

A guide for families of children with an acquired brain injury



From the Pediatric Acquired Brain Injury Team of McMaster Children's Hospital at Hamilton Health Sciences

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Introduction

At McMaster Children's Hospital, your child will be cared for by a team of health care providers called the **Acquired Brain Injury Team (ABI Team)**.

You and your family are an important part of this team. Together, we will identify your child's needs and design a plan of care to meet those needs.

The health care providers will give you information and support. We believe that you need to know as much as possible about your child's injury so that you will be able to take part in all stages of his or her care.



We welcome your questions at any time.

This book can help you learn:



- about brain injury and the stages of recovery
- how the health care providers on the team can help
- about the tests your child may need
- how you can help your child
- ways to cope or help yourself through this experience
- where you can get more information

Use the blank pages at the end of the booklet to write down your notes and questions about your child's condition and progress.

This may be a stressful time for your family

Having a child who has had an acquired brain injury can be very stressful. You and your family may be feeling many emotions. Family members may have different reactions to this situation.

You and your family may be feeling:

shock and disbelief
 helplessness

fear and anxiety
 relief that your child is alive and recovering

frustration or angerhope

guilt
 loss of your role as a parent

All of these feelings are normal.

Take care of yourself

It is important to take care of yourself, so that you can take care of your child.

- ✓ Take time to rest and eat well.
- ✓ Talk about your feelings with a family member, close friend or a health care provider on the team.
- ✓ Get information and support from other families who have had a similar experience by joining a support group. Or find support online see page 28 for some ideas.
- ✓ If you become depressed or overwhelmed by your feelings, talk with the Social Worker. The Social Worker and other health care providers can support you and help your family learn to cope with this crisis in your lives.



✓ You may have other children who also need support during this time. A Child Life Specialist can help your children cope and understand what is happening to their sibling in the hospital.

What is an acquired brain injury?

An acquired brain injury is damage to the brain that occurs any time after a person is born. There are 2 types of acquired brain injury; traumatic and non-traumatic.

Traumatic Brain Injury

A traumatic brain injury is the result of a physical force from outside the head, such as:

- a fall
- a bicycle or motor vehicle accident
- a sports injury
- an assault

Non-traumatic Brain Injury

A non-traumatic brain injury is the result of a problem other than trauma, such as:

- an infection, such as meningitis or encephalitis
- blocked or interrupted blood flow to the brain, called a stroke
- a swollen or ruptured blood vessel in the brain, called an aneurysm
- not enough oxygen to the brain, such as in near drowning
- a growth in the brain, called a tumour

What type of damage has occurred?

Depending on how the brain was injured, there can be different types of damage.

Damage to the brain	Medical term
Temporary loss of consciousness, confusion and/or vomiting.	concussion
Bruising of the brain.	contusions
Broken skull bones.	skull fractures
Bleeding in or around the brain.	hemorrhage
A build up of blood in the tissue of the brain or surrounding areas.	hematoma
Twisting or tearing of nerves and blood vessels throughout the brain.	diffuse injury
Bruising of the brain opposite from the point of impact.	contrecoup injury
Swelling of the brain. This can occur rapidly after an injury from an increase in blood flow through the brain or in a matter of days from an increase in fluid in the brain.	edema
Increased pressure inside the skull. Too much pressure can cause further brain problems by slowing down blood flow into the head.	intracranial pressure or ICP

Each child's brain injury is unique.

How much damage has occurred?

Health care providers determine the extent of the damage to the brain by:

- knowing how long your child lost consciousness
- giving your child a physical examination
- reviewing the results of tests (described on page 7)
- learning what your child was like before the injury
- seeing what activities your child is able to do
- finding out the amount of memory loss

The extent of the brain injury can be described as mild, moderate or severe. Be aware that your child's symptoms may not fit into just one level.

It may be difficult to determine the extent of damage early on.

Glasgow Coma Scale

We use the Glasgow Coma Scale to assess the extent of the brain injury. This measures the level of consciousness, based on your child's ability to open his or her eyes, and respond with words or movements. The scale ranges from 1 to 15. Lower numbers indicating a more severe injury.

13 to 15	9 to 12	1 to 8
Mild Traumatic Brain Injury	Moderate Traumatic Brain Injury	Severe Traumatic Brain Injury
May cause: loss of consciousness for a few seconds or minutes dizziness headache nausea or vomiting fatigue irritability poor concentration and memory difficulty in learning new tasks or school work	May cause changes in:	 May cause problems with: daily living skills, including eating and tolerating food, toileting and dressing behaviour movement thinking, concentrating and learning speech and communication personality and emotions social skills, relating to family and friends

Each child's symptoms are unique.

What tests will my child need?

Here are some common tests that may be done after a brain injury. The tests that your child needs will depend on the extent of his or her brain injury. It may not be possible for tests to show all of the damage from the brain injury.

Magnetic Resonance Imaging (MRI)

- Powerful magnets and radiowaves are used to create a clear, detailed picture of the brain and spinal cord.
- Sedation or anesthesia may be needed to help your child remain still.

Computerized Axial Tomography (CT Scan)

- A special computer uses x-rays to create a clear, detailed picture.
- No special medical preparation is needed for this test.

Electroencephalogram (EEG)

- This machine records your child's brain electrical activity from electrodes placed on your child's head.
- This test shows how the brain is working and if seizures are likely.

Arteriogram and Angiogram

- These tests show the blood vessels of the brain.
- A special dye, given through an intravenous (IV), shows the blood flowing through the brain.

Intracranial Pressure Monitor

- A device used to measure pressure in the brain.
- To have this monitor, your child will go to the operating room and have a general anesthetic.

What happens when the brain is injured?

The processing of new information may be affected.

• The brain takes longer to understand messages as they come in; what we see, hear and think, and how we move our limbs and body.

Storing new information becomes difficult.

• The brain has a harder time learning new things.

Some information becomes permanently lost.

• The brain loses recent or past memories.

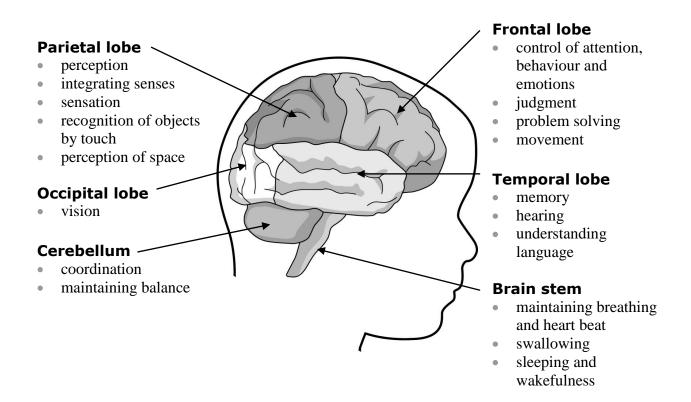
To understand the problems your child is having as a result of the brain injury, it may help to take a closer look at the brain and what it does.

How does the brain work?

The brain is the body's control centre. The brain controls our:

- movements
- thoughts
- feelings
- senses: sight, hearing, touch, taste and smell
- communication: what we say or write to others, how we understand what others are saying, how we read

Each part of the brain has a different job or function.



What does each part of the brain do?



The Cerebral Cortex

The cerebral cortex is made up of 4 lobes (frontal, temporal, parietal, and occipital) and is divided into left and right sides.

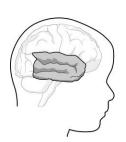
The sides and lobes have different functions.

	What is it responsible for?	What may happen if this part is injured?
Left side	 controlling movements on the right side of the body how we use and understand language 	Difficulty with: • movements on the right side of the body • understanding language • speaking and communicating
Right side	 controlling movements on the left side of the body how we use and interpret what we see in our environment 	 Difficulty with: movements on the left side of the body seeing and interpreting the environment



The Frontal Lobe

What is it responsible for?	What may happen if this part is injured?
 knowing what we are doing within our environment responding to our environment using judgment responding with emotions remembering how to do things thinking before we act controlling inappropriate impulses and behaviour controlling movement of our body parts 	 Difficulty with: simple movement of various body parts planning a series of movements to do a task spontaneous interaction with others flexibility in thinking focusing on a task problem-solving speech and language Mood changes, impulsiveness. Changes in personality and social behaviour.



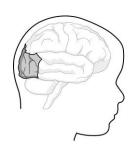
The Temporal Lobe

What is it responsible for?	What may happen if this part is injured?	
 hearing remembering things putting things into categories interpreting what we see talking 	Difficulty with: recognizing faces understanding spoken words language and hearing short-term and long-term memory managing behaviour speaking and communicating	



The Parietal Lobe

What is it responsible for?	What may happen if this part is injured?
 understanding the feeling of touch paying attention to what we are doing controlling movements using different senses together 	Difficulty with: concentrating on more than one thing at a time naming objects locating words for writing reading drawing telling left from right mathematics hand-eye coordination focusing eyes on a task Lack of awareness of certain body parts.



The Occipital Lobe

What is it responsible for?	What may happen if this part is injured?
seeing everything in our environment	Difficulty with: • vision, identifying colours • locating objects in the environment • understanding what is seen • seeing objects or people clearly • recognizing words or pictures • recognizing movement of an object • some aspects of reading and writing



The Brain Stem

What is it responsible for?	What may happen if this part is injured?
 maintaining breathing maintaining heartbeat swallowing reacting to sudden noises and sights controlling sweat, blood pressure, digestion, temperature and level of alertness sleeping 	 Difficulty with: breathing swallowing food or fluids organizing or perceiving the environment sleeping relaying information between the brain and the rest of the body eye movements Dizziness and nausea.



The Cerebellum

What is it responsible for?	What may happen if this part is injured?
 coordinating our movements maintaining balance remembering how to move our body parts 	Difficulty with: coordinating fine movements of arms and hands balance walking reaching out and grabbing objects making quick movements Shakiness or dizziness. Slurred speech.

What happens during recovery?

During recovery, the brain starts to heal. Brain cells may:

- recover on their own, which restores abilities
- make new connections, which allows abilities to be regained
- be damaged, which prevents some abilities from being regained

We use the Rancho Los Amigos Levels of Cognitive Recovery Scale to describe your child's recovery. This scale has eight levels. Your child will change levels at his or her own rate. He or she may also fit into more than one level at a time.

Rancho Los Amigos Scale	
Level I	No response to stimuli. Appears in deep sleep.
Level II	Generalized Response. First reaction may be to deep pain. Has delayed, inconsistent responses.
Level III	Localized Response. Inconsistent responses, but reacts in a more specific manner to stimulus. Might follow simple command "squeeze my hand".
Level IV	Confused, Agitated. Reacts to own inner confusion, fear, disorientation. Excitable behaviour, may appear abusive.
Level V	Non-agitated, Confused, Inappropriate. Usually disoriented. Follows tasks for 2 to 3 minutes, but easily distracted by environment, frustrated.
Level VI	Confused Appropriate. Follows simple directions consistently. Memory and attention increasing. Self-care tasks performed without help.
Level VII	Automatic Appropriate. If physically able, can carry out routine activities. Appears normal. Needs supervision for safety.
Level VIII	Purposeful, Alert, Oriented. May have decreased abilities relative to pre-injury state.

The abilities your child regains will depend on the cause, severity and location of the injury. Recovery may take months or years.

Each child's recovery is unique.

There are 2 main stages in your child's recovery:

- hospital care after the injury
- rehabilitation services

Hospital care after the injury

The goal of this stage is to stabilize your child's condition and prevent further damage or complications. Some early rehabilitation services may also begin at this stage.

At this time, your child may need a lot of care from many types of health care providers. Your child may also need medical equipment such as:

- monitors to check heart rate, breathing, blood pressure, oxygen levels and pressure in the brain
- an intravenous (IV) a thin flexible tube to give fluids and medications into the bloodstream
- a catheter a thin, flexible tube that drains urine from the bladder
- a nasogastric (NG) tube a flexible tube that can put nutritious fluids into the stomach as a way of feeding, or remove stomach fluids with suction to keep the stomach empty
- a ventilator to help with breathing and give oxygen

Your child may be cared for in different areas of the hospital, depending on the level of care he or she needs.

- The Pediatric Critical Care Unit (PCCU) for intensive care and support from medical equipment and technology
- The Children's Ward for general care by staff with training and experience in children's health

Rehabilitation services

Rehabilitation services may be needed to help your child learn and practice everyday activities, and begin to get back into a daily routine. The goal of this stage is to help your child become as independent as possible.

Your child's rehabilitation is like a journey.

It starts in the Pediatric Critical Care Unit, continues on the children's ward and may go on long after your child leaves the hospital.

Types of rehabilitation services

Depending on your child's needs, your child may require many types of rehabilitation services.

Rehabilitation services include:

- Child Life Services
- Modified School Programs
- Neuropsychological Services
- Nursing Services
- Occupational Therapy
- Physiotherapy
- Social Work
- Speech Language Pathology Services

These services may be provided in the hospital, at a rehabilitation facility, at home or in the community.

How will my child's behaviour change during recovery?

During recovery, your child may have a wide variety of behaviours. Although each child's behaviour is different, there are some common behaviours.

Early in recovery, your child may:

- have varying levels of consciousness
- be unfamiliar with surroundings
- have difficulty processing information
- be confused and easily agitated
- have difficulty remembering past and recent events (for example, your child may not remember the event that caused the injury)

By the middle of recovery, your child may:

- behave differently each day
- be more awake and alert at certain times of the day
- get tired easily because the brain or body needs to rest
- show extremes of emotion that you have not seen before
- have a short tolerance for any activity
- continue to have problems remembering recent events

Later in recovery, your child may:

- be tired and not have a lot of energy
- have difficulty in social situations
- change emotions more quickly than you are used to
- do things without thinking about them
- have difficulty paying attention
- have difficulty controlling his or her anger
- have difficulty remembering past and recent events

How much will my child recover?

We will discuss your child's condition and the goals for recovery, but it is difficult to predict the extent of recovery with certainty. Recovery depends on the child, the type of injury and the amount of damage.

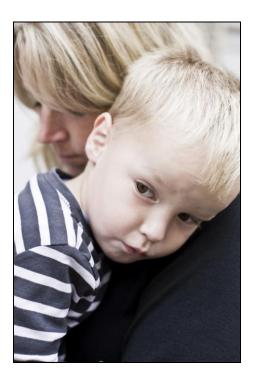
Children with mild injuries may recover completely. With more serious injuries recovery may continue for months or years, and there may be lasting changes.

Some children with severe traumatic brain injury:

- recover enough to do most things for themselves
- need long-term care and follow-up
- may stay in a coma or not survive

Each child's recovery is unique.

Talk with the health care providers if you are concerned about your child's condition or progress.



How can I help my child recover?

You and your family are important members of the health care team. We encourage you to take part in your child's care and therapy.

Your love, attention, support and encouragement will help with your child's recovery.

There are many ways to help your child. Other families with a child who had a brain injury have made these suggestions:

- read to your child
- play his or her favorite music
- show your child pictures of family and friends
- keep a guest book of visitors
- use a calendar to record what happens
- talk to your child in short, clear sentences





You know your child best. You can recognize when your child is feeling well, and when he or she needs some quiet time to rest.

Parents are important members of the health care team.

You can give the health care providers valuable information about the changes in your child's personality, behaviour and learning. Tell the health care team what your child was like before the injury, such as his or her likes and dislikes, favorite toys and school performance.

It may help to keep a journal and write down the changes you notice. When you review your journal, you can see your child's progress.

A guide for families of children with an acquired brain injury

To make informed decisions about your child's care, try to learn as much as you can about:

- your child's brain injury
- the risks and benefits of treatment options and alternatives

Write down your questions as you think of them. The health care providers welcome your questions at any time.

You and your family will be invited to attend family meetings to share information and review your child's progress.

How do the health care providers help my child?

Each child has different needs. Your child's needs will determine which health care providers make up your child's health care team. As you meet each team member, write their name in the following chart.

Team Member	How they help your child
Pediatric Intensivist Name:	 a doctor who specializes in the care of very sick children is responsible for the total care of your child in the Pediatric Critical Care Unit
Pediatric Neurosurgeon Name:	a doctor trained to care for all types of brain problems and perform brain surgery
Developmental Pediatrician Name:	a doctor who specializes in children's development and rehabilitation
Pediatric Neurologist Name:	a doctor with special training and experience in caring for children with brain injuries
Pediatrician	a doctor who specializes in the care of children
Name:	• is responsible for your child's care on the ward
Pediatric Resident	a doctor who is specializing in pediatrics
Name:	• is responsible for your child's day to day care
	works in the hospital on a monthly rotation and is on-call at night and on weekends

Team Member	How they help your child
Child Life Specialist Name:	explains tests and procedures to your child in a child friendly way
rume.	 helps your child express his or her concerns
	 helps your child and family, including siblings, learn to adjust and cope with the changes in your child
	 provides therapeutic play and learning activities
Clinical Dietitian	assesses your child's diet and food preferences
Name:	 helps plan a diet for your child that provides the right amounts of fluid and calories
Neuropsychologist Name:	 assesses your child's thinking and behaviour, including:
Tume.	- attention and concentration
	- learning and memory
	- problem-solving
	- behaviour and interaction with others
	 provides recommendations to help your child return to home and school
Occupational Therapist Name:	 assesses your child's ability to be independent in self-care activities, including feeding and swallowing
	 helps your child improve co-ordination, strength and thinking - using familiar activities or adapting the environment to improve function
Physiotherapist Name:	assesses your child's strength, flexibility and ability to move
	 helps your child improve strength and balance, moving and walking to become more independent

Team Member	How they help your child
Speech Language Pathologist	assesses and treats your child's speech and language skills
Name:	assesses and treats your child's skills related to memory and thinkng
	 helps your child's social communication skills
	 provides other ways to communicate if needed
Ward/Unit Nurse	a registered nurse
Name:	 provides nursing care and assists with co-ordination of daily routine
School Teacher Name:	provides individual or classroom lessons while your child is in hospital
Social Worker	 provides emotional support and counseling
Name:	 helps your family deal with changes in their lives
	gives practical help with finances, legal issues or community referrals
Student Name:	as this is a teaching hospital, you will meet students from all health care fields
	 each student is supervised by a health care professional
Volunteers Name:	trained volunteers can talk, play games and do activities with your child
Tumo.	 during a volunteer's visit, parents have a chance to take a break

How do we work together?

The health care providers will work with you to identify:

- your child's needs
- the goals for care during the acute and rehabilitation phases
- a care plan to help your child reach the goals

Each day, health care providers and family members share information and work together to help your child reach his or her goals. The health care providers communicate with each other in person, or through your child's health record. They welcome your thoughts, suggestions and questions at all times.

At a team meeting you can:

- talk with health care providers
- provide information about your child and family
- take part in setting goals and planning for your child's discharge
- ask questions and get information
- discuss your concerns

What happens when my child is ready to leave the hospital?

Planning for your child's discharge starts soon after admission to the hospital and continues throughout your child's hospital stay. You and your family will take part in making these plans along with members of the health care team.

Depending on your child's condition and needs, your child may:

- Go home with care from your family doctor or pediatrician (no further need for rehabilitation services).
- Go home and continue rehabilitation services. These services may come from your local Children's Treatment Centre, the Community Care Access Centre (CCAC) or private therapy.
- Transfer to another health care facility, such as the Holland Bloorview Kids Rehabilitation Hospital.

If your child goes home, he or she will need a follow-up appointment in the Pediatric Acquired Brain Injury Clinic one month after leaving the hospital.



Returning to activities

Depending on your child's symptoms and needs, he or she may slowly resume daily activities. The doctor will decide if and when it is safe for your child to resume exercise or sports. If your child is well enough, your therapist will help you plan how your child can gradually and safely return to play.



Returning to school

If your child is well enough, he or she may return to school. The occupational therapist and hospital school teacher will work with you and your child's school staff to plan your child's return to school. This will happen gradually, depending on your child's symptoms and need to rest.

If your child has difficulty with learning or tasks at school, an Individual Educational Plan will be developed so everyone will know how to best help your child.

Where can I get more information?

There are many sources of information about brain injury in children. The following pages can give you some ideas. Health care team members may also recommend other resources for you.

Community resources

The Hamilton Family Network

22 Leming Street Hamilton, Ontario L8L 5T3 905-526-7190

www.hamiltonfamilynetwork.com

E-mail: hamiltonfamilynetwork@hwcn.org

The Hamilton Family Network puts parents in touch with another parent who is facing a similar situation. They believe that when parents are informed, supported, and connected to other families who have been there too, they will be better able to define and meet the needs of their children.

Ontario Brain Injury Association

Caregiver Information Support Link 1-800-263-5404 www.obia.on.ca

A charity dedicated to preventing traumatic brain injuries and improving the quality of life for survivors of acquired brain injury, their families and the community with which they interact. Check their website for a local community association.

Internet resources

If you do not have a home computer, you can access the internet from the computer in the Ronald McDonald Room on the 3rd floor of the hospital or at your local public library. Please discuss the information you find on the internet with your child's health care team. Make sure it is accurate, complete, and relevant to your child's needs.

The Ontario Brain Injury Association

www.obia.on.ca

Information and links to pediatric brain injury, family, legal and financial issues. Links to brain injury associations across Ontario.

The Brain Injury Law Group

www.tbilaw.com

Links to advocacy support and legal consultations.

Chat Line for Acquired Brain Injury

www.tbichat.org

Opportunity for the child and family to discuss concerns with other people who are going through the same experience.

Thames Valley Children's Centre

www.tvcc.on.ca

An overview of brain injury in children, team members, interacting with a child who has a brain injury, recovery of the family and planning to go home.

Holland Bloorview Kids Rehabilitation Hospital

www.hollandbloorview.ca

An overview of the children's treatment centre programs and services, including the neurorehabilitation program.

SNOW: Special Needs Opportunity Windows

http://snow.utoronto.ca/prof_dev

An overview of the educational needs of children with acquired brain injury, including practical strategies to encourage learning and an interactive bulletin board.

CNS: Centre for Neuro Skills

www.neuroskills.com

Traumatic brain injury resource guide. A source of information, services and products related to brain injury, recovery and rehabilitation. This site has a map of the brain and its functions.

CanChild Centre for Childhood Disability Research

www.canchild.ca

Provides information on the latest research related to children and youth with disabilities, and their families. There are short reviews, called Keeping Currents, and in-depth reviews, called Research Reports. Includes links to other childhood disability sites.

International Brain Injury Association

http://internationalbrain.org

Provides access to research journals such as The Brain Injury Journal. Provides publications, newsletters, research and links to other sites related to brain injury and rehabilitation.

Brainline Kids

www.brainline.org/landing_pages/features/blkids.html

Information about preventing, treating and living with traumatic brain injury.

Gillette Children's Specialty Healthcare

www.gillettechildrens.org

Information for patients and families about brain injury and rehabilitation therapies.

The websites listed in this book were correct at the time of printing. Please remember that websites and health information on the internet change frequently, without notice.

Definitions of common medical words

Word	Definition
Catheter	A thin, flexible tube that can put fluids in, or take fluids out of the body. A catheter in the bladder can drain out the urine.
Cognitive function	The brain's ability to take information from the environment, think about it, and take action to respond.
Concussion	A violent jarring or shaking of the brain which causes a temporary loss of consciousness, confusion and/or vomiting.
Contrecoup injury	Occurs when the head collides with a solid object. The blow to the skull causes bruising of the brain at the point of impact (coup) and more bruising when the brain is driven against the opposite side of the skull (contrecoup).
Contusion	Bruising of the brain.
Diffuse injury	Occurs when the head hits an object and stops, but the brain keeps on going. The sharp twisting and shifting movements of the brain causes stretching, shearing and tearing of nerve fibres in the brain, causing widespread damage and loss of function.
Edema	Swelling of the brain due to a build up of fluid in the tissue.
Glasgow Coma Scale (GCS)	A scale to measure the degree of impairment of a person's level of consciousness. Based on a person's ability to open his or her eyes, and respond with movements or words.
Hemorrhage	Bleeding in the brain.
Hematoma	An accumulation of blood in the brain tissue.

Word	Definition
Intracranial pressure (ICP)	The level of pressure inside the brain.
Intravenous (IV)	A thin, plastic tube inserted into a vein. Fluids and medications can be put into the bloodstream through the intravenous tube.
Nasogastric (NG) tube	A thin, plastic tube inserted into the patient's nose, to reach the patient's stomach. The tube can be used to "feed" the patient nutritious fluids. When connected to suction, this type of tube can be used to remove fluids and keep the stomach empty.
Rancho Los Amigos Levels of Cognitive Recovery Scale	A scale to rate a person's recovery from a brain injury. There are 8 levels, from "no response" to "purposeful and appropriate".
Respirator or Ventilator	A machine that does the breathing work for an unresponsive patient. It delivers warm, moist air with precise amounts of oxygen at constant rate of flow.
Level of consciousness (LOC)	How awake, aware and responsive your child is. The Glasgow Coma Scale (GCS) is used to measure your child's level of consciousness.
Skull fracture	A broken bone of the skull caused by a traumatic injury.
Tracheostomy	An opening made through the neck into the trachea (windpipe) to place a tube used as an airway for breathing.

Questions and notes	

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