

After intensive care

(Eastern services)

Other formats

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- 01392 402093 (for Mid Devon, East Devon and Exeter services)
- 01271 314090 (for North Devon services)
- rduh.pals@nhs.net

Contents

Introduction	1
Going to the ward	2
Exercise and mobility	2
Sleeping	3
Eating normally again	3
Changes in mood	3
Changes in appearance and voice	4
Your family and relationships	4
Helplines	5

Introduction

Patients who have been on intensive care may have been very ill, or may have simply been there as part of their post-operative stay for a period of close monitoring. Whichever of these is the case, it is common that you may not feel back to your normal self for quite a while. This booklet aims to explain why you feel like you do, and provide information about further support that is available to you and your family as you recover.

Going to the ward

Going to the ward is a big step on the way to getting better and eventually going home.

You and your family may feel worried about your transfer to the ward for a number of reasons. The nature of the intensive care unit (ICU) means that you and your family have high levels of support, both medical and nursing, and easy access to a lot of information about your progress. You may feel anxious that you will not be as closely monitored on the ward as you are on the ICU, and that you will not have the same relationship with the staff there.

We would like to reassure you that going to the ward is a very positive step in your recovery - it reflects the fact that you are getting better and do not need such close monitoring. It also allows rehabilitation and preparation for your eventual discharge from hospital. We would not discharge you to the ward if we did not think that it was the right place for you. Similarly, the ward will not discharge you from the hospital until the teams are happy that you are well enough, and have the right support in place.

The staff on the ward are used to looking after patients after they have been in intensive care. Please ask them about anything that concerns you. They are comfortable looking after people who have been seriously ill.

You will also notice that there are fewer nurses for each patient compared to intensive care. This reflects that you are now able to do more for yourself. You will have a call button to press if you need help, which the nurses will answer as soon as possible.

Sometimes, a member of the intensive care team will come out to see patients on the ward after discharge from ICU. This is to support the patients and the staff on the ward. If you have a specific query about your time on the unit, or are worried about how you feel, please ask a member of the ward staff if they think it would be useful for you to see a member of the ICU team.

Exercise and mobility

Patients who have been on intensive care almost always feel exhausted, and find that the smallest thing or slightest activity takes tremendous effort. This is absolutely to be expected. Your muscles have become weakened by your illness and your time in bed, and it takes time to build them up again. Take it slowly at first and gradually increase your activity over the weeks as you prepare for, and then go home. Everyone is different and it is difficult to predict how long it will take you to get back to normal, but it is not unusual for people to feel tired and washed out for a number of weeks. In some cases, if you have been very ill, or had a long stay, you may not feel back to your normal self for months. This may sound worrying, but understanding that this degree of illness takes a great toll on the body may help you understand why it is that you feel as you do.

Before you left the ICU, you will have been seen by a member of the physiotherapy team, who will have made a plan for your rehabilitation. You may be seen on the ward by some of the same members of the team, or by others who will have handed over any relevant information about you. The physiotherapy team will continue to work with you and your nurses to increase your strength and mobility and enhance your recovery. It may all feel very difficult at the beginning but will get better with time.

Sleeping

Sleep disturbance is very common after a stay on the intensive care unit. There are many reasons for this, and include the degree of illness you have suffered, some of the sedative and anaesthetic drugs that may have been used whilst you were unwell, lack of sleep due to noise at nighttime, and a disturbance in your usual environment and day and night sleep cycle.

Sleep disturbance is very difficult to cope with, but it will get better over time. Sometimes, it is helpful to use a sleeping tablet, especially in the short term, but as you recover and go home, attention to a bedtime routine such as bath or shower, and a warm drink before retiring may help you relax and sleep more soundly. Try to 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-time can be worrying and things seem to get out of proportion. It is common for a small problem to become overwhelming in the early hours when you are the only person awake. This is quite normal when you have been ill. If you are awake at night then you may find it useful to read or listen to the radio.

Some patients experience nightmares during and after their stay in intensive care. These may be very vivid and frightening. We know from talking to our patients that these dreams may continue for some time, but they will eventually diminish.

Eating normally again

You may find that you have lost your appetite since being ill or you may find that food does not taste the same. Common changes include an unusual metallic taste and foods tasting saltier or sweeter than usual. These taste changes are only temporary and so it is best to concentrate on foods that you like and leave those that are unappealing. Try them again a few weeks later when your taste buds should hopefully have returned to normal. Many people find that sharp foods such as fresh fruit, fruit juices and boiled sweets are refreshing and leave a pleasant taste in your mouth.

You may find it easier to eat small meals and have nourishing snacks in-between. Take your time when eating, avoid very heavy fatty foods and relax for a while after eating. If you are having problems with eating and have dietary needs, then ask your doctor or nurse to refer you to the dietitian for more specific information on a nourishing diet for home.

Changes in mood

Being critically unwell is a very stressful experience for patients and their families. Many patients experience changes in their mood, which may include feelings of hopelessness and despair, feeling irritable and sad, feeling anxious and worried, as well as difficulty coming to terms with what has happened to you, and any lasting changes in your health or appearance that have resulted. All these are a normal reaction to illness and should resolve with time. Knowing this may not make the problem go away, but it may make it easier to manage. However, if these feelings persist, or worsen, please contact your GP. We also have access to a clinical psychologist, and in some cases our patients have found it very useful to talk to them. If you would be interested in using this service please ask a member of the ward staff.

It is important at this time to be realistic in what you can expect yourself to be able to do. Sometimes it may feel that you will never get back to normal and any progress you make is unbearably slow. Remember that recovery from a serious illness will leave you feeling very weak and your body has a lot of work to do to get back to being fit. Set yourself attainable targets to help you to build your confidence, rather than overly ambitious ones. While you are in hospital, ask the doctors, nurses and physiotherapists to tell you what you can reasonably expect to do and try to be patient with any set-backs you may have.

Remember that the period of recovery after critical illness can be stressful for you. It may be useful to look back at each week's events through your recovery phase and focus on what has gone well.

If you spent more than a few days in ICU, you should have had a patient diary completed, with entries from your family or staff caring for you. Reading through this can sometimes be helpful in giving you a better understanding of what you have been through and help in coming to terms with this.

Changes in voice and appearance

To begin with, your appearance may have changed as a result of your illness, but these changes are usually temporary. Sometimes our patients suffer hair loss or a change in the quality of hair. Similarly, the texture of your skin may change and it is quite common for your skin to be drier than before. Again, these changes are almost always temporary. You may also have lost a lot of weight, but time, exercise and sensible diet will get you back to normal. If you came to Intensive care after having surgery, you might have some scars that you feel are unsightly. These will fade with time and as your skin returns to normal, they will not seem so obvious. If you have had a tracheostomy as part of your care, this scar will also heal quickly, and fade with time. If you are still concerned about any of the above, then seek further advice from the ward staff or your own GP if at home.

You may also find that your voice has changed. It may have become deeper or weaker than normal. This may be as a result of having a breathing tube in your windpipe if you were on a ventilator, or may be as a result of having a tracheostomy. Less commonly, patients who have had neither of these things experience voice changes, and this may simply be a result of disuse and weakness in the muscles which control your voice box. In most cases, these changes resolve over time.

You may also find that you have difficulty swallowing. This is related to generalized muscle weakness, as well as having been on a ventilator. There is a specialist team within the hospital (speech and language therapists) who can come and see you and help with exercises and strategies to improve this.

Your family and relationships

Though it is you who have been ill, your family and friends have experienced it too, albeit from a different point of view. We know that having a family member or friend in intensive care is extremely upsetting, and relatives often feel helpless and frightened. They may have been worried that you would not get better and this can take some people a long time to recover from. Sometimes, as a result of this, they become overprotective and you may feel that you are able to do more than they will let you. Try to understand their points of view, and seek help from one of the doctors, nurses or other team members if you would like to.

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 and you should do what you both feel comfortable with. You should be able to return to your normal relationship but it is important to recognise that this takes time and patience from both of you.

Further help and support

The intensive care team runs a follow up clinic for some patients who have been on intensive care. You may receive an invitation to attend such a clinic in the first few months after you leave the hospital, with details about the clinic. This clinic aims to support your recovery further, dealing specifically with the issues described above and we encourage you to attend if you would like to. If you do not receive an invitation, but would like to attend this clinic, please contact us on rduh.ensure@nhs.net

Help lines

- Anaphylaxis Campaign
01252 542029
www.anaphylaxis.org.uk
- Arthritis Care
01719 161500
- Asthma Helpline
08457 010203
- Benefits Agency, Exeter
01392 474700
- British Epilepsy Association
0808 8005050
www.epilepsy.org.uk
- British Allergy Association
0181 3038583
- British Heart Foundation
0207 9350185
www.Bhf.org.uk
- British Nutrition Foundation
www.nutrition.org.uk
- Cancer Research UK
0800 226237
Cancer.info@cancer.co.uk
- Diabetes UK Careline
0207 4241030
- Headway
01159 240800
www.headway.org.uk
- NHS 111
111
<https://111.nhs.uk>
- National Kidney Patients Helpline
0845 6010209
www.kidney.org.uk
- SANE – Mental Health Charity
0300 304 7000
www.sane.org.uk
- Stroke Association
0845 3033100

ICU steps (www.icusteps.org) is an organization set up by relatives and ex-patients of intensive care, as well as ICU staff to support patients and their families along the road to recovery.

This information booklet has been produced for patients who have been on the intensive care unit at the Royal Devon. Please contact us if you would like any further information. **01392 402425.**

We are very grateful for the help we have received from the Whiston Hospital, Liverpool who have allowed us to use much of their text and ideas in creating this information booklet for the Royal Devon University Healthcare NHS Foundation Trust.

PALS

The Patient Advice and Liaison Service (PALS) ensures that the NHS listens to patients, relatives, carers and friends, answers questions and resolves concerns as quickly as possible. If you have a query or concern, please contact PALS:

- 01392 402093 (for Mid Devon, East Devon and Exeter services)
- 01271 314090 (for North Devon services)
- rduh.pals@nhs.net

Have your say

Royal Devon University Healthcare NHS Foundation Trust aims to provide high quality services. However, please tell us when something could be improved. If you have a comment or compliment about a service or treatment, please raise your comments with a member of staff or the PALS team in the first instance.

You can also share your feedback on the Care Opinion website at www.careopinion.org.uk or freephone 0800 122 3135.



Scan the QR code to visit the Care Opinion website →

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