

Your Stay in 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

Contents

| | |
|--|---|
| Admission | 1 |
| What your visitors can expect | 1 |
| Hallucinations, delusions and nightmares | 2 |
| Feeling weak and loss of weight | 2 |
| Transfer to another hospital | 3 |
| Research | 3 |
| Further information | 4 |

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
President
Intensive Care Society*

Admission

Following admission to the intensive care unit it can take an hour or more to settle you and start treatment.

You might still be recovering from your anaesthetic following surgery or you may have been sedated to allow treatment to start straightaway.

After this initial period visitors are normally welcome at the bedside and will, in all probability, see various pieces of medical equipment connected to you.

There will be a high level of activity round the clock. Noise levels are likely to be higher than on a general hospital ward largely because of the operation of the equipment, often beeping or sounding an alarm. If you do hear an alarm it doesn't necessarily mean something's wrong, just that there's something the staff need to be aware of. Staff will explain the equipment and noises should you have concerns.

The first few hours on intensive care are often a very unstable time and your condition can change minute to minute. Frequently one of the team will, at this stage, summarise what has happened so far and what they are expecting in the next few hours. Don't be afraid to ask questions.

What your visitors can expect to see when they visit you.

Admission to intensive care can be a time of great stress and worry for both you and your relatives. Your relatives should be prepared for you to appear different from the last time they saw you.

The experience of first seeing someone in intensive care can be upsetting but intensive care nurses and doctors are highly skilled and experienced in supporting relatives to deal with these difficult circumstances, so your relatives shouldn't hesitate to express their feelings and to ask questions of a member of the intensive care team.

It is also important for your relatives to focus on your needs. Your relatives need to be strong, supportive and positive. They may find you confused or bewildered because of the sedation or medication and it will help your recovery if they help you to remember what has happened to you, to reassure you, to have patience and to try to find a level of normality in conversation.

While sedated, it may be difficult for you to think clearly. Sometimes the medication may change your perception of what is happening and you may seem angry, hostile, or just different.

You will find that some days are good and some are bad as your condition changes. Concentrate on the good days and view the bad days as hurdles that can be overcome. Try not to become discouraged and keep a positive outlook. It is not uncommon for you to feel you are getting worse before you get better.

Hallucinations, delusions and nightmares

Patients vary as to how much they remember of their stay in intensive care. Some remember nothing at all, some remember very little, but most patients can recall the days immediately following the removal of the breathing tube (extubation), although these memories are fragmented. Patients can often remember in detail "un-real experiences" - particular objects, individual nurses and important emotional experiences. Some of these experiences may be described at a later date, often based on a misinterpretation of events going on around them at the time. The experience may have been frightening, pleasant or simply very peculiar and "unreal". You should not be afraid to discuss these experiences with the nurses and it is very rare that they recur after recovery.

Poor recall and loss of memory are due to a combination of the type and severity of the illness, drug treatment and other factors that are, as yet, not understood completely.

Feeling weak and loss of weight

During your stay in intensive care, you may lose 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. These problems can be quite distressing, but, as you become more active, muscle weakness and joint stiffness will improve as part of the recovery process. Physiotherapy will help you to regain your physical strength and that of your lungs if you have needed a breathing tube. Even though you are getting better, you may feel anxious and depressed about the effects of being critically ill. This is an understandable reaction and you can help by talking to the staff and your relatives about your feelings.

Transfer to another hospital

Sometimes you may need be transferred to another hospital because it has the very specialised care which you require. This should be done during the day whenever possible, although it may, because of a sudden emergency, occur during the evening or night. The decision to transfer is 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 procedures to safeguard your wellbeing.

Research

Advances in medical knowledge and treatment have been brought about through research and the practice of medicine today is based on evidence of what works.

There are always a number of research trials being undertaken in intensive care units throughout the country into different aspects of medical care all of which have to be approved by an independent ethics committee of outside experts.

Patients and increasingly relatives are asked to take part in research trials. Intensive care units have one or more staff who supervise trials in their units and they will be the staff who seek patients' and sometime relatives' approval to take part in an approved trial. Taking part is entirely voluntary and no one is under any obligation to consent. Even after giving consent withdrawal can take place at any time. The full details of any trial will be explained by the staff in the unit who are co-ordinating it.

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.



Intensive Care Society

Churchill House, 35 Red Lion Square
WC1R 4SG
T: 020 7280 4350, F: 0207 280 4369
www.ics.ac.uk



The Intensive Care Foundation

“Science in the Service of Saving Lives”

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

Registered No: 2940178 (England) Registered Office as above
Registered as a Charity in: England and Wales No: 1039236
Scotland No: SC040052