

Recovering after a stay on the Intensive Care Unit

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Critical Care Outreach - Bleep 7719

Intensive Care Unit B12 - Ground Floor - 01225 824964

Intensive Care Unit B36 - First Floor - 01225 826813

Critical Care Follow-up Clinic - 01225 825057



Introduction

This information booklet aims to assist you and your family with your recovery and rehabilitation after your stay on the Intensive Care Unit (ICU). Being ill on the Intensive Care (or Critical Care) Unit is often referred to as being 'critically ill'. This booklet has been written by the doctors, nurses, therapists and psychologist who work in the Intensive Care Unit as a source of information to assist you and your family with your recovery from critical illness.

As you have been critically ill, it may take some time to get back to feeling like your normal self. Exactly how long after leaving ICU depends on a number of variables, such as how ill you were, the nature of your illness or trauma, how long you were ill and whether you lost a lot of weight. This booklet describes some of the common problems that can occur and suggests simple ways to try to solve them. We want to emphasise that you will probably not experience all the problems described here, but if you do suffer from any of them, we hope that you will find this advice helpful. We want to stress that there is every chance that most people will slowly return to their previous or similar state of health.

While everyone will have different experiences both during and after they have been in Intensive Care, most people will undergo some reaction to their stay. The following are some of the more common experiences:

Physical experiences:

- Extreme tiredness, fatigue and weakness
- Reduced physical ability
- Reduced appetite
- A loss of independence
- Loss of interest in sex
- Physical aches and pains
- Becoming more breathless or more tired doing a given activity than before the period of critical illness

Psychological experiences:

- Feeling guilty about causing so much trouble and worry
- Sleep disturbances - not sleeping at night and feeling exhausted during the day
- Bad dreams and hallucinations
- Memory and concentration problems. Your brain is likely to feel quite sluggish for a while
- Not wanting to see other people or do things that you might have enjoyed before being critically ill
- Not caring what you look like
- Mood change – becoming easily tearful, irritable, sad and low
- Not fully understanding or being able to remember what has happened to you
- Fear about becoming ill again
- Less confidence or a sense of vulnerability
- Flashbacks or nightmares of distressing events either seen or thought to have seen
- Confusion and disturbance caused when cared for by staff who were wearing Personal Protective Equipment (PPE)



- Worrying about how long it's taking to get better
- Anxiety or depression
- Post-Traumatic Stress Disorder

Reasons why people might experience these symptoms

- The severity of your illness, the effect it has had on all of your organs and the general deconditioning that takes place when you are very ill can affect your physical and mental well-being when you begin to recover. It is normal not to regain your pre-critical illness level of physical fitness for at least 18 months, given all that your body has been through. The same may be true of your mental agility.
- The types of medication that people are often given during their stay in Intensive Care in order to make them better can have side effects on memory, concentration, sleep and thoughts. Your brain will need time to reprogram itself after receiving these medications.
- More than half of those treated on ICU experience delirium as a consequence of being very ill. Delirium describes disordered or muddled thinking and difficulty in being attentive to the world around you. It can be difficult to process these experiences as you begin to get better.
- Sleep patterns can be affected by the lack of difference between night and day in Intensive Care, so that the usual cues to sleep are missing which can lead to the sleep/wake cycle being disrupted. Also the sedatives given on Intensive Care do not help 'normal' sleep. For these reasons it can take a long time for the brain to re-learn a normal sleep/wake pattern.
- Since COVID-19, inpatients have not been able to have visitors owing to infection control, which can be distressing for both them and their families.
- When we have been through a major life event or trauma, our brain needs time to make sense of and work through some of the memories to be able to put them away like a librarian filing books away in the library. This can cause our dreams and memories to become very vivid and, at times, disturbing and frightening. Usually these experiences start to fade over the course of a few weeks after leaving Intensive Care. Sometimes however, they can get stuck, for example, as nightmares or flashbacks. Help for these experiences can be found at the Critical Care Follow-Up Clinic.
- Often people will experience low mood, a loss in confidence, irritability and tearfulness because an admission to Intensive Care is a major life event. This event can feel traumatic or be associated with feelings of loss. Life can feel very different, and the recovery process is not always a smooth journey. These are all reasons why people can find themselves frustrated, lacking confidence and tearful as they adapt to their new life. Again, support from the follow up clinic can help to process this.



Going to the Ward

Going to the ward is a big step on the journey to getting better and going home, and it is quite normal to feel apprehensive. You will have become familiar with the staff and routine on the Intensive Care Unit. Staff on the ward will understand that you may be feeling anxious. They are used to looking after people who have been critically ill, so feel free to ask them about anything that concerns you.

You will notice that on the ward there are fewer nurses for each patient compared to the Intensive Care Unit. This reflects the fact that you are getting better and don't need such intensive nursing input. Even if you cannot see the nurses all the time, they are still nearby. You will have a call bell to use if you need any help, which the nurses will answer as quickly as they can. Going home is now in sight so you will need to work with the staff to be ready for discharge.

The Critical Care Outreach Team will visit you on the ward within the first 24-48hrs after your move from the ICU. They will work with the ward staff to monitor your physical recovery, assisting where necessary. They will discuss with you any issues you or your family have regarding your physical and psychological rehabilitation.

By the time you are fit to leave the RUH, you are unlikely to feel 100% back to your previous health. The ward staff will make sure that your healthcare needs have been identified and any ongoing care arranged. It is important that you know when you are due to leave the RUH and what has been arranged to help you to make a full recovery. If you do not know, be sure to ask.

Critical Care Follow up Clinic

All our patients are eligible to attend a dedicated Critical Care Follow-Up Clinic, 2-3 months after leaving the ICU.

You will either receive an appointment for the clinic or a letter offering you the opportunity to book an appointment if you wish. The clinic offers medical, nursing, psychological and physiotherapy support for patients who are having ongoing difficulty recovering from their period of critical illness. You may wish to book an appointment if you are still suffering from some of the psychological or physical problems described in this booklet, or if you wish to better understand what happened to you during your time on the Intensive Care Unit. Not all patients need this service, so not all patients are immediately offered an appointment, but the clinic is there for you if you think you need it.

The clinic can be contacted in the following ways:

Phone: 01225 825057

Email: ruh-tr.criticalcarefollowup@nhs.net

More information about the clinic is available on our website:

www.ruh.nhs.uk/patients/services/wards/critical_care_services/follow-up-clinic.asp



How to use this booklet

The following pages provide you with information and advice on the most common problems experienced after a stay on the Intensive Care Unit. You can choose to read all sections or just look at the themes that are significant to you and your recovery. There are a number of useful contacts at the end of this booklet which may offer more information and support to you and your family.

General strategies that can help recovery	page 5
Exercise and mobility	6
Eating normally again	7
Sleeping	8
Nightmares, hallucinations, confusion	8
Your family and relationships	9
Changes to your body	10
Stress	10
COVID-19	11
Useful contacts	12

General strategies that can help

Perhaps the most important aspect to recovery is in recognising and accepting the time required to heal. It is important to take one day at a time, not thinking too far beyond 'today'. Many of these symptoms will go over time.

Listen to your body - if it is craving rest or peace and quiet, this is probably exactly what it needs.

Routines can be really helpful, as we all need some sense of structure – building in time to rest as well as opportunities to be more active. It can be helpful to steadily reduce the number of day-time naps taken, to help re-establish a good sleep routine and to reset your body clock.

Pacing yourself is really important in making sure that you don't over-do things. If a situation feels too difficult at first (often social situations can feel particularly overwhelming), try to break it down into smaller steps. Remember that even the smallest steps are valuable progress.

Allowing emotions and thoughts to come and go can help your brain work through what has happened, rather than blocking or pushing them away. Talking these things through, writing them down, and filling in gaps in memory - either through speaking to family, ICU staff or, when possible, visiting the unit - can make a huge difference.

Finally, don't be too hard on yourself if you are finding things difficult and do contact the Follow-Up Clinic on the number or email on page 4 if you think you could do with more support.

Exercise and Mobility

When you first read this you will probably find that the slightest activity takes tremendous effort and leaves you feeling very tired. This tiredness is normal and will improve with time. Unfortunately, it is difficult to put a time scale on your recovery because everyone responds at a different rate. It also depends on a number of factors, such as: your age, your previous level of fitness, how ill you have been and how long you have been ill. While you were ill your body took what it needed to survive from nutrients stored in the muscles. This means that your muscles will have got smaller and weaker. You can rebuild your muscles to what they were before and in some cases even better. However, do not be alarmed if it takes you weeks or even months to return to normal. Unless you are fully independent and mobile when you leave ICU, physiotherapists will continue to work with you on the wards; they will devise a rehabilitation plan that will include exercises to rebuild strength and fitness that you do with them and some that you can do by yourself.

Exercise is important after being unwell and has the following beneficial effects:

- Strengthens your heart
- Helps rebuild lost muscle
- Helps reduce stress
- Helps to get good refreshing sleep
- Improves movement in your joints
- Improves your confidence

When you go home from hospital it is also important to continue with some form of exercise. Activities could include:

- Walking (indoors and outdoors)
- Swimming
- Yoga
- Pilates
- Gardening
- Cycling
- Walking up and down stairs

**Important points about exercise:**

- Do not try to do too much too soon. This could make you feel over-tired and disheartened. Pacing yourself is really important.
- If you have a bad day try not to get upset, everyone feels like that at some point
- Always warm up before and cool down after exercise
- If you feel unwell reduce your normal level of exercise until you feel well again

You should stop exercising and rest if you experience any of the following:

- Severe chest pains
- Increased chest tightness
- Dizziness or feeling faint
- Much more breathlessness than you experienced the last time you exercised
- Joint or muscle pain

If these symptoms persist, inform one of the nurses or contact your G.P immediately. If the symptoms settle in 2-3 minutes, do not continue with the exercise but contact your G.P or nurse for advice.

Eating Normally Again

Since being ill, you may find that you have lost your appetite or that your sense of taste has changed. You may notice that food tastes different or stronger especially if you have not been able to eat normally for a while. Many people find that foods such as fresh fruit, fruit juices and boiled sweets are refreshing and leave a pleasant taste in the mouth. These taste changes are only temporary and should return to normal within a few weeks.

During the early stages of your recovery, it is important to eat a healthy balanced diet with plenty of protein (such as beans, peas, lentils, cheese, yoghurt, milk, fish, eggs, tofu, chicken and lean cuts of meat). Even though you may find it difficult to eat, it is important to maintain a well-balanced diet because:

- Helps you fight infection
- Helps you feel less weak and tired
- It will prevent you from losing weight and help you regain any weight you will have lost

If your appetite is poor, then small meals with nourishing snacks in between are often easier to manage. Eating will be more enjoyable if you take your time, avoid heavy fatty foods and relax for a while afterwards.

In hospital you may be given a high protein diet with some of the foods fortified for extra nourishment. You may see a Dietitian. The ICU and ward staff can arrange nourishing drinks that you can take between meals.

When you go home you may need to continue to take some of these nourishing supplements for a while, but you will be advised if this is necessary. If you are having problems with eating, then ask your GP to refer you to the dietician for more specific advice on a nourishing diet at home.

Sleeping

You may find that your sleep pattern has changed. It may be more difficult to fall asleep or you may wake frequently during the night. When your body is not active, it does not need as much sleep as normal. As you recover and become more active you should find your sleep pattern returns to normal.

Routines can be really helpful to recovery because we all need some sense of structure – build in time to rest as well as opportunities to be more active. It can be helpful to steadily reduce the number of day-time naps taken, to help re-establish a good sleep routine and to reset your body clock.

Sleep can be improved by doing the following;

- Go to bed at the same time each evening
- Get up at the same time each morning, even if you have not slept well. This will help you return to your normal sleep pattern
- You may find taking a bath or shower shortly before going to bed will help you feel more relaxed, making it easier to fall asleep
- A bedtime drink may be helpful, but you should avoid tea, coffee and large amounts of alcohol
- Reading just before going to sleep is a good way of relaxing

Being awake at night can be worrying and negative feelings can feel unsolvable. It is common for a small problem to seem overwhelming in the early hours when you are the only person awake. This is quite normal but when you have been ill, it is often harder to cope with things like this. If you are awake at night then you may find it helpful to read or listen to the radio. Even if you do not fall asleep this will at least help to pass the time.

Finally, the most important thing is not to worry. A lack of sleep will not necessarily do you harm, and as you recover, things will get back to normal.

Nightmares, Hallucinations, Confusion

People feel differently about their time in the Intensive Care Unit. Some have no clear memory of it, or they try to forget it. For some the experience is no more worrying than any other stay in hospital. It is not uncommon for people to find the experience of being ill very traumatic.



The degree of illness as well as the strong drugs and the treatments given to patients in the Intensive Care Unit may affect the body and mind. Sometimes our patients experience nightmares and hallucinations, or have been bothered by them when they first leave. They may have dreams or feelings of being tortured, trapped in bed or being held captive. This is the way the mind processes a significant event and is nature's way of healing. This is quite common, and you are not going mad. Although they may be very vivid and frightening, they usually settle over a few days or weeks. It may be helpful to discuss your nightmares and hallucinations with your family and friends (who may have featured in them) as it can help to explain their meaning and may help your state of mind.

You may also have felt some paranoia as you tried to make sense of things when you were confused. Confusion or disordered thinking on the ICU is sometimes called ICU delirium. This too normally passes with time. The increased use of staff wearing personal protective equipment (PPE) including masks, goggles and gowns can contribute to feelings of confusion and paranoia.

If you had a prolonged stay on the unit, the multi-professional team on ICU routinely establish a patient diary that keeps a record of the day-to-day events during your illness which can help you make sense of what happened to you. Any member of the ICU team can write in the diary. When you leave ICU, you will be given the choice of keeping the diary or leaving it on ICU. As you get better you can record your own thoughts and experiences in the diary. The diary is yours to take home and keep.

If coming back to the hospital for follow up appointments makes you feel anxious you may want to bring someone you trust with you.

Your Family and Relationships

The people close to you will be pleased that you are getting better and are out of the ICU or home from hospital altogether. Seeing someone you love in ICU can be very upsetting. It can be even more upsetting when you are not allowed to visit as has been the case during the COVID pandemic. They may have worried that you wouldn't get better which can take some people a long time to get over. Sometimes as a result of this they may be overprotective and not let you do as much as you feel you are able to do. They may not understand why you feel moody or are irritable. Talking to each other about how you feel and sharing your experiences and worries can help you work towards recovery together. If your mood does not settle or you feel you are becoming depressed speak to your GP who will be able to offer you support or arrange counselling.

The old adage 'a little of what you fancy does you good' is particularly true for sex during your recovery from illness. Your illness may have reduced your sex drive and it is possible that either you or your partner is concerned that sex could be harmful for you. This is rarely the case, but as with other forms of exercise, you should do as much as feels comfortable. You will be able to return to your normal relationship, but recognise this may take some time and patience from both of you.



Changes to your body

Your appearance may have changed as a result of being ill, for example, you may have lost or gained weight and your muscles may have become weak and small, but these changes are usually temporary. If you have been ill for some time and especially if you were on a breathing machine, the muscle weakness can be significant. You will normally put weight on again as you begin to recover and exercise. Physical recovery can take months rather than weeks. It may take up to 18 months to feel fully recovered and back to your normal self. Even if you do not fully recover, you can still achieve a lot and live a full life. There are people who have been critically ill for months and a year later you would never know they had been ill.

You may find that your voice has changed. It may have become husky or may be so weak that you are unable to raise your voice or shout. This is probably the result of having a 'breathing tube' passing through your voice-box or of having a tracheostomy in the neck. Both are made worse by weakness which can affect the talking muscles.

Your Skin and Hair

You may have some scars that you feel are unsightly. These will fade in time, and as your skin returns to normal, they will not seem as obvious. You may find that your skin is drier than before and itchy at times. Moisturising regularly can help.

You may notice that the texture of your hair changes and some of it may fall out. This is not unusual and may happen months after you leave hospital. It often grows back but may be curlier, straighter, thinner or even a different colour.

Your Taste, Touch, Hearing and Sense of Smell

Your taste, touch, hearing and sense of smell can be affected by critical illness. Some of the drugs used to treat you can affect your hearing or leave a metallic taste in your mouth. If you were unable to eat and drink normally, you may have been fed through a tube into your stomach or have nutrition via a drip in your vein.

You may notice that food tastes different or stronger, especially if you have not been able to eat normally for a while. You may also notice that your sense of smell is affected; this is because taste and smell are closely connected.

If you were sedated for a while your eyes may be sore and feel dry or puffy and swollen, this is because of the fluids you were given to keep you hydrated.

Stress

The period of recovery after a critical illness can be stressful. The degree of stress and how long it lasts varies. Previous sections discuss some of the symptoms that may be related to stress, such as disturbed sleep, loss of appetite, change of mood, and problems with family relationships. You may find following the advice offered there helpful.



Recovering from a stressful event takes time. If at the end of each week you can look back and say that overall things were better than the previous week, then you are making good progress. However, if you feel that you are making no progress, you may wish to make use of the Critical Care Outreach service that will be able to help you whilst you are in hospital, or the Critical Care Follow-Up Clinic after you have gone home. Your GP or one of the self-help groups listed in the back of this booklet may also offer useful advice and support.

Occasionally some patients experience severe symptoms of stress. This may include symptoms that require support or treatment, and at its worst can amount to a condition called post-traumatic stress disorder (PTSD). This does get better over time and we know that early intervention is important. If you think you are suffering from PTSD (for example, experiencing nightmares, flashbacks, pain, sweating, feeling sick or trembling), you should ensure you have an appointment with the Critical Care Follow-Up Clinic to see our psychologist.

COVID-19

The impact of COVID-19 on ICU has been significant. At the RUH, like all other NHS hospitals, we have changed the way we deliver ICU care by increasing the number of beds, the size of our unit and the way we care for our patients.

The biggest changes we have had to make to keep our staff and patients' safe has been in the use of personal protective equipment (PPE) and unfortunately but necessarily not allowing friends and family to visit.

Wearing of PPE by staff may have made communicating your needs difficult. It may have felt frightening to see staff wearing masks, visors, long gowns and gloves. You may have felt more vulnerable if you were on ICU during this time due to the risk of catching the virus or by being on ICU because you have the virus. Staff wearing PPE may have caused you to feel confused, disorientated, or scared.

By stopping visiting, the lack of contact with friends and family may have made you feel isolated or unsupported. You may have felt low or anxious through not being seen or comforted by those you care for.

While everyone will have different experiences both during and after they have been in Intensive Care, the physical and psychological experiences described in this booklet can be the same, or similar, for patients that have had COVID-19 as they are for those with other critical illnesses.

More information on recovering after COVID-19 is available on the following, highly recommended, NHS website: www.yourcovidrecovery.nhs.uk



Useful Contacts

ICU information and support

RUH Critical Care Follow-Up Clinic
Phone: 01225 825057
Email: ruh-tr.criticalcarefollowup@nhs.net

ICU Steps

www.icusteps.org

A UK support group for patients affected by critical illness and their families.

www.royalcornwall.nhs.uk/services/critical-care

This webpage has some excellent videos to consider memory loss, stress and anxiety, nightmares, poor sleep and common psychological problems post critical care.

Health Talk.Org

<https://healthtalk.org/intensive-care-patients-experiences/overview>

You can find out about experiences of ICU from other people (patients and their families) by seeing and hearing people share their stories on film. This webpage will link you directly to the ICU resources.

<https://icssoa.wordpress.com/2015/04/21/david-aaranovitch-recounts-his-experience-of-icu-delerium-ics-soa-2013/>

This weblink will take you to a video of a patient who experienced ICU delirium.

General information and support

NHS COVID recovery information and advice

www.yourcovidrecovery.nhs.uk

British Heart Foundation

www.bhf.org.uk

Helpline: 0300 330 3311

British Lung Foundation

www.blf.org.uk

Helpline: 03000 030 555

Guillain-Barré Syndrome

www.gbs.org.uk

Helpline: 01529 469910

Headway – Head Injuries

www.headway.org.uk

Helpline: 0808 800 2244

Macmillan Cancer Support
www.macmillan.org.uk
Helpline: 0808 808 00 00

Mind – the mental health charity
www.mind.org.uk
Helpline: 0300 123 3393

Samaritans
www.samaritans.org
Helpline: Freephone 116 123

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Royal United Hospitals Bath NHS Foundation Trust
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01225 428331 www.ruh.nhs.uk

Please contact the Patient Advice and Liaison Service (PALS) if you require this leaflet in a different format, or would like to feedback your experience of the hospital. Email ruh-tr.pals@nhs.net or telephone 01225 825656 / 826319.