

TRAUMATIC BRAIN INJURIES

(HEAD INJURIES)

*A booklet for the Traumatic Brain Injured (TBI) survivor
and his/her family and friends*

*Intended for providing information and support during the acute stage –
with some pointers for the long-term "road" ahead.*

This information is general in nature. It is important to keep in mind that the circumstances differ from person to person, from injury to injury and from hospital to hospital.

When a Traumatic Brain Injury (TBI), otherwise known as a Head Injury (HI) happens to someone, it could be an event which causes anxiety and distress among family members and friends.

Recovery from TBI is often a lifelong process for both the TBI individual and his/her family members.

WHAT IS A TBI ?

A traumatic brain injury means an injury that is the result of an outside force. A traumatic injury can be an open or closed injury - the difference between the two being whether the skull has been penetrated or not.

IN THE INTENSIVE CARE UNIT !

A person with a TBI is usually admitted to the Intensive Care Unit (ICU). The role of the neurosurgeon and intensive care personnel is to try to prevent damage to cells that are still viable. They medically stabilize the survivor.

While a survivor is in ICU, he/she may

- have a Tracheotomy – an opening in the windpipe to allow breathing and suctioning of the lungs
- be on a Ventilator – to assist breathing
- have a Breathing Tube or Mask – that fits over the nose, to improve quality of oxygen intake
- have an Intravenous Line in the arm, chest, leg or neck – to administer fluids, nutrients and medicine
- have a Feeding Tube – either in the nose or abdomen
- have a Bladder Catheter – to obtain urine out of the bladder
- have a Chest Tube – for draining blood or air
- have an Intracranial Pressure Screw – to monitor brain swelling
- wear a Blood Pressure Cuff – around the arm, to measure blood pressure
- have a Saturation Probe – a device on a finger to measure oxygen levels

WHO ARE ALL THESE PROFESSIONALS ?

- A Neurosurgeon is a doctor who has studied brain surgery
- Nurses or Sisters care for the survivor and have a lot of knowledge of and experience in neurosurgical nursing
- The Physiotherapist joins the nurses in caring for the patients' lungs, keep the joints and muscles mobile and inhibit abnormal movements
- The Occupational Therapist is involved in all the activities of daily life
- The Speech -Language-Hearing Therapist is the person who is trained to treat problems in speech and language and to facilitate communication
- The Social Worker is there to help family members and patients to cope with the emotional trauma

Depending on the nature of the injury, other doctors or professionals can also be involved with the TBI person e.g. the Ophthalmologist, Psychologist/Neuropsychologist, Psychiatrist, people involved with biokinetics and brain gym.

ARE THERE LEVELS OF CONSCIOUSNESS ?

Stages of recovery include

- Comatose / Non-responsive
- Comatose / Responsive
- Conscious / Non-responsive
- Conscious / Responsive
- Agitated / Confused
- Rude / Confused
- Appropriate / Confused
- Automatic / Appropriate
- Capable / Appropriate

WHAT CAN WE DO ?

Family and friends can make a large contribution in the area of stimulation and may follow one or more of these suggestions (in consultation with the Professionals):

- Talk to the survivor in a calm, slow, normal voice
- Touch the survivor while you are talking to him/her
- Tell him/her about things that are happening at home, about other relatives and friends, about the cat and the dog, or even a joke
- Introduce him/her to the nurses and other personnel
- Make sure you meet his/her doctors and other therapists
- Communication is less confusing when one or two close family members talk to the TBI survivor
- Reassure the survivor
- Don't discuss the survivor's condition as if he/she is not there
- Stimulate the survivor when he/she is awake, but not for longer than 5-10 minutes at a time
- Continue to show the survivor love and affection
- At intervals, play music that the survivor likes (starting with 5-10 minutes at a time)
- Ask the survivor to obey simple commands like "lift your arm" or "close your eyes"
- Every time you see the survivor, say who you are, what day and date it is, where he/she is, how he/she was injured and that he/she is recovering
- Limit the number of visitors and explain to them to speak calmly
- Talk to the survivor about familiar people and things
- Bring the photo album and show photos of the people you're discussing.
- Help the survivor to start doing the routine activities of caring for him/her self, like washing his/her own face with a face cloth
- Ask the survivor questions about his/her past, which can be answered with a "yes" or "no", allowing enough time for him/her to answer
- Keep a diary of the survivor's progress
- You may initially feel afraid to leave the hospital. Learn to ask for and accept help from friends and family.
- Not everyone experiences the same feelings at the same time. Some family members may be upset by the attitudes of others. Do not be ashamed to discuss these conflicts with the Social Worker.

WHY SO AGITATED ?

It is normal for a survivor to go through an Confused / Agitated phase when he/she may be aggressive and too active when not asleep. He/she cannot be held responsible for his behaviour and may swear a great deal at this stage.

Suggestions for the family dealing with the confused / agitated survivor (in consultation with the professionals):

- This stage is a sign of improvement, not a personality change
- Limit visitors to one at a time. Don't do too many things at once – this leads to more confusion
- Point out unacceptable and inaccurate reactions to him without making a fuss. Don't argue with him/her – rather change the subject.
- Don't ever scold, threaten or humiliate the survivor
- Don't ignore the survivor or walk away when he/she gets upset
- Don't take childish behaviour personally
- Don't forget about the other members of your family – they too need your attention
- Tears and screams are a generalised reaction to stimuli. Don't label the survivor as stubborn or uncooperative.

THINGS SEEM SO NORMAL, BUT...

During the Automatic / Appropriate phase, the survivor seems normal, but can't remember everything. He/she has poor judgement and problem-solving ability, cannot plan the future realistically and has very limited insight into his/her problems. He/she can take in new information, but more slowly and with difficulty. He/she can take part in and enjoy more recreational and social events.

Suggestions for the family and friends (as always, in consultation with the professionals):

- Encourage the survivor to write in his/her diary
- It is important to ensure that your words, actions and movements are clear
- NB: Don't allow the survivor to drive a car or motorbike
- The survivor may still react slowly to questions
- He/she may behave in a socially unacceptable way – give feedback in a calm, matter-of-fact manner

NOW THIS IS BETTER !

Memory of information from the past during the Capable / Appropriate phase is good, but recent memories are still vague. He/she can learn a few new facts, although not rapidly.

Suggestions for the family and friends (in consultation with the Professionals, of course):

- Allow the survivor to take responsibility for specific tasks. If h/she needs regular medication, when appropriate, it should be his/her own responsibility to take the correct dose at the right time
- The survivor should have a stable daily routine to make him/her feel safe in his/her environment
- Try to measure improvement since the accident, rather than to compare the survivor to how he/she was. LEARN TO APPRECIATE THE NEW PERSON!
- Use of alcohol should be discouraged

STILL SOME BEHAVIOURAL AND EMOTIONAL PROBLEMS, THOUGH...

The behaviour of the survivor at this stage may include one or more of the following :

- Intellectual problems
- Lowered level of consciousness and psychological blunting
- Outbursts of rage and irritation
- Limited emotional control
- Apathy
- Lack of insight and denial of disability
- Self-centeredness and egocentricity

WHAT ABOUT THE COGNITIVE PROBLEMS ?

A range of cognitive problems may arise including:

- Concentration problems
- Confusion
- Inability to carry out a plan of action
- Memory loss/ short term memory problems
- Poor judgement and abstract reasoning
- Inability to learn new tasks and skills
- Impulsiveness and loss of inhibitions
- Lower alcohol tolerance

LET'S IMPROVE COMMUNICATION

Ideally the family and survivor should work closely with a Speech - Language - Hearing Therapist who will assist them in making communication as efficient and easy as possible.

Tips to improve speech and communication may include the following:

- Many patients may struggle to understand the spoken and written word, so try and ensure that the patient is concentrating before speaking. A communication chart with photos or a book may help the TBI patient understand at this stage of his recovery.
- In the more severe cases, talk slowly and clearly so that the patient can understand you.
- In more severe cases, use drawings or a communication board so that the patient can understand what you are talking about.
- Always remember to talk to the TBI patient with the dignity and respect that he deserves.

PHYSICAL DIFFICULTIES

These may include difficulties with walking and balance; spasticity of the arms and legs; as well as a range of visual difficulties.

REACTION OF FAMILY MEMBERS TO BRAIN INJURY

The reaction of the family to brain injury can be compared to the grieving process. The initial reaction is shock and disbelief. When the crisis has passed and the survivor begins to awaken from coma, the family has to handle the unique circumstances associated with the early recovery of the brain-injured survivor. Discharge from hospital is usually a sign that the crisis is past and the support from family and friends gradually lessens. When outpatient treatment is stopped, the family begins to realise that some aspects of the injury are permanent. This frequently leads to depression of family members, who with appropriate support and counseling will hopefully accept the fact that recovery from TBI is a lifelong process.

WHERE DO WE TURN FOR SUPPORT ?

There is always hope after a brain injury. With the support of family and friends, the relevant Professionals and support groups, as well as a strong belief, great progress is possible.

There are many success stories of TBI survivors in South Africa. These include :

- a survivor who completed a Doctorate in Transport Economics after injury
- a survivor who was in coma for 7 months, participated in a Provincial Chess Tournament, completed a Psychology degree and Advanced Diploma, is a motivational speaker and is busy with further studies
- a survivor who participated in the SA Biathlon Championships

Support groups normally consist of people who have been involved, in one way or another, with the traumatic experience of TBI. Such groups can give support to the survivor, family and friends.

Sometimes a TBI survivor has no physical deficiencies and the difficulties experienced by such a person are not easily noticeable to other people. This person may gain a lot from joining a support group, where he/she can meet others who experience the same difficulties and needs no longer feel alone.

Contact **BIG** (the **B**rain **I**njury **G**roup) at **0867 222 100** for support group contact information.

The Internet is a powerful source of information. Pay a visit to some of the following sites (many more exist):

- <http://www.gomemory.co.za/BIG>
- <http://www.tbinet.org/>
- <http://www.tbichat.org/>
- <http://community.webtv.net/bjscloset/TraumaticBrainInjury>
- <http://www.med.harvard.edu/AANLIB/home.html>
- http://www.uke.uni-hamburg.de/institute/imdm/idv/gallery/early_works2.en.html
- www.amazon.com/exec/obidos/ISBN=0895297914/centreforneuroskA
- www.amazon.com/exec/obidos/ISBN=1565938275/centreforneuroskA
- <http://www.neuroskills.com/~cns/tbi/vision.html>

WE NEED FINANCIAL ASSISTANCE

Due to a long recovery period, it may be necessary to apply for a Temporary Disability Pension. Contact The Department of Health and Welfare for further information.

Most of the information used in this booklet is from a publication drawn up by the Neuro Department at Pretoria Academic Hospital and the Speech, Voice and Hearing Clinic at the Department of Communication Pathology, University of Pretoria . We thank them for the use of their information.