



**Adjusting to life after oncology critical care:  
oncology critical care follow-up**

<b>Contents</b>	<b>Page number</b>
Introduction.....	2
Going to the ward .....	2
Tiredness and activity.....	3
Sleeping .....	3
Eating and drinking.....	4
Wounds and scars.....	5
Changes in feelings, memory and moods .....	5
Future concerns and anxieties .....	5
Oncology Critical Care follow-up clinic .....	5
Your family and relationships .....	5
Support groups.....	6
Contact details.....	6

## **Introduction**

This information is designed to help you make sense of your stay in the oncology critical care unit and to address some of the issues you might come across after critical care. You may not have all these issues, but they do concern a number of patients who have been in critical care.

When you have been ill, it may take some time for you to get back to feeling your normal self. How long this will take will depend upon various things. 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
- your state of health before your illness, and after your illness
- whether you have lost weight
- if you have had any memory or thinking difficulties such as problem-solving, flashbacks and dreams

## **Going to the ward**

Going to the ward is a big step on the way to getting better and going home. Although this is an important step forward, it is normal to feel apprehensive as you and your family have become familiar with the staff and routine in the oncology critical care unit.

You will notice that on the ward there are fewer nurses for each patient compared to critical care. This reflects the fact that your health is improving and you are ready to be more independent. Doing more for yourself is a very important part of your recovery and rehabilitation. Even if you can't see the nurses all the time, they are still nearby. You will have a call bell to use if you need any help, which the nurses will answer as quickly as possible.

The first few days on the ward may not be easy for you and your family. You may feel scared, insecure and anxious. These are all normal fears and the ward staff are aware of them. It is important to remember that you are getting better and are well enough to be on the ward. The ward staff will understand your feelings as they are used to looking after people who have been seriously ill.

During your first few days on the ward you will be visited by the critical care follow-up team. This is a specialist team with considerable critical care experience consisting of a critical care consultant, acute oncology outreach nurses, physiotherapists, dietitians and a psychiatrist. They work closely with the ward team to support you and plan your care and rehabilitation to ensure that your recovery progresses well.

### **Tiredness and activity**

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 when you have had a prolonged stay in critical care so you might need intensive physiotherapy. You will gradually need to increase your activity over the following days and weeks. At first you might need help from the nurses, physiotherapist and sometimes, occupational therapists or speech and language therapists. Your physiotherapist will give you some exercises and you will need to do these independently or with your family throughout the day. This will help to build your muscles after being ill and lessen the effects of fatigue. If you are having difficulties with fatigue you can discuss this with your occupational therapist or physiotherapist. Everyone is different and improves at a different rate, so it is difficult to place a time scale on your recovery.

You may also need to wear splints in order to prevent further joint problems developing. You will see an occupational therapist for this who will also advise how often you need to wear them.

If you feel worried or frightened about doing certain activities, discuss this with your physiotherapist, the ward nurses or critical care follow-up team and they can reassure you about what to expect from yourself during your recovery. Following illness and major surgery you will be weak and your body has a lot of work to do to get back to being fit. It is important for you to be realistic about what you will be able to do for yourself. Try not to set targets which are too difficult for you to reach as you may feel as if you have failed. You may wish to talk to the critical care follow-up team who will be able to advise you about how much you can reasonably expect to be able to do.

### **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 the oncology critical care unit and on the wards. Your body is less active, the wards may be noisy and you may have received medication in critical care which could have changed your sleep pattern.

Lack of sleep may make you feel very tired and lethargic. However, it is important not to worry about it as lack of sleep over a short period of time should do you no harm. As you recover things should get back to normal. If it is troubling you we can review this.

Some patients experience nightmares or strange dreams while in critical care or when they first leave the unit. These feelings may not just be at night and can come back as 'flashbacks'. Flashbacks are mental images of something that has happened and can be recurring. They can be related to certain drugs used in critical care, but not always. These may be vivid, graphic and disturbing but they usually subside over a few days or weeks and again it can be quite normal to experience this. Occasionally, these don't subside and might become frequent and more bothersome. If this happens please discuss this with the critical care follow-up team who will assess this further.

## **Eating and drinking**

Whilst you were on the unit you may not have been able to eat and drink, or manage to take enough to eat to meet your needs.

You may have had to have a feeding tube placed through your nose into your stomach (called nasogastric feeding or NG) or you may have had to have another type of nutrition called parenteral nutrition (PN) through your central line directly into your vein. This would have been used if your gut was not working or could not be accessed.

If you were able to take food and drink you might have been recommended some additional snacks or nutritional supplement drinks as a top up to your intake.

Now you are back on the ward you might still need to have the special feeds via the NG or PN route, or you may have been able to stop these and you can eat and drink again.

Sometimes swallowing can be a little difficult after having had a tracheostomy; the speech and language therapist, dietitian and ward nurse will advise you on what to eat if this is the case.

If you are able to eat and drink, you may find your appetite has reduced since being ill, or you may find that your food does not taste the same. These changes are only temporary and should return to normal in time.

You may need some help with your dietary needs. We may offer you high energy meals and snacks, along with nutritional supplement drinks to provide extra nourishment and help your recuperation. Sometimes it may be necessary to continue these for a while at home. Your dietitian will advise if this is the case.

It may be beneficial for your local community dietitian to see you when you are at home. Your dietitian will discuss this with you before your discharge, or if you feel once you are at home you would like input, you can arrange this via your GP.

A sensible balanced diet is an essential part of your recovery. Eating the right foods and drinks for your needs will help your recovery both now and later when you are discharged home. It is equally important for you to enjoy what you eat and drink. You may find the following Christie booklets useful for further information:

- Eating – help yourself
- Nutritional products
- Advice about a soft and liquidised diet

You can get copies from your dietitian, on your ward, the cancer information centre or via The Christie website.

## **Wounds and scars**

You might have surgical wounds from major surgery or you might have scars from a tracheostomy, drain, central venous catheter or arterial line. These can affect how you feel about yourself but will improve over time. Any wounds will be reviewed by the ward staff and later by your oncology team.

## **Changes in feelings, memory and moods**

Some patients complain of fluctuating moods: one day feeling up, the next day down. You may also feel irritable for no real reason at times. Feelings of anxiety and depression have also been reported by some patients. These are normal reactions to illness and should subside with time. They will be assessed by the critical care follow-up team.

Some patients also find it hard to concentrate for any length of time after a period of critical illness. This is especially the case if you had periods of confusion or 'delirium' in critical care. It can take time for memory to recover too 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. For this reason it is important not to rush back to work or study.

Coming to terms with what has happened to you may take a while. It may help if you can find someone to talk to about your experience. You may wish to talk to someone other than family or friends in which case the nurses and doctors on the ward will be happy to help as well as the critical care follow-up team. We also link closely with our psycho-oncology service and the ward team or acute oncology outreach nursing team can refer you.

## **Future concerns and anxieties**

You might also have specific concerns about your cancer treatment in relation to your recovery following critical care. The critical care outreach team can liaise with your cancer nurses and doctors on your oncology team to discuss this further as needed.

## **Critical care follow-up clinic**

Once you have returned home from hospital the critical care follow-up team will contact you by phone. This gives you the opportunity to discuss your progress or any concerns you may have after leaving hospital. We will also give you the option to attend a critical care follow-up clinic run by the critical care follow-up team. Here, you will have a health assessment and any referrals can be made to help you continue with your rehabilitation after critical care. At the follow-up clinic, we can give you a diary of your stay in critical care and offer you the chance to visit the oncology critical care unit if you wish.

## **Your family and relationships**

Your family and friends will be pleased you are getting better, but they may also be a little overprotective. They have been through a worrying time. It may take a while for them to adjust to you getting better and being more independent again.

You may feel their attitude to you has changed. Seeing someone you love in critical care can be upsetting. Relatives often feel helpless and frightened. They might also be very tired from worrying about you. This experience may take a while for you all to get over. If a member of your family would like to talk through any issues we can see them and offer support at the follow-up clinic as well.

## Support groups

In addition the follow-up clinic there are web-based support groups that can help such as:

[www.healthtalkonline.org](http://www.healthtalkonline.org)

[www.youthhealthtalkonline.org](http://www.youthhealthtalkonline.org)

[www.anaesthesiauk.com/page.aspx?id=86](http://www.anaesthesiauk.com/page.aspx?id=86)

[www.ics.ac.uk/patients\\_relatives/patients\\_relatives\\_section](http://www.ics.ac.uk/patients_relatives/patients_relatives_section)

[www.icusteps.org.uk](http://www.icusteps.org.uk)

## Contact details

For any further information about the critical care follow up clinic or any other queries about your critical care stay you can contact the duty acute oncology outreach nurse via the main switchboard or e-mail:

**0161 446 3000**

**[kelly.carter@christie.nhs.uk](mailto:kelly.carter@christie.nhs.uk)**

This booklet was produced with the help of staff at the Royal Marsden.

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact **[patient.information@christie.nhs.uk](mailto:patient.information@christie.nhs.uk)**

© 2016 The Christie NHS Foundation Trust. This document may be copied for use within the NHS only on the condition that The Christie NHS Foundation Trust is acknowledged as the creator.

For more information about The Christie and our services, please visit **[www.christie.nhs.uk](http://www.christie.nhs.uk)** or visit the cancer information centres at Withington, Oldham or Salford.

The Christie NHS Foundation Trust  
Wilmslow Road  
Withington  
Manchester M20 4BX

Tel: 0161 446 3000  
[www.christie.nhs.uk](http://www.christie.nhs.uk)

The Christie Patient Information Service  
December 2016 - Review December 2019

