



University Hospitals Birmingham
NHS Foundation Trust



Critical Care Follow-up Information

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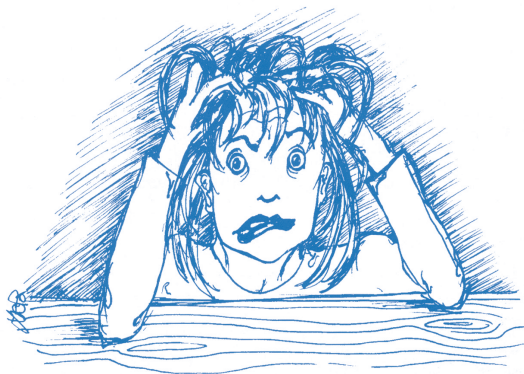
Introduction

This booklet has been designed to help patients and their relatives who have been on one of the critical care units at Queen Elizabeth Hospital Birmingham for a number of days. It gives some advice on the problems or worries you might have now that you are getting better and going to the ward. It can take quite a while to get back to feeling like your normal self but we hope that the information in this booklet will be helpful and will assist you in your recovery process.

We appreciate that being a patient or relative on one of these units is difficult and that you may have questions or worries that you want to discuss. For this reason, a follow-up service is run and coordinated by the Critical Care Follow-up team.

Critical Care Follow-up service

The recovery period after a serious illness can be stressful.



Some of the symptoms that may be caused by stress, such as disturbed sleep, lack of physical energy, loss of appetite, mood changes or depression and problems with family relationships will be explained in this booklet. 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.

However if you feel that you are not making the progress that you expect and you would like to talk to someone about this, you may wish to make use of the advice offered through the Critical Care Follow-up team.

The role of the Critical Care Follow-up Team is to support you and your relatives during your stay on the critical care unit. They will visit you on the ward once discharged from the critical care unit and will invite you back to the critical care follow-up clinic 3-4 months after you have been discharged from hospital.

If there are any issues that you or your family would like to discuss at any time, then you can call the Critical Care Follow-up team on **0121 371 2830** or e-mail the team on **CriticalCareFollowup@uhb.nhs.uk**. We are not always in the office so please leave a message and one of us will return your call as soon as we are able to.

A Critical Care Follow-up clinic is offered to patients who have been on the critical care unit for 7 days or more.

Research has shown that a significant number of people who have had a critical illness may benefit from attending a follow-up appointment.

The one-hour appointment will provide you and your family or carer with an opportunity to discuss your experience with us and we will hopefully be able to answer any questions that you have about your illness or critical care stay.

It also offers us an opportunity to check that you are continuing to make good progress with your physical and psychological recovery. You will be offered the opportunity to visit the critical care unit during this appointment.

Plus it allows us to learn from you and your family, which in turn, will help us to continue to improve the care we provide for future patients and their relatives.

If you have not been offered an appointment for the Critical Care Follow-Up clinic within 3–4 months post-discharge from hospital and would like one then please contact the Follow-up team on the above number.

Support and resources to help your recovery

Patient Diaries

Some patients will have a patient diary commenced during their critical care stay and is given to a patient after discharge from critical care. Patient diaries are a simple but valuable tool in helping patients come to terms with their critical illness experience.

Patients who've had a stay in critical care may be sedated for some time while they're mechanically ventilated. After discharge from critical care, they often report having gaps in their memory from their illness or may remember nightmares, hallucinations or feelings that people were trying to hurt them.

To help fill this memory gap and help patients to understand what has happened we complete a diary. It is usually written directly addressing the patient and diary entries are completed by members of the critical care staff and relatives.

It is your choice when or if to read the diary. You may choose to read the diary during your critical care follow-up appointment with the support of the critical care follow up nurses and your relatives.

A post-critical care rehabilitation class runs on a Friday between 12.30–14.00. This aims to continue to improve your strength and mobility following discharge from hospital and is run by our critical care physiotherapists. You are welcome to attend the class for 6–12 weeks along with your relatives or carers who are welcome to stay with you while you exercise.

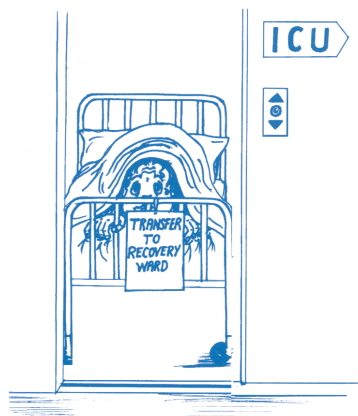
Following the class, we meet for tea and coffee. A member of the Critical Care Follow-up team will be there to discuss and answer any questions you may have regarding your stay in critical care. This is also an opportunity for you to meet other patients who have been on critical care.

If you are interested in attending these classes please contact the Physio rehab team via the Critical Care Follow-up Nurses on the following email address: **CriticalCareFollowUp@uhb.nhs.uk**

You can also find help by seeing your general practitioner (GP) or by contacting the helplines at the back of this booklet.

Going to the ward

Going to the ward is a big step towards recovering and going home. You will notice that on the ward there are fewer nurses for each patient compared to the critical care unit. Initially you will be closely monitored but as you improve you will be encouraged to do more for yourself. If you need any help, you can use the call bell and the nurses will answer you as quickly as they can.



It is quite normal to feel anxious when you change wards. You will have got to know the staff on the critical care unit very well and you will have become used to the routine there. The staff on the ward do understand how you feel as they are used to looking after people who have been seriously ill. Please feel free to ask them about anything that concerns you.

Some patients while they have been on critical care and/or when they are first discharged to the ward may experience episodes of delirium sometimes know as “acute confusional state”.

You may have had vivid dreams, which are often frightening or be unsure about where you are or what you are doing there.

These are some of the common signs of delirium but should improve and settle as you recover on the ward.

While you are on the ward a member of the Critical Care Follow up team will come and visit you and speak to you about your stay on the critical care unit. Going home is now in sight so you will need to work with the staff on the ward as they will help you prepare for going home.

Going home

It can take some time to recover fully from being critically ill. You may find that it affects your mobility and movement. You may have difficulty with eating and sleeping and you may experience mood swings. This may impact on your relationships with people around you therefore learning how to relax can be an important factor in helping you to deal with any frustrations and tiredness that you may be experiencing.

Exercise and mobility

You will probably find that at first the slightest activity takes tremendous effort and leaves you feeling very tired. This tiredness is normal and will improve with time. You may want to plan rest times into your day.



Unfortunately we can't say how quickly you will recover as everyone responds at a different rate and it also depends on a number of things, such as your age, your previous level of fitness, how ill you have been and for how long you have been ill. Do not be alarmed if it takes you weeks or even months to get fully back to normal.

During your stay on the critical care unit you will probably have lost some weight and muscle strength. Your joints may be stiff as you have been resting in bed for some time. The ward physiotherapist will make an assessment of your problems and will work out exercises which are suitable for you.

Below are some simple exercises that you can do whilst sitting out in a chair:

- Tap your toes whilst keeping your heel on the floor
- Bend and straighten your legs at the knees
- Reach each arm up above your head one at a time
- If you are able, shuffle your bottom to the edge of the chair and then push down with your arms on the arm rests to lift yourself up

Before you go home your ward physiotherapist may give you some suggestions on exercises that you can do at home to further improve your strength. With all exercises it is important to start at an easy level and build up as your strength returns. Expect a certain amount of stiffness when you first start a new exercise, but if this does not ease in a few days then seek advice.

As a rough guide you should not feel your heart racing during the exercise and although exercise may make you a little breathless, you should not be so breathless that you cannot talk. Do not exercise if you have recently eaten or feel ill.

You should stop exercising if you experience any of the following symptoms:

- Severe chest pain
- Increase in chest tightness
- Dizziness or feeling faint
- Significantly more breathless than you experienced the last time you exercised

If these symptoms persist, please contact your GP.

As your strength returns you may want to take more vigorous exercise. Swimming, fast walking or cycling will help to strengthen your limbs and build up your muscle strength if practiced regularly. Ask your doctor or physiotherapist for more specific advice if you want to take part in other sports activities.

You may be referred to an occupational therapist who will help with the functional tasks such as washing and dressing. They will also be involved in ensuring you are safe to return home, when it is appropriate.

Eating normally again

While you have been on the critical care unit you will probably have been receiving food via a tube through your nose into your stomach, or sometimes nourishment is given directly into your blood circulation. As soon as you are able, you will be encouraged to take your food normally by mouth.



Since becoming 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 or sweeter than normal. These taste changes don't last long 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 take. 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.

If you are having problems with eating then ask your doctor to refer you to the dietitian for more specific advice on following 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 up 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.

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

Reading before going to sleep is also a good way of relaxing. It may be better to do this sitting in a chair and going to bed when you feel sleepy. That way falling asleep in bed becomes a habit.



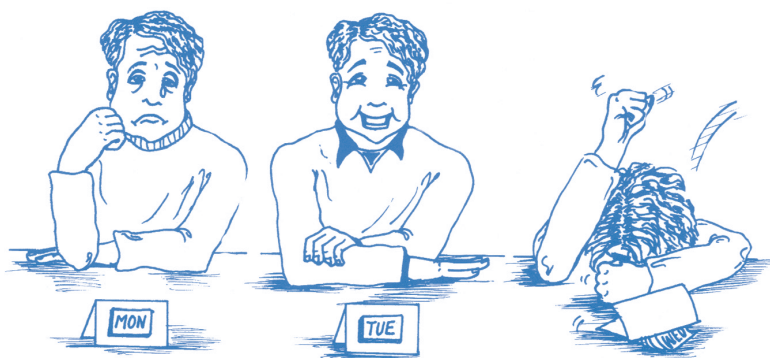
Being awake at night can be worrying, things easily seem to get out of proportion. It is common for a small problem to seem huge in the early hours when you are the only person awake. This is quite normal, but when you have been ill it is often harder to cope with things like this. If you are awake at 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 of our patients experience nightmares or vivid memories known as 'flashbacks' while on the critical care unit or when they leave the unit. These may be particularly likely to occur when the events leading to your admission to the unit were sudden or traumatic. Although these flashbacks may be very realistic and frightening at the time, they

usually subside over a few days or weeks. It is quite normal to experience these things. However if they persist it is worth discussing these symptoms with your GP. The Sleep Charity (thesleepcharity.org.uk) also has lots of useful tips and further advice. Finally, the most important thing is not to worry about lack of sleep because as you recover things will get back to normal.

Changes in mood

Once at home, you may experience emotional changes as well as physical changes. Many patients complain of varying moods – one day feeling good, the next feeling down or tearful. This is a normal reaction to illness and will subside with time. Talk about it with your family or whoever is caring for you so they understand how you feel.



This applies equally whether you are a patient or a relative. If you have been very seriously ill or ill for a long time, you may find that you feel low in mood for a while. Sometimes it may seem that you will never get back to normal and that any progress you make seems very slow. The up and down struggle to recover your physical strength in itself can be discouraging so it is important for you to be realistic about what you will be able to do for yourself. Gradually take on the activities that you did before you became ill.

It may help boost your morale if you set yourself targets you can manage and this will help to build your confidence. Do not set yourself targets that are too difficult to reach and tick them off. It is important not to be too ambitious as you may feel that you have failed if you don't achieve everything as quickly as you had hoped to.

Ask the nurses, doctors and physiotherapists to tell you what you can reasonably expect to do and try to be patient if you have set backs.

Your family and relationships

Your 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 you are 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 of 'a little of what you fancy does you good' is particularly true for sex during your recovery from illness. Your illness may have reduced your sex drive and it is possible that either you or your partner are concerned that sex could be harmful to you. This is rarely the case, but as with other forms of exercise you should do as much as feels comfortable. You will be able to return to your normal relationship, but try to understand that this may take time and patience from both of you.

Changes in appearance or voice

Your appearance may have changed as a result of being ill, but these changes don't usually last long. You may experience hair loss, a change in the quality of your hair or find that the texture of your skin has changed and has become drier than before. You may also have lost a lot of weight, but time, exercise and a sensible diet will get you back to normal. You may also have some scars that you may feel are unsightly. These will fade in time, and as your skin returns to normal they will not seem as obvious.

You may find that your voice has changed. It may have become husky or be so weak that you are unable to raise your voice or shout. This is probably the result of being intubated or having a tracheostomy. This should return to normal over time. If not, please speak to your GP for further advice.

Stress and relaxation

Everyone can benefit from periods of relaxation. This can be whatever you enjoy such as sitting watching television, gardening or knitting. It can be particularly valuable to plan your relaxation periods and use the following techniques to relieve anxiety and help you rest:

- Find a quiet room
- Get into a comfortable position
- Wear loose and comfortable clothing
- Adopt a passive attitude – this means letting go of your worries for a while so that for the time that you are relaxing you accept that there is nothing you should be doing – the world can turn without you
- Use a slow, deep breathing pattern from your tummy. Breathe in through your nose and out through you mouth with pursed lips
- Use a repeated word, image or thought to empty your mind of other thoughts
- Tense and relax the muscles in every part of your body, in turn concentrating on what it feels like as you prolong the tension and leave them relaxed. Move slowly through your body, tensing and relaxing the muscles on both sides working from your hands and feet through your limbs in towards your body, shoulders, neck and face
- Find the best position and technique for yourself and practice regularly so that you can be confident to use these skills when you need them

Helplines

Critical Care Follow-Up Service

Queen Elizabeth Hospital
Birmingham Critical Care Support
Mindelsohn Way, Edgbaston,
Birmingham, B15 2GW
Nurses Telephone: 0121 371 2830
E-mail:
CriticalCareFollowUp@uhb.nhs.uk

ICU Steps – The intensive care patient support charity

www.icusteps.org
Telephone: 0300 302 0121

Critical Care Support Network

Telephone: 07955 848596
www.cc-sn.org

Asthma

Asthma and Lung
Telephone: 0300 222 5800
Monday–Friday, 9am–5pm
www.asthmaandlung.org.uk

Bereavement

Cruse
Helpline: 0808 808 1677
www.cruse.org.uk

Cancer

Cancer Research UK
Telephone: 0300 123 1022
www.cancerresearch.org.uk

Carers

Carers UK
Carers line: 0808 808 7777
Monday–Friday, 9am–6pm
www.carersuk.org

Diabetes

Diabetes UK
Telephone: 0345 123 2399
www.diabetes.org.uk

Disabled

Disabled living
Telephone: 0161 214 4590
www.disabledliving.co.uk

Epilepsy Action

Helpline: 0808 800 5050
www.epilepsy.org.uk

Family and relationship problems

www.relate.org.uk

Heart disease

British Heart Foundation
Telephone: 0808 802 1234
www.bhf.org.uk

Head injuries

Headway the brain injury association
Free helpline: 0808 800 2244
www.headway.org.uk

Liver disease

British Liver Trust
Helpline: 0800 652 7330
www.britishlivertrust.org.uk

Mental health

National Association for
Mental Health (MIND)
Information line: 0300 123 3393
www.mind.org.uk

Samaritans

Free 24hr helpline: 116 123
www.samaritans.org.uk

Stoma

Colostomy UK 24hr
Helpline: 0800 328 4257
www.colostomyuk.org

**OPA cancer charity
Oesophageal and gastric
cancer support**

Telephone: 0121 704 9860
www.opa.org.uk

The Stroke Association

Telephone: 0303 303 3100
www.stroke.org.uk

Please use the space below to write down any questions you may have
and bring this with you to your next appointment.

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How did we do? 😊 😐 😞

If you have recently used our services we'd love to hear about your experience. Please scan the QR code or follow the link to share your feedback to help us improve our services. **Thank you.** www.uhb.nhs.uk/fft



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