

COVID-19: Information pack Coping after a prolonged stay in hospital

Patient Name:

Please refer to your discharge summary for advice specific to your care plan or contact your Doctor/GP with any outstanding medical queries.

ABOUT THIS BOOKLET

Recovery from COVID-19 may take some time. Even though you have been discharged from hospital, this does not mean that your recovery journey has ended. These booklets are designed to give you information and advice to support you on this journey.

The booklet, '*Recovering from COVID-19*' provides advice around physical health problems such as fatigue, breathlessness and mobility issues, as well as information on local services and resources.

This booklet focuses on difficulties related to COVID-19 that are more to do with the brain or the mind. This booklet will provide information on common emotional experiences following a prolonged admission in hospital. This booklet also discusses problems with memory, attention and other thinking skills that you may notice after being in hospital for a long period of time.

We would advise you to read these two booklets in small chunks – take your time and highlight or make notes on key sections as you go along.

SECTION 1: MOOD & EMOTIONAL PROBLEMS

After being in hospital with a serious illness such as COVID-19, you may notice that you feel more anxious, angry or upset than usual. High levels of distress can affect the way we feel physically and mentally. This is a normal and understandable response to a traumatic experience, such as being in hospital with a serious illness.

Is Being in Hospital With COVID-19 a Traumatic Experience?

A traumatic experience is a situation where you feel you are at serious risk or harm, or when you witness an event where other people are put at serious risk or harm. Common examples of traumatic experiences include:

- Serious accidents
- Falls
- Assaults/attacks
- Death of a loved one
- War
- Natural disasters
- Terrorist attack
- Serious illness or injury

Many people have described being in hospital with COVID-19 as a traumatic experience. There are many aspects of being in hospital with COVID-19 that can be particularly difficult for people, for example:

- Being in an acute medical environment (e.g. critical care)
- Being told your life may be at risk
- Having invasive medical input (e.g. being on a ventilator)
- Having lots of strong medications (especially sedatives)
- Being surrounded by medical staff wearing masks and other protection equipment, and lots of very unwell people
- Having to lie in bed for long periods of time
- Not being able to breathe normally
- Not being able to speak or communicate
- Not being able to see friends/family

- Confusion and delirium
- Experiencing hallucinations
- Things being out of your control
- The extensive media coverage and wider impact on society

Traumatic experiences can trigger strong levels of emotional arousal or distress within us. Sometimes this is an immediate response; sometimes there is a delayed response once the initial shock and adrenaline surge wears off. These responses might be triggered by a single incident, or the combined effect of multiple challenges – such as being in hospital for an extended period of time.

People react in different ways following a traumatic experience. You may experience mixed feelings over the first few days and weeks after you leave hospital. Sometimes these emotions can be very intense and volatile; sometimes we might feel ‘numb’. Our emotions can feel out of control.

Common and understandable feelings after a traumatic experience can include:

- Feeling helpless or vulnerable that you could do nothing to stop yourself getting unwell or might become ill again in future.
- Feeling more panicky, on edge, easily startled or frightened
- Feeling angry about what has happened and with whoever might hold some responsibility (e.g., how did I acquire the virus?).
- Feeling ashamed or embarrassed that you have these strong feelings that you can’t control, especially if you need others to support you.
- Feeling detached and emotionally numb, as if in a state of ‘shock’
- Feeling confused; not feeling fully ‘yourself’.
- Feeling tired, fatigued or emotionally exhausted.
- Feeling guilty, that you could have done things differently or how you may have impacted others (e.g., worries about “infecting others”).

Our feelings have an impact on the way our body works. Common physical responses after a traumatic experience can include:

- | | |
|--------------------------|---------------------------------|
| • Heart racing/pounding | • Sweating |
| • Tightness of chest | • Changes in breathing |
| • Tense or stiff muscles | • Dizziness or light-headedness |
| • Disturbed sleep | • Trembling/shaking |

These changes in our body's arousal level in the time after a traumatic experience commonly lead to changes in the way we think and act. For example, people commonly have thoughts such as:

“I’m going to die” “I’m going to make my family unwell” “I’m cracking up”

“ I can’t cope” “Was it all my fault?”

“If I hadn’t done...(X).....I wouldn’t have ended up unwell”

It is also common (and normal) for your mind to bring up and revisit what has happened to you. This is a normal process that can result in reduced levels of intense emotional arousal over time, in a pattern of continual adjustment. However, this can be difficult – it is natural to want to avoid thinking about what has happened, as this may be feel too scary or challenging. People may want to avoid going out and doing ‘normal’ activities – and restrictions may limit our ability to do things that would usually be helpful. People may want to avoid being around other people, or they may struggle with being alone.

WHY DO I FEEL LIKE THIS?

Anxiety

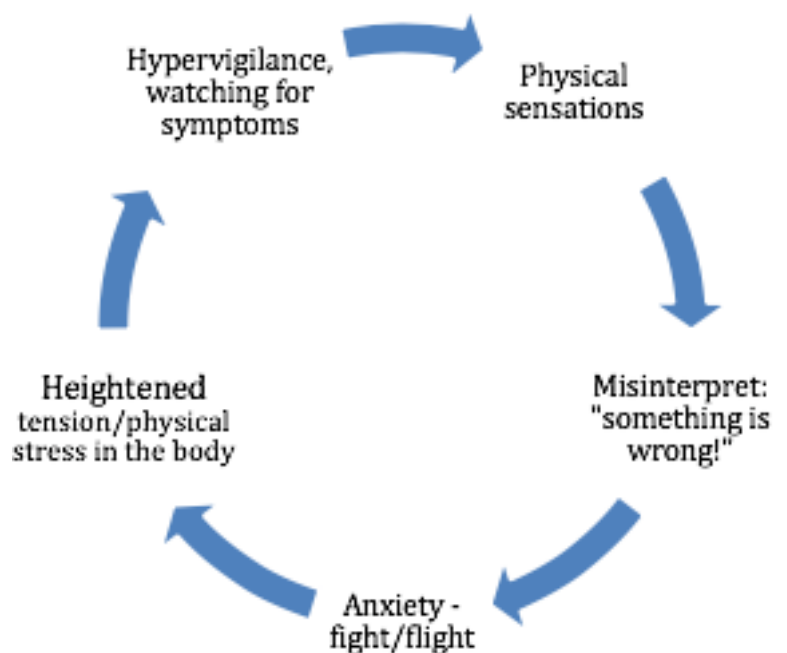
Anxiety is the feeling that we get when our body is responding to a frightening or threatening experience. Commonly known as the fight or flight response, this is your body preparing for action; either to fight danger or run away from it as fast as possible. Adrenaline is released, and the physical symptoms that we experience as a result are our body's response to cope with threat. For example, we breathe quickly to get more oxygen into our bodies. Our body tenses as our muscles get primed to react.

A good way to think about these systems is like a burglar alarm. If a burglar got into our house, we might reset the sensors to keep our house safe and reduce the chance of it happening again. Our fight or flight system is like our own “internal alarm” and is an important evolutionary response to danger.

However, if the sensors on a burglar alarm are too easily triggered, the alarm would go off at inappropriate times; perhaps when it's windy outside or when a friendly cat wanders up to our window. Even though there is no direct threat, the alarm system has been programmed to be “better safe than sorry” and the alarm sounds when we don't need it to. This is understandable; but not very helpful once the danger has passed.

The same can happen with our fight or flight system – it can continue to trigger long after the acute need for such responses has passed, or it can trigger at unhelpful times. This is a useful way to understand why we might feel anxious after a traumatic experience such as being unwell in hospital.

Any thought, memory or experience can trigger our “internal alarm” and result in us feeling anxious. We might become overly focused on any signs or symptoms in our body and think that we are becoming unwell again – this “hypervigilance” can become a problem, as if we focus too much on our body or normal bodily processes (e.g. aches/pains, breathing) we can notice things that would usually be completely harmless, but mistake them for being a sign that something is seriously wrong. This usually makes us feel anxious, which can lead to more physical sensations that we misinterpret. This can feed in to a “vicious cycle”.



After going through such a traumatic experience, our assumptions about the world being a safe and secure place can be shattered. You may feel as though any situation or place is potentially dangerous. Seeing and hearing lots of stories about COVID-19 may make this worse.

It will take time for your fight or flight system to calm down and for things to return to normal. For some people, this might lead to greater focus on strategies to try and keep

themselves safe – e.g. excessive hand washing or worry about things not being clean enough. This can become unhelpful. We suggest you focus on following national advice, and at the end of this booklet you will find some exercises that might be helpful in managing these difficult feelings.

Flashbacks and Nightmares

Following a traumatic experience, it is common to experience “flashbacks” – these can be images, thoughts or experiences in which our mind takes us back to the traumatic event. This might involve misinterpreting things you see or hear, or seeing/hearing things that aren’t really there. This can sometimes feel like we are “reliving” the experience, or that it is happening all over again. This can be extremely difficult and understandably adds to the distress you might already be experiencing.

It can also be very common to experience vivid dreams or nightmares, as our brain is trying to process and make sense of the experience. Experiencing hallucinations or unusual fears (e.g. the nurse is trying to kill me) during hospital admission is very common, especially for people who were on strong medications or experiencing delirium. Sometimes these fears persist long after we know logically that we are safe.

Low Mood

It is also common to feel low in mood or down following a traumatic event. Common thoughts may include: “It was all my fault”, “Why did this have to happen?”, “Why me?”. It may seem that progress is slow, and you may feel that things will never get back to normal. It can be difficult to go through such a significant change in your life, especially if you cannot do the things that used to give you pleasure and enjoyment, either due to your health problems, fatigue, or the restrictions on activity and socialising.

These feelings can affect the way we behave in a general sense – we may feel less able to handle going to work or doing things we enjoy (e.g. volunteering, seeing friends, hobbies). The way we communicate with those closest to us can also be affected. This can make our mood even lower and can become another vicious cycle.

Feeling low or down can lead to physical changes; we might feel more tired than usual and have less energy, our appetite may be lower or higher than usual, and sleep

patterns are often affected. Such mood changes can also fuel avoidance and withdrawal patterns, both physically and emotionally (which, again, if left unrecognised and unchecked can lead to growing difficulties).

Post-Traumatic Stress Disorder

You might have heard of post-traumatic stress disorder (PTSD). As we have discussed, symptoms of PTSD such as heightened and persistent arousal, flashbacks, sleeplessness and nightmares are all common responses following a traumatic event. These are all normal and understandable responses which, for many people, naturally resolve after a few weeks. PTSD is a diagnosis given to someone who continues to experience these problems persistently in the months (or even years) after the traumatic experience.

We know that having a good understanding of what to expect after a traumatic experience can help people to recover more quickly. That is why this booklet talks about common reactions that people have; it is important to understand that you are not going “crazy” or losing your mind. It is a normal response to an abnormal situation. It is important to try not to block out any thoughts or feelings you might have, and allow yourself some time to process the natural responses you experience.

Experiencing ongoing difficulties does not reflect any weakness on your part. If you feel that things are not improving after a few weeks and these difficulties are disrupting your ability to live normally, we recommend speaking to your Doctor or Consultant about specialist support services available to help you.

WHAT CAN I DO TO HELP?

- Take the time to read this leaflet carefully – having a good understanding of what is happening can be helpful in the early stages.
- Be familiar with your medical condition – talk to your doctor about what signs/symptoms might be cause for concern, and what you can safely not worry too much about.

- Recognise that you have been through a distressing and frightening experience and that you will have a reaction to it.
- Try to accept that you may not feel your normal self for a while, but that it can pass in time. Avoid comparing yourself to “how I used to be” or “what I used to be able to do”. It is important to remember that you are doing the best you can in your current circumstances. Be kind and gentle with yourself, responding to yourself in just the same way you would toward someone you care about if they were struggling.
- Don’t bottle up your feelings. When you feel ready, talk to someone who can support and understand you. Allow family and friends to help you by telling them what you need, such as time out or someone to talk to.
- Write a list of activities you used to enjoy prior to your hospital admission and aim to gradually start re-engaging in the activities you can do right now – and plan out what you might want to do in the future.
- Set small daily or weekly goals to achieve, and break them into small steps. This will help give you a sense of achievement and confidence.
- Don’t be afraid to talk to your GP or Doctor if you feel you are struggling – help is available.
- At the end of this booklet (p.16) you will find some simple exercises you might like to try – exercises like this can help you to relax (but stop if you don’t feel they are helpful).

Managing Sleep Problems

After a hospital admission you may experience differences in your sleeping pattern. You may find it harder to fall asleep initially and may spend periods of the night awake. Try and implement a routine by awaking at the same time each day and going to bed at the same time every evening. Try to avoid napping during the day – if you do need to, keep these naps short (under an hour).

In order to try and help you sleep you may wish to:

- Engage in a relaxing activity before bedtime such as reading, having a bath or listening to calming music.

- At the end of this booklet (p.16) you will find some exercises that might be helpful in relaxing and 'switching off'.
- Avoid coffee, tea and alcohol in the evening.
- Reduce exposure to blue light in the evenings. This involves avoiding the use of electronic devices prior to bedtime.
- Make sure your bedroom is a comfortable environment. This involves checking the temperature of the room, noise, and minimising artificial light sources (such as light from alarm clocks and televisions). You want your bedroom to feel relaxing, clean and quiet.
- Sometimes people may suffer with nightmares which can be vivid, appear real and can be frightening in nature. Ensure you speak to family and friends through this time in order to separate fact from fiction, and to provide support to you.

SECTION 2: COGNITIVE PROBLEMS

We do not yet know the longer-term impact of COVID-19 on cognitive (thinking) skills such as memory and concentration. However, some people may notice difficulties following discharge from hospital – this could be a direct result of COVID-19, or caused by secondary complications (e.g. the brain not getting enough oxygen). Anxiety and mood problems can also affect all of these areas. If you are worried about any of the following, discuss your concerns with your Doctor.

Memory

Memory can sometimes be affected by COVID-19. Upon leaving hospital you may find you struggle to remember incidents which occurred on the ward, and may find you have little to no memory at all of being on the unit. Many patients upon discharge from hospital may need help to 'fill in the gaps' about what has happened, and may need support from healthcare staff, family and friends in order to aid their memory. As many hospitals are limiting visitors due to COVID-19, it may not be possible to get a complete picture of everything that went on.

Short-term memory might be affected, and people may find it harder to remember new information (e.g. what you did this afternoon), or they might find themselves forgetting things they would usually remember (e.g. people's names, upcoming appointments). Your Doctor might do a short screening test with you and, if needed, refer you to a memory assessment service for a more in-depth check of your memory skills.

Attention

You might find it difficult to concentrate or pay attention for long periods of time – e.g. when reading or watching TV. You might find it more difficult than usual to “divide” your attention, e.g. trying to speak on the phone while the TV is on in the background, or talking to more than one person at once. You might find these activities are more tiring than they were before, as they take more ‘effort’. Attention problems can affect memory – if we are not able to focus on something, we are unlikely to remember it later.

Executive Function

Some people may experience changes in “executive functioning” skills; that is, their ability to plan, organise, monitor their behaviour and successfully complete tasks. People with problems in these areas may act impulsively, struggle to manage their medications, fail to start or finish tasks, lose focus in conversations and use poor judgement. Sometimes this can seem like a “personality” change – the person themselves may not realise, but family and friends might notice some changes. Problems like this can also be affected by mood and stress, as well as medical factors such as medications. If you or a friend/family member notice any changes of this type, speak to your Doctor who can organise further assessment and support.

Confusion & Delirium

Some patients – especially those who were in critical care - may have experienced confusion or delirium while they were in hospital. Delirium is a type of disturbed cognition and altered consciousness. Delirium can be caused by a range of factors or an interaction of factors – things like medication, infection, medical complications, surgery or sleep deprivation can all contribute.

Although delirium is usually temporary, it can be upsetting for both patients and families. People experiencing delirium may have anxiety/depression, may experience

hallucinations and/or delusions, may not be aware that they are in hospital, and may not recognise their loved ones. This can be frightening both in the short-term and in the longer-term, as people adjust to recovering from the illness. Delirium can be considered as a traumatic experience in itself, and as outlined earlier in this booklet, this can lead to a range of physical and psychological responses.

If you experienced delirium during your stay in hospital, remember that you are not to blame for things you said or did – this was part of your illness. You may have seen or heard things that were upsetting or frightening – this is an unpleasant but normal symptom of delirium. It is quite normal for your memory of these times to be vague, incomplete or completely missing. You may want to talk to your family/friends about what happened during this time to help you fill in the blanks, if this feels helpful for you.

If you or someone who has experienced COVID-19 appears much more confused than normal and this does not seem to be improving, speak to a medical professional as soon as possible.

Cognitive issues - What can I do to help?

- Remember that recovery takes time. Slow down and take things at a gentle pace.
- Avoid comparing yourself to “how I used to be” or “what I used to be able to do”. It is important to remember that you are doing the best you can in your current circumstances. Be kind and gentle with yourself, responding to yourself in just the same way you would toward someone you care about if they were struggling.
- Inform family and friends of your difficulties and ask for help. They may need to change their approach in order to help you (e.g. using shorter sentences when communicating, writing things down to help you).
- Think about whether your mood could be affecting your cognition. Improving your mood can help improve cognitive ability – what could help you to feel calmer and more in control?
- You may find use of communication aids helpful. These can include things such as signs or pictures around the house (e.g. notes on kitchen cupboard doors to

remind you where items are, or written names on family photographs to help you recall family members' names).

- Use a daily planner to help you organise your day – e.g. a whiteboard you write the date on, including daily meals and activities you have planned. You can tick off meals (to remind you that you've eaten) and refer back to the board at any point during the day. This can be wiped clean each morning.

Fatigue

Fatigue appears to be a common symptom affecting people who have been in hospital with COVID-19. You may feel very tired very quickly, even if you are not doing much physical activity within your day. Your tolerance for physical exercise may have reduced significantly, and you may not be able to complete daily tasks you could prior to your hospital admission. You may find that sleep does not 'recharge' you as it usually would.

Mental fatigue is also common; even if you are physically not moving much, you may feel more drained than usual by activities that require concentration such as watching TV or talking to friends.

Over time, by slowly increasing your physical activity daily and rehabilitation you can regain strength within your muscles. Everybody is different and so people will recover at different rates, therefore it is important to **set your own goals** and targets and focus only on **your own recovery**. It is important within this to accept that you may need to take your time in getting back to your activity levels before the illness – try not to do too much too quickly and take things slowly.

Top tips for managing fatigue

- Try to get back to as normal routine as is possible, but remember this might take some time. Do some low energy fun activities if you can, like reading or watching things for short periods - resting regularly. Remember that both physical and mental activities use up energy.
- Find an activity level which is manageable - you may get more fatigued the day after doing the activity so wait to see the result. Be realistic and kind to yourself.
- When you feel able, slowly increase your activity each day. Set small goals each week and review these weekly in order to keep your mind focused on achieving

an outcome. These could include physical goals such as “I will mow the grass” or “I will make the bed”, or mental goals such as checking emails, planning shopping and talking to family members. Make sure you plan in rest and recovery time.

- Eat healthily and drink plenty of water. Avoid excess alcohol and other drugs.
- Consider limiting the amount of time you spend watching the news or going on social media.
- Unless you feel fully well you should not return to work. You may benefit from a graded return to your job.
- COVID19 will affect people to different degrees so give yourself the time you need to recover from it. There will often be pressure to get back to your usual activities as soon as possible - do not rush. If your fatigue levels do not seem to be improving after a few months, talk to your GP for advice.

SUMMARY: KEY THINGS TO REMEMBER

It is normal to have strong emotional reactions following a distressing or frightening event such as being in hospital with COVID-19. People will experience a range of physical, cognitive, emotional and behavioural reactions; everyone is different. Even when people experience the same thing, it is normal for their emotional responses to be different. Just because others may seem okay, doesn't mean you should not feel the way you do.

There are many things you can do to help yourself cope and adjust following a traumatic experience (as described in this booklet). By taking this time to look after yourself, you can recover to the best of your ability to focus on what is most important in your life.

Seek help via your Doctor or Consultant if you feel you need further support, or have any questions about your health needs going forwards.

This booklet was written drawing on the best information available at the time of writing – the guidance may change as more information becomes available on COVID-19.

SECTION 3: RESOURCES

Progressive Muscle Relaxation Guidance

Sit in a comfortable chair (or lie on the floor or on a bed). Ensure you will not be disturbed by other noises. If you become aware of sounds - just try to ignore them and let them leave your mind just as soon as they enter. Make sure the whole of your body is comfortably supported - including your arms, head and feet.

Close your eyes. Feel the chair supporting your whole body - your legs, your arms, and your head. If you can feel any tension, begin to let it go. Take 2 slow and deep breaths, and let the tension begin to flow out.

Become aware of your head - notice how your forehead feels. Let any tension go and feel your forehead become smooth and wide. Let any tension go from around your eyes, your mouth, your cheeks and your jaw. Let your teeth part slightly and feel the tension go.

Now focus on your neck - let the chair take the weight of your head and feel your neck relax. Now your head is feeling heavy and floppy. Let your shoulders lower gently down. Your shoulders are wider, your neck is longer. Notice how your body feels as you begin to relax.

Be aware of your arms and your hands. Let them sink down into the chair. Now they are feeling heavy and limp.

Think about your back - from your neck to your hips. Let the tension go and feel yourself sinking down into the chair. Let your hips, your legs and your feet relax and roll outwards. Notice the feeling of relaxation taking over.

Notice your breathing - your abdomen gently rising and falling as you breathe. Let your next breath be a little deeper, a little slower...

Now, you are feeling completely relaxed and heavy.... Lie still and concentrate on slow, rhythmic breathing.... When you want to, count back from 5 to 1 and open your eyes. Wiggle your fingers and toes, breathe deeply and stretch. Look around the room, becoming more alert as you notice what you see, hear and feel. Pause before gently rising.

‘Leaves on a Stream’ – Mindfulness-based visualisation

Find a comfortable seating position and close your eyes. Focus your attention on you breathing – breathing in, and then breathing out. Be aware of your breathing and of the feeling of calmness and relaxation you can feel begin to wash over you, as you breathe inand out, in.....and out. Find a breathing rhythm that feels comfortable to you.

Imagine there is a balloon in your stomach, with the balloon inflating as you breathe in.....and deflating as you breathe out.....the balloon getting larger as you breathe in.....and smaller as you breathe out.

You’ll notice thoughts pop in your mind as you breathe – just be aware of them, notice them but don’t pay them too much attention. Be aware of them, and bring your mind back to your breathing, and the feeling of increasing calmness on each out breath.

Notice sounds around you that you would not normally be aware of – both inside and outside of the room. Just be aware of these – don’t pay any one thing too much thought. Notice...then continue to bring your attention back to your breathing.

Notice different feelings in different areas of your body.....some parts may feel warmer or colder than others; some muscles may feel tighter and some looser than others; some areas of your body may feel more comfortable than others. Just be aware of these differences that you can notice...and then bring your attention back to your breathing.

Now imagine you are sat at the side of a stream, which is calmly flowing down a hill, on a warm sunny day. There is a tree next to the stream and its leaves are falling, one by one, into the stream, as the wind gently blows. Picture this in your mind. Take each thought that pops in your mind and place each on one of the leaves, drifting down the stream. Watch each thought drift away, gently, as the stream runs gently down the hill. For every thought that pops in your mind, place it on a new leaf and watch it drift down the stream...calmly and gently.

Bring your attention back to your breath, feeling calmer with every out breath. When you are ready, bring your attention back to the room and open your eyes.

Developing Self-Compassion



Self-Criticism Vs. Self-Compassion

- Think for a moment about some of the things you find most challenging and tend to beat yourself up about:
 - What do you say/think to yourself in these moments?
 - How does this make you feel?
 - Is this helpful?

Self-Criticism Vs. Self-Compassion

- Now think for a moment about what a more compassionate response might look like:
 - What would you say to a friend in having a similar difficulty?
 - What would you feel toward a friend having a similar difficulty?
 - What is it like to try and direct similar thoughts and feelings towards yourself?
 - Is this helpful?