

After Discharge from Critical Care

Patient information leaflet



Introduction

Moving from the Critical Care 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 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, and how long you were unwell for.

This booklet has been developed to help the transition from Critical Care Unit to the ward and from the ward to home. It also identifies 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.

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 give you some reassurance about how to deal with them

At the end of this section there are useful contact numbers

Section 3: Rehabilitation

This section will give you guidance on physical rehabilitation, how to set goals to aid your recovery and provide you with a structured exercise diary.

Section 1: Moving to the ward

This section will try to answer some of the questions that you may have about going to the ward.

It is quite normal to feel apprehensive about moving to the ward. You may have become familiar with the staff and routine on Critical Care. You may have felt reassured by the number of staff on Critical Care and monitoring equipment used to observe you. It is therefore important that you are prepared for your move and you feel reassured that you no longer need to be in Critical Care and you are getting better.

Before going to the ward, your nurse or doctor will explain which ward you will be going to and what will happen when you arrive there. The nurse will help you pack your belongings ready to take with you. You will be moved on to a ward bed or into a wheelchair and taken to the ward by porters and the nurse that has been looking after you.

How will the ward be different to the Critical Care Unit?

Before you move to the ward, the doctors and nurses will hand over your care to the ward Consultant and team. This means that team can get to know you and carry on with your treatment. They will also be made aware of any rehabilitation needs you may have.

You will notice that on the ward there will be fewer nurses caring for each patient than compared to the Critical Care Unit. Don't worry – you are here because your condition has improved and you don't need the same level of observation from staff and equipment. Even if you cannot see a nurse all the time, they are nearby. There is a call button by your bed which you can press if you need any help.

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

Will I still see staff from the Critical Care Unit?

Yes. The hospital has a Critical Care Outreach Team. This is a team of expert nurses who work across the hospital setting. They offer follow-up support and education for staff, patients and relatives for those who have recently stepped down from Critical Care. If you have been on Critical Care for more than 72 hours, you will see them on your new ward and potentially on more than one occasion depending on your needs.

When will I be able to get up and move around?

On the ward your Nurses and Physiotherapists will gradually increase the amount of activity you do. The Critical Care Physiotherapist will work closely with the ward physiotherapist to ensure you have a structured rehabilitation plan in place. You will receive therapy sessions during the week.

These sessions will 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 an oxygen mask but it is very important you do your exercises. This will help you to get better quicker.

When will I be ready to go 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.

Section 2: Physical and psychological changes

After you have been ill, especially for a long time, it can take a while to feeling yourself again.

This section will describe some of the common problems that can occur after being critically ill. You might not experience some or any of the problems, but they are common things that patients who have been critically ill might experience.

Tiredness and exercise

Why do I feel weak all the time?

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 muscle. 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 breathing machine.

Even if you were only unwell for a few days, you will probably experience some loss of muscle and joint stiffness due to not being able to get out of bed for a while.

Because of this you may feel tired very quickly even when you are not doing much, you have difficulty moving about and your balance might not be as good as it used to be. With regular exercise and rehabilitation sessions you can regain strength in your muscles. It is difficult to put a time scale on how quickly your muscle strength will get better because everyone responds at a different rate. It also depends on a number of factors, such as: age, previous level of fitness, how ill you have been, and how long you have been ill for.

Sleep

Why am I finding it difficult to sleep?

You might find that your sleeping pattern has changed. It might be more difficult to fall asleep or you wake frequently during the night.

If you have been sedated for a number of days this can disrupt your 'body clock', and you may find it easier to sleep during the day. When you feel tired, have a morning or afternoon nap, but try not to sleep all day. Go to bed at the same time every evening. Most importantly get up at the same time each morning, even if you have not slept well during the night. This will help you to recover your normal routine and sleeping pattern.

Discomfort or any worries you have can seem much worse being awake at night. When this happens, reading or listening to music to help pass the time and make you feel more relaxed. Taking a bath or a shower shortly before going to bed can make it easier to fall asleep. To help you sleep, try to avoid tea, coffee and alcohol.

As your activity levels increase you should find that your sleep patterns return to normal. Exercise should be done in the morning to help you sleep.

Why am I having 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 Critical Care Unit 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 separate fact from fiction.

Some people may experience delirium. Delirium is a type of confusion caused by infections, drugs, kidney or heart failure and sleep deprivation.

People that have delirium may not know that they are in hospital, may feel that staff may be trying to hurt them or may not recognise friends and family. They may feel absolutely 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 ICUsteps website (you can find the address for this website on page 10 of this leaflet).

Changes in mood

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 often a normal reaction to illness and 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.

Memory

Why don't I remember being on the Critical Care Unit?

Some people leaving Critical Care may have little or no memory of being on the unit. Asking your family and friends about what happened can help to 'fill the gaps'

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

You may have very frightening memories about your time on Critical Care. Coming to terms with what has happened to you may take time and it can really help to talk it over with family, friends and medical staff.

Changes in your appearance and senses

These changes may occur after being seriously ill but should only be temporary. If however symptoms persist or you are concerned please discuss this with your ward doctor.

Hearing

You may notice changes in your hearing. This may vary from slight loss to your hearing to hearing becoming more acute. Also sometimes your sense of balance may be affected and you may experience dizzy periods. Please seek Doctors advice should this continue.

Eyes

You may experience temporary changes to your vision especially when you are tired. It is therefore important to rest your eyes as well as your body.

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 and which colours or perms to use or not.

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. You may also notice some scars that you feel are unsightly: these will eventually fade to your normal skin colour

After a serious illness you may have lost a lot of weight all over your body whilst other areas look swollen. Exercise and sensible diet will help to restore your weight and shape.

Voice

Your voice may have become husky or weak. This is probably the result of having a tube in your windpipe to help you with your breathing.

This may irritate the throat and vocal cords making it difficult to swallow and talk. This should return to normal over a period of time. However you continue to have problems with your speech and swallowing, speech and language therapy is available.

Eating and drinking

Food tastes different and I don't feel hungry– why is this?

Whilst you have been on the Critical Care Unit it is likely that you were fed through a tube into your stomach or via a drip in your vein. As a result of this, you might find that

- You have lost your appetite
- Your mouth maybe sore
- Food doesn't taste the same (it may taste metallic, saltier or sweeter than usual)

It is important to remember that this is only temporary and is best to concentrate on foods that you like and leave those you don't. Try them again in a few weeks when your taste may have returned to normal.

If your appetite is poor then small nourishing meals with snacks in-between are easier to take. Try to choose nutritious drinks such as milk and do not fill up on tea and coffee.

If you are concerned about your appetite, then discuss with nursing staff on the ward that can refer you to the Dietician.

Going home

Once at home you may find that 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.

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

Once at home you may find it helpful to have your G.Ps telephone number at hand and a family member should you have any problems.

Follow up clinic

This is offered to patients who have been in the Critical Care Unit for several days.

This gives us a chance to check on your recovery and gives you the opportunity to discuss any worries or concerns that you may have regarding either your time on Critical Care Unit to your recovery from your illness.

This is normally 3 months following your discharge from Critical Care. Within the clinic you will have opportunity to speak to a Critical Care Outreach Nurse, Physiotherapist, Dietician and a Psychologist.

Useful contact numbers

Critical Care Unit

T: 01616 9226066/ 0161 9224271

Critical Care Outreach Team

T: 0161 9226868

Chaplaincy and Spiritual Care Tameside General hospital

T: 0161 922533

Alcohol and drug abuse

Alcoholics Anonymous Helpline

T: 0845 764755

W: www.alcoholics-anonymous.org.uk

Frank drugs Helpline Freephone

T: 0800 776600

W: www.talktofrank.com

Narcotics Anonymous Helpline

T: 0207730009

W: www.ukna.org

Age Concern

T: 02087657200

W: www.age.concern.org.uk

Asthma UK

A charity dedicated to improving the health and wellbeing of people in the UK whose lives are affected by asthma

T: 0800 1216244

W: www.asthma.org.uk

British Heart Foundation

A charity that gives information and support on the health of your heart

T: 0300 3303311

W: www.bhf.org.uk

British Association for Counselling and Psychotherapy

For details of counsellors and psychotherapists in your area.

T: 0870 4435252

W: www.bacp.co.uk

Citizens Advice Bureau for Tameside

T: 0161 3425005

Diabetes UK

Driver and Vehicle Licensing Agency (DVLA)

For information on medical conditions and driving

T: 0300 7906801 (option 2)

ICUsteps

A charity set up by former critical care patients and their families. The website includes information about the experiences of former patients and family members, a bulletin board and more contact details.

W: www.icusteps.com

Medical Equipment Loan

The Red Cross has a large selection of aids available for loan for a small donation

Stockport branch – 14 Derby Way, Stockport, SK6 7AH

T: 0161 4278366

Macmillian Cancer Support

W: www.macmillian-trust.org

Meningitis Trust

T: 08457 909090

W: www.meningitis-trust.org

Samaritans

T: 08457 909090

W: www.smaritans.org

Spinal Injuries Association

T: 0800 9800501

W: www.spinal.co.uk

The Stroke Association

T: 0303 3033100

W: www.stroke.org.uk

Section 3: Rehabilitation

Patients leaving Critical Care will have vastly different ranges of mobility, some will be walking quite well and others may be bedbound in the beginning and need more rehabilitation. An appropriate level of exercise is important to help in getting you back to doing the things you used to. Exercise will: -

- Strengthen your heart and lungs
- Rebuild the muscle you lost during your illness
- Help to reduce stress
- Help you to get a good night's sleep

Feeling tired after any exercise is quite normal when you've been in Critical Care. Even if it was only for a few days, you'll probably be experiencing some loss of muscle strength and joint stiffness. Even if you feel tired doing exercise, it is important to make sure you do some as this will help your recovery.

Your Physiotherapist is there to help you get back to normal or as close to it as possible. They will help you with an exercise regime and will alter exercises to suit your needs. Whilst you will see your Physiotherapist regularly on the wards, it is important to complete the exercises they have set for you by yourself as well so you can achieve your goals.

Setting goals

It is easy to be disheartened by the slow physical recovery after critical illness. Often people are starting to get better and are thinking about going home but are physically not ready to do the things that they did before they came into hospital.

Setting yourself goals is important to help structure your recovery. Setting yourself short term goals can help you reach your longer term goals much more quickly and keeps you focused. Your Physiotherapist will listen to what you feel is important to achieve in your recovery and help to set achievable goals around this.

Here are some tips on setting your own goals

1. Keep them few in number
2. Make sure your goals are "smart"
 - ✓ Specific – your goals must identify exactly what you want to accomplish
 - ✓ Measurable – “ you can't manage what you can't measure
 - ✓ Actionable – every goal should start with an action
 - ✓ Realistic - Don't think too far ahead
 - ✓ Time – every goal needs a date associated with it
3. Write them down
4. Review them regularly

Important points about exercise

- Don't worry how long you exercise for. Judge yourself how much exercise to do by how you feel. You should feel tired after exercise but not exhausted.
- As a rough guide, you should not feel your heart race during exercise, and although exercise will make you a little short of breath, you should not be so breathless you cannot talk.
- You can use the Borg Exertion Scale (see on next page) to help you determine how difficult you are finding the exercises
- Don't try and do too much too soon, because this will make you feel overtired and disheartened.
- If you have a bad day or take a step backwards, try not to get upset about it. Everyone feels like that at some point. Ask yourself if you have been doing more than normal over the past few days. This may explain why you feel so tired.

When to stop exercising

You should **stop** exercising and rest if you experience any of the following:-

- Chest pain
- Chest tightness or heaviness
- Dizziness or feeling faint
- Much more breathlessness than you experienced last time you did this exercise

If the symptoms persist over 2-3 minutes then contact your doctor

Perceived	Description
0	Nothing at all
0.5	Extremely weak
1	Very Weak
2	Weak (light)
3	Moderate
4	Somewhat Strong
5	Strong (heavy)
6	
7	Very Strong
8	
9	
10	Extremely Strong
*	Maximal

How to use the Borg Scale

The Borg Scale above allows you to record how hard it is for you to do the exercise set by the physiotherapist

The scale is made up of numbers from 0- 10 and you can see by some of the numbers there are words explaining what level of exertion should feel like to you

When you're first able to do an activity you may find that it takes a lot more effort and this would be a score of 7 or above

Exercise Diary							
Goals						Achieved?	
1.							
2.							
3.							
Exercises done		Date.....					
List exercises down in the spaces below		Exertion score using the Borg Scale					
	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
Comments: How well did you manage with your exercises this week? Any problems?							
Other exercises:							

Exercise Diary								
Goals						Achieved?		
1.								
2.								
3.								
Exercises done		Date.....						
List exercises down in the spaces below		Exertion score using the Borg Scale						
		Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
<p>Comments: How well did you manage with your exercises this week? Any problems?</p>								
<p>Other exercises:</p>								

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<p>Other exercises:</p>								

Exercise Diary							
Goals						Achieved?	
1.							
2.							
3.							
Exercises done		Date.....					
List exercises down in the spaces below		Exertion score using the Borg Scale					
	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
Comments: How well did you manage with your exercises this week? Any problems?							
Other exercises:							

If you have any questions you want to ask, you can use this space below to remind you

If you have a visual impairment this leaflet can be made available in bigger print or on audiotape. If you require either of these options please contact the Patient Information Centre on 0161 922 5332

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