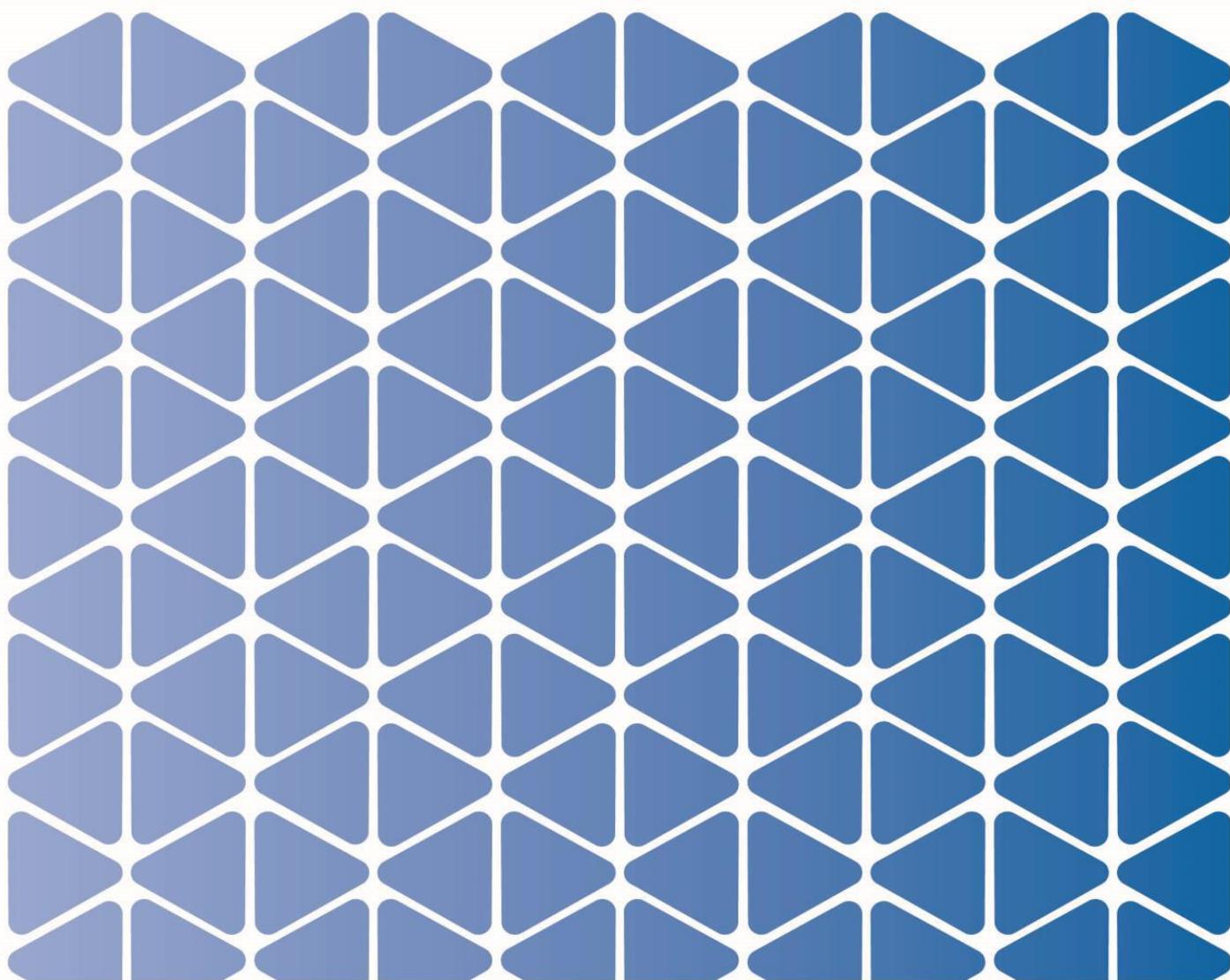




## PATIENT INFORMATION

# MOVING ON FROM THE INTENSIVE CARE UNIT



## **Introduction**

Following your stay on Intensive Care you will begin your recovery. This can be a difficult time for you and your family. This booklet is designed to help you understand some of the common problems that occur following critical illness. You may not experience any of the problems we describe, but the longer your stay on the Intensive Care Unit the more likely they are to occur.

Please remember that recovery can be a long and slow process and that it might be helpful to think about it in terms of months rather than weeks. It is usual to have good and bad days and to feel frustrated. The length of time it takes to recover will depend on many things including: how long you have been ill and how much weight you have lost.

You will probably feel exhausted and tire easily. This is normal; your muscles have been doing very little for a while and need time to build up their strength. The Physiotherapists will continue to support you in your rehabilitation. You will need to find ways to keep motivated and focusing on better times ahead can be helpful.

## **Leaving Intensive Care**

Although you may feel apprehensive about leaving the Intensive Care Unit, it is a really significant step in your journey to recovery. The decision to leave the unit is made by the Intensive Care Consultant in consultation with the rest of the team and the medical or surgical team who share responsibility for your care.

The Critical Care Outreach Team (experienced Intensive care nurses) will be made aware of your transfer and will review you before you leave the unit to ensure a good handover of your care between the Intensive Care Unit and the ward.

We know from our patients that one of the things they find most daunting is the change in the number of nurses that are visible on the ward. Please be reassured that the reduction in nursing staff is because you are ready to do more for yourself and become more independent. You will still be allocated a nurse, but they will have a greater number of patients to look after. You will have a call bell to use should you need attention.

Within 24 hours of your discharge to the ward a member of the Critical Care Outreach Team will come and assess you to see how you are feeling and to ensure that everything is okay.

During the first few days on the ward you might feel a bit strange or out of sorts whilst you adjust to the transition. Try to be positive and remember that you are at the heart of all we do.

It might seem unkind to keep pushing you to be more independent but we are trying to get you back to being as healthy as you can be.

A patient diary may have been kept for you on the unit; the nurses, doctors and perhaps your family and friends will have had the opportunity to write in it. Reading the diary may help you to understand what you have been through. It can be emotive, as it is so personal to you. It can be helpful to read the diary with a loved one and to talk through some of the things that may have happened to you when you feel ready.

If you have any concerns you can ask to speak to the Physiotherapist or the Critical Care Outreach Team.

## **Returning Home**

As with your discharge from Intensive Care, you will have been assessed thoroughly to ensure all of the things that you may need are in place. You are likely to experience mixed emotions about returning home and although the rate of your progress may sometimes be frustrating this is a major step in your recovery.

When you have been critically unwell even simple tasks can seem exhausting. You will get there, but please remember it can be a long and slow process. Keep doing the exercises the Physiotherapist has given to you. Some patients find it useful to keep a diary during this time.

Try setting yourself small, realistic tasks within your daily and weekly routine-to start with this could be as simple as making a cup of tea.

Once you are discharged home your GP will become involved with your care and recovery, so if you experience any problems please make an appointment to see them.

During your stay there may have been changes to your medication, your GP will have received a discharge letter from the Intensive Care Unit so they should be aware of what has happened and will be able to discuss this with you.

## **Nutrition**

You might experience poor appetite, swallowing difficulties, taste changes and weight loss. These are normal following critical illness. We have dietary advice sheets available. The rule of thumb is "little and often", most patients find a full plate of food very daunting. Loved ones often want to feed you up, and whilst their intentions are good this can have the opposite effect.

## **Sleeping**

Sleep is a very important part of your healing process, and many patients who attend our Intensive Care Follow-Up Clinic tell us their sleep pattern has changed; they find it difficult to fall asleep, have disturbed sleep or just don't feel rested when they rise in the morning.

Despite best efforts, the Intensive Care Unit is often a very noisy place to be, and very difficult for you to get good natural sleep. This can affect your internal 'body clock' and when prolonged can lead to sleep deprivation, confusion and disorientation. Just being ill and having to take certain medications can add to this problem and can lead to a delayed recovery. Disturbed sleep patterns may have led to you needing to sleep during the day or waking and remaining awake for the rest of the night.

The normal patterns of sleep take time to return, so when you finally get home, try not to worry too much – most patients find this improves over time. You should find that as you become more active in the day your sleep pattern will improve.

Being awake at night can be worrying, especially when you have been unwell. It is normal for post critical care patients to have these problems. If you still have problems, discuss them with your GP or come and talk to us at the Intensive Care Follow Up Clinic.

## **Body Image**

Since being in hospital, you may have noticed changes in your appearance. You may have lost weight and muscle bulk, both of which may change the way you look. Some patients get a degree of hair loss, change in hair quality or suffer from dry skin.

These problems are normally a result of being critically ill and not being able to have a normal diet.

These changes are almost always temporary and will improve over time. However, if you are concerned you should seek advice from your GP or the Intensive Care Follow Up Clinic.

You may also have some scars. Some of these will be from intravenous drips or drains. Others could be from having had an operation or suffering trauma to the body.

The appearance of scars can improve over time. It can take a while to get used to the changes in your appearance. If scars continue to bother or worry you, you can seek advice from your GP.

## **Stoma**

Many Intensive Care patients are admitted for post-operative care. Some bowel or bladder cancer patients' are booked for planned surgery and therefore prepared for the possible outcomes which may include the placement of a stoma or 'bag'. However, many patients require emergency bowel surgery and in some extreme cases those patients may not be well enough to understand what may happen to them.

For anyone the days after stoma surgery can be challenging. You have a pouch attached to your abdomen and lots of new things to learn. It's important to remember that it takes time to adjust, but it will get easier. With support from your stoma care nurse and practical guidance on how to change your ostomy pouch and care for your skin, you should soon be able to do the things you've always done.

If you are finding caring for your stoma a challenge, you can discuss this with the stoma specialist nurses.

## **Tracheostomy**

Some patients in Intensive Care have undergone a procedure called a tracheostomy. This is where a tube is placed into the windpipe (in the neck) through the skin. This helps patients to breathe and be more comfortable when being weaned from a ventilator (breathing machine). It will leave a wound in the throat, but this will heal to form a small scar and should not cause further problems.

If you have had a tracheostomy and have problems such as redness, itching and/or discharge from the site, the wound not healing, difficulty swallowing or narrowing of your airway, you must seek help from your GP who may feel it necessary to refer you to an Ear Nose and Throat Specialist (ENT).

## **Voice**

You may find that your voice has changed because of having a tube in your windpipe. You may get hoarse when talking, or your voice may weaken over the course of the day. This should improve a few weeks after discharge from hospital. If it doesn't, discuss it with your GP or at the Intensive Care Follow up Clinic. It may be necessary to ask for an earlier clinic appointment.

## **Mood**

Following a period of critical illness it normal to experience fluctuations in mood. Patients often report having good days and the next day feeling very low. You may also lose interest in things that would normally find interesting. You might feel more irritable, frustrated and find it difficult to concentrate.

Please be reassured that this is normal and that mood should stabilise over time. Remember recovery from critical illness can be a protracted process, but also that it is individual to you so you shouldn't measure your recovery against anybody else.

## **Post Traumatic Stress Disorder**

Some patients experience symptoms of persistent stress or anxiety following severe illness and intensive care treatment. These symptoms of 'Post-Traumatic Stress Disorder' (PTSD) include irritability, loss of concentration and memory lapses, low mood, withdrawal, disturbed sleep, nightmares, and flash-backs, being jumpy or having negative feelings about the future. You may experience some or all of these symptoms, but most find that the symptoms improve after a few weeks.

PTSD is when the symptoms described above are more severe and become overpowering. Perhaps the most worrying part of having PTSD is that frightening memories may flood and distract your mind without warning and when you are least prepared.

Some memories are mental pictures of very distressing events that upset you (intrusive memories).

They might only last a few seconds, and simply be re-occurrences of your intensive care experience, but these flashbacks can feel unbearable to some and may cause physical feelings, such as palpitations.

Over time these memories should become less vivid and gradually fade away. The other symptoms of post-traumatic stress should also bother you less.

If you find that the symptoms continue, are severe, or if you would like to discuss them, it is important that you seek professional help. Your GP can refer you to an appropriate service to help you.

Counselling has been shown to be of great benefit in these circumstances (see also the 'Help lines' section at the end of this booklet). You can also contact the Intensive Care Follow Up Clinic for more advice.

### **Families and Relationships**

Supporting a relative or friend through a period of critical illness can be a worrying and stressful time. Although their experience will be very different to yours, coping and coming to terms with your illness will take time.

You might find that they are over protective because they are worried about you. It is usually helpful to keep talking to each other.

Most people find it difficult to talk about sex. Following critical illness you may be concerned about resuming your usual sexual relationship for lots of reasons. If you are worried seek advice from your GP.

### **Employment, Hobbies and Socialising**

If you worked before becoming unwell you might find that your circumstances have changed after such severe illness. Many patients begin with a phased return to work; this may be worth discussing with your employer. The Occupational Therapist in the Intensive Care Follow Up Clinic will be able to advise you on this and give advice regarding financial concerns.

It is normal to find socialising more difficult after critical illness but hopefully given time you will feel confident to go out and enjoy the hobbies and activities that you used to.

### **Intensive Care follow up clinic**

You may be offered a clinic appointment depending upon the duration of your stay on the Intensive Care Unit. The clinic is run once a month. An Intensive Care Consultant and a Critical Care Outreach nurse will talk to you about any psychological issues you may be experiencing and give you the opportunity to ask anything about your stay on the Intensive Care Unit.

There will also be a Physiotherapist and Occupational Therapist to help you with any physical or mobility issues.

During your attendance to the Intensive Care Follow up clinic it may be suggested to you that attending the Intensive Care Support group could be beneficial to your recovery, an invite to the group would then be sent to you directly.

If we cannot help directly we can signpost you to the appropriate service or department, or liaise with your GP.

## **HELP LINES AND INTERNET SITES**

### **NHS Direct**

0845 46 47

[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

### **Patient Health Information**

[www.patient.co.uk](http://www.patient.co.uk)

### **British Heart Foundation**

020 7554 0000

[www.bhf.org.uk](http://www.bhf.org.uk)

### **Diabetes UK**

0845 120 2960

[www.diabetes.org.uk](http://www.diabetes.org.uk)

### **Asthma UK**

0800 121 6244

[www.asthma.org.uk](http://www.asthma.org.uk)

### **NHS Smoking Helpline**

0800 022 4332

[www.smokefreenhs.uk.co.uk](http://www.smokefreenhs.uk.co.uk)

### **British Association for Counselling and Psychotherapy**

01455 883300

[www.bacp.co.uk](http://www.bacp.co.uk)

### **British Psychological Society**

0116 254 9568

[www.bps.org.uk](http://www.bps.org.uk)

### **Oxford Cognitive Therapy Centre**

01865 738 816

[www.octc.co.uk](http://www.octc.co.uk)

**Samaritans**

08457 90 90 90

[www.samaritans.org.uk](http://www.samaritans.org.uk)

**Cruse Bereavement Care**

0844 477 9400

[www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

**Age UK**

0800 169 8787

[www.ageuk.org.uk](http://www.ageuk.org.uk)

**Alcoholics Anonymous**

0845 769 7555

[www.alcoholics-anonymous.org.uk](http://www.alcoholics-anonymous.org.uk)

**Terence Higgins Trust (HIV/AIDS)**

0808 802 1221

[www.tht.org.uk](http://www.tht.org.uk)

**Carers UK**

020 7378 4999

[www.carersuk.org](http://www.carersuk.org)

**Princess Royal Trust for Carers or Carers Trust**

0844 800 4361

[www.carers.org](http://www.carers.org)

**Cancer Care**

020 7242 0200

[www.cancerresearchuk.org](http://www.cancerresearchuk.org)

**Marie Curie Cancer Trust**

0800 716 146

[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

## **Macmillan Cancer Support**

020 7840 7840

[www.macmillan.org.uk](http://www.macmillan.org.uk)

## **Shelter Line (housing and homelessness)**

0808 800 4444

[www.shelter.org.uk](http://www.shelter.org.uk)

## **Disabled Living Foundation**

0845 130 9177

[www.dlf.org.uk](http://www.dlf.org.uk)

## **Telephone Helplines Association**

020 7089 6321

[www.helplines.org.uk](http://www.helplines.org.uk)

## **National Drugs Helpline**

0800 77 66 00

[www.talktofrank.com](http://www.talktofrank.com)

## **Headway**

A charity that supports people with brain injury and the people who care for them.

0808 800 2244

[www.headway.org.uk](http://www.headway.org.uk)

## **ICU Steps**

A registered charity run by ex-intensive care patients, relatives and ICU staff to support patients and families through the long road to recovery from critical illness.

[www.ICUsteps.org.uk](http://www.ICUsteps.org.uk)

## **Healthtalkonline**

A website covering a variety of personal experiences of health and illness. It includes sections for critical care patients and their relatives.

[www.healthtalkonline.org](http://www.healthtalkonline.org)

## **Lee Spark NF Foundation**

This is a charity and support group for people who have been affected by severe streptococcal infections or necrotising fasciitis (a rare and serious infection that causes skin and the tissues beneath it to die).

01254 87 87 01

[www.nfsuk.org.uk](http://www.nfsuk.org.uk)

**If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.**

## **Patient Experience**

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

## **Feedback**

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

## **Patient Advice and Liaison Service (PALS)**

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

## **How to contact PALS:**

**Telephone Patient Services: 0300 123 1732 or via email at:**

**[wah-tr.PET@nhs.net](mailto:wah-tr.PET@nhs.net)**

## **Opening times:**

The PALS telephone lines are open Monday to Thursday from 8.30am to 4.30pm and Friday: 8.30am to 4.00pm. Please be aware that a voicemail service is in use at busy times, but messages will be returned as quickly as possible.

If you are unable to understand this leaflet, please communicate with a member of staff.