

## **For relative and patients who have been in critical care**

### **HELP AND ADVICE FOR PATIENTS**

We have produced this booklet to help you and your relatives overcome some of the common problems encountered after a stay on the Intensive Care Unit (ICU).

As you have been ill, it may take some time to get back to normal again. We hope this information will aid your recovery.

#### **Critical Care Outreach Team – you are not alone.**

The Outreach team consists of intensive care trained nurses who will see you once you are back in the ward environment. They will visit each day to observe your progress and offer support and advice to yourselves and to ward staff. If you have any questions about intensive care, then please ask them.

Once you have settled in the ward they will visit each week until you go home to help you to adjust back to normal. You will then be invited to attend a post critical care follow-up clinic run by an anaesthetic consultant. You will be invited to attend at 2, 6, and then 9 months after you have been discharged from hospital.

The outreach team operate 7 days a week, including bank holidays from 8:00-18:00, on ext 6227 and bleep 2146.

#### **Going to the ward**

Going to the ward is a big step on the way to getting better and going home, it is quite normal to feel apprehensive. You may have been in Intensive Care for some time, and have become familiar with the staff and daily routines, and just as you are getting better you now have to get used to new faces and a new routine.

You will find that being on the ward is very different to intensive care. You will notice that there are fewer nurses for each patient. This reflects your improvement in recovery and being able to do more for yourself. Even if you cannot see the nurses all the time, they are still close by. 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 nurses to be ready for discharge.

#### **Exercise and getting around**

When you first read this you will probably find the slightest activity takes tremendous effort and leaves you feeling very tired. This tiredness is normal and will improve with time. It is difficult to say how long your recovery will take as everyone is different. It will vary according to your age, previous level of fitness, how ill you have been, and how long you have been ill. Do not be alarmed if it takes you weeks or even months to get back to normal.

During your stay in ICU you may well have lost some weight and muscle strength and your joints may be stiff if you have been immobile for some time. The ward physiotherapist will assess your problems and will devise an exercise programme that is suitable for you. These exercises can be taught to members of your family so they can become involved in your recovery.

#### **Eating**

Since you have been ill you may find you have lost your appetite or your sense of taste has changed. It is common for food to taste either salty or sweeter than usual, or you may experience a metallic taste. Many people find that sharp foods like fresh fruit; fruit juice and boiled sweets are refreshing and leave a pleasant taste in the mouth. These taste changes are temporary and should return to normal in a few weeks.

If your appetite is poor, small meals with nourishing snacks in between are often easier to take. Eating will be more enjoyable if you take your time, avoid heavy fatty foods and relax for a while afterwards. If your doctor has not advised you to avoid alcohol, a small drink before or with your meal may help to stimulate your appetite.

If you think you are having problems that have not been addressed, talk to the doctor or nurse looking after you, who may ask a Dietician for more specific help.

### **Sleeping**

It is not uncommon to find your sleep pattern has changed. It may be more difficult to fall asleep or you may wake at frequent intervals 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.

Being awake at night can be worrying and things can easily seem to get out of proportion. This is quite normal but can be harder to cope with when you have been ill. If you are awake at night, it can help to read or listen to the radio, even if you don't fall asleep it will help pass the time. A warm milky drink is also helpful, but you should avoid tea or coffee. Large amounts of alcohol should be avoided as this may disrupt your sleeping pattern.

Some people experience nightmares when they are in the ICU or shortly afterwards. Although these may be very vivid and frightening at the time, they usually go away after a few days or weeks – again this is quite normal. Sometimes a visit to the ICU to have aspects of your care explained can help to make sense of, and resolve these nightmares. It can also sometimes help you to remember being in the ICU, as it is quite normal not to remember the experience.

The most important thing is not to worry if you are not sleeping well, it will not do you any harm and will improve as things get back to normal.

### **Your family relationships**

Your family and friends are obviously delighted that you are getting better. However, you may feel they are being over-protective and will 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 recover.

The old saying "a little of what you fancy does you good" is particularly true as regards to sex as you recover. Your illness may have reduced your sex drive and you or your partner may be concerned that sex could be harmful to you. This is rarely the case. As with other forms of exercise, you should do what feels comfortable. You will be able to return to your normal relationship but it may need some time and patience from both of you.

### **Changes in appearance or voice**

Your appearance may have changed while you've been ill but this is usually temporary. You may have lost some hair or find that your skin is drier than before. You may also have lost a lot of weight but time, exercise and a sensible diet will put this right. You may also have some scars that you find unsightly, these will fade in time as your skins gets back to normal.

Your voice may have changed, becoming husky or weak so you can't raise your voice or shout. This is probably as a result of being intubated (tube inserted into your windpipe to help you breathe) or from having a tracheostomy (tube inserted through a tracheostomy in

your neck) and should return to normal in time. If you have an unsightly scar from your tracheostomy, you can be referred by your GP to a plastic surgeon.

### **Mood changes**

You may find you have fluctuating moods – up one day, down the next. This is a normal reaction to illness and will improve with time. If you have been seriously ill or ill for a long time, you may be quite depressed for a while. You may feel that your progress is unbearably slow or fear you will never get back to normal; the up and down struggle to recover your physical strength in itself can be discouraging.

It is important to be realistic about what you can do for yourself and gradually take on the activities you did before you were ill. Set yourself attainable targets to help build your confidence. Don't set yourself difficult, targets as you may feel you have failed if you don't reach them.

Ask the doctors, nurses, outreach team and physiotherapist what you can reasonably expect to do and try to be patient if you have setbacks.

### **Stress**

Recovering after a critical illness can be stressful. The degree of stress and how long it lasts varies. Some of the symptoms are discussed earlier in this booklet.

Getting well after a stressful event takes time. If, at the end of each week, you can look back and say that overall things are better than the previous week, you are making good progress.

Some patients do experience severe symptoms of stress following serious illness and treatment in intensive care. Whilst this improves with time, counselling can be of great value and can be arranged through the hospital or your own GP.

### **Helplines:**

Age Concern:	01354 696677
Benefits Agency:	01733 297600
Citizens Advice Bureau:	01480 388900
Compassionate friends: (Bereaved parents and their families supporting those in similar circumstances)	0117 9539639
Relate (relationship counselling):	01788 573241
Samaritans:	0845 7909090
Victim support (for victims of crime):	0845 303 0900
Cruse (Bereavement Counselling):	01480 414511
DISH (Disability Information Service):	01480 830833



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