

Intensive Care

A guide for patients, relatives, and friends.



This guide contains advice and information about intensive care. It tells you how critical illness may be treated and what recovery may be like. Not every patient will experience all of these things, but they are more likely to if they have been in intensive care for more than a few days.

Most of this guide is written for patients but there is a section specifically for relatives, friends and visitors. By reading this guide, you will learn what a patient's recovery may involve and it will give them the answers to some of the questions they may have.

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Introduction

Recovery from critical illness is often a long and slow process. To begin with, patients may not feel up to reading this information, so if you are a relative or friend, please keep hold of this guide and pass it on when the patient is ready.

One of the scariest things about having a critical illness is not knowing what's going to happen. This guide can't answer all your questions, but it will answer many of them. It will try to tell you what may happen and where you can find out more information.

Each section covers a different stage of the process of treatment and recovery. You can read it all in one go, or you can just read each section when you need to.

This guide is produced by ICUsteps, a charity that supports intensive care patients. It has been written by people who have either been treated in an intensive care unit or are close relatives or friends of someone who has. It has also been reviewed by a wide variety of intensive care professionals.

If you have any comments about this guide we'd like to hear from you. Visit our website, icusteps.org, where you can fill in the 'contact us' form, or e-mail your comments direct to contact@icusteps.org.



Information for relatives, friends and visitors

A patient may be in intensive care because of an accident, an illness, or for treatment after having a major operation, and relatives and friends will be worried about them. This section gives information that should reassure you and let you know where to turn to for help when you need it.

The early days

Your relative or friend has been admitted to the intensive care unit (ICU) because their body cannot work normally. If they do not get special help, they may have serious long-term effects to their health or they may die.

Seeing the patient there for the first time can be very distressing. They are likely to be connected to a number of machines and drips and will often look very different from how they normally look. They may also be unconscious, sedated (given drugs to help make them sleepy and comfortable) and may not be able to communicate.

When a patient is first admitted to an ICU, it is normal for you to feel helpless, and desperate to know everything you can about their chances of recovery. However, the patient will need time to let their body rest and get

over the shock of becoming so ill. Sometimes they will be given strong pain-killing drugs or sedatives to help the healing process begin.

If you have questions about what is being done, ask the staff in the ICU. They may be very busy, but it is important that you get the information you need, so ask again, if you need to. They will answer your questions as well and as sensitively as they can, but they will not want to give you false hope. The staff will be happy to explain what they are doing and they will be able to update you as time goes on.

Occasionally patients in an ICU may have to be moved to an ICU in a different hospital. This could be because the patient needs specialist care that is not available locally, beds are needed for new patients who are more seriously ill or because there aren't enough beds. This can be very upsetting for you, and you may have to travel further to visit your friend or relative, do speak to the Consultant or nurse in charge if you are concerned. However, patients are only moved to a different hospital when it is absolutely necessary.

What can I do to help?

Days may go by with no change in the patient's condition. There may be nothing for you to do but sit by their bedside and wait. Nurses will often talk through what they are doing even if the patient is unconscious. This is because, even though they may be sedated, the patient may be able to hear what is going on around them and may be aware of being touched, but they are unlikely to remember things as clearly as they would when fully conscious.

- Helping the patient

The nurses may ask you to bring in some of the patient's personal belongings to help them recover, such as their favourite perfume or music. Talking to your relative or friend may also help. Keeping up a one-sided conversation can be difficult, but talking about shared experiences of holidays and good times can make you feel better too. You could also try

reading a newspaper, magazine or book to them. A 'Who am I' board may be completed with your help to support staff to personalise care of your loved one.

Even if the patient is conscious, you may find it hard to communicate with them. If they can't speak, they may be able to write, or spell out words by pointing to some letters, numbers and common words you have written on a piece of paper. If this is too difficult, try asking yes/no questions.

- Helping the staff

Some relatives find it helpful to be more involved in caring for the patient when they're recovering. You may be able to help by doing things such as brushing their teeth or massaging or moisturising their hands and feet. This will depend on how ill the patient is, and won't always be possible but if you want to help in this way, ask the staff.

You can help the intensive care staff by choosing a family member or friend to be the main contact. Staff can tell the main contact how the patient is doing and they can pass on the information to other family members. This will save time for staff and relatives.

- Patient diaries

Some ICU departments will start a patient diary as a record of what is happening during their stay, including what treatment they have received, the weather, and other events. Alternatively, relatives may also find it helpful to keep a diary of what is happening. It can help you to look back and see any improvements the patient has made. You can ask staff members to add short entries too.

A diary can be very useful later on to help the person who is ill. They may have very confused memories of their time in the ICU or no memories of it at all. A diary can help them to understand what happened to them and fill in the gaps in their memory.

- Preventing infection

Patients who are critically ill may have difficulty fighting infections and, because of how ill they are to begin with, this can be very serious. The staff will do all they can to make sure the patient is protected. You can help too by washing your hands and using the anti-bacterial creams, gels or sprays you'll see around the unit before you go near or touch the patient. You should also ask other visitors to do the same. Additional precautions such as gloves, apron and a mask may be required.

Other things you can expect

There may be times when staff ask you to leave the patient's bedside. This is because some of the necessary medical procedures are not pleasant and may upset you. It also gives the staff room to do their job.

- Treatment

If the patient is ventilated (on a breathing machine), the nurses have to regularly clear the chest of mucus and fluid. They do this by putting a thinner tube into the breathing tube to suck up the mucus. This is quite noisy and can cause the patient to cough or retch. The fluids given to the patient to keep them hydrated may make them look bloated and swollen. This is normal and will improve as the patient gets better.

Some of the machines that the patient is connected to have alarms that may sound to let staff know that something needs doing, for example if a drip needs to be changed. It can be worrying to hear these alarms, but there is usually nothing to be concerned about – the staff will monitor the patient very carefully at all times. This might be by their bedside, or from their central nursing station.

- Behaviour

Sometimes, the patient may behave out of character. This may be because of their illness or medication. They may be agitated, confused, scared or paranoid. Paranoia is a form of anxiety or fear that can make you believe people are plotting against you or trying to hurt you. They may also have hallucinations (see things that aren't really there) and nightmares that seem

very real to them. Patients sometimes believe the staff are trying to hurt them. This can be extremely distressing for you and the patient but it will improve as they get better and begin to recover.

This behaviour is commonly referred to as delirium. You can help by reassuring the patient when they are agitated, explaining to them where they are and that they are safe, and making sure they have their glasses and hearing aids if they usually use them. Further information can be found about delirium on the ICUsteps website www.icusteps.org.

If the patient in the ICU has been given sedatives, the sedatives will be gradually reduced as the patient gets better. Depending on how ill they were, the drugs they needed and how long they were sedated for, this process can take hours, or it can take days. During this time, the patient may be drowsy and confused, particularly in the early stages, but it's a necessary step and it means they're getting better. The sedation may need to be increased and decreased during this process according to the patient's condition, confusion, breathing and other factors. This is very common across ICU patients.

If you're unhappy with the care being given to a patient

The staff normally do all they can to keep relatives informed about what treatment is given and why. Where possible, they will let the patient and relatives know what treatment options they have. If there is anything you don't understand or want to know more about, ask the staff. If you're unhappy with the care being given to the patient and you are not able to deal with this through the ICU staff, you can contact the hospital Patient Advice and Liaison Service (PALS) who will help you to find the answers you need.

Looking after yourself

You can help the patient by taking care of yourself. You shouldn't feel guilty for not being by their bedside 24 hours a day. You need to give yourself a break and this will also give the patient time to rest. The patient will be very well cared for and the staff will contact you straight away if they need to or if there is any change in their condition.

Your family and friends will be concerned about you and the patient, and they will want to know how things are. You may appreciate their concern, but it can be tiring if the phone is ringing all the time when you're at home between visits to the hospital. Passing on the information by e-mail or text message to several people at once can be easier. Or, you could speak to one person regularly and they could pass the information on to others.

You may not feel like eating and you may have difficulty sleeping, but do take time to eat regularly and rest when you can. If you become tired and ill, you won't be able to care very well for the patient.

Many ICUs will give you an information sheet about contacting the unit by phone, hospital parking, meals for relatives and visitors and overnight accommodation if it's needed. If you're not given this information, ask a member of staff.

Visiting hours for ICUs are usually more flexible than for normal hospital wards, and staff will be able to give you details.

If the patient is your partner

If the patient is your partner, you may suddenly feel very isolated and alone. You might have less time to do things like cooking, food shopping and may need help with childcare. Do consider accepting offers of help from friends and family, who may want to support you. You may also need to contact your partner's employer and advise them of current circumstances.

Often, in times of worry and stress, people turn to their partner for support. If you don't feel like you can tell other family members about your worries or what may happen in case you upset them, you could get help from one of the organisations listed on the ICUsteps website icusteps.org.

It is important to familiarise yourself with household finances during this time. Make sure that your bills are being paid and if you need to get access to your partner's bank account, contact your bank and explain the situation. It may also be necessary to consider Power of Attorney. You may be able to

get temporary control of the account while your partner is not able to deal with these things. If money becomes a problem, contact Citizens Advice for information on any financial help and benefits that are available to you. There may be a social worker at the hospital that can support you.

When the patient comes out of the ICU

You may have a reaction to the stress that you have been under once the patient is out of danger. It is important for you to know that feeling stressed and exhausted is completely understandable, and that you may feel like this for some time. If you feel guilty, worried or depressed, you can get help and information from the organisations on the ICUsteps website icusteps.org. Or, see your GP (family doctor) if you need more support. They may be able to support you with medication, or arrange counselling, so that you can talk to someone about what has happened.

Helping children who have a relative in an ICU

You may need to consider whether a child should visit their parent or a close relative in an ICU. You should check with staff before bringing children to the unit and talk to the child about it. If the child decides they want to go into the ICU, prepare them for what they might see, including the machines, what they do and how the patient might look. ICUsteps have an activity booklet to support children's understanding of having a family member or friend in ICU icusteps.org.

What you can tell the child will depend on their age and why their parent or relative was taken into the ICU. You can help a child deal with the situation by:

- trying to keep to their routine as much as possible
- telling the school, and any other relevant groups, that the child's parent or relative is in intensive care
- explaining the situation and being honest if you don't know what is going to happen – if you are not sure, try to say something they can understand that will help the child feel secure and reassured, for example, 'Daddy is very ill but the doctors are doing everything they can to help him', and

- encouraging them to keep a diary. It could include a brief description of each day and any souvenirs that they would like to include (such as pictures and so on). This helps the child understand what is happening and makes it easier for them to talk to the parent about what happened in their life while the parent was in hospital.

Once the patient is out of the ICU, the child may need help dealing with what happened. This can be a gradual process and can take several months. At times, it may be helpful to mention the patient's stay in hospital so the child knows they can talk about it. Let them ask questions, and ask them how they felt at that time. If the child is very young, they may find it easier to show their feelings by drawing pictures or acting out what happened.

Remember that children can ask very blunt questions, so if the patient doesn't feel strong enough to cope with this, ask another family member or friend to talk to the child about their experiences and feelings.

If the patient does not survive

Despite the best efforts of the ICU staff, sadly sometimes patients are too ill and do not survive. A person dies when their heart stops beating or they have no more activity in the brain. If the doctors believe the patient is brain stem dead, they have a set of tests they must follow to confirm this.

Sometimes the doctors will discuss stopping treatment if they feel the patient is not going to get better. This may mean stopping the ventilator and the patient will stop breathing. This could be a short or long process, but the emphasis will be on making sure they are kept comfortable.

If your family member or next of kin is approaching the end of their life, you may be approached to discuss organ and tissue donation.

If you know the patient's wishes regarding organ and tissue donation this can help in making the right decision for your family. Most families who agree to donate one or more of the patient's organs or tissues find it

comforting that something good will come from their loss.

It may help you to talk to a bereavement counsellor at this difficult time. They can offer support and understanding for adults and children (see organisations listed on the ICUsteps website icusteps.org).

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Your time in the intensive care unit (ICU)

When you've been critically ill and you have been asleep for long periods because you were unconscious or sedated, you may have difficulty remembering what happened to you. Also, you may have had vivid dreams, nightmares or hallucinations which upset you.

You may even believe that staff were trying to hurt you, because of the treatments you were given to make you better. These experiences are common for someone who has been critically ill and can be caused by the illness or the drugs used to treat it. You may find it difficult, but it can help to talk to someone you trust about this and it really is nothing to be ashamed or embarrassed about. These experiences are known as delirium and can affect up to 80% of patients in ICU.

Below is some information about some of the things that happen in an intensive care unit. It may help you make sense of things you remember.

Staff in the ICU

Doctors in the ICU are usually trained or training in intensive care medicine. As well as the nurses, you may also see speech and language therapists, physiotherapists, dietitians (specialists in food and nutrition), clinical psychologists, occupational therapists, pharmacists and other support staff on the unit.

You are likely to meet a lot of these people, but you may only remember a few names and faces.

- Doctors

In an ICU there will usually be a consultant who leads a team of doctors. The consultant and their team usually go around the unit each day to check on each patient and make decisions about their treatment and care. There may be other staff with them, and you may remember them examining you or hearing them discussing your treatment. The doctors and their team may spend time with you each day to see how you are getting on. They may examine you, listen to your lungs with a stethoscope and look at any wounds you may have, in order to plan your treatment and care. Doctors who are specialists in other areas may also visit you. They may be medical, surgical or orthopaedic doctors, who you saw before you were admitted to the unit. They will look after you again once you are well enough to be looked after on a general ward.

- Nurses

In an ICU, one nurse will usually look after one, or at most, two patients. Your nurse will be responsible for providing most of the care you need and, in the early stages, will spend most of their time at your bedside. They will also work with other professionals, such as doctors or physiotherapists, to make sure you receive the correct treatment and care when you need it.

The nurses will do things for you that you can't do yourself, including:

- taking regular blood tests
- changing your treatment depending on your test results
- giving you the drugs and fluids that the doctors have prescribed
- recording your blood pressure, heart rate and oxygen levels
- clearing fluid and mucus from your chest using a suction tube
- turning you in your bed every few hours to prevent you getting sores on your skin
- cleaning your teeth and moistening your mouth with a wet sponge
- washing you in bed

- changing your sheets
- changing your surgical stockings, which may be used to help your circulation when you are inactive (lying still) for a long time, and
- putting drops in your eyes to make it easier for you to blink.

- **Physiotherapists**

During your stay in intensive care, you will be seen and treated by a physiotherapist. They will try to make sure your lungs are kept clear by carrying out physiotherapy on your chest. They will also exercise your arms and legs when you are asleep to work your muscles and to stop your joints becoming stiff. If you were ventilated (connected to a machine to help you breathe) in the ICU, the physiotherapist will give you exercises to help strengthen your lungs and breathing muscles so you can breathe without the machine as you get better. This will reduce the chances of you getting a lung infection.

As you get better, physiotherapists also help you with exercises to get you strong enough to get out of bed. When you're ready, they will help you get up and moving about again.

- **Occupational therapists**

Occupational therapists (OTs) will help you regain functional independence to optimise quality-of-life following illness or injury. They focus on physical, cognitive, and psychological aspects to enable patients to participate in meaningful activities and daily tasks.

- **Clinical Psychologists**

Clinical Psychologists can support you and your family during recovery. They can help you make sense of frightening, confusing or traumatic experiences, such as nightmares, delirium or near-death experiences, and help manage distress and anxiety. They can also help with any cognitive effects on thinking or memory, and support adjustment to any changes in your body, confidence or relationships, to help rebuild wellbeing.

- Dieticians

A dietitian will visit you to work out your nutritional needs and how you will be fed. You may be fed through a nasogastric tube (a tube that goes up your nose and down into your stomach) or, if you cannot have food in your stomach, you may be fed through a drip straight into your vein.

- Speech and Language Therapists

A speech and language therapist, sometimes referred to as SALT, may also visit you, especially if you have a tracheostomy. A tracheostomy is a procedure to make a hole in your throat and insert a tube, which is connected to a 'breathing machine' (a ventilator). The speech therapist may see later if you can have a speaking valve on the tracheostomy. They will also monitor you to see if you can swallow well enough to start to drink and eat normally.

Planning for your recovery

After being critically ill, it may take you several months to recover. The staff may carry out health checks to find any likely physical or psychological problems you may face because of your illness.

If they think you are at risk of having problems later in your recovery, they may carry out more checks:

- before you leave the ICU
- before you're discharged from hospital, and
- after you've been out of the ICU for two to three months.

Depending on the results of these checks, the intensive care staff may prepare a rehabilitation plan for you. What is in this plan will depend on how long you were in intensive care and your needs, but may include information on:

- the difference between intensive care and ward-based care
- the physical, dietary or medical needs you are likely to have in the future, and
- who will be responsible for your care when you are in the hospital and when you leave.



When you leave the ICU

Before you leave

As you start to get better, you will not need the machines that were helping to support your body's normal functions and monitoring your condition. The physiotherapist will probably give you exercises to help strengthen your muscles to get you moving around again. You will be very weak and get tired easily at first.

As you become able to do more for yourself, you may be moved to a different section of the ICU or transferred to another ward in the hospital with a reduced level of nursing.

Many hospitals have high dependency units (HDU), where each nurse will normally look after two or three patients. Some hospitals might send patients from the ICU to the HDU as they get better, until they're well enough to go to a general ward.

Moving to a general ward

This can be a difficult time for patients and relatives because there is no longer the one-to-one nursing that there was in the early stages, but you are still far from being well. You may need to re-learn how to do simple things such as walking, eating, drinking, or even breathing for yourself. This can be frightening but is normal at this time in your recovery.

When you move to a ward, there should be a written plan that includes:

- a summary of your care and treatment while you were in the ICU
- a monitoring plan to make sure you continue to recover
- a plan for ongoing treatment, and
- details of your physical and psychological rehabilitation needs.

From this time you will be cared for by the ward staff, but they will be able to talk to the ICU staff if they need to. If the hospital has an 'Outreach' service, you may be visited by an ICU nurse while you're on the ward to check on your progress.

The visiting times in a general ward may not be as flexible as they are in the ICU and you may be disturbed more by other patients and visitors around you.

Your normal sleep pattern may be upset due to the constant activity while you were in the ICU. This does return to normal in time. Rest when you can. You may find that a personal music player with headphones helps you to relax and pass the time.

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Returning home – what will life be like now?

Leaving hospital and returning home is a major step in your recovery and is likely to have been a goal you've been working towards for some time. It is a very positive step but it will take time and effort to get back to a normal life.

Before you leave hospital, your physiotherapist may give you an exercise plan to help with your recovery. If not, you (or a friend or relative) can ask them for a plan.

When you leave hospital

When you're well enough to leave hospital, you may have an assessment to find any difficulties you might face when you get home. This would include psychological or emotional problems, as well as any care and equipment you need.

Your healthcare team should discuss and agree with you what your rehabilitation goals are (what you want to achieve as you get better), and organise any referrals and any other care or rehabilitation you will need before you leave the hospital.

When you leave the hospital, you may be given:

- a letter that summarises your time and treatment in ICU (this is called an ICU discharge summary')

- the contact details of the person co-ordinating your rehabilitation, and
- if appropriate, a copy of your rehabilitation plan.

When you get home

You won't have the same support you had in hospital and it can be a difficult time for you and for your relatives. It's normal to go through times where you feel depressed or frustrated because you don't seem to be getting better.

Setting small goals in your daily routine can help you recover and show you that you are improving. A small goal could be something as simple as making a drink for yourself, or walking a few steps further without needing to rest. Don't push yourself too hard as this can end up making your recovery take longer.

When you've been critically ill, you'll probably feel very tired and won't have much energy. It will take time before you feel well enough to cope with everyday life and many more months to get back to full strength.

Set yourself targets to help you get back to normal, and keep doing the exercises your physiotherapist gave you. Don't overdo your exercise as this can set your recovery back.

You will need to slowly increase your activity to build up your strength, but make sure that you rest when you need to. In the early days you may need to take things very slowly.

If you've had an operation, you must follow your surgeon's advice. Your body will tell you if it's getting tired or is in pain. If you feel unwell or get out of breath, stop what you're doing and rest.

Checking up on your recovery

A member of your healthcare team may offer to meet with you two to three months after you left the ICU. The meeting will be to discuss any physical, psychological or other problems you've had since you left hospital. If you're recovering more slowly than expected, they should be able to refer you to the appropriate rehabilitation service.

Who can I ask for help?

When you're back home, your GP will be involved in your general care and recovery. They should be able to refer you to other services if you need them, such as community-based physiotherapy.

If your GP isn't able to help, you can always contact the ICU where you were treated. Before you left the hospital you may have been given the contact details for a person in the ICU who can help.

Social life and hobbies

When you've been seriously ill, you may feel differently about things and you may not want to do things you used to enjoy. For example, you may not feel like seeing lots of people at once, so start by seeing one or two friends at a time for short periods.

You may find it difficult to concentrate and may even find it hard to follow a TV programme. Your concentration will get better. During your recovery you may be forgetful, but your memory will usually improve as you get better.

Your recovery may take a long time and, as you get better and begin to do more, you may find that things get on top of you. During this time you may lack confidence, worry about your recovery, or even feel depressed. Talking about this to your family or a close friend can help.

Relationships and family

After you've been critically ill, you and the people around you may seem to change. Your family may make a fuss and might not understand why you seem different, or why you aren't keen on the hobbies and interests you used to enjoy.

Your family and friends were afraid you might die, so they may want to do everything for you when you get home. If this annoys you, talk to them calmly about how you feel. Don't bottle things up and get angry.

You may not remember your time in hospital clearly, and this can be confusing and frightening. It may help to talk to your family about what they remember about your stay in hospital, how they felt when you were ill and the things that happened while you were there. If your relative kept a diary while you were in the ICU, it can be helpful to look at this with them.

Getting back to your daily routine

Lots of people worry about coming home from hospital or returning to work after a critical illness. It's normal to wonder whether you'll be able to cope.

Talk about it with your family and think about how you can adapt things at home to help you. Recovery takes time and you won't be able to do everything you used to straight away. Ask friends and family for help if you need it until you're strong enough to do things yourself.

If you used to work, you may not be well enough to return full-time straight away. When you're feeling better, it's a good idea to arrange to go back and see your colleagues and talk to your boss. Depending on your job, you may be able to do a few hours a day at first.

If you have young children you may feel under even greater pressure to get back to normal. Do the important things first – other jobs can wait. Take a nap at the same time as the children and don't be afraid to ask your friends and family for help.

Sexual relationships following critical illness

It's normal to be worried about when it's safe to start having sex again. Your partner is likely to be worried about this too.

You may be concerned about the following.

- Will my scars be healed enough?
- If I have to use a medical device, such as a colostomy bag, catheter or pacemaker, will it get in the way?
- Will I hurt or ache too much?

- Will I have the strength?
- What if my partner doesn't want to have sex?
- What if I can't continue or can't reach an orgasm?

You may worry because you don't know what will happen. If you're worried about your strength, compare the energy needed for sex with the energy you need for your exercises. If you're coping well with your exercises, you may be able to cope with sex.

Most people find it difficult to talk about sex, but try to relax and keep a sense of humour. Cuddles are really important. Take things slowly and see what happens.

Sometimes, medical problems such as impotence (being unable to get and keep an erection) can affect your sex life. If you're worried, talk to your GP.

Notes:



How a critical illness can affect your body

Weakness and weight loss

Don't be surprised if you feel very tired and weak at first. Your muscles will have lost strength while you were ill and not active. The longer you were ill for, the more your muscles will have weakened. This muscle loss happens faster for patients who have been on a breathing machine.

You may also have lost a lot of weight because of this muscle loss. You will put weight on again as you begin to get better and exercise. You will get stronger, but it will take time. Physical recovery will be measured in months rather than weeks, and it may take up to 18 months for you to feel better or to adjust to your new normal. Set yourself realistic goals. Keeping a diary that you can read at times when you don't feel so well can make you realise how much progress you are making.

Even if you don't make a full recovery, you can still achieve a lot and live a full life. There are people who have been critically ill for months, and a year later, you'd never know what they'd been through. Try to stay positive, even if it means making some changes to the way you live.

Breathing

You may have needed to have a tracheostomy. This is a procedure to make a hole in your throat and insert a tube, which is connected to a breathing

machine (a ventilator). The tracheostomy makes it easier for you to breathe and to reduce your body's need for sedation and the ventilator. If you had one of these you will have a scar on your neck where the tube was inserted. The scar will gradually fade and become less obvious. Keep doing the breathing exercises the physiotherapist gave you to strengthen the muscles and reduce the risk of chest infection.

Your voice

If you've had help with your breathing, your voice may have changed. At first your throat may be sore so don't strain your voice. Try to relax as much as you can when you speak, and drink plenty of water. You may have marks at the corners of your mouth caused by the tape used to keep your breathing tube in place. You may also have a dry mouth caused by a lack of saliva.

Your skin and hair

Your skin may be dry or itchy after your illness. Moisturising it regularly can help stop this. You may notice changes to your hair and some of it may fall out. This is not unusual and can even happen months after you leave hospital. It usually grows back but it may be more curly, straight or thin, or a different colour from how it was before.

Bruising

If you were on a drip or had other tubes in you, you may have bruises and scars. These are usually on your hands, arms, wrists, neck, groin or sides of your chest. You may also have bruises on your stomach because of injections to stop your blood from getting clots.

Changes to your hearing, taste, touch and sense of smell

Your senses may be affected by your stay in the ICU, but the effects don't usually last for very long. Your hearing, sight, taste, touch and sense of smell may have changed, which can be upsetting. Some of the drugs you may have to take can affect your hearing. Other types of drugs can leave a metallic taste in your mouth. You may have been fed through a tube into

your stomach, or by a drip into your veins. When you begin to eat and drink normally again, food may taste stronger or just different. Your sense of smell may also be affected because it is closely linked to your sense of taste. You may have sore, dry eyes because you were sedated for a long time, or your eyes may be puffy and swollen because of the fluids you were given to keep you hydrated. Things that touch your skin may feel odd and you may experience tingling in parts of your body. This can be caused by some of the drugs you were given or by your body's reaction to your illness. These changes are usually temporary and should disappear over time.

Problems going to the toilet

When you were in the ICU, a doctor may have put a tube in your bladder. This is called a urinary catheter. It drains urine from your bladder and allows the staff to check your fluid levels. When the tube is taken out, your muscles may be weaker so you may find it difficult to control your bladder. Don't worry, this usually returns to normal, but you can ask your medical team for exercises that may help in the meantime.

If you have problems urinating, you may have an infection, so see your doctor or a nurse as soon as possible. Symptoms include:

- not being able to pass urine for several hours
- having a burning pain while urinating, and
- blood in your urine.

Sometimes medication can change the amount and colour of your urine. It may even affect how often you go to the toilet. The medication may also affect your bowel movements. If you're worried about any of these things, talk to your doctor about them.

Smoking

If you smoked before your illness, now is an ideal time to give up. If you stopped smoking while you were in hospital, don't start again when you are at home. If you have been critically ill and on a ventilator, smoking can damage and weaken your lungs even and make it harder for your lungs to recover. The NHS Smoking Helpline can give you support and advice.

Phone: **0300 123 1044** Website: www.nhs.uk/smokefree.



How might I feel after being in the ICU?

After being critically ill, it may take up to 18 months for you to recover and some people may have changes to their health that last even longer. Everyone's journey is different, and life might be different after a stay in intensive care. Being weak and having to put a lot of effort into doing simple things, such as getting dressed and moving about, can make you feel low for a while. You can also feel like you've lost your independence if you need a lot of help from other people at this early stage.

Your mood may change often and you may:

- feel upset and tearful
- always feel tired or not be able to sleep properly
- not care what you look like
- be quick-tempered and snappy
- feel guilty for causing so much trouble and worry
- forget things
- not feel hungry
- not understand what has happened to you and how ill you have been
- feel scared that you almost died, and
- worry about getting ill again and how long it's taking to recover.

Your family and friends will be pleased to have you home, but they may

not understand your feelings or why you are acting differently. Talk to them about how you feel. Also, go to see your GP who may be able to offer you treatment or counselling to help you through this difficult time. As you get better and start doing more, you will face new challenges. They can make you feel scared – try to keep calm and take slow, deep breaths.

After ICU you may experience some psychological symptoms, such as anxiety, depression, stress or post-traumatic stress.

It is possible to develop post-traumatic stress disorder which does need clinical intervention. If left untreated it can be triggered by a sound, smell or something you see.

Symptoms may include the following:

- intense, vivid dreams or nightmares that feel very real
- disturbing, sudden, vivid memories of events in the past (flashbacks)
- experiencing hallucinations by seeing things that aren't there
- feeling much more worried, nervous or anxious about things than usual
- feeling tearful or depressed, or having deep feelings of hopelessness, and
- not enjoying the things that you usually do or lacking energy or interest in life.

These symptoms can be quite normal in the immediate aftermath of critical care, but if they worsen over time but you may need to talk to a healthcare professional, or if the symptoms are long lasting or if they are worrying you. The ICU or your GP may be able to advise you where you can get some help.

Treatments, such as EMDR (Eye Movement Desensitising and Reprocessing) aim to reduce symptoms of trauma by changing how your memories are stored in your brain. An EMDR therapist does this by leading you through a series of bilateral (side-to-side) eye movements as you recall traumatic or triggering experiences in small segments, until those memories no longer cause distress.

Sleep

You need regular sleep to keep your body healthy. It can take time to get back into a normal sleep routine. You may find it harder to fall asleep, or you may often

wake during the night. Try a milky bedtime drink but avoid tea and coffee as the caffeine can keep you awake. Reading or listening to the radio before you go to sleep may also help. Your GP can give you advice if you have trouble sleeping, but things should return to normal as you become stronger and more active.

Understanding what has happened to you

People feel differently about their time in intensive care. For some the experience is no more worrying than any other stay in hospital. Some have no clear memory of it, or they may try to forget it. For others, being so ill can be a very traumatic experience and it may take time for them to come to terms with it afterwards. The strong drugs and the treatment the ICU staff had to give you to help support your body, will have affected your body and mind. It is common for patients in an ICU to experience hallucinations, nightmares or dreams that can seem real and very frightening. At times, you may have felt slightly aware, but didn't know where you were or what was happening.

Hallucinations and paranoia

It's common for patients in an ICU to have hallucinations or nightmares often called ICU Delirium. You may have had dreams or feelings of being tortured, trapped in bed or felt as if you were being held captive. This can be caused by having drip lines and catheters inserted into your body to help support your body's normal functions and monitor your condition. The fear this causes can remain for weeks after you have been transferred to a general ward or discharged from hospital.

You may also have felt some paranoia as you tried to make sense of things when you were confused. This too normally passes with time. If going back to hospital for a follow-up appointment frightens you, take along someone you trust to reassure you. .

Things that may help you get over what happened

After leaving hospital you may have questions about your stay in the ICU. Some hospitals offer a follow-up clinic. This usually involves being invited back to the ICU you were in to look around and find out more about what happened to you. The idea of going back to the unit can be frightening and

it may be some time until you feel ready to do it. However, it can be very helpful to see where you were and find out more about what happened to you. Some ICUs keep diaries for their patients during their stay, and you may receive this at the clinic appointment.

You won't remember everything that happened to you in the ICU. Writing down what you can remember may help you to collect together your memories. You could try to remember something about each day you were in hospital to help make sense of the time you lost. It may help to ask your family and friends what they remember about it.

If your relatives or visitors kept a diary while you were in the ICU, reading it can help you understand what happened. It may take a while before you feel ready to read it, and it can be very emotional, but many patients who have read their relative's diary find it helps them understand what happened. If it helps, take the time to understand the medical side of what happened to you. Staff at the follow-up clinic will be able to help with this or you can ask your GP about it.

Notes:



Eating well to get better

While you were in intensive care you may have received your food as a liquid. You may have been fed through a tube inserted into your nose and down into your stomach, or by a drip straight into your vein. Your body will have used its stored fat and muscle for energy to help fight your illness.

When you are well enough to have solid food again, you may have difficulty eating because:

- you don't feel hungry
- your mouth is too sore to eat
- food tastes different, or
- it hurts to swallow.

Try starting off with small portions and eating more often throughout the day. Instead of having full meals, have small meals and two or three snacks each day. You can buy specially prepared milk drinks and desserts, like the ones you were given in hospital, which contain lots of vitamins and minerals.

Take your time when eating and relax afterwards to avoid indigestion. If some foods taste very salty or sweet it is likely that your taste buds are taking time to get back to normal. This is common and will soon improve, but don't add extra salt or sugar to your food in the meantime.

If you enjoy drinking alcohol, check with your doctor that it is safe to drink it with the medication you are taking and that it will not have a bad effect on your condition. Even if it is considered safe, be aware that drinking too much alcohol can be harmful and is not recommended.

Sometimes, taking strong antibiotics and steroids can lead to infections, such as oral candida (thrush in your mouth), which can give you a thick white substance on the roof of your mouth and tongue, making it painful to swallow. If you think you might have thrush, your GP will be able to treat it easily.

During your recovery you must make sure you drink enough. Take care not to become dehydrated. Dehydration can:

- dry out your skin
- make you produce less urine, which can have a bad effect on your kidneys, and
- make you feel very weak and tired.

Drink regularly throughout the day so you don't become dehydrated. You can have hot drinks as well as water and squash.

If you need more support or have symptoms that you're worried about, you should see your GP.

You should also talk to your GP if:

- you have trouble getting back to your normal weight
- your bowel movements don't return to normal
- there is blood in your urine, or
- you get severe indigestion.

Your GP may be able to offer you advice or refer you to a dietician.



Useful contacts

Further resources can be found online at icusteps.org or scan the QR code below using your smart phone.

Please use the 'contact us' to let us know if you find any information that's not correct, there are any other organisations you think should be listed, or there are areas of help that aren't covered by any organisation here.



Scan me to go to
icusteps.org/useful-contacts

Notes:

Notes:

Our information and general advice is based on experiences of former ICU patients and it should not replace the advice you receive from healthcare professionals. ICUsteps cannot accept responsibility or liability from the use of this resource.

ICUsteps is a patient-led support charity. For more information, resources or to make a donation, visit our website: icusteps.org

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