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Traumatic Brain Injury

An Information Manual

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Head injury patients at St George's Hospital

Patients with head injuries at St George's are cared for by doctors from a variety of medical specialities including neurosurgery, general surgery and orthopaedics, depending on the nature of their injuries. As patients begin to recover early rehabilitation can start. This process is co-ordinated by a team of head injury specialists from several different professions.

The head injury team consists of:

- Consultant Neurologist
- Neurology Registrar
- Head Injury Co-ordinator
- Senior Physiotherapist
- Senior Occupational Therapist
- Senior Speech and Language Therapist
- Clinical Nurse Specialist
- Neuro-Psychologist

Introduction

A traumatic brain injury is overwhelming and frightening both for the person who has suffered the injury and their carers. Trying to understand this complex condition can be confusing.

Everyone deals with the crisis in his or her own way. However, basic information can help.

This manual has been written to improve your understanding of brain injury and suggests points to consider at each stage of recovery.

The information provided here, and the descriptions given of difficulties following brain injury are typical for many people.

However, this does not mean that your relative or friend will experience each and every symptom or problem.

Every brain injury is likely to be different, making it harder to predict the effects on a particular person.

Remember:

- No patient will have all of the problems described in this manual.
- Problems may vary. Many may be mild but some can be more severe.
- Many problems improve with time and rehabilitation.
- It can take weeks, months or years to gain a clear picture of someone's potential for recovery.

Early Stages – What to Expect

Immediate Care

In the first stages of recovery the immediate care may be delivered in the Intensive Care Unit (ICU). This is where the brain-injured person is usually being looked after on a one to one basis. From there they will be moved to a ward appropriate to their injuries. If St George's Hospital is not their local hospital, then they are likely to be repatriated to their local trust once stable. When they are ready they may then be discharged home for further rehabilitation, or alternatively to another hospital for inpatient rehabilitation.

Questions to Ask at This Stage

- Who is the doctor responsible for treatment?
- What is the plan of care?
- Are there any operations planned and what are they for?
- Who are the therapists involved?

Actions to Consider at This Point

- Make contact with your relative/friend's employer to let them know what has happened.
- Ask the nurse for a sick note.
- If you need advice or information about claiming benefits and financial problems ask to see the hospital social worker.
- If appropriate, contact a solicitor specialising in personal injury. Further information regarding this can be found later in the manual.
- Start keeping a diary of your relative/friend's progress and a list of expenses (including receipts). This will be helpful for you to look back on and may also be useful to your solicitor if appropriate.

Looking After Yourself

Through all stages of recovery it is important to keep up your emotional and physical strength by not ignoring your own needs.

Make Sure You:

- Get enough rest and sleep
- Eat and drink as normally as possible
- Share your problems and worries by talking to people
- If friends offer help, accept it, being specific about what you would like them to do
- Arrange for one person to be the main contact for information about your relative/friend's progress. Others can contact them for the information they need
- As your relative/friend improves you may feel able to spend time away from the hospital, perhaps taking a day off from visiting.

Medical Terminology

Contusion: A bruise in the brain tissue. A contusion is an area of damaged brain that may swell in the initial phase, causing a rise in intracranial pressure (see below for an explanation of intracranial pressure).

CT scan: Computer Tomography (CT) is where a computer builds an image of a body part from x-rays. This picture shows a slice through that area, like an apple being cut in half. If the head is examined it shows where the brain has been damaged.

Haematoma: Where blood forms a clot that may prevent blood getting to a part of the brain, or cause pressure leading to damage of nerve centres. Neurosurgery may be required; for example to remove the clot or reduce pressure. Investigations/scans are often necessary to assess the extent of the damage.

Haemorrhage: Where there is bleeding within the brain or on its surface

Intracranial Pressure (ICP): This is the pressure inside the skull caused by the brain injury. It can be caused by a haemorrhage, haematoma or bruising of the brain. Stress can also raise the ICP.

ICP Monitoring: To monitor the pressure a thin tube is inserted through the skull to lie on the surface of the brain. The tube is then attached to a monitor.

Management of ICP: The management will depend on what is causing the pressure to be raised. It can mean your relative/friend is put on a ventilator, given drugs or might need surgery.

MRI Scan: Magnetic Resonance Imaging (MRI) uses a computer and a strong magnetic field to examine slices of the body.

Oedema: Swelling. Damaged tissue swells up (as with a twisted ankle) and the brain is no exception. Cerebral oedema (brain swelling) is dangerous because it causes the ICP to rise.

The Function of the Brain

To understand what has happened to the brain-injured person we need to look at the normal brain.

The brain is part of the central nervous system. This is the most highly developed and important system of the body. The brain controls the body's functions, such as:

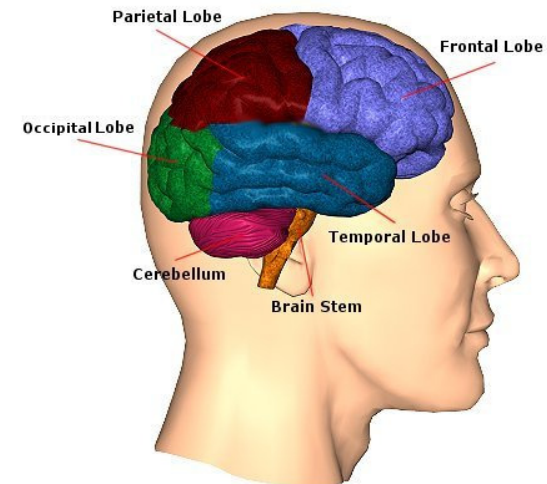
- movement
- speech
- thought
- memory.

It also controls and helps us to identify feelings and emotions which make up our personalities. It allows us to make sense of the world around us and enables us to make decisions.

The brain has two halves (called hemispheres). These are divided into different sections (called lobes) all with separate functions. Each half of the brain controls the movement and feeling in the opposite half of the body. In general the left side also deals with speech (written and spoken word), and the right side of the brain controls the ability to:

- judge distance
- make sense of shapes
- recognise objects and faces.

Towards the front of the brain is the part used in making complex decisions and solving problems.



What happens in a Traumatic Brain Injury?

To start with, a brain injury is caused by trauma (a shock) to the head. However it also includes complications which can follow, such as damage caused by lack of oxygen, and rising pressure and swelling in the brain.

There are two main types of traumatic brain injury – **closed and open**.

Closed Head Injuries

Closed head injuries are the most common type, and are so called because the skull remains intact. These often happen as a result of rapid acceleration (speeding up) or deceleration (slowing down or stopping suddenly), for example when a car hits a brick wall, or a car is hit from behind at traffic lights. The head is rocked back and forth or rotated, and the brain follows the movement of the skull. This causes the billions of nerve fibres which make up the brain to be twisted, stretched and even torn in the process.

The front of the skull has sharp bony ridges with which the brain can also collide, causing more damage. Arteries and veins running through the brain can be damaged, allowing blood to leak.

Open or Penetrating Wounds

These are not so common. In this type of injury the skull is opened and the brain exposed and damaged. This could be due to a bullet wound, or collision with a sharp object. If the damage is limited to one specific area, outcomes can be quite good, even though the accident may have seemed horrific. In many cases, however, this type of injury may be combined with an acceleration type injury as well.

Injury Severity

Coma

Whether it lasts a few seconds or a few weeks, the usual immediate effect of a head injury is a loss of consciousness.

Coma can be described as a state of depressed consciousness where the person is unresponsive to the outside world.

In hospital, while your relative/friend is on a ventilator, they may be given a sedative. This has the effect of reducing their consciousness even further and it allows the person to use as little energy as possible to try and protect the brain from further damage. The medical team will decide when they are ready to have the sedation switched off. You may hear the phrase “wake him/her up”.

Switching off the sedative drugs does not have an immediate effect. It can take up to 48 hours for the drugs to wear off. People do not wake from a coma and say “where am I?” as can be portrayed in films. Your relative/friend may then take days, weeks or even longer to become more responsive or aware. This will be due to the effects of the head injury, not the sedation. The medical and nursing teams will monitor your

relative/friend for signs of responsiveness to different stimulation.

Post Traumatic Amnesia

For a while after a traumatic brain injury, the person may seem to be aware of things around them but is confused and disorientated. This can happen whether or not the person was actually unconscious for any length of time. They are not able to consistently remember everyday things or conversations, and often do or say strange things. They may be restless, agitated or disinhibited (which means they have limited control of certain behaviours). This is called **Post-Traumatic Amnesia (PTA)**, and is a stage through which the person will pass.

The length of PTA and/or coma are important as they give an indication of how severe the injury is and what the long term effects might be. In general, the longer a person is in PTA, the more severe the brain injury, although it is worth noting that **everyone is different**.

The Occupational Therapist conducts a PTA assessment daily. The brain-injured person is said to be “out of PTA” when they have scored full marks for three days in a row. This shows

they are now able to form new memories and retain (keep) new information

What can be done about it?

- Reduce the risk of harm – this may include having a staff member sitting with your friend/relative at all times to prevent them wandering or pulling our tubes for example.
- Try not to force your relative/friend to remember. This should gradually improve with time. They may repeat the same incorrect information over and over again; you can gently correct them, but do not try and force them to retain this.
- Remember the person is not in control of what they are saying or doing, and should not be held responsible for their actions. Your friend/relative will probably have very little memory of this stage once they are out of PTA.
- Try not to get distressed or irritated when with your friend/relative – this can add to their confusion and agitation. The brain is struggling to recover after the injury and too much stimulation should be avoided.
- Take time out for yourself, and share the visiting with others if you can.

Rehabilitation

Rehabilitation is offered to the brain-injured person once they are medically stable. It aims to maximise the person's recovery and to help them to adjust to any difficulties or disabilities they may have.

The type and amount of therapy will depend on your relative/friend's individual needs. The rehabilitation staff will be willing to discuss how things are going with both you and your relative/friend, so don't be afraid to ask. It is useful for you to be aware of therapy aims so that you can encourage your relative/friend outside therapy sessions. Research suggests that patients who make the best recovery are those whose family is actively involved.

The rehabilitation team treating your relative/friend may consist of some, or all, of the following:

- Physiotherapist
- Occupational Therapist
- Speech and Language Therapist
- Neuro Psychologist
- Social Worker
- Dietician
- Doctors and Nurses.

Physiotherapist:

The Physiotherapist may be involved in the very early stages, helping with the management of chest problems and positioning. As your relative/friend recovers, they will aid (facilitate) any movement present and monitor any changes which may occur. The Physiotherapist will carry out an assessment of your relative/friend and plan a treatment programme appropriate to his/her needs. This aims to facilitate activity where possible and help the person achieve as much independent function as possible within their own limits. Quite often people with brain injuries make a good physical recovery.

Occupational Therapist:

Occupational Therapy will help the survivor of brain injury with the everyday problems that they may be experiencing, and to find ways of coping with them. This may involve looking at the way their thinking processes work, (for example memory, concentration, mood) and how they are functioning (e.g. dressing, cooking and leisure activities through to return to work.)

The aim of occupational therapy is to help the brain-injured person to return to being as independent as possible.

Speech and Language Therapist:

The Speech and Language Therapist is involved in all aspects of a person's communication, e.g. verbal expression, understanding what is said, reading or writing, changes in social skills.

These can range from severe communication problems to subtle changes in the way your relative/friend communicates. Speech and Language Therapists will also assess and advise on eating and drinking difficulties if required.

Neuro Psychologist:

The Neuro Psychologist is able to assess and treat cognitive (thinking), behavioural and emotional problems. Your relative/friend may not see him while they are an inpatient at St George's Hospital, but it is worth considering a referral to see him as an outpatient further down the line. Simply ask your GP to make the referral if you feel this would be of benefit.

Social Worker:

Social Workers are skilled in helping families receive the practical help that is needed. This may be on benefits, accommodation, or on counselling on emotions and feelings.

Dietician:

The Dietician is concerned with ensuring that the nutritional (eating) requirements of the person are met, including working with the Speech and Language Therapist where there are swallowing problems.

Nurses:

The nursing team are available to provide 24 hour care for your relative/friend while they are receiving treatment as an in-patient. They will assist with medication, meals, personal care and transfers (getting from one place to another, such as from bed to a chair) if the patient requires help. However, they work with the therapy team to encourage independence, and so will encourage the brain injured person to try to do as much as possible for themselves.

Doctors:

In the early stages the doctors and nurses are involved continuously with your relative/friend's care. During the later stages of rehabilitation, your relative/friend will have less direct contact with medical staff than previously. They will however,

remain under the care of a Consultant during their rehabilitation.

Head Injury Co-ordinator:

The Head Injury Co-ordinator is your link throughout your relatives/friend's stay in St George's Hospital. You will be offered the chance to meet them to discuss your relative's/friend's progress, future plans and any concerns you may have.

Recovery

The time it takes for a brain-injured person to recover varies greatly. The course of recovery depends on many factors, including:

- the area of the brain affected
- the extent of injury
- if there are any complications
- the quality of rehabilitation received
- the person's ability to adapt to changes in circumstances.

In the early stages improvements are noticeable nearly every day but these gradually slow down until progress is less obvious. Recovery can continue for several years. In some cases those injured do not recover to their former level of ability.

Staff working with the brain-injured person will help them set targets about what they want to achieve. These are called goals and they help direct the person's treatment.

Recovery - Summary

The course of recovery can be slow, and depends on:

- the amount of the brain that has been injured
- the area of the brain which has been affected
- the ability of the injured person to adapt to changes in circumstances.

Problems Caused by Brain Injury

The problems caused by brain injury depend on:

- the part of the brain that has been affected
- any complications such as brain swelling or blood clots
- the nature of the injury (closed or open).

Often there are several areas of damage throughout the brain.

This means that the brain as a whole may be less efficient and the person can experience an assortment of difficulties.

The problems which a brain-injured person is likely to encounter can include any one or more of the following:

- physical changes such as loss of movement
- cognitive (thinking) problems for example. problems with memory
- communication difficulties for example. difficulties understanding and speaking
- emotional changes for example depression, disinhibition
- change in social circumstances

Physical Changes

After brain injury, physical disabilities vary from person to person. The time taken for them to recover varies too. Some of the most common problems are discussed in the following pages and some suggestions that may help.

Many people make an excellent physical recovery after a brain injury, which can mean there are few, or no, outwards signs that an injury has occurred. There are often physical problems present that are not always so apparent, but can have a real impact on daily life.

In this section we cover problems with:

- movement, balance and co-ordination
- dyspraxia
- loss of sensation.

Movement, Balance and Co-ordination

One side of the brain affects the movement and co-ordination on the opposite side of the body This means that a person often experiences a weakness or paralysis (hemiplegia) of one side.

The fine co-ordination of the muscles can also be affected, and can mean your friend or relative may have jerky or uncontrolled movement, and may have continuing problems with dexterity even after a period of improvement.

Difficulties with balance can be common after a brain injury. Learning to walk again after a brain injury involves re-learning some of the basic skills developed in childhood.

Contractures are abnormal shortening of muscles that makes it very hard to stretch limbs (arms and/or legs). They can seriously affect posture. Exercises provided by the physiotherapist are essential in helping to overcome this in the early stages. More severe contractures may require the muscle to be covered in a plaster-cast and gradually stretched.

Dyspraxia

Dyspraxia is a disorder of deliberate voluntary actions. This means that the person may not have a problem with actual movement, but with being unable to put movements together when wanting or trying to. For example, a person who cannot bend his elbow when instructed to, but a few minutes later could tell the time by looking at his watch. Although looking at

his watch involved involves bending his elbow, he was not thinking about it and did it automatically.

This kind of problem can often seem like the person is not co-operating. Rehabilitation aims to break actions down into a sequence of activities. These are then practised with cues and prompts (words to help and remind the person). Over time the cues and prompts are needed less and then hopefully not at all.

Loss of Sensation

Different parts of the brain deal with sensations in different parts of the body. After a head injury, people may experience a loss of:

- sight
- hearing
- taste
- smell

This can happen without actually damaging any of the sense organs. If the sensory cortex (an area in the brain) has only

been bruised, a gradual recovery of sensation may be possible.

The occipital lobes at the back of the brain are responsible for processing what we see through our eyes. Damage here can result in either full or partial blindness, or gaps in the visual field. Something called **visual neglect** is covered in the section on cognitive problems.

Summary

For all these problems, it is important to think of the following points:

- give them plenty of time
- always explain clearly what you mean
- always give the same instructions
- always allow them to try to complete a task
- if you are not sure what to do, ask one of the team involved in your relative/friend's care.

Cognitive Changes

Cognition is a word that describes the way a person is able to think, learn and remember.

Different mental abilities are located in different parts of the brain, so a head injury can damage some, but not necessarily all, of these abilities. Often it is a combination of more than one which may affect rehabilitation and prevent the person leading a normal life.

After a brain injury, some problems are common:

- such as memory loss,
- difficulty in making decisions
- unusual behaviour
- confusion.

Cognitive recovery tends to be much slower than physical.

The greatest improvement occurs within the first year after the injury, but smaller improvements may still take place even after many years.

The cognitive system can be divided up into six separate areas:

- memory
- attention and concentration

- speed of information processing
- planning, organising and problem solving (executive functions)
- visuo-spatial and perceptual difficulties.

Memory

Memory is easily damaged by brain injury because there are several different structures within the brain that are involved in:

- processing information
- storing information
- retrieving information.

Damage to those parts of the brain can lead to poor memory.

Short-term memory loss is the most common and troublesome type of memory problem. Examples of this are:

- forgetting what has been just said
- having difficulty in learning a new skill
- repeating the same question over and over
- forgetting people's names

- getting details mixed up
- forgetting a change in routine
- forgetting where things have been placed.

People often think that if you practise enough (a bit like building up muscles) it will improve memory, but unfortunately the brain does not work like this. The therapists will try a variety of strategies to help memory problems to see which works best for each individual.

Attention and Concentration

A reduced concentration span is very common after head injury, as is a reduced ability to pay attention to more than one task at the same time. These problems are usually caused by damage to the frontal lobe.

These problems tend to get worse when the person is tired, stressed or worried. When there are problems with concentration, other skill areas can be affected. It is difficult to follow instructions, plan ahead, be organised and so on, when there is a problem concentrating.

Working in a place with as few distractions as possible can help and, as concentration improves, distractions can be

increased. In this way, someone can slowly learn to concentrate better in every day situations.

Speed of Information Processing

Slowing down the speed at which the brain processes information is common. This results in problems such as:

- not understanding fast speech
- being unable to absorb instructions first time around
- not being able to reply quickly to a question.

To improve the speed of information processing, it is advisable to avoid overload by keeping stimulation down. For example, allow plenty of rest breaks and limit the number of visitors your relative/friend has to two at a time.

Executive Functions - Planning, Organising, Problem Solving

Damage to the frontal lobe can affect these skills, resulting in a subtle set of difficulties which have been called '**Dysexecutive Syndrome**'. This covers problems in making long-term plans, goal setting and setting up steps to achieve objectives. The ability to stand back and take an objective view of a situation

may be lacking, as may the ability to see anything from another person's point of view.

Encouragement and feedback may sometimes help the person change their behaviour. It can help by breaking tasks down into manageable chunks.

Visuo-Spatial and Perceptual Difficulties

Organs such as ears and eyes may be working perfectly well, but the part of the brain which makes sense of incoming information from these sources may not be working properly. This can cause several different types of difficulty.

Problems in judging distances, spatial awareness and orientation can mean, for example, that a person may bump into furniture that they have seen, but have misjudged where it is in relation to themselves.

Sometimes a person will have a visual neglect – a problem where one side of whatever they are looking at is not seen. A person may only eat half the food on their plate, or read only halfway the across the page. The ability to recognise something viewed from a different or unusual angle can be lost. This can also apply to sounds as well as vision.

Summary

To Help Them to Concentrate

- Make sure they are in a quiet room, if they are trying to do something.
- Be patient and help them where necessary
- Attempt only one task at a time
- Encourage them to take regular rests.

To Help Them to Remember

- Give them time to remember on their own
- Be patient
- Encourage them to use a diary/schedule
- Speak about what is done each day by using the diary.

To Help Them to Make Decisions and Solve Problems

- Limit their choices
- Give them plenty of time
- Give them help when necessary
- Tell them when they have done well

Communication and Swallowing

Communication:

Some brain-injured people may experience difficulties with communication. There are many different types of speech and language disorders and the extent to which the brain-injured person is affected can vary greatly from person to person.

They may have difficulties with:

- understanding speech, for example, difficulties following conversation and commands
- expression, for example, difficulties finding the right word or name or using the wrong word. The speech may sound confused, disorganised or repetitive
- difficulties with reading and writing
- difficulties articulating words, for example, slurring speech (dysarthria)
- difficulties in the way we communicate, for example, poor eye contact, shifting from topic to topic, rambling or repetitive speech.

Difficulties with memory, concentration, attention and reasoning will also affect communication.

At times the brain-injured person may use rude and offensive language which can be embarrassing. It is best to try and remain calm and show little reaction to this.

A Speech and Language Therapist will assess your relative/friend and advise you on the best way to communicate with them.

Communication problems - Suggestions

- Don't overload the person, use simple sentences
- Switch off distractions
- Stick to one subject at a time
- Don't encourage inappropriate responses such as rude or offensive words, inappropriate laughing or crying – ignoring it may reduce the stress to both you and your relative/friend
- Be patient and calm
- Get advice from a Speech and Language Therapist.

Swallowing:

Dysphagia is a problem affecting the ability to chew and swallow. This can cause choking or malnutrition, and may result in a person being fed using a tube through the nose or directly into the stomach, at least in the short term. The speech and language therapist will work with your friend or relative in order to try and reintroduce food as and when it is safe to do so.

It is very important you do not try and feed your relative/friend against the advice of the speech and language therapist as this can be dangerous and can affect their recovery.

Emotional Changes

These are closely linked to cognitive changes, and can be very upsetting to experience.

One of the most common remarks made by the relative/friend of a brain-injured person is that:

- "He/she isn't the same person that I knew before".
- "He/she flies off the handle at the smallest thing".
- "One minute laughing, the next shouting- losing all control".

Not everyone will experience all of the problems discussed here, and the severity of these problems will vary.

Agitation and Anger

Restlessness, pacing and pulling at tubes often occurs in the early stages after brain injury and is usually a stage through which the patient will pass.

After brain injury, people's personality can change. They can become angry and easily irritated at the slightest thing. These changes in personality can be very difficult to cope with and

require a great deal of understanding. The cause of changes can vary.

- There may be too many distractions and they cannot concentrate.
- They may feel that they are under pressure to make decisions.
- They may feel very frustrated because they cannot complete any tasks.

Often brain-injured people cope with these frustrating situations by lashing out or shouting at the nearest person – that is usually you. Explosive situations can often be avoided if you learn to recognise what has set it off.

- Is it because your relative / friend is tired?
- Do they have a headache?
- Are they anxious?
- Is it too noisy?
- Has their routine been changed, with little warning?
- Are they in an unknown environment, forgetting why they are there?

It can help if you try to remember that it is due to the brain injury and not your relative/friend's fault. However, you should not have to tolerate violence or ongoing verbal abuse.

Suggestions:

If the reason for their change in behaviour is due to something specific, it may then be possible to do something about it, such as:

- Encouraging them to take more rest periods.
 - Reducing your expectations of what they can do.
 - Explaining more clearly what you would like them to do.
 - Giving them more time to complete the task.
 - Ensuring that they have a routine - and discuss any changes to that routine well in advance.
 - Make sure there aren't too many people around. This can be overwhelming.
-

Social Behaviour

Social behaviour is being aware of what is normally acceptable in social settings.

We know what is expected of us, what to say and what not to say, when we are in certain social situations. This is something which we do not really have to think too much about.

Unfortunately the brain-injured person may lose the ability to understand the situation they are in and they can become disinhibited. This means they might be:

- Outspoken
- Over friendly
- Sexually suggestive
- Childish/self-centred.

These are elements of a cognitive-communication problem, and a Speech and Language Therapist may be able to help/advise you.

Suggestions

There are various ways to try to discourage unwanted behaviour. These are:

- Try to ignore it....it may be a way of attracting attention.
- Never laugh at odd behaviour or sexual comments.
- Ask them why they behaved the way they did or why they said such an offensive thing. This helps them to identify unacceptable behaviour.
- Explain clearly what was unacceptable and why, as they may not be able to understand or realise.
- Encourage others to do the same.

- When he/she does behave well - tell them so.
- Try to find something that will make them want to behave well, such as:
 - A cup of tea
 - Watching a TV programme he/she likes
 - Giving them all your attention for half an hour.

(This list could be endless, some work better than others).

Avoid using alcohol or cigarettes as a reward - this brings other health problems.

Lack of Insight

"I can do it, I don't need any help".

"I'm just going to work",

"Where are the car keys? I want to go for a drive".

These are a few comments that a brain-injured person might make. Although you might try your best to get them onto another subject or get them to do something else, they often come back to these ideas.

The problem arises because they are unaware of what their limitations are. If it is something that is not going to cause a problem, it sometimes helps to allow them to try. If they fail then you can suggest something that they can do.

Suggestions

- Explain their brain injury to them again.
 - This explanation should always be the same (use the same words to explain it).
 - Repeat it often, to help them understand.
 - After a while you can ask them why they think that it is no longer possible for them to do what they want to do.
- Emphasise what it **is** possible for them to do.

It is very important though that they are not allowed to try things that could endanger their life or others' lives,

Depression

Depression often results after brain injury. This can become more obvious when your relative/friend comes home from hospital. The symptoms of depression are:

- lack of interest in eating or over-eating/drinking/smoking
- not caring what they look like
- unable to sleep at night
- continually feeling sorry for themselves
- having no confidence in themselves.

The reason for this may be that they are only now coming to terms with the many changes to their life since the accident, such as:

- they may no longer be the main earner
- they are not in charge of the house
- their friends don't visit as often
- nothing seems to be getting better.

Suggestions

- Encourage friends to come and visit, but first explain to them the changes that have taken place so that they know what to expect.
- Encourage your relative/friend to do small jobs about the house.
- Involve them in the running of the house as much as possible, and in family decisions.
- It is important to talk about the way they feel and not just ignore it.
- Discourage him/her from over eating/drinking/smoking.
- Ask advice from the team.

If you are seriously worried about your relative/friend being very depressed, it is important to contact your GP immediately.

Other Effects

Tiredness (Fatigue)

Fatigue after head injury can be one of the most limiting symptoms because it affects everything a person does. Energy stores are easily depleted (run down), and it can take a long time to build up the reserves again. By pushing themselves too hard a head injured person can exhaust the supply of energy, so it is important to recognise the early signs of fatigue and to rest.

Headaches

Around a quarter of people with severe head injuries continue to suffer from headaches two years after the accident. The effects range from mild, occasional inconvenience to nearly total incapacitation (not being able to do anything). These headaches are generally aggravated by stress, or by trying to 'do too much'.

Headaches can be helped by:

- a stress management programme
- the same medication as is used for migraine treatment
- muscle relaxation
- acupuncture.

Discuss this with your GP for further information on discharge, or discuss it with the ward staff if you are still in hospital.

Bladder and Bowel Incontinence

Continence is both:

- a cognitive skill since the subtle signs that a person needs to use the toilet must be recognised
- a physical skill, in that the person needs to be able to act on the signs.

After a head injury, a number of basic skills like this need to be relearned.

Other factors affect continence and all need to be taken into account such as:

- medication
- physical disability
- communication difficulties
- embarrassment.

If incontinence continues once physical problems have been overcome, a behaviour modification programme may help.

This can be worked out with the help of nursing staff, or a clinical psychologist for more severe problems.

Changes in Social Circumstance

70 to 80% of people who suffer from brain injury are men, between the ages of 20 and 45. They may be married, or in a relationship, and the main earner of the family. This can affect the income of the family.

This means there may be less money coming into the house which can only increase your worry more. It is extremely important to get help to sort out finances as soon as possible. Speak to a social worker as soon as possible. If you are paying a mortgage, discuss the situation early on with your building society or bank.

If the brain-injury survivor is claiming compensation, and if this claim has good prospects of success, then your solicitor may be able to obtain an interim payment from the Court before the case is finally settled.

There will be more information on this in the section on "Benefits".

Effects on you and your family

It is not just your relative/friend who has been affected by the brain injury. Your life and the lives of those who are closely involved with them are also changed.

The stages of the family's emotional reaction

- Shock, panic, denial, "Please let him live"
- Relief, elation, denial, "He's going to be fine"
- Hope, "He's still making progress, but it's slow"
- Realisation, anger, depression "He's not getting back to his old self"
- Acceptance, recognition, "Our lives are different now".

There are many, many changes that may occur in your family life following your relative/friend's brain injury. These changes can sometimes feel like too much to cope with, and as a result you may feel:

- Very anxious
- Guilty
- Depressed.

Stress/Anxiety

We all need a certain amount of stress to make sure we respond to certain situations. However, when there is too much stress we find it difficult to work or function properly.

Stress causes tensions to build up, causing your body to react in certain ways. It is important to learn to recognise when you become over-stressed or you could become ill. If you are over anxious and worried, you may experience:

- loss of sleep
- headaches
- high blood pressure
- digestive problems
- excessive sweating
- palpitations (rapid heart beats)
- feeling easily irritated
- being unable to concentrate
- being unable to make simple decisions
- feeling upset at the slightest thing
- crying easily.
- feeling as if you are going crazy
- feeling depressed
- feeling completely alone.

If you recognise these signs, it is important to do something about it.

Some suggestions:

- Try some relaxation exercises or yoga
- Go to a friend's house
- Take some time to be on your own, maybe going for a walk
- If you have children take them away for the day
- Take up a hobby, or join a club.

If you find it is impossible to do any of these things and the feelings of stress are too much to cope with, you may need to seek further help by contacting your GP.

Guilt

There are many reasons why relatives/friends may feel guilty.

It could be that:

- You feel it should have been you that was injured, not the other person
- Your feelings towards your partner may have changed since they appear not to be the same person you knew before

- You feel you should care more
- You feel angry with your relative/friend.

Guilt can add to your anxiety. This then affects how you cope with your brain-injured relative/friend and the rest of your family. Remember, feeling this way just shows that you are absolutely normal.

Suggestions

- Admit to yourself that you feel guilty
 - Tell someone how you are feeling, perhaps a close friend, doctor, minister or priest
 - Attend a support group. You will find that many relatives/friends of the brain-injured feel exactly the same way you do.
-

Depression

Depression can happen at any time after your relative/friend's brain injury. Reasons for feeling depressed might be because:

- You have to change your lifestyle
- You feel there is no hope

- You feel that no-one else understands what you are going through.

You might feel unhappy, confused, or unable to eat, sleep or work. These feelings are natural after what you have come through. What you have to learn to do is to accept what has happened to you, which will take time. If you are finding it impossible to cope with every day living, you probably need to get help from someone who is used to dealing with this natural reaction. It can be useful to discuss how you are feeling with your GP. If appropriate, they can refer you on for further help.

Time for Yourself

To get time on your own, you may have to find someone to look after your relative/friend for short periods. Social Services may be able to help you to find someone to care for your relative/friend while you go out.

It is important that time is spent to explain what brain injury is to anyone who volunteers to look after the brain-injured person. To give you more confidence, it is easier to leave him/her with the 'sitter' in stages. Try leaving your relative /

friend, each time longer than the last time, so that they get used to having someone else in the house.

Suggestions

Introduce the 'sitter' to your relative/friend. Leave them together for a short time, go into another room. Go out to visit a neighbour, return in about 10 minutes. Go to your local shop on your own, return in 20 minutes.

Each time you return:

- Do not make any fuss
- Try to be as relaxed as possible
- Gradually stay out for longer periods.

If this is successful, the time that you have on your own becomes something to look forward to. You can spend time on your own or time with the children if you have any. This could give you the space you need to help you cope better.

Summary

- Your own health is important
- You have to look after yourself
- You must have time on your own
- Spend time with your family - they have needs as well
- Find some one you can talk to
- Share your problems
- Don't give up
- Get help from your Social Work Department.

Return to Work

Returning to work can be difficult for people with brain injury.

The reason for this is mainly due to cognitive, behavioural and personality changes. It can be difficult for the brain-injured person to cope with the many demands that are made on people when at work.

Try to keep the employer well informed about how your friend/relative is getting on. Try to persuade them to keep his/her job open if possible. You can ask your consultant to contact the employer for you.

Not every employer is willing to take on someone who cannot work as before. It may be that the brain-injured person could cope with a less demanding job, perhaps where she/he is well supervised or has a shorter working day.

Before an employer can accept a brain-injured person back on their work force, both employer and the brain-injured person need to understand:

- about brain injury
- what the possible problems are
- what level of help is needed.

The employer may ask for written confirmation from the employee's GP that they can return to work.

Each job centre currently has access to a Disability Employment Advisor (DEA) who specialises in helping disabled people stay in their job or find a new one.

Appointments can be made by telephoning the local job centre.

There are also Vocational Rehabilitation Programmes which aim to get people back into work.

Summary

- Keep the employer well informed about your relative/friend's progress.
- Encourage them to keep the job open.
- Obtain information about the benefits your relative/friend is entitled to.
- Contact your local Disability Employment Advisor at your local job centre for help with work issues

Other Information

Post Traumatic Epilepsy

Seizures (fits) can often occur after severe brain injury.

Epilepsy can occur immediately after the injury or it can occur months or years after the injury. Seizures often involve jerky movements of one part of the body or the whole body can be affected.

If a brain-injured person does develop epilepsy, this can sometimes be controlled by drugs. The doctor will advise on the recommended dose. When on drugs for epilepsy it is advisable to avoid alcohol. Ask your doctor for advice about this. Potentially hazardous activities should be supervised, such as swimming or climbing ladders.

Further information be required can be obtained from the GP, Consultant or by contacting the Epilepsy Association.

It is a legal requirement that the DVLA is informed if epilepsy is diagnosed in a person with a driving license. This may result in statutory loss of licence for a period of time, depending on whether your relative/friend has a fit. In certain circumstances some people who become unable to drive may find help with

getting to/from work via the Access to Work Scheme; contact telephone 020 8426 3110 or via the local job centre for further details.

Driving

There is a legal obligation to inform the DVLA if a license holder has sustained a serious injury (not just epilepsy related) which can impair the ability to drive. This should be done without delay. The address for the DVLA can be found at the end of the handbook in the Contacts section.

The DVLA will make a judgement about if and when a person who has sustained a brain injury should resume driving. They may ask for reports from your relative/friend's doctors before making a decision. This is in the interest of all road users.

If a person is unable to drive, in certain circumstances they may be able to get help with getting to/from work via the Access to Work Scheme; contact telephone 020 8426 3110 or via the local job centre for further details. This can be discussed with a member of the team.

Fitness

After brain injury, the person's whole life changes and often they have a lot of spare time.

Very quickly they can become bored and disinterested. Often the brain-injured person is unwilling to take part in any sort of activity due to lack of motivation. For some people benefits can be gained by carrying out regular exercise. Not only does it prevent increase in weight but it can help to encourage the brain injured person to concentrate better. Taking part in a sporting activity may also help improve the way they behave in company.

Activities such as swimming, walking, snooker and bowling may be appropriate. Discuss this with the professionals involved in your care. In general, contact sports, such as football and rugby should be avoided, especially in the early stages of recovery.

Drugs and Alcohol

After a head injury, the effects of alcohol are greater. It will not take much for your relative/friend to get drunk. It is important for them to drink less alcohol or better still not to drink alcohol

at all. Low alcohol drinks may be a solution. Remember – many medicines **do not** mix well with alcohol

The use of non-prescription (street) drugs can seriously impair recovery from a brain injury, as they affect the brain's ability to learn new skills.

Look After Yourself

It is easy to be so busy looking after the brain-injured person, as well as doing your other chores, that you can forget to look after yourself.

Consider what you eat. It is only too easy to keep yourself going by eating biscuits and crisps. Make use of convenience food, such as frozen vegetables, pre-prepared meals, tinned soups and puddings. Take time to eat and enjoy your meals. Treat yourself to a meal out with friends.

You may find it beneficial to take regular exercise. Activities such as aerobics, swimming or yoga are ideal as they provide you with exercise and relaxation.

Joining a club might encourage you to do exercise more often, especially when you cannot really be bothered.

Legal Matters

Compensation

Compensation will probably be the last thing on your mind when your relative/friend is in hospital. However once the critical stage is over, and they are more stable you start to think about the future:

- will they get back to work?
- will they be able to live independently?

As soon as possible you should try and find a specialist solicitor who can help you.

Not everyone will be able to make a claim, as compensation depends on the way the injury happened. If the accident was caused through a road traffic collision, at work or through criminal assault, it is very important to consider the possibilities of making a claim.

Claiming for compensation can be very complicated, and it is important that you find a solicitor who specialises in traumatic brain injury – a comprehensive list of specialist solicitors is available on the Headway website

Claims for compensation for brain injury can commonly take three to five years and in some cases longer. The reason for this is that it is important to establish how your relative/friend's brain injury is going to affect their future and to assess all future needs. You should not expect the case to be settled quickly - **indeed, it is unlikely that a fast settlement would be in your relative/friend's best interests.** Delaying the settlement of your claim should not prevent your solicitor from obtaining an interim payment for you in most cases.

Why Bother with Compensation?

Compensation can help to make up for the financial loss or additional cost resulting from traumatic brain injury.

The money may be useful for:

- If your relative/friend is unable to return to their job, or has to return to a less well-paid job
- If it is necessary for someone to look after him/her so that you can go back to work yourself
- To help pay for private rehabilitation, or training outside of the NHS
- To help pay for extra costs, such as adaptations to the house.

Costs

Do not worry about legal costs. Your chosen solicitor should offer a free initial consultation. They will then advise you on legal costs and how to fund them. Some solicitors offer a “no win, no fee” option.

Benefits from the department of Social Security – an Outline

These are constantly being reviewed and updated. The information below is correct at the time of writing, however for full information and advice contact your local Benefits Agency (previously known as the DSS office) or the Benefits Enquiry Line on Free Phone 0800 882200, or online at <http://www.direct.gov.uk/en/MoneyTaxAndBenefits/index.htm>. You can also ask your social worker.

Statutory Sick Pay

This is paid, via the employer, for 28 days to people in employment when they become sick. Some people may receive Occupational Sick Pay as well depending on their terms of employment. Send sick notes to employers.

Employment and Support Allowance

Employment and Support Allowance offers you personalised support and financial help, so that you can do appropriate work, if you are able to. It also gives you access to a specially trained personal adviser and a wide range of further services including employment, training and condition management

support, to help you manage and cope with your illness or disability at work

Disability Living Allowance

Disability Living Allowance (DLA) is a tax-free benefit for children and adults who need help with personal care or have walking difficulties because they are physically or mentally disabled. You can get Disability Living Allowance whether or not you work and it isn't usually affected by any savings or income you may have.

Attendance Allowance

Attendance Allowance (AA) is a tax-free benefit you may get if you're aged 65 or over and need help with personal care because you're physically or mentally disabled. Attendance Allowance isn't usually affected by any savings or income you may have.

Direct Payments for Care and Services

Some people, who have been assessed as needing help from Social Services, may like to arrange and pay for their own care, rather than receiving carers directly from the council. Direct Payments enable this to happen at no further cost to the

person requiring help. A person must be able to give their consent to getting direct payments and manage them, even if they need daily help to do this.

Incapacity Benefits

If you can't work because of illness or disability you may be able to get Incapacity Benefit, a weekly payment for people under State Pension age. You will need to check the eligibility criteria for this, either online or by phone – the contact details are at the start of this section.

Industrial Injuries Disablement Benefit

You may be able to get Industrial Injuries Disablement Benefit if you are ill or disabled because of an accident or event that happened at work or in connection with work. The amount you may get depends on your individual circumstances. You cannot claim Industrial Injuries Disablement Benefit if you were self-employed in work that caused your accident.

Disabled Facilities Grant

This is a local council grant to help towards the cost of adapting your home to enable you to continue to live there. A grant is paid where the council considers the changes necessary to meet your needs, and is happy that the work is reasonable and practical. Types of work might include widening doors and installing ramps, or providing/improving access to rooms and facilities - for example, by installing a stair lift or providing a downstairs bathroom.

Blue Badge Scheme

The Blue Badge Scheme is an important service for people with severe mobility problems that enables badge holders to park for free, close to where they need to go.

Carer Benefits

Carer's Allowance

This is a benefit to help people who look after someone who is disabled. You don't have to be related to, or live with, the person you care for, but you must be over 16 and spend at least 35 hours per week caring for that person.

Home Responsibilities Protection

The Home Responsibilities Protection scheme can help you protect your entitlement to State Pension if you're not working or your earnings are low because you are a carer. Go online or call for further information.

Support Services

Day-to-day support services could allow you to go to work or take a break during the day. They could also help you when the person you care for needs specialist care or a substantial amount of looking after. Although you access their services through your local authority, social services may work with other agencies to provide different types of support - for example, charities and private sector organisations.

There is a lot further information and advice on the website (www.direct.gov.uk) or if you prefer call the number provided at the start of this section.

Support Groups/Contacts

Benefits Enquiry Line

Freephone 0800 882200

British Brain and Spine Foundation

Tel: 020 7404 6106

Email: bb.sf@virgin.net

Website: www.brainandspine.org.uk

British Epilepsy Association

Tel: 0113 243 9393

Helpline: Freephone 0800 30 90 30

Email: epilepsy@bea.org.uk

Website: www.epilepsy.org.uk

The Brain and Spinal Cord Injury Charity (BASIC)

Tel: 0870 750 0000

Website: www.basiccharity.org.uk

Carers National Association

Tel: 0808 808 7777

Website: www.carersuk.org.uk

CRUSE

Bereavement Counselling

Tel: 0844 477 9400

Email: helpline@cruse.org.uk

Website: www.crusebereavementcare.org.uk

Department of Employment and Learning

Website: www.nidirect.gov.uk

Driver and Vehicle Licensing Agency (DVLA)

If you need to tell the DVLA about a medical condition before starting to drive again

Tel: 0300 790 6806

Website:

www.direct.gov.uk/DrivingAndMedicalConditions

Headway – The Brain Injury Association

Tel: 0808 800 2244

Website: www.headway.org.uk

Headway South-West London

Tel: 07722 861 642

Website: www.headwayswLondon.org.uk

Relate

Relationship Counselling

Tel: 0300 100 1234

Website: www.relate.org.uk

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