



Recovery after Critical Care

Advice and support for adult patients and relatives following a critical illness

Name:

Dates of Critical Care stay:

From: To:

Contact name:

Tel:

"My experience in hospital was a few years back. To have had a booklet like this for me to read through when times got a bit harder would have been invaluable.

The advice and knowledge in this booklet, about what your body's going through during its recovery time, would have set my mind at ease. It provides information that's true and relevant helping towards a faster and healthier recovery." *Simon*

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Introduction

It is recognised that recovering from critical illness does not end when you are discharged from Critical Care. Some people feel well, even better, and do not feel they need any extra support, but for others this is not the case. It is very important that if you are one of these people that you receive the help you need. We hope that by highlighting possible issues that other people have experienced, whether it be physical, psychological or social, you will feel reassured that it is normal to feel this way and confident to seek support.

This booklet contains advice and information about rehabilitation following a critical illness. It is written for the patient, but has information for relatives so that they can be involved and understand what the patient has been through and what to expect for the future. Recovery is sometimes quite a long and slow process and you may not feel up to reading the information at this point but keep hold of the booklet for when you do feel able to.

It is important not to be worried about the amount of information in this booklet, it is likely you will only have a few of the problems highlighted in the booklet, but please use it as a resource to pick out the areas where you may require some information, reassurance and advice.

Your stay on Critical Care

Critical Care units are areas within a hospital that look after patients whose conditions mean they are seriously ill or injured. They will require constant, close monitoring and support from equipment and medication to keep normal body functions going and their condition could be life threatening. Critical Care units have higher levels of staffing, specialist monitoring and treatment equipment only available in these areas and the staff are highly trained in caring for the most severely ill patients.

People who have been critically ill or seriously injured often have difficulty remembering what happened to them, especially if they have been on a ventilator (breathing machine), which usually requires sedation. You may have experienced vivid dreams, nightmares, hallucinations and delirium. These are very common and can be experienced by up to 80% of ICU patients. When this happens it is difficult to separate delusions from reality. Your brain is often able to take in sensory messages (sounds, images, touch etc) but is too unwell to make sense of them. What you remember will be mainly delusion with elements of truth. It can be very frightening but over time your memories of these experiences should fade and you will be able to understand what was real and what wasn't.

advice
reassurance

transition

Transfer to the ward

Once you are assessed as well enough, you are transferred to a ward, which is the first step towards going home. Some people can find this a difficult transition as you will have been receiving one-to-one or one-to-two nursing care on Critical Care and this ratio is very different on the wards. Hopefully patients are able to see their move to the ward as a sign of progress, a step towards getting home but some patients can feel unsettled for a while. This is natural as on critical care you will have become used to a higher visibility of staff, who you have also got to know. This can also be an adjustment for your family and friends too who may well have developed a strong relationship with the critical care staff whilst you were very unwell. Remember that you have been discharged to the ward because you are ready, and need less care and support from the nurses. You will continue to have reviews by your medical/surgical team throughout your recovery and the nurses and therapy team will now help you become more independent as they prepare you for discharge from hospital.

Whilst on Critical Care you have been under the care of a multi-professional team led by Consultant Intensivists who specialise in Intensive Care medicine. On returning to the ward your care is transferred back to an appropriate Consultant and their team for your continuing care.

A few hospitals have Follow-up sisters or Rehabilitation nurses who make occasional visits to patients who were in Critical Care for more

than three or four days; on the ward they focus on supporting ongoing rehabilitation needs.

Critical Care Outreach or Trigger / Rapid Response Teams

Most hospitals have a specialist team of nurses with expert skills in the care of seriously unwell patients and those patients recently discharged from Critical Care. The staff on Critical Care will plan for your discharge and start to prepare you for the change in staffing ratios, encouraging you to be more independent.

For those discharged from Critical Care our aim is:

- To support the ward nursing and medical teams to ensure your safety is paramount and you are continuing to improve.
- To provide the advice and emotional support you need regarding any concerns or issues you may have surrounding your Critical Care stay.

Usually what will happen:

- Usually within 24 hours of your discharge from Critical Care, a member of the team will visit you and carry out a full assessment of your medical condition and review your plan of care.
- You may only require one visit, but the team are available to the ward staff for consultation throughout your hospital stay.
- You may require a number of visits by the team to ensure you have settled into the ward and your condition is improving.

Common problems after a critical illness

Breathing

It is common to experience breathing problems after a critical illness. Below are some of the main reasons for experiencing these difficulties and advice on ongoing care.

1. Shortness of breath: When doing activities which you would not normally expect to make you breathless. You may require some supplementary oxygen this will be reviewed and reduced as appropriate.

2. Muscle Weakness – of the muscles involved in breathing: Being on a ventilator means that the respiratory (breathing) muscles do very little work for themselves and so they become weak. Prolonged periods of immobility cause significant muscle weakness throughout the whole body. You will probably have noticed that daily activities are much harder to do and that you have less stamina. It is not just your limbs, which have become weak; your respiratory muscles have also lost strength and this may make simple tasks quite difficult. As you started to recover from your illness in Critical Care, you gradually required less help from the ventilator but as with your other muscles, the breathing muscles now need to learn to work again and to build their strength. This can take some weeks or months to achieve; your Physiotherapist will give you advice on how to improve the amount of exercise you can tolerate, how to pace yourself and how to expand your

lungs. Your Occupational Therapist (OT) will give you advice on managing / optimising your independence.

3. Infection – particularly of the lungs:

You may experience a persistent cough and difficulty clearing phlegm. This could be a result of resolving infection and may take time to clear. Your Physiotherapist will advise you on clearance techniques.

4. Complications of Proning: With some illnesses, getting enough oxygen from the lungs to the rest of the body can be a problem even with the help of a ventilator. Changing the body to the prone position can sometimes really help in these situations. Proning is the technical name for laying on your front, it is a technique used in critical care as it can help deliver oxygen to different parts of the lungs, can improve your oxygen levels and also survival. You may have been proned several times until your breathing improved. This will have involved periods of time alternating between laying on your front and being turned back onto your back or side. Most patients are still sedated when we do this but sometimes awake patients will also benefit from lying in this position. Despite every care being taken to position you carefully there are some complications that can occur, such as temporary facial swelling, pressure sores, foot drop and brachial plexus injuries; this is when the nerves from the spinal cord to your arm are stretched or compressed causing pain, weakness and in some cases numbness.

Changes to your voice

Your voice may sound hoarse, breathy or quiet. This is common and could be for several reasons:

- If you had an endotracheal (oral) breathing tube, this will have been placed through your mouth and past the vocal cords. This may have caused some temporary bruising or swelling to the voice box and you may experience a sore throat.
- Weakness of the respiratory muscles, causing reduced airflow coming up from your lungs and through your vocal cords (voice box). This can affect how the vocal cords come together to produce voice.
- Your body may be generally weak and this could also affect your voice strength.

Your voice should return to normal as you become stronger and/or as the bruising or swelling heals. Relax and do not force or strain your voice and drink plenty of water (unless you are 'nil by mouth' or fluid restricted).

If you find that voice changes persist after going home, please ask your Follow-up clinic, if available or General Practitioner (GP) to refer you to Ear, Nose and Throat (ENT).

If you needed a TRACHEOSTOMY, please read this section

If you needed a ventilator to help you breathe for a prolonged time during your illness, the doctors may have decided to perform a tracheostomy. This is a procedure that is performed under a general anaesthetic either in Critical Care or in an operating theatre. A small incision is made into the front of your windpipe (trachea) and then a tracheostomy tube is inserted for you to breathe through.

A tracheostomy has many benefits compared to an endotracheal (oral) tube including:

- It is more comfortable over the long term.
- It is easier to reduce and stop sedation because you are more comfortable. Being more awake has many advantages. For example, you are able to exercise the respiratory muscles by starting to take over the breathing yourself, so it is quicker and easier to come off the breathing support that you needed from the ventilator.
- It aids rehabilitation because you are more awake to join in exercises and it is safer for getting out of bed. This all helps to resolve delirium and aid recovery.
- It is easier for nursing staff to keep your mouth clean and prevent chest infections.
- You will be able to move your mouth which may help you communicate by mouthing words. A speech and language therapist can also help you find alternative ways to communicate.

communication

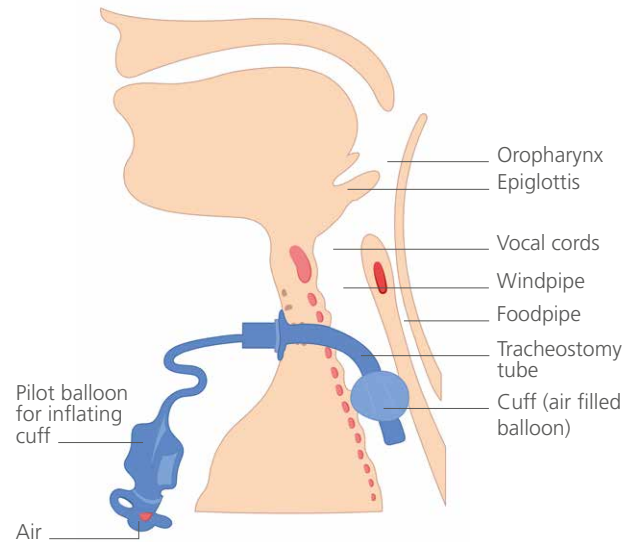
- A tracheostomy is inserted below your voice box so there is less chance of damage to the vocal cords.

You may have returned to a general ward with the tracheostomy still in place. This may be because your swallow isn't working as well as it needs to and your saliva might go down the wrong way, or your cough is not strong enough to clear phlegm off your chest. The tracheostomy will enable it to be removed for you using a suction tube. In most cases the tracheostomy is temporary until you regain some strength.

If you have or had a tracheostomy with an inflated cuff, this will have stopped the air from reaching your vocal cords, and you will not have been able to produce voice. During the time leading up to removing the tracheostomy, you may have practised having the air redirected up through your vocal cords, allowing you to use your voice with a speaking valve fitted to the end of the tracheostomy tube. During this time, and after the tracheostomy is removed, this change in airflow can be a strange sensation, and your voice might sound weaker than normal.

A Speech and Language Therapist can provide advice on exercises that can help to resolve any ongoing problems that you may have with your voice or other communication problems such as talking or understanding.

Any voice problems are also usually temporary and should return to normal once the tracheostomy



is removed. Tracheostomies are usually removed painlessly. The opening in your neck requires no stitches and will close naturally over time, which should leave a thin horizontal scar.

Tips for talking after a tracheostomy removal

- Remember the site needs time to heal. The tight dressing that is placed over the tracheostomy site prevents air going in and out and will help make talking easier. Try pressing lightly on the dressing while you talk if your voice is too quiet or you feel breathless.
- Use your normal voice. Try not to force your speech through a whisper.

Swallowing

Due to critical illness you may experience muscle weakness and shortness of breath. If so, you may find that eating is very tiring or that it is hard to co-ordinate your swallowing and breathing. You may find that eating small portions, with snacks in between, throughout the day, instead of having full meals is more comfortable for you. Remember assistance is available at mealtimes if you are too tired or weak. Please ask if you need help and explain how weak you feel.

You may have experienced discomfort or difficulty with your swallowing, including food or drink 'going down the wrong way'. These symptoms usually resolve quickly, however if you experience ongoing discomfort or difficulty, a feeling of food, drink or tablets "sticking" in your throat, coughing when eating or drinking, or chest infections, then you should be referred to Speech and Language Therapy for a swallowing assessment. A speech and language therapist can recommend foods and drinks that are easier and safer to swallow and provide you with swallow rehabilitation exercises. If you are not able to eat and drink enough for any of the reasons given above then you may need to be seen by a Dietitian and to continue with nasogastric tube feeding in hospital or supplements for a while at home.

Nutrition

During your stay on Critical Care it is likely that a Dietitian will have been involved in your care and treatment. If you were unable to eat you may have been fed a liquid diet via a feeding tube placed through your nose and down into your

stomach. A liquid nutritional feed would have been prescribed by the Dietitian to meet your individual nutritional needs.

Once on the ward you may have returned to full eating and drinking or you may need to continue with tube feeding if you're having difficulties swallowing and/or reduced appetite. Feeding in this way is usually temporary until your swallowing and dietary intake improves.

Why is Nutrition Important?

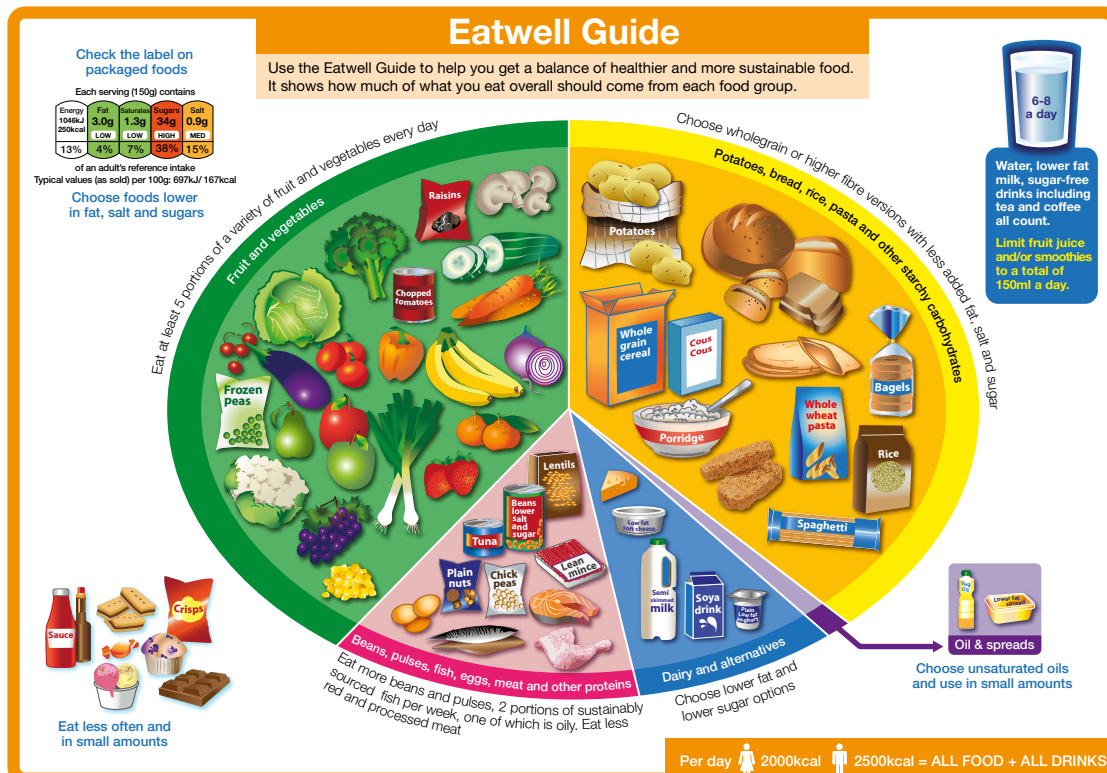
Staying strong is important. During critical illness your body's protein reserves (mainly muscle) are in constant breakdown in order to supply the building blocks for other substances such as immune cells. During this period providing nutrition can help minimise the losses of protein as well as reduce the extent of any reduction in muscle mass and strength.

During the recovery phase, your body's ability to build protein (muscle) returns. You're likely to be starting to eat and drink and becoming more mobile at this time and your need for energy and protein increases. However, you may be finding it difficult to eat as much as you would normally. The need for extra energy and protein, along with a reduced intake/appetite, can compromise your nutritional status and contribute to further weight and muscle loss, which will have an impact on your overall recovery and rehabilitation.

Providing nutrition through the critical phase and maintaining adequate nutrition throughout the recovery phase can have the following beneficial effects:

- Minimise muscle loss and weight loss
- Shorten your stay in hospital
- Maintain your muscle tone which will help to keep good lung function
- Improve wound healing and promote a faster recovery from illness
- Reduce the likelihood of you being re-admitted to hospital
- Reduce feelings of tiredness and lethargy
- Help to improve your mood

In hospital, your Dietitian will advise you on your diet. Whilst recovering from illness the main priority will be to have a diet that provides enough energy and protein to support your recovery. The proportions of the different food groups may therefore be different, for example you may need to eat more food high in fat and sugar to obtain enough energy. Below are some tips on how to meet your nutritional needs. The ward staff or the Dietitian will also be able to advise you on the types of foods to choose.



nourishment

Food may not taste as you expect – This is normal and taste changes are often only temporary.

Ways to improve your nutritional intake

- If you are put off by large meals or have a small appetite then try having smaller portions more regularly. Aim for 3 small meals and 3 snacks each day.
- Snack in between meals. This can be anything that you fancy. Some snacks may be available on the wards for patients with a reduced appetite.
- Whilst in hospital you might like to ask your family or friends to bring in some foods or snacks that you enjoy.
- While your appetite is poor you should avoid low fat, low sugar options unless otherwise advised.
- Try to drink nourishing fluids such as juice, milk, hot chocolate or hot malty drinks. These are usually available on the ward.
- Drink plenty of fluids aiming for 8-10 glasses a day unless you are directed otherwise i.e. 'nil by mouth' or fluid restricted – this can include both hot and cold drinks.
- Avoid having fluids with meals, which can reduce how much food you eat.
- Fresh air can help improve appetite. Aim to get fresh air by being outside or by an open window prior to or during meals.

Supplement Drinks

If you are struggling to eat enough, you have lost weight or you are already underweight the Dietitian might prescribe nutritional supplement

drinks in addition to your diet. These are normally milkshake or juice type drinks, which are available in a variety of flavours. Nutritional supplement drinks are designed to be an addition to your food intake **not** as an alternative to food, so aim to sip these between your meals.

If the Dietitian is not already seeing you, then you may be referred for more specialist nutritional advice. You can also ask to be referred to the Dietitian if you would like advice on your nutritional intake.

Nausea and Sickness

Some people may experience feelings of nausea or sickness during their hospital stay. This may be due to illness or the treatment that is being administered. If you are suffering from nausea or sickness speak with your doctor or nurse as medications can be prescribed to help with this. The following measures may also help to alleviate symptoms:

- It may be easier to eat cold foods rather than hot, this could include sandwiches, cold meats and chilled desserts e.g. yoghurts and mousse.
- Try sipping fizzy drinks such as ginger beer or lemonade
- Try dry food such as crackers, toast or biscuits
- Try not to drink with a meal, but have one 30 minutes before or after eating
- Peppermint oil can be helpful; talk to your ward team or local pharmacist/GP

Bowel Changes

Many people can experience changes with their bowel function while in hospital. This may include diarrhoea or constipation. If you do experience these changes then tell your doctor or nurse so that you can get the appropriate treatment. Your Dietitian will also be able to advise you on foods that may help to alleviate these symptoms. If you are experiencing changes in your bowel habits it is important to increase your fluid intake unless otherwise advised. If you have a stoma – the stoma nurse will visit you with advice and teach you how to care for it.

After Discharge from Hospital

If your dietary intake has improved by the time you are ready to be discharged from hospital and you are well nourished then your priority should be to follow a healthy balanced diet. Information on eating a healthy balanced diet including an interactive Eatwell Guide, can be found on the NHS Choices website: www.nhs.uk/Livewell/Goodfood/Pages/the-eatwell-guide.aspx

As you recover you may wish to pay particular attention to eating to support your gut microbiome which will have been affected by being critically unwell and by any antibiotics you may have needed as part of your treatment. The British Dietetic Association has a series of patient information leaflets that can be accessed at All Food Fact pages: <https://www.bda.uk.com/food-health/food-facts/all-food-fact-sheets.html>. The leaflets on “Probiotics and Gut Health” and “Fibre” are most relevant to supporting the gut microbiome but there is other information there that may help you too. If you have had surgery on your bowel or

presented with a bowel issue please ensure you understand from your treating team if you have any special dietary requirements going forwards.

If your dietary intake continues not to improve when you're back at home then you may need to continue having more nourishing foods. The Dietitian will be able to advise you on food fortification at home. If there are still concerns about your intake and nutritional status, you should approach your GP and discuss the option of seeing a community Dietitian.

Mobility

Supporting your way home

During your stay on Critical Care you may be assessed by an Occupational Therapist. Occupational Therapists have specialist skills in activity analysis and can complete holistic assessments to identify any difficulties you may be experiencing with performing activities of daily living or your daily routine. They will work closely with the physiotherapists to enable you to regain your strength and ability to perform activities which are important or meaningful to you, such as personal care tasks.

Once you no longer need Critical Care you may be transferred to another ward. The ward Occupational Therapist will take over your care, helping you work towards your rehabilitation goals and, also support your discharge planning once you have been medically optimised to leave hospital. They will collaborate with you and your family/care givers to identify any further support, rehabilitation, or equipment needs you may have to facilitate a safe discharge.

activity is the key to recovery

Occupational Therapists can send a referral for a new or increased package of care via social services or reablement services; referrals for inpatient general or specialised rehabilitation or issue you with any essential small pieces of equipment. They are also able to send referrals for community occupational therapy to complete further assessments for any further aids or adaptations (non-essential to facilitate discharge) or to work on ongoing rehabilitation goals within your home.

Building strength

Due to your illness and immobility whilst in Critical Care, you may have lost considerable muscle mass; up to 2-4% a day. If immobility lasts 2 weeks or more, this can be half your muscle mass and this may explain why the smallest of tasks (e.g. leaning forward, or feeding yourself) seem so difficult at the moment. Some patients will still be severely weak even when they are well enough to go to a ward. When you have been immobile, your joints can also become stiff and sometimes painful making the activity even more of an effort.

During your time in Critical Care, physiotherapists will have been treating you daily as soon as possible after your arrival. Occupational Therapists or rehabilitation assistants may have started some personal care activities or activities that are important to you. As your health improves you may have started doing breathing exercises, exercises in bed, sitting out in the chair, mobilising and

other activities. You will continue to be assessed whilst on the ward by the physiotherapists and occupational therapists.

Exercise under the guidance of a physiotherapist will assist you in regaining strength, activities and exercise tolerance. If you have specific needs, these will be discussed with you and a programme will be designed for you.

Exercise Guidance

Patients leaving Critical Care will have vastly different ranges of mobility, some will be walking quite well and others will be bed bound in the beginning and need rehabilitation. An appropriate level of exercise is important, however little in the beginning as it will:

- Strengthen your heart and lungs
- Help to rebuild the muscle you lost during your illness
- Help to reduce stress
- Improve sleep
- Allow you to regain the activities which are meaningful to you

Feeling exhausted after any exercise is quite normal when you've been in Critical Care; even if it was only for a few days. Try not to worry. Little by little things should improve. The Physiotherapists are there to help you get back to normal or as close to it as possible. Sometimes this can take some time.

When starting exercise after a period of illness it is important for you to know how hard you should

be working. Your Physiotherapist will be able to advise you, but generally you should feel like you are pushing yourself a little and/or are feeling moderately breathless. This means you are reaching an adequate exercise level to improve your fitness.

Important points about exercise

- It is important to pace yourself and listen to your body. Doing too much too soon can end up making you overtired and disheartened.
- It's normal to have some not so good/bad days. Ask yourself if you've been doing more over the past few days. This may explain why you feel so tired. You may need a quiet day or perhaps look to divide your day up into manageable chunks and prioritise what you would like to achieve.
- Don't worry about how long you exercise for. Judge how much exercise to do by how you feel. You should feel a little tired after the exercise, not exhausted.
- As a rough guide, you should not feel your heart racing during the exercise and although exercise may make you moderately breathless, you should not be so breathless that you cannot talk.
- Stop exercising if you feel dizzy or faint, take a rest and try again more gently. Seek medical advice if these feelings persist.
- You should stop exercising straight away and seek medical advice if you experience any of the following: severe chest pain, increase in chest tightness or if you are much more breathless than the last time you did this exercise.

As your strength and fitness improves you may find you are doing the same exercises but finding it much easier. This is an indication for you then to progress your exercises.

You should aim to progress your activity every week. Your physiotherapist can help guide you whilst you are in hospital. Please ask if you would like some exercises written down to remind you what to do; you can then work on them at other times when you feel up to it.

Pain

Spending even a few days unwell in bed can impact pre-existing pain or create new pain, so it is not surprising that a critical illness will exacerbate pain at some point. This can be through general aches and pains at the time or pre-existing pain, that has initially improved with bed-rest and then becomes more intense when trying to get moving again during rehabilitation. Try simple pain killers to start, but if this is affecting your abilities to move about and exercise then please talk to your hospital doctors or GP to review your pain and options for optimising management to assist your ongoing rehabilitation.

Tiredness / severe fatigue

Even when ready to go home, weakness and fatigue may continue to be a significant issue. Where people may have been very physically active prior to their hospital admission this can be quite difficult to accept and may result in frustration and impact on mental well-being. It may also impact on family and carers as they have to accommodate

for what may be a temporary level of activity for the patient. This tiredness is normal and should improve with time.

Managing tiredness and energy conservation

The best approach is to focus on managing the fatigue and living with it in the early days knowing it should improve as you progress through your rehabilitation journey. To support your recovery you should take into consideration the following:

- **Plan your day:** Prioritise your activities and spread them out over the week and break down your activities into smaller chunks.
- **Set individual realistic targets**
- **Prioritise activities:** Is this an activity that is meaningful to you? Or can someone else do it until you have built up your energy reserves?
- **Take frequent rests:** Balance light activity, heavy activity and rest periods
- **Organise your environment:** Prepare your space for your chosen activity so you have everything within easy reach, before starting. Also consider sitting down for the activity to save energy.

- **Posture:** Correct posture can minimise physical stress and maximise your energy.
- **Relaxation:** Learning relaxation techniques may be useful for when you are frustrated or feeling anxious about your activity levels.

Occupational Therapists can assist you with your fatigue management and energy conservation by advising you on energy saving techniques, how to balance your activities of daily living and daily routines.

Sleep and relaxation

You may find that your sleep pattern has changed, making it more difficult to fall asleep or waking frequently in the night. This is quite normal and although it can persist for several months there are things you can do to help. Relaxation techniques have many benefits for health and general well-being as well as helping you to sleep, such as:

- Reducing stress
- Reducing pain
- Reducing fear and anxiety



- Coping with problems
- Helping to lower blood pressure
- Helping to give up smoking
- Reducing anger and irritability

Initially don't worry if your sleeping pattern is disrupted, it won't harm you to miss some sleep because you are not as active. As you recover things should get back to normal. An experience of critical care can disrupt your 'body clock' and you may find sleeping during the day easier. Only take a daytime nap if you feel very tired but try not to sleep very long because you need to restore your day/night routine, as constantly being awake at night can be difficult. Discomfort, and any worries you may have, can seem much worse at night. Try not to let things get on top of you; sometimes listening to some relaxing music or practising relaxation at night and then talking about your worries during the day might help.

If you are still unable to sleep after some time has passed, or you already had difficulties with your sleep pattern before your admission, then after trying the following Dos and Don'ts, please speak

to your GP or IAPT service (Improving Access to Psychological Therapies) who may be able to offer further advice and/or access to the following on-line resources sleepstation.org.uk/ or sleepio.com

Do

- Establish and maintain a regular bedtime routine
- Ensure your bedroom is a comfortable, quiet and relaxing place
- Exercise regularly during the day
- Relaxation exercises in bed
- Remember that sleep requirements change
- Remember that short awakenings are normal
- Reduce activity during the evening and be aware that blue light emitted by electronic devices can impact on the ability to sleep. Avoid using electronic devices (including television) close to bedtime, typically 1-2 hours is usual but even 30 minutes can make a difference
- Stop daytime naps or limit to short naps (less than 20 mins) before 2 pm



remember

Don't

- Don't consume caffeine within 6 hours of bedtime
- Preferably don't drink alcohol within 3 hours of bedtime. Any amount of alcohol can impact on sleep, but if you do choose to have a drink then a limit of 1-2 will minimise the impact on your sleep
- Ideally you have given up smoking, but don't smoke close to bedtime
- Don't go to bed hungry or within 2-3 hours of a large meal
- Don't use your bedroom for anything other than sleep and sexual activity

Delirium and lasting memories

Lasting memories of delirious dreams, nightmares and hallucinations are common although they affect some people more than others. For a small number of people, particularly when memories have been quite frightening and involved paranoia or thoughts that staff and/or family have been holding you against your will, some post-traumatic stress symptoms may be apparent, such as flashbacks, avoidance behaviours etc. These symptoms are a known and recognised problem and for the majority of people time and talking will resolve these feelings.

Delirium occurs when the mind is trying to process a disturbing event, and during your critical illness, your brain is not working very well. This can occur particularly when coming out of sedation, it can be very confusing and disorientating and produce

some quite disturbing dreams that you believe at the time are real. The reason they occur is due to a combination of any or all of the following: the nature of your illness or injury, sedation and strong pain killers, infection, the Critical Care environment, strange noises from the equipment at your bedside and lack of mobility or sleep (sedation is not natural restorative sleep). The delirium itself has usually ceased by the time you reach the general ward but the belief that some of the memories are real can continue. The important thing is to remember is what you are experiencing is very common and will fade in time. It is helpful to discuss this with the staff in hospital and also your family and friends. However, if the memories or any other psychological or emotional issues are not settling over time, please see your GP or Critical Care follow up team if applicable.

For more information about delirium access this leaflet from the ICUsteps website: <https://icusteps.org/assets/files/information-sheets/delirium.pdf> or visit www.icudelirium.org/

Stress / Anxiety / Depression

For some people coming to terms with how ill you have been, and what you have gone through can cause stress, anxiety and degrees of depression. Some people find it easier to cope than others, there is no normal pattern. Reasons for these feelings can include frustration at not being able to do what you could before, worry that you may not get back to your normal fitness, anxiety about days of your life that you cannot account for, fear that

it can take

you are vulnerable to it happening again, or your illness may have been completely unexpected and so the whole experience can take time to sink in.

The stressful time you and your family have been through together, sometimes with a long recovery, can give rise to many different emotions or physical problems. Examples include; feeling tearful, feeling withdrawn, mood swings, panic attacks, uncharacteristic episodes of anger, not being able to sleep, poor appetite, increased pain, a loss of interest in activities you once enjoyed. Some people describe a 'brain fog' or find that simple noises or images create feelings of despair they cannot explain, or that out-of-the-blue they become emotional. Some people feel that at times they find it difficult to even function.

Do not feel embarrassed by these feelings; they are part of the healing process. Talking through these issues with your family and friends, or at your Follow-up Clinic, if available, can help. It is important to realise that being able to understand what causes these feelings and that a few simple steps can help rationalise them will help in learning to cope. We can talk this through with you as we have had experience of many people who have felt exactly as you are feeling.

You may have received a diary of your time in Critical Care, written by your family and the staff looking after you; this will help you account for lost time. Your family and friends can often help fill in these gaps, and many people find it useful to talk

this through with them. However, it is important to remember that although you may have been sedated and asleep for some part of your Critical Care stay, your family were present and coping with this difficult time and therefore they may find reliving this time as difficult as you.

Often just knowing that you and/or family members can be going through a turmoil of emotions is reassuring but also remember to seek any form of support you can find. For example, the ICUsteps groups mentioned at the end of the booklet, the Chaplains or Lay Chaplains in the hospital and/or your Follow-up Clinic, if available.

It is important to accept that it can take time to recover completely and not to punish yourself if you feel it is taking too long. Be realistic in your goals and gradually increase your activities. Some people find keeping a diary of their achievements useful, so they can compare how much they have improved on a weekly basis.

Psychological therapies

Leading on from some of the common problems we have discussed, we know that people experience critical care differently and this can depend on many factors such as

- Length of stay
- Not remembering parts of or all of your stay
- The type of treatment you may have received in critical care
- Your experience of recovery at home
- Significant life changes due to a change in your physical health

time to recover

It is a natural response to feel distressed and emotional for a month or two following a stay on critical care and patients often say that it takes time to feel like themselves again. Many patients will experience what can be thought of as natural recovery psychologically after they are discharged and start to feel like they are making sense of their experience and noticing an improvement with their overall mood and emotional wellbeing. However, because we are all different and respond uniquely to distress some people will need more time to recover and, in some cases, benefit from a form of psychological or emotional support. It is worth checking if your unit has a psychological therapist/psychological therapies team, as this is now becoming more common within critical care. If they do, you may be able to access:

- Individual psychological therapy as an Outpatient or;
- Be signposted to relevant therapeutic options within the community.

Psychological therapy as an outpatient would be able to offer you an opportunity to begin to process your experience of critical care, so that you feel in a better position to make sense of what has happened to you and where needed coping strategies for some of the common issues experienced such as:

- Lack of sleep
- Increase/change to experience of anxiety and depression
- Coping with difficult dreams

- Flashbacks
- Fear
- Loss of interest in life more generally

We know that relatives also feel the impact of seeing their loved one in critical care and can feel distressed as a result. Some critical care units can offer short term psychological therapy in such circumstances, and again it is worth checking with your specific unit, to see if this is on offer.

Changes in mood

Many people complain of fluctuating moods: up one day, down the next; it is also common to feel very irritable for no reason. This is a normal reaction after serious illness and although it can be hard for family and friends, particularly as they too have been through a very stressful time, it is important to know that it does subside in time.

Concentration and memory

Many people complain of being unable to concentrate on every day things such as reading a book, watching television or doing simple tasks. This is very normal and in time usually passes.

Short-term memory can also be affected which can be distressing for some people, but again is entirely normal. This should improve, however finding strategies that work for you to help manage it, can be beneficial. For example: keeping a diary to recall key appointments and the date or using electronic reminders.

Concentration and memory can both take some time to resolve and sometimes it is hard to know if the memory has recovered. If you are worried, you should seek advice from your Follow-up Clinic if available or your GP.

Relationship issues

Some people can suffer sexual dysfunction following critical illness which can be ascribed in various ways:

- No longer any desire
- Have desire but are unable to perform
- Limited by physical issues e.g. shortness of breath, surgical disfigurement
- Worry that it could precipitate serious illness again

For many people this can be very embarrassing and difficult to talk about; we tend not to include this in our discussions during rehabilitation for that very reason. However, it is a very important problem and we are more than happy to discuss this with you if you need to, or we can refer you to professionals trained in this area to give you confidential advice.

Bladder control

You may have been catheterised to collect urine, for some days or weeks, and although this very rarely leaves any long term problems, you can understandably suffer with some bladder weakness initially.

Skin / Hair

Due to the stress that your body is under, as well as the drugs you are given to combat severe illness, some people experience changes to their skin, hair and nails.

- Dry Skin / itching – This is a very common problem and is best treated with daily moisturising.
- Bruising – You may find that your skin bruises more easily than usual. You are likely to have been given heparin injections to help prevent clots forming in your legs whilst you were immobile.
- Numbness / Pins and needles – You may experience numbness or ‘pins and needles’ in your fingers, toes, legs or any part of your body. If this persists or is particularly painful you should seek advice from your Follow-up Clinic if available or your GP.
- Hair Loss – It is common to experience hair thinning/loss following a critical illness, although this can be distressing, it is usually temporary, and often hair will grow back, sometimes more luxurious!

Eye sight / hearing

Some people find that their eye sight is not as good as it was before their critical illness, particularly if you wear glasses normally. Unless you have a dramatic deterioration in sight, or you develop a new disorder, it is advised that you wait a while before having an eye test and possible

A painting of a rural landscape. The scene is dominated by a wide, unpaved dirt road that curves from the left towards the center. The road is flanked by a line of trees with autumn foliage in shades of orange, red, and brown. In the foreground, there are dark, spiky bushes in the lower corners. The sky is a clear, bright blue. The overall style is soft and painterly, with visible brushstrokes and a warm, atmospheric light.

going back to work

change of lens. Usually any minor deterioration corrects itself as the body slowly repairs.

Hearing is more rarely affected than eyesight and is less likely to improve on its own. Please ask your GP for a referral to ENT / Audiology if you are experiencing new problems.

At home

Medicines

While you are in critical care, a pharmacist will be involved in your care and advise on the most appropriate and safe use of medicines. For those patients taking medicines regularly prior to an admission to critical care, it may not always be appropriate to continue these while you are critically ill (for example, we may withhold medicines you may have been taking for high blood pressure if your blood pressure is low, if you take medicines for a fast or irregular heartbeat, it may not be appropriate to continue these if your heart rate is low, or if you take medicines for diabetes mellitus these may be withheld or adjusted if your blood sugar is irregular). These long-term medicines will require review while you are in critical care and depending upon your circumstances, some will be appropriate to restart and some may be discontinued permanently.

It is important however that any medicines that you were taking prior to admission are reviewed by your respective medical or pharmacy teams and any changes communicated to the ward teams for your ongoing ward-based care. Most of the medicines that are started in critical care (for example to

support your blood pressure or to help you tolerate a breathing machine) will only be temporary and will have been discontinued before you are discharged to the ward. There are some medicines that may be started and continue to provide benefits after you have been stepped down to the ward. These should be reviewed periodically and it is possible that some of these medicines may need to be taken long term.

Before you are discharged from hospital, a plan should have been made for all of your medicines, including those you may have been taking prior to coming into hospital and for those that may have been started in hospital.

You should be informed of the following:

- Any changes to your medicines
- What you are taking
- Why you are taking it
- How much and when to take it
- How long the treatment is likely to continue for
- Unless you have been told specifically, not to stop any medicine without first consulting your GP

Remember, your pharmacist and GP are valuable sources of information if you have any queries regarding any of your medicines.

Driving

It can be difficult to decide when you are ready to drive again, just remember you require a good level of muscle strength to use the steering wheel and pedals for any length of time and to perform an emergency stop. You also need prolonged

concentration and mental agility, which can also be lacking in the early stages. If in doubt consult your GP for advice. Some conditions require reporting to DVLA and you should think about whether you have any problems that your insurance company should be aware of.

If you are taking long term strong pain-killers, then you need to check with your GP if it is permissible for you to drive, as there are new DVLA rules about driving under the influence of some strong pain-killers.

Going back to work

If you work, this can sometimes be a source of stress for those who have had a long illness and different employers offer different levels of support. Other patients have found it useful to start back part-time because, although you may feel well recovered at home, working will physically and mentally test you. Working a full week will have a cumulative effect and may be too exhausting at first.

Lifestyle changes

Having been seriously ill in critical care, can be a good time to make lifestyle changes, such as giving up smoking, drinking less or no alcohol and eating healthier foods. Your body will have undergone immense changes and interrupted bad habits, so it is a good time to introduce a new, healthier you.

Chemicals produced by nicotine and excessive alcohol both raise blood pressure. Unhealthy living also causes an array of other illnesses such as heart disease, stroke and cancers.

If you smoked, it is important to stop now, it will only harm your recovery. It is vital the lungs are allowed to recover and not to allow further damage and decline to any spare lung capacity which may have been affected by a critical illness. If you need help to give up then speak to your hospital nurses/doctor, your GP or telephone the NHS smoking helpline (number at end of leaflet).

When you give up:

- You will do no further damage to your lungs
- You will have less chance of further serious illness
- You will save money

Critical Care Follow-up or Rehabilitation Clinic

Most hospitals now offer an appointment to attend a Critical Care Follow-up or Rehabilitation clinic to many of their patients once they have returned home. However, it is generally for those who spent a prolonged stay in Critical Care, or for those who would like to self-refer for particular difficulties with rehabilitation.

The clinic appointment is an opportunity for you to ask questions about your stay, understand what happened to you and to discuss your recovery, both physical and psychological. Some clinics are nurse-led, and others involve a wider team including a critical care doctor, nurse and therapists. It can be an opportunity to make sure you have had appropriate medical follow up, and referrals can be made to other specialities if ongoing issues are

not resolving. Your GP may be sent a letter after the clinic so that they are aware of any discussions and ongoing recommendations/referrals made by the critical care team. If you would find it helpful for your recovery, the team may offer you a visit to the critical care unit on the day of the clinic, or at a later stage when you are ready.

Family members and/or those who were involved at the time of your illness, are also welcome to attend the clinic with you, as often they too can have questions and issues relating to this period and it is important to support them as well.

If you do not hear from the clinic and would like an appointment, please use the contact number on the front cover of this booklet, or you may find some useful information on the websites given on Page 26.

Involving your GP

It is very important to involve your GP in your care after you leave hospital. On your discharge they will have received a discharge summary, outlining what happened to you during your hospital stay including your critical care experience. If you are struggling at home with practical issues such as managing activities of daily living, then speak to

your GP; there may be some help that can be accessed, perhaps through social services (or you can phone them yourself – number at end of leaflet). Even if you only need it for a short time, they should be able to advise you on what is best for your situation.

If you have any health problems or ongoing worries you should visit them at the first opportunity as they are now the primary contact for your care. It is also a good idea to have your medication reviewed and a check on how well you are progressing. You will probably be the best judge as to the timing of this, but about 4-8 weeks would be a good guide and sooner if you are unwell.

Finally

The fatigue felt by the majority of people should not be underestimated and can last for quite a long time. This often leads to frustration, particularly if you were previously fit and active prior to your critical illness. Recovery can seem slow and it is different for each individual. Full return to a normal lifestyle can take weeks or months and sometimes as long as 12–18 months or even longer in a few people. Unfortunately, it is difficult to place a time scale on recovery as everyone responds at a different rate. It also depends on a number of factors, such as: age, previous level of fitness, degree and length of illness. You should not, however, be alarmed if it takes a long time to get to your best level of recovery.

follow-up

rehabilitation clinic

your GP

"All attending ICUsteps benefit from the mutual exchange of experiences. As an ex-Critical Care patient, I can testify to the benefit to be gained by sharing with others within such a group." *Mike*

Visit the ICUsteps group in your area

A patient's perspective

This group is a welcomed get-together of former patients of Critical Care, who have a unique platform to address their personal experiences, with other patients, medical professionals, family and friends. The group has a small committee, who organize the meetings and in our group arrange guest speakers, from the medical

profession, addressing medical topics, physical, psychological and other health issues, appertaining to the patients hospitalization and rehabilitation programme.

The meetings offer support, re-assurance and are beneficial to everyone and particularly those patients, who live alone. There is an evident social element, which positively encourages and nurtures the patients ongoing rehabilitation, from this life-changing experience. *Jean and Tom*

"I attended a rehabilitation physiotherapy class, I made friends with Freda and we chatted, we both had very similar experiences, at last someone who understands how crazy I was!

A year later Freda and I set up the ICUsteps meetings, so all those people who felt as lonely, different and scared as us, could come and chat and realise that they are not alone. We understand, we have been there, do come to see us, it WILL help!" *Trace*

"I wanted to give something back as a thank you and also wanted to help people that had experienced the same things as myself in and after their stay in Critical Care." *Chairman, Chris*

"A friendly and informal gathering of fellow survivors. An uninhibited place to chat about your hopes, fears and experiences..... or just have a pint and a laugh." *Steve*

"You are not alone – there are people to help with the problems you are facing." *Freda*

www.icusteps.org.uk – As part of the ICUsteps initiative on support groups for people who have been affected by a stay in Critical Care, some hospitals hold "drop-in" evenings or coffee mornings every month or two depending on the area. Details and dates of group drop-ins can be found at **www.icusteps.org/support/support-groups**. There is also a contact form should you have any questions. Participating hospitals are usually happy to welcome people who have been in critical care units in other hospitals outside of their own, so there is an option for everyone. Some groups operate on-line, so no travelling is required; this is particularly useful if you do not live near a group venue.

useful information

Useful telephone numbers

Samaritans for help with emotional distress:
116 123

Citizens Advice

Customer Service: 0808 223 1133

To speak to an advisor: 0800 144 8848

NHS smoking helpline: 0300 123 1044

Driver and Vehicle Licensing Agency (DVLA)

Information on medical conditions:

0300 790 6801 Option 2

Financial Benefits –

Department of work and pensions:

To make a claim if you are unable to work:

Job Centre Plus: 0800 055 6688

Benefit Enquiries: 0800 169 0310

Attendance Allowance (AA)

for the over 65s: 0800 731 0122

Personal Independence Payment (PIP)

for the under 65s: 0800 121 4433

Useful websites

For information on benefits, driving, pensions
and much more go to the government website:
www.gov.uk

For information on medical conditions:
Search for 'Can I drive'

NHS website – www.nhs.uk

- Social care – search on NHS website for care and support assessment
- Improving Access to Psychological Therapies (IAPT) – search on NHS website for talking therapies

Citizens Advice website

www.citizensadvice.org.uk

Critical Care Websites

- Intensive Care Society Patient Resources
www.ics.ac.uk/about-icu/patient-resources.html
- Faculty of Intensive Care Medicine
www.ficm.ac.uk/for-patients
- Critical Care Recovery
www.criticalcarerecovery.com



- ICUsteps, the intensive care patient support charity

www.icusteps.org/

www.icusteps.org/information for information booklets incl. for delirium, breathing, nutrition, worry, children visiting and more

www.icusteps.org/support/support-groups to find a support group

Helping Critical Care patients on the road to recovery

Take a tour and understand your Critical Care stay and recovery on You tube. This tour was created when recovering patients were unable to visit Critical Care due to Covid-19 restrictions, but it is still very useful and may answer a lot of questions for you – With thanks to East Suffolk and North Essex NHS Foundation Trust.

<https://www.youtube.com/watch?v=F7cc21rPVLk>



- Spinal Injuries Association
www.spinal.co.uk/
- GAIN, Guillain-Barre & Associated Inflammatory Neuropathies
www.gaincharity.org.uk
- The Lee Spark Necrotising Fasciitis Foundation www.nfsuk.org.uk/

Local information – telephone numbers

Specific Support Websites:

- Critical Illness, Brain Dysfunction, and Survivorship (CIBS) Center
www.icudelirium.org/
- NHS Covid Recovery website
www.yourcovidrecovery.nhs.uk
- Sepsis Trust
www.sepsistrust.org/
- BRAKE, The Road Safety Charity
www.brake.org.uk
- Headway, The Brain Injury Association
www.headway.org.uk/
- Stroke Association
www.stroke.org.uk

Contributors:

Claire Gray, Practice Educator, Critical Care Outreach Team, East Suffolk and North Essex NHS Foundation Trust, Ipswich Site

Claire Rock, Highly Specialist Occupational Therapist, Mid and South Essex NHS Foundation Trust, Basildon Site

Clare Merchant, Senior Dietitian, West Suffolk NHS Foundation Trust

Dalena Christian, Senior Occupational Therapist, Queen Elizabeth Hospital King's Lynn NHS Foundation Trust

David Sapsford, Consultant Pharmacist Critical Care, Cambridge University Hospitals NHS Foundation Trust

Dr. Deborah Easby, Consultant in Intensive Care Medicine, Norfolk and Norwich University Hospitals NHS Foundation Trust

Diana Stewart, Clinical Specialist Occupational Therapist, Peterborough & Stamford Hospitals NHS Foundation Trust

Eleanor Caulfield, Specialist Speech & Language Therapist, Cambridge University Hospitals NHS Foundation Trust

Eleni Savvides, Counsellor, Mid and South Essex NHS Foundation Trust

Esther Rawlinson, Critical Care Follow-Up Sister, West Suffolk NHS Foundation Trust

Helen Stewart, Physiotherapy Professional Lead, West Suffolk NHS Foundation Trust

Jennifer Powner, Specialist Physiotherapist in Respiratory Care, East Suffolk and North Essex NHS Foundation Trust, Colchester Site

Jess Wardill, Counsellor, Mid and South Essex NHS Foundation Trust

Jill Hyde, Critical Care Clinical Nurse Specialist, Cambridge University Hospitals NHS Foundation Trust

Karen Bending, Lead Physiotherapist ICU and Surgery, Queen Elizabeth Hospital King's Lynn NHS Foundation Trust

Karen Cotton, East of England Critical Care Network Innovation and Nursing Lead

Kira Neal, Clinical Specialist Physiotherapist, Cardiothoracics, Mid and South Essex NHS Foundation Trust, Basildon Site

Lisa Enoch, Critical Care Clinical Nurse Specialist, Cambridge University Hospitals NHS Foundation Trust

Lisa Wood, Rapid Response Team Lead Nurse, Cambridge University Hospitals NHS Foundation Trust

Dr. Mark Blunt, East of England Critical Care Network Clinical Director and Consultant in Intensive Care Medicine, Queen Elizabeth Hospital King's Lynn NHS Foundation Trust

Melanie Wright, East of England Critical Care Network Director

Nicola Stead, Highly Specialist Speech & Language Therapist, Cambridge University Hospitals NHS Foundation Trust

Nikki Swales, Lead Counsellor, Mid and South Essex NHS Foundation Trust

Rebecca Charles, Specialist Respiratory Physiotherapist, West Suffolk NHS Foundation Trust

Sarah Griffith, Senior Physiotherapist Cardiothoracics, Mid and South Essex NHS Foundation Trust, Basildon Site

Sarah Williams, Clinical Nurse Specialist, Mid and South Essex NHS Foundation Trust

Shirley Morrison, Highly Specialist Occupational Therapist, Mid and South Essex NHS Foundation Trust, Basildon Site

Silke Sutton, Senior Physiotherapist, Mid and South Essex NHS Foundation Trust Southend Site

Sophie Graves, Clinical Specialist Occupational Therapist, North West Anglia NHS Foundation Trust, Peterborough Site

Sue Parrotte, Senior Sister and Critical Care Rehabilitation Clinics, Mid and South Essex NHS Foundation Trust, Broomfield Site

Tamara Pendry, Senior Sister, The Princess Alexandra Hospital NHS Trust

Tracy Carroll, Outreach Clinical Nurse Specialist, East Suffolk and North Essex NHS Foundation Trust, Colchester Site

Thank you also to the following for sharing information

- Papworth Respiratory Support and Sleep Centre
- Extracts from Dr. Christina Jones – Intensive care recovery Manual V3
- Outreach Team from Hinchingsbrooke Health Care NHS Trust

East of England Adult Critical Care operational delivery network

eoeccn.org

For feedback on this booklet, please contact: add-tr.eoeccn@nhs.net



Digital version of booklet available here.

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