

Patient information factsheet

Recovering after intensive care

This factsheet is a guide to your recovery after a stay on one of the intensive care units (ICUs). We hope it helps to answer some of the questions you may have throughout your recovery, both on the general ward and also later at home. At first, you may struggle to read more than a paragraph or two, so we suggest looking for a section that relates to you now or asking a relative or friend to read it to you.

While you were on the ICU

It is a huge step in your recovery that you are well enough to be leaving the ICU. You may have:

- no recollection of your time in the ICU or even the days before your admission, or
- clear or patchy memories from when the sedation was reduced. For example, you may recall:
 - being unable to speak due to the breathing tube
 - various therapy sessions
 - strange dreams or delusions.

Leaving intensive care

We know that leaving intensive care can feel daunting, so we have tried to give you as much information as possible in this factsheet about what to expect throughout your recovery. We also understand that this may be a worrying time, so please see the end of the factsheet for where you can get further support.

Once you are on a general ward, a member of the critical care outreach team may visit you depending on how quickly you are recovering and which ICU you were on. This team reviews patients' progress and makes sure that the move to the new ward goes smoothly.

Where possible, the therapy team will work alongside the ward staff to continue your ongoing rehabilitation plan, increasing your strength and getting you mobile again. It is likely that your muscles will be extremely weak and your joints will be stiff after being in intensive care and you may find it hard to do even simple tasks or movements when you first arrive on the general ward. The therapy team may give you an exercise programme to help with this.

The therapy team will also encourage you to take an active role in looking after yourself, such as getting washed and dressed in your own clothes. This will increase your independence as you progress towards going home.

The therapy team will continue to work with you, as needed, until you are fit enough to be discharged to your own home, a rehabilitation unit or to your local hospital.

Common physical symptoms after a stay on the ICU:

- shortness of breath
- fatigue (extreme tiredness)
- muscle and/or nerve weakness
- weight loss
- poor appetite or weak swallow
- quiet or hoarse voice (when your voice sounds breathy, raspy or strained)
- hair loss
- taste changes
- skin changes
- persistent cough (particularly if you had pneumonia or COVID-19)
- stiff joints

Common psychological problems after a stay on the ICU:

- vivid dreams or delusions from the ICU
- guilt
- struggle with 'losing' time while sedated
- poor sleep
- unable to process complex thoughts
- delusions
- poor concentration or memory
- feeling low or anxious
- weird dreams

Caring for your mind

As you recover from your illness, it is common to experience many of the problems listed above. This is normal at this stage and will improve over the months ahead.

Many people experience vivid dreams and hallucinations while they are in intensive care. These may be frightening or bizarre and you may find it difficult to differentiate dreams from reality. These usually stop before you leave the ICU but in some cases, they may continue for a while on the general ward. Please be aware that the memory of these dreams may remain 'vivid' for many years to come.

You may find it helpful to download some of the free apps recommended below onto a smart device to use at home:

- Calm (sleep and meditation)
- CaringBridge (a safe, secure place for you or a relative to easily provide your wider network of family and friends with updates about your recovery, saving you time and energy)
- Headspace (mindfulness)
- MyPlate (track daily calories, exercise and more)
- NHS Couch to 5K (exercise progression)
- Peak (brain training)
- Rise Up + Recover (diet, mood, nearby help, resources, exercise, emotions and custom reminders to inspire you)
- Stay Alive (a suicide prevention resource)
- WellMind (NHS mental health and wellbeing app to help with stress, anxiety or depression)
- What's Up? (mental health app to help you cope with depression, anxiety, anger and stress)

Call 4 Concern (C4C) service

If you are concerned that your clinical condition has worsened (also known as 'clinical deterioration') while you are on the ward, speak to the ward nurse caring for you.

If you do not feel your concerns have been addressed, ask to speak to the nurse-in-charge.

If after speaking to the nurse-in-charge you still feel that your concerns have not been resolved, you, or a relative or friend, can call **023 8077 7222** and ask to speak to the 'Call 4 Concern team'. A member of the C4C team will listen to your concerns and ensure that the correct person assesses your condition, attempting to resolve your concerns within an agreed time frame.

Leaving hospital

When you are close to leaving hospital, your therapist will aim to meet with you to discuss ways in which you can continue to work on your rehabilitation once you leave hospital.

Everyone takes a different amount of time to fully return to their normal level of function. Be prepared that full recovery may take six to 12 months. Use the last page of this factsheet to write down some goals for when you get home.

Eating well to get better

It is important to get as much energy, protein and nutrients from your diet as possible, as this can help speed up your recovery.

After your illness, you may experience a variety of side effects, such as changes to your sense of taste, pain in your mouth or throat, and feeling full quickly, which may affect the amount you can eat.

To make sure you are eating enough:

- you should aim to have two to three snacks between meals
- you should choose high-energy and high-protein options
- you may need to have 'build-up' drinks that contain extra vitamins and minerals
- you may need to choose softer foods
- you may need to experiment with flavours

The amount of fluid you drink is also very important. We advise drinking six to eight glasses of fluid a day. Hot drinks, water and squash all count. To help you stay on track, we recommend setting yourself a fluid target to aim for by the end of the day.

You may have been seen by one of the dietitians in the therapy team. If you have not and you are struggling with any aspects of eating or drinking, please speak to one of the staff on your ward. If you have left hospital, you can ask your general practitioner (GP) for advice or request a referral to a dietitian. For further information, you can also visit the ICUsteps website or email the ICU recovery team (see next page for details).

Work and financial support

Recovering from illness can be stressful at the best of times. It is a different experience and a different time frame for everyone. You may experience some changes to your physical, mental and emotional abilities, which may affect your ability to look after yourself and your children, and return to work or to your hobbies.

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We know this process can be very difficult for families too, which can add additional stress to your recovery. You will be given a medical fit note to give to your employer to let them know how long you need to be off work. This note can then be reviewed by your GP if you need extra time. We also recommend that you have a phased or staged return to work (for example, reduced hours or days, or lighter duties for a while).

There are also a number of schemes that may be able to support you financially. You can find out more information about these from your GP, Citizens Advice Bureau or on NHS websites, such as the NHS Low Income Scheme. If you need any legal advice or assistance, ask a member of the hospital ward team or contact the legal firm 'Stewarts Law' for **free** advice. They can offer advice about welfare benefits, housing, financial or employment issues. To arrange an appointment with Stewarts Law, email: lrobinson@stewartslaw.com

Medicines advice

If you have any questions about your medicines after your hospital stay, please contact our medicines helpline on: **023 8120 6907** (Monday to Friday, 9am to 6.30pm) or email: medicinesadvice@uhs.nhs.uk

Who should I contact?

The recovery process is different for everyone and there are many different factors involved. If you have any questions about your recovery process or your condition while you are in hospital, please ask a member of the hospital ward team.

Once you are home, please contact your GP or you can contact the ICU recovery team with questions about your recovery.

If the condition of your health deteriorates significantly, please call NHS **111**, your GP or **999** if it's an emergency.

ICU recovery service

Going home or on to a rehabilitation ward can be scary for some people, as you are leaving behind staff who have got to know you and your condition. However, it is important to remember that this is a major positive step in your overall recovery from critical illness and the ICU recovery team is here to support you.

A senior nurse from the ICU recovery team may call you after you have been at home for a few weeks. The nurse will be able to provide information about your time on the ICU, offer support and answer any questions you may have about your recovery. If needed, the nurse may refer you for a video clinic appointment with the ICU multi-disciplinary team. If this is the case, the nurse will explain what this means for you in more detail.

If you have not heard from the ICU recovery team and would like some support, please contact the team using the details below.

ICU recovery team

Email: icurecovery@uhs.nhs.uk

Telephone: **023 8120 6116** (if this goes to voicemail, please leave a message with your name, date of birth and a contact number and a member of the team will be in touch)

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Peer support

Facebook groups: **UHS ICU peer support**

Online peer support is available from those who have been unwell on the ICU or have had close relatives affected by an intensive care stay.

Peer support meetings are run by the ICU recovery team and are held online and in person. These meetings allow past patients and relatives to share stories, give and receive support from each other and access healthcare staff if they have any ongoing concerns. Please email icurecovery@uhs.nhs.uk if you would like to join one of these meetings.

Useful links

The two websites below are run by the critical care community (previous patients, relatives and staff members) and can be very reassuring, as many other people and their relatives will be experiencing the same issues as you when you go home.

www.criticalcarerecovery.com

www.icusteps.org

ICUsteps 'Road to recovery – Critical care rehabilitation guide'



www.icusteps.org/rehabilitation/critical-care-rehabilitation-guide

If you have had cardiac issues or cardiac surgery, you may find the following website helpful:
www.bhf.org.uk

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Individualised recovery plan

Goal	Action plan	Completed by: (MDT)

Additional information as required (chair exercises, bed exercises, exercise regime)

Physical:

Non-physical:

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **patientsuppothub@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**