

General 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 website 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 website 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

What is Intensive Care?

Intensive Care Units (ICUs) are very specialised areas within a hospital. They look after patients whose conditions are life-threatening and need constant, close monitoring and support from highly trained staff, equipment and medication. Intensive Care Units in the United Kingdom are run and staffed by specialist doctors and nurses who have undergone extensive training in intensive care. There will also be other specialist staff such as physiotherapists, pharmacists, dieticians and speech therapists who may be involved in the patient's treatment.

The length of time patients spend in ICU depends on how ill they are and may vary from a few days to a number of months. As patients get better they are sometimes transferred to an area called a high dependency unit (HDU) and then to a general ward in the hospital.

There are many reasons why people may need care in ICU. These range from a planned admission for very close observation following a major operation to supporting the function of major organs such as the lungs, heart and kidneys following a sudden illness.

Once a patient is admitted to the unit, the intensive care team will manage their care, although staff from other branches of medicine may be consulted if needed.

Why are people admitted to intensive care?

Planned admissions

After some very big or complex operations patients are admitted to intensive care for a period of time for close monitoring. The theatre staff will contact the intensive care unit and arrange to transfer the patient there at the end of the operation.

Emergency admissions

If you are admitted to the hospital as an emergency you will be seen by the emergency department team or by one of the general medical, surgical or specialist teams. They may decide that you need a higher level of monitoring or specialist treatment than is available on the general ward and then they will contact the intensive care team. If the teams feel that you will benefit from intensive care you will be admitted to the unit. The most senior doctors and nurses make these decisions with as much involvement from the patient and relatives as is possible.

What is it like on intensive care?

Intensive Care is different from any other ward in the hospital. There are large amounts of special equipment, more staff, activity 24 hours a day and many patients are asleep or sedated.

Equipment

Patients in intensive care are often very ill and need constant monitoring. This is done by having a lot of staff on the unit and specialist monitoring equipment which may look complicated and even frightening. All beds will have this equipment around them, although it may not all be needed. Some equipment will make beeping noises, others will be silent but may have a bewildering display of graphs and numbers which change. Do not be alarmed at the equipment and the noises being made. The nurses understand what they mean and will, if requested, explain the purpose of the equipment being used.



Many patients in intensive care need help at some time with their breathing. This support can simply be oxygen through a face mask. Other patients need more help, with a tube inserted into their windpipe either through the mouth (endotracheal tube) or directly into their throat

(tracheostomy). These tubes are connected to a mechanical breathing machine called a ventilator.

Many patients will, because of their condition, be unable to eat food normally and are therefore fed by different methods depending on their condition. A common method is by a tube through the nose and into the stomach (nasogastric tube).

Why are some patients sedated?

Patients who need help with their breathing often need to be sedated to tolerate the mechanical ventilation. This level of sedation is much less than is needed for an operation and patients are often partially awake. Relatives often want to know if they can talk to the patient or touch them and this is usually encouraged. Reassuring voices and contact can be of real help.

It is a common misunderstanding that patients would be better being kept "completely" asleep but research shows that patients recover much better if the least amount of sedation as necessary is used, even though patients can look and appear more agitated or distressed at the time.

How might all this affect the patient?

No two experiences of intensive care are the same. However for many patients being so ill is a very stressful time.

As they wake up or if they are not fully asleep patients may feel confused about where they are and what has happened. They may also appear anxious or in pain. Sedation and medication to relieve pain and anxiety may be needed.

While sedated, it may be difficult for a patient to think clearly. Sometimes the combination of the medication and being so unwell may change their perception of what is happening and they may seem angry, hostile, or just different.

As mentioned before, at times some patients will need help with

breathing and will be supported on a ventilator. Usually in these circumstances, it will not be possible for the patient to talk and this can be frustrating.

It is important, however, that relatives and friends talk to the patient and where appropriate hold their hand. Often patients who are sedated will recognise their relative or friend by touch or the sound of their voice and be reassured by their presence.

One of the results of sedation is that the patient may not have any memory of that time and some relatives have found it helpful to keep a diary of the patient's stay in critical care and some critical care units help with this. This can be of great help to the patient later, during their recovery, by filling in the gaps in their memory caused by sedation or medication, particularly for long periods.

What can relatives do to help?

Visiting

One of the most helpful things that friends and relatives can do is to visit. Most intensive care units do not have set visiting times but some ask relatives not to visit between specified times. This allows the patient to have some time to rest. It may also be necessary to limit the number of visitors allowed at the bedside at any one time.

It is advisable to check with the nursing staff what the visiting times are.

Infection control

Infection control in intensive care is extremely important because patients are very ill and therefore can pick up infection easily. **It is essential that all visitors comply with local hygiene policies.** The nursing staff can advise what you need to do.

Involvement in nursing care

Sometimes relatives and friends can feel that they are like 'spare parts' but they can help, if they wish to, by carrying out simple but important tasks such as combing the patient's hair or helping with giving sips of water. The nurses will be happy to describe what tasks relatives and friends can do which will benefit the patient and assist in support and comfort during what can be a difficult time for both.

One main contact per family

The intensive care team, as part of the patient's treatment, will keep relatives informed of progress and of any difficulties being encountered. The team will always do its best to answer immediately your questions but at busy times there may be delay before a team member is available. It is always possible to make an appointment to see a senior team member.

Experience has shown that this works more effectively if the family nominates one person as the contact point. It is also advisable to limit the number of names of any relatives and friends to whom the intensive care staff can give information on the patient's progress. Having one

contact also helps to safeguard patients' confidentiality.

Similarly it is helpful if relatives establish a number of main contacts within the medical team. This avoids the problem of receiving information from staff who may not be fully appraised of the patient's condition.

Bereavement

Sadly, in spite of all the efforts of the staff and medical knowledge, some patients will deteriorate and die. This will rarely be a sudden and unexpected event and the doctors and nurses will have time to discuss the patient's deterioration and likely consequences with relatives.

Bereavement will be a sad time and the doctors and nurses will do all they can to prepare relatives and ease the burden. Religious support is always available to those who wish it.

Organ and tissue donation

Organ and tissue donation is the gift of organs and/or tissues donated after death to help someone who needs a transplant. Hospital staff are committed to doing everything possible to save lives and organ and/or tissue donation is only considered after all attempts to save life have failed. When people die in intensive care it may be possible for them to donate organs and/or tissues. Many people have made decisions in their lifetime about donation and it is important for the hospital staff caring for your relative/friend to find out what these wishes are. To be able to explore if a patient had expressed a wish to donate, hospital staff will always check the organ donor register and ensure that they discuss organ and/or tissue donation with you as the patient's relatives/friends.

You will be offered the option of discussing organ and/or tissue donation with a donor co-ordinator who will be able to answer any questions that you may have.

Other things you may need to know

Religious support

All hospitals have multi faith support and the staff will be happy to arrange for the appropriate person to be contacted should the patient or relative or friend want to discuss any issue.

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 these research trials are approved by an independent ethics committee of outside experts to make sure patients' best interests are protected.

Patients are often too ill to give their own consent to enter a study. It is therefore very common for a close family member to be asked to act on the patient's behalf and help decide if the patient would wish to take part in the research. 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.

Patient confidentiality

When the patient is in hospital, their condition and treatment must remain strictly confidential between them and the staff looking after them. Any information about the patient will not be disclosed to anyone unless that person has been named by the patient. Occasionally, particularly in emergency admissions, the patient will be unconscious and information about the patient which is vital to their treatment will be required from the relative or next of kin. In such instances the relative or next of kin will be kept informed of treatment and progress but the staff will not disclose any of that information to any one else.

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

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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