

Life after Coronavirus (Covid-19) for patients who were cared for in the Intensive Care Unit or High Dependency Unit

You may feel much better now or you may feel like you are still recovering. Both are perfectly normal. Life after critical illness can be challenging and for some people it can take a long time to get back to a normal life.

This leaflet has been written by clinical psychologists, to help with your recovery. It provides information about understanding and managing problems with thoughts and feelings after a stay in an Intensive Care Unit (ICU) or High Dependency Unit (HDU). Not everyone will have these problems, everyone is different. It may be helpful for your family, friends or carers to read this leaflet, so they understand more about your recovery.

You needed specialist care in the unit because you were very unwell as a result of COVID-19. After leaving the unit, there is a period of recovery - which includes your physical health, emotional health and cognitive (process of thinking) health.

Some of the difficulties you may have will naturally get better over time. In this leaflet you can read more about when it may be helpful to seek help and support. Please speak to your GP if you have any worries or concerns.

Starting to recover

Now you are recovering from COVID-19, you may have mixed thoughts and feelings about your experience, and these can change over time. This is normal - you have been through a very difficult time.

Spending time on the unit can be a traumatic experience. It may have been a very difficult experience due to staff wearing personal protective equipment (PPE), not having many

visitors and being a part of a pandemic. It is likely that you felt very ill and you might have been aware that other people on the unit were also very ill.

The recovery process will be different for everyone. You might already feel much better or you might feel that you are still struggling. However you are feeling right now, this is OK.

Given how unwell you were, it is important to remember that it might take some time for you to feel better again (both physically and emotionally).

Every person who spends time on the unit is different and each experience is unique. However, there may be some shared experiences from this time.

Your feelings (emotional health)

I feel low in mood

It is common for people to feel low in mood or report feeling depressed when they return home. There are many reasons - being ill may have left you with changes in your body and in the way you think and feel. You might feel:

- sad and down
- more tired and lethargic
- uninterested and noticing a lack of enjoyment or pleasure

These feelings might come and go, or you may have been feeling this way for a few weeks.

You might have experienced low mood or

anxiety before COVID-19 and this experience may have made things worse. Things that can help if your mood is low:

- Talking to someone that you feel comfortable with to share how you are feeling.
- Keeping in touch with people you care about
- Doing things to look after yourself, like sleeping well and physical activity
- Doing things you have enjoyed in the past, e.g. a hobby, watching a favourite film or television programme, or listening to music.

I feel anxious

Anxiety is the normal response to stress, uncertainty and lack of control. Many people are

- feeling anxious during the COVID-19 pandemic.
- After spending time in hospital, it is very normal to feel worried about going home and
- wondering how you will cope. Some people may feel a sense of guilt about having survived
- when others have not. At this time in particular you may also be worried about how you can
- be supported by your friends and family during periods of social distancing.

If you are feeling anxious you might notice:

- Feeling very worried, agitated or restless
- Feeling tension in your body
- Finding it hard to concentrate

Things that can help if you are feeling anxious:

- Find a quiet place and take some slightly deeper breaths to calm your body.
- Talk about your worries. This can help us to see that others may feel the same, may suggest something that might help, or may help us to see that we don't need to worry.

I have lost my confidence

You may find that you don't feel confident doing things - even things that seem relatively simple. This is normal. Things that can help if you feel you have lost some confidence:

- Try to slow things down that you are doing
- Try to slowly build up what you are doing, maybe with the support of a relative. The more you do things, the easier they should become.

Your experience of ICU or HDU

I'm finding it hard to make sense of what happened to me

You might have spent some time under sedation. As you were becoming more alert, you may have found it hard to remember or understand what had happened and you might feel that you lost track of time.

It is common to feel confused and have gaps in your memory. A number of things may have added to this - being sedated, the environment (lack of natural daylight), medication and other people not being able to spend time with you due to the risk of infection.

It might be helpful to try to make sense of what happened by finding out as much as possible about your time on ICU/HDU:

- Talk to the team that cared for you. You could also talk to your GP.

- Talk to your friends and family about what they remember. Due to COVID-19, they may not have been able to spend as much time with you and may not have all the answers.
- You may wish to visit the unit, once the current restrictions are relaxed.

I have difficult memories of my time on the unit

While there may be gaps in your memory, you may also have some very clear and possibly distressing memories, e.g. not feeling in control or not being able to communicate with others because of medical and protective equipment.

It might feel really difficult to have unpleasant memories, but it is not uncommon. You may be unsure about whether the memories are based on real or unreal events.

I have traumatic memories about my time in the unit

A traumatic memory can relate to any traumatic experience.

A traumatic experience is an event that is unexpected, out of the ordinary and often contains a significant fear about our safety and wellbeing.

Being cared for in ICU/HDU or having a serious health condition (such as COVID-19) can lead to traumatic experiences.

People react differently, but it is common to experience:

- **Re-living the traumatic event:** Having dreams or nightmares, feeling that it is happening again, having unwanted images (flashbacks) or feeling very upset when reminded about the event.
- **Avoidance:** You might find that you avoid

thoughts, feelings or conversations about

- the time you spent in hospital, or you feel numb or detached from reality.
- **Mood:** You might feel angry, irritable or bad tempered, it might be hard for you to relax or fall to sleep, or you might find it hard to pay attention and concentrate. You might feel 'on edge' and easily alarmed.

All these experiences are normal reactions to a life-threatening experience, and should get better with time.

For a small number of people, these experiences don't naturally get better, and they may need support to help them cope.

Where the experiences don't go away on their own and last for a prolonged period, they can be described as post-traumatic stress reactions. Please speak to your GP if these experiences do not improve within four weeks.

ICU delirium

When people are unwell on the unit, it is very common to experience 'delirium', which can be described as a state of severe confusion.

Delirium is caused by a change in the way the brain is working.

It can be a result of medication side-effects, needing support with breathing, effects of sedation, infection within the body and reduced oxygen in the body and brain.

Delirium can cause people to feel confused, find it hard to think clearly and not understand what is going on around them.

It is also common for people to see or hear things that are not there, which at the time can feel very real to the person.

ICU delirium is usually a short-term condition and resolves before you leave hospital.

However, it is common for people to have

long-lasting effects, which can affect quality of life. You might experience any of the following:

- You may notice problems with the way you think, how well you can pay attention or concentrate, or it might be more difficult for you to remember things.
- Many people report feeling low in mood or sad after a period of critical illness. This might not be noticeable until a few weeks or months after discharge from hospital.
- Post-traumatic symptoms. You may have unpleasant thoughts/memories of your time on the unit. The thoughts might be intrusive - they may come into your mind suddenly and feel as though you are re-experiencing the event. You may have unpleasant dreams or nightmares that wake you up. It can be very frightening to experience these things, but it is important to remember that you are not alone and it is not uncommon.

Some things that may help you to manage unpleasant thoughts and feelings:

- Spend a small amount of time daily to review and go over unpleasant memories or dreams. You could either talk with someone or write down a few notes. This is thought to be effective at reducing the unpleasant nature of these experiences. It will also allow you to have some control over your thoughts.
- Try to think about the positive parts about your current situation and what you can take from the experience.
- Try to think about or write down one thing you are grateful for each day, what has made you smile, or been positive.

I feel that my life has changed

People often describe being in the unit as a very important moment in their lives. You may be more aware of your mortality. You may feel this has been a life-affirming experience which has helped you to think about what you want from life. These are all normal feelings.

My family are different with me

After being critically ill, you and the people around you may change. Your family may make a fuss and might not understand why you seem different, or why you aren't keen on the hobbies and interests you used to enjoy. Your family and friends were afraid you might die, so they may want to do everything for you when you get home. If this annoys you, talk to them calmly about how you feel. Try not to bottle things up and get angry.

Sometimes people may assume that once you left hospital you are better, and may not appreciate you need a recovery period. Try to talk to them about how you are feeling.

You may not remember your time in hospital clearly, which can be confusing and frightening. It may help to talk to your family about what they remember about your hospital stay, how they felt when you were ill and things that happened while you were there. If your relative kept a diary while you were in the unit, it can be helpful to look at this with them.

Your thoughts and concentration (cognitive health)

After being in the unit, your body needs a period of time to recover physically. In the same way - your brain also needs to recover. It is very common for people who have been cared for on the unit to have difficulty concentrating, remembering or thinking things through.

I'm finding it hard to concentrate

You may find it difficult to concentrate and even find it hard to follow a television programme. You may get tired more quickly or easily overwhelmed if too much is happening around you. Your concentration will get better over time. These things can help:

- Do one thing at a time. Finish a task before moving to the next. Do important things first. Other jobs can wait
- Avoid distractions, it may be hard to have a conversation with a TV/radio on
- Rest regularly. You feel cognitively tired and fatigued

I'm finding it hard to remember things

During your recovery you may be more forgetful. Sometimes this can be because it is hard to concentrate and pay attention and therefore you won't be able to take things in, so don't recall them later on. As you recover, your memory should improve. These things can help:

- Use a calendar, phone reminder, note etc. to help you remember important things. Ask people to remind you about important things
- Understand it is harder to remember things when tired or can't give your full attention
- Ask people to give you information in small chunks and ask them to repeat it

I feel very tired whenever I try to think things through

Any task requiring a lot of 'brain power' could make you feel tired - even if you found it relatively easy before you were ill. Your brain and body will use a lot of energy trying to help you recover, so at the start there may not be a lot of energy left over for other tasks.

These things can help:

- Get someone to help you with tasks that feel difficult
- If something is feeling hard - leave it and

come back to it later (if you can)

- Try to tackle things when you feel you have the most energy
- Remember to rest when your body is telling you that you need it. Sleep is one of the best things to help with fatigue

If your memory or other cognitive abilities are not improving, speak to your GP.

Tips to support your recovery

Setting small goals

Setting small goals in your daily routine can help you recover and show you that you are improving. A small goal could be something as simple as making a drink for yourself, or walking a few steps further without needing to rest. Try not push yourself too hard as this can end up making your recovery take longer.

Looking after your sleep

Whilst recovering from COVID-19, it is understandable that you might be feeling more tired.

You may find that you need to sleep a lot when you first leave hospital. After being in hospital with COVID-19 your normal sleep routine is likely to have been disrupted. Some things that may help your sleep:

- Keeping to a routine, where you can
- Getting some fresh air early on in the day, if you can
- Reducing electronic use before bed
- Ensuring that you cannot see the bedroom clock

If you have difficulty sleeping for over four weeks, contact your GP for more support.

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References

The British Psychological Society, 'Meeting the psychological needs of people recovering from severe Coronavirus (Covid-19)':

www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/Meeting%20the%20psychological%20needs%20of%20people%20recovering%20from%20severe%20coronavirus.pdf

Oxford University Hospitals NHS Foundation Trust, 'Life after Discharge from Intensive Care':

www.ouh.nhs.uk/patient-guide/leaflets/files/13972Plife.pdf

9am-1pm)

Support Details

For medical help and advice

NHS 111

- 111
- www.nhs.uk

Emergency and life-threatening situations

- 999
- Attend your nearest Accident and Emergency Department

Your GP

- Contact as usual

Chesterfield Royal Hospital NHS Foundation Trust website
<https://www.chesterfieldroyal.nhs.uk/patients-and-visitors/coronavirus>

For help with your mental health

Derbyshire

Tips on looking after your emotional health:

Derbyshire County Council 'Coronavirus pages'

<https://www.derbyshire.gov.uk/social-health/health-and-wellbeing/health-protection/disease-control/coronavirus/coronavirus-covid-19.aspx>

Derbyshire Mental Health Support line

- 0800 028 0077
(24 hours a day, 7 days a week)
- <https://www.derbyshirehealthcareft.nhs.uk/getting-help/coronavirus-covid-19/mental-health-support-line>

Joined up Care Derbyshire

www.joinedupcarederbyshire.co.uk/covid-19-information-and-advice

Additional help and support

Derbyshire

'Call Derbyshire' service:

- 01629 533190

Derbyshire County Council (DCC)

- www.derbyshire.gov.uk/social-health/health-and-wellbeing/health-protection/disease-control/coronavirus/coronavirus-covid-19.aspx

DCC Community Response Unit

- 01629 535091 (Mon-Fri 9am-5pm, Sat

National

NHS Every Mind Matters:

- www.nhs.uk/oneyou/every-mind-matters

Samaritans

- 116 123 (24-hour free support service)
- www.samaritans.org

Northumberland, Tyne & Wear NHS Trust leaflets:

- www.ntw.nhs.uk

MOODJUICE self-help resources:

- www.moodjuice.scot.nhs.uk