by Richard Carlson

Fighting Fatigue: Managing the Symptoms of CFS/ME by Sue Pemberton and Catherine Berry

How to be Human the Manual by Ruby Wax

Notes on a Nervous Planet by Matt Haigh

Silence Your Mind by Ramesh

The Four Pillar Plan by Rangan Chatterjee

The Power of Now by Eckhart Tolle

Podcasts

All about ME – supported by the ME Association

Feel Better, Live More by Rangan Chatterjee



Get in touch

Research and Innovation for post Covid-19 Rehabilitation (RICOVR)

RICOVR is a research and innovation unit set up to identify what works, and what doesn't, in terms of helping people recover and rehabilitate from Covid-19. For more information visit <https://www.shu.ac.uk/research/specialisms/advanced-wellbeing-research-centre/ricovr>

<https://www.shu.ac.uk/research/specialisms/advanced-wellbeing-research-centre/ricovr>

For any queries, please contact RICOVR@shu.ac.uk

The Patient Advice and Liaison Service (PALS) can offer on-the-spot advice and information about the NHS.

Visit: <https://www.nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service/>

If you would like further information about health conditions and treatment options, you may wish to have a look at the NHS Choices website at www.nhs.uk. On this website, there is an information prescription generator www.nhs.uk/ips which bring together a wealth of approved patient information from the NHS and charity partners which you may find helpful

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The Newcastle upon Tyne Hospitals
NHS Foundation Trust

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