
Adjusting to life after critical care

Critical Care Unit

Patient Information



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Introduction

This booklet has been written to help prepare you for leaving the Critical Care Unit (CCU) or Intensive Care Unit (ICU). It answers some of the questions you and your family may have about your recovery and rehabilitation from critical illness.

Recovery from Critical Care

Patients looked after in CCU are critically ill and require life-saving treatment. Some patients stay in CCU for a few days, but for some patients their stay may be much longer. During your CCU stay you will have been looked after 24/7 by a specialist team of doctors, nurses and other staff who care for people who are critically unwell.

The amount of time it takes to recover from critical illness and 'get back to normal' is different for each person but can take a long time, sometimes up to a few months. The time it takes to recover depends on:

- The state of your health before your illness
- The length of time you have been ill
- Whether your illness means you will have to change some aspects of your lifestyle
- Whether you have lost weight
- Whether you have problems with memory
- Pre-existing conditions related to feeling down, anxious or depressed.

Being ready to leave CCU is therefore an important step in your recovery. Your rehabilitation and recovery journey will continue on the hospital ward and beyond.

Rehabilitation is the process of psychological and physical recovery. This is one of the most important aspects on your road to recovery as it focuses on how to return to a healthy life after your critical illness.

Leaving CCU

Before leaving CCU, the team will explain to you which ward you are going to and what to expect once you are there. Before leaving the unit you will meet one of our critical care outreach team nurses. They will discuss your recovery plan with staff on the ward which you are going to, and may also visit you on this ward.

Your recovery plan will include information about your rehabilitation goals and a plan to help you to get back to normal as quickly as possible. Depending on your needs, different members of the intensive care team may be involved in supporting you with this, including doctors, nurses, physiotherapists, speech and language therapists, occupational therapists and psychologists.

What happens after CCU?

Will I still see staff from the Critical Care Unit?

Yes. Physiotherapists, speech and language therapists and occupational therapists involved in your care will also visit you on your new ward and introduce you to your new therapy team. The psychology team may also see you on the ward during your hospital stay. This helps to ensure a smooth transfer of your care between staff in the intensive care unit and the ward. It also ensures you are supported with your recovery plan throughout your hospital stay.

Which ward will I move to?

The ward you will move to will depend on the reasons for your stay on CCU and the ongoing level of support you may need. The doctors, nurses and therapists will hand over your care to the ward consultant and the rest of the team.

Who will look after me on the ward?

Nurses, doctors and other healthcare professionals such as physiotherapists and dietitians will continue to treat you.

Your team of doctors will not be based on the ward but they will do a ward round once a day to visit you. If you need to see a doctor at other times, the ward team will contact them for you.

Who else will I meet?

Physiotherapist

The critical care physiotherapist will work closely with the ward physiotherapist to ensure a smooth transition from CCU to ward care. This will also ensure you can continue to work towards the rehabilitation goals you set on CCU. You will have therapy sessions on most days, which may involve one or more therapists at the same time.

These sessions will focus on improving your muscle strength and general fitness, as well as working towards independent activities such as standing, walking and climbing stairs.

In addition to these rehabilitation sessions, we will provide you with an exercise plan to complete independently. Even though you are likely to feel tired, low in energy and may still need an oxygen mask, it is very important you do your exercises. This will help you to recover as quickly as possible.

Occupational therapist

An occupational therapist may also see you on the ward. The occupational therapist will review your ability to perform daily tasks, such as washing and dressing. They may suggest providing adaptive techniques and assistive equipment to make things easier for you. The occupational therapist will also consider what you may need at home to increase your independence and safety when you are discharged from hospital.

The occupational therapists and physiotherapists work closely together and may see you during the same treatment session. You may also be seen by a therapy assistant, who will help you to complete your rehabilitation programme prescribed by your therapists.

Pharmacist

The CCU pharmacist will work closely with the doctors to optimise your medication during your stay in CCU.

You may have been given sedation and analgesia (painkillers) to keep you comfortable. Sometimes patients may experience side effects such as disorientation and vivid hallucinations from these medications. This is entirely normal and you will recover from these. However, if you would like to discuss any concerns about side effects, you can ask to speak to the pharmacist or doctor.

When you start to recover, the pharmacist will ask you to provide details of regular medicines that you were on prior to admission. This is to ensure that, when appropriate, your medicines are restarted.

Some of the regular medicines that you normally take at home will be temporarily stopped on CCU as they will not be required at this time. As you recover from the acute phase of illness and are being prepared for discharge from CCU, some of those medications will be gradually reintroduced.

Psychologists

Psychologists are an integral part of the specialist intensive care teams. Their role is to support patients recovering from critical illness, and their relatives and families, by providing information, advice and practical tips on coping with emotional reactions to being critically ill. Emotions such as feeling tearful, sad, or low in mood are completely normal. Other common problems may include trouble sleeping, worrying about getting back to 'normal', the effect of your illness on everyday life and activities, or concerns about changes in your appearance.

Please check with your team if psychologists are available at your intensive care unit.

Physical rehabilitation and exercise

Exercise is important after being unwell, as it helps you recover from your stay in CCU. It may take some time to get your strength back. Exercise is beneficial and can:

- Strengthen your muscles
- Strengthen your bones
- Improve your heart function and function of your breathing muscles
- Help to clear sputum
- Reduce stress
- Help sleep pattern
- Improve movement in joints
- Improve confidence and mood.

It is very important that the rehab process starts as early as possible. Your physical rehabilitation journey will continue after your discharge, and we will support you to achieve your goals in trying to return to your normal level of activity.

While in hospital, you will continue to work with your physiotherapist to rebuild your strength, balance and function. You will see them regularly to help achieve your goals and also work independently on your own exercise programme that they have given you.

Will I be able to move around?

The team on the ward will help you to gradually increase the amount of physical activity you do. You may feel very tired at first. Do not worry; this is normal and will improve in time

What if I still need help to get dressed?

You may need help with some personal care such as eating, dressing, washing and perhaps walking.

The healthcare staff will be there to help you, and the occupational therapists will work with you to improve your independence with these tasks.

Will I be in pain?

There are many reasons why you may experience pain after your stay in intensive care. This may be a result of some of the medical procedures you had while on the unit, you may have had surgery, or you may have painful stiff joints after prolonged bed rest.

Please let the nurse or the medical staff know at any time if you are in pain so that they can make sure you are getting the right pain relief.

There are many forms of pain relief that can help you, so please let us know if you have any concerns about your current analgesia.

The hospital's pain team may also be involved in your care. It is important that your pain is controlled as pain may prevent you from moving around or being able to breathe deeply and cough. This is very important to prevent chest infections and aid your physical recovery.

The intensive care team psychologists may sometimes work with doctors, nurses and physiotherapists to help patients who are worried about pain or causing further damage. They work together to find ways to increase your confidence in achieving your rehabilitation goals.

When will I be discharged home?

The doctors, nurses, therapists and psychologists will work with you to achieve your goals, so that you can leave hospital as soon as possible.

Sometimes people will need further rehabilitation to reach their full potential. This may happen at home or in another inpatient facility. If this is something you need, the team on the ward will discuss this with you in detail at the time.

Your GP will receive a summary of your stay in hospital so that they can follow up your care in the community.

When you have been ill, it can take quite a while to get back to feeling your normal self. Exactly how long this will take will depend on the length of time you have been ill, how much your illness has affected your body, or whether there are aspects of your lifestyle that you wish to change, such as developing healthier eating habits, giving up smoking, or reducing alcohol consumption.

If you have had problems with your physical health, mental health, or addictions before you became critically unwell, you may wish to have additional support with these once you are back home as part of your recovery plan.

Common questions about problems experienced after CCU

In this section we have outlined some common problems that can occur, along with practical suggestions to help you with these.

Please note this does not mean that you will experience these issues.

Tiredness and exercise

I feel weak all the time - why?

Do not be surprised if you feel very tired and weak at first. While you were ill, your body took what it needed to survive from its stores in the muscle. This means they will have reduced in size and strength. This muscle loss happens faster for patients who have been on a breathing machine.

Because of this, you may feel tired very quickly even when you are not doing much. You may have difficulty climbing stairs and your balance might not be as good as it used to be. With regular exercise, you can regain strength in your muscles and get back to doing all the things you enjoy.

Sleeping

I'm finding it hard to sleep - what can I do?

You may find that your sleeping pattern has changed. It may be more difficult to fall asleep or your sleep may be broken. This is normal.

If you are struggling to sleep at any time during your admission, please inform someone. There are many ways we can help you with this, including getting you one of our **Sleep well** packs. These packs include items that can help you sleep better, such as eye masks and ear plugs. The packs also help you to 're-set' usual night/day sleeping patterns where possible, for example, by ensuring natural light in the daytime and reducing noise and lights at night.

As you increase your activity, you should find your sleep patterns return to normal. Exercise is best done in the morning to help you to sleep.

Using music relaxation exercises and managing stress, worry, or bad dreams, can also help improve sleep.

Common emotional reactions during recovery from critical illness

I feel emotional at times - why?

Many patients recovering from critical illness describe feeling like they are on an 'emotional rollercoaster'. You may feel hopeful and confident sometimes, and tearful or irritable for no reason at other times. This is a normal reaction to illness and will often settle over time.

Being physically weak and having to put a lot of effort into simple things, such as dressing or moving around, can make you feel low in mood. Sometimes it may seem that you will never get back to normal and any progress is very slow. It is common for your mood to fluctuate and you may feel you experience some of the following:

- Always feeling tired
- Being quick-tempered and snappy
- Feeling scared that you almost died
- Worrying about getting ill again
- Worrying about how long it's taking to recover
- Being extra alert to physical symptoms
- Not wanting to do things you used to enjoy
- Not wanting to be around others.

While many people experience these symptoms in hospital, some may continue to feel this way for some time once they are home. There may be many changes that you have to deal with, perhaps to your lifestyle, work, appearance and your role within your family. Talking with those close to you can be helpful and will help them understand how you are feeling. You may find that setting small realistic goals helps you see the progress you are making. This may also help you feel better in yourself by giving you a sense of achievement. For some people, keeping a diary helps this process. The team looking after you can guide you on what you can expect from yourself at this stage of your recovery.

It is important to be aware of how you are feeling, as low mood and worry can slow down your recovery and can develop into problems such as depression and anxiety. Depression and anxiety are health conditions that affect people in different ways and can cause a variety of symptoms, both physical and emotional. These conditions often occur at the same time and can have a significant effect on your daily life. If you feel anxious or depressed lasting weeks or months, please speak to your GP. They will be able to advise you on different forms of treatment and sources of support in your community.

For further reading, we have provided a list of websites on page 19. These resources will provide more information and support about recovering from critical illness and signpost you on how to access psychological support.

I have bad dreams or nightmares about being in CCU - what can I do?

Some patients have bad dreams or even nightmares in CCU that may continue for a few days or even weeks after they have left CCU. The dreams may be unpleasant, but can also be frightening or upsetting, as they are so vivid that they seem real.

The experience of vivid dreams in CCU is very common. This is often due to delirium or confusion as a result of being critically ill. For example, this could be due to infection, kidney or heart failure, or as a side effect of the strong medications used in CCU, such as painkillers or sedatives.

The experience of vivid dreams is usually temporary, lasting a few days to a week, but can be very upsetting for some patients. Worrying about bad dreams can stop patients going to sleep at night, making them more tired in the daytime, which affects their recovery. You may benefit from talking about your dreams to family, friends, or a member of staff.

There is a booklet on delirium written by ICU steps. Please ask a team member about how to access this booklet or see page 19 for details on the ICU steps website.

Talking to the CCU doctors and nurses can help to fill in 'gaps' in your memory about what happened. They can also answer any questions you might have about your treatment and care in hospital.

I have flashbacks or upsetting memories after traumatic events related to being critically unwell

Some patients may have experienced traumatic events relating to their experience of becoming critically unwell.

For example, they may have had a serious accident, suddenly become unwell due to a serious illness or infection, or had complications during surgery.

In the days or weeks following stressful or traumatic events, it is completely usual to experience flashbacks or upsetting memories, and to feel upset, tearful or scared. About one in four people (25%) will experience reactions like this, following a very stressful or traumatic experience.

In most cases, memories of traumatic events will gradually fade. Talking through your experiences can help to make sense of, and process these memories.

Sometimes people prefer to talk to one or two people who are close to them, or to a healthcare professional or psychologist, trained to support people who have experienced traumatic events.

It is okay to tell people if you don't want everyone to ask you about your experiences. Talking about these experiences can be upsetting and make you feel like you are 'reliving' these all over again. It can sometimes be helpful to prepare a short 'script' to tell people so they know how best to support you. For example: *'I really appreciate that you have asked about what happened, I was very ill and am not ready to talk about everything that happened yet as I need to focus on my recovery. I have great support from the hospital team. Is it ok if I let you know when I am ready to talk?'*

Things you can do if you experience flashbacks or bad dreams:

- Remind yourself that these experiences happened in the past, and that you are safe now
- Calm your breathing by taking slow deep breaths in while counting to 5, then breathe out slowly while counting to 5

- Focus on something neutral in the room (a painting, the view from the window). Try to describe it to yourself in as much detail as possible (what colours/textures/patterns/images do you see).

Do I have PTSD?

Post-traumatic stress disorder (PTSD) is a mental health condition that can occur after traumatic events such as a life-threatening illness. PTSD symptoms include:

- Re-experiencing the trauma through vivid and distressing memories or dreams
- Avoiding situations that remind you of the traumatic event
- Feeling emotionally numb or detached as if the event happened to someone else
- Feeling on 'constant alert' - watching out for new danger.

Many of these symptoms get better in time with support from family and friends. It is important to talk to your GP and seek help if these symptoms are troubling you.

Further information about PTSD and how to access help is provided on page 22.

I'm feeling guilty - why?

Some survivors of critical illness experience guilt and worry about the impact that their CCU stay has had on friends and family.

It is important to be open with one another and discuss your thoughts and feelings. You have all experienced critical illness from different perspectives and there is no need to feel guilt.

Some patients find it helpful to talk to others who have had similar experiences. The ICU steps charity runs online forums and support groups for patients (see page 19 for details).

Patients may also wish to attend one of the focus groups the CCU team run for patients and relatives once they are back home. Please contact the CCU team for more information about these.

I look different - why?

You may experience some changes in your appearance, for example, hair loss or weight loss. These are quite common after critical illness but improve as you continue to recover.

The skin on your hands and feet may become dry and shed. These changes are temporary. Moisturising your skin regularly can help to stop this.

Your nails may develop ridges where the nail stopped growing when you were ill, and then restarted again during recovery. These ridges will grow out with time.

You may have some scars from surgery or drips. Scars can sometimes be treated with massage and laser surgery. Your GP can help with this, should you wish.

Memory problems

I do not remember my stay on CCU - why?

Some patients leaving the CCU may have little or no memory of being on the unit. Asking your family and friends about what happened can help to 'fill in the gaps'.

The CCU team can provide you with information about what happened to you during your CCU stay. The nurses who looked after you in CCU may also have kept a diary to help with this. Patient diaries are usually kept for patients who have been on a ventilator and sedated for more than 48 hours.

I am having trouble with forgetfulness or concentration – why?

During your recovery you may have trouble with short-term memory, confusion and difficulty concentrating. This can be due to the medication you may have received while in the CCU.

Asking a friend or relative to keep a note of any important information or questions you have about your illness or treatment can help during your stay. In most cases this should also improve with time. If this does not improve within a few months, please speak to your GP who can refer you to have these problems assessed.

Patients who have had strokes or brain injuries may experience longer-term problems with memory, concentration or problem-solving. You may be offered assessment or rehabilitation by a specialist team during your hospital stay, or once you get home.

Speaking and eating

Why has my voice changed?

You may find your voice has become husky or very weak. This is probably because you have had a tube inserted into your windpipe to help you with your breathing.

This may irritate the throat and vocal cords making it difficult to swallow and talk. In time this should improve. However, if you are having problems with your speech and swallowing, the speech and language therapist will work with you to help improve this.

Food tastes different - why is this?

Getting better depends on eating well. It is very likely that you were fed through a tube into your stomach or via a drip into your vein while you were on CCU.

As a result of this, you may find that you have lost your appetite, your mouth may be sore and food may not taste the same. It may taste metallic, saltier or sweeter than usual.

It is important to remember that this is only temporary and it is best to concentrate on foods that you do like and leave the ones that don't appeal for now. You can try them later on when your taste is back to normal.

You may find it easier to eat small meals and have nourishing snacks in between if you get hungry. Remember 'little and often', and have 5–6 small meals or snacks, rather than 2–3 larger meals. Choose nutritious drinks such as milk and do not fill up on tea or coffee. Remember that drinking before a meal can fill you up. You can see a dietitian for more help with this.

Take your time, eat slowly and relax afterwards. If you have lost interest in food, think of a food where the smell or sight of it usually makes you look forward to tasting it, then try a small portion.

If you are still struggling to eat and drink enough when you leave CCU, a dietitian can come and see you on the ward. If you need help to eat and drink, please ask your friends, family or nursing staff to help you.

Sometimes I pass small amounts of urine before I get to the toilet - when will this stop?

Many patients with critical illness require long periods of bed rest and urinary catheterisation (this is where a tube is used to collect urine from the bladder).

Long-term use of a catheter can lead to urinary incontinence ie. the loss of urine without being able to control it.

This is because both the muscles and the signals that control your bladder become weak from not being used.

Symptoms may include increased frequency, which is the need to urinate too often during the day, or stress incontinence, which is the leakage of urine with effort (jumping, sneezing or coughing).

Incontinence may improve as you get stronger and begin to move around more, but pelvic floor exercises may also help.

If you are still concerned, you can ask for advice from your physiotherapist or ask your GP for advice from a specialist physiotherapist.

I would like to resume my sexual relationship with my partner - will my illness affect this?

It's normal to be worried about when it's safe to start having sex again. Your partner may share these worries.

You may be concerned about the following:

- Will my scars be healed enough?
- If I have to use a medical device, such as a colostomy bag, catheter or pacemaker, will it get in the way?
- Will I hurt or ache too much?
- Will I have the strength?
- What if my partner does not want to have sex?
- What if I cannot continue or cannot reach an orgasm?
- What will happen and how will I feel?

If you're worried about your strength, compare the energy needed for sex with the energy you need for your exercises. If you're coping well with your exercises, you may be able to cope with sex.

Sometimes, medical problems such as impotence can also affect your sex life. If you're worried, please talk to your GP. Most people find it difficult to talk about sex, but try to relax and keep an open mind.

Support

Sometimes as a patient or carer, you need to talk to someone who has been through the same experience as you. This may make you feel less isolated and give you hope that what you are experiencing is normal and will get better. In this section we identify what we do on the unit and provide a list of useful contacts.

Critical Care Follow-Up Clinic

The Critical Care Follow-Up Clinic at The Royal Marsden is run by senior Critical Care Nurses. If you have been a patient on the unit for five days or more, we will contact you. If you have experienced delirium, we will also contact you. The aim is to find out how your recovery is progressing and to address any concerns or issues during your stay. The nurse will complete a health assessment, arrange any referrals that you may need, and help you plan for the future.

After your initial review you might feel that a visit to Critical Care Unit is beneficial and this is something we can arrange for you. If you had a patient diary completed, we will go through this with you over the phone.

If you have any questions about any aspect of your stay or would like to get in contact with CCU, please get in contact via email: CCUFollowUP@rmh.nhs.uk

Contact details

For further information about the critical care follow-up clinic or any other queries about critical care, you can contact:

CCU Follow-Up Team

Tel: 020 7352 8171 Ext 1639

Email: CCUFollowUp@rmh.nhs.uk

Social Work Department

(for benefits advice and support available)

Tel: 020 8661 3386 or 020 7349 9618

Alternatively, please call:

The Royal Marsden Macmillan Hotline: 020 8915 6899
(available 24 hours a day, 7 days a week)

Call us straight away if you are feeling unwell or are worried about the side effects of cancer treatments.

This service provides specialist advice and support to all Royal Marsden patients, as well as to their carers, and both hospital and community-based doctors and nurses caring for Royal Marsden patients.

Further support

Listed below are self-help groups and support groups in the community that you and your family may find useful once you have left hospital.

ICUsteps

ICUsteps is the UK's only charity dedicated to providing information and support to patients recovering from critical illness during their long recovery.

Website: www.icusteps.org

Asthma + Lung UK

A charity dedicated to improving the health and wellbeing of people in the UK whose lives are affected by asthma.

Helpline: 0300 222 5800

Website: www.asthmaandlung.org.uk

British Heart Foundation

A charity that gives information and support on the health of your heart. BHF also has an online community to connect with others.

Heart helpline: 0300 330 3311 (for medical enquiries)

Website: www.bhf.org.uk

British Association for Counselling and Psychotherapy

BACP provides details of counsellors and psychotherapists in your area.

Phone: 01455 883 300

Website: www.bacp.co.uk

Carers Trust

Carers Trust is the largest provider of support services for carers in the UK.

Helpline: 0300 772 9600

Website: *www.carers.org*

Citizens Advice

The Citizens Advice service helps people deal with their legal, money and other problems by providing free, independent and confidential advice.

Advice line: 0800 144 8848

Website: *www.citizensadvice.org.uk*

Critical Care Recovery

A website created by researchers, patients, family members, and healthcare staff, based on over 120 interviews with former intensive care patients and relatives at different stages of recovery.

Website: *www.criticalcarerecovery.com*

Diabetes UK

The largest charity in the UK for the care and treatment of people with diabetes.

Helpline: 0345 123 2399

Website: *www.diabetes.org.uk*

Healthtalk

This covers a wide variety of personal experiences of health and illness. It includes video interviews of people who have been through different illnesses and includes sections for intensive care patients and their relatives.

Website: *www.healthtalk.org*

Stroke Association

An organisation that provides support and information on strokes and guidance on coping with life after a stroke.

Helpline: 0303 3033 100

Website: *www.stroke.org.uk*

UK Sepsis Trust

The Trust promotes awareness of sepsis and provides support to those affected by it.

Phone: 0800 389 6255

Website: *www.sepsistrust.org*

Emotional and mental health support

Psychological therapies, also known as ‘talking therapies’, are free on the NHS and can be accessed from your local community mental health service. You can be referred by your GP or many services accept self-referrals. Check the NHS website www.nhs.uk/nhs-services/services-near-you to locate your nearest service.

Mind is a national mental health charity which provides advice and support to people experiencing mental health problems. Their website www.mind.org.uk offers lots of useful information on mental health problems such as depression, anxiety and PTSD, including how to access help and support.

How to get help in a crisis or emergency

If you feel like you might attempt suicide, or may have seriously harmed yourself, you need urgent medical help. Please:

- Call 999 for an ambulance
- Go straight to A&E, if you can
- If you can keep yourself safe for a short while, but you still need urgent advice: contact NHS 111.

Samaritans

Samaritans provides confidential, emotional support, 24 hours a day, for people who feel distressed, desperate or suicidal.

Helpline: 116 123

Website: www.samaritans.org

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References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

Telephone: Chelsea 020 7811 8438 / 020 7808 2083

Sutton 020 8661 3759 / 3951

Email: patientcentre@rmh.nhs.uk

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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