Wrightington, Wigan and
Leigh Teaching Hospitals
NHS Foundation Trust

A Guide to Discharge from ICU / HDU

Patient Information

Intensive Care Unit

The Patient Information Leaflets page on the Trust website is available on the link: https://www.wwl.nhs.uk/patient-information-leaflets or scan the QR code.

Author ID: RW
Leaflet Ref: ICU 003
Version: 4
Leaflet title: A Guide to Discharge from ICU / HDU
Date Produced: September 2024
Expiry Date: September 2026

Introduction

Moving from the Intensive Care and High Dependency Unit is a positive sign, as it means that you are getting better. For some people however, this can be an anxious time. After you have been ill, especially for a prolonged period of time, it can take a while to feel like yourself again. How you feel and how long it takes to return to normal living will depend upon the type of illness you have had, and how long you were unwell for.

This booklet has been developed to help the transition from the Intensive Care and High Dependency Unit to the ward, and then from the ward to home.

It also identifies some common problems that patients may experience when they leave ICU/HDU. However, everyone is different, and you might not experience any of these problems at all.

It is divided into three sections:

Section 1: Moving to the Ward

This section gives you information on what will happen on your discharge to the ward and how the ward environment will be different from the critical care environment.

Section 2: Physical and psychological changes

This section helps you to understand why you might have certain symptoms after having a critical illness and will give you some reassurance about how to deal with them.

Section 3: Rehabilitation and follow-up

This section will give you guidance on physical rehabilitation and setting goals to aid your recovery. It will also provide details regarding the support available after your discharge.

Section 1: Moving to the Ward

It is quite normal to feel apprehensive about moving to the ward environment. You may have become familiar with the staff and routines on ICU/HDU and felt reassured by the number of staff based on the unit, as well as the continuous monitoring equipment used to observe you. It is very important that you are prepared for your move and feel reassured that you no longer need to be in the ICU/HDU.

Once the ICU staff and your consultant are happy with your progress, you will be transferred to a ward. The wards have fewer nurses, and more patients compared to the ICU. The change from having your own nurse to sharing a nurse can make you and your relatives feel apprehensive. You may also feel worried because you are leaving surroundings which are familiar to you. You are moving to the ward because your condition has improved, and you don’t need the same level of observation from staff and equipment.

Meeting new staff and other patients on the ward may also make you feel a little vulnerable. This is quite normal. The ward staff are used to looking after people who have been seriously ill and will help you all they can in your recovery. Please ask them questions and even if you cannot always see a nurse, there will be one close by.

You might not see your consultant every day, but the doctors will do a ward round at least once a day to check on your progress. Feel free to ask any questions you have during this time. If you need to see a doctor at other times, the ward team will contact them for you.

Some wards do have side rooms, but it is likely that you will be cared for in a bay with other patients. Your bay and bathroom facilities are single sex, which means that you will not have to share with a member of the opposite sex.

Outreach Team

This is a team of expert health care professionals who work across the hospital setting. They offer follow- up support and education for staff, patients and relatives of those who have recently stepped down from the ICU/HDU.

The Outreach team will visit you on the ward; this tends to happen within the first 24 hours of your discharge. The service is available to help you with the transition from HDU to the Ward. The Outreach Team ensures you continue to make progress and will highlight any issues that occur with your parent Consultant. The Outreach team can help answer your questions and hopefully relieve some of your anxieties.

About one third of patients have no recollection of Intensive Care. This is due to a combination of severe illness, sedation and painkillers. If you are one of these people, it can be very frightening to wake up in hospital and find out that you have ‘lost’ days or weeks of your life and had no control over what happened to you. You may also feel very weak and feel your appearance has altered. The staff on the ward will be able to tell you some of what has been happening to you, and it often helps if a member of the ICU staff or Outreach team comes to talk with you about that time, discuss your progress and answer your questions. You may have some memory of ICU, which is hazy, and incomplete; again, this is not unusual.

Patient Diaries

You may or may not be aware that during your time on ICU, a Patient Diary was commenced. We do this for everyone, regardless of whether you have been intubated (presence of a breathing tube) and ventilated or not. Often, memories of your time as a patient are limited for a variety of reasons, and your friends and family are the ones who will have a first-hand memory of this. The diary provides day to day entries and significant events that you have encountered whilst on the unit, written by staff caring for you. There is also a section for family and friends to document their feelings and thoughts during this time. The contents of the diary may be upsetting to read. Therefore, these diaries are not returned to you for approximately 3-6 months, and a scheduled time and place will be arranged for you to sit and meet with a member of staff who can answer any questions or queries you may have regarding your stay.

Getting up and Moving Around

On the ICU/HDU you may have been assisted to get out of bed and will have received physiotherapy on a daily basis. On the ward, your Nurses and Physiotherapists will gradually increase the amount of activity you do. A structured rehabilitation plan will be put in place, and you will receive therapy sessions during the week.

These sessions focus on improving your muscle strength and general fitness, as well as working towards independent activities such as standing, walking and climbing stairs. At first you may feel very tired, low in energy and may still need oxygen, but it is very important that you do your exercises. This will help you to get better quicker.

Clinical Psychology

Being on ICU/HDU can be a distressing and scary experience. It is common for people to feel worried, down or confused about what happened to them. Whilst you are in hospital, you may be seen by the ICU Clinical Psychologist. They can talk with you how about how you are feeling and give you some strategies to cope. If you feel this would be beneficial, ask your consultant or the Outreach Team to refer you.

Going Home

The Doctors, Nurses and Therapists will work with you to achieve your goals, so that you can leave hospital as soon as possible. They need to make sure that you are physically and medically fit enough to go home safely.

Sometimes, even if people are medically well enough to go home, they need more rehabilitation to reach their full potential. This may mean that they need to go into a specialist centre for further rehabilitation, or support packages will be arranged to support you at home.

Section 2: Physical and Psychological Changes

Time for Change

So far, whilst you have been in hospital, treatment has focused on your acute illness. This will change to focus on treatment, care and your rehabilitation and preparation for home. This may take several weeks, but your aim will be to move from dependence to independence.

When you have been ill, it can take some time to get back to feeling your normal self. Exactly how long this takes will depend on things like the length of time you have been ill, how much weight you have lost and whether your illness means you will have to change aspects of your lifestyle.

Activity, Tiredness and Exercise

It is quite common to feel very weak and tired after being critically ill. Whilst you were ill, your body took what it needed to survive from its stores in the muscles. This means that your muscles will be smaller, and you might have lost weight. This muscle loss happens faster for patients who have been on a ventilator.

During the time you were inactive in ICU, your muscles will have become weak and even a little movement may seem impossible at first. It will take time for you to build up strength again. When a joint has not been used for a while, it stiffens up, even in young people. This stiffness will ease as the joint is used more. Exercising the muscles will help, and the ward staff and physiotherapist will support your efforts and give you exercises to do. Setting short term, realistic goals for yourself will help you feel more independent. Gradually building up the amount of exercise you do is better than trying too hard one day and being unable to do anything the next.

It is not unusual to feel very tired after a serious illness; this will improve with time, but it is important not to spend all your time resting and sleeping either, as you will feel even less fit.

Remember - don't be too impatient. Even several months after discharge, you may feel tired compared to how active you used to be before your illness. Compare how you feel and your activity level week by week; this will give you a realistic impression of your progress.

Sleep

You may find you have difficulty getting off to sleep, or your sleep is broken. Your sleep pattern will have been severely disrupted and it will take some time to get back into your normal routine. If you are inactive during the day or need to nap in the day, you may find you cannot sleep so well at night. Increasing your daytime activity will probably make you more tired by the evening.

Tryptophan rich foods can help with sleep; herbal drinks e.g. chamomile or milk-based drinks, and a starchy snack may be helpful before bed, or a warm bath or shower. You may be having sleeping tablets whilst you are in hospital and may be still having them when you go home. If so, these are not intended for long term use, and you should discuss their usage with your GP. Do not worry if your sleep is disturbed for some time.

Vivid Dreams/Nightmares

Some people suffer with hallucinations, flashbacks or even nightmares during and following a stay in critical care. They can be very vivid and frightening. This is very common and is related to the medications used on the ICU/HDU, as well as the experience of being critically ill.

Some dreams seem so real that they are hard to separate from reality. It is important to talk about your dreams to family, friends or medical staff, so that you can separate fact from fiction. The patient diary may be helpful in this situation.

Some people may experience delirium. Delirium is common. About 2 out of 3 patients in ICUs get delirium. Seven out of 10 patients get delirium while they are on a breathing machine or soon after. Experts think delirium is caused by a change in the way the brain is working. This can be caused by:

- Less oxygen to the brain
- The brain's inability to use oxygen
- Chemical changes in the brain
- Certain medicines
- Infections
- Severe pain
- Medical illnesses
- Alcohol, sedatives, or pain killers
- Withdrawal from alcohol, nicotine

People who have delirium may not know that they are in hospital or may not recognise friends and family. They may feel convinced about the reality of the confused world that they are in. This can be upsetting and frightening for both the person having this experience and their relatives.

Delirium is usually temporary but can last from a few days to several weeks. You can read a factsheet about delirium on the ICU Steps website (details provided at the end of this document).

Mood Changes

Many people experience emotional changes as well as physical changes. You may feel irritable for no reason. Many people complain of varying moods; feelings can range from feeling happy at being alive to feeling worried that you may become sick again. This is a normal reaction to illness, and it will subside.

If you have been critically ill for a long time, you may feel that you are low in mood or even depressed. Sometimes it may seem that you will never get back to normal and progress is slow. Remember that critical illness may leave you weak and your body needs time to get back to being fit. It is important for you to be realistic about what you will be able to do for yourself. Do not set yourself targets that are too difficult to reach, as you may feel as though you have failed, and this will make you feel worse. Ask nurses, doctors and therapists to tell you what you can reasonably expect to be able to do. Try to be patient when you have setbacks. When you are at home, it is important to involve family and friends in setting targets or goals. They will often be the people who are best able to monitor your progress and encourage you.

Another extreme mood change is depression. It is not unnatural to feel low in spirits after illness and hospitalisation, but if you have a persistently low mood, unable to enjoy anything, not able to sleep and poor appetite lasting more than two weeks, you may be clinically depressed. It is important to be assessed by your healthcare team, because early intervention improves your ability to cope with your illness, and it reduces the recovery time. So, speak to your nurse, doctor or the outreach team if you are concerned about feeling depressed.

Memory

Some people leaving ICU/HDU have little or no memory of being on the unit. Asking your family and friends about what happened can help to ‘fill the gaps’. The patient diary is also a useful tool in remembering key events.

During your recovery, you may also have trouble with short term memory, confusion and difficulty concentrating. This is mostly due to the medication you have received on the unit. This should improve with time.

Concentration and attention may be reduced, and even small tasks may seem difficult to complete initially. Decision-making may also appear difficult but should improve over time.

Nutrition

Your appetite will no doubt have been affected by your illness and your body will have used some of its muscle and fat stores for energy during this time. If you are only able to eat a small amount of food, it is important that you should eat foods which are nourishing and will help to build up muscle rather than fat; you should eat foods which are high in protein and energy; eating smaller meals more often can help you to manage these changes in your appetite or the feeling of fullness that may occur very quickly. It is not uncommon to find that you have some degree of altered taste, and food does not taste as it should. This is usually temporary so keep trying

The dietician will review your requirements whilst you are in hospital and possibly when you return home.

It is very important to drink plenty of fluids unless your doctor has advised you to restrict them. You may find that specially prepared, nourishing milk-based drinks are more palatable than food at first, or they could be used in combination with a small amount of food.

If you wear dentures, you may find that they don’t seem to fit as well as they should. This may be due to generalised weight loss or gum shrinkage. A denture fixative may help until you are able to visit the dentist. Some dentists now do home visits, so it may be worth finding out about this facility if it will be a while before you can visit yourself.

You may have a feeding tube in your nose that leads to your stomach. This has been inserted because you have not been able to take food by mouth, either due to medical reasons or because you were sedated or too weak to eat. You may be starting to eat but may still require some supplementary food by the tube to keep you well nourished.

Intravenous nutrition (into your veins) is sometimes used when your digestion is not working as well as it normally does, and you are not absorbing enough nutrition from what you eat or can get through a feeding tube.

Usually, feeding into your veins is only used for a short time until you can start either enteral tube feeding (using a feeding tube into the stomach) or eating by mouth again.

Toilet Habits

Constipation and diarrhoea are not uncommon after illness and medication. Please let the ward staff know about any problems you may have or discuss the problem with your GP or pharmacist if you are having problems after discharge.

Changes in Appearance and Body Image

After a serious illness, you may look and feel different. The first time you see yourself in a mirror you may be shocked to realise how much weight you have lost, or other areas of your body may be scarred, discoloured or swollen. Obvious scars will fade in time and exercise and a healthy diet will improve the elasticity of your skin, speed up healing and restore your weight. The Outreach practitioners will be able to discuss any scars you may have. Small scars on your wrists and neck may be due to monitoring and drug lines that had been inserted during your critical time in ICU.

Skin

The texture of your skin may change. It is quite common to find that your skin has become much dryer than before; regular moisturising will help. After a serious illness, you may have lost a lot of weight all over your body, whilst other areas look swollen. Exercise and a sensible diet will help to restore your weight and shape.

Hair

You may experience hair loss and changes in the quality of your hair as a result of being unwell. It may take up to a year to recover. Tell your hairdresser if you are having this problem. They will advise you on how to improve your hair condition.

Hearing

You may notice some changes in your hearing. This may vary from some hearing loss or hearing that is extra sensitive or heightened. Sometimes your sense of balance is affected, and you may feel dizzy. If these problems persist, you can seek assistance from your GP.

Eyes

Your eyes may feel gritty and sore for some time. Lubricating eye drops or gel may help. You may experience some temporary vision changes, especially when you are tired.

Your Family, Friends and Relationships

Seeing you seriously ill and the uncertainty of the outcome has been a very stressful time for your relatives and friends. It is important that both parties try to appreciate each other's feelings. You may feel your relatives or friends are becoming a little over-protective of you and this may cause a clash of opinions as you try to become more independent. It is important that everyone tries to be patient. Set goals in discussion with your relatives and try to make them realistic.

Sexual relationships

Either or both of you may feel unable to resume a loving and sexual relationship for fear of causing some harm. This can result in a total communication and emotional block. Resuming sexual relations after illness can take some time, and both partners should feel comfortable with the timing. Sex drive is usually reduced after illness but will become stronger as the body recovers. Impotence in men is not uncommon, particularly after some major abdominal surgery. Your surgeon should be able to inform and advise you; do not feel too embarrassed to ask.

Smoking

If you smoked before your illness, now would be a good time to stop, particularly as you will have had a period without smoking. Smoking is a major killer and causes heart disease, strokes, bronchitis, emphysema and cancer, to name but a few diseases.
Your GP will be able to give you advice on how to stop smoking.

Going Home

Once at home you may find the first few weeks are euphoric, but this may fade; this is to be expected. Soon you will find that you are getting stronger week by week. Be patient with yourself - some days will be better than others.

As time goes on, the rate at which you improve will slow down and it will be harder to see changes happening.

Try to focus on the improvement there has been in the last two weeks, rather than how you felt and behaved before your illness. It may be beneficial to keep a diary to show yourself how you have made progress.

If you live alone or you or your family feel you will have difficulty with anything after discharge, please discuss this with the staff. Help is available in the community, and preparation for discharge is important.

It may be useful to have the telephone number of a friend or family member or your GP close at hand in case of problems.

Section 3: Rehabilitation & Follow Up

The following services are to help support you following your ICU stay. Should you need to contact the team about your follow-up, or you wish to access these services sooner, please email: **PostICU@wwl.nhs.uk**

Post ICU Clinic

If you have spent more than 4 days in the ICU or HDU, we aim to contact you within 3 months of your discharge home, to offer you an assessment in our Post ICU clinic. We will try to contact you by phone, but if we are unable to, we will send a letter asking you to get in touch if you would like to be seen.

Our clinic is held at Wrightington Hospital, and we aim to see how you are doing now you are back home, and if there is any further support we can give you. Your relatives are welcome to attend with you. Even if you feel OK at the time we contact you, you can contact us on the email **PostICU@wwl.nhs.uk** if at any point things change.

ICU Experience and Support Group

This group, in collaboration with a neighbouring ICU unit, was established to connect a core of ex-patients who have largely recovered from their ICU experience and are now able to share their experience with others to offer support.

The group takes place usually every 6 weeks, and you will be invited to attend for an ‘afternoon tea’ and informal support group session, to share your experiences with others.

Patient Diary Clinic

The Patient Diary Clinic gives you the opportunity to sit down with a member of staff and go through your patient diary. You will also be offered a visit to ICU/HDU. This can help process and understand your experiences.

You should be contacted by a member of staff approximately 3-6 months after your discharge; they will arrange a date and time for you to attend.

Psychology Follow-up Clinic

Being critically unwell is a distressing experience for both patients and relatives. It is common for people to feel anxious, frustrated, or low after an ICU stay. Sometimes, people find it challenging to process what has happened or make sense of their ICU delirium.

You may be invited to the ICU Psychology follow-up clinic 2-3 months following discharge. This is run by the ICU Psychologist, who you may have met whilst you were an inpatient. Appointments aim to give you an opportunity to talk about your experiences, understand how you have been coping since your discharge, and explore further psychological support if needed.

This clinic is open to both patients and relatives impacted by an ICU stay.

Rehabilitation Clinic

We run 3 rehabilitation clinics every Wednesday at Ashton Health Centre, WN4 9AZ. They consist of an exercise class, with a range of exercises designed to help improve your fitness, strength and exercise tolerance following your ICU stay, and also the opportunity to talk to others who have been through similar experiences to yourself.

Useful Contact Details

Wigan ICU/HDU	01942 822591
Wigan Post-ICU Support	PostICU@wwl.nhs.uk
Wigan Talking Therapies (self-referral)	01942 764 449 https://www.gmmh.nhs.uk/wigan-talking-therapies
ICU Steps	www.icusteps.com
The Samaritans	116 123 (from any phone) www.samaritans.org
Mental Health Urgent Response Team (Wigan)	0800 953 0285

Please use this space to write notes or reminders.

Comments, Compliments or Complaints

The Patient Relations/Patient Advice and Liaison Service (PALS) Department provides confidential on the spot advice, information and support to patients, relatives, friends, and carers.

Contact Us

Tel: 01942 822376 (Monday to Friday 9am until 4pm)

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Ask 3 Questions

Become more involved in decisions about your healthcare. You may be asked to make choices about your treatment. To begin with, try to make sure you get the answers to three key questions:

1. What are my options?
2. What are the positives and negatives of each option for me?
3. How do I get support to help me make a decision that is right for me?

How We Use Your Information

For details on how we collect, use, and store the information we hold about you, please see patient information leaflet, Ref. **Corp 006** How we use your information, this can be found on the Patient Information Leaflets page on the Trust website, see details on the front cover.

This leaflet is also available in audio, large print, Braille, and other languages upon request. For more information, please ask in the department/ward.

Call 111 first when it’s less urgent than 999.

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