Recovery after Critical Illness  
Information for patients

INTRODUCTION

Ill health affects people in different ways. As you have been unwell it may take some time to feel your normal self again. The length of time this takes will depend on the illness you have had; how long you have been ill for; how much weight you may have lost and other factors individual to you. Many people experience both physical and emotional changes, while others experience very little. Research shows that because of a lack of memory of the illness while in intensive care, patients find it difficult to understand why it takes so long to return to normal.

This booklet aims to give you information about what to expect following a period of critical illness and some advice on how to help your recovery and rehabilitation both in hospital and when you go home.

GOING TO THE WARD

A major step on your road to recovery involves your discharge from ICU. For many patients this is a positive step, but also an anxious time. You will have become familiar with the ICU staff and the environment; therefore it is possible that the transition from ICU to the ward may cause some apprehension.

As a patient on ICU you required close observation, you were connected to monitors, pumps and other equipment, much of which is no longer required when you are ready to go to the ward. For this reason one nurse cares for one or two patients in the ICU. However you will notice that there are fewer nurses caring for patients on the ward, this is because you no longer require the same level of observation or technical support and can do more for yourself.

The ward nurses will be close by and you will always have a call bell. Members of the medical and nursing staff from the ward will visit you regularly. If required, you may also have visits from the ICU staff to monitor your progress. Please feel free to raise any concerns with them.
MUSCLE WEAKNESS AND MOBILITY
During your stay in ICU you may have lost some weight and muscle strength. Profound muscle wasting is common following a period of critical illness and your joints may be stiff, as you have been immobile for sometime. It is difficult to predict how long it will take for these problems to resolve as it depends on the individual. The physiotherapists will have worked with you in the ICU and this will continue on the ward, with an exercise programme suitable for you. Practising these exercises will gradually improve your strength and stamina. Do not worry if your progress is slow, it may take weeks or months for you to get back to normal.

At home you will probably find the slightest effort exhausts you. Simple tasks such as climbing stairs or getting out of the bath may be affected. Many patients find it difficult to concentrate. You may find relaxing activities such as reading or watching television tiring. This is normal and will improve with time. The important thing is that you keep trying to be as active as possible.

NUTRITION AND A CHANGE IN APPETITE
Maintaining a healthy diet is an essential contribution in aiding your recovery. The body needs a well balanced diet and extra calories, usually in the form of build-up drinks or nutritional supplements, to help with healing and recovery.

While in ICU many patients are fed via a tube through their nose (nasogastric tube) and this may continue while on the ward. If you are being fed in this manner, your doctor and dietitian will decide when it is best for you to commence dietary intake by mouth. Sometimes patients may be encouraged to eat as normally as possible during the day and are fed via the nasogastric tube at night. This is to help supplement their diet. However your illness may leave you with a loss of appetite or a change in your sense of taste or smell. Food you previously enjoyed may taste bland or unpleasant. Chewing and swallowing may be tiring if you are breathless.

Loss of appetite is common after hospital stay or major illness and can lead to reduced intake of food and subsequent weight loss. Small, frequent meals and nutritious snacks are a good way to improve your appetite and to ensure sufficient calorie input. Your dietician may advise fortifying your food with extra calories to add energy to your diet. Once you are home, if you experience problems with eating or unintentional weight loss, you should contact your GP for advice and for referral to a dietician for nutritional management.
PHYSICAL CHANGES

Some patients have reported physical changes as a result of their ill health: these are usually temporary. The most common change is an altered voice. You may find your voice to be weak or husky, perhaps you feel the need to clear your throat often. This is probably the result of having had a breathing tube or a tracheostomy inserted to facilitate adequate lung function and breathing this should resolve in time. You may have scars from surgery, tracheostomy or even drips.

Your hair may feel brittle and limp, your skin may feel dry but as you regain your appetite and any lost weight, your hair and skin condition will return to normal. Poor eyesight is also common, this should also return to normal over time.

SLEEPING

Problems with sleep are the most common complaint of patients who have been in ICU. You may find that you are unable to sleep or wake frequently throughout the night. Being awake at night can become frustrating. It is a time when worries or anxieties can seem much worse. This is quite normal, as people who have experienced a critical illness often feel vulnerable until they return to normal health. If you are still having problems getting to sleep at home try writing down things that are worrying you or that you need to remember.

Some patients experience vivid dreams or nightmares while in the ICU and these can continue whilst on the ward. Although they may be very real or frightening they usually disappear in the coming days or weeks. Please remember that these experiences are common and will improve.

When your body is not active you may not require as much sleep as normal. As you become more active your sleep pattern should improve. Try to stick to a routine at night and go to bed at about the same time.

Emotional changes

Critical illness can be very disruptive both physically and emotionally. Often patients complain of fluctuating moods, feeling up one day and down the next. Some patients report feeling depressed, often frustrated by the speed of their recovery. All these feelings are normal and understandable.
It is important for you to be realistic about your recovery and what you are able to do for yourself. Seek advice from the nurses, doctors and physiotherapists with regard to what you can expect to be able to do. Avoid setting yourself targets that are too difficult as you may feel you have failed if you do not achieve them.

Also, try to be open and honest about the way you are feeling with hospital staff, family and friends. You may find your family is very over-protective, not allowing you to do as much as you are able to. Your illness has been a worrying time for them too, so talking over what has happened and sharing your concerns will help you to work together towards your recovery.

Many patients feel they do not want to worry their partner: this is very individual. However, with time and patience, emotional and physical relations with your partner will return to normal.

If you would like to talk to someone in greater depth about how you are feeling a professional counselling service is available.

This service is free of charge and available to all patients who have been cared for within the Intensive Care Unit. If you wish to avail of this service please contact Jo Ashcroft – Clinical Psychologist on 01895 279 374.

MEMORY

Many patients have little or no memory of their stay in ICU. Others may have hallucinations or nightmares. It is important to talk about these hallucinations if you are able to. Our brains try to make sense of things we don’t understand so some hallucinations may be directly linked to your experience in ICU, such as a patient who felt he had been on a ship at sea may have been interpreting the rocking or ripple motion of the mattress.

Research suggests that patients who have a degree of factual recall of events on ICU are less likely to suffer from long term psychological difficulties. Factual recall may include being suctioned, bathed or any other events. It is for this reason that we have introduced Patient Diaries in an attempt to help your factual recall. If a diary has been kept for you, we will contact you about two months after you have left the unit to discuss whether you would like to keep it.
SUPPORT FOLLOWING ICU

One of the ICU nurses will visit you on the ward to discuss your progress and to answer any queries you may have about your stay on ICU. We may write to you once you are home to invite you to a follow up clinic to support you in your recovery.
If any problems continue, contact your GP or Simon DuPont, Clinical Psychologist on 01895 279588

ASSIST - TEL: 01788 560800
http://www.traumatic-stress.freeserve.co.uk
Assistance, support and self-help in surviving trauma

ASTHMA UK – TEL: 08457 01 02 03
http://asthma.org.uk/

BBC HEALTH
http://www.bbc.co.uk/health

THE BRITISH HEART FOUNDATION
Tel: 0845 0708070 (information line open Mon, Tues, Fri 9am-5pm. Wed, Thurs 8am – 6pm). Main telephone no. 0207 935 0185. http://www.bhf.org.uk/

BRAKE – THE ROAD SAFETY CHARITY
Tel: 01484 559983 http://www.brake.org.uk
Brake is a road safety charity dedicated to stopping deaths and injuries on roads and caring for people bereaved and injured on the road.

BRITISH ASSOCIATION FOR COUNSELLING AND PSYCHOTHERAPY
Tel: 0870 443 5252, www.bacp.co.uk
For details of counsellors and psychotherapists in your area.

CITIZENS ADVICE
http://www.citizenadvice.org.uk
Find your local branch telephone number by entering your postcode on their website or looking them up in the phone book

THE COLOSTOMY ASSOCIATION
Helpline: 0800 587 6744 or 0800 328 4257
CRUSE Bereavement Care Helpline
Tel: 0844 477 9400, http://www.crusebereavementcare.org.uk/
Young person’s helpline: 0808 808 1677
Promotes well-being of bereaved people and enables anyone bereaved by death to understand their grief and cope with their loss. The organisation provides counselling and support. It offers information, advice, education and training services.

Diabetes UK
http://www.diabetes.org.uk
Diabetes UK Careline: 0845 120 2960, Monday-Friday, 9am-5pm

DIPEX
Personal experiences of patients who have been in intensive care units
http://www.dipex.org/intensivecare
Experiences of relatives – http://www.dipex.org/relativesofintensivecare

Headway (Head Injury Support)
Freephone: 0808 800 2244, Open 9am - 5pm, Monday to Friday
http://www.headway.co.org.uk

ICUSTEPS
Tel: 0870 471 5238, http://www.icusteps.com
This charity is a support group set up by former intensive care patients and family members based in Milton Keynes. They hold regular informal drop-ins and offer support for other ex-patients or family members. The web site includes ex-patients and family members’ own experiences, offers a bulletin board and a contact page.

ICNARC
http://www.icnarc.org/patients
Professional organisation for doctors working in critical care. It has useful information for patients and relatives including an excellent list of contacts for specific illnesses.

The Intensive Care Society
http://www.ics.ac.uk/
Has useful ‘Patient & Relative section’ which explains many aspects of critical care, such as staffing, equipment, treatments, recovery etc.
MACMILLAN CANCER LINE (FREE)
0808 808 2020 Monday to Friday 9am - 10pm, http://www.macmillan.org.uk

MENINGITIS TRUST
Tel: 0800 028 18 28, http://www.meningitis-trust.org/

NHS DIRECT
Tel: 0845 4647, http://www.nhsdirect.nhs.uk/

NHS SMOKING HELPLINE
Tel: 0800 169 0169

NICE (NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE)
http://www.nice.org.uk/
Information source on a broad range of medical issues

PRINCESS ROYAL TRUST FOR CARERS
Tel: 0844 800 4361, http://www.carers.org
Largest provider of comprehensive carers support services in the UK.

SAMARITANS
Tel: 08457 90 90 90, http://www.samaritans.org

SPINAL INJURIES
Freephone Advice Line: 0800 980 0501, 9.30am to 4.30pm (closed 1pm to 2pm) Mon to Fri. http://www.spinal.co.uk/

THE STROKE ASSOCIATION
Tel: 0845 3033 100 http://www.stroke.org.uk/
Open Monday to Friday, 9am to 5pm.

WINSTON’S WISH
Tel: 08452 03 04 05
A charity for bereaved children. Winston’s Wish helps children rebuild their lives after the death of a parent or sibling, enabling them to face the future with hope. http://www.winstonswish.org.uk/
Languages/ Alternative Formats

Please ask if you require this information in other languages, large print or audio format. Please contact: 01895 279973

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