

Discharge from Intensive Care

Information for Patients and Relatives

Produced by The Intensive Care Society

with the support of the Department of Health, the BACCN and the National Outreach Forum.

Improving the quality of life for patients in Intensive Care

The Intensive Care Foundation aims to save lives by funding research into new treatments for all critically ill patients. We are the research arm of the Intensive Care Society a professional body for all intensive care professionals and a registered UK charity.

There are two main reasons for supporting research in this area - one to save lives, the other is to improve the quality of life of patients who survive intensive care. Symptoms of survivors can include; post traumatic stress disorder, chronic pain and the social and emotional problems that can result in loss of jobs, depression, stress on families.

What we do:

Develop new clinical research focused on direct patient benefit and supported by the intensive care community.

Support important pilot studies with funds and ICS members support.

Develop and refine new research ideas.

Support young intensive care professionals through grants and research support.

Over time, the Foundation expects to have a significant impact on the critically ill saving more lives and enabling a higher quality of life after care.

How we do it:

Set priorities for clinical research

Undertake national audits and surveys of practice to inform clinical trials

Award research funds for pilot projects

Make and assist with applications to grant awarding bodies

Support post graduate training in clinical trials

To support the following trials:

ICON, OSCAR, SimSept, BALTI-prevention, ICAN-UK Completed Trials: TracMan, ACRE, PERMIT

How you can help

- Make a donation via just giving www.justgiving.com
- Participate in one of our many fundraising events
- Organise your own fundraising event for the Intensive care foundation

For further information email: foundation@ics.ac.uk

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Introduction

Approximately 100,000 patients are admitted to Intensive Care Units in the country every year and the number is increasing. For patients and relatives this experience can be frightening and very worrying. The Intensive Care Society which is the professional body in the UK for standards and safety has a section on its web site which offers advice and guidance for patients and relatives and over the years has received comments and requests for additional information. This booklet, which is one of three, is based on the comments we have received and reflects the current best practice in intensive care medicine and the views expressed to us. The Society established some years ago a Patient Liaison Committee to give it better understanding of what patients and relatives require in improved safety and treatment and this Committee has since inception made information and help available to patients and relatives and has been the guiding hand in the preparation of this booklet. The advice contained has also been endorsed by the Department of Health, the BACCN and the National Outreach Forum and represents the latest and definitive information. We hope that you find it helpful and that if you have any comments on the content or lack of it you will let us know. Please visit our web site www.ics.ac.uk for further information and where there is a section for you to let us know your comments.

Dr. R Winter FRCP FRCA DM

How do the teams decide when you are fit to leave intensive care?

These decisions can be very difficult. Where there has been a specific reason why you needed critical care and that has been treated and there are no ongoing problems, then it is straightforward. However, you may have multiple problems, which only get better slowly and therefore you will be in intensive care for a longer time. In these circumstances there is not a specific point at which everything is resolved and therefore assessing when you are fit for transfer is a more complex process involving the critical care team and the ward team.



It may seem to you and your relatives that you are too fragile and ill to transfer to a general ward but a point is reached when it would make your recovery more difficult if you were kept in intensive care longer than clinically necessary. Being fit enough for discharge from intensive care should be viewed as a positive step on the road to recovery.

To the ward

Once you are recovering and well enough to be transferred to the ward, your care will be managed by the ward team. Some hospitals have a Critical Care Outreach Team (CCOT) consisting of intensive care trained nurses, physiotherapists and doctors. They will visit you on the ward and assess your condition. The CCOT works closely with the ward team to

support and optimise your clinical management and will ensure there is a seamless transfer of care as possible and may come to visit you regularly to ensure that your recovery is progressing well.

You are leaving intensive care because you are getting better and are now well enough not to need the highest levels of care. However, this can be a very difficult time for you and families, particularly if your stay in intensive care has been long. There will be fewer nurses and less equipment on the ward. It might seem a bit of a shock going to an environment where there is less attention, and it is natural to worry that there is less care. However this is not the case and you should be reassured that you have been transferred to the ward because you are getting better and need less support.



The key issues you are likely to face, but which will pass, are:

The change in environment

The daily routines on the ward are different from intensive care, the staff are different, the sounds are different. There will not be the complex equipment on the ward and the beeps and alarms which will have become familiar in intensive care. Their absence can be just as worrying for some patients. Some patients are likely to be well enough to talk to you but some may be confused or noisy and this can be very disturbing.

The change to you

The process of recovery from severe illness is not easy. During your stay in intensive care you may, depending on how long you were there, have lost weight and muscle tone. Joints may also be stiff due to the long time spent in bed and there may be some loss of sensitivity in the fingers and other small joints. You may have had a tracheostomy and be conscious of the small scar. These problems can be quite distressing, but as you become more active, muscle weakness and joint stiffness will improve as part of your recovery. Physiotherapy will help you to regain the strength in your muscles and lungs.

Change of appearance may occur as a result of being ill, but these changes are usually temporary. You may suffer hair loss or a change in the quality of your hair, not initially but usually several months into your recovery, or find that the texture of your skin has changed and has become much drier than before. You may also 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.

If you were intubated (having a tube inserted in your windpipe through the mouth to help breathing) or had a tracheostomy (having a tube inserted externally into your windpipe to allow breathing) you may find that your voice has changed and become husky or may be so weak that you are unable to raise your voice or shout. This should return to normal over time.

Going back to the ward often means you are able to do a lot more for yourself. This can be very hard work and tiring, particularly if you are adapting to new disabilities or injuries. Learning to eat and swallow normally again, to go to the toilet normally are far from trivial, and can be very embarrassing.

Even though you are getting better, you may feel anxious and depressed about the effects of being critically ill. This is understandable and you may find it a help to talk about your feelings to your family or a member of staff.

The change in the staffing

Intensive care has higher number of nurses for each patient than a ward where there may only be two or three nurses for the whole ward, especially at night time and not all of them will be trained to the same level as the intensive care nurses. You will have to learn to use call bells to get attention and there can be delays in someone responding. Your family has to appreciate that the nurse isn't just looking after one patient and can't give the detailed ongoing explanation of each change in your condition and what is happening which the intensive care nurses could. Consequently you and your family may sometimes feel neglected or deserted. This isn't the case. You are being looked after; it's just that the change in the level of care is different.

The medical team

The team looking after you will have been given a thorough handover from the intensive care team but it will still take time for them to get to grips with all the detail.

To another hospital

Sometimes a patient has to be transferred to another hospital for more specialist care and treatment. These decisions are always made by the most senior doctors and nurses and all transfers to another hospital must be carried out strictly in accordance with nationally agreed protocols designed to safeguard the patient.

Discharge from hospital

During your stay in intensive care the team will have been constantly assessing your ongoing needs, if any, for further treatment when you leave intensive care and ultimately the hospital and based on these assessments a treatment plan will be drawn up which will be discussed with you when you are ready.

It should be stressed that not all patients will require ongoing treatment but where the teams' assessments identify there is a need for rehabilitation, hospitals are now required to prepare care packages prior to/at hospital discharge which may include visits from a district

nurse, occupational therapist and ongoing physiotherapy. Your family doctor will receive details of your treatment including any recommendations for further treatment.

After discharge

If you have been in intensive care for a long time recovery and rehabilitation can continue long after discharge from hospital and there are a number of common problems that you might experience. **Not all of these will affect all patients** and their severity will lessen with time or pass altogether but it can help knowing that these challenges are normal and are a part of the recovery process.

Once you have been discharged from hospital, the hardest part of your recovery may be over but, if you have been in intensive care for a length of time, you may still have further to go before you will be completely better. It could be a long time before your strength is back to normal and the emotional impact of having been critically ill may last for some time. The prolonged recovery period can lead to several problems and you can experience considerable levels of anxiety and depression. You may find you want to avoid company and show less affection for your partners, family and friends.

You may, understandably, feel that the recovery phase of your critical illness is the most stressful period as you come to terms with how ill you have been. Often your distress is a reflection of the stress the family and close friends have been under while you were unaware. It is natural to feel weepy and have disturbed nights and this can be viewed as part of the healing process. If you are finding it hard to cope then seek advice from your GP or intensive care follow-up clinic, where available. Support for relatives providing care after discharge from hospital will vary according to local provision and should be discussed with the hospital and GP.

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.

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. Provided that your doctor has not advised you to avoid alcohol, you may find that a small drink before your meal, or with your meal, will help to stimulate your appetite.

In hospital, you may have been given a high protein diet with some of the foods fortified for extra nourishment. Nourishing drinks that can be taken between meals can be arranged and there are also glucose syrups and tasteless glucose powders available that can be taken as drinks or added to food to increase energy intake. 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 doctor 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 and 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 sleep pattern.

You may find taking a bath or a shower shortly before going to bed will help you feel more relaxed, making it easier to fall asleep. Many people find that a bedtime drink is helpful, but you should avoid tea, coffee and large amounts of alcohol. Reading just before going to sleep is also 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.

Some patients experience nightmares while in intensive care, or have been bothered by them when they leave the unit. Although they may be very vivid and frightening at the time, 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 dreams or nightmares 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. If they continue after your discharge home and you find them distressing, it may be advisable to discuss them with your family doctor.

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.

Changes in mood

Fluctuating moods, one day up, the next feeling very down are a common occurrence. This is a normal reaction to illness and will lessen with time. If you have been very seriously ill, or ill for a long time you may find that you feel quite depressed for a while. Sometimes, it may seem that you will never get back to normal and that any progress you make is unbearably slow. The up and down struggle to recover physical strength in itself can be discouraging.

It is important to be realistic about what you will be able to do for yourself. You should gradually take on the activities that you did before you became ill and set attainable targets to help build up your

confidence.



(This lady spent 7 weeks in intensive care and a little over one year later is able to enjoy a full and active life)

Targets that are too difficult to reach should not be set as you may feel you have failed. Ask the nurses, doctors and physiotherapists what can be reasonably expected and try to be patient when setbacks occur. It is also important to involve family and friends in setting the targets or goals, because they will often be the people who are best able to monitor progress and give encouragement.

Family and relationships

Family and friends are obviously delighted that you are getting better, but they may be overprotective and not let you do as much as you feel able to do. It has been a worrying time for them too, so talking over what has happened and sharing your worries will help you to work together towards your recovery.

The old adage 'a little of what you fancy does you good' is particularly true for sex during 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. This is rarely the case, but as with other forms of exercise, you should do only 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.

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, moods or depression, and problems with family relationships.

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. Some patients experience severe symptoms of stress which may not appear for a few months following their stay in intensive care. This is known as post traumatic stress disorder (PTSD) and does get better over time, often with professional counselling. However, if you feel that you are not making progress, you may wish to make use of the advice offered through the intensive care follow-up service, your GP or one of the organisations listed in the further information page.

Intensive Care Follow-up Clinics

Some intensive care units have follow-up clinics that give you the opportunity to discuss your concerns and progress after discharge from hospital and more units are setting these up. Follow-up clinics allow you to talk to staff and understand more about what happened in intensive care, the procedures that you underwent and generally fill in the gaps that the sedation and medication will inevitably have left. Most units can provide specific information regarding issues related to critical illness and its consequences.

Further Information – download from the ICS website

Your Questions Answered

(http://www.ics.ac.uk/patients___relatives/your_questions_answered)

An ICS guide to coping with a stay in critical care covering many of the topics on the website.

Critical Insight

(http://www.ics.ac.uk/patients___relatives/critical_insight)

An Intensive Care Society introduction to UK adult critical care services.

Links

BRAKE - The Road Safety Charity (<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.

Cruse Bereavement Care (<http://www.crusebereavementcare.org.uk/>)

Cruse Bereavement Care exists to promote the well-being of bereaved people and to enable 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.

DIPEX - Database of Individual Patient and Relative Experiences

(<http://www.healthtalkonline.org>)

An Oxford based registered charity. It is a database of audio, video and transcript of interviews with patients and relatives experiencing a particular illness or health problems which includes a module on critical care.

Headway (<http://www.headway.org.uk/>)

A national charity that supports people with a brain injury and those who care for them.

ICNARC - Intensive Care National Audit and Research Centre (<http://www.icnarc.org/patients/>)

Is a sister organisation of the Intensive Care Society (ICS) the pro-

professional organisation for doctors and other professionals working in intensive care.

ICS – Intensive Care Society (<http://www.ics.ac.uk>)

The Intensive Care Society is the longest established intensive care society in the world and sets the professional standards of care in intensive care. It is the professional organisations for doctors and other professionals working in intensive care. It is the acknowledged world leader in patient and relative involvement in all aspects of intensive care treatment and has a dedicated division specially for this work. It also supports medical research into better treatments in intensive care.

I-Canuk (<http://www.i-canuk.com>)

A professional and independent national organisation which aims to improve the long term care of patients who have suffered critical illness

National Institute of Health and Clinical Excellence (NICE) (<http://www.nice.org.uk>)

A government funded organisation which contains a considerable number of relevant and important publications and guidance documents for the NHS.

Patient UK (<http://www.patient.co.uk/>)

An independent service leading to high quality UK internet health sites.



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The Intensive Care Foundation

“Science in the Service of Saving Lives”

The Intensive Care Foundation is the research body of the Intensive Care Society

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