Neuro Intensive Care Unit
Ward K1

Information for patients and relatives
Neurosurgery
Your care team

Named nurse

Named physiotherapist

Named occupational therapist

Named speech and language therapist
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Introduction

This booklet contains advice and information about the Neurosurgical High Dependency and Intensive Care Unit in Sheffield. It is aimed at patients as well as relatives, friends and carers. If you are a patient, recovery is often a long and slow process, so in the initial stages you may not be able to or even feel up to reading this information.

Knowing what to expect

If you are a relative or friend, the doctors and nurses on the unit appreciate the significant distress that comes from seeing your relative and loved ones critically ill. They also understand that for both patient and relatives, one of the scariest things about having such an illness or severe injury is not knowing what's going to happen. We know how important it is to have information and the relief that can come from knowing what to expect or that what you're experiencing is normal for someone in your position. This booklet covers the different stages of treatment and recovery, you can read it all at once, or you can just read each section when you need to. It is intended to be used with the care and support of the neurosurgical care team and not in isolation. It can’t answer all your questions, but it will answer many of them and may help form some of the questions you wish to ask the clinical staff. It will also tell you where you can get more information.

Keeping a diary

If you are a relative / carer it can be useful to keep this booklet or even keep a diary to pass on when the time is right (we have included some blank pages at the end of this booklet that you might find useful). Your relative or friend will have very confused memories of their time in the intensive care unit / high dependency unit or may have no memories at all. A diary can help them to understand what has happened to them and may help to fill the gaps in their memory. A diary can also be very useful to record progress and see the small improvements they have made. If you would like to do this, please ask nursing staff for a diary.
Information for relatives, friends and visitors

Your relative or friend may require intensive care for many reasons, maybe an accident, an illness, or for treatment following major surgery. Seeing them for the first time can be very upsetting and painful. They are likely to be connected to complex medical equipment and may look very different to how they usually look.

Admission to intensive care

Your relative or friend has been admitted to the neurosurgical intensive care unit (ICU) or high dependency unit (HDU), to allow the doctors and nursing staff to keep a careful watch on vital systems such as:

- How swollen the brain is
- How well the brain is functioning
- How well the lungs, heart, kidneys or liver are performing

Treatment is given to correct specific problems, for example:

- Drainage of fluid from the canals in the brain
- Removal of a piece of bone that lies over a swollen brain

Some of the treatments are aimed at trying to prevent the initial injury from getting worse, for example:

- Some patients are kept in an unconscious state with drugs
- Some have their bodies cooled to protect the brain from further swelling

Patients who are very ill like this are also at risk of developing other problems, which may need further treatment, for example:

- Chest or blood stream infections
- Problems with the heart
- Poorly functioning gut
- Blood clots in the blood vessels
These treatments aren’t always successful, particularly when the initial damage to the brain is severe. It is likely that there will be some serious long-term effects on their eventual recovery or they may even die.

**Time in theatre**

Sheffield admits patients from a large geographical area and you may already have travelled a long distance from an ICU in a different hospital. Neurosurgery is extremely intricate and complex and usually involves many hours in theatre; it is often the case that you have to wait a long time before anyone is able to give you any information about the progress of your relative. On return from theatre, it will take some time for the nurses to attach the necessary equipment to the patient and it may take a while for the doctors to speak with you as they may have other cases or clinics to attend. It is normal to feel helpless and desperate at this time, but the nurses will answer your questions as well as they can. If you have questions about what is being done, please ask the nurse caring for your relative.

**Keeping in touch with the hospital**

You will want to keep in contact with the hospital by telephone. Please feel free to ring as often as you need to; however, if this could initially be after 10.30am we will be able to give you more information following the doctors' ward round. It is extremely helpful to the care team if a family member could be nominated to be the main contact for the hospital. Staff can tell the main contact how the patient is doing and they in turn can pass this information on to other family members. This will save time for both staff and relatives. If there are any sudden changes in the patient’s condition, the nursing staff would always contact the person whose name has been given for this role.
Hospital transfers

As your relative improves, or they no longer require specialist care, we will transfer them to a hospital closer to home, known as repatriation. This may be an upsetting time for you as you have come to know and trust the doctors and nurses; however, the beds are needed for other seriously ill patients who need our specialist care.

Neurosurgical ward (N2)

If there is any delay to repatriation, or we feel that your relative still requires observation and nursing care, they will be transferred to Ward N2 for a period of time. The visiting times will be different so please enquire before visiting the hospital.

Contact information

Ward N2: 0114 271 2891
          0114 271 2896
Staff in the intensive care unit (ICU)

There are many different people who work and help out on the neurosurgical unit. As well as the nurses, doctors and anaesthetists, you may also see speech therapists, physiotherapists, dieticians and other support staff on the unit.

Doctors/anaesthetists

The doctors review the care of every patient each day and make decisions about changes to treatment and care. This may include further investigations, brain scans, further surgery or specific therapy interventions. The timing of each of these will vary according to the clinical condition of the patient and some may not happen on the same day that they have been requested.

Nurses

Whilst in the ICU, one nurse will usually look after one, or at most, four patients. The nurse is responsible for providing most of the care your relative needs and, in the early stages, will spend most of their time at their bedside performing various tasks including:

- Taking regular blood tests
- Changing their treatment in line with their test results
- Giving drugs and fluids that the doctors have prescribed
- Monitoring blood pressure, heart rate and oxygen levels
- Clearing fluid and mucus from the lungs using a suction tube
- Adjusting their position in bed every few hours to prevent the development of pressure sores
- Providing mouth care
- Washing them in bed and changing their sheets
- Changing their surgical stockings, which help circulation when a patient is inactive or lying still for a long period of time
- Instillation of eye drops to protect their eyes
Physiotherapists

One of the roles of a physiotherapist is to try to make sure your relative's lungs are kept clear by carrying out physiotherapy on their chest at least once a day. The therapist will also exercise a patient’s arms and legs, even when they are asleep, to ensure that the muscles are kept active, preventing the joints becoming too stiff and painful. If the patient is ventilated (connected to a machine which breathes for you), the physiotherapist will administer exercises to help strengthen the lungs and the muscles used for breathing; this will reduce the chance of the patient getting a lung infection. As the patient improves, the physiotherapists will help with other exercises to get them physically fit and strong enough to get out of bed and begin to mobilise.

Dietitians

The dietitian will assess the nutritional needs of the patient and how they are to be fed. The patient may be fed through a nasogastric tube (a tube that goes up into the nose and down into the stomach) or, if a patient is not allowed food in the stomach, they may be fed through a drip straight into a vein.

Speech therapists

A speech therapist will assess your relative's ability to speak and communicate, especially if they have a tracheostomy. They will also monitor them to see if they can swallow well enough to start to drink and eat normally.
Occupational therapists

Rehabilitation begins as soon as your relative is physically stable. Initially, the therapist will assess them and look for signs of awareness. As the patient improves, they will implement strategies to try and help them overcome the effects of their disability, enabling them to improve their co-ordination, strength and dexterity so that they can hopefully return to their daily life and work.

Chaplains

The hospital offers a 24-hour a day chaplaincy service where someone is available to talk to you about any issues you may have. This is run by the hospital chaplaincy service and is supported by chaplains from several denominations. They are available to support you, or to access support for you from other faith ministers. Chaplains are always available to provide spiritual and pastoral care as well as attending to religious needs. You do not need to be a member of any faith tradition to receive support from a chaplain.
What can I do to help?

Infection control

Patients who are critically ill may have difficulty fighting infections. In the early stages of their illness they are often very vulnerable and any infections can be potentially serious. The staff will do all they can to make sure patients are protected. You can also help by washing your hands and using the anti-bacterial gels that are situated around the unit before you go near or touch your relative or friend. You should also remind other visitors to do the same.

What can I bring for my relative/friend?

Unfortunately, there is limited space on the unit for storing your relative's clothing and valuables, so we may ask you to take them home. However, it would be appreciated if you could supply the following personal items such as:

- Body wash (not soap)
- Deodorant
- Shampoo and conditioner
- Facial moisturising cream
- Toothbrush and toothpaste
- Lip balm
- Hairbrush
- Glasses or hearing aids

We provide gowns that are easy to use when the patient is attached to a lot of monitoring equipment. But, when the equipment is removed, they will be able to wear their own nightwear. Loose fitting cotton garments are best.
Is there anything I will not be allowed to bring onto the unit?

For hygiene and safety reasons we ask that you do not bring the following:

- Flowers or plants
- Food or drinks
- Balloons (helium filled)
- Valuable items or cash

Photographs and cards are welcome.

Daily routine

Immediately following the injury or acute illness, it can be quite upsetting and frustrating for visitors as there will be long periods when you are unable to be with your relatives due to their treatment and we do not expect you to stay in the hospital during this time. There will be times when staff will ask visitors to leave the patient’s bedside to allow them to receive various treatments. If they are being ventilated, the nurses have to regularly clear the mucus from the chest by passing a thin tube into the patient’s airway, this is quite noisy and may cause the patient to cough or retch.

The fluids given to patients to keep them hydrated may cause them to look bloated and swollen, this is normal and will improve over time. Some of the machines that they are connected to have alarms that may sound to let staff know that something needs doing; for example, if more fluid is required. Usually, there is nothing to worry about - the staff will closely watch them at all times.

No visible change

It is normal for days to 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 speak to the patient and explain what they are doing,
even if they are unconscious or heavily sedated, in case they can hear or are aware of being touched.

**Communication whilst they are unconscious**

We do not know what the unconscious patient can actually hear, but it is possible that their awareness may be higher than their ability to respond. Following any severe injury to the brain, the brain's ability to organise and filter out sounds, smells, visual stimuli (such as bright lights), and even touch is damaged. *Sensory over-stimulation,* commonly called 'flooding', often triggers feelings of panic and a physical response such as an increase in heart rate and blood pressure, sweating and tremors which are distressing for the patient. It is really important to keep noise and stimulation to a minimum. The nurses will show you how to talk in a soft quiet voice, whilst at the same time gently stroking the patient's hand can help reduce their agitation. Talking to your relative or friend about shared experiences of holidays and good times may be useful but keeping up a one-sided conversation can be difficult. As they improve you could try reading a newspaper or book to them.

**Weaning**

As the patient improves, sedation is gradually reduced, a process known as weaning. The weaning process can take hours or several days depending on the initial severity of the illness and how long they have been sedated. It can take several days, weeks or months for a patient to regain full consciousness and become aware of their surroundings. The term ‘coma’ is sometimes used to describe this indefinite period of unresponsiveness. Recovery from coma is a gradual process. Initially, the patient may only be able to open their eyes, later they will start to respond to touch or pain until eventually they will begin to respond to voices or commands. The longer the period of unconsciousness, the greater the possibility of long term symptoms and disability.
As the patient begins to regain consciousness, it is quite normal for them to be drowsy, extremely confused, agitated, disinhibited or even violent. This is caused by the initial injury or illness and the patient is not responsible for their anti-social behaviour during this time. Although this can be extremely distressing for the patient and the family, the behaviour usually improves as the patient begins to recover.

It is understandable that you will have many questions about the long term effects of the brain injury. Unfortunately, this is always difficult to determine as brain scans are not always able to show the extent of the injury. We do know that the more severe the injury and the longer the period of unconsciousness, the greater the likelihood of long term symptoms and disability (The charity 'Headway' may be a useful resource at this time).

We work hard to ensure that the patient and their family are kept informed of progress. Unfortunately, when the ward is particularly busy, communication can sometimes be overlooked. If you feel that this is the case, please speak with the nursing staff so that we can address your concerns.

**Helping with personal care**

Once your relative is stable and some of the more invasive monitoring devices have been removed, relatives might find it helpful to become more involved in delivering care. This will obviously depend on how ill they are, but doing things such as massaging or moisturising their hands and feet or helping with mouth care can be helpful.

**Communication when conscious**

Even when they are conscious, many patients experience communication difficulties and are unable to express what they want to say. As they improve, they may be able to write, spell out words by pointing at letters or common words written on a piece of paper or a picture chart.
Other things you can expect

Deprivation of Liberty (DOL's).

The Human Rights Act states that 'no-one shall be deprived of his or her liberty [unless] in accordance with a procedure prescribed in law'. The Deprivation of Liberty Safeguards is the legal procedure and documentation that the hospital has to complete when a patient who lacks capacity to consent to their care and treatment is seen to be deprived of their liberty.

Family or friends, who know the person well, will always be consulted as part of the assessment process and there will be a regular review of the authorisation as the patient's condition improves.

Restraints

Many patients experience periods of confusion and agitation and may inadvertently remove essential tubing and monitoring equipment, which can be life threatening or result in infection. To prevent these complications occurring, the nurse will apply padded gloves to restrain and restrict the patient's movement. The nurse will periodically remove the gloves to assess whether they are still needed.
Looking after yourself

You can help your friend or relative by taking care of yourself. It is important that you do not spend 24 hours a day by their bedside; you need to give yourself a break and this will also give them time to rest. The staff will contact you straight away if they need to or if there is any change in the patient's condition.

You may not feel like eating and you may have difficulty sleeping, but do take time to eat regularly and rest when you can as it will not help if you become tired or ill.

Managing contact with family and friends

Your family and friends will be concerned about you and your loved one and they will want to know how things are. You may appreciate their concern, but it can be tiring if the phone is constantly ringing when you're at home between visits to the hospital. Passing on the information by email or text message to several people at once can be easier; alternatively, you could speak to one person regularly and ask them to pass the information on to others.

If the patient is your partner

If the patient is your partner, you may suddenly feel very alone. Accept offers of help from friends and family. You will have less time to do things like shopping and may need help with childcare. Often, in times of worry and stress, people turn to their partner for support. If you don't feel like you can tell other members of your family about your concerns in case you upset them, it may be helpful to contact one of the organisations listed in the 'Useful contacts' section at the end of this booklet.
Financial matters

Make sure that your bills are being paid. If you need to get access to your partner's bank account, contact your bank and explain the situation. You may be able to get temporary control of the account while your partner is not able to deal with these things.

Every Wednesday afternoon, a local solicitor runs a clinic on the unit where they can offer free advice and support - please ask the nursing staff to book you into a session. The Citizens Advice Bureau is also able to provide information on any financial help and benefits that are available to you (details of local CAB services can be found in the appendix).

Following transfer from intensive care

It is normal for relatives to have a reaction to the stress that they have been under once the patient is out of danger. It is also normal to feel worried, depressed, angry or even guilty. Help and information is available from the organisations listed at the end of this booklet, or see your family doctor who will be able to offer more support.
Helping children who have a relative in intensive care

It is important to consider whether a child should visit their parent or a close relative during the first few days. It can be very distressing for children under 12 years old and relatives should check with staff before bringing them to the unit. 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 your loved one might look.

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

- Trying to keep to their routine as much as possible (including school trips, seeing friends and going to after-school clubs if the child wants to).
- Making sure the child is looked after by someone they know, so they can feel safe at a difficult time.
- 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'.

Keeping a diary for Mum or Dad

The child may like to keep their own diary to record a brief description of each day and what they did and any souvenirs of the day (pictures etc). This helps the child understand what is happening and makes it easier for them to talk to their Mum or Dad about what happened in their life whilst Mum or Dad was in hospital.
Children’s behaviour and questions

Some children may begin to act younger than they are. For example, they may start to suck their thumb or carry a favourite toy with them. This shouldn’t be discouraged because the child is trying to find comfort at a worrying time. If you are concerned about them ask your GP for advice or support.

Once your relative is more stable, the child will need help dealing with what has happened. This can be a gradual process and can take several months. At times, it may be helpful to mention your relative'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 your relative or friend 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 your relative dies, bereavement counselling services can provide special help for young people. (See the 'Useful contacts' section for details of organisations that provide bereavement counselling).
General hospital information

Visiting hours

We try to offer flexible visiting hours immediately following admission. However, once the patient is stable, it is important to adhere to normal visiting times to give the therapy staff an opportunity to provide rehabilitation and treatment. It also allows the patient and other patients in the room a chance to eat their meals, rest and have some privacy.

Contact information

Ward K1 (Neuro Intensive Care):

- 0114 271 2047
- 0114 271 2326

Overnight accommodation

Unfortunately, there is no overnight accommodation in the hospital. Please ask the nursing staff for a list of bed and breakfasts or local hotels within walking distance of the hospital.

Parking

Parking can be difficult and expensive – please speak to the nursing staff who may be able to advise you about applying for a parking pass.

Refreshments

There is a large dining room and coffee lounge on D floor. They provide a range of hot and cold food. The main servery is open from 5.00am until 2.00pm and 5.00pm - 7.00pm. Drinks and cold snacks can be purchased 24 hours a day.

Snacks are available from WRVS on A Floor of the out patient department as well as B Floor near to the main entrance. There is also a Boots chemist on C floor that sells food, drinks and toiletries.
Newsagents and cash machines

A newsagents and confectionary shop is situated on B Floor of the main entrance hall.

The nearest bank ATM machine is on B Road outside the main hospital entrance.

Other hospital facilities

For further details of hospital facilities, please refer to the Royal Hallamshire Hospital Inpatient Guide.
For patients

Your time in the intensive care unit

When a patient has been critically ill, unconscious or sedated for a long period, it is often difficult to remember details of what has happened. This period of amnesia (inability to remember day to day events), is normal following any brain injury or surgery to the brain. Uncharacteristic behaviour, disorientation and severe agitation may be made worse by vivid dreams, nightmares and hallucinations.

If you are able to talk to someone to put the experience into perspective, it might be of some help. Below is some information that may help you make sense of things.

How a critical illness can affect your body

Fatigue

Weight loss is common, as being ill and inactive will cause the muscles to weaken. Intense feelings of fatigue and tiredness are frequent complaints that often take many months to improve. It is important to set realistic goals. Keeping a diary that can be read at times when you don't feel so well may help you realise how much progress you are making.

Breathing

A tracheostomy involves inserting a tube into a hole in the throat. The tracheostomy makes it easier for you to breathe either on your own or with the help of a ventilator. Whilst you have the tracheostomy, it is impossible for you to speak and make yourself heard. This can be very frustrating but staff will try and help you find other ways to allow you to communicate. Once the tracheostomy has been removed there will be a scar on your neck, this will gradually fade and become less obvious.
Swallowing

There are many reasons why swallowing can be difficult following a brain injury. You will have a regular assessment so that food and drink can be gradually re-introduced.

Speech and language

If you have had help with your breathing, you may notice that your throat is sore and your voice has changed. It is important to try and relax as much as possible when speaking and avoid over-straining the voice.

Some patients find it difficult to understand what people are saying to them; this is known as receptive dysphasia. Sometimes they experience problems finding the right words, referred to as expressive dysphasia. This is extremely frustrating and upsetting but the speech and language therapists will be able to assess your particular problems and assist you with your communication needs.

Loss of movement

Any injury to the brain can cause a loss of movement or feeling in the arms or legs. Everyone is affected differently and the severity of the problem can vary from a very slight weakness to a complete loss of power and poor co-ordination. Dyspraxia is a term we use to describe difficulties with making deliberate voluntary actions. The patient may not have a problem with moving an arm or leg but are unable to initiate or co-ordinate a deliberate response. In the early weeks or months it is impossible to say whether there will be a complete recovery; however, the therapists can help with these problems and develop an exercise programme to address your specific needs.

Your skin and hair

Your skin may appear to be very dry after an illness. Moisturising it regularly can help stop this. Patients often notice changes to their hair; surgery may have resulted in areas that have been shaved off and it is
not uncommon for you to experience some degree of hair loss (it is not unusual for this to occur months after you leave hospital).

**Bruising**

Bruises and scars on the hands, arms, wrists, neck, groin or sides of the chest will occur as a result of all the tubes and invasive monitoring that have been required since admission. Bruising over the stomach area is a result of the injections administered to prevent the blood from clotting, these will gradually heal and fade.

**Changes to your hearing, sight, taste, and sense of smell (anosmia)**

Your hearing, sight, taste, touch and sense of smell may have changed due to the area of damage in the brain. If there has been local bruising then there is a good chance of recovery. However, if the brain has been more severely damaged, it is unlikely to return to normal. When you get home it is important to ensure that there is a fire or smoke detector fitted at home and always check that food is within its ‘use by’ date. For further details on managing anosmia see the Headway website.

Patients may have been fed through a tube into the stomach, or by a drip into a vein. When you begin to eat and drink normally again, food may taste stronger, metallic or different. This may also affect your sense of smell as it is closely linked to your sense of taste. Your eyes may be sore and dry as a result of long periods of sedation or they may be puffy and swollen because of surgery. Patients often experience tingling on their skin and in different parts of the body. This can be caused by some of the drugs or by the body's natural reaction to an illness. These changes are usually temporary and should improve over time.
Problems going to the toilet

Following brain injury, continence is a skill that may need to be re-learnt. The nurses will help you to overcome your difficulties by assessing your particular problem and advising on various alternatives. When you were acutely ill you will have needed a catheter to collect and measure the urine draining from the bladder. When the tube is taken out, the muscles controlling the bladder may have become weaker so it is not unusual for patients to experience some difficulty in controlling the bladder for a short period of time. There are many reasons why it might be difficult for you to pass urine, the most common of which is a urine infection which can be easily treated with medication. Symptoms may include:

- Not being able to pass urine for several hours
- Having a burning pain whilst urinating
- Blood in your urine

Sometimes medication can change the amount and colour of your urine. At the same time, it is not uncommon for patients to have problems with their normal bowel movements. If you’re worried about any of these things, please talk to your doctor about them.

Emotions

It is natural to feel tearful, angry or depressed following your brain injury. However, as time goes on patients can find it difficult explaining to others how they are feeling, especially as they might appear to have recovered physically. It sometimes helps to talk to a good friend or relative. Your GP may also be able to help by providing some reassurance and support.
Smoking

If you smoked before your illness, now is an ideal time to give up. Smoking can severely affect the blood supply to the brain and will damage and weaken your lungs. If you stopped smoking whilst you were in hospital, don't start again when you are at home. The NHS Smoking Helpline can give you support and advice; phone 0800 022 4332 for details.
Moving to a general ward

As you begin to improve, the physiotherapist will encourage and support you to move around and become more independent. This can be a long process but as you improve and no longer require specialist treatment, you will be moved to a different area of the unit, transferred to another ward or to a hospital closer to home. The transition to an area with a reduced level of nursing supervision can be a difficult and daunting time for patients and relatives. However, this is an important next step towards normality and independence.

Visiting times

The visiting times on a general ward will not be as flexible as they were on the intensive care unit. The wards are busy and often noisy places so it is important to try and rest whenever possible. A personal music player with headphones may help you to relax and pass the time.
Returning home - what will life be like now?

Leaving hospital and returning home is a major step to recovery. It is a very positive step but it will take time to get back to a normal life. You and your relatives will not have the same support you experienced in hospital and it can be a difficult time for you and your family.

Goal setting

It is normal to feel very tired and it will take time before you feel well enough to cope with everyday life and many more months to get back to full strength. Setting small goals in your daily routine can help show you that you are improving. A small goal could be something as simple as making a drink, or walking a few steps further without needing to rest. Patients should avoid ‘pushing themselves’ too hard as this can end up making the recovery period take longer.

In the early days, you need to be kind to yourself and take things very slowly. Set yourself targets to help you get back to normal, and keep doing the exercises your physiotherapist gave you. Don’t overdo your exercise, make sure that you rest when you need to and listen to your body, slowly increasing your activity to build up your strength.

Social life and hobbies

Patients often feel differently about activities and hobbies which they did before becoming ill. It is common to not want to return to these. Many patients have reported that they found it difficult seeing lots of people when they returned home and they disliked a lot of noise. This can be a difficult time so start by seeing one or two friends for short periods and avoid going into places where there are crowds e.g. shopping centres.
You may find it difficult to concentrate and may even find it hard to follow a TV programme. During your recovery period you may be forgetful or struggle to remember recent events. It is easy to become frustrated. Remember these feelings and experiences are very normal.

**Relationships and family**

When you have been critically ill, it may appear to you that people around you have changed. It is natural for your family to want to make a fuss of you and to try and encourage you to return to your ‘old’ way of life. This may include work, hobbies and activities. However, it must not be understated that your family and friends have also experienced a traumatic time whilst you have been critically ill. They may have had feelings of helplessness or have been afraid that you might die, so it is normal that they may want to do everything for you when you get home. This can create tension within the home and puts a strain on relationships. It is important to share your feelings in a calm manner. You could also speak with your GP who may be able to offer support or refer you for counselling.

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

**Getting back to your daily routine and work**

Lots of patients worry about coming home from hospital or returning to work. Many people wonder whether they’ll be able to cope. Talk about it with your family and think about how you can adapt things to make it easier. If you used to work, you may not be well enough to return for some time. The length of convalescence will depend upon the kind of work that you do. It is important to stay positive even if it means making some life changes. When you feel ready to return to your job, you may only 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.

**Driving**

Epileptic seizures are a possible complication following any brain injury and may develop one to two years after the initial injury. You are legally obliged to notify the Driver and Vehicle Licensing Agency (DVLA) about your condition and must not drive until you have DVLA approval. Failure to do this could have serious consequences, especially if you continue to drive without DVLA approval as this will invalidate your insurance in the event of an accident.

**Sexual relationships following critical illness**

It is quite normal to be worried about when it's safe to start having sex again. Partners are also likely to be worried about this. Commonly asked questions are:

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

Brain injury may sometimes upset the normal hormone balance which can be evident in problems with sexual function or behaviour. 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.
How might I feel after being in the intensive care unit?

Following any kind of brain injury, it can take months or years to recover. Being weak and having to put a lot of effort into doing simple tasks can make you feel low and demoralised. You can also feel like you’ve lost your independence if you need a lot of help from other people. Mood changes and fluctuations are common and you may experience:

- Feeling upset and tearful
- Not being able to sleep properly
- Being quick-tempered and angry
- Poor short-term memory and difficulty recalling information
- Inability to cope with pressures
- Lack of concentration and inability to organise yourself
- Sexual difficulties such as impotence and altered sex drive
- Visual disturbances
- Feeling scared that you almost died
- Worrying about how long it's taking to recover

Loss of memory

Most people will experience some problems with their memory and concentration. It is normal to have difficulty remembering recent events whilst being able to remember things that happened a few years ago. Your memory should improve with time, although it might never be quite as good as it used to be. There is no way of restoring lost memories, but there are techniques that can help you to recall and process information more efficiently. The Headway website ([www.headway.org.uk](http://www.headway.org.uk)) offers advice and useful hints including the use of memory aids, adapting your environment and coping with memory problems.
Depression

Recovery may take a long time and it is natural to go through times where you feel depressed, frustrated and worried about your recovery, particularly if you don’t seem to be getting any better. At the same time, your family and friends will be pleased to have you home, but they may not understand why you may feel depressed. Talking about this with your family or a close friend can help. Your GP may be able to offer treatment or counselling to help you through this difficult time. As you start to do more and face new challenges it is normal to feel scared - try to keep calm and be patient.

Headaches

Many patients struggle to cope with a persistent and niggling headache that affects concentration and mood. This can take weeks and sometimes several months to improve. The effects can range from mild (relieved with simple painkillers) to more severe debilitation. Again, be patient, take frequent rests and avoid stress. Try to identify what aggravates it or the times of the day when it isn’t so bad so that you can tailor your activities around it.

Sleeping

It can take time to get back into a normal sleep routine. You may find it harder to fall asleep, or you may experience vivid dreams, nightmares, flashbacks and severe anxiety that can be triggered by a sound, smell or something you see. If you have trouble sleeping, try a milky bedtime drink but avoid tea and coffee as caffeine can keep you awake. Reading or listening to the radio before you go to sleep may also help. If your relatives or visitors kept a diary whilst you were in hospital, reading it may help you understand what happened. However, if you continue to experience extreme symptoms of stress, your GP can refer you to a professional counsellor.
**Personality changes**

Changes in personality can be subtle, for example withdrawal or quietness, and may only be obvious to close family members, but may also be quite challenging and difficult to cope with or understand. It is important to seek support from your GP and advice from specialist centres or organisations such as Headway who will be able to offer help and suggest coping strategies.

**Eating and drinking**

Whilst you were unconscious it is likely that you were fed through a feeding tube inserted into your nose and down into your stomach. Your body will have used its stored fat and muscle for energy to help fight your illness and consequently you may have difficulty eating because:

- You don't feel hungry
- Your mouth is too sore to eat
- Food tastes different
- It hurts to swallow

Eating smaller more frequent portions of food along with nutritional supplements can help your appetite to improve.

During your recovery you must make sure you drink enough. Take care not to become dehydrated. Dehydration will make you feel very weak and tired and increase your risk of developing an infection. You should consult with your GP if:

- You have trouble getting back to your normal weight
- Your bowel movements don't return to normal
- You experience severe indigestion
**Alcohol**

Avoid drinking alcohol. Following a brain injury, the amount of alcohol that you used to drink before the injury can affect you more quickly. Check with your doctor that it is safe to drink with the medication you are taking and that it will not have an adverse effect on your condition.

**Infections**

Sometimes, taking strong antibiotics and steroids can lead to infections, such as oral candida (thrush in your mouth); this produces 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.
Rehabilitation

The majority of patients who have sustained a brain injury will make an excellent physical recovery. However, there may be other problems that aren’t so visible. Everyone’s injury is unique and a number of symptoms may be experienced which can range in severity from mild to severe. Difficulties with normal skills such as understanding, reasoning, memory, concentration and problem solving can have a real impact on daily life and are often very difficult for you and your relatives to deal with.

Rehabilitation will be an essential part of the recovery process, but this must be ‘tailored’ according to the severity of your injury. Rehabilitation units specialise in different aspects of care and the decision regarding when and where you should be treated is complex and is dependent upon your particular physical or psychological needs.

The goal of rehabilitation following a brain injury is to improve your ability to return home and adapt to any disabilities. Not all patients will recover completely from their initial brain injury. Some problems will be physical but other problems will be less obvious, the effects of which should not be underestimated.
Frequently asked questions

Where will I go for my rehabilitation?

This will depend on where you live. We will try to transfer you to a suitable rehabilitation centre close to where you live. However, these centres are highly specialised and not every town has its own centre. In Sheffield, patients will be assessed at Osborne 4 based at the Northern General Hospital.

How long am I likely to be in rehabilitation?

This will depend on the severity of your initial problem. Often a few weeks of therapy will be sufficient to give you the support that you need to become more independent. However, for some people this can be significantly longer.

What happens when I am at the rehabilitation unit?

A short period of assessment by members of the rehabilitation team (nurses, occupational therapists, physiotherapists, speech and language therapists) will be able to identify any physical or cognitive issues and will enable them to target any remaining difficulties. This is done by working together to set personal goals aimed at regaining your independence.

Planning for your eventual discharge home begins from admission with consultation with family and friends. However, although most people will be able to return home, a small number of individuals will experience longer term problems and a nursing or residential home may be better able to support your needs.
When will I be able to return to work?

It is important not to try and return to work too soon as fatigue, reduced concentration and difficulty making decisions are common problems following any brain injury. Try not to make any hasty decisions concerning work. In the early days, you may feel that you should leave your current employment and you wouldn’t be able to cope, but it is important that you keep in regular contact with your employer so that they are able to support you as much as possible.

How will I manage my finances whilst I am in hospital?

There are some excellent sources of help including the Citizen’s Advice Bureau, rehabilitation services or the occupational therapists and local Headway groups. Speak to them about how to manage your finances during this time.
Useful contacts

Brain and Spine Foundation
Telephone: 0808 808 1000
Website: www.brainandspine.org.uk

Brain Tumour UK
Telephone: 0845 4500 386
Website: www.braintumouruk.org.uk

Citizens Advice Bureau
Website: www.citizensadvice.org.uk

Cruse
A national charity offering support to anyone who has been bereaved. Cruse volunteers live locally and can visit you in your home or talk to you over the telephone.
Telephone: 020 8939 9539
Helpline: 0870 167 1677
Email: Helpline@crusebereavementcare.org.uk
Website: www.crusebereavementcare.org.uk
**Health Talk Online**
Website covering a wide variety of personal experiences of health and illness. It includes video interviews of people who have been through different illnesses and includes sections for intensive care patients and their relatives.

Patient's website:
www.healthtalkonline.org/intensive_care_Patients_experiences

Relative's website:
www.healthtalkonline.org/intensive_care_experiences_of_family_friends

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**Headway UK**
A charity that supports people with brain injuries and the people who care for them.

National helpline: 0808 800 2244
Website: www.headway.org.uk

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**Headway Sheffield**
A local group who provide support and an opportunity for patients and carers to meet and share their concerns. They provide regular coffee mornings and monthly social evenings.

Helpline: 07849 338 380
Website: www.headwaysheffield.co.uk
Facebook.com/headwaysheffield
ICUsteps
A charity set up by former intensive care patients and their family members. It aims to promote better support and rehabilitation after a critical illness. The website includes information about the experiences of patients and family members, a bulletin board and more contact details.

Telephone: 0870471 5238
Website: www.icusteps.com

Intensive Care National Audit and Research Centre (ICNARC)
ICNARC is a charity that is dedicated to improving intensive care treatment and helping patients to get better sooner, with fewer complications. It has useful information for patients and relatives including an excellent list of contacts for people with specific illnesses.

Website: www.icnarc.org/patients

The Intensive Care Society
The Intensive Care Society is a professional organisation for doctors working in intensive care. The website has a very useful 'patients and relatives' section that explains many areas of intensive care, such as staffing, equipment, treatment and recovery.

Website: www.ics.ac.uk/patrel

Macmillan Cancer Support
Macmillan Cancer Support improves the lives of people affected by cancer. They provide practical, medical, emotional and financial support and campaign for better cancer treatment.

Helpline: 0808 808 2020
Website: www.macmillan.org.uk
Meningitis Trust
The Meningitis Trust provides support and information on identifying, and recovering, from meningitis.

Helpline: 0800 028 18 28
Website: www.meningitis-trust.org

The National Association of Bereavement Services
An association that can help you find an organisation that supports bereaved people.

Helpline: 020 7247 1080

NHS Direct
An NHS service with a health encyclopaedia that provides information on a range of medical conditions, symptoms, types of surgery, medicines, and health and lifestyle advice.

Telephone: 111
Website: www.nhsdirect.nhs.uk

NHS Smoking Helpline
An NHS phone line and website with detailed information about the free NHS support services for people trying to stop smoking.

Helpline: 0800 022 4332
Website: www.nhs.uk/gosmokefree

NICE (National Institute for Health and Clinical Excellence)
The NICE website contains information on a broad range of medical issues.

Website: www.nice.org.uk
Patient UK
A health website that provides evidence-based information covering a wide range of medical and health topics.
Website: www.patient.co.uk

The Pituitary Foundation
Address: PO Box 1944, BS99 2UB
Telephone: 0845 450 0376
Website: www.pituitary.org.uk

Princess Royal Trust for Carers
The Princess Royal Trust for Carers is the largest provider of support services for carers in the UK.
Telephone: 0844 800 4361
Website: www.carers.org

Samaritans
Samaritans provide confidential, unbiased emotional support, 24 hours a day, for people who feel distressed, desperate or suicidal.
Helpline: 08457 90 90 90
Website: www.samaritans.org

Spinal Injuries Association
A support charity for people suffering from spinal injury.
Helpline: 0800 980 0501
Website: www.spinal.co.uk
The Stroke Association
An organisation that provides support and information on strokes and guidance on coping with life after a stroke.

Helpline: 0845 3033 100
Website: www.stroke.org.uk

Waiting.com
A website dedicated to those with a family member in a coma.

Website: www.waiting.com

Winston's Wish
A charity for children whose parent, brother or sister has died. Winston's Wish helps them to rebuild their lives and face the future with hope.

Helpline: 08452 03 04 05
Website: www.winstonswish.org.uk
Organ and tissue donation

Sadly, not all patients will recover from their injury and some may die as a result, despite the best efforts of the medical and nursing team. It may be possible for your relative to be an organ donor after their death. Consideration of organ and tissue donation after death is a normal part of end of life discussions at Sheffield Teaching Hospitals.

Only when all further medical interventions are known to be futile will this option be discussed. A specialist nurse in organ donation will come to talk to you about the possibility of organ donation.

If you are not asked and would like some information, please ask a member of the intensive care team to contact the specialist nurse.

For information about organ donation, visit the NHS Organ Donation website:

www.odt.nhs.uk

To join the NHS Organ Donor register go to:

www.organdonation.nhs.uk

Call 0300 1232323
Text SAVE to 84118

For support contact The Donor Family Network:

www.donorfamilynetwork.co.uk
Call 0845 680 1954
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