

# 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 of been invaluable.

The advice and knowledge in this booklet, about what your body's going through during its recovery time, would of 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 seriously ill or injured often have difficulty remembering what happened to them, especially if they have been put on a ventilator (breathing machine), which would have required sedation. You may have had vivid dreams, nightmares, hallucinations, and/or delirium. This is when you think something has happened but although it seems very real, it is not really true. Some people experience the feeling that staff or family members are threatening and trying to hurt them. Although these can be very upsetting feelings, they are very common and are caused by many aspects of your critical illness and the drugs used to treat this.

advice  
reassurance

# transition

## Transfer to the ward

Once you are assessed as well enough, you are transferred to the ward, which is the first step towards going home. Many people 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.

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.

Nurses on the ward will have a number of other patients to care for as well as you. We therefore encourage you to try and do as much for yourself as you feel able to. You may find it difficult to adjust to this after having your own nurse whilst on Critical Care but you will soon settle in and get to know the ward staff and routine. You will continue to have regular reviews by your medical/ surgical team throughout your recovery. The ward nurses and therapy teams will help you to gain the independence needed to prepare you for your discharge from hospital.

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.

to build  
strength

# communication

## 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.

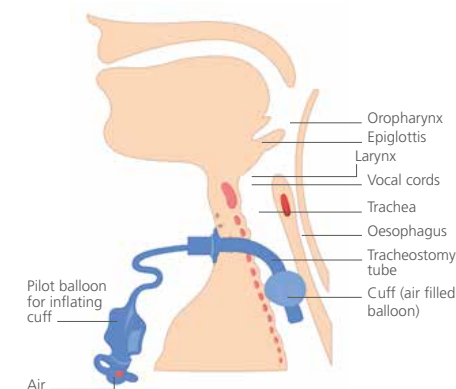
- A tracheostomy is inserted below your voice box so there is less chance of damage to the vocal cords.

You may have returned to a general ward with the tracheostomy still in place. This may be because you are very weak and not strong enough to clear the 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.

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.



# nutrition tips appetite

## 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. Foods that are soft and moist or drinks that are slightly thicker, such as smoothies, may be easier to swallow.

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. 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?

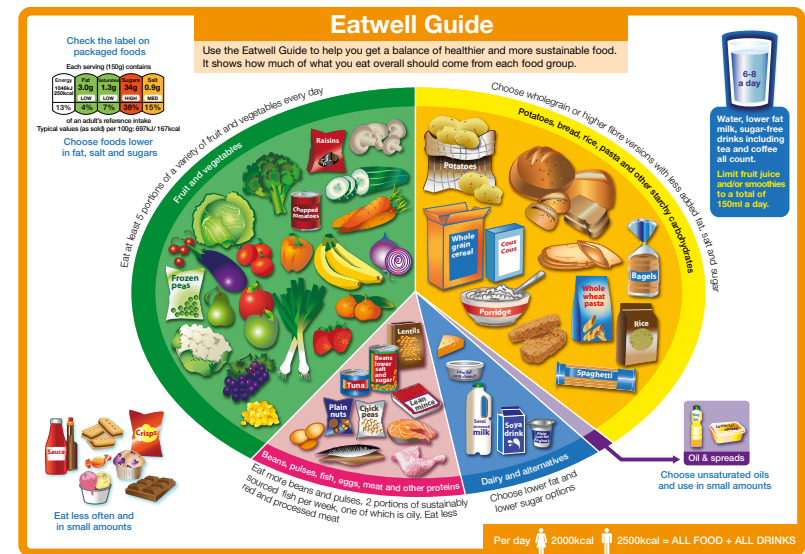
Staying strong is important. During critical illness your body's protein reserves (mainly muscle) are in constant breakdown in order to supply the building blocks for other substances such as immune cells. During this period providing nutrition can help minimise the losses of protein as well as reduce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



# rehabilitation

- 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.

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.

# recovery

## 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: <http://www.nhs.uk/Livewell/Goodfood/Pages/the-eatwell-guide.aspx>

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.

## 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

## 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.

# activity is the key to recovery

## Mobility

Due to your illness and immobility whilst in Critical Care, you may have lost a lot of muscle mass; you can lose around 2% of muscle mass a day, making you feel very weak, resulting in severe weakness and sometimes disability when returning to the ward. When you have been immobile, your joints can become stiff and sometimes painful making the slightest activity an effort.

During your time in Critical Care, physiotherapists will have been treating you daily as soon as possible after your arrival. As your health improves you may have started doing breathing exercises, exercises in bed, sitting out in the chair and mobilising. You will continue to be assessed whilst on the ward by the physiotherapists. Exercise under the guidance of the Physiotherapist

will assist you in regaining strength, function 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 it will:

- Strengthen your heart and lungs
- Help to rebuild the muscle you lost during your illness
- Help to reduce stress
- Help you to get good refreshing sleep

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 be moderately breathless to pushing yourself a little. This means you are reaching an adequate exercise level to improve your fitness.

## Important points about exercise

- Do not try to do too much too soon, because this will just make you overtired and disheartened.
- If you have a bad day, try not to get upset about it. Everyone feels like that at some time. Ask yourself if you've been doing rather more than normal over the past few days. This may explain why you feel so tired. **'Listen to your body.'**
- 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 a little breathless, you should not be so breathless that you cannot talk.

- You should stop exercising straight away and seek medical advice if you experience any of the following: severe chest pain, increase in chest tightness, dizziness or feeling faint and 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.

## Tiredness / severe fatigue

The most common physical and psychological problems reported by critically ill patients is the overwhelming feelings of weakness and fatigue experienced when they first go home; the slightest activity can take tremendous effort and leave patients feeling very tired. This can be a shock to some people as they may have been physically active prior to their hospital admission and in some cases this will have an impact on their mental well-being as they become frustrated with their reduced levels of activity. It can also have an 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 for a person managing their own fatigue relies on an individual reflecting on the way it affects their daily activities. The focus should be on management rather than

elimination, particularly in the early days. In the long term, good management can maximise physical ability, increase independence, improve quality of life and promote recovery from the physical and psychological effects of critical illness. To support your own 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 equally
- **Organise your work area:** Prepare your work area, have everything to hand or can you do this activity when sitting?

- **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're not as active. As you recover things should get back to normal. If you were sedated for a number of days this can disrupt your 'body clock', and you may find sleeping during the day easier. When you feel very tired, have a morning or afternoon nap, 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





# remember

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, then try the following:

## 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
- Ensure you spend adequate time in bed
- Remember that sleep requirements change over a lifetime
- Remember that short awakenings are normal
- Reduce activity within 3 hours of bedtime, including using electronic devices
- Reduce and try and stop naps during the day or evening to help restore day/night routine

## Don't

- Don't consume caffeine after 5.00pm
- Don't drink excessive amounts of alcohol particularly close to bedtime
- 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

## Dreams / Nightmares

Disturbing dreams, flashbacks and hallucinations are very common; this is the way the mind processes a disturbing event. They may be very vivid and at times can be frightening; often there is difficulty differentiating dreams from reality. This is quite normal and there is no need to feel embarrassed about these dreams. The reason why you may be experiencing these could be the physiological effects of being critically ill, the use of the sedatives or painkillers given to you, disorientation and lack of sleep. They can continue even when you get home, the important thing is to know it is perfectly normal and they should fade with time. However, if they do not subside or you are getting anxious or worried about them; then let us know and we can discuss this further with you to find a solution.

## 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 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 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 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.

# it can take time to recover



### 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 in the coming weeks and usually returns to normal.

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

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



# going back to work

## At home

### Medication

On discharge from hospital, your medication could have been altered or you may be taking medication for the first time. It is very important for all patients and their relatives to understand fully:

- What you are taking
- Why you are taking it
- When you should take each dose
- How long the treatment is likely to continue
- Not to stop any medicine without talking to your GP or consultant

### 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.

### Smoking

Smoking will only harm your recovery so now is a great time to quit. It causes heart disease, strokes, bronchitis, emphysema, cancer, duodenal ulcers, sinusitis and more. Also nicotine produces chemicals that make the heart work faster and so raises your blood pressure.

For patients who have been seriously ill in Critical Care it is important that they stop smoking. This is because the lungs are affected by the illness and can be damaged. People normally have a considerable amount of spare lung capacity

so they do not notice this damage, but it is important not to continue smoking, causing further damage and this allows the lungs to recover. If you need help, ask 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**

For people who have spent a prolonged time in Critical Care or have expressed difficulties with rehabilitation, most hospitals (but not all) offer the opportunity to attend a Critical Care Follow-up or Rehabilitation Clinic. This is run by a Critical Care specialist who has experience with the issues highlighted in this booklet. The clinic is based on an informal meeting rather than a physical examination and aims to support you on the road to the best recovery possible. It's a chance to discuss any issues or problems you may have and to understand what has happened to you, possibly with a visit to Critical Care to see where you were and meet the staff who you may not remember.

It is also a chance to get extra help if needed, as our team can refer you to specialists if that is what is decided by you both. Your GP may also be kept informed of your progress, so they too can understand more fully the implications of what you have gone through.

Family and those who were involved with you during your illness are also welcome to come, as often they too can have physical and psychological issues relating to this period and it is important to support them as well.

If, however, you are not able to cope in the meantime, or a problem arises, please contact us and we will do our best to help in any way. The contact number is at the end of this booklet. If there is no-one available at the time, please leave a message with the Critical Care staff and they will get back to you as soon as possible.

**Involving your GP**

Please remember, the Follow-up/rehabilitation clinic can only help you with problems related to your Critical Care stay. It is very important to involve your GP in your care, especially if your problem is urgent. 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.

Your GP should be up to date with your progress because information about your recent hospital stay will have been received from the hospital. 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*

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

"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**

**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, Chelmsford, Colchester, West Suffolk and Bedford hospitals hold “drop-in” evenings or coffee mornings every month or two depending on the area, details and dates can be found at **www.icusteps.org/support**



ICUsteps  
Bedford



**ICUsteps**  
Colchester & Essex



**ICUsteps**  
West Suffolk

## Notes

## Goals

[illegible]

# useful information

## Useful telephone numbers

**Driver and Vehicle Licensing Agency (DVLA)**  
information on medical conditions:  
**0300 790 6801**

**NHS smoking helpline: 0800 022 4332**

**BRAKE**, the road safety charity –  
helpline: **0808 8000401**, open 10am - 4pm  
(Mon-Fri) or email [helpline@brake.org.uk](mailto:helpline@brake.org.uk)

### **Financial Benefits**

#### **Department of work and pensions:**

To make a claim if you are unable to work  
**Job Centre Plus: 0800 055 6688**

**Attendance Allowance (AA) for the over 65's:**  
**0345 605 6055.**

Personal Independence Payment (PIP) for the  
under 65's: **0800 917 2222**

PIP general enquiries: **0345 850 3322**

To claim for carers allowance (If you are caring for  
someone receiving AA or PIP): **0345 608 4321**

For support from the social fund (most have to be  
repaid) call **Job Centre Plus: 0345 603 6967**

**Pension service: 0345 606 0265**

**Tax Credits: 0345 300 3900**

## Useful websites

For information on benefits, driving, pensions and  
much more go to the government website  
[www.direct.gov.uk](http://www.direct.gov.uk)

**Intensive Care Society**  
[www.ics.ac.uk/ics/patients-and-relatives/](http://www.ics.ac.uk/ics/patients-and-relatives/)

### **NHS choices – [www.nhs.uk](http://www.nhs.uk)**

- Social care - search on NHS choices website  
for care and support assessment
- Improving Access to Psychological Therapies  
(IAPT) – search on NHS choices for  
Psychological Therapies in your area

**The Brain Injury Association**  
[www.headway.org.uk](http://www.headway.org.uk)

**The Stroke Association**  
[www.stroke.org.uk](http://www.stroke.org.uk)

**The Spinal Association**  
[www.spinal.co.uk](http://www.spinal.co.uk)

## Local information – telephone numbers

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## East of England Critical Care operational delivery network

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

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