

# Critical Care Services Outreach Team: Rehabilitation and recovery after Critical illness.

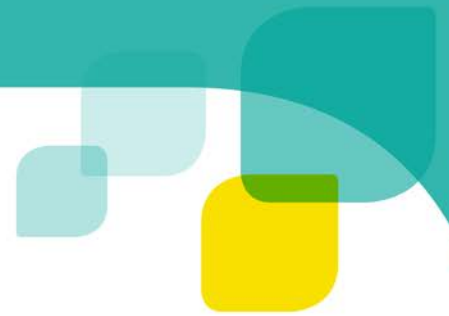
**Telephone Number: 01225 824964 / 1485**

**or via switch board on Bleep 7719**

**Location B12 – Ground Floor.**



**Royal United Hospital, Combe Park, Bath, BA1 3NG**



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## Introduction.

This information booklet aims to assist you and your family with your critical illness rehabilitation and recovery.

As you have been ill, it may take a while to get back to feeling your normal self. Exactly how long this will take depends on things like the length of time you have been ill, whether you have lost a lot of weight and whether your illness means that you will have to change some aspects of your lifestyle. This booklet sets out to describe some of the common problems that can occur and suggests simple ways to try to solve them. We want to emphasise that you will probably not experience all of the problems described here, but if you do suffer from any of them, we hope that you will find the relevant advice helpful. We want to stress that there is every chance that most people will slowly return to their previous or similar state of health.

## Going to the Ward.

Going to the ward is a big step on the way to getting better and going home, and it is quite normal to feel apprehensive. You will have become familiar with the staff on the Critical Care Unit and the routine there. The staff on the ward understand you may be feeling anxious. They are used to looking after people who have been seriously ill, so feel free to ask them about anything that concerns you.

You will notice that on the ward there are fewer nurses for each patient compared to the Critical Care Unit. This reflects the fact that you are now able to do more for yourself. Even if you cannot see the nurses all the time, they are still nearby. You will have a call bell to use if you need any help, which the nurses will answer as quickly as they can. Going home is now in sight so you will need to work with the staff to be ready for discharge.

The Critical Care Outreach Team will visit you on the ward within the first 24-48hrs after your move from the ICU. They will work with the ward staff to monitor your physical recovery, assisting where necessary. They will discuss with you any issues you or your family have regarding your physical and psychological rehabilitation.



## Exercise and Mobility.

When you first read this you will probably find that the slightest activity takes tremendous effort and leaves you feeling very tired. This tiredness is normal and will improve with time. Unfortunately, it is difficult to place a time scale on your recovery as everyone responds at a different rate. It also depends on a number of factors, such as: your age, your previous level of fitness, how ill you have been and how long you have been ill. While you were ill your body took what it needed to survive from stores in the muscles. This means that your muscles will have got smaller and weaker. You can rebuild your muscles back to what they were before and in some cases even better; however, do not be alarmed if it takes you weeks or even months to get fully back to normal. The physiotherapists will continue to work with you on the wards; they will devise a rehabilitation plan that will include exercises that you do with them and some that you can do by yourself.

## Exercise is Important after Being Ill and Will:

- Strengthen your heart.
- Help rebuild lost muscle.
- Help reduce stress.
- Help to get good refreshing sleep.
- Improve movement in your joints.
- Improve your confidence.

When you go home from hospital it is also important to continue with some form of exercise. Activities could include.

- Walking (indoors and outdoors)
- Swimming.
- Yoga.
- Gardening.
- Cycling.
- Walking up and down stairs.



## Important Points about Exercise.

- Do not try to do too much too soon. This could make you feel over tired and disheartened.
- If you have a bad day try not to get upset, everyone feels like that at some point.
- Always warm up and cool down before and after exercise.
- If you feel unwell reduce your normal level of exercise until you feel well again.

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

- Severe chest pains.
- Increased chest tightness.
- Dizziness or feeling faint.
- Much more breathlessness than you experienced the last time you exercised.
- Joint or muscle pain.

If these symptoms persist, inform one of the nurses or contact your G.P immediately. If the symptoms settle in 2-3 minutes, do not continue with the exercise but contact your G.P or nurse for advice.



## Eating Normally Again.

Since being ill, you may find that you have lost your appetite or that your sense of taste has changed. It is common for food to taste saltier and sweeter than normal, or to have an unusual metallic taste. Many people find that sharp foods such as fresh fruit, fruit juices and boiled sweets are refreshing and leave a pleasant taste in the mouth. These taste changes are only temporary and should return to normal within a few weeks.

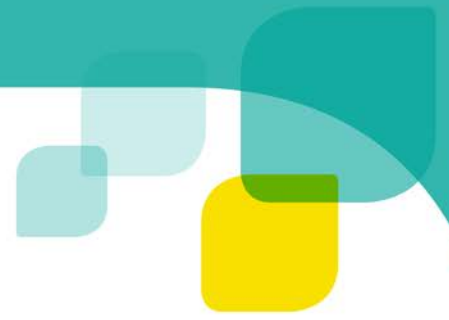
During the early stages of your recovery it is important to eat a healthy balanced diet with plenty of protein. Even though you may find it difficult to eat it is important to maintain a well-balanced diet as it:

- Helps you fight infection.
- You will feel less weak and tired.
- It will prevent you from losing weight and help you regain any weight you will have lost.

If your appetite is poor then small meals with nourishing snacks in between are often easier to manage. Eating will be more enjoyable if you take your time, avoid heavy fatty foods and relax for a while afterwards.

In hospital you may be given a high protein diet with some of the foods fortified for extra nourishment. We can arrange nourishing drinks that you can take between meals.

When you go home you may need to continue to take some of these nourishing supplements for a while but you will be advised if this is necessary. If you are having problems with eating, then ask your GP to refer you to the dietician for more specific advice on a nourishing diet at home.



## Sleeping.

You may find that your sleep pattern has changed. It may be more difficult to fall asleep or you may wake frequently during the night. When your body is not active, it does not need as much sleep as normal. As you recover and become more active you should find your sleep pattern returns to normal.

- Go to bed at the same time each evening.
- Get up at the same time each morning, even if you have not slept well. This will help you return to your normal sleep pattern.
- You may find taking a bath or shower shortly before going to bed will help you feel more relaxed, making it easier to fall asleep.
- A bedtime drink may be helpful, but you should avoid tea, coffee and large amounts of alcohol.
- Reading just before going to sleep is a good way of relaxing.

Being awake at night can be worrying. Things easily seem to get out of proportion. It is common for a small problem to seem overwhelming in the early hours when you are the only person awake. This is quite normal but when you have been ill, it is often harder to cope with things like this. If you are awake at night then you may find it helpful to read or listen to the radio. Even if you do not fall asleep this will at least help to pass the time.

Finally, the most important thing is not to worry about the lack of sleep as it will not do you any harm, and as you recover, things will get back to normal.



## Nightmares and Hallucinations.

People feel differently about their time in Critical Care. Some people have no clear memory of it, or they try to forget it. For some the experience is no more worrying than any other stay in hospital. It is not uncommon for people to find the experience of being ill very traumatic.

The strong drugs and the treatments given to patients in Critical Care Unit may affect the body and mind. Sometimes our patients experience nightmares and hallucinations, or have been bothered by them when they first leave. They may be dreams or feelings of being tortured, trapped in bed or being held captive. This is the way the mind processes a significant event and is nature's way of healing. This is quite common and you are not going mad. Although they may be very vivid and frightening, they usually settle over a few days or weeks and again it is quite normal to experience this. It may be helpful to discuss your nightmares and hallucinations with your family and friends (who may have featured in them) as it can help to explain their meaning and may help your own state of mind.

You may also have felt some paranoia as you tried to make sense of things when you were confused. This too normally passes with time. If coming back to the hospital for follow up appointments makes you feel anxious you may want to bring someone you trust with you.

The Critical Care Outreach Team will visit you on the ward 24-48 hrs after transfer out of the Critical Care Unit. The Outreach team can answer any questions you have about your stay on Critical Care or discuss any concerns you or your family have about hallucinations/nightmares. If you had a prolonged stay on the unit you may have a patient diary that kept a record of the day to day events during your illness which can help you make sense of what happened to you. The Outreach Team will also monitor your progress on the ward.

**The Critical Care Outreach Team can be contacted via switchboard on Bleep 7719 between the hours 07:30-19:30**





## How You Might Feel.

The recovery from a period of serious illness may take many months. Being physically weak and having to put a lot of effort into simple things can make you feel very low for a while. Sometimes it may seem that you will never get back to normal and that any progress you make is unbearably slow.

You may find that your mood fluctuates and you may experience some of the following.

- Feeling emotional and prone to crying
- Feeling tired most of the time.
- Inability to sleep well.
- Not caring what you look like.
- Being short tempered and irritable.
- Feeling guilty about causing so much trouble and worry.
- Having problems remembering things.
- Lack of appetite.
- Not understanding how ill you've been what has happened to you.
- Feeling frightened that you almost died.
- Worrying about getting ill again.
- Worrying about how long it's taking to get better.
- Loss of interest in sex.
- Physical aches and pains.

It is important for you to be realistic about what you will be able to do for yourself. Gradually take on the activities that you did before you became ill. Set yourself attainable targets to help you to build up your confidence. Do not set yourself targets that are too difficult to reach as you may feel as though you have failed. Ask the nurses, doctors and physiotherapists to tell you what you can reasonably expect to be able to do, and try to be patient when you have setbacks



## Your Family and Relationships.

The people close to you will be pleased that you are getting better and are out of the Critical Care unit or home from hospital altogether. Seeing someone you love in Critical care can be very upsetting. They may have worried that you wouldn't get better and this can take some people a long time to get over. Sometimes as a result of this they may be overprotective and not let you do as much as you feel you are able to do. They may not understand why you feel low in mood or are snappy. Talking to each other about how you feel and sharing your experiences and worries can help you work together towards recovery. If your mood does not settle or you feel you are becoming depressed speak to your GP who will be able to offer you support or arrange counselling.

The old adage 'a little of what you fancy does you good' is particularly true for sex during your recovery from illness. Your illness may have reduced your sex drive and it is possible that either you or your partner is concerned that sex could be harmful for you. This is rarely the case, but as with other forms of exercise, you should do as much as feels comfortable. You will be able to return to your normal relationship, but recognise this may take some time and patience from both of you.

## How Critical Illness can Affect Your Body.

Your appearance may have changed as a result of being ill, but these changes are usually temporary. You may have lost a lot of weight and your muscles may have become weak. If you have been ill for a while and especially if you were on a breathing machine the muscles weakness can be significant. You will put weight on again as you begin to recover and exercise. Physical recovery can take months rather than weeks, and it may take up to 18 months to feel fully recovered and back to your normal self. Even if you do not fully recover, you can still achieve a lot and live a full life. There are people who have been critically ill for months and a year later you would never know they had been ill.

You may find that your voice has changed. It may have become husky or may be so weak that you are unable to raise your voice or shout. This is probably the result of having a 'breathing tube' or of having a tracheostomy. (Breathing tube in the neck)



## Your Skin and Hair.

You may have some scars that you feel are unsightly. These will fade in time, and as your skin returns to normal, they will not seem as obvious. You may find that your skin is drier than before and itchy at times. Moisturising regularly can help.

You may notice that the texture of your hair changes and some of it may fall out. This is not unusual and may happen months after you leave hospital. It often grows back but may be curlier, straighter, thinner or even a different colour.

## Your Taste, Touch, Hearing and Sense of Smell.

Your taste, touch, hearing and sense of smell can be affected by critical illness. Some of the drugs used to treat you can affect your hearing or leave a metallic taste in your mouth. If you were unable to eat and drink normally, you may have been fed through a tube into your stomach or have nutrition via a drip in your vein.

You may notice that food taste different or stronger, especially if you have not been able to eat normally for a while. You may also notice that your sense of smell is affected; this is because taste and smell are closely connected.

If you were sedated for a while your eyes may be sore and feel dry or puffy and swollen, this is because of the fluids you were given to keep you hydrated.

Some of the drugs used to treat you and how the body reacts to illness may cause things that you touch feel strange and you skin feel different. You may have tingling in some parts of your body. These changes are usually temporary and should disappear in time.

## Your Voice.

If you had help with breathing, your voice may have changed. It may be hoarse or quieter than normal. If your throat is sore try to relax when you talk and drink plenty of water so you don't strain your voice



## Stress.

The period of recovery after a critical illness can be stressful. The degree of stress and how long it lasts varies. Previous sections discuss some of the symptoms that may be related to stress, such as disturbed sleep, loss of appetite, change of mood, and problems with family relationships. You may find following the advice offered there helpful.

Recovering from a stressful event takes time. If at the end of each week you can look back and say that overall things were better than the previous week, then you are making good progress. However, if you feel that you are making no progress, you may wish to make use of the Critical Care Outreach service that will be able to help you whilst you are in hospital. Your GP or one of the self-help groups listed in the back of this booklet may offer useful advice and support.

Occasionally some patients experience severe symptoms of stress. This may include symptoms that require support or treatment, and at its worst can amount to a condition called post-traumatic stress disorder (PTSD) this does get better over time and we know that early intervention is important. If necessary we can facilitate referral to specialist services.



## Useful Contacts.

### AIDS/HIV

Sexual Health helpline (24hr) free phone: 0800 567123.

Terrence Higgins Trust: 0845 12 21 200

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

### Alcohol and Drug Abuse.

Alcoholics Anonymous helpline: 0800 9177 650

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

### Asthma UK.

Helpline: 0800 121 6244

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

### Bereavement

Cruse Bereavement Care 0808 808 1677 (National)

01761 417 250 (Bath and District area)

Website: [www.cruse.org.uk](http://www.cruse.org.uk)

SOBS 0300 111 5065 Helpline for survivors of bereavement by suicide.

### British Heart Foundation:

Helpline: 0300 330 3311

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



## British Association for Counselling and Psychotherapy. (BACP)

Helpline: 01455 883300

Website: [www.itsgoodtotalk.org.uk](http://www.itsgoodtotalk.org.uk)

## Guillain-Barré Syndrome.

Helpline: 01529 469910

Website: [www.gbs.org.uk](http://www.gbs.org.uk)

## Head Injuries

Headway

Helpline: 0808 800 2244

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

## ICU Steps

Voicemail: 0300 3020 121

Website: [www.icusteps.org](http://www.icusteps.org)

## Macmillan Cancer Support.

Helpline: 0808 808 00 00

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

## Meningitis

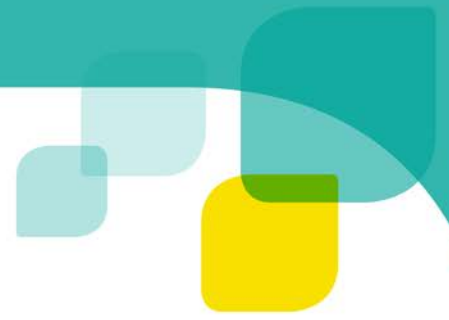
Meningitis Trust

Phone: 0808 800 3344

Website: [www.meningitis-trust.org](http://www.meningitis-trust.org)

Meningitis Now

Helpline: 0808 801 0388



## Samaritans

Helpline: Freephone 116 12

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

## Acknowledgements.

Life after a critical illness. Royal Berkshire NHS Foundation Trust: 2014.

Rehabilitation after Critical Illness, Non-physical (psychological) factors.  
Nottingham University Hospitals NHS Trust.