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# Life after Discharge from the Critical Care Unit



## Information Leaflet

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## Useful Websites

Critical Insight

[www.ics.ac.uk/patients\\_relatives/critical\\_insight](http://www.ics.ac.uk/patients_relatives/critical_insight)

Database of individual Patient and Relative Experiences

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

ICNARC

Intensive Care National Audit and Research Association

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

ICS

Intensive Care Society

[www.ics.ac.uk](http://www.ics.ac.uk)

ICU Steps

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

## Life after Discharge

Leaving the Critical Care Unit is a major step, but you may still not feel yourself, even on discharge from 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 advise you on this. If your place of work has an occupational health department then it is advisable to speak to them. 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 dependent 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 ongoing rehabilitation. This will be discussed with you before discharge from hospital.

## 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 will depend upon the type of illness you had, and how long you were unwell.

This booklet deals with some common problems that patients may experience when they leave critical care. Everyone is different and you might not experience any of these problems at all. 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 you will be discharged to a ward.

We appreciate that this can be an anxious time for you and your family as you will have become familiar with the routine of the Critical Care Unit (CCU).

In critical care 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.

A member of the Critical Care follow-up team will visit you on the ward when you are discharged.

Do speak to the nurses on the ward if you or your family wish to speak to a doctor; a mutually convenient time can be arranged.

# Commonly Asked Questions after Critical Care Admission



## **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 your joints may be stiff.

The most common physical problem reported by critically ill patients is severe weakness and fatigue. You will have lost approximately 2% of your muscle mass per 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 time scale on recovery as everyone recovers at a different rate. You should not be alarmed if it takes weeks or even months to get fully back to normal. If you experience problems that concern you, you should go and see your GP.

You will have started some exercise (sitting, walking, arm exercises) while on CCU. 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. As your strength returns, you may want to take more vigorous exercise.

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

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

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.

Severe symptoms of stress which do not get better with time may be due to Post Traumatic Stress Disorder. It is advisable to speak to your GP in such instances as counselling may be of benefit.

## **Is there other support available to me and my family?**

Your time in the Critical Care Unit, and hospital, particularly if prolonged, 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.

We occasionally have families and patients who visit the Unit and discuss their critical care stay with the doctors and nurses. This is usually done after discharge from hospital and can be arranged by contacting one of the consultants via the consultant's secretary.



## Is it common to have such changes in my moods?

Yes! Although your condition is improving, many patients experience fluctuating mood swings such as irritability, tearfulness and lethargy. These are all common complaints after a prolonged period of illness. It is important to accept these and appreciate that it will take time for you to recover both psychologically and physically.

Some people find that setting small realistic goals helps them to see progress and thus feel better in themselves. Others have found that keeping a diary helps this process. It may be helpful to speak to the doctors, nurses and physiotherapists caring for you as to 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 prolonged hospital stay. There may be many changes that you have to deal with, such as changes in lifestyle, appearance and role within the family. It is important to talk with those close to you. If the feelings persist then it is advisable to speak to your GP, who will be able to advise you on different forms of treatment.



## Why can't I eat normally?

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

Due to a critical illness or injury, you may not be able to eat in the usual manner. You may need to have nutrition through a feeding tube (directly into the gastrointestinal tract), or intravenously (into a vein). The preferred way to provide nutrition is through a feeding tube so that normal gut function can be maintained. However, not all patients can receive nutrition through a feeding tube, for example if the gut is not working. These patients can be fed intravenously.

Once you are transferred to a ward you may be starting to eat normally but still need some supplementary food by the tube. The ward dietician will review your needs. You may be given high protein meals or foods/drinks fortified with extra nourishment such as Fortisip or Fortijuce drinks. It may help to keep a food diary.



## Why can't I sleep at night?

You have received care both day and night, which can alter your body's day and night routine. Perhaps you feel tired during the day and unable to sleep at night. Part of the reason for this could be the effect of some of the drugs you have been given.

Problems with sleeping after you have left the 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 or doctor.



## I have been having bad dreams, is this common?

Yes! Some people experience dreams or even nightmares that can be related to their stay in critical care. If they continue, some patients have found it beneficial to visit the CCU and see where they were cared for. This will happen during a visit to the after care clinic and can sometimes makes sense of the dreams you have been having. These dreams generally do disappear as time goes on.

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

Some of 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 critical care.

## **When will I look more like myself?**

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

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?**

This is a result of having the breathing tube in your throat or having had a tracheostomy and will improve over time.

## **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 have been through a very anxious and stressful time which they also need to recover from.

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.