

Worry after Critical Illness

It is very common to have worries after being a patient on an Intensive Care Unit (ICU).

This information sheet will help to explain how you may feel after leaving hospital, and what might help you.



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How your body and mind can feel after critical illness

A critical illness is an injury or illness which meant you needed treatment in Intensive Care (also called Critical Care).

It is very common to have worries or feel anxious after being a patient on an Intensive Care unit (ICU).

“I feel on edge and jumpy since I came home from hospital”

“I worry about my health, and when I will get back to normal”

“I’m scared I might get sick again and go back into ICU”

Having a critical illness is a difficult and upsetting experience and a stay on Intensive Care and the ward afterwards can be a very difficult and frightening time. It takes time to recover. During this recovery time, it is very understandable to feel worried and anxious.

Leaving hospital and returning home is an important step in your recovery, but sometimes it can feel hard to be back at home too.

“How you feel may change often during the day.”

Your body may feel very different than how it did before your critical illness. You may feel very weak and find it tiring to do everyday activities, such as washing and dressing yourself. You may feel breathless and find it hard to move around. Many of these problems will become easier as you begin to do more and become stronger. It’s normal to feel frustrated that your recovery is taking longer than you expect. Recovering from a critical illness can feel a slow process and can take up to 18 months. Keeping a diary about what you’re able to do and setting yourself small goals in your daily routine (such as making a drink for yourself) can help to show you that you are making progress and getting better.

As well as your body feeling different after a critical illness, you may feel lots of different emotions. How you feel may change often during the day. Some patients describe it as a ‘rollercoaster’ of feelings after critical illness.

You might experience a lot of different feelings and emotions, including:

- feeling upset and tearful
- being quick-tempered and snappy
- feeling guilty
- feeling frightened
- not being able to sleep, or waking and feeling very anxious in the night
- feeling relieved to have survived and feel more positive about life.

It is very common to have worrying thoughts after critical illness.

You might worry about:

- particular symptoms, such as breathlessness
- becoming unwell again
- how long it is taking for you to recover
- when you will be well enough to get back to work again
- worried because you do not fully understand what has happened to you and/or have upsetting and confused memories
- memories of your time in the intensive care, which can also pop into your thoughts or dreams
- thinking about what happened to you, and that you could have died
- your finances
- the impact on your family, perhaps having thoughts about what your family experienced during your hospital stay.

You might experience change in your usual behaviour:

These worries and feelings might make you act differently than before your ICU treatment, such as not wanting to do some things or not wanting to go to places or see some people. You might not feel like taking care of how you look. These behaviours are all an understandable reaction to what you have been through.

Helping Your Recovery

Over time, these changes in your body, emotions, thoughts and behaviour should naturally recover.

However, here are some ideas to help you in this recovery:

Learning more about your time in Intensive Care

You may not have many memories from your time in the Intensive Care unit or you may have lots of confused memories. You may not know what actually happened and what things you think happened but didn't. This is because it is common to have delirium in Intensive Care. Delirium is a name for acute confusion. It is sometimes described as like being in a nightmare, but it feels very real when you are in it and you can see, hear, or feel things that don't exist outside your mind. ICUsteps has a delirium information sheet if you would like to know more about delirium.

Some people find that they want to know more about their time in Intensive Care. It can feel very frightening if there are gaps in your memory or if you have very confused memories. Learning more about your time in ICU can help you make sense of what you have been through.

Here are some things you could do:

- If you feel ready to and if you want to, you could ask your relatives or a healthcare professional who has been involved with your care about what happened to you in Intensive Care, such as what treatments you had.
- Your Intensive Care unit staff or family may have kept a "patient diary". This is an account of your stay in Intensive Care. You can read this to understand about what happened to you. You may want to do this gently and slowly, at a pace that suits you and stop when you have had enough. Come back to it another time if you want to.
- Your Intensive Care unit may invite you to a follow-up clinic where you can ask questions about what happened.

- You may find it helpful to join an Intensive Care support group. ICUsteps and other organisations have support groups around the UK, and there are some online support groups too. It can help to be with people who have had similar experiences to you, and to know that what you are feeling is normal after a critical illness.

Only find out more about your time in ICU if you want to and when you want to. You might want to pace yourself and go gently rather than finding out everything you can straightaway, as it might feel upsetting or difficult to hear more about this time. Stop when you feel you have had enough and come back to it another time if you want to.

Understanding more about what happened to you while you were in Intensive Care might feel reassuring, as it makes sense of your confused memories. It might help some feelings of worry. However, it is fine not to want to know more about what happened to you as well. You may want to find out more at a later time, or not at all.

General activities to help your mood and distract you

It is very common to have worries after being a patient on an Intensive Care unit. In time, and as you get stronger, you might feel less worried. In the meantime, there are lots of things you can do which may help.

You may find that certain activities can help distract you from your worrying thoughts or improve your general mood, even if it's for a short time. You can try different things and see what helps you. Activities which might be helpful include:

- doing different gentle activities to see if you can find ones that feel ok. There may be activities that you used to do, which you aren't strong enough to do at the moment, but see if you can adapt them so you can do them now, or find new ones
- being outside and having fresh air might help you, or looking at nature such as the sky or watching for birds

- finding things to occupy your mind, such as doing a crossword or playing a game on your phone or doing a jigsaw
- listen to music, Podcasts or watch television. Choose music and programmes that you enjoy listening to
- try different arts or crafts to see if you can find some that are relaxing such as painting, colouring, or sewing
- Have a Wellbeing Action Plan. Each week you could plan which things you would like to do to help your recovery and wellbeing. You could write these down and make a note when you have done them and how you found them. Keep the activities gentle and ones that you will be able to do, rather than feeling bad if you can't do them.

*“trying gentle exercise
can help with worrying
thoughts”*

When you are doing these activities, try to focus on what you are doing, and not on your worries. You may only be able to do this for a very short time, such as five minutes. This will give your mind and body a break, as worrying is very

tiring. As you practise doing these activities, you might find that you are able to not think about your worry for slightly longer times. Don't give yourself a hard time if you find that your worries or feelings make it hard for you to enjoy things. Try not to expect too much, and even a few minutes focusing on something else is good progress. If you find your mind wandering onto worries, you can gently bring your thoughts back to what is in front of you.

Some people find that trying gentle exercise can help with worrying thoughts. When you first come home, you may feel very weak and doing things to look after yourself (such as washing yourself or getting dressed) may feel all you can manage. But gently build on what you are able to do, and this will help you get stronger. When you are able, do more and be more active, such as go for a walk or do some sitting exercises. You might find this helps your feelings of worry even for a short time.

Don't push yourself too hard or expect yourself to do all the things you could do before Intensive Care. It will take time to recover. Pace yourself in the exercise and

activities you do and who you see if talking makes you very tired. Some people find it helpful to think of their energy like a battery. You only have so much each day, so choose what you want to spend that energy on and rest when you need to. As you do things during the day, keep an eye on how you are feeling and what things help you to feel settled and less worried, and try and do more of those activities. See ICUsteps information sheet [Helping you to recover after critical illness](#) for some gentle exercises you could do.

Activities to help with worry

You might feel better when doing an activity, but then find that the worries come back very quickly when you stop. There may be times when the worry is worse, such as during the night. The tips below might be able to help at these times:

- Try doing relaxation exercises or breathing control exercises. There are two exercises on page 10 but there are many different ones on apps or YouTube. Try different ones until you find ones that you like.
- Some people find mindfulness exercises helpful. Mindfulness means to pay attention to the moment, rather than thinking of what happened in the past, or worrying about the future. To begin with, it can help to try and really focus on what you are doing, even a very simple task such as making a cup of tea or brushing your teeth.
- You could use simple techniques to help you (such as concentrating on your breathing, counting up to 10 a few times, or concentrating on what you can hear or see around you) so you can do them at any time.
- You could take a few moments to concentrate on your senses and notice what is around you. While taking slow breaths, notice what five things you can see. What four things can you hear? What three things can you feel? What two things can you smell? What can you taste?
- You could give yourself a worry time. Rather than worrying all day, try setting aside a time and place during the day when you deliberately think of all your worries for up to 15 minutes (but no more than this). Do this once each day, and not at bedtime or during the night. Notice when you start worrying outside of this time and see if you can wait until the 'worry time' to think about them.

Stronger feelings of worry and panic

Some people find they can have very strong feelings of worry - these are called panic attacks. Here is some information about panic attacks, and what might help.

What are panic attacks?

Sometimes, worries can come in a “wave” of feeling. Sometimes these feelings are felt so strongly that they feel to be a ‘panic attack’. Panic attacks are a very quick response of fear, which usually lasts up to about ten minutes. This can feel a very long time when you have these feelings. It can happen at night or during the day. This can be started by a worrying thought, or a sensation in the body. It can lead to feelings in your body, such as:

- your heart might pound, so you can feel your heartbeat very strongly which may feel like chest pain
- you might sweat or tremble
- you might find it difficult to breathe or feel dizzy
- feeling faint.

People can sometimes feel like they are having a heart attack or dying, and it can feel very frightening, especially after a critical illness when they have had the experience of being very ill.

On page 10 are some relaxation exercises which might be able to help you. It is very hard to try to do breathing exercises for the first time during a panic attack, so it is very helpful to practise them at other times of the day and night, so that they are there for you if you need them.

What can help panic attacks?

When you are having a panic attack it can help to ‘Stop, Breathe, then Think’:

- Say to yourself “STOP” to stop the worrying thoughts in their tracks.
- Try to regain control of the strong feelings, by slowing down your breathing and counting your breaths. IN....1...2....3... OUT 1...2...3....

- Try to accept that the panic attack is happening, but also understand that it will pass in a few minutes.
- When the panic attack is over, try to do something that you find relaxing or soothing.

“it will take time for your body and your mind to feel better”

It can help panic attacks if you practise the relaxing breathing exercise when you are calm, and then you can use it to help if you are having a panic attack.

Overall try to be kind and gentle to yourself. It is normal to feel these strong feelings after a critical illness, and normal to have good days and not so good days. You have been through a very difficult and frightening time, and it will take time for your body and your mind to feel better.

Could relaxation exercises help me?

Relaxation exercises can help to manage worry. When we are stressed, our muscles tense up, and our heart and breathing get faster. But when we focus on relaxing, our muscles can relax and our breathing slows down.

It can help to practise these up to a few times a day, as the more we become used to doing these exercises, the more they can help and be calming. They can also help if you are struggling to sleep.

Here are two exercises you might like to try:

Relaxing breathing exercise

This exercise is useful for panic, worry and slowing down anxious breathing. When we are anxious, our breathing rate often gets faster. This produces other physical changes such sweating, dizziness, blurred vision, or your heart rate getting faster. Slowing down our breathing can help control these physical feelings, and also help feelings of panic.

- Go to a room where you can be by yourself and where you won't be interrupted. Find a comfortable position, either sitting or lying down.
- Breathe in for four counts, hold for two counts and breathe out for six counts.
- Practise this exercise for five or ten minutes.
- You can adjust the breathing pattern to suit you (for example, breathe in for 3 counts, hold for 1 count and breathe out for 5 counts). Do the exercise the way that suits you best.

Don't worry if your mind wanders onto other thoughts. Just gently bring your thoughts back to your breathing. Try to practise this exercise a few times a day.

'Safe place' relaxation exercise

- Go to a room where you can be by yourself and where you won't be interrupted. Find a comfortable position, either sitting or lying down.
- Close your eyes.
- Think of a place that you love, or the most beautiful and relaxing place you can imagine. This might be a place outside – a beach, wood, or sunset: it can be a place you've been to, or just imagined, or a place that you've seen in a picture. This is your "safe place".
- Working around the body, think about relaxing your muscles one by one. Start by thinking about relaxing the muscles in the feet. Move slowly up through the body, relaxing the muscles in each part of your body - ankles, shins, knees and so on - until you reach the top of your head.
- Don't worry if your mind keeps thinking about other things, just keep gently bringing your mind back to focusing on relaxing.
- When you feel relaxed, keep your eyes closed and imagine you are walking through this place that you like. Look around you. What do you see? What do you hear? What can you smell? Take a moment to look at the sky and see the clouds move, feel the pleasant breeze on your face. Stay in this place for a while. Breathe deeply. Enjoy the sensations.
- When you are ready, slowly open your eyes and try to stay in this calm feeling for as long as you can. Allow yourself to enjoy the moment.

You can visit this safe place in your mind whenever you want to. You may find the more times you practise it, the easier it gets to stay focused on the exercise, and to relax more fully.

When should I ask for help from a healthcare professional?

It is very common to feel anxious and worried after a critical illness, and you may find some of the tips and activities in this information sheet can help you. Overall, try to be kind and gentle to yourself. It is understandable to feel cross or frustrated if you aren't recovering as quickly as you want to. You have been through a very difficult and frightening time, and it will take time for your body and your mind to feel better – so be patient with yourself while you recover.

Many people also find that these feelings do settle and become less strong as time goes by.

However, you may find that these feelings are affecting your everyday life and you may need some extra support to help you.

It is ok not to feel ok after all you've been through, and important to ask for help if you need to

It might be helpful to talk to a healthcare professional if you:

- are often feeling overwhelmed by your feelings. It is common to feel this way at the beginning of your recovery, but if you feel you are struggling to cope every day, and this goes on for more than a month after returning home
- feel anxious or worried every day, and these feelings get in the way of what you are able to do
- have a low mood every day, which may impact on motivation, your opinion of yourself, and your thoughts about the future
- have poor sleep, including ongoing nightmares or flashbacks
- are acting very differently to before being in ICU

- finding your relationships with friends and family difficult
- are using drugs or drinking too much.

More help

- Some Intensive Care Units offer a follow up service, which can see how you are, if you need any support from healthcare professionals, and where you can find out more about what happened while you were in ICU.
- Speak to your GP about what you are feeling. They might be able to refer you to counselling or psychology to support your mental health.
- Contact a charity for support, or to talk to someone, such as:
MIND, the mental health charity www.mind.org.uk or the Samaritans who work to make sure there's always someone there for anyone who needs someone
www.samaritans.org
- You can find helpful self-help resources on:
www.nhs.uk/mental-health
www.nhs.uk/mental-health/self-help/guides-tools-and-activities/breathing-exercises-for-stress
www.nhsinform.scot/illnesses-and-conditions/mental-health
- You can choose to access private counselling or psychological therapy. The following professional bodies have a list of practitioners in your area:
www.bps.org.uk/public/find-psychologist
www.bacp.co.uk/search/Therapists
www.cbtregisteruk.com

These resources have more information about recovery after Intensive Care:

- www.criticalcarerecovery.com/ and covid19.criticalcarerecovery.com/
- University College London Hospitals Your Recovery After Critical Care
www.uclh.nhs.uk/patients-and-visitors/patient-information-pages/your-recovery-after-critical-care
- Cardiff and Vale University Health Board rehabilitation pages
keepingmewell.com/

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With thanks for permission to use elements of the following resources:

University College London Hospitals *Your Recovery After Critical Care.*

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