
Adjusting to life after critical care

Critical Care Unit

Information for patients



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Introduction

This booklet is designed to help familiarise you with the Critical Care Unit (also called CCU or the Intensive Care Unit) and to address some of the issues you may face after critical care.

When you have been ill, it may take some time for you to get back to feeling your normal self. The time this takes will depend upon various factors. These can include:

- The length of time you have been ill
- Whether your illness means that you will have to change some aspects of your lifestyle
- The state of your general health before your illness
- Whether you have lost weight
- If you have had any memory or 'thinking' (such as problem solving) difficulties
- If you have any previous issues related to feeling down, anxious or depressed.

On the ward

Being fit enough to be transferred from CCU to the ward should be viewed as a positive step on the road to recovery and going home. You will not go to the ward until the critical care team has assessed you and decided that you are medically well enough. For the first few days on the ward you will be visited daily by the Critical Care Outreach Team. These nurses are highly experienced in caring for patients who have been in critical care. They work closely with the ward team to support you and plan your care and rehabilitation to ensure that your recovery progresses well. In some cases the Critical Care Outreach Team may only need to see you for one day after your discharge from critical care; the amount of support you may need differs for each person and is tailored accordingly.

You have left CCU because you are getting better and are now well enough to not need critical care. However, this can be

difficult for you and your family to adjust to, particularly if your stay in CCU was prolonged. There are fewer nurses and less equipment on the ward which may be an adjustment for you and your family. This simply reflects the fact that your health is improving, you need less support and are ready to be more independent. You are being looked after; it is just that the level of care is different.

The first few days on the ward may not be easy for you and your family. You may feel scared, insecure, anxious or have difficulty sleeping; this is normal. The ward staff will understand your feelings as they are experienced in looking after people who have been seriously ill. If you have any questions or concerns the ward staff or Critical Care Outreach Team will be happy to come and speak to you.

It is important to get back to a normal level of walking and independence before you go home. You will be encouraged to get up and about as much as possible when you go to the ward; you will be assisted by the nursing team or therapists with this. If you are not getting back to your normal level of independence as fast as you would expect, or if you have any concerns about how you will manage when you get home from hospital, your nursing staff can refer you to the physiotherapist and occupational therapist on your ward, or to the complementary therapists for massage therapy or reflexology.

Eating and drinking

You may find that you have lost your appetite since being ill and that your food does not taste the same. These changes are only temporary and should return to normal with time. You may not be allowed to eat or drink when initially on the ward, especially if you have had certain types of surgery. This may mean that you are being fed via a line into your bloodstream or via a tube into your nose or intestine. Sometimes swallowing can be a little more difficult after having had a tracheostomy or certain head and neck surgery. The ward staff, speech

and language therapist and dietitian will advise you in these situations and will continue to see you on the ward. Sometimes the feeding tube will remain in use on discharge to the ward and occasionally on discharge home.

If you have lost some weight during your stay or have a lack of appetite, this can be managed by choosing smaller meals with nourishing snacks in between. Eating may be more enjoyable if you take your time and try to relax for a while afterwards. The dietitian may offer supplement drinks which can help to provide extra nourishment until you are eating better. They can also help you to regain some weight. Sometimes these may need to be continued for a while at home. Your dietitian will advise you if this is necessary and will stay involved in your care during your hospital stay and then often via an outpatient clinic (once discharged) until you are managing to eat better.

A balanced diet is an essential part of your recovery. Eating the right foods and drinks will help your recovery both on the ward and later when you go home, but it is equally as important for you to be happy and enjoy what you eat and drink. Please see The Royal Marsden booklet *Eating well when you have cancer* for meal ideas and further information.

Wounds and scars

You might have surgical wounds from major surgery or you may have a scar from a tracheostomy, drain, or central venous catheter. These should improve over time but can affect how you feel about yourself. Any surgical wounds will be reviewed by the ward staff and later by your oncology team at your medical or surgical outpatient clinic appointment.

Tiredness and fatigue

You may feel easily tired and find it hard to do some activities at first. This tiredness is normal and to be expected, however it will improve with time. Muscle weakness, joint stiffness or soreness can be particular problems if you had a prolonged stay

in CCU. Help is available to gradually increase your activity over the following days and weeks. At first you might need help from the nurses, physiotherapist and occupational therapists but you will gradually be able to do more for yourself. Everyone is different and improves at a different rate, so it is difficult to place a time scale on your recovery.

If you feel worried or frightened about doing certain activities, please discuss this with the ward nurses, physiotherapist or occupational therapist.

If you have been on CCU for some time you will have a personalised rehabilitation folder. This has a plan for your rehabilitation care from your critical care physiotherapists, occupational therapists and any other teams involved in helping you to return to your normal activities.

Sleeping

You may find that your sleep pattern has changed. It may be more difficult to fall asleep or you may wake frequently during the night. This is probably due to the disruption of sleep in hospital, and can be related to certain drugs used in the CCU. As you recover and become more active you should find that your sleep pattern returns to normal.

Go to bed at the same time each evening and most importantly, get up at the same time each morning, even if you have not slept well during the night. This will help you to recover your normal routine and sleep pattern.

Being awake at night can be worrying. It is common for a small problem to seem overwhelming 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. If you are awake at night then you may find it helpful to read or listen to the radio (earphones are provided on the ward). The critical care follow-up team also has various sleep and relaxation resources to help. We can also refer you to an occupational therapist (OT) for relaxation or massage therapy.

Some patients experience nightmares or strange dreams while in critical care and when they leave the CCU but these usually settle over a few days or weeks. If they do not subside or become more frequent, please talk to the ward staff, Critical Care Follow-Up nurses or GP as there are a number of ways in which they can help.

Changes in feelings, memory and moods

As well as nightmares, some people experience flashbacks or distressing memories. Some patients may also experience fluctuating moods; one day feeling up, the next day feeling very down. If you have been seriously unwell or ill for a long time, you may find that you feel depressed for a while. Sometimes it may seem that you will never get back to normal and that any progress you make is unbearably slow.

It is important to be realistic about what you will be able to do for yourself. You should gradually take on the activities that you did before you became ill and set achievable goals to help increase your confidence. The staff on the ward can advise you on how much you can reasonably expect to do.

Some people also find it hard to concentrate for any length of time. It can take time for memory to recover so you might find you are more forgetful. Problem solving can be harder too; this will resolve but it can take weeks and sometimes longer. Some people find that they also feel irritable for no real reason. This is a normal reaction to illness and should subside with time.

Delirium

Delirium is the name for acute confusion. It is not a disease but a group of symptoms. It is very common to experience this when in the critical care unit. You may find it difficult to retain information and irrational thoughts may occur. These symptoms often fluctuate throughout the course of the day and night, but please be reassured that these symptoms will resolve with time.

The staff may ask you a series of questions to help assess whether you are experiencing delirium. It is important for you to communicate any concerns to a health professional so we can support and provide further information for you and your visitors.

Your family and relationships

Your family and friends will be pleased that you are getting better, but they may be overprotective and not let you do as much as you feel able to do; it has been a worrying time for them too. It may take a while for them to adjust to you getting better and being more independent again. Talking over what has happened and sharing your worries will help you to work together towards your recovery.

Financial support

You may have been in hospital for longer than you expected or you may take longer to return to your 'normal' once at home. This can have an impact on household routines and finances.

There are welfare advisors based at The Royal Marsden who can give you financial advice and help you apply for any benefits you may be entitled to. Please do not hesitate to discuss these issues either with the nurses or directly with the welfare team.

The contact numbers for the welfare rights advisors are:

020 8661 3386 (**Sutton**) or 020 7349 9618 (**Chelsea**).

Critical Care Follow-Up Clinic

The Critical Care Follow-Up Clinic at The Royal Marsden is run by senior critical care nurses. If you have been cared for in CCU for 96 hours or more, we will contact you by phone from three months after your discharge.

If you or the staff at The Royal Marsden have recognised signs and symptoms of delirium, we will call you as a priority at two months after your discharge. The aim is to allow an opportunity to review your recovery from Critical Care as well as providing guidance for any concerns related to your CCU stay. The nurse will complete a health assessment and can arrange any referrals that you may need and help you plan for the future. The clinic provides specialist nurses to help you understand more about what happened in CCU and generally fill in the gaps that sedation and certain medication may have left. After this initial review, you may feel that a visit to the Critical Care Unit or meeting with the clinic nurses may be beneficial - this is something we can organise for you. If you have had a patient diary completed whilst you were cared for in the unit, we will go through this with you over the phone.

If you have any questions at all about any aspect of your stay in Critical Care or if you are outside the inclusion criteria and wish to receive a phone follow up review, please get in touch via email: CCUFollowUp@rmh.nhs.uk

Critical Care Experience Group

The Royal Marsden Critical Care Unit patient and family experience group meets twice a year. This is a group where you can help us look at how we can improve CCU services, and develop CCU work, but also meet and share your experiences on CCU. If you have been treated in the unit for more than seven days, you may be invited to this group. If you wish to attend, please email: CCUPatientExperience@rmh.nhs.uk.

Other support

In addition to this clinic, there are web-based support groups that can help such as:

DIPEx – Database of Individual Patient and Relative Experiences

www.healthtalk.org

This is a database of audio, video and transcript of interviews with patients and relatives experiencing particular illnesses or health problems which includes a module on critical care.

ICS – Intensive Care Society

www.ics.ac.uk/ICS/patients-and-relatives.aspx

This is the professional organisation for doctors and other professionals working in Intensive Care. ICS is a world leader in patient and relative involvement in all aspects of Intensive Care treatment and has a dedicated division especially for this work.

ICUsteps

www.icusteps.org

ICUsteps is the United Kingdom's only support group for people who have been affected by critical illness and has helped many former patients, their relatives and medical staff from organisations around the world.

Contact details

For any further information about the critical care follow-up clinic or any other queries about critical care you can contact:

CCU Follow-Up Team:

Tel: 020 7352 8171 Ext 1639

Email: *CCUFollowUP@rmh.nhs.uk*

Social Work Department

(for benefits advice and support available)

Tel: 020 8661 3386 or 020 7349 9618

The Royal Marsden Macmillan Hotline 020 8915 6899

You can ring the hotline 24 hours a day, 7 days a week.

Call us straight away if you are feeling unwell or are worried about the side effects of cancer treatments.

This service provides specialist advice and support to all Royal Marsden patients, as well as to their carers, and both hospital and community-based doctors and nurses caring for Royal Marsden patients.

Questions and notes

References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

Freephone: 0800 783 7176

Email: patientcentre@rmh.nhs.uk

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.



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