

Leaving Critical Care: your ongoing care and recovery



Information for patients

This booklet contains information for you and your family about your transfer from the Critical Care Unit. It also contains advice on any concerns you might have, now you are getting better. Not everyone will experience all or any of the signs or symptoms described in the booklet; the intention is to provide you with as much information as we can to ensure that your physical and psychological recovery is as successful as possible. Please speak to your doctors and nurses if you have any questions.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.

Ensuring your safety is our primary concern.

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How the Critical Care team will help you

You are being moved from the Critical Care Unit (CCU) to a regular ward because your condition has improved and you no longer need the same level of care. This is a very positive step towards your recovery. Next, you will be discharged from hospital, either home or to a residential rehabilitation centre.

While you are at the PRUH, our Critical Care and Beyond (CCAB) and iMobile teams will continue to check on your progress and make sure you get the care you need. These teams of critical care nurses will help you to get ready for your journey from the CCU to the regular ward and then home. They can also visit you on the ward if you need support and advice.

When you move to the ward there will be a written plan that includes a summary of the treatment you have received while you were in the Critical care. This includes a plan for your on-going treatment and any necessary investigations plus your physical and psychological rehabilitation needs.

They will give this plan to the nurses on the regular ward to ensure you get the right care. Other members of the Critical Care team will be involved in your rehabilitation plan as well, such as doctors, physiotherapists, occupational therapists, dietitians and pharmacists.



Leaving Critical Care

Who decides I can be moved?

The Critical Care consultant and the consultant in charge of your overall care (i.e. medical or surgical teams) will be involved in making the decision to transfer you to a regular ward.

When will I move?

Once the decision has been made that you are ready for transfer, this can happen very quickly. If there is a delay in a bed being available, you will stay on the CCU but you will be monitored less closely and your nurse will look after other patients as well as you. They will also take out most of the lines used to check your blood pressure and to give you fluids.

What happens when I am moved?

A Critical Care nurse will come with you to your new ward and do a full handover to your new team of nurses to ensure you get the right care. This includes: a summary of your treatment while you were in the CCU

- a plan for your ongoing treatment and any tests you may need
- your physical and mental recovery needs.

Medication on discharge from CCU

Your regular medications may have changed during your stay in CCU. If you would like to discuss this with a pharmacist before moving or when you arrive on the new ward, please let us know.

Your care on the ward

Care provided by ward nurses

There are fewer nurses on this ward because you no longer need one-to-one care. There will always be a nurse nearby and you can use your call bell to alert them should you need help. The nurse may not come straight away because they will be looking after several other patients, but please be assured that help will come.

Care provided by Critical Care nurses

You will also be seen by the Critical Care nurses who are part of the specialist iMobile team. They check the care of patients throughout the hospital after they have left CCU. You will know who they are by their red uniforms. They will check your progress and can make recommendations about your treatment. They also advise the ward nurses.

If you have any concerns about your care, please ask to speak to the ward manager.



Your recovery and rehabilitation

How long will it take to recover?

After you leave the CCU the aim is to support your recovery and rehabilitation. This may take some time, but it is important to remember that everyone is different; although the steps you take may be small, they all count towards getting better.

How long you take to recover depends on several things, such as:

- how severe your illness was
- how long you were in the CCU
- the procedures and tests you had
- your pre-existing medical conditions
- how your body has coped with your illness.

It is normal to feel frustrated that you may not be able to get back to normal very quickly, but there are people you can talk to about this, such as the Doctors, Nurses and Therapists on the ward or members of the Critical care team.

How will you help me with my recovery?

To help with your physical recovery, while you are on the regular ward you may continue to have physiotherapy, occupational therapy and speech and language therapy, if needed. You may be given goals to work towards and these will be reviewed regularly. Plans will also be made with you about the next steps in your rehabilitation.

Once the medical team is happy with how you are recovering, your therapists will let you know if you need help with your recovery after you leave hospital.

You have two main options:

- **Rehabilitation centre:** If you still need some support with getting about, and your mobility is different to before you came into hospital, we may advise you move to a bed-based rehabilitation centre. This aims to help you get stronger and more independent and is a stepping stone to going home.
- **Rehabilitation at home:** If you are managing most of the things you normally would but you still have some goals you would like to achieve, we can refer you to have therapy at home to continue with your physical recovery.

CCU follow-up clinic and patient diary

We may invite you to a CCU follow-up clinic about six months after you have left hospital. This is a chance for you to talk about your stay and experiences, including talking through your patient diary, and following up on any medical or other problems.

Your patient diary aims to help you understand your stay on the CCU because you may remember very little about what happened. We asked staff and visitors to add to this diary when you were with us, to help you make sense of any time you may feel you have lost by being so unwell.

Getting back to normal life

Going home is a big step on your road to recovery but it may take a while to get back to normal life. You may have physical and mental changes which can make you feel depressed and frustrated, but these changes are usually temporary.

You may feel very tired, have little energy and a low mood, so try to set yourself small goals, such as making yourself a drink or taking a short walk.



Keep doing the exercises you were given by your physiotherapist but be careful not to overdo it, as this may set back your recovery.

Rest when you need to and put sleep and a good diet first.

Things you might feel

- Guilty for being ill and causing others to worry
- Upset and tearful
- Tired from lack of sleep
- Easy to lose your temper
- Forgetful
- Not very hungry
- Worried that you might get ill again
- Anxious about how long it is taking you to get better

How can I get help?

- **See your GP:** Your GP will be involved in your care after you leave hospital. We will send them a copy of your discharge letter, which explains your condition, the treatment you have had and your current care needs. If necessary, they can refer you to community services, such as physiotherapy and counselling.
- **Contact the Critical Care department:** If you need any more help, contact us and we will point you in the right direction. (01689864090)

Your daily routine

Activities: You may find you are more easily distracted and have a shorter attention span, and you might not be so keen on the hobbies and other activities that you used to enjoy. You may find it hard to read or to watch TV, although this will improve over time.

Visitors: Try not to get overwhelmed by visitors and family. They may be keen to see you, but it is important not to get too tired.

Work: You may not be well enough to return to full time work for a while. Talk to your employer and make plans for your return; perhaps see your colleagues to catch up on the world of work.

Relationships and family

You may find your family cannot understand why you feel differently about the activities you used to enjoy. Remember that they were very worried about you when you were ill, so they might find it hard not to do everything for you. It might help to talk things over with a trusted friend or relative. Your GP can refer you for counselling.

If you have young children you may feel under pressure to get back to normal as soon as possible, but try to focus only on the important jobs and let others wait. Take naps and ask friends or family for help.

Sexual relationships

You and your partner may be worried about when it is safe to start having sex again, particularly if you have scars, or a medical device such as a pacemaker, a colostomy bag or a catheter. Take things slowly, and talk to your GP about any medical problems such as impotence.



Your physical and mental recovery

You may have some physical and mental changes but these are often only temporary. Here we list some common changes you may notice while you are recovering and what you can do about them.

Physical changes

Hair loss: You may lose some hair or notice a change in its quality. This is common and should get better on its own. A good diet will help and you can also ask your hairdresser for advice.

Dry skin: Your skin may be drier than before you were ill and you may also feel itchy. Ask your pharmacist or GP for advice.

Bruising: You may have bruises from the drips or injections. These will gradually fade.

Scarring: You may have scars on your hands, wrists or neck caused by drips and injections. If you had a tracheostomy (a tube in your windpipe to help you breathe) you may have a scar on your neck. These scars will gradually fade and eating a healthy diet will help.

Speech: Your voice may have become husky or weak, particularly if you had a tracheostomy or were intubated (had a tube put into your windpipe through your mouth to help you breathe). You may also find it difficult to cough. This should return to normal over time, but if you are worried or keep having problems with your voice, then speak to your GP and they can refer you to the speech and language therapy team for advice.

Hearing: You may have hearing loss or your hearing may be more sensitive. This can alter your sense of balance and cause dizziness. Please see your GP for help if you have hearing problems.

Sight: Your eyes may feel gritty and/or sore. Your GP can prescribe eye drops to help with this. You may have some temporary changes to your sight, especially when you are tired. Talk to your GP about this. You may need to visit your optician to see if you need a new prescription. Being on a ventilator to help you breathe while you were in the CCU can change the pressure in your eyes, so tell your optician you have been ventilated in critical care.

Taste: You might have a metallic taste in your mouth as a result of some of the drugs that you have had. Food and drink may taste differently to how you remember them and your tastes may have changed. Your sense of smell, which is closely linked to taste, might also have changed. These changes are usually temporary and you should soon start to enjoy your food again.

Pins and needles: You might have pins and needles, usually in your hands and feet. This is very normal and may last up to 12 months. If it becomes painful, see your GP.

Problems going to the toilet: You will probably have had a catheter to drain your urine when you were unwell and it can take a while for your bladder get back to normal. Keep an eye out for signs of an infection, such as not being able to pee, a burning sensation when you pee or blood in your urine. See your GP if you have any concerns about going to toilet.



Exercise: Carry on with the exercises recommended by your hospital physiotherapist. Your strength and stamina will take some time to recover from illness, and you can expect to get slightly out of breath and to feel tired. Make sure you get plenty of rest as well. Gentle walks, swimming or stretching are all good activities that will help you to recover.

Sleep: Regular sleep is important to ensure your body remains healthy. You may find that your sleep pattern has changed. Once you become more active again your sleep pattern should settle down. Setting regular sleep and waking times can help. Milky drinks can help but avoid caffeine – found in drinks such as coffee and tea – near bedtime. Reading or listening to the radio can also help.

Smoking: If you smoked before you became unwell, now is a good time to try to kick the habit. Contact the NHS Smoking Helpline for advice, tel: 0800 022 4332.

Mental recovery

You may have little or no memory of your stay in CCU but you may feel confused about the events leading up to your admission and anxious about what you remember of what happened.

Some of the symptoms can include:

- vivid dreams/nightmares and sleep disturbances
- hallucinations
- flashbacks
- anxiety
- memory loss
- poor concentration.

Nightmares/flashbacks: You may have had hallucinations and nightmares while in CCU which were scary and made you very anxious. One cause can be the drugs you were given, which can lead to hearing or sight disturbances, making it hard to tell the difference between what is real and what is not. Waking up when you have been sedated can also leave you feeling very out of it. Although nightmares and hallucinations usually gradually stop, if they upset you, you may find it helpful to talk to your family or your GP about them.

Depression: It is normal to feel down while you are recovering. But if this does not go away and you are struggling to cope, it is important you see your GP. You may be depressed and your GP will be able to help.

Post-Traumatic Stress Disorder (PTSD): A few patients suffer severe symptoms of stress after critical illness. This is called Post Traumatic Stress Disorder (PTSD). If you think you might be suffering from PTSD, please see your GP, who can refer you for specialist treatment



How to eat well to help your recovery

Eating well and making sure you have the right nutrition is important for your recovery. When you were unwell you may have been given your food as a liquid through a tube put into your nose and down into your stomach, or by a drip into your vein. This can affect how you eat when you get home. For example, you may lose weight because you do not feel hungry, you have a sore mouth, food tastes different or it is painful to swallow.

Some ideas to get you eating well

Because you may not feel like eating much, you should add extra calories and protein to your diet to avoid losing weight. By doing this you can eat more calories without eating larger amounts of food. Here are some ways in which you can add calories and change how you eat, to help you get back to normal.

- Snack during the day, when you feel hungry
- Eat smaller portions
- Use full fat milk, cheese, butter and cream
- Eat ready meals and convenience foods
- If you are feeling sick:
 - ask someone else to cook for you, if possible
 - eat dry crackers and avoid greasy, fatty foods
 - avoid lying down straight after a meal
- If your tastes have changed:
 - make the most of the foods you do like and come back to others another time
 - use herbs/spices to enhance flavours
 - try refreshing, sharp-tasting foods such as fruit or boiled sweets
 - brush your teeth after eating

- When you are too tired to cook:
 - ask friends or family for help
 - try ready meals such as microwave meals and tinned foods.

What to drink

Make sure you drink regularly and try not to become dehydrated. If you do not drink enough you can become constipated, your skin can become dry, you will not be able to pee as much and this will all leave you feeling even more tired. Have regular hot drinks, water and squash. Try fortified drinks which give you extra nutrients.

When to see your GP

Talk to your GP if:

- you are having trouble getting back to your normal weight
- you have bladder or bowel problems
- you get severe indigestion

They may refer you to a dietitian for advice.

What makes up a healthy balanced diet?

Protein: This is essential for healing wounds, growing tissue, building muscle strength and fighting infection. Good ways of getting it include eating meat, fish, milk, cheese, eggs, beans and pulses.

Carbohydrate: Foods such as potatoes, bread, pasta, cereal and biscuits give you energy.

Fats: Foods such as butter, milk, cheese and cream provide energy and help you to put on and maintain weight.

Fruit and vegetables: These provide essential vitamins and minerals and include fresh/frozen/tinned fruit and vegetables and juices. You may also find it helps to take multivitamins.



Who can I contact with queries and concerns?

Critical Care

Princess Royal University Hospital

Tel: **01689 864090**

Other information

ICU Steps (intensive care patient support)

www.icusteps.org

Asthma UK

www.asthma.org.uk

British Association for Counselling and Psychotherapy

www.itsgoodtotalk.org.uk

British Dietetic Association

www.bda.uk.com

British Heart Foundation

www.bhf.org.uk

British Lung Foundation

www.blf.org.uk

Citizens Advice Bureau

www.citizensadvice.org.uk

The Colostomy Association

www.colostomyassociation.org.uk

Diabetes UK

www.diabetes.org.uk

Headway (brain injury charity)

www.headway.org.uk

Macmillan Cancer Support

www.macmillan.org.uk

Meningitis Trust

www.meningitisnow.org

NHS **111**

NHS non-emergency phone number

NHS Smoking Helpline

0800 022 4332

www.nhs.uk/smokefree

Samaritans

Tel: **116 123**

jo@samaritans.org

www.samaritans.org

The UK Sepsis Trust

www.sepsistrust.org



Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is in the main hospital foyer at PRUH and they would be happy to advise you.

Tel: **01689 863252**

Email: **kch-tr.palskent@nhs.net**

You can also contact us by using our online form at www.kch.nhs.uk/contact/pals

If you would like the information in this leaflet in a different language or format, please contact PALS on 01689 863252.



