NHS
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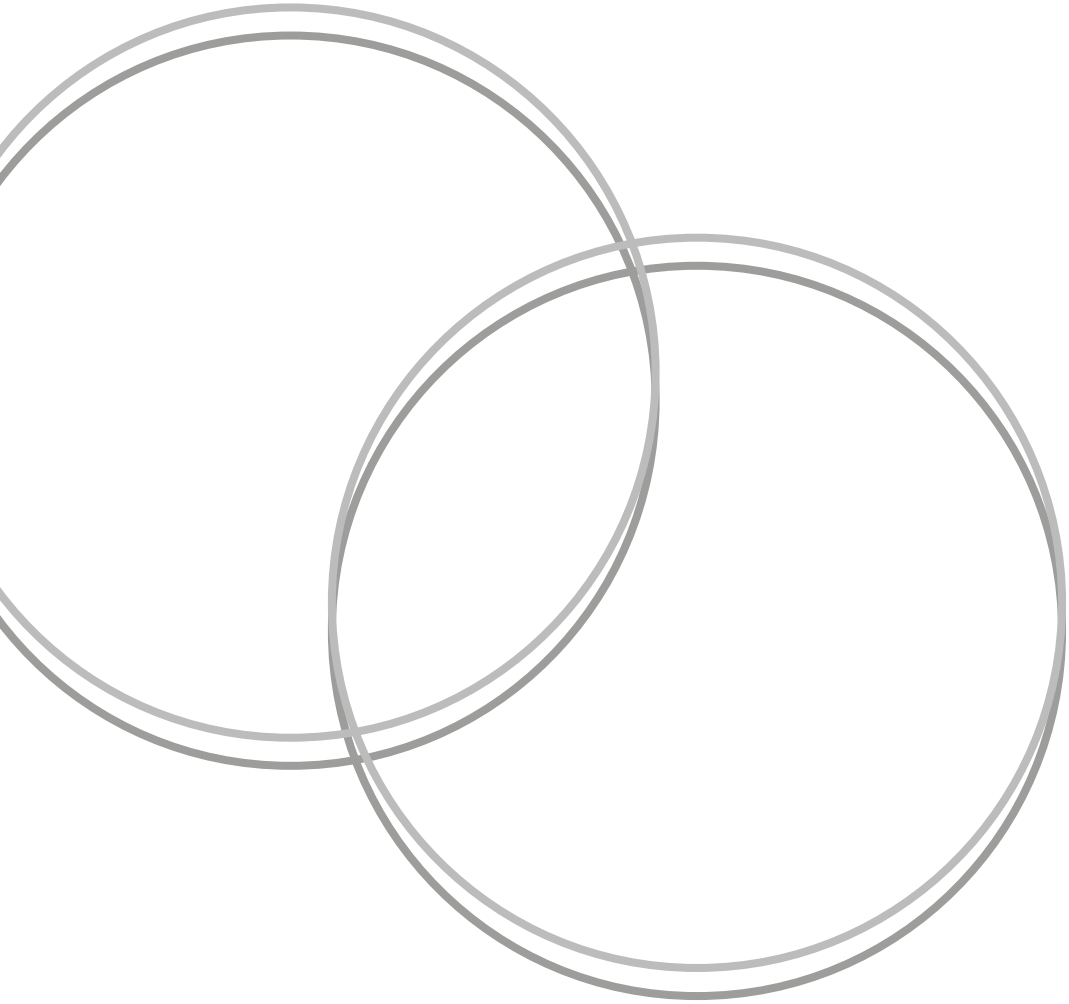
Life After Discharge from Cardiothoracic Critical Care Unit (CTCCU)

Information for patients



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 patients may experience when they leave intensive 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.

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 Cardiothoracic Critical Care Unit (CTCCU). Try to view being fit for discharge from CTCCU as a positive step on your road to recovery.

In CTCCU there is one nurse to each patient. 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 the Cardiothoracic Critical Care Unit. 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 intensive 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 CTCCU you will probably have lost some weight and muscle strength, and your joints may be stiff.

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 way to recover and to get stronger is to walk and exercise – "little and often" is a good principle to follow. 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 fully back to normal.

You will have started some exercise (sitting, walking, arm exercises) while on CTCCU. 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 swimming, fast walking or cycling. Please speak to your doctor/GP or physiotherapist for more specific advice before returning to other sports activities.

Why can I not eat normally?

A dietitian will visit you regularly on the Intensive Cardiothoracic Critical Care Unit to review your nutritional needs if required. 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.

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 I not sleep at night?

Whilst on CTCCU 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 drugs you have been given. Problems with sleeping after you have left the Cardiothoracic Critical Care Unit 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 Intensive Care stay following their discharge from CTCCU. These can seem very real and frightening.

If they continue, you may find it beneficial to visit the CTCCU. to see where you were cared for. This sometimes helps to make sense of the dreams you have been having. These dreams generally do disappear as time goes on.

Why can I not remember my stay in intensive care?

You may find you have no memory of your intensive care stay. This is one of the most common feelings after having an intensive care admission. The drugs which were 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 intensive care. If you would like to discuss how you are feeling, the staff can reassure you and make sure you get the help you may need.

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 distresss, 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 would have had in place in CTCCU, but your voice should return to normal over time. If you find this as a recurrent issue please contact your GP so they will be able to refer you to the pertinent specialist.

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 intensive 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 overcome 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 the Cardiothoracic Critical Care Unit 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 the Cardiothoracic Critical Care Unit is a major step, but you may still not feel yourself, even when you have left the 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.

Cardiothoracic Critical Care Follow-Up Clinic

The CTCCU Follow Up Clinic offers an opportunity for you to discuss your progress and recovery, particularly if you had a longer than expected stay in CTCCU. You will also be able to discuss any issues you or your family may have had since your discharge home. If you meet the referral criteria, a nurse will contact you 6 to 8 weeks after discharge home to book an appointment with the follow up team. If you feel that you would benefit from this service but have not been contacted, it is also possible self-refer.

The appointment may be by telephone or face-to-face and will allow you time to discuss your experience on CTCCU. We will try our best to answer any questions that you have about your illness and your admission. It is also a good opportunity for us to check that you are continuing to make good progress with your physical and psychological recovery. Lastly, it allows us to learn from your experience, which will help us to continue to improve the care we provide for future patients and their loved ones.

You can self-refer to the CTCCU Follow-Up Clinic by emailing us, leaving us a voicemail or using the QR code below.

Scan the QR code to self refer to CTCCU Follow-Up Clinic.

Answerphone: **01865 572 647**

Email: **CTCCU.FollowUp@ouh.nhs.uk**

Please contact us if you have any questions about the CTCCU Follow-Up Clinic.

Cardiac and Thoracic Critical Care Follow-up Team.

Patient Advice and Liaison Service (PALS)

Oxford University Hospitals (OUH) Patient Advice and Liaison Service (PALS) is committed to improving the service we give to our patients.

It is a confidential service that aims to:

- Advise and support patients, their families, and their carers listen to patients' concerns, queries and suggestions.
- Help sort out problems quickly on your behalf inform patients, their families and their carers about the Trust's Complaints Procedure.
- Assist you if you have any concerns about your rights as a patient and how the OUH is fulfilling its part of the NHS Constitution with regard to your own care.

Telephone: **01865 221 473**

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

Website: **www.ouh.nhs.uk/patient-guide/feedback/pals.aspx**

Useful websites

Healthtalk.org

Database of individual patient and relative experiences.
www.healthtalkonline.org

Depression Alliance

www.depressionalliance.org

ICS

Intensive Care Society.
www.ics.ac.uk

ICU Steps

The intensive care patient support charity. The Steps leaflet is available in many different languages.
www.icusteps.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.

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