

Booklet 2

Information for patients leaving the Adult Critical Care Unit

Information for patients and visitors



This booklet is designed to help you and your relatives during your recovery on the ward after your stay in the Adult Critical Care Unit (ACCU).

Discharge from Critical Care

Transferring to the ward can be quite stressful as you may have spent a long time on ACCU, but moving to a ward is a positive step in your rehabilitation journey.

As you started to improve on ACCU, you might have noticed there was less monitoring. This continues to reduce as you progress to the ward. You will meet new members of staff and be in a different routine. We understand that these changes can be unsettling.

You will have a new team looking after you which often includes physiotherapists, dietitians, pharmacists, speech and language therapists, occupational therapists and other specialist nurses.

When you are discharged from Critical Care, you will be referred to the Critical Care Outreach Team (CCOT). This means that a team of nurses who have a lot of critical care experience will follow you up on the ward to check that you are coping well without the higher level of critical care. This follow up will usually start the day after you have been discharged and will continue for as long as required.

Physical rehabilitation

After critical illness, it is common to find it difficult to do things you usually take for granted. You may need help with washing and dressing, moving in bed or getting to the toilet. It may be that you cannot get out of bed yourself or walk very far without help, especially if you have been ill for a long time. The two main reasons for this are:

- You may feel weak, tired and stiff because you have not been able to use your muscles while you have been ill.
- Increased activity may cause you more discomfort or make you more short of breath.

The physiotherapy team will continue to review you on the ward. They will ensure your chest remains clear and will monitor your breathing.

You will be given exercises to improve your muscle strength and help you get stronger. You may need walking aids such as a frame or stick as you recover to help you walk. Staff will be aware of what you can and cannot do and will assess how you progress.

You may be referred to an occupational therapist who will help with the functional tasks such as, washing and dressing. They will also be involved in ensuring you are safe to return home, when it is appropriate.

Discharge to the ward with a tracheostomy

You may return to the ward with a tracheostomy (a tube in a hole in your neck to help you breathe).

This will be cared for by the nurses on the ward, the physiotherapist, critical care outreach and other specialist staff. Hopefully it will be removed once your breathing muscles have improved.

During this time talking, eating and drinking may be difficult or you may be unable to do these things. This can be stressful, but with support and explanation we will help you and your family understand what we are doing for you and how we aim to remove this tube over a period of time. If required, we will give you aids to help you communicate with the healthcare professionals and your visitors.

Nutrition

Depending on what has been wrong with you, the nurses on ACCU and on the ward will know what type of diet you require and whether or not you can drink. Please ask if you are unsure.

If you can eat, you may find your appetite is slow to return to normal. This is because you may not have eaten much since you became ill. You may have been fed by a tube up your nose, into your stomach or via a drip into one of your veins. You may still need these now that you are on the ward.

You may find that food does not taste the same, particularly if you have been on a ventilator (breathing machine) for a long time. Common changes include a metallic taste in the mouth or food may seem sweeter than normal or have no flavour at all. This will settle with time.

Whilst on ACCU, to ensure you have no swallowing problems you may have seen the speech and language therapist, and may be given exercises to help with your speech and swallowing as you continue your rehabilitation on the ward.

Sleep

ACCU can be a busy environment including at night. With both your ongoing recovery and the critical care environment (the high noise levels, around the clock activity, artificial lighting, lack of normal routine etc.) you may have found it very difficult to sleep or at least get periods of good quality sleep. It is very common to have significant alterations to your normal sleep patterns with frequent awakenings, lighter sleep and possibly more sleep occurring during the daytime than at night. It can take time for your normal sleeping and waking cycles to return after being in critical care.

If you are still finding it difficult to sleep, once on the ward, please let someone know and we will try and find ways to help you.

Here are some useful tips.

- Create a morning and evening routine which signals your body to wake or rest. Asking family to bring in some comfortable clothes for you to wear during the day and toiletries from home.
- Eye masks and ear plugs may help.
- If eating and drinking, try and avoid caffeine later in the day.
- Try to avoid sleeping for long periods during the daytime. Sit out of bed if possible (you may require support with this from staff) and ask family to bring in any activities that might help to keep you alert during the daytime e.g. reading materials, music, puzzle books.
- Avoid screen time e.g. T.V, smart phones, and tablets before bed.
- Reading or listening to relaxing sounds or music may help you fall asleep. You may find sleep or relaxation/ mindfulness apps helpful.

The Sleep Charity (website: <https://thesleepcharity.org.uk/>) also has lots of useful tips and further advice.

Critical Care follow-up clinic

Many survivors of critical illness face a long and difficult recovery period. Physical and psychological problems, such as nightmares, anxiety and panic attacks are very common.

If you have spent more than three days on ACCU, you will be sent a letter one month after you have been discharged from hospital inviting you to attend our follow-up clinic.

Research has shown that a significant number of people who have had a critical illness may benefit from attending a follow-up appointment.

The one-hour appointment will provide you and your family or carer with an opportunity to discuss your experience with us and we will hopefully be able to answer any questions that you have about your illness or hospital stay.

It also offers us an opportunity to check that you are continuing to make good progress with your physical and psychological recovery. You will be offered the opportunity to see your bedspace.

Lastly it allows us to learn from you and your family, which in turn, will help us to continue to improve the care we provide for future patients and their relatives.

Clinics run on Wednesdays, with appointments at 10am, 12pm and 2pm, and are led by a nurse. When you book, you will be asked questions which will let us know which specialist members of our team to invite to support you best at clinic.

Support and resources to help your recovery:

- **Patient diaries**

A patient diary is given to a patient after discharge from critical care and is the patient's property. Patient diaries are a simple but valuable tool in helping patients come to terms with their critical illness experience.

Patients who've had a stay in critical care may be kept sedated for some time while they're mechanically ventilated. After discharge from critical care, they often report having gaps in their memory from their illness or they may remember nightmares, hallucinations or feelings that people were trying to hurt them.

To help fill this memory gap and help patients to understand what has happened we complete a patient diary. It is usually written directly addressing the patient. Diary entries are completed by the critical care healthcare staff and relatives.

Relatives are encouraged to also write about what is happening at home as there may be important events there that the patient is missing.

It is your choice when or if to read the diary. You can also choose to read the diary during your critical care follow-up appointment with the support of our critical care team members and your relatives.

- **Contact ACCU**

If you feel you are having problems, are not coping well once you have left, wish to visit the ACCU when you are feeling better, or you have returned home and wish to talk to someone, please ring us.

You may phone ACCU at any time on 01623 672268 to make any enquiries or ask questions, or alternatively you can contact the ACCU Family Liaison Team **Monday to Friday 8am to 4pm on 07584 331 934.**

- **Online resources**

ICU Steps: <https://www.icusteps.org/>



Further sources of information

ICU Steps: www.icusteps.org

Our website: www.sfh-tr.nhs.uk

King's Mill Hospital:

01623 672222

Newark Hospital:

01636 685692

Email: sfh-tr.PET@nhs.net

If you have any questions regarding your ACCU stay, you can contact the Critical Care Family Liaison Team on 07584 331 934, Monday - Friday 8am to 4pm.

Patient Experience Team (PET)

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PET@nhs.net.

This document is intended for information purposes only and should not replace advice that your relevant health professional would give you. External websites may be referred to in specific cases. Any external websites are provided for your information and convenience. We cannot accept responsibility for the information found on them. If you require a full list of references (if relevant) for this leaflet, please email sfh-tr.patientinformation@nhs.net or telephone 01623 622515, extension 6927.

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