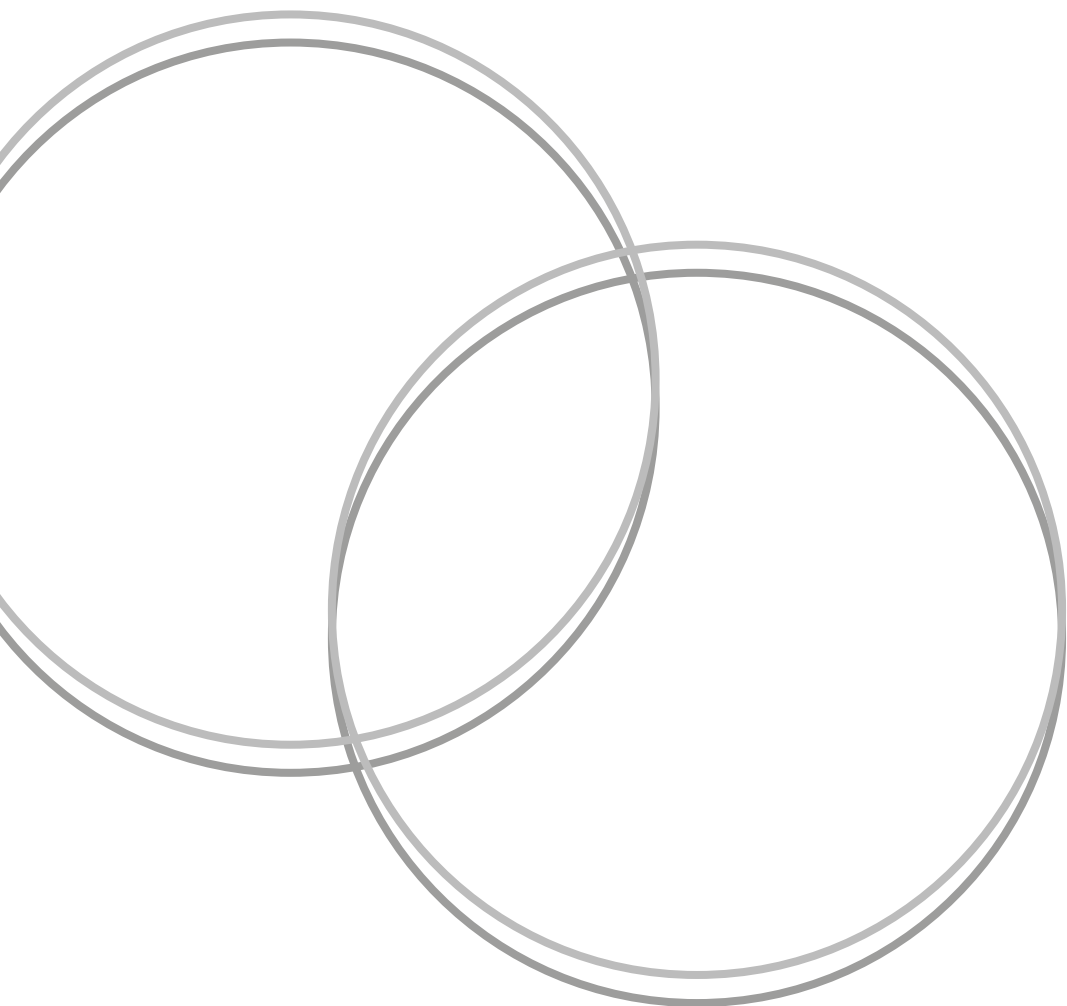




Oxford University Hospitals
NHS Foundation Trust

Life after critical illness

**Information for patients and
relatives who have been in
Oxford Critical Care**



Introduction

After you have been ill, especially for a long time, it can take a while to feel 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, as well as how long you were unwell.

This booklet deals with some common problems that people may experience when they leave Critical Care. However, everyone is different and you might find you do not experience any of these problems at all. If you do, we have tried to offer some ways of dealing with them, which we hope will be helpful to you and your family. Critical care includes both Intensive and high dependency care.

Please speak to your doctor or nurse if you have any particular worries or concerns.

Going to the ward

As your condition improves the decision will be made by the consultant that you are fit to be discharged to the ward. We appreciate that this may be an anxious time for you and your family, as you will have become familiar with the routine of the Critical Care. Try to view being fit for discharge from Critical Care as a positive step on your road to recovery.

In Critical Care there is either one nurse to each patient or one nurse for two patients. On the ward the nurses are never far away and you will be given a call buzzer to call them.

The doctors' rounds may be different to those in Critical Care. Do speak to the nurses on the ward if you or your family wish to speak to a doctor, so that they can arrange a convenient time for them to see you.

Questions commonly asked after a stay in Critical Care

I feel that I have no energy, why is this?

At the time of your discharge, the slightest activity can take tremendous effort and leave you feeling very tired. This tiredness is normal and will improve with time. During your stay in Critical Care you will probably have lost some weight and muscle strength, and you may lose some range of movement at your joints.

The most common physical problem reported by people who have been critically ill is severe weakness and fatigue. You will have lost approximately 2% of your muscle mass each day during your illness.

The only recommended way to recover and to get stronger is to walk and consider doing some exercise. "Little and often" is a good principle to follow, and gradually build up what you can do. It is difficult to place a timescale on recovery, as everyone recovers at a different rate. You should not be concerned if it takes weeks or even months to get closer or fully back to normal.

You will have started some during your rehabilitation (such as walking or arm exercises) while on the Critical Care. This will be continued by the ward physiotherapist, who will lead your rehabilitation. If you are given an exercise plan before you leave hospital it is important to follow this at home. If you experience problems that do not ease after a few days of exercising, you should go and see your GP.

As your strength returns, you may want to take more vigorous exercise, such as fast walking swimming, or cycling. Please speak to your doctor /GP or physiotherapist for more specific advice before returning to other sports activities.

Why can't I eat normally?

A dietitian will visit you regularly on the Critical Care Unit to review your nutritional needs. They will discuss this with the medical and nursing staff caring for you, to make sure you are getting enough nutrition to support your recovery.

Depending on your illness or injury, you may not be able to eat in the usual way. You may need to receive nutrition through a feeding tube (directly into your gastrointestinal tract), or intravenously (into a vein). The preferred way to provide nutrition is through a feeding tube, so that your gut can continue to work as it would normally. However, you may not be able to receive nutrition through a feeding tube, for example if your gut is not working. If this is the case for you, you can be fed intravenously.

Some people find it hard to swallow. A Speech and Language Therapist may come to see you. They can help by suggesting safer food and drinks. They may also give you some simple exercises to help your swallow get better.

When you are transferred to a ward you may be starting to eat normally but are likely to still need some supplementary food by tube or intravenously, to keep you well nourished. The ward dietitian will review your needs and you may be given high protein meals or foods/drinks, fortified with extra nourishment.

Why can't I sleep at night?

Whilst on the Critical Care you will have received care both day and night, which can alter your body's day and night routine. You may find you feel tired during the day and unable to sleep at night. Part of the reason for this could also be the effect of some of the medication you have been given. Problems with sleeping after you have left Critical Care are common and do get better with time.

You should find that as your activity levels increase, your sleep pattern returns to normal. The most important thing to remember is not to become too worried about lack of sleep – it will get easier to sleep; if it doesn't, mention it to your nurse , hospital doctor or GP.

I have been having bad dreams/hallucinations, is this common?

Yes! It is common for people to experience dreams and hallucinations related to their Critical Care stay following their discharge from Critical Care. These can seem very real and frightening.

If they continue, you may find it beneficial to visit the Critical Care to see where you were cared for. Please contact the Critical Care Team to arrange this with the Follow Up Clinic Nurse. This sometimes helps to make sense of the dreams you have been having. These dreams generally do disappear as time goes on. It is important to mention these to the ward team.

Why can't I remember my stay in Critical Care?

You may find you have no memory of your Critical Care stay. The medications which may have been used to keep you asleep can also affect your memory. Your family will be invaluable in helping to fill you in on the time that you have lost during your stay in Critical Care.

During the rehabilitation process after critical illness, patients often want to understand what has happened to them and fill in the memory gaps. Some patients find a written diary of their critical care stay helps.

Please ask your family member if they may have used a patient diary pack from the Critical Care. The patient diary is not part of the Hospital health care record but is a personal record of the things they think would you like to know. The diary is confidential. To ensure privacy, photographs are not allowed for the diary.

When will I look more like myself?

You may have noticed changes in your appearance – for example, hair loss or change in its condition, dry skin, weight loss. Now that your condition is improving, along with your diet and your normal patterns of self care, these problems should get better.

Your surgical scars may not have healed as neatly as you may have expected. This could be due to a combination of problems, such as the nature and seriousness of your illness, repeated surgery and infection.

These scars should fade with time and become less obvious, as your skin returns to normal and your general health and diet improve. If these scars continue to cause you some distress then speak to your GP.

Why does my voice sound so hoarse?

You may find that your voice has changed. It may have become husky or weak, so that you are unable to raise your voice or shout. This is probably the result of the 'breathing tube' that you may have had in place in Critical Care, but your voice should return to normal over time. If you have any lasting problems we can refer you to the Speech and Language therapists.

My family appear to worry about me more. Why?

You may find that your family and friends react slightly differently to you. For example, you might feel that they are overprotective towards you. They will have been through a very anxious and stressful time, from which they also need to recover.

They may be relieved that you are no longer in Critical Care, whereas you are perhaps just coming to terms with the fact that you have been very ill. It may be helpful to talk about these feelings with each other. This might help both you and your family come to terms with your period of illness.

Is it common to have such changes in my moods?

Many people suffer from changes in mood, such as irritability, tearfulness and lethargy. This is a normal reaction to being critically ill. It is important to accept that it will take time to recover both physically and psychologically.

You may find that setting small realistic goals helps you to see progress and feel better in yourself. You may also find that keeping a diary helps this process. It may be helpful to speak to the doctors, nurses and physiotherapists caring for you to find out what you can expect from yourself at this stage of your recovery.

I feel quite depressed, what can I do?

Depression can be a problem after a long-term hospital stay. There may be many changes that you are having to deal with, such as changes in lifestyle, appearance and your role within your family. It is important to talk with those close to you. If the feelings continue, please speak to your GP, who will be able to advise you on different forms of treatment and support in your community.

I feel stressed all the time, what can I do?

Feelings of stress are common after a prolonged illness. Symptoms of stress can include sleepless nights, loss of appetite, mood swings and changes in relationships.

These feelings should ease with time, especially as you begin to feel better and are able to do more. However, if these feelings continue then you may find it useful to speak to your GP. They will have information about local services and activities that may help you feel better.

Is there other support available to me and my family?

Your time in Critical Care and hospital, particularly if over a long time, may have given you and your family many causes for concern. It is important to use the various sources of support to help you all deal with these concerns.

At the back of the booklet there is a list of useful websites which you and your family may find helpful.

The hospital chaplains are also available to speak to you and your family, if you wish.

Life after discharge

Leaving Critical Care is a major step, but you may still not feel yourself, even when you have left hospital. This is not unusual.

It may take a considerable time before you are well enough to return to work. Your GP will continue to care for you once you are at home and will be able to tell you when you may be ready to return. If your place of work has an occupational health department then it is a good idea to speak to them, as they may have a return to work scheme after long-term or serious illness.

Many people worry about when it is safe to resume sexual activities. This should be gradual and will depend on how you are feeling.

You may find that you become tired very easily and that you need to take naps in the day and go to bed early. This is quite common and you should follow your body's needs.

You may be referred to a physiotherapist for on-going rehabilitation. This will be discussed with you before your discharge from hospital.

What is the ICU Follow Up Clinic?

The ICU Follow Up clinic is offered to patients who have been in either Oxford Critical Care or Churchill ICU for four days or more or have specific ICU related follow up needs.

The ICU Follow Up clinic team consists of an Intensive Care Consultant, a Psychiatry Consultant, a follow up clinic nurse, and a Physiotherapist. The aim of this service is to review your progress and recovery after your Critical Care admission and provide an opportunity to discuss any questions that you or your family have about your time in Critical Care.

How will I be contacted?

You will be contacted by the follow up clinic nurse by telephone to ask some screening questions following your hospital discharge.

The specialist nurse will feedback your progress and any highlighted issues from your screening call at our multi-disciplinary team (MDT) meeting where we will also review your medical notes.

Following the MDT decision, you may be contacted by letter from the critical care administration staff to invite you back to a face-to-face appointment in the ICU Follow Up clinic which we encourage you to attend. However, if you already have specialist input from other hospital services, an ICU Follow Up clinic appointment may not be required, but if you would value an appointment with the ICU Follow Up team then please let us know.

What should I expect at the clinic appointment?

The clinic appointment will last up to 90 minutes. You will speak to members of the ICU Follow Up clinic team. During these conversations, we will discuss if you need further support or referral onto other services.

How can I prepare for the appointment?

Some people find it helpful to write down any questions they may want to ask at the appointment. We welcome having a family member present at the appointment.

Please bring a list of your current medication.

Medicine

During your medical review with an ICU consultant, the focus will be ensuring your ongoing clinical recovery is continuing. This will include discussion with specialist services where relevant.

Physiotherapy

Following discharge from hospital, a physiotherapist will review your notes and if you are a risk of physical problems you will be contacted and assessed. Physical problems may include weakness, fatigue, difficulty performing activities of daily living, shortness of breath when walking or undertaking daily activities, or reduced balance. The physiotherapist will discuss with you how best you can be supported and often invite you to a face-to-face appointment, and to attend subsequent treatment sessions.

Please contact the Critical Care Follow Up Secretary if you have any questions about the Follow Up clinic.

Tel: **01865 740397**

Email: **criticalcarefollowupteam@ouh.nhs.uk**

Concerns

If you would like to discuss any issues relating to your stay on the Critical Care Unit, please contact the Matron on Critical Care:

Telephone: **01865 220 621**

Email: occenquiries@ouh.nhs.uk

Useful websites

ICU Steps

The Intensive Care patient support charity. The Steps leaflet is available in many different languages. ICU steps was established in 2005 and became a registered charity in 2006. Run by former intensive care patients and relatives we aim to improve the care and support available to patients recovering from critical illness during their long recovery.

icusteps.org

Faculty of Intensive Care Medicine

Recovery after Intensive Care.

www.ficm.ac.uk/forpatients/recovery-after-intensive-care

Critical Care Support Network

Established in 2016 via ICU steps Chester. The aim is to help all Critical Care patients and their families, make the best possible recovery from their illness. All sessions are held online.

www.cc-sn.org

Critical Care Recovery Service

Researchers, patients, family members, health care staff and website developers have come together to create this website. It is based on over 120 interviews with former Intensive Care patients and family members at different stages of recovery.

www.criticalcarerecovery.com

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

We are grateful for all those who have helped to devise this booklet.

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