Post COVID-19

Patient Information Book

Any queries contact: DMRC-COVIDRehabGroupMailbox@mod.gov.uk

Preface

This booklet is intended to assist patients in their recovery from COVID-19 through education, explanation and signposting. It has been compiled by the senior clinical team at DMRC Stanford Hall and will be reviewed and updated as our experience in treating recovering patients increases. Please contact us at the group mailbox if you wish to check you have the latest version or wish to provide feedback to help make it better.

I am very grateful for the hard work of all those who contributed to the final document.

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Clinical Director DMRC Stanford Hall
11th May 2020

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What happens when we catch a Virus?

Coronaviruses are not new; they are responsible for other illnesses such as the common cold or seasonal flu.

COVID-19 is a new and novel strain – symptoms vary from none to severe. Recovery after a moderate or severe case can take longer than you might be expecting.

When a virus invades our bodies, it hides in our own cells and makes copies of itself. When this happens, we have what is called an immune response. This is where our bodies make cells to destroy the cells that the virus is hiding in so we can get rid of it.

This is a perfectly normal response to anything that invades our bodies that doesn't belong there, virus, bacteria etc. Sometimes this response is in a small area e.g. infection in a cut or following a sprain and sometimes it's more widespread e.g. colds and flu. This response happens very quickly so that the minimum damage happens

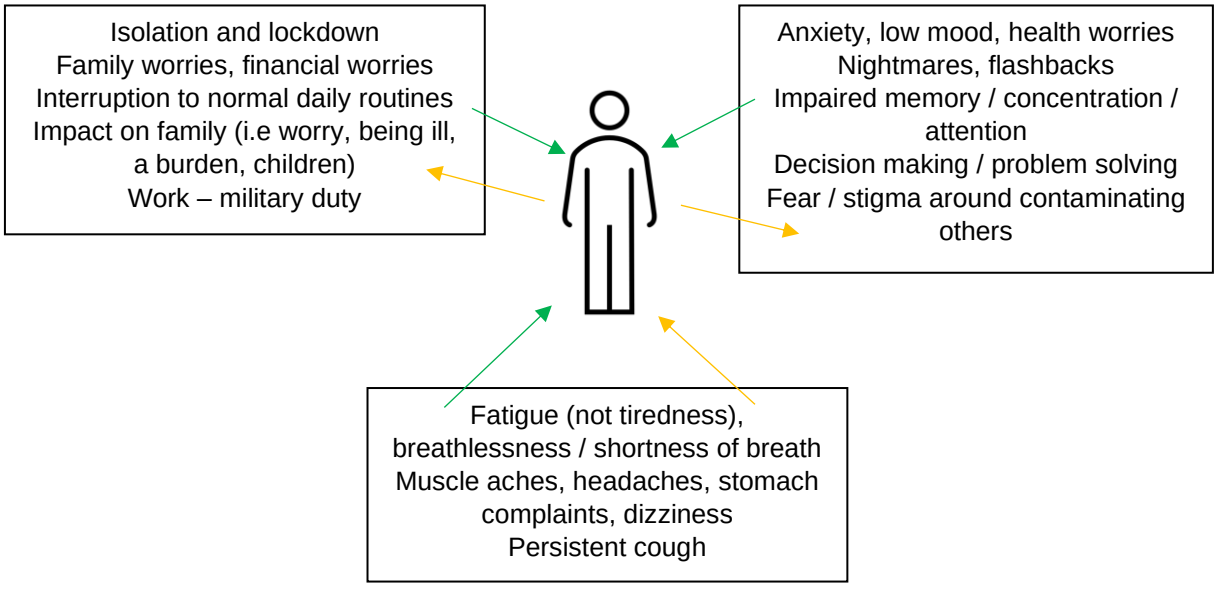
When the cells are destroyed, we get inflammation – you may have experienced inflammation in the past when you've had an injury e.g. swollen ankle after a sprain. Try to think of a time when this has happened to you. We all know how painful that is and how long it can take to get better, so when this happens as the result of a virus it's not surprising that we feel so bad.

With new viruses the response is often greater and takes longer because we remember viruses we've met before, so the response doesn't need to be so great.

Most of the time our bodies repair themselves and we go back to how we were after a couple of weeks of feeling ill. But we know that for some people this doesn't happen.

There are lots of reasons that recovery may be slow, and they are not all to do with our physical response to the virus. The way that we think and feel affects us physically too. Our whole body, including our brain, reacts to this inflammation.

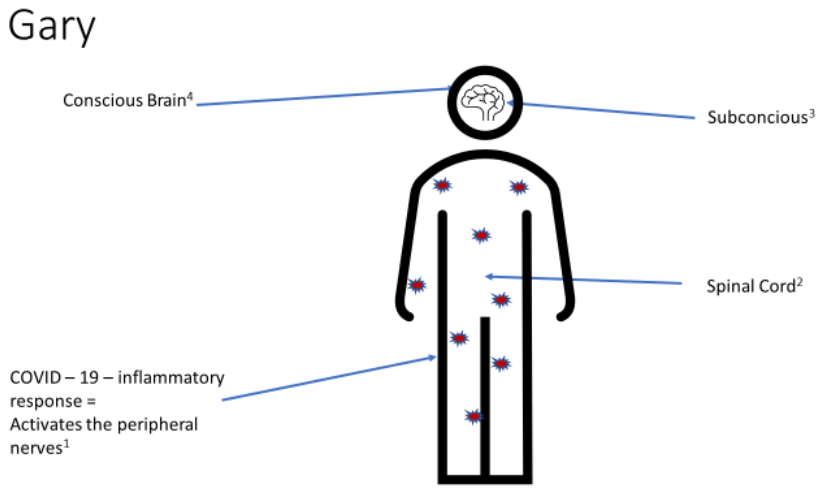
Also because COVID-19 is a new virus a lot has had to change for us and this can mean that a lot of things that we think and feel can contribute to our symptoms, as well as our symptoms contributing to the way we think and feel.



The Threat Response

Whenever we have an illness or injury our bodies and brains respond to it so that we can protect ourselves from further problems and start the recovery process. This is known as the threat response (or sometimes it is called the stress response).

In order to understand how this works we need to understand more about our nervous system. So, meet Gary.



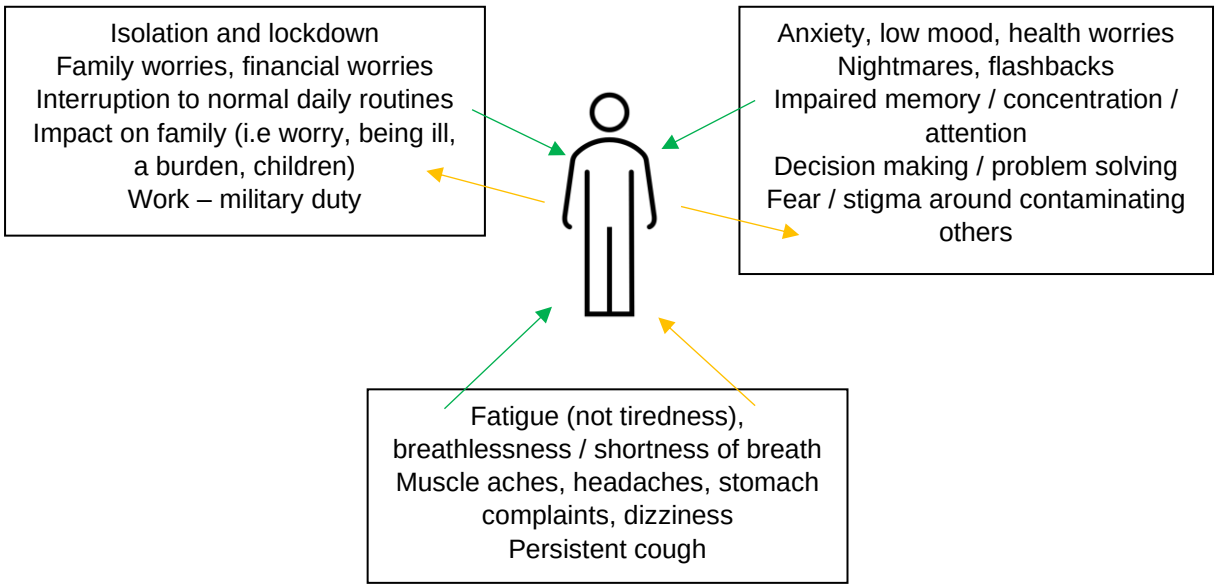
1. Peripheral Nervous System (PNS)
This is made up of the nerves in the 'outside' bits of our bodies e.g. skin, muscles, bones, internal organs and blood vessels. Some of these nerves detect changes in our bodies such as temperature, chemicals and hormones and pressure. This information is sent to the spinal cord.

2. Spinal Cord
A 'filter' for information, it will only allow information to the brain that is important. For example, your PNS will be sending information to your spinal cord that you are wearing socks. It's not particularly interested in this because you wear them every day and they are not dangerous to you. But if you banged your leg or caught a virus it would be really interested and pass this information on.

3. Subconscious Brain
Next this information reaches the subconscious part of your brain. This is an ancient brain that all animals have. It has only two jobs – survival and reproduction! When information reaches this part of the brain it immediately initiates the fight and flight response. This sends information back to our PNS, via the spinal cord, and makes things like our blood pressure, breathing rate, heart rate and muscle tension increase so that we can fight or run away. Sometimes it will make us freeze as that is the safest thing to do. In the case of a virus this can help the body to fight it. At the same time as it starts the fight and flight process your subconscious brain passes the information on to your conscious brain.

4. The Conscious Brain
This is our big, human brain. It's the bit that makes you – you. We process the information given through our memory first to see if we have encountered this situation before and to store it in case it happens again. We then compare the situation to other 'knowledge' that we have e.g. our beliefs, decision making, reasoning and previous experiences. In some cases,

we are happy that the input is not really a threat e.g. standing on a Lego and we everything goes quickly back to normal.
When we come across something that we are not sure about we react differently. Our conscious brain wants more information so it 'winds-up' the fight and flight response and lots of things can then contribute to how we feel physically, mentally and emotionally as we can see below. They can also happen as a result of this process.



As you can see lots of things can impact on how we feel and how we feel can impact on a lot of other things including our physical and emotional wellbeing.

But there is good news! You haven't always felt this way and you can get back to feeling more like you again with some time and practice.

Optimal Breathing Re-education

Breathing re-training can take a while to master but changes and benefits can be seen quickly. It is a process that works on initially being a conscious practice, but this will eventually become an automatic process and your normal pattern of breathing. To maximise the benefits of the exercises you will first need to do some activation activities to improve the effectiveness of your breathing mechanics.

Foam Roller

Upper back stiffness will have an impact on your ribs (and diaphragm) ability to move and work effectively. Using a foam roller allows you to start improving your upper back and rib mobility. Lie with your mid back over a foam roller, keeping your arms low roll up towards your shoulders. Repeat 6 times, then cross your arms across your chest and repeat the rolling action – this may feel slightly more uncomfortable as you are increasing the loading across the tissues of your back. Once you have completed this repeat the process with your arms above your head – again this may feel more challenging.

You may wish to add some foam mobilising activity to the rib angles – initially this may be uncomfortable. It will get easier with regular practice – If it is too challenging speak to your physio or ERI.

1. 

2. 

3. 

4. 

Chair Based Exercises

These exercises are useful in that they not only help improve the mobility of the spine and ribs, they can also work as a quick check to see if you need to move or do some mobility exercises. Sitting on a chair cross your arms across your chest and turn to the left, then right – your movements should be equal and you should be able to turn your shoulder about 90'. If you are unable to then a dynamic stretch may help – as in the picture turn to the right, drop your left arm and hold the arm of the chair. Gently turn back to the middle but stop yourself from moving using the left arm. Hold the resisted pull for 3 breaths. Relax and try to turn to the right again – hopefully you can move further. Repeat this process twice to the right and then towards the left.

Placing your hands on your lower ribs – breathe normally and feel how much your ribs move – it should be between 5-10cms. If they don't move the towel exercise may help. Wrap a towel round your body at the level of your lower ribs. Cross your hands over and pull the towel tight. Take a deep breath in but resist the outward movement of your ribs with the towel. Breath out – you should feel the towel loosen slightly – pull it tighter to 'take up the slack' from the lower rib movement. Repeat 3 times.

Beach Pose Breathing

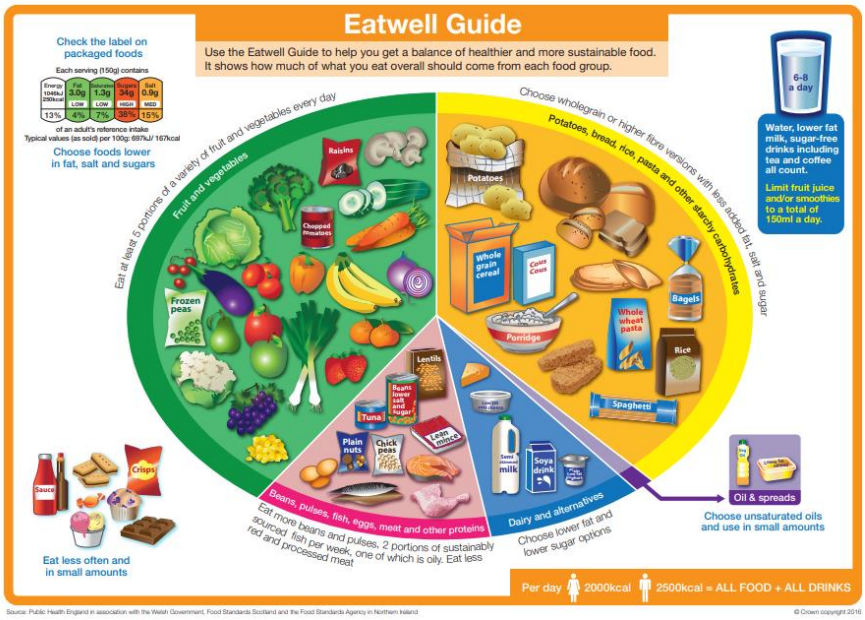
Lie on your back with your knees bent and hands behind your head. Try to breathe in and out through your nose, aiming at your diaphragm leading the process. This may feel very un-natural and difficult – this is a common response, there isn't a problem with breathing through your mouth to alleviate this feeling – just return to nasal breathing when you are able to. Do this for up to 5 minutes, repeating several times through the day as you are able.

Eating Well for Recovery Post COVID-19

Background

Although COVID-19 is a new disease that we are still learning about, a lot of information on how it impacts individuals nutritionally can be transferred from our knowledge of other respiratory diseases. This leaflet will focus mainly on malnutrition as many people will experience reduced dietary intake and unplanned weight loss because of COVID-19.

If you have not experienced any weight loss and are eating normally then please follow general healthy eating advice as shown in The Eatwell Guide below.



Include foods from each of the main food groups:

- Protein Foods - For healthy strong muscles (including those that help with breathing)
  - Try to eat protein foods 3 or 4 times a day, (lunch, dinner and snacks)
  - Foods that provide protein include: meat, fish, eggs, dairy products (cheese, yogurt, milk), tofu, beans, lentils

- Carbohydrate Foods - For energy
  - Always include a starchy food at each meal
  - Examples of these foods include: potatoes, bread, pasta, cereals, cakes, puddings

- Fruit and Veg - For essential vitamins and minerals to boost immune system
  - Include plenty of fruit and vegetables in our diets – 5 a day
  - Your fruit and vegetables can be fresh, frozen, canned

- Dairy Foods - For strong bones, Vit D and as a source of protein and energy
  - Include: cheese, milk, yogurt, cream, fromage frais - include a portion of dairy in your diet 3 times per day - don't choose low fat options
  - Non-dairy foods providing the same important nutrients (e.g. calcium) include: leafy green vegetables, beans (e.g. kidney beans), chickpeas (eg. hummus), nuts (e.g. almonds), seeds (e.g. sesame), fruit (e.g. oranges, dried figs) and seafood (e.g. salmon, sardines)

Staying hydrated is also very important to prevent dehydration and constipation. Aim for 8-10 glasses/2 litres of fluid each day, such as water, fruit cordials, fresh fruit juice, milk, decaf tea/coffee or herbal teas.

COVID related weight loss

Following a period of acute respiratory distress and illness, it is common to experience a significant amount of weight loss, predominantly loss of fat free mass/muscle, which can impair your functional strength but also the strength of the muscles you use to breathe.

You may be malnourished or at risk of malnutrition if you currently have:

- Changes in appetite, need for assistance with feeding or swallowing difficulties affecting ability to eat and drink
- Taste and/or smell changes impacting on the amount you are eating
- Fatigue or reduced strength preventing you from preparing and cooking meals or eating full portions
- A reduction in current dietary intake compared to 'normal'
- Experienced a significant amount of weight loss (BMI less than 20kg/m^2 or more than 5% unplanned weight loss in 3-6months) or muscle weakness

Although you are now in recovery, if you are or have experienced any of the above in the past 6 weeks it is important to maximise your nutritional intake in order to recover to the best of your ability. You will need to think differently about the foods you are eating.

Tips for eating when you are short of breath

If you find you are eating less because you are short of breath

- Aim to eat something 6 times per day, try to eat 3 smaller meals and have snacks in between meals or nutritious drinks e.g. milky drink or fruit smoothie
- Soft foods which require little chewing may be easier to eat e.g. soups, stews, scrambled eggs, yoghurts, milky puddings

Tips for coping with a dry mouth

Dry mouth can be caused by using oxygen, nebulisers or inhalers. It can make it difficult to chew and swallow foods, and sometimes it can lead to taste changes.

- Firstly, ensure you are drinking plenty of fluids,
- Choose softer or moist foods, e.g. minced beef in shepherd's pie rather than pieces of meat
- Suck fruit sweets, ice lollies made with fruit juice or squash, or chew sugar-free gum
- Your doctor or nurse may prescribe some pastilles or saliva sprays if the problem continues
- If you are finding it difficult to swallow, are frequently coughing during meals or your voice becomes gargly ask your doctor or nurse to refer you to a speech and language therapist who will be able to advise you
- Always make sure you keep your mouth clean and moist to avoid infections. Ask your dentist for advice if needed

Tips for coping with taste changes

If your taste changes you may lose your appetite and may not feel like eating your usual foods

- If you are using a steroid inhaler rinse your mouth and gargle with water to prevent oral thrush after use

- Look after your mouth: regularly clean your teeth/dentures, use water and floss
- Try sharp, spicy or sugary foods, as they have a stronger taste. Experiment with different seasonings and sauces
- If you go off a particular food, try it again regularly as your tastes may continue to change

Tips for making the most of your food and drinks to avoid further weight loss

Whilst these foods are usually recommended in moderation, they can help you gain weight, or avoid losing more weight. Include them in your diet as often as possible as part of meals or snacks

- Choose full fat foods (e.g. whole milk) or high energy foods - those high in fat (e.g. chips, fried foods), sugar (e.g. fizzy drinks, sweets) or fat and sugar (e.g. chocolate, cream cakes)
- Avoid low fat or 'diet' varieties
- Add cream, grated cheese or cream cheese or ground almonds to food e.g. soups, sauces, curries, scrambled eggs
- Use mayonnaise, salad cream or dressing in sandwiches and on salads
- Add extra butter, margarine or ghee to vegetables, potatoes, scrambled eggs and bread
- Fortify your usual milk: whisk 2-4 tablespoons of milk powder into one pint of milk
- Add honey, syrup and jams to porridge, milky puddings, on bread, toast or tea cakes
- Take nourishing drinks e.g. smoothies, soups, fruit juice, milkshakes or hot chocolate
- Use convenience foods from the cupboard or freezer e.g. biscuits, baked beans, soup, tinned puddings, custard
- Powdered supplements (ask your pharmacist for further information) are available from most supermarkets and pharmacies and can be used in between meals
- Don’t fill up on drinks before or during your meal
- Eat more of the foods that you enjoy at the times of day when you feel more like eating

If you feel too tired to shop for, prepare or cook meals

- Ask for help with cooking, shopping or ordering food for home delivery
- Home delivery services offering pre-prepared meals
- Try to eat with people in your household or at a social distance in the mess
- For more information about how to deal with Post Viral Fatigue/ME see the British Dietetic Association Food Fact Sheet available here https://www.bda.uk.com/resource/chronic-fatigue-syndrome-diet.html

Other useful resources:
https://www.bda.uk.com/resource/malnutrition.html
https://www.bda.uk.com/resource/patient-information-leaflet-guide-to-eating-well-with-respiratory-disorder-pdf.html
https://www.bda.uk.com/resource/eating-well-during-coronavirus-covid-19.html

IF YOU CONTINUE TO EXPERIENCE WEIGHT LOSS AND/OR POOR DIETARY INTAKE DESPITE FOLLOWING THIS ADVICE FOR 2-3 WEEKS THEN PLEASE SEEK FURTHER ADVICE FROM YOUR MO.

Information to help you improve your sleep

What is Sleep Hygiene?

Sleep hygiene is the name given to a set of good practices for making your night-time sleep better and improving how alert you feel during the day.

How Do I Make My Sleep Better?

After a trauma, illness, or other significant life event, it is not uncommon to experience poor sleep. Whilst you may have been a very good sleeper before this change, the best way to re-establish good sleep is to follow sleep hygiene advice.

Medications may affect your sleep. If you believe this is the case, you should raise your concerns with your treating medical team.

There are medications available to support with sleep in severe cases. These medications are not for long term use and are primarily used to re-set your routine, rather than solve the underlying cause. Whilst useful as a short-term aid, the best way to cause long term change is to follow sleep hygiene advice.

Changing your sleep routine can take time, but persevering with regular habits is the best way to cause a positive change.

Sleep Hygiene Tips

In the Evening	*Getting Ready for Bed*	*Your Sleep Time*	*During Sleep Time*
Avoid caffeine, nicotine, and alcohol	Develop a bedtime ritual to prepare you for sleep	Keep to regular 'going to bed' and 'wake up' times	**Do not clock watch!**
Avoid heavy meals within 2 hours of bedtime	Reduce light, temperature, and noise in the room	Keep the bedroom for sleep and intimacy only	If awake for longer than 20 minutes, get out of bed, wind down, and return when tired.
Avoid energetic exercise within 2 hours of bedtime	Wind down with quiet time spent reading, listening to music, etc	Banish screens from the bedroom (TV, iPad etc)	Do not worry about not sleeping. The more you worry, the more you wake up.

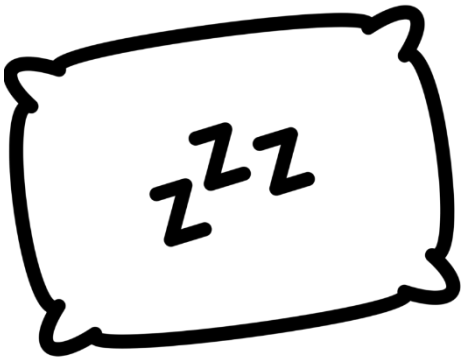
Other ways to improve sleep

Relaxation & Mindfulness

Exercise

Yoga

Diet



Breathing Exercise

It is best to practice this exercise before using it as a sleep tool. Until this becomes easy for you, practice it out of bed, and during the day. Practicing this will allow you to relax and get better at sleep.

Sit up straight but in a position that is comfortable for you

Allow your hands to rest on your lap and make sure that your legs are uncrossed

Close your eyes and bring attention to your breath

Take a deep breath in for four seconds

Hold your breath for two seconds

Exhale for eight seconds

Repeat

Pain after COVID-19

Recovery from COVID-19 will take time and this is perfectly normal.

The length of time needed will vary from person to person and it is important not to compare yourself to others.

Ongoing symptoms could last for some months after your initial recovery from COVID-19.

Post COVID-19 effects could include:

- Muscle weakness and joint stiffness
- Generalised muscle pain
- Extreme tiredness or lack of energy
- Loss of appetite and weight loss
- Sleep problems
- Problems with memory or being able to focus or think clearly
- Changes in mood

Management of muscle pain and joint stiffness, by using non-drug strategies such as:

- Pacing
- Goal setting
- Relaxation
- Mindfulness
- Low – moderate activity
- Hot / cold packs

Leaflets will be available to support you in these strategies

Muscle pain can also be managed utilising simple over the counter medication:

- Paracetamol 1g (2 tablets) up to four times a day as required. **No more than 8 tablets in 24 hours and no more often than 4 hourly**

- Medications such as Ibuprofen and Naproxen should be taken only after consultation with your MO or the DMRC team.

Cognitive and Emotional Health Advice

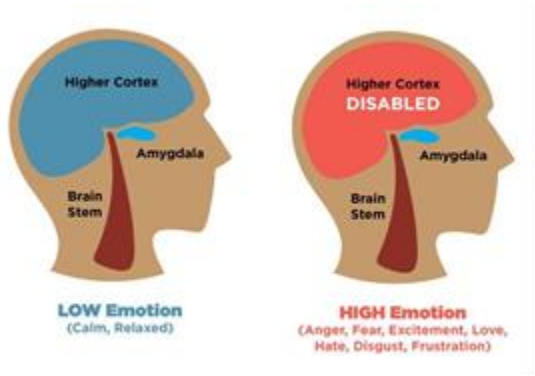
Overview
We are in a situation that most of us are unlikely to have experienced before. During this outbreak and in the period that follows, there will be a lot of natural adjustment to its impact on our lives, health, and relationships.

No one will come out of this situation unchanged. Some will have lost loved ones; some will have been unwell and will have received hospital care; all of us will have lived with restrictions placed on our movements and ways of life.

It is okay to not be okay, or to not be operating as you usually would. You may find you are more anxious, particularly about your health. You may notice you are lower in mood or have less interest in the things you previously enjoyed. We know that people who have previously struggled with their mood, may find it more difficult to get back to their normal, especially if they are socially isolated. It is important to recognise:

- We are experiencing **normal** reactions to an unpredicted abnormal situation
- There are many types of normal reaction; it is okay if we are reacting differently to our friends and family members
- We know from literature that many of the emotional consequences **ease naturally over time** as we incorporate the experience into the story of our lives
- In some cases, you may need a bit of extra support through this process and this handout will give you some pointers

The brain



Threatening situations impact on our brains and how they function. Effectively, they get hijacked into survival mode. This is driven by our amygdala and switches off the prefrontal cortex, or thinking bit of the brain, used in planning and organising. We may find it harder to concentrate or struggle with our memory (see next page). It can even change our perception of time; with time appearing to speed up or slow down.

Here are some things that you can try in order to manage these reactions:

- Reaching out to family and friends (even if this is remotely!)
- Making the most of opportunities to exercise within your current exercise threshold, i.e. accounting for fatigue and pacing yourself
- Being outside (increasing vitamin D)
- Simple grounding exercises (e.g. name 5 things you see, hear, feel, smell or taste)
- Focusing on the positives, noticing the small things
- Practicing good self-care (e.g. engaging in hobbies, watching films, relaxation, treating yourself)
- Keeping a good routine
- Practice good sleep hygiene
- Eating a balanced diet and making sure you eat regularly

Finally, if you feel overwhelmed and would like additional support, contact your MO or speak to a healthcare professional who will be able to signpost you to additional services to help you.

Anxiety and Cognition

Most people know that anxiety can lead to persistent worry and physical symptoms such as a faster heart rate and sweating, but anxiety can also cause other problems such as trouble focusing or staying on a task, and forgetfulness.

Focusing

As human beings, we have evolved to focus our attention on a threat, which normally helps to keep us safe. COVID-19 threatens our health, family and way of life so we are consumed by reading and learning as much as we can and therefore have little to no capacity for anything else, which makes concentrating harder.

- Try reducing your tasks to the most essential ones and then schedule times for tackling those that are most urgent – give yourself a break *at least* every 45 minutes.
- Be kind to yourself. It's completely normal to not be functioning as well as you might expect at such as stressful time.

Forgetfulness

Anxiety can negatively affect our memory, particularly our working or short-term memory. Relaxation techniques such as gentle physical exercise and spending time outside can help with this. Hobbies or activities that keep us focused and engaged are also good for working memory function.

Cognitive Problems Post-ITU

Patients who have been critically unwell and admitted to ICU sometimes go on to experience new cognitive symptoms which can complicate recovery. Examples of these might be:

- Memory problems
- Difficulty concentrating
- Slowed thinking or trouble thinking clearly
- Inability to multitask or problem-solve

These symptoms might cause people to feel 'different' to how they were before they became unwell and may make everyday tasks such as finding a parked car or following a simple recipe feel challenging. Unsurprisingly, these difficulties can then lead to some people feeling anxious or experiencing low mood.

It often takes a while for these symptoms to get better and can take weeks, months or sometimes longer for them to resolve. Remember that our cognitive functions (our mental processes) can be affected by many things, such as pain, fatigue, stress and medication, so these could all contribute to a longer recovery.

Rest assured that these symptoms are **common** following an ITU stay. If you have noticed any changes and believe that the way you think or would normally function has been affected, **speak to your MO or another health care professional** as they might be able to suggest further avenues for support.

In the meantime, you may find the following strategies helpful for coping with some of the difficulties faced:

- Use a notebook, calendar or alarm system to make reminders for yourself
- Break tasks down to make them more manageable and allow yourself extra time to complete these
- Try and focus on only one task at a time, and take regular breaks from anything that requires you to concentrate for long periods
- Minimise background distractions where possible to help you stay focussed
- Limit the tasks that are more complex when you are feeling physically and emotionally overwhelmed – take a break and come back to them later

Supporting Mental Health and Wellbeing

It can be useful to think about how you can look after your emotional well-being, as this is especially important when you are experiencing any changes to normal life.

Here are some simple tips on how to do this:

Listen to Music
Do you have a favourite track you like to listen to?

Do Things You Enjoy
This could include watching a favourite film, phoning a friend, or playing a computer game.

Relaxation
Listen to a formal relaxation and do some practical relaxation, like gardening or doing a craft/woodwork project.

Be Active
This could just be taking a short walk or being in the garden, not necessarily going to the gym. Speak to your therapist about what is right for you.

Connect with People
It can be hard to talk to people but try to speak to someone you trust about your worries. Also, try and speak with friends and family regularly.

Routine
Keep to a good routine – it can be hard when we feel fatigued, but it is important to still get up and go to bed at the same time each day

Be Present
Spend time taking notice of the sights and sounds around you. You could also try some formal mindfulness practice.

Try Not to Be Too Hard on Yourself
Recognise that you have been through a very difficult time and try not to expect too much of yourself.

Worry Time
It can be useful to give yourself time in the day (not too close to bedtime) to write down or think about your worries. It can also be useful to try and see if you can problem solve your worry; maybe write it down.

Journaling
Consider writing a journal, it can be useful to write one thing you are grateful for each day.

Set a Daily Intention
This is setting a small personal goal each day; this can really support motivation and a sense of satisfaction.

Eat Healthily and Stay Hydrated

Stay on Top of Difficult Feelings
Try to focus on the things you can control, such as your behaviour. Limit who you speak to and where and how often you get information. Have a break from social media.

Look After Your Sleep
Good quality sleep makes a big difference to how we feel mentally and physically so it is important to get enough sleep.

Mindfulness means maintaining a moment-by-moment awareness of our thoughts, feelings, bodily sensations, and surrounding environment, through a gentle, nurturing lens. When we practice **mindfulness**, our thoughts tune into what we're sensing in the present moment rather than rehashing the past or imagining the future.

The MOD have an 8-week free course available online, via the Defence Gateway Link

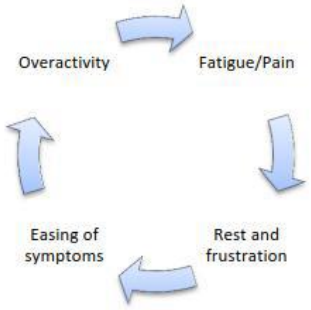
How to manage your mental health: at a glance

Speak to your MO if you are finding that you are struggling with your mood and mental health.

What is Pacing?

Introduction

Many patients who have had a stay in the Intensive Care Unit (ITU) found that they could no longer perform certain tasks without experiencing increased fatigue when discharged home. This could lead to them becoming increasingly inactive, or catching up on jobs when they had a good day, which then lead to a flare-up of pain or general weakness and the need to rest for a few days. This overactivity/underactivity pattern can be represented in a cycle.



What is Pacing?

"a way of increasing your activity level without stirring up your fatigue too much"

Aim: to maintain an even level of activity throughout the day instead of doing as much as possible in the morning and then resting all afternoon.

How to use Pacing

1. Work out what you can manage now:

- Decide on your baseline – how much of your activity can you do on a good day and a bad day
- This may take a couple of attempts to get right
- **DO NOT** compare yourself to others or what you think you ought to be able to do

2. Decide on a realistic build-up rate:

- Too much too soon will make you overdo things
- Build up the task slowly and at a steady rate regardless of your fatigue

3. Write your plan down and record your progress

- Write down your plan and your daily progress (maybe in a diary)
- This will allow you to easily notice your progress or if you're slipping back.
- On a daily basis it is also difficult to remember things or how you were.

Applying Pacing to a Task – The Rule of the 3 Ps

Prioritise

Do you need to do the entire task today / in one go?
Can you get someone else to help?
Does the task need to be done at all?

Plan

Can you break the job into different stages?
What do you need to carry out the job?
What basic activities does each stage involve?
(e.g. walking, sitting, standing)

Pace
See Pacing Techniques outlined below
Pacing Techniques

There are 3 main aspects to pacing:

1. Breaking tasks down into smaller bits – Part of prioritising

2. Take frequent short breaks

a. Do something for a set time
b. This breaks the overactivity / underactivity cycle
c. Helps to even out your activity over the course of a day
d. 'Taking a break' does not mean stopping completely
e. Change your position or do something else for a short while

3. Gradually increase the amount you do

a. You may seem like you are going backwards and activities can take longer
b. Gradually build up the amount you do
c. 'Pace up' by a set amount
d. Do not be tempted to try to do more on a 'good day' stick to pacing levels

Additional hints for using pacing

- Start on activities that are easier
- For activities that you cannot leave, it is most important that you still try to pace
- yourself as much as possible
- Try to change your position regularly
- It is ok to ask for help with specific tasks
- Keep to your targets and plans if possible

If you understand and put into practice the concept of pacing, you should have fewer flare-ups of pain or episodes of fatigue and gradually do more and more.

Setback or flare-ups

- Fatigue and setbacks are normal and everyone has them
- It does **NOT** mean you are back to square one
- How much pain or fatigue you experience will depend on how you react
- It is important to remember that pacing has worked for you before and can still continue to work for you

Tips for changing habits:

- write a list of your plans and stick it on the fridge
- start off with a small change and build on this
- make a list of why you want to change
- explain to others why you are changing a habit, get
- support and help from others if needed
- reward yourself with a treat
- do not worry if you fall back into your old habits, everyone does when they try to change, look at your plan and start afresh
- find a new way of doing something with pacing rather than stopping it altogether

Remember - be positive about what you can do rather than what you cannot do