If a member of the family or a close friend has had a serious trauma and sustained injury to the brain this information may help you to understand what is going on.

What Is Happening?
This is a challenging time because you will need to make decisions, understand difficult technical information and also maintain the threads of your own family life.

The hospital system, like most institutions, may seem impersonal. You may feel overwhelmed by advice. The language used by hospital staff may be difficult to understand and you may not be able to absorb all the information. Keep asking if information is unclear.

Injuries and Treatment
The acute phase of Traumatic Brain Injury (TBI) includes emergency care and stabilisation. A number of emergency and medical staff care for the patient at this point, and may include surgeons, neurosurgeons, neurosurgical registrars, anaesthetists, intensive care specialists and nurses. If the person also has a spinal injury he/she may be placed in a hard collar to prevent further injury to the spine.

Stabilisation
At first it is not easy to know how much damage has been done. The emergency department’s job is to make a diagnosis, stabilise the patient’s condition and arrange appropriate treatment. This includes helping with breathing and perhaps using a ventilator. The staff will also treat secondary problems such as swelling. They will also ensure that oxygen to the brain and blood circulation is maintained.

CT Brain Scan
The patient will have many x-rays and tests. One of the most important is the CT scan which is a series of x-rays taken at different levels of the brain. This is done to determine the nature of the injury, note any changes and also to see if surgery is needed. Medical therapy cannot mend the destroyed brain cells as this is irreversible, but the brain may learn new ways of processing information.

Brain Swelling (Cerebral Oedema)
The brain fits inside the skull with little space to spare. If it continually swells, pressure inside the skull rises and the brain is compressed, which can cause further damage away from the original site of injury.
Controlling Brain Swelling

The pressure within the skull is measured to estimate the amount of brain swelling. Treatment includes drugs which sedate the patient and reduce the swelling. A ventilator is used to assist with breathing.

Intensive Care Unit (ICU)

Patients are admitted to the Intensive Care Unit (ICU) if they require help with breathing or special drugs. Each patient has their own nurse and their condition is monitored 24 hours a day. The patient is attached to numerous tubes and machines to sustain life.

They may be unconscious and/or heavily sedated. Their eyes may be covered with eye pads to keep them closed and to stop them from drying out. A ventilator assisting their breathing may be attached to a tube in their nose, mouth or throat. Their hair may have been partly shaved during the operation. They may perspire excessively and be unable to speak. Family and friends can visit, but it is advisable to keep visitors to a reasonable number. You should talk quietly to the patient and behave as if he/she were conscious. When their condition is stable, patients with a brain injury are sent to a ward.

Visiting the Patient

The machinery in the ICU may seem frightening at first. Ask the nurse to explain it. Opinion is divided as to whether young children should see a severely injured person and families must make up their own minds about this. If death is a possibility, coming to terms with it may be easier if the child sees the patient, but if children do visit they should be prepared beforehand.
Neurosurgical Ward
This ward specialises in patients with a brain injury. Staff includes nurses with special training in spinal and brain injury, a neuro-physiotherapist, occupational therapist, dietician, speech pathologist and a social worker.

Coming out of Coma
When patients are coming out of a coma, they open their eyes and track people round the room. The process is slow. They may be increasingly wakeful or attempt to pull out their tubes.

Post Traumatic Amnesia (PTA)
The period of Post Traumatic Amnesia (PTA) includes the phase where the person is emerging from coma. At this time, they may be disinhibited in their actions, and may swear or show inappropriate sexual behaviour. They may be confused, aggressive, noisy, restless or disoriented, and later will not recall most of this period. They may also be unable to cope with noise and need quiet. Visitors should be kept to a minimum. Sometimes the patient is placed in a floor level bed surrounded by padding to reduce stimulation and risk of injury.

Informing the Patient
You may be reluctant to tell the patient anything to upset them especially if someone else’s death has been involved. Talk with the staff as they can often help. It is usually preferable to tell patients any traumatic news, although they may forget what you have told them. Due to the brain injury their reaction may be different and unexpected.

Looking after Yourself
This is an emotional time and it is important to do at least one thing a week that you enjoy, such as seeing a movie, taking a walk or talking to a friend. Make time to communicate with other family members. Accept help.

Who Is In Charge?
It is important to find the right doctor to answer your questions. You also need to know the departments, wards and key nurses providing treatment. In some hospitals, all patients with a brain injury are attached to the neurosurgical unit and cared for by the neurosurgeon. In other hospitals, patients with multiple injuries will be attended by a number of specialists. In cases of bone injury, an orthopaedic surgeon will be in charge. In the ICU, the patient is under the care of the intensive care physician. If you have difficulty contacting a doctor, the nursing staff or ward clerk will find them for you. Don’t be hesitant about asking. Another good contact is the Clinical Service Coordinator who is highly qualified and usually on duty on the 8am – 4pm shift. Social workers can also be helpful.

Waiting for The Prognosis
Understandably you will want to know the prognosis as soon as possible. You are entitled to clear, precise and timely information and have every right to ask questions, express your viewpoint and expect good care.
Sometimes staff will say, ‘There’s nothing more we can do’, ‘This is as much information as you can expect’ or ‘We don’t know’. These are honest answers because predicting the future for a person with TBI is impossible.

The condition of the patient can change rapidly and doctors are usually cautious about early prognosis. Other factors that make prediction of outcome more difficult are the patient’s previous physical and mental health, and whether he or she was drinking alcohol at the time of the accident.

The most appropriate person to ask in this acute stage is the neurosurgeon. A written report about the person’s condition is useful to take away and study.

**Understanding Medical Information**

Understanding the language of medicine is hard and even more so when someone is in shock. The medical staff would prefer you to ask 50 times rather than not understand. If you want privacy, ask if you can go into a quiet room. It is a good idea to appoint one or two people as family spokespersons to avoid any misunderstanding which can occur when too many people ask questions.

**Hospital Support Services**

There are many support services that you can use while you are visiting the hospital. For example, the social work department may be able to arrange emergency child care and parking concessions.

Hospitals have many facilities but these vary from one to another. A written letter to authorise you to eat in the cafeteria can be provided in some hospitals. If you need to go to the car at night, ask for a security escort. There may be lounge chairs which can be converted into beds, or a visit to the hospital chapel may be organised if you would like some quiet time. All hospitals have on-call access to chaplains and priests. If you prefer counsel from your own, ask staff to call them.

**Parking**

If you arrived at the hospital in a hurry following an accident and have parked your car illegally, consult the social work department. They may be able to help you to appeal against the fine. Hospitals often has a list of nearby parking facilities and some hospitals issue low cost parking tickets for longer-term visitors – ask about this at the information desk.

**Support and Compensation**

At some stage you will need to think about the financial impact of the injury. It could include loss of earnings, hospital and rehabilitation costs.

**Compensable Patients (Motor Vehicle Accident)**

Patients who have brain injury due to a motor vehicle accident in South Australia may be eligible for compensation for reasonable costs related to medical, ambulance, rehabilitation, nursing and other services. Such patients may have access to rehabilitation and medical care in the private sector. Talk to the social worker at the hospital and contact a solicitor experienced in injury claims. Contact the Brain Injury Network of South Australia Inc. (BINSAN) if you would like assistance.
Non-compensable Patients

Patients whose injury is caused by a sporting accident, fall or assault are not eligible for third party compensation but may have a case in common law if there was a negligent act attached to a person other than themselves.

Advocacy

The best interests of a patient and their family can occasionally be overlooked. This can occur as a result of systems breaking down or poor communication. Hospitals have services to provide you with information and to make decisions. These include:

- Patient Advocate
- Social Work Department
- Patient Liaison Officer or Quality Assurance Officer.

Apart from internal hospital reviews, Brain Injury Network of South Australia Inc. (BINSA) offers advocacy under the National Disability Advocacy Program (NDAP) specifically for those for people with an ABI and their carers affected by an ABI. BINSA advocacy services can provide assistance and support. See BINSA Advocacy pamphlet for more information.

Private Health Insurance

In South Australia, patients who are seriously injured in an accident are automatically taken to a major public acute hospital. If the patient is treated as a public patient, all bed and medical costs will be charged directly to Medicare. Private patients may elect to accept costs and claim against their private benefits. If you or your relative is a private patient, ask about assessment and don’t assume that you are fully covered. Check with your insurance company. Patients with TBI usually stay in an acute hospital for several weeks. Generally private health insurance rebates for hospital bed charges reduce after a period of time.

Planning

You or your family should ask about discharge planning. Patients are entitled to participate in the discharge planning process and to ask about assessments. A member of the family should ensure these have been conducted. Ask for a meeting to be scheduled so that you and if possible, the patient, can attend.

If the patient is being transferred to a rehabilitation centre as an inpatient, check that:

- an assessment is conducted
- the patient’s family has assessed the facility
- the transfer to the rehabilitation centre has been arranged

If the patient is going home, check that:

- transfer requirements are addressed if going to an outpatients service
- medication is provided
- a referral to Disability Services has been made
- home nursing requirements are established and arranged
- domiciliary care is arranged
• if appropriate, in-home support is arranged, such as household help, Meals On Wheels and a home nursing service such as Royal District Nursing Service (RDNS)
• an occupational therapist has arranged all aids and appliances to help you in the home
• counselling is arranged
• respite care is organised
• attendant care is in place
• referral to local rehabilitation services, gym, physiotherapy is organised.

Disability Services (Dept. for Communities and Social Inclusion)

Disability Services provides a state-wide range of specialist community and accommodation services to people with disability, and their families and carers.

Disability Information Service
Ph: 1300 786 117 (local fee only for country callers).
After-hours Service: 08 8372 1414.
Assistance with personal care is included within this service.

103 Fisher Street
Fullarton SA 5063
Ph:  08 8272 1988
Fax:  08 8372 1429
Email: disabilityinfo@dcsi.sa.gov.au

National Relay Service
TTY/Voice
Ph:  133 677
Speak and listen (SSR)
Ph:  1300 555 727