Critical Care Rehabilitation Manual
The road to recovery

Information for patients

This leaflet can be made available in other formats including large print, CD and Braille and in languages other than English, upon request.
This manual is designed to help you recover in the quickest and safest way. It has been written using research and information, some of which was provided by patients who have previously been in Critical Care.

It will provide you with information about the Critical Care Unit and some common problems that may occur. The information will answer some of your questions and provide you with simple suggestions to try and resolve any problems you encounter. If you live with someone, let them read the information with you, it can help them understand what has happened.
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What is the Critical Care Unit?

The Critical Care Unit is a ward within our hospital which delivers care for patients whose conditions are life-threatening and need constant, close monitoring and support from equipment and medication to keep normal body functions going.

Due to the specialist treatments and the constant monitoring that patients require on Critical Care, it has a higher level of staffing.

The staff who work here are highly trained in caring for the most severely ill patients.
What equipment is used in Critical Care?

The equipment in a Critical Care Unit can seem frightening at first. It is common for patients to be connected to a number of different machines or devices if they are critically ill. As patients recover the equipment is slowly removed as it is no longer needed.

A monitor is positioned by each bedside and records your heart rate, blood pressure and the oxygen levels in your blood.

The monitors are connected to you by a number of leads and bleep if your levels are falling or rising outside normal ranges.

You may remember hearing these alarms. On most occasions, the monitor is simply drawing the attention of a Nurse to check your condition.

A breathing machine or ventilator is a machine that helps you to breathe.

A tube may be inserted into your windpipe through your nose or mouth.

It may also be inserted into your trachea (windpipe) through an incision (cut). This is called a tracheostomy.
As your condition improves it is possible to be weaned off the ventilator.

Infusion pumps are used to give drugs and fluids through drips into your veins.

A kidney filtration machine, known as a Continuous Veno-Venous Haemofiltration (CVVH) can be used if your kidneys are not working normally.

This works in a similar way to a dialysis machine and removes waste from your blood and manages your fluid levels.

Blood circulates from your body through the machine, where it is filtered and then returned to your body.
What is a tracheostomy and if I had one why did I need it?

A tracheostomy is a tube passed surgically through an incision in your neck, which is more comfortable than a tube in your mouth to help you breathe. It allows you to be awake comfortably while on a ventilator, which helps your breathing muscles to gain strength.

You may have been discharged from the Critical Care Unit (CCU) to a ward with the tracheostomy still in place. This may be because you are not yet strong enough to clear your chest of phlegm (mucous) without the help of suction.

There may also be an ongoing issue with keeping your airway open which requires a tracheostomy tube to stay in place.

In nearly all cases the tracheostomy tube is temporary until you regain some strength.

Tracheostomies are usually painless to remove and the opening in your neck does not require stitching as it will close naturally over time, leaving a thin horizontal scar.

Sometimes swallowing can be a bit uncomfortable, this should settle in time.

At first your voice may be weak, husky or non-existent but this is temporary and should eventually return to normal. The tight dressing that is placed over the tracheostomy site prevents air going in and out and makes talking and coughing easier.
If your voice is too quiet or you feel breathless, try putting a finger on the dressing while you talk. Not being able to communicate can be very frustrating. Using a pen and paper can be a helpful alternative to speech.

**What is a Critical Care Diary?**

Patients who are mechanically ventilated for more than 3 days will have a diary started for them by the nursing staff. This is because patients who have been ventilated while in critical care often remember very little of their stay on the Unit.

Patients are usually sedated in the early stages of their illness. When patients regain consciousness it is common not to remember what happened, they may not know where they are or how ill they have been.

Being a relative of someone in critical care can be very stressful. Diaries can help your relatives and close friends by giving them something to focus on, an opportunity to gather their thoughts after each visit and the chance to express their feelings.

Your diary will tell a story of what has happened to you while you have been in critical care.

A photograph of you will have been taken at the beginning of your stay.

This will not be added or shown to anyone else until you have seen it and consented to it being added to your diary.

Patients who have seen photos of themselves when they were critically ill may find it easier to come to terms with their experience.
You will receive your diary when you leave the Critical Care Unit and you are settled on to a general ward. A healthcare professional will show you your diary and photo and give you the opportunity to discuss some of the content and ask any questions.

**If you don’t want to keep your diary or the photo they will be destroyed after 1 year.**

**Possible effects on my family and friends**

Your family and friends have been through a very worrying time and will be delighted you are getting better.

You, your family and friends may see your illness in a different way and may remember events differently. This can make it difficult for you to understand what they have experienced during your illness.

They may have watched helplessly as you underwent a very traumatic experience attached to machines and tubes and, as a result they may be overprotective towards you.

Try to be patient with them. Listen to their fears but remember to tell them how you feel too. They want to help with your recovery and can probably fill in the parts of your experience that you don’t remember.

**What will happen when I am transferred to a ward?**

The decision for you to leave the CCU rests with a Critical Care Consultant. These decisions are made in close consultation with the Nurses and doctors on the Critical Care Team and the specialist teams involved.

When you are transferred to the ward there is a detailed handover between the Critical Care Nurses and the ward Nurses and between the medical teams.
Leaving Critical Care should be a time for celebration. You are getting better and are well enough that you no longer need the higher levels of care.

However, we know this can be a very difficult time for you and your family, particularly if your admission to critical care has been a long stay. No matter how much preparation has been done, patients will find a big difference in the level of care between the CCU and general wards.

After you have transferred to a ward, one of the Critical Care Outreach Team (CCOT) Nurses will visit you. The CCOT are experienced critical care Nurses familiar with the effects of critical illness. They will support the ward staff with your ongoing care until they are happy your condition is stable.

Some of the key issues patients face when being transferred to the ward are the change in:

- environment
- staffing
- yourself.

**Environment**

Although the CCU can be a challenging place to be, for some patients it is a safe place and it is a big change moving to a ward. The daily routines, staff and sounds are different. The other patients are likely to be well enough to talk and this is very different from the CCU.

Some patients on the ward may be confused or noisy and you may find this very disturbing. Most of the beeps and noises from the machines in the CCU will have stopped. These beeps and alarms will often have become familiar and their absence can be just as worrying for some patients.
Most medical and surgical wards in our hospital are made up of 4 - 5 single-sex bays, with 4 beds in a bay.

There will also be a small number of individual rooms on the ward to accommodate patients with specific health problems.

**Staffing**

In the CCU there is usually 1 Nurse per patient or 1 Nurse for 2 patients depending on the level of care required. On a ward there will be fewer Nurses, especially during the night.

You will be given a call buzzer to attract the attention of the staff, sometimes there can be delays in someone responding. This is due to the number of patients on a ward and the nursing demands at that time.

Transferring to the ward can be a very stressful time for you and your family.

While in the CCU, your family would become used to getting detailed information and explanations about you from the team whenever they asked.

On the ward, your relatives will more than likely have to wait to be updated on your condition. Sometimes as a result, patients and families can feel neglected. This is not the case, it is just the change in the level of care is different. You will still receive the right level of care for you.

**Please feel free to speak to your Nurse if you have any questions or concerns.**
The process of recovery from critical illness is not easy. Going back to the ward often means you are becoming more independent and this can be very hard work and tiring.

Everyday tasks can be challenging, for example:

- learning to eat and swallow normally again.
- getting washed and dressed.
- going to the toilet.

Setting small, realistic goals with the therapy team and nursing staff will help you.

Following a critical illness your confidence may be low due to changes in how you look and feel. You may be carrying a little extra fluid and over time you may notice you have lost weight.

You should regain your weight with exercise and a sensible diet. You may also have some extra scars, which may be upsetting at first but they will fade with time as your skin condition improves.

How will I recover from critical illness?

When you have been in the CCU it can take quite a while to get back to feeling like your normal self. For some people this recovery can take up to 1 year.

Your recovery will depend on many factors, for example, how long you were ventilated, any weight loss and whether you need to make any lifestyle changes.
These are some of the complications that patients may face:

- Social problems
- Sleep disturbance
- Anxiety
- Depression
- Difficulty walking or getting out of bed.
- Breathing difficulties
- Pain
- Weight loss
- Communication problems
- Swallowing difficulty
- Weakness
- Post Traumatic Stress Disorder (PTSD)
- Cognitive dysfunction (for example, memory loss, poor concentration)

**How will my sleeping be affected?**

You may find that your sleeping pattern has changed since leaving the CCU. It may be more difficult to fall asleep or your sleep may be broken.

When your body is not active it does not need as much sleep. As you increase your activity, you should find your sleeping pattern returns to normal.

The most important thing is not to worry about a lack of sleep; it won’t actually do you any harm and as you recover things will get back to normal. If you are worried or need further advice you should speak to a healthcare professional.

**What if I have nightmares or altered memories?**

Some patients experience nightmares while they are in the CCU or when they first leave. They may be very vivid and frightening. They usually stop after a few days or weeks and is not unusual.
Some patients experience hallucinations or feelings that someone was trying to hurt them while they were in CCU. Again, these experiences are normal and are caused by a combination of you being extremely poorly and the medication given to keep you comfortable.

If you have had or are having problems like this it is important not to keep it to yourself. You may find it helpful to talk to a family member and/or look at your patient diary to help make sense of what has happened.

If the memories or nightmares continue to trouble you it is important to talk to someone about it.

**How can critical illness affect my mood?**

Many patients suffer from changing moods. You may also feel very irritable for no reason at times. This is a common reaction. Knowing this will not make the problem go away but perhaps it will be easier to understand. If you have been very seriously ill or ill for a long time, you may find that you are anxious and/or depressed.

If you are suffering from anxiety or depression it is important to discuss this with your family or a healthcare professional. For the majority of people, simply discussing thoughts and feelings help to ease the problem.

It is important to set yourself small, achievable goals. Be proud of your progress. Often patients have unrealistic expectations of the pace at which they recover.

**What is Anxiety?**

It is normal to worry after being critically ill. When we are worried, scared, in danger or under stress our bodies automatically produce chemicals to help us cope. The main chemical is called Adrenaline. In a real emergency it can help to save our life.
Frightening events, words, thoughts or memories that you may have from Critical Care will cause the body to produce adrenaline. There is nothing wrong with this as it is part of nature’s way of helping you to cope with danger and live to fight another day. If we are in real danger we run or fight and so we don’t notice the effects it has on our body.

The problems start when we have a worrying thought but can’t run away. The adrenaline gets our body ready in the same way as above, but as we aren’t running or fighting it doesn’t get used up and it causes unpleasant physical and mental symptoms.

**Signs and symptoms of Anxiety:**

Anxiety can:

- make your thoughts race, so you can’t relax, or it may make getting to sleep difficult.
- increase your breathing rate; this floods your brain with oxygen, making you feel dizzy or faint and far away.
- speed up your heart rate; you may notice that your heart is racing or pounding.
- shut down the stomach, giving you a feeling of butterflies or a sinking feeling.
- shut down the blood supply to your hands and feet; you may notice that they feel cold and clammy.
- produce an unpleasant cold sweat; it may make your forehead feel clammy.

If you are suffering from any of these symptoms it is important to discuss this with a family member or a health professional.
For the majority of people, simply discussing thoughts and feelings help to alleviate the problem, rarely will it require specialist treatment.

**What is Depression?**

Depression can range from feeling sadness or tearful to absolute despair. Low spirits are very common after being extremely ill. For most people these feelings usually go as time passes and they start to recover.

However, people suffering from clinical depression will experience a low mood and other symptoms each day for at least 2 weeks. Symptoms can become severe enough to interfere with day-to-day activities.

**Signs and Symptoms of Depression**

It is common to have several symptoms:

- Sadness
- Tearfulness
- Poor appetite
- Early waking
- Loss of interest in things that were once enjoyable
- Loss of interest in appearance.

Most people with depression will get better without any treatment. However, this may take several months or even longer. Meanwhile living with depression can be difficult and distressing.

If you are suffering from any of these symptoms at home it is important to discuss this with your GP, who can guide you towards one of the many treatment options available.
How can I help myself recover?

Your body will have to do a lot of work to get back to normal, this will take time.

- Physical activity
- Rest and relaxation
- Nutrition

Physical activity

During your Critical Care stay you will have had an Individualised Exercise Programme with a Physiotherapist. Patients leaving CCU will have vastly different ranges of mobility, some will be walking quite well while others may be bed bound and in need of extensive rehabilitation.

It is important that you undertake some physical activity every day, however little. The level will depend on your condition. This will help strengthen your heart and lungs, rebuild the muscle loss during your illness, reduce stress and may aid sleep.

Feeling tired after physical activity is normal when you have been critically ill. You may have experienced some loss of muscle tone, joint stiffness and weight loss due to being immobile.

The Physiotherapists are there to help you get back to what is normal for you, or as close as possible. This may take some time and is dependent on a number of factors such as age, previous level of fitness, how ill you have been and for how long.

The Multidisciplinary Team (Physiotherapist, Occupational Therapist, Speech and Language Therapist, Dietitian, Doctors and Nurses) will help you to regain your independence.
Important points about physical activity:

- Do not try to do too much, too soon. This will only make you overtired and disheartened.

- Do not worry about how long you exercise for. Judge how much to do by how you feel. You should be a little tired after exercise not exhausted.

- As a guide, during physical activity you should not feel as though your heart is racing, although it may make you breathless you should still be able to talk.

If you experience any of the following during exercise STOP and seek medical advice:

- Severe chest pain.

- Increase in chest tightness.

- Dizziness or feeling faint.

- If you are much more breathless than the last time you did this exercise.

Rest and relaxation

Your body does most of its repair work while you are sleeping. At the moment it has more repairs to do than usual, so you need plenty of rest.

Do not worry if you are easily tired in the early stages, this is your body’s way of telling you to rest. It will improve over time.

Nutrition

Your body responds in very specific ways during critical illness.
Food is not used normally and the body uses up its own reserves such as muscle and fat. This makes you weak as your muscles may now have wasted, you may notice that they are not as bulky as before.

It takes quite a lot of work to get the muscles back to normal and can only be achieved with a combination of exercise and good nutrition. A balanced diet is essential to your recovery as this will help you feel less weak and tired and also help prevent infections.

Getting your appetite back after critical illness can be difficult. Your sense of taste may be affected and for a while food may taste sweeter, saltier and metallic or have no flavour at all.

If your appetite is poor try small meals with nourishing snacks in between. Ensure you drink plenty, eat slowly and relax afterwards. It is expected that you will lose some weight following your critical illness. If you have continued to lose weight try nourishing drinks such as full cream milk or homemade milkshakes between meals.

Useful tips for poor appetite:

- Aim to eat 3 small main meals per day.
- Try to make meals balanced; include protein, carbohydrate and fruit and vegetables.
- In addition aim to eat 2 - 3 small snacks per day.
- Take advantage of times when you are hungry.
- Eat slowly and relax afterwards.
- Use full fat dairy products, for example cheddar cheese, yoghurts, ice cream, butter or margarine.
• Have a dessert each day, for example, a piece of cake, scone, sponge pudding, trifle, chocolate mousse, thick creamy yoghurts, ice cream or biscuits.

• Try to include nourishing drinks between meals, for example, homemade milkshakes.

If you are experiencing ongoing problems with a poor appetite or weight loss, please ask your GP to refer you to the Dietician for an individual assessment.

**Is it normal to experience diarrhoea?**

It is common for people to have loose stools / diarrhoea on discharge from Critical Care and on discharge home. This may be due to a change in your diet and the medications you have received.

It is important to continue to drink plenty of fluids when you experience this problem. It should resolve after a few days but if you find this problem continues you should contact your GP.

**When can I have sex again?**

Your illness may have reduced your sex drive and your partner may be concerned that sex could be harmful for you and you may even feel that yourself.

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 recognise that this may take some time and patience from both of you.

A small number of people will have genuine medical problems, for example, impotence. If you require advice or support regarding these issues please talk to your GP who may be able to refer you to a specialist who can help in these situations.
What lifestyle changes can help my recovery?

**Quitting smoking**

If you smoked before your illness now is an ideal time to give up. If you stopped smoking while you were in hospital keep going now you are home.

For patients who have been seriously ill in critical care it is important that they stop smoking. This is because the lungs are affected by the illness and can be damaged.

People normally have a considerable amount of spare lung capacity so they do not notice the damage but it is important that you do not continue to damage your lungs after your illness by smoking and allow your lungs to recover. There is lots of support available to you if you decide to stop smoking. For more information ask a health professional

**Reduce alcohol intake**

Men and women should not regularly drink more than 2 - 3 units a day. ‘Regularly’ means drinking every day or most days of the week.

You should aim to have 2 alcohol-free days each week.

The more you drink above these limits, the greater the risk of developing serious problems, to find out more please speak to a health professional or contact our DART Team.
This is one unit...

For more detailed information on calculating units see - www.units.nhs.uk/

Half pint of regular beer, lager or cider
1 very small glass of wine (9%)
1 single measure of spirits
1 small glass of sherry
1 single measure of aperitifs

How many units did you drink today?

...and each of these is more than one unit

2 A pint of "regular" beer, lager or cider
3 A pint of "strong"/"premium" beer, lager or cider
1.5 Alcopop or a 275ml bottle of regular lager
4 440ml can of "regular" lager or cider
4 440ml can of "super strength" lager
2 250ml glass of wine (12%)
9 Bottle of wine (12%)

There are times when you will be at risk even after one or two units. For example, with strenuous exercise, operating heavy machinery, driving or if you are on certain medication. If you are pregnant or trying to conceive, it is recommended that you avoid drinking alcohol.

Your screening score suggests you are drinking at a rate that increases your risk of harm and you might be at risk of problems in the future.

<table>
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<tr>
<th>Risk</th>
<th>Adults</th>
<th>Common Effects</th>
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| Lower Risk      | No more than 2-3 units per day on a regular basis. No more than 14 units per week | • Increased relaxation  
• Sociability  
• Reduced risk of heart disease (for men over 40 and post menopausal women) |
| Increasing Risk | More than 2-3 units per day on a regular basis                          | Progressively increasing risk of:  
• Low energy  
• Memory loss  
• Relationship problems  
• Depression  
• Insomnia  
• Impotence  
• Injury  
• Alcohol dependence  
• High blood pressure  
• Liver disease  
• Cancer |
| Higher Risk     | More than 6 units per day on a regular basis or more than 35 units per week | |

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Benefits of cutting down

Psychological / Social / Financial

- Improved mood
- Improved relationships
- Reduced risk of drink driving
- Save money

Physical

- Improved sleep
- Lose Weight
- Reduced risk of injury
- Better physical shape
- Reduced risk of cancer
- Reduced risk of liver disease
- More energy
- No hangovers
- Improved memory
- Reduced risk of High Blood Pressure
- Reduced risk of brain damage

When can I go home?

The decision for you to be discharged from hospital will be made by your Medical or Surgical Consultant. However, these decisions are made with the MDT.

The support that you will require when you are discharged will vary depending on many factors including your personal circumstances, illness and length of hospital stay.

Once you have been discharged from hospital your recovery will take several months to 1 year. The emotional impact of having been critically ill can last for some time.
Critical Care follow-up clinic

Approximately 3 months following your discharge from the CCU you may be invited to attend an outpatient follow up clinic to discuss your progress. This is not appropriate for everyone but if you have particular interest in this please contact us.

This clinic is run by an experienced Critical Care Consultant, Specialist Critical Care Nurse and Specialist Critical Care Physiotherapist.

Involving your GP

Your GP should be up to date with your progress because information about your recent illness and treatment will have been sent from the hospital. It is very important that you involve your GP in your care, especially if your problem is urgent as they are now your primary contact for your care.

Contact numbers

If you are experiencing problems coming to terms with your critical care stay you can contact us even after you have gone home.

University Hospital of North Tees

Critical Care Unit
Telephone: 01642 382820
7 days a week, 8.00am – 5.00pm

Chaplaincy Team
Telephone: 01642 383138

Drug and Alcohol Rehabilitation Team (DART)
Provides advice on drug and alcohol service providers in your area.
Telephone: 01642 624715
Further information is available from:

ICU Steps Tees

ICU steps Tees is a support group for ex-ICU patients, their families and friends run by former intensive care patients, relatives and health professionals. It was developed to provide on-going support during and after discharge for patients and relatives who have encountered critical illness.

The support is provided in the form of “drop in meetings” where patients and relatives can come and talk to others who may be further down the recovery journey to share similar experiences.

The meetings take place every 6 weeks on Wednesday 15.00 till 17.00 at St Cuthbert’s Parish Hall, Stokesley Road, Marton, TS7 8JU.

For more information we have provided you with a leaflet or you can look at the website: www.icusteps.org/support/tees or contact: 01642 624328.

Stockton Carers
70 - 74 Brunswick Street
Stockton on Tees. TS18 1DW
Telephone: 01642 524494
Monday - Friday, 9.00am – 5.00pm
Email stocktoncarers@sanctuary-housing.co.uk

Advice on support for someone who becomes a carer. A carer is someone who looks after an ill, frail or disabled partner, relative or friend.
Carers Together
23 Queens Street
Redcar. TS10 2DX
Telephone: 01642 488977
Monday - Friday, 9.00am – 5.00pm
Email carerstogether@btconnect.com

Or

St Mary’s Centre
82 - 90 Corporation Road
Middlesbrough. TS1 2RW

Hartlepool Carers
19A Lowthian Road
Hartlepool. TS24 8BH
Telephone: 01429 283095
Monday - Thursday, 9.00am – 5.00pm
Friday, 9.00am – 3.00pm

Will you be looking after someone when they leave hospital?
Then carers together may be able to offer support and advice

Age UK Teesside

Are you 65+ living in the Stockton borough area? Age UK can help with free:

- Welfare and Benefit checks
- Local social and activity groups
- Befriending services
- Social care referrals for homecare, aids and adaptations

Contact the Health and Wellbeing Department on 01642 803324
This leaflet has been produced in partnership with patients and carers. All patient leaflets are regularly reviewed, and any suggestions you have as to how it may be improved are extremely valuable. Please write to the Quality Assurance Team, University Hospital of North Tees or email: patientinformation@nth.nhs.uk

Comments, Concerns, Compliments or Complaints

We are continually trying to improve the services we provide.

We want to know what we’re doing well or if there’s anything which we can improve, that’s why the Patient Experience Team is here to help.

Our Patient Experience Team is here to try to resolve your concerns as quickly as possible. If you would like to contact or request a copy of our PET leaflet, please contact:

  telephone: 01642 624719
  Monday – Friday, 9.00am – 4.00pm
  Messages can be left on the answering machine and will be picked up throughout the day.

  freephone: 0800 092 0084

  Email: patientexperience@nth.nhs.uk

Out of hours if you wish to speak to a senior member of Trust staff, please contact the hospital switchboard who will bleep the appropriate person.

  telephone: 01642 617617
  24 hours a day, 7 days a week

The Patient Experience Team is available to discuss your concerns in person Monday – Friday, 1.30pm – 4.30pm. The office is based on the ground floor at the University Hospital of North Tees.

Data Protection and use of patient information

The Trust has developed a Data Protection, Caldicott and Disclosure Policy (IG5) in accordance with the Data Protection Legislation (General Data Protection Regulations and Data Protection Act 2018) and the Freedom of Information Act 2000. All of our staff respect this policy and confidentiality is adhered to at all times. If you require further information please contact the Information Governance Team.

  telephone: 01642 383551 or email: information.governance@nth.nhs.uk

University Hospital of North Tees, Hardwick, Stockton-on-Tees. TS19 8PE
University Hospital of Hartlepool, Holdforth Road, Hartlepool. TS24 9AH
Telephone: 01642 617617 Fax: 01642 624089

PIL1123 September 2019