

Road to Recovery



CRITICAL CARE REHABILITATION GUIDE

“

The overwhelming feeling I had, reading about others that had been in ICU, was that I was no longer alone

ICU Survivor

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Critical care may save our lives, but we need support and rehabilitation to give those lives back to us

ICU Survivor

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This booklet has been created to give you a framework to use with your clinical team and your loved ones to support your recovery after being critically ill.

Life after severe illness can be challenging and it can feel like a series of stepping-stones to getting back to 'normal' again.

Your rehabilitation journey will take time, effort and energy for you and your family. Remember to give yourself time to adapt, change, recharge and support yourself or your loved ones through this process.

You may also wish to seek support and reassurance from those who have been through a similar experience to yourself. You can visit healthunlocked.com/icusteps or the "Critical Care Support Network" site www.cc-sn.org for lots of helpful tools and information.

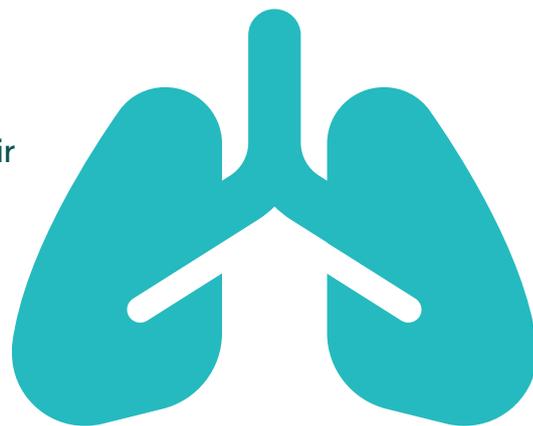
Introduction to critical care

Waking up on critical care can be a frightening experience. There are lots of machines, wires and alarms sounding around you and lots of different health care professionals will visit to carry out assessments. This can be quite scary and overwhelming. To help you understand your surroundings the picture below shows some of the machines and attachments that you may have required. Not all patients require all of these.



Tracheostomy

Patients in an Intensive Care Unit often need help with their breathing. If you were on a ventilator machine for a long period of time then you may have needed a tracheostomy tube. This information sheet will explain more about tracheostomies - <https://icusteps.org/assets/files/information-sheets/tracheostomy.pdf>



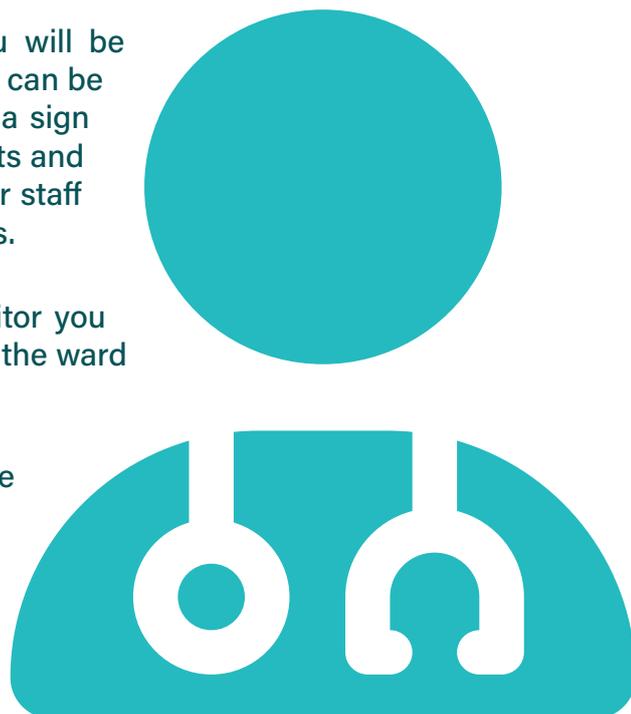
Transfer to the ward

When you no longer need critical care treatment you will be transferred to another ward. This is a positive step, but it can be difficult to adjust to the change. While ward transfer is a sign of improvement and a step closer to going home, patients and families must adjust to less monitoring and having fewer staff close at hand. It is normal to feel apprehensive about this.

Most hospitals have an outreach service that will monitor you closely in the early days to ensure that your transition to the ward goes smoothly and that you continue to recover well.

Different therapy teams will continue to see you on the ward to help progress your rehabilitation goals and help guide you with any exercises they have given you. It's important to keep doing your exercises to help build your muscle strength. Your ward physiotherapist will inform you how many repetitions should be done and advise you how to progress your exercises.

Ward Team: Nurses, Doctors, Pharmacists, Dietitians, Occupational Therapists, Clinical Psychologist, Physiotherapist, Speech and Language Therapists and more may be involved as required in your continued recovery.



Discharge Home

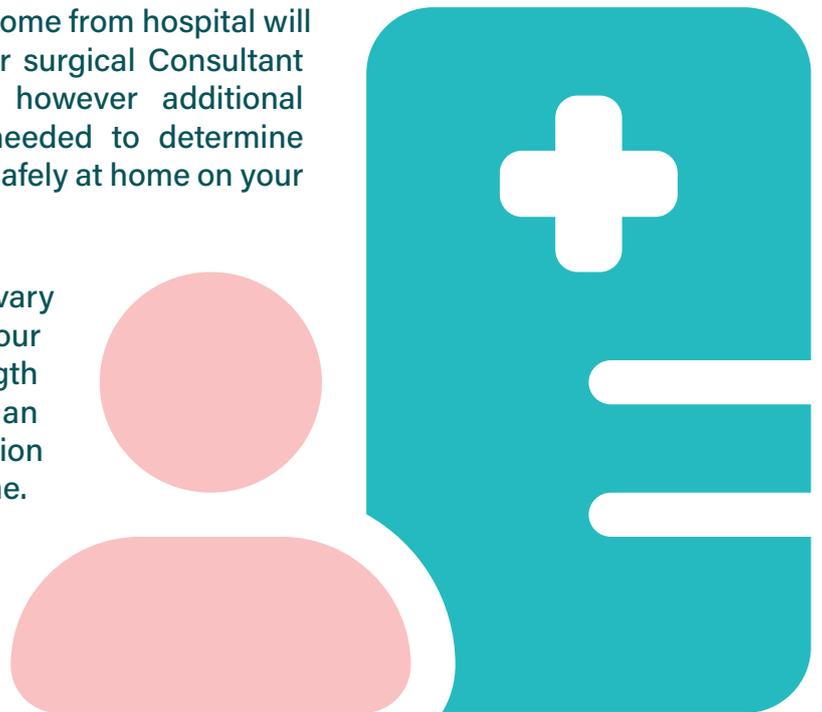
The decision for you to be discharged home from hospital will ultimately be made by your medical or surgical Consultant once your condition has improved however additional discussion with the wider MDT is needed to determine whether you are fit enough to manage safely at home on your own (with or without support).

The support that you require will vary depending on many factors including your personal circumstances, illness and length of hospital stay. Some patients require an additional period of time at a rehabilitation hospital or centre before returning home.

When you are ready to be discharged from hospital your exercise plan and ongoing rehabilitation goals will be reviewed according to your ability and progress. Your physiotherapist and/or Occupational therapist will decide whether you need further therapy once home and assess for any assistive equipment that you might need at home. Often hospital discharge teams are available to help identify the right support for you whether this be ongoing physio at home or carer visits to support you in day to day tasks.

Once you have been discharged from hospital your recovery will be well underway, however many patients still have a long way to go before they begin to feel like themselves again. For many patients this recovery phase of their illness is the most stressful. The emotional impact of having been critically ill can last for some time.

The speed of your recovery can depend on lots of things. For example, how unwell you were, how fit you were before coming into hospital and how well you are able to join in with the rehabilitation process.





Getting back to everyday life

Getting home is a huge step on the road to recovery. While it is often an enormous relief to be home, some may find the first few weeks a bit of an emotional rollercoaster in terms of readjusting to everyday life, and being without constant clinical care and support.

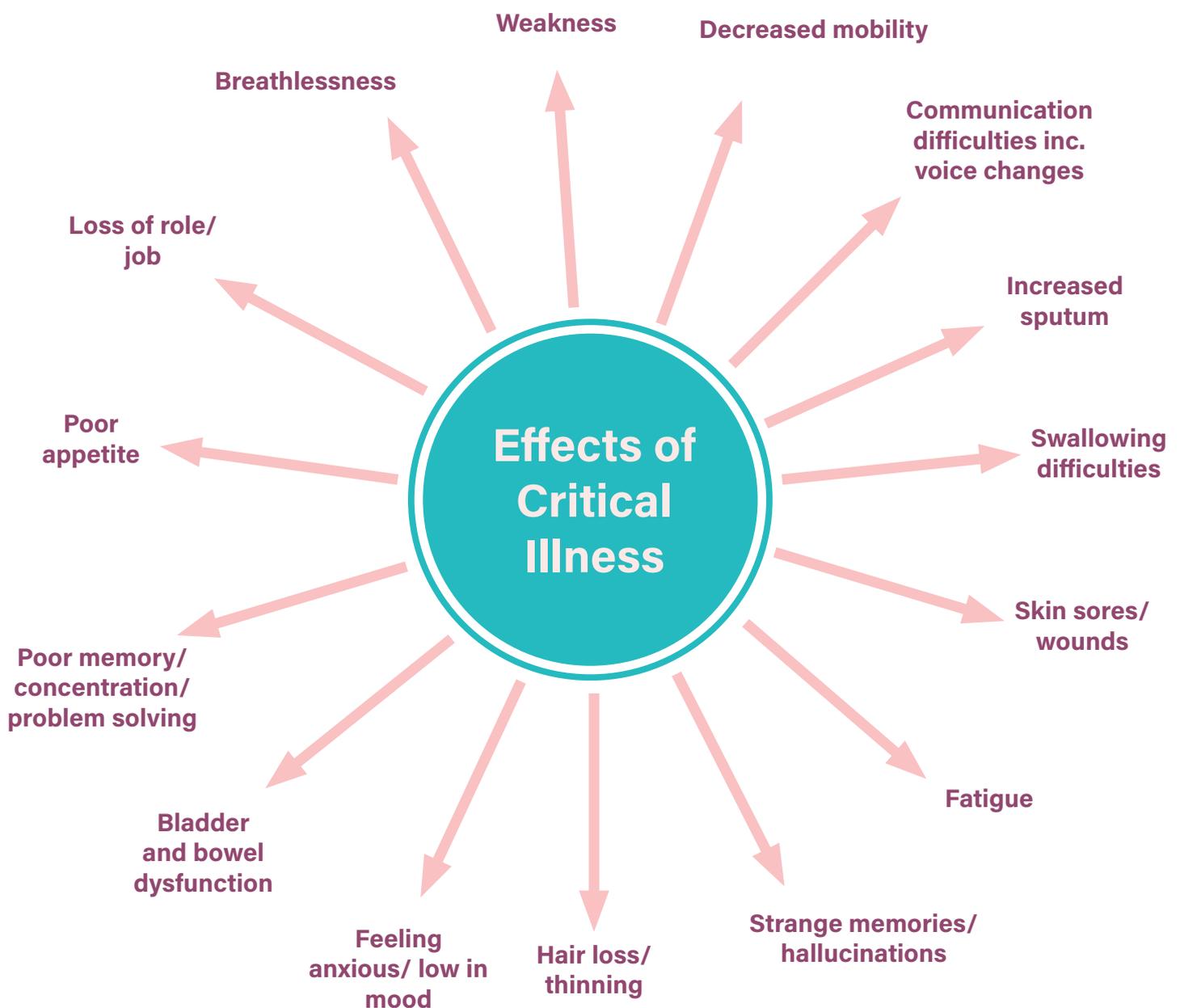
Getting back to work can be an additional worry for many critical care survivors. You may need a prolonged period of time recovering at home before you are able to think about returning to work. Your GP will be able to guide you here. The following leaflet may provide you with some useful tips and advice. <https://gstt.criticalcarerecovery.com/file/returning-to-work-after-critical-care.pdf>

In the following sections, we've provided some general information and advice on the common physical and psychological issues you might face, what you can do to help the recovery process along, and the types of help that might be available to you and your family after you get home.

Common problems during & after a critical illness

Individuals are likely to have different problems due to the impact of critical illness. All of the following symptoms are normal following a hospital stay in Critical Care – it does not mean that these effects will last forever.

Sometimes patients have a combination of these problems (both physical and mental) and this is often referred to as Post intensive care syndrome or “PICS”



Mobility & Physical Activity

After being critically ill your body is weaker and you may experience stiffness of joints and loss of muscle mass. You might feel unsteady or unbalanced when walking, and generally see a reduction in fitness. This is normal, but it is important to begin rehabilitation and building strength as soon as possible to support your mental and physical recovery. Below are exercises you can do to help rebuild your muscle strength. If you feel unwell during these exercises, stop, and inform a member of staff on your ward.

Your Physiotherapist will guide you through these exercises and make suggestions as to how often to repeat. This can be slowly increased as you become stronger.

Bed exercises



Lying on your back – bend your ankles up and down. You can do one ankle at a time, or both at the same time.

Repeat times.



Lying on your back – bend your knee as far as is comfortable then straighten it back down.

Repeat times on each leg.



Lying on your back with legs straight.

Bend your ankles and push your knees down firmly against the bed. Hold for secs.



Lie on your back with one leg straight and the other bent. With your straight leg, pull the toes up and straighten the knee. Slowly lift the leg 20cm off the bed. Hold for approx. 5 seconds then slowly relax. Repeat times on each leg.



Lie on your back with both knees bent. Slowly lift your bottom off the bed, and then relax.

Repeat times.

Chair exercises



Sitting down with your feet flat on the floor, slowly raise your heels up, and then relax. You can do this one foot at a time or both at the same time.

Repeat times on each leg.



Sit upright in a chair. March your legs up and down. Repeat times on each leg.



Sit upright in a chair. Slowly straighten your knee out in front of you, and then relax.

Repeat times on each leg.



Sitting upright, lift your arm above your head, then lower it down.

Repeat times on each arm.

Standing exercises



Stand straight holding on to a chair or windowsill. Bring your leg backwards keeping your knee straight. Take extra care not to lean forwards, keep your trunk still. Repeat times on each leg.



Stand straight holding on to a chair or windowsill. Bring your leg to the side, keeping your knee straight and trunk still. Repeat times on each leg.



Stand straight holding on to a chair or windowsill. Slowly rise up onto your toes, and then slowly relax back down.

Repeat times on each leg.

Fatigue Management

What is fatigue?

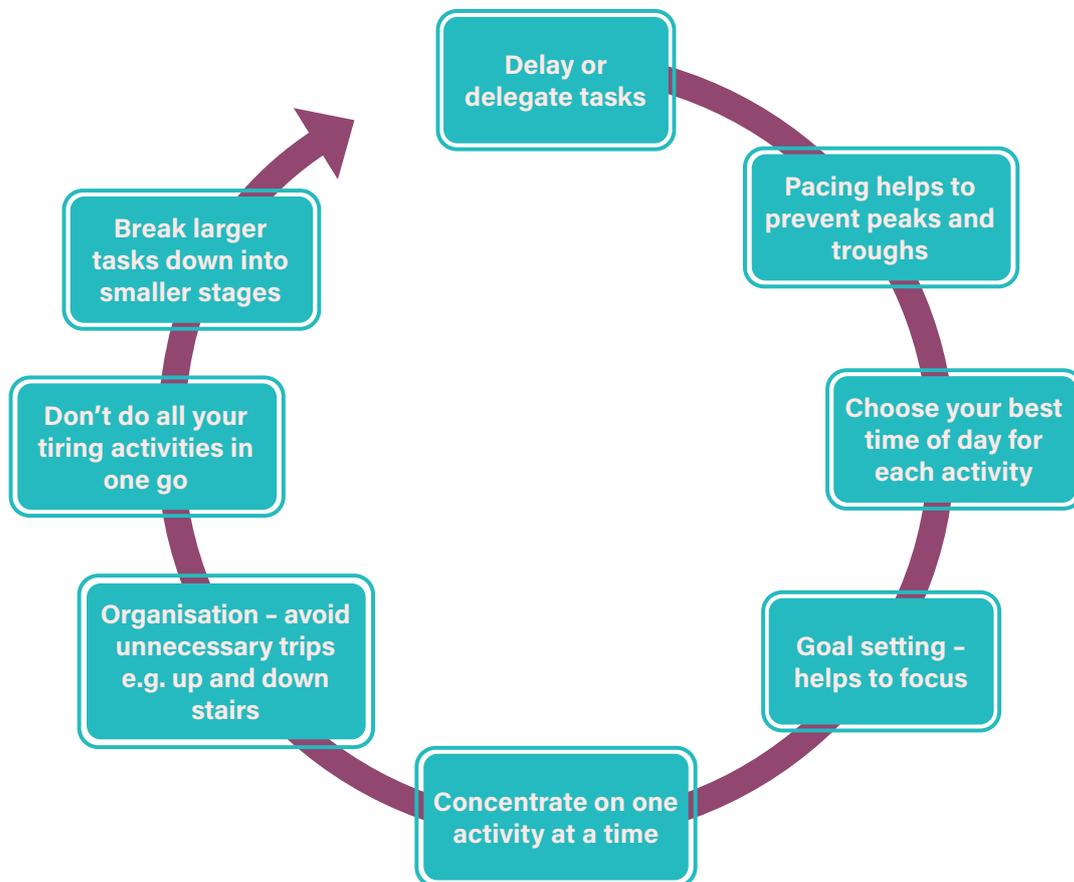
Fatigue is a common symptom following critical illness. For most people, fatigue usually subsides within a few weeks, but for some it can persist longer. Fatigue is often felt to be both physical and mental tiredness and is said to be overwhelming:

- A feeling of having no energy, like you could spend the whole day in bed.
- Feeling breathless after only light activity.
- Difficulty sleeping.
- Feeling more emotional than normal.
- Having trouble thinking or making decisions.

The feeling of fatigue is often exacerbated by activity and can sometimes develop the following day, taking several days to improve.

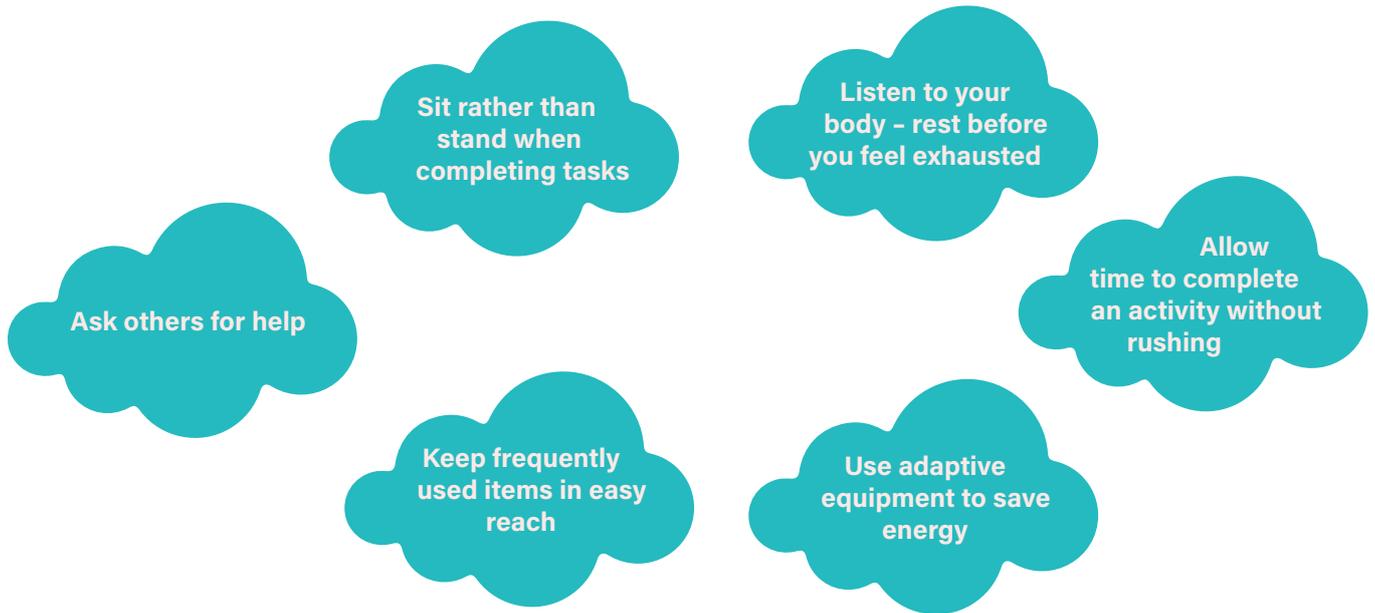
Managing Fatigue

Planning, pacing and prioritising activities.



Energy Conservation

The aim of energy conservation is to improve your quality of life, by conserving your energy for the activities you “like to do” as well as those you “have to do”, within a safe and well structured environment.

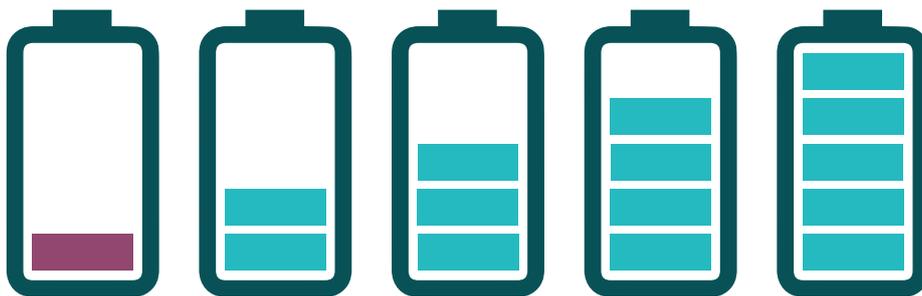


Grading activity

Grading activity involves looking at the things we do in every-day life and breaking them down into achievable steps which can be adjusted as able.

The Human Battery

People often associate the concept of energy with batteries and describe that having fatigue makes them feel like they have an empty battery, reporting that even on the ‘good’ days their energy levels are still significantly lower than prior to their illness.



Pacing and grading activity rations energy and uses it to best effect. The intention is to avoid flattening the battery and allow opportunities for energy levels to rise. Pacing uses smaller amounts of energy at one time and spreads the total energy used out over longer periods.

Managing breathlessness

Breathlessness is a very common symptom for people who have been critically unwell. Everyday activities such as walking, washing or household tasks can make you feel breathless, and being breathless can make you panic or feel frightened.

Below are some techniques that your therapist may teach you to help you to manage your breathlessness:

Relief of breathlessness:

- Stop speaking and moving, give yourself time to recover your breath.
- Choose a position which will make it easier for you to breathe.
- Use breathing control techniques.
- Gradually try to make your breaths slower and deeper.
- Find a distraction – it may help to focus on a picture, or view from a window.

Step 1: Positions to ease breathlessness

- The following positions support the muscles in the body that help us with breathing.
- Try to relax your hands, wrists, shoulders, neck and jaw as much as possible.



Make sure you are fully over on your side. Resting your upper arm on a pillow may also help.



Relax down onto the pillows as much as possible. Having your legs apart may also help.



Experiment with your arm position – find what is comfortable with you. When sitting, sit upright, have your legs uncrossed and keep your head up. Leaning forward will also help.

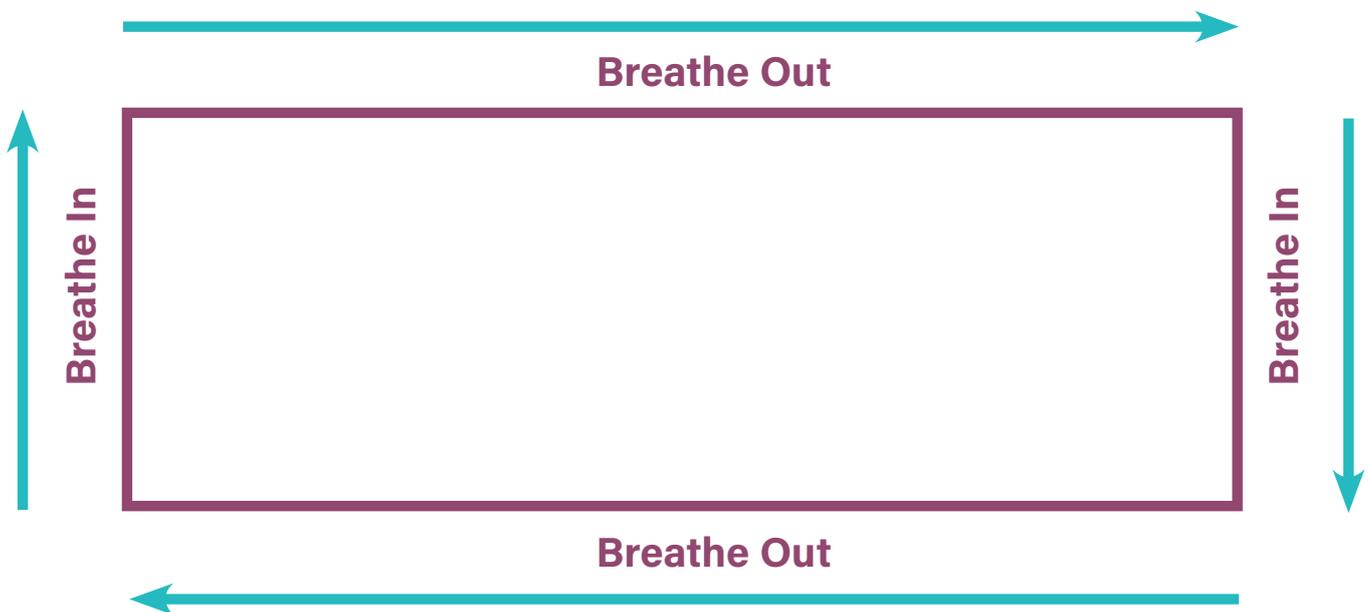


Step 2: Breathing techniques

- The aim is to move from fast, upper chest breathing to relaxed, slow tummy breathing. You may find it helpful to rest your hand on your tummy as you do this, feel it rise and fall gently with each breath.
- Remember 3 Rs: Rise the tummy as you breathe in, Relax the breath out, Rest and wait for the next breath to come.

Breathing Rectangle

- Follow the sides of the rectangle with your eyes as you breathe in (nose) and out (pursed lips).
- Gradually slow the speed your eyes move around the edge of the shape to slow your breathing.



Practice these techniques regularly so they will feel more natural to use when you are breathless.

Pursed lip breathing

- Breathe in gently through your nose.
- Breathe out with your lips pursed as if you are whistling.
- Try to blow out as long as comfortable, do not force your lungs to empty.

Blow as you go

- Breathe in before you make the effort.
- Breathe out whilst making the effort (e.g. as you lift an object).
- Always breathe out on the hardest part of the action.

Secretion Management

Active Cycle of Breathing Technique (ACBT)

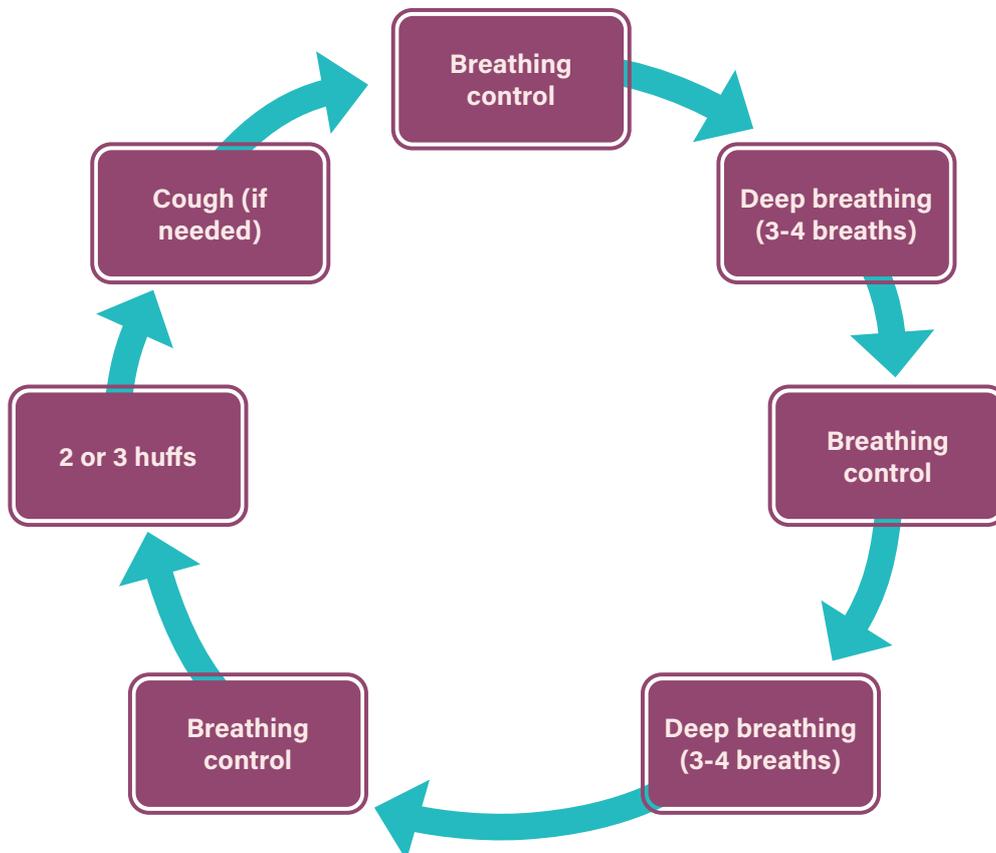
The Active Cycle of Breathing Technique is a set of breathing exercises that can be used to help you clear sputum ("Phlegm") from your chest. Coughing alone can be tiring and ineffective, so the ACBT is designed to:

- Loosen and clear sputum.
- Help you breathe more easily.
- Improve the efficiency of your cough.
- Reduce the risk of chest infection.

You can use this method of breathing in whatever position you find comfortable or seems to clear the most sputum. Make sure the position you use is comfortable and has your head, neck and arms well supported, with your shoulders relaxed down. Your physiotherapist may advise you of specific positions to try.

Another effective way of clearing sputum is engaging in activity – this will be guided by your physiotherapist.

Stages of active cycle of breathing



Breathing Control

Breathing control is the part of the cycle to allow you to rest and relax your airways between the deep breathing and huffing. Breathing control can also help when you are short of breath, anxious or in a panic.

Refer to the instructions above in “breathing techniques” on how to perform this.

Deep Breathing Exercises

Deep breathing is used to get the air in your lungs behind the secretions stuck in your small airways.

Take a long, slow, deep breath in, through your nose if comfortable, if not through your mouth. Breathe out gently and slowly through your mouth. Some people find it helpful to hold their breath for two or three seconds at the end of each breath in, before breathing out or to ‘sniff’ air in through your nose quickly at the end of the deep breath in.

Once you have completed the deep breathing exercises, go back to breathing control again to ensure your airways are relaxed.

Huffing

Huffing helps to move sputum up your airways by making it ‘rattle’

- Take a medium sized breath in.
- Breathe out quickly with your mouth wide open, as though you are steaming up a mirror. Your tummy muscles should tighten when ‘huffing’
- Repeat two-three times with breathing control in between each huff.

If you are wheezing with each huff you may be huffing too hard or for too long.

Return to the start of the cycle and begin again if your lungs do not feel clear of sputum. Ensure you rest when you have completed three to four cycles before beginning again.

The importance of goal setting

Setting goals that are realistic can help you to stay positive and provide a sense of achievement. These goals can be physical and/or mental. They should be achievable and will help to track your progress in your recovery.

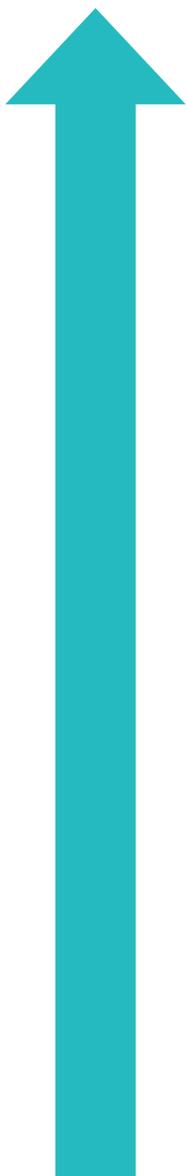
Begin with initially setting yourself small achievable goals without planning too much within your day. Initially think of planning your day hour by hour once that becomes easier progress to planning half a day and then by day as you physically recover from critical illness.

It will be beneficial to continue to set goals when you are at home. These could be based upon activities of daily living (ADLs), for example to make a hot meal, doing some gardening, reading a book.

Remember to challenge yourself but gradually.

Examples

- Transfer from bed to chair
- March on the spot
- Mobilise around the bed space
- Wash myself sat in a chair
- Manage feelings of panic



My goals	Achieved date

Swallowing & Communication

Critical illness and the treatments you have during your hospital stay on Critical Care can affect your swallowing, communication and voice. It is important to keep yourself safe and comfortable as you continue your rehabilitation at home.

Eating, Drinking and Swallowing

Some people who have been critically unwell may experience difficulties with eating, drinking, and swallowing. This could be due to your underlying condition, altered taste, reduced appetite, breathlessness and fatigue, muscle weakness, or, for some people, the need to be intubated whilst in intensive care. You may have managed to eat and drink whilst in hospital or you may have required a feeding tube. If you do not use your swallowing muscles for a while, they may become weaker and may make eating and drinking become more difficult.

You may have been seen by a speech and language therapist (SLT) in hospital who may have given advice on how to modify your diet/fluids, provided strategies to make swallowing easier or given you rehabilitation exercises to improve your swallowing.

If you notice any of the following symptoms, please contact your GP who can refer you to the relevant team for further support:

- Coughing or choking when eating or drinking
- A wet, gurgly voice quality after swallowing
- A sticking sensation in the throat when eating and drinking
- Frequent chest infections

Strategies that may make eating, drinking and swallowing easier include:

- Making sure you are sat fully upright when eating and drinking
- Not eating or drinking if you're feeling extremely tired or breathless. Rest, and return to eating and drinking later
- Taking your time when eating and drinking. A 'little and often' approach may help
- Taking smaller sips or bites
- Opting for foods that do not need to be chewed as much, if you are becoming tired/breathless when chewing
- Avoiding talking when you are eating and drinking, as this can open up your airway and food can go down the wrong way

Looking after your mouth

Sometimes, individuals can experience a very dry mouth, with cracked and sore lips, particularly when in hospital. This is especially the case if an oxygen mask is needed. It is important to keep your mouth moist and clean to prevent bacteria building up and causing infections.

Make sure you:



Brush your teeth or dentures, twice daily, using toothpaste and remember to remove your dentures overnight.



Drink plenty of fluids (if you have been told it is safe to do so) Water is best for hydration and feeling of thirst.



Use a lip balm to keep lips moist and prevent cracking

Communication

Communication refers to speech, voice and language. Following critical illness you may experience changes to your communication.

This may be as a result of your underlying condition or the treatment and equipment used to help you get better. Talking can be more difficult if you are breathless and your voice might sound weak, quiet, rough or hoarse.

You may have a sore throat if you have been coughing a lot or if you needed a breathing tube during your hospital admission.

A good breath is very important in helping us to speak in a clear voice that can be easily heard and understood by others. You may feel that your voice is weak and your speech is not as clear as it used to be. This should improve as your symptoms resolve.

Here are some strategies of how to look after your voice and use clear speech:

- Sit in an upright position and take a breath before talking.
- Speak in shorter sentences and take regular breaths to avoid straining at the end of sentences.
- Reduce background noise when communicating with others.
- Avoid shouting or forcing your voice out. It is better to use your voice without straining, even if it means it is quiet and breathy.
- Do not whisper.
- Avoid throat clearing. Try clearing your throat by swallowing instead.
- Stay hydrated by drinking plenty of water.
- Reduce caffeine and alcohol intake.
- If your voice feels tired, stop, rest and try later.

On rare occasions the voice does not improve without treatment and a referral to Ear, Nose and Throat (ENT) and Speech and Language Therapy (SLT) may be necessary. This can be arranged by your GP.

Symptoms should resolve as you recover but if you are experiencing difficulties with understanding other people's speech, forming your own sentences, producing clear speech or voice, then a Speech and Language Therapist (SLT) will assess this and support you to manage or rehabilitate these difficulties. Speak to your GP who can refer you onto your local Speech and Language Therapy team.

Nutrition

A good nutritional intake is important to help you recover from your critical care stay. It is common to lose weight and muscle during your critical care and hospital admission. If you are struggling to meet your nutritional needs, below is some information to support you so that you can start to return to your usual activities of daily living and what is important to you.

When people first come to critical care, they often cannot eat or drink as they normally would and therefore may need some help to ensure their body receives the energy, protein and micronutrients required in this phase. These may include:

<p><u>A nasogastric or NG tube</u></p> <p>This is a feeding tube placed through the nose, down the throat and into the stomach</p> 	<p><u>A nasojejunal or NJ tube</u></p> <p>This is a feeding tube placed through the nose, down the throat, through the stomach and into the small bowel</p> 
<p><u>A gastrostomy tube</u></p> <p>A feeding tube placed directly into the stomach as some people may not be able to eat and drink normally for a longer period of time</p> 	<p><u>Parenteral Nutrition or TPN</u></p> <p>Nutrition delivered directly into the blood stream via a specially placed line if unable to use the gut to absorb nutrients</p> 

If you are taking food via mouth, your Dietitian or medical team may prescribe you high energy and protein drinks or puddings called nutritional supplements.

 <p>Nutritional supplements are often prescribed to help supplement your diet</p> <p>This may be when you are building up your eating and drinking, if you have a low appetite and/or have lost weight.</p>	 <p>Nutritional supplements come in a variety of flavours, textures and presentations e.g. milkshake or juice style.</p> <p>You may also be advised to continue these when you leave hospital</p>
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Recovering from critical illness:

Recovering from critical illness can come with physical and emotional difficulties which may last for several months after leaving hospital. Your nutritional needs will also change throughout your critical care recovery. During your critical care stay and after you have been discharged, it is common to struggle to eat and drink as normal for several reasons. Although you may not have all these difficulties, you may have had some of these which have now improved, but other difficulties may last longer. It is also important to have enough to drink and to eat the right foods to help with your recovery and also to help your hair, nails and skin.

The amount of energy and protein our bodies need varies from person to person, but to help with recovery after critical illness, it is likely you will need to eat more than you did before. This is because you may need to regain lost weight, or rebuild muscle in order to improve strength and activity levels.

Alternatively, some people will struggle with weight gain post critical care admission. If you are looking to reduce your weight, it is advisable to wait until you are feeling well and recovered from your recent hospital stay. A slow and steady weight loss is preferred.

The resources at the bottom of this page will provide you with further information and support.

Difficulties with nutrition you may experience when recovering from critical illness:

Reduced appetite	Smaller portions to usual
Reduced interest in food	Taste changes
Feeling full quickly	Gut issues e.g. nausea, bloating, constipation and loose stools

Tips to help with poor appetite and weight loss:

1. Try to eat 'little and often' throughout the day. Aim for 5-6 smaller meals or 3 smaller meals with 3 high energy and protein snacks in between e.g. milky puddings, yoghurts, cheese and crackers, breadsticks and hummus, nuts, peanut butter on toast
2. Eat when you feel like it
3. Try to avoid filling up on drinks just before eating
4. Try to drink higher energy drinks, such as 'fortified milk,' milkshakes with ice-cream and smoothies with full fat yoghurt, hot chocolate or coffee made with full fat milk.
5. Try to eat a 'fortified diet' which means adding extra energy and protein to your food without significantly increasing the amount e.g. crushed nuts, honey, jam, syrup or dried fruits added to your porridge, cereals and desserts
6. Avoid low fat or 'diet' products and choose full fat alternatives
7. You may struggle to eat 5 fruits/vegetables a day when you have a poor appetite. Consider taking a multivitamin and mineral supplement if you are struggling



Tips to help with increasing protein in diet:

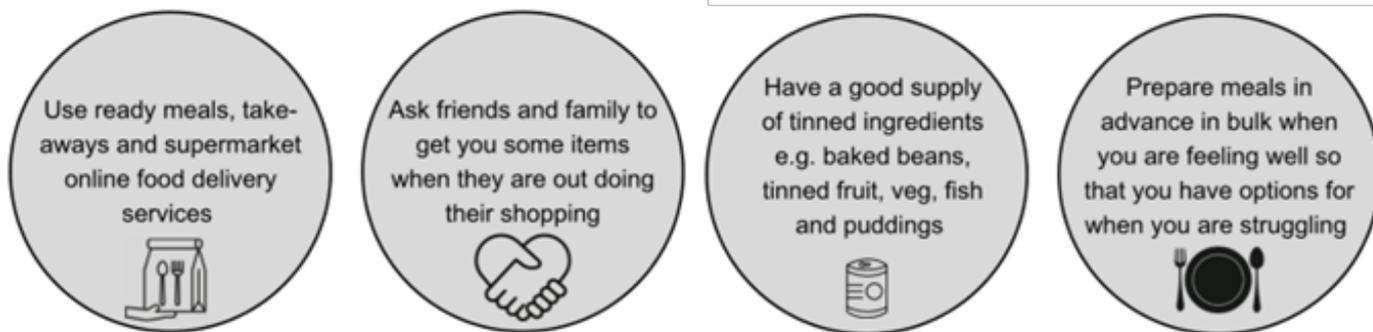
The long term after effects of critical illness often include a loss of muscle protein and difficulty in regaining some muscle mass and strength. Eating enough protein along with physical activity will help with this. It is often a good idea to ensure that our bodies are getting adequate protein to regain muscle mass alongside advice you may be given by your Physiotherapy team regarding physical rehabilitation.

Some ideas to ensure you are eating enough protein are:

1. Aim to include a portion of meat, fish, beans, soya protein or cheese at each meal
2. Include higher protein snacks between meals or desserts such as milky puddings, yogurts, custards, cheese or nuts
3. Use a high protein food 'topper' on your meals. This could be cheese sprinkled on baked beans or potatoes, crushed nuts or seeds added to porridge, cereals or desserts
4. Include milky drinks between your meals, such as 'fortified milk,' milkshakes made with ice-cream, smoothies made with yoghurt, hot chocolate or coffee made with milk

Tips for getting the food you need:

When you are feeling unwell and recovering from critical illness it can be difficult to go shopping and prepare the foods you need.



For more information on local companies providing food deliveries and local food banks speak to your local healthcare provider.

Further resources:

The resources below will provide you with further information and support if you are experiencing some of the problems mentioned above:

- Nutrition in hospital: [ICUsteps - Nutrition in hospital after critical illness](#)
- Nutrition at home: [ICUsteps - Nutrition at home after critical illness](#)
- Tips to help with eating problems: [ICUsteps - Tips to help with eating problems after critical illness](#)

If you are struggling with your eating and drinking and/or with your weight please consider contacting your GP or Dietitian who can offer you more advice and/or refer you for further Dietetic support. This information is not necessarily appropriate for all patients so does not replace personalised advice provided by your Dietitian or healthcare team.

Psychological Recovery

Following a period of time in critical care, you may experience a range of unfamiliar feelings and reactions associated with the shock that you have been through. You may have little or no memory of the events leading up to your admission or your time in hospital which can be confusing. Waking up after being sedated in an unfamiliar environment can leave you feeling anxious and frightened.

You may have difficulties collecting your thoughts and may experience a range of emotions about what's happened which could include:

- Feeling anxious or worried, fearful, angry, or low in mood
- When we are struggling with our emotions it is normal to also feel a range of physical symptoms:

shaking and trembling	lack of energy	dizziness
tension and muscular aches	poor concentration or forgetfulness	feeling nauseous
sleep disturbance	palpitations	Need to use the toilet more frequently
tiredness	shallow or rapid breathing	

Emotional and physical changes can feel scary and unpleasant. But be assured that these changes are often our body's normal responses to the stress of having been through a significant or life threatening situation.

Many people after these traumatic events will initially be shaken, and over time will recover. However sometimes these feelings can be difficult to understand and navigate and they might need some support. All reactions are individual and not everyone experiences the feelings that are described here. The important thing is to acknowledge that you have been through a difficult time and and it is normal to experience a range of emotions during your recovery.

Sometimes, people feel they are reliving traumatic events through nightmares and flashbacks after the event has passed, and this can lead to feelings of isolation, irritability and guilt. They may also have difficulties sleeping and concentrating. Although these are normal experiences after a traumatic event, if you are still having difficulties about 6 weeks after the event, or if these experiences are particularly troublesome, you should seek advice from your GP.

Try to respond kindly and compassionately to yourself, noticing your frustration, disappointment and allowing time to come to terms with what you have been through. It can help to monitor your symptoms initially to see whether they improve or get worse without treatment.

Talking about your worries:

Talking to others such as family, friends and your usual social support network can help you to come to terms with the experiences you have had, yet sometimes this may feel particularly difficult. There are resources available you can access to talk to others who might understand some of how you are feeling. The services available are listed at the end of this document.

Taking care of yourself

Avoid unhelpful ways of coping: such as drug and alcohol use, sleeping all day, isolating yourself from friends and family, neglecting self-care; and do not over or under exercise (See mobility and physical activity section).

Sleep: It can take time for your normal sleeping and waking cycles to return after being in hospital. Below are some helpful sleep hygiene tips:

- Avoid caffeine later in the day.
- Try to avoid sleeping for long periods during the day.
- Avoid screen time e.g. TV, smart phones, and tablets before bed.
- Create a morning and evening routine which signals your body to wake or rest.
- Try to expose yourself to natural light during the day if possible – this can help establish your body's natural waking and sleeping cycle.
- Create a calming and comfortable sleeping environment – aim to keep the temperature at around 18 degrees.
- Reading or listening to relaxing sounds or music may help you fall asleep. You may find sleep apps helpful (see relaxation section).
- Eating and drinking: (See Nutrition section).

Staying connected: It is important to stay connected with family and friends during your recovery. In the case that face-to-face contact isn't an option ensure to use other mediums of communication such as phone or video calls.

Grounding strategies: Sometimes when we are dealing with difficult thoughts and feelings it can be easy to get lost in them. You may find you have vivid memories that make you feel like you are back in hospital. This is a common experience for many and can be unsettling if unexpected. It can be useful to have a 'grounding technique' to help you remind yourself and your body that you are safe. Anything that reminds you of the present moment and that you are safe can be using for grounding, however, here are two techniques that can be useful:

- Having a 'grounding object'. This is an object you purposely focus all your senses on. For example; how does it feel, is it smooth, rough, light or heavy? What colour is the object, what shape, is it matte or shiny etc. When you use your senses in this way it helps ground you in the here and now and reminds your brain and body where you are and that you are safe.
- Pick a small spot in the room you're in, about the size of a 50 pence piece. It could be anywhere, the corner of a door, some wallpaper etc. Now describe 5 things you notice about that small area. Colours, shapes, textures and so forth. You do not need to rush this, take your time. Once you have noticed five things, see if you can notice any more. If you need to continue grounding, you can pick another spot and continue the exercise.

Creating a safe space: This can be a real place which you can go to or a place you imagine in your mind where you feel safe. It's important that this place is easily accessible. You can fill this place with things which bring you comfort, real or imaginary, for example a warm blanket, happy photos or a scented candle.

Other ways of taking care of yourself

Activities: what did you used to enjoy at home? Start to pick up some manageable activities that give you a sense of relaxation, pleasure and achievement. Remember to be gentle with yourself and set realistic goals.

Resilience: Think about specific challenges you have faced in the past – how do these experiences help in this situation?

- Consider useful advice you received from others
- Who was supportive or helpful at the time?
- What did you say to yourself?
- Could anything you did to help you cope in the past be helpful now?
- What did you learn about how to cope with challenges?
- How did you get through it?
- What did you do that was most helpful?
- What did you do to be compassionate with yourself?

Anxiety: Feelings of tension and anxiety are normal experiences following difficult or life threatening experiences. Anxiety can make you experience physical feelings which may be new to you, including:

- fluttering chest – palpitations
- racing heartbeat
- breathlessness
- “butterflies” in stomach
- shaking
- feeling more sensitive to surroundings
- dry mouth

These feelings are normal and will pass. They are the body's automatic response to physical danger, so we are ready to fight, run or freeze. This is ideal if there are physical dangers around but can feel scary and over-warranted when the trigger for anxiety is not something we can fight or run away from such as worry and memories of difficult situations.

Brain Fog

Many people experience difficulties with their concentration and memory following a critical care admission. This is normal, and for many it resolves over time.

There are a number of things to be mindful of that can make this worse:

- Lack of sleep
- Loss of routine
- Dehydration
- Poor diet
- Infection
- Feelings of anxiety, low mood and stress.

It is important to rest, remain hydrated and have a good nutritional intake.

Delirium

Severe confusion called delirium, is usually temporary and resolves as illness improves, but can take a while to clear and feels scary for the person experiencing it and their families or carers. People who are experiencing delirium, in addition to being confused may experience visual and auditory hallucinations. Whilst this can be scary it is a common experience for many who have been cared for in Critical Care.

“Delirium” is most commonly experienced by people whilst they have been in ICU or have needed breathing machines in hospital, in addition to other factors such as pain, medications and type and severity of illness. Delirium is sometimes obvious to others, called hyperactive delirium. Patients may become very agitated or even aggressive because of the frightening things they are experiencing and can be very restless. However, delirium is sometimes hard to notice, and this is called hypoactive delirium. It might not be obvious that the patient is having frightening thoughts. They may appear to be very still and quiet and withdrawn from others.

If the onset of new severe confusion is experienced at home, please seek medical attention. This may be a sign that something else is going on in the body.

What are the signs of delirium?

People may see or hear things which are not there but seem very real to them – called hallucinations. They can be frightening, especially when realising that other people haven't shared their experiences. This can cause feelings of isolation and fear. People with delirium cannot think clearly or pay attention and can struggle to understand what is going on around them.

For example, a person might:

- not know who they are
- think they can see a frightening object, people or animals
- think they have been kidnapped or are in danger
- think people are trying to harm them, including staff
- believe noises are threatening and signs of danger
- feel agitated and struggle to concentrate
- behave in a way which is not usual for them.

Delirium can change quickly so there may be periods when someone is able to join in a conversation with those around them one moment and then lapse into a confused state again the next. Delirium is temporary but can take a while to completely clear. It is important to remember that full recovery can take time and people can continue to feel distressed by their experiences, or memory of them, for a long period. An increase in anxiety, reduced concentration and memory problems may be noticed, or perhaps someone may be bothered by disturbing images or dreams of delirious experiences.

Some symptoms can continue following discharge from hospital

There may be some continuation of difficulties such as:

- Confusion
- Difficulties remembering things
- Unexpected emotional changes
- Disturbances to sleep pattern
- Unusual behaviour
- Feeling drowsy
- Feeling agitated

What helps recovery from delirium?

The mind is very resilient, and most people will process what has happened and find ways through these experiences without lasting emotional effects. Delirium is temporary and feelings will resolve, however, some ways to help manage and process them are:

- Talking to others about your experiences and how you are feeling can help you make sense of what has happened.
- Writing down what you can remember from your hospital admission, talking through the timeline that people tell you; and reading diaries that have been kept may help you make sense of your memories.
- Some people find that when ready and it feels safe to do so, they choose to arrange to revisit the hospital. This may feel challenging, but it is one way to make sense of what was real and imaginary.

Some people may not want to remember and may feel unable to talk about their experiences in critical care or may find it very painful to remember and may need to take their time before they can begin to think about what has happened. It is important that you do what feels helpful to you.

Follow up clinics

Once discharged from hospital, you may be invited back for a follow-up clinic appointment. This is a clinic run by specialists who are part of the critical care team who cared for you during your stay on the unit. It provides the opportunity for patients to discuss their recovery and discuss any concerns, physical or psychological. Patients often find this helps them make sense of their time on the unit as they are able to ask questions about what happened to them. If you would like to revisit the unit, this can often be facilitated during your follow up clinic.

The team will provide support and may signpost to other services if appropriate including specialist Critical Care Psychology. The critical care psychology team specialise in helping people with their recovery from the psychological impact of being on critical care.

What if you feel things are not improving?

If you continue to experience difficulties that are persistent or become overwhelming, it is important to seek advice from your GP or local mental health crisis team.

Relaxation

Relaxation can help to control your breathing, improve pain, sleep problems and any stress or anxiety you may have.



There are various techniques you can use that when built into your rest periods can help you to manage your recovery.

Relaxation techniques

Breathlessness can make us feel anxious, which in turn can add to our breathlessness. The following relaxation exercises can help:

- **Visualise** a relaxing scene, such as a favourite place, a walk, a garden, the beach or somewhere from your imagination that makes you feel happy and secure (not places that evoke bad or sad memories). Imagine what you can see, hear, feel and smell.
- **Body scan:** Scan your body from head to toe, trying to release any tension in your muscles.
- **Let go of thoughts:** Imagine you are sitting on a riverbank watching leaves drifting downstream. When a thought or feeling comes into your mind, try to see this as a leaf and let it drift away from you, and disappear.
- **Velindre App:** This is a free App to download, use the relaxation exercises section.
- **Relaxed Melodies App:** This is a free App where you can choose your favourite relaxing sounds.

Useful Resources and links

ICU Resources

	<p>Critical Care Recovery Designed to support patients and families in and after Intensive Care Website www.criticalcarerecovery.com</p>	
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	<p>ICUsteps Founded by ex-ICU patients, their relatives and ICU staff to support patients and families through the long road to recovery from critical illness. Website www.icusteps.org</p>	
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	<p>Critical Care Support Network Founded by Ex- ICU patients, a support network for those recovering from critical illness Website www.cc-sn.org</p>	
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	<p>Bradford Teaching Hospital NHS Foundation Trust Online resources to support critical care recovery Website www.bradfordhospitals.nhs.uk/post-icu-recovery</p>	
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<h1>AfterTrauma</h1>	<p>Critical Care Recovery Designed to connect survivors of traumatic injury and their families to a community to rebuild lives and offer support. Website www.aftertrauma.org</p>	
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	<p>ICU Delirium Designed to help understand the problems that critically ill patients experience Website www.icudelirium.org</p>	
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Macmillan

Support and advice designed to support people affected by cancer Support and advice designed to support people affected by cancer

Website www.macmillan.org.uk

Telephone 0808 808 0000



Spinal Injuries Association

Charity designed to help people with or affected by a Spinal Cord Injury

Website www.spinal.co.uk

Telephone 0800 980 0501



Samaritans

Offer a safe place to talk any time you like, in your own way about whatever's getting to you.

Website www.samaritans.org

Telephone 116 123



the brain injury association

Headway

A charity that works to improve life after brain injury

Website www.headway.org.uk

Telephone 0808 800 2244



Stroke Association

Providing help after a stroke

Website www.stroke.org.uk



Asthma + Lung UK

Website <https://www.asthmaandlung.org.uk/>



British heart Foundation

Heart and circulatory conditions - BHF

Website www.bhf.org.uk/information-support/conditions



ICU Steps / Birchall Blackburn

Claire Cully from Birchall Blackburn Law talks about benefits that critical care patients and relatives can apply for, including lots of tips on which benefits may be appropriate, and how to go about applying. Very useful and practical advice.

Website [ICUsteps Webinar with Birchall Blackburn Law - YouTube](#)



healthtalk.org

Thousands of people have shared their experiences of health on film to help you understand what it's really like, from people who've been there.

Website healthtalk.org



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ICU steps

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Contributors

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Blackpool Teaching Hospitals NHS Foundation Trust

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Sheffield Teaching Hospitals NHS Foundation Trust

PINC- UK

Critical Care Support Network

RCSLT Tracheostomy Clinical Excellence Group

East Lancashire Hospitals NHS Foundation Trust

We really value your feedback!

Please scan the QR code or click [here](#) to complete a quick 2 minute survey.





Hospital switchboard -



Patient Relations Department

The Patient Relations Department offer impartial advice and deal with any concerns or complaints the Trust receives.



You can contact them via tel:



or by email:



Further information is available on our website:

If you'd like a large print, audio, Braille or a translated version of this booklet then please call:

